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Parents defend decision to keep disabled girl small

January 03, 2007 | Sam Howe Verhovek | Times Staff Writer

SEATTLE — This is about Ashley's dignity. Everybody examining her case seems to agree at least about that.

Ashley is a 9-year-old girl who has static encephalopathy, a severe brain impairment. She cannot walk or talk. She cannot keep her head up, roll over or sit up by herself. She is fed with a tube. Her parents call her "Pillow Angel" because she stays right where they place her, usually on a pillow.

Her parents say they feared that their angel would become too big one day -- too big to lift, too big to move, too big to take along on a family outing.

And so they decided to keep her small.

In a highly unusual case that is stirring ethical debate in the medical community and elsewhere, doctors at Seattle Children's Hospital and the parents involved are describing how Ashley has received treatment over the last few years designed to stunt her growth.

The treatment, known as "growth attenuation," is expected to keep Ashley's height at about 4 feet 5 and her weight at about 75 pounds for the rest of her life. Doctors expect her to have a normal lifespan. Had she not been given the treatment, doctors estimate, she would have grown into a woman of average height and weight -- about 5 feet 6 and 125 pounds.

The parents' decision has drawn criticism and even outrage from some doctors and caregivers, who say such treatment is a violation of a person's dignity. Some say it's also a violation of the medical oath: First do no harm.

But Ashley's parents say the move was a humane one, allowing her to receive more care, more interaction with her younger brother and sister, and more of the loving touch of parents and others who can carry her.

As a result, they say in a written account posted on the Web this week, "we will continue to delight in holding her in our arms and Ashley will be moved and taken on trips more frequently and will have more exposure to activities and social gatherings (for example, in the family room, backyard, swing, walks, bathtub, etc.) instead of lying down in her bed staring at TV (or the ceiling) all day long."

The treatment has involved a hysterectomy, surgery to prevent breast growth and subsequent high doses of estrogen.

Doctors say that the treatment's major risks come from the surgeries, but that it also carries potential benefits such as eliminating the risk of ovarian and breast cancers.

High-dose estrogen to inhibit growth was used occasionally in the 1950s and 1960s, mostly on teenage girls whose parents were concerned about the social stigma of being too tall. The drugs could stop a 5-foot-9 girl from becoming, say, 6 feet tall.

As that stigma has gone out of fashion, so has the treatment, medical ethicists say.

But Ashley's case involves an entirely separate ethical realm, that of whether a severely disabled person might be better off having his or her growth impaired.

Publication of the case in a national pediatric journal in October set off criticism of the parents' decision; "eugenics," "slippery slope," "despicable" and "Frankenstein-esque" are some of the printable contributions to websites on the topic.

But it wasn't until 11 p.m. on New Year's Day that Ashley's parents told their side of the story.

That was when Ashley's father hit the send button on an e-mail to doctors, reporters and others, and began entering chat rooms with a link to their story -- <http://ashleytreatment.spaces.live.com/blog> -- and to photos of the girl: <http://ashleytreatment.spaces.live.com/photos>.

The parents have declined all media requests for an interview.

"I cannot explain something this complicated in an interview," he said by telephone Tuesday.

He added: "People think it must have been a horribly difficult decision" to have the treatment performed. "It really wasn't."

The parents have not identified themselves publicly, and, in family photos of Ashley they have a dark box on the faces of her siblings, who are not disabled.

Medical experts could not say for certain whether the case was unprecedented, but they did say treatment to inhibit growth of a severely disabled person had never been discussed in mainstream medical journals before.

"It's simply the first reported case any of us know about," said pediatrician Jeffrey Broesco of the University of Miami, a co-author of an editorial criticizing the treatment in the October issue of the Archives of Pediatrics & Adolescent Medicine.

"I think most people, when they hear of this, would say this is just plain wrong," Brosco said. "But it is a complicated story, and when you get into this issue, you can understand the difficulties.

"And," he said, "our societal ethics may change.... But we are going to have to discuss this as a society. We are going to have to say this is right or this is wrong, and thus decide whether we will allow it."

In the editorial, Brosco and co-author Chris Feudtner called growth attenuation "ill advised," though they applauded the Seattle doctors for publishing the case report and helping to "advance our ethical dialogue" on the topic.

If the treatment becomes more widely available, Brosco and Feudtner wrote, parents of severely cognitively disabled children might feel pressured to have their children undergo it to avoid the agonizing choice of whether to put them in a special-care facility once they're fully grown.

"High-dose estrogen therapy to prevent out-of-home placement simply creates a new Sophie's Choice for parents to confront, where neither letting the child grow unchecked nor imposing shortness is without peril," they wrote.

"If we as a society want to fundamentally revise the nature of the harrowing predicament that these parents face, then, in the end, more funds for home-based services, not more medication, is what is called for."

But Daniel Gunther, a pediatric endocrinologist who has overseen Ashley's treatment at Seattle Children's Hospital and Regional Medical Center, said the approach was a humane alternative that parents such as Ashley's could find to be in the best interest of the child.

"Certainly we would never want the option for growth attenuation to become an obligation for growth attenuation," Gunther said.

"It's very natural for people hearing about this case to have an initial sort of, 'You're kidding me ... how could you do this?' reaction," he said in an interview. "What I have found is that if you really examine it, if you actually lay out the benefits of this to the child, then people start to see the possible wisdom in this."

The case arose when the girl, at age 6 1/2, began to show unusually early signs of pubescence, including pubic hair and initial stages of breast growth.

As the parents consulted doctors, Gunther wrote in his description of the case in the pediatric journal, it became clear that "the parents particularly feared that continued growth eventually would make it untenable for them to care for their daughter at home, despite their strong desire to do so."

Gunther told the parents that growth attenuation was a possible option, and soon the parents were strongly pressing for the treatment.

The case was brought before the hospital's ethics committee in 2004. At one meeting, the father -- described as a software executive by some involved in deliberations -- made a PowerPoint presentation listing several benefits of the treatment.

Given that the child was found by a variety of doctors to be severely impaired, with virtually no indications of improvement in her intellectual development, the committee found in favor of the parents' right to seek growth attenuation. The case was not publicized at the time, and therefore did not draw any legal challenge.

Ashley's father, who said in the phone conversation that he was speaking on behalf of her mother, said they were especially bothered by critics' allegations that the treatment was undertaken for the "convenience" of the parents.

"That's simply not true at all," he said. "Anybody who thinks that, I'd ask them to read what's on the website.

In that account, the parents wrote: "Ashley's biggest challenges are her comfort and boredom.... [The treatment] goes right to the heart of these challenges and we strongly believe that it will mitigate them in a significant way and for the rest of her life."

They continued: "The objection that this treatment interferes with nature is one of the most ridiculous objections of all; medicine is all about interfering with nature. Why not let cancer grow and nature takes its course. Why give antibiotics for infections?"

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In Her Best Interests: Ashley X and Parental Choice

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Ashley X is a Seattle girl with static encephalopathy. She is, at this writing, approximately 10 years old. She is, and always will be, unable to sit up, roll over, grasp objects, or speak. She must be fed through a gastrostomy tube. She is able to experience the cognitive and emotional life of, at best, a typical 3- to 6-month-old child. Over a period of 3 years, Ashley received high doses of estrogen, a growth attenuation treatment that will result in her remaining relatively small in stature, perhaps 4 feet 6 inches (1.37 m) tall, and weighing about 65 or 70 pounds (29–32 kg). Ashley also underwent a hysterectomy to eliminate future menstrual cramps and bleeding, and breast tissue removal to assure the development of small breasts. This article argues that: (a) criticisms of the deliberative process leading to this "Ashley Treatment" are unpersuasive; (b) the Ashley case affords no reason to believe that formal, adversarial, judicial proceedings to review parental decisions would best serve either disabled individuals or the families who love and care for them; and (c) the Ashley case provides no reason to think that parents and other responsible parties should no longer continue to enjoy wide discretion in terms of what medical treatment they may elect for their dependents.

Keywords: static encephalopathy; parental discretion; surrogate decision making; judicial review of medical decisions

Ashley X is a Seattle girl with static encephalopathy. She is, at this writing, approximately 10 years old. She is, and always will be, unable to sit up, roll over, grasp objects, or speak. She must be fed through a gastrostomy tube. She is able to experience the cognitive and emotional life of, at best, a typical 3- to 6-month-old child.

Ashley's case history was published in the October 2006 *Archives of Pediatrics and Adolescent Medicine* (Gunther & Dikema, 2006). The case history indicated that, over a period of 3 years, Ashley received high doses of estrogen, a growth attenuation treatment that will result in her remaining relatively small in stature, perhaps 4 feet 6 inches (1.37 m) tall and weighing about 65 or 70 pounds (29–32 kg). Ashley also underwent a hysterectomy to eliminate future menstrual cramps and bleeding, and breast tissue removal to assure the development of small breasts (Gunther & Dikema, 2006). This particular collection of medical interventions has become known as the "Ashley Treatment."

The Ashley Treatment has been greeted, it is fair to say, with both praise and outrage, and a modest body of literature is beginning to grow up around it

(Newsom, 2007). Much of that literature addresses the ethical implications of the Ashley Treatment, with little attention given to legal questions surrounding it. This article considers two extant legal analyses of the Ashley Treatment, one offered by the report of a disabilities advocacy agency (Carlson & Dorfman, 2007), and one provided by a legal scholar (Ouellette, 2008). The article concludes that the Ashley Treatment affords no reason to believe that formal, adversarial, judicial proceedings to review parental decisions would best serve either disabled individuals or the families who love and care for them, and no reason to think that parents and other responsible parties should no longer continue to enjoy wide discretion in terms of what medical treatment they may elect for their dependents.

THE WPAS REPORT

The relative absence of extended discussion of the legal aspects of the Ashley Treatment is in part due to the fact that no court proceedings resulted from it. However, the WPAS, a federally mandated advocacy agency, initiated an investigation in order to determine

whether (a) Ashley X had been abused or neglected, as those terms are defined by pertinent federal regulations, by the Ashley Treatment; and (b) whether the Ashley Treatment constituted a violation of Ashley X's civil and constitutional rights. This investigation resulted in the issuance of a report by the WPAS, and an agreement between the WPAS and Seattle Children's Hospital to implement a number of procedures to assure compliance with putative legal requirements (as understood by the WPAS) that may govern medical interventions performed on individuals with disabilities in the state of Washington.

The report leaves little doubt that WPAS is convinced that at least one component of the Ashley Treatment, the hysterectomy, required court approval in order to be lawful in the state of Washington, and that the failure to obtain such approval in this case constituted a violation of Ashley X's civil and constitutional right to be protected from involuntary sterilization. The report also suggests that, had a hearing been held, it would be very unlikely that Washington courts would have granted permission to perform the hysterectomy. The report further concludes that the other, growth limiting features of the Ashley Treatment should also require court approval (Carlson & Dorfman, 2007, p. 27).

Hysterectomy

In making its determination that performing a hysterectomy on Ashley X was unlawful absent a judicial review, the WPAS placed principal reliance on the 1980 Washington case of *In re Hayes* (Carlson, 2007, p. 17). At first glance, the case seems to provide strong support for the WPAS position. In *Hayes*, a mother sought to have her sexually active, 16-year-old, severely mentally retarded daughter, Edith Hayes, sterilized, and brought an action in the Superior Court for Grant County, Washington, to obtain judicial approval for the procedure. The trial court dismissed the mother's petition on a motion for summary judgment on the ground that it had no authority to issue an order for sterilization of a "retarded" person, and the mother appealed (*In re Guardianship of Hayes*, 1980).

The Washington Supreme Court reversed the trial court. In a lengthy opinion, the Court held: (a) the courts of general jurisdiction in Washington possess the inherent powers necessary to exercise common law *parens patriae* jurisdiction over incompetents; (b) Washington courts may order the sterilization of an incompetent when it is in the best interest of the incompetent to do so; and (c) sterilization may only be ordered when a lengthy list of conditions, both substan-

tive and procedural, have been satisfied (*In re Guardianship of Hayes*, 1980).

While *Hayes* might seem to stand, clearly and squarely, for the proposition "no sterilization of incompetents without judicial approval," it is less than clear that the Supreme Court of Washington intended it to stand for the proposition "no hysterectomies for incompetents without judicial approval." There is a considerable difference between the two.

Desire for sterilization is not ordinarily an indication for hysterectomy. Sterilization is typically accomplished by far less invasive and sometimes reversible procedures, such as tubal ligation. Hysterectomy is indicated for any number of other reasons, such as: dysfunctional uterine bleeding, genital prolapse, endometriosis and adenomyosis, chronic pelvic pain, pelvic inflammatory disease, endometrial hyperplasia, cancer, and cancer prophylaxis (Carlson & Nichols, 1993).

It is difficult to imagine that the *Hayes* court intended to require judicial review for every beneficent, medically indicated hysterectomy performed on an incompetent in the state of Washington. Rather, the harms that the *Hayes* court and others have sought to prevent are results like the one reached in 1927 by the U.S. Supreme Court in the notorious *Buck v. Bell*, where individuals having no medical indications whatsoever for any form of gynecological surgery, and deriving no benefit whatsoever from it, were forced to undergo it. This wretched American experiment in eugenics has been roundly and ably criticized many times by the legal, scientific, and medical communities (see generally Gould, 1996). Yet, the position adopted in the WPAS report would seem to be that judicial review is required for any procedure whose consequence will be the sterilization of an incompetent, no matter how remote from the facts of *Hayes* and *Bell* the particular situation might be, and no matter how many other benefits might be conferred upon the patient by the procedure.

Permissibility of Hysterectomy

Even if one accepts the necessity, or simply the desirability and prudence, of some form of judicial approval for Ashley X's hysterectomy, and others similarly situated, the question of whether the substantive requirements of *Hayes* apply remains. When would hysterectomy be permissible?

The court in *Hayes* fashioned stringent requirements for the issuance of an order approving sterilization. First, the "retarded" person must be represented by a disinterested guardian *ad litem* in any proceedings. Second, the court hearing the matter must consider:

(a) the individual's age and educability; (b) the individual's potential to acquire parenting skills; and (c) the degree to which sterilization is medically indicated as the last and best resort for the individual (*In re Guardianship of Hayes*, 1980).

Matters do not end there. When these three broad requirements have been met, the court must then make the following specific findings in order for an order approving sterilization to issue: (a) that the individual is incapable of making his or her own decision about sterilization; (b) that the individual is unlikely to develop sufficiently to make an informed judgment about sterilization in the foreseeable future; (c) that the individual is physically capable of procreation; (d) 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; (e) that the nature and extent of the individual's disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders him or her permanently incapable of caring for a child, even with reasonable assistance; (f) that all other contraceptive methods are unworkable or inapplicable; (g) that the proposed method of sterilization entails the least invasion of the body of the individual; (h) that no other workable contraceptive method or reversible procedure will be available in the near future; and (i) that the individual's disability will not be treatable for the foreseeable future (*In re Guardianship of Hayes*, 1980).

That is an extraordinary list; Ashley X meets some, but not all of the requirements. Specifically, she meets a, b, e, and i, but either does not, or never will, meet the others. However, other people who have surrogate decision makers, and for whom (unlike Edith Hayes) hysterectomy might clearly be indicated, could not meet all of the requirements either. A young woman might, for example, become severely cognitively impaired due to neurological injuries caused by an automobile accident, and would meet conditions a, b, c, d, e, and i, but not f, g, and h. But what can, or should, be said about conditions f, g, and h when hysterectomy is indicated for one of many possible reasons having nothing to do with sterilization? Does such an individual's surrogate need court approval to consent to a hysterectomy if it is indicated due to, for example, adenomyosis?

Since hysterectomy and sterilization have different indications, it seems mistaken to conflate them in any way, and there is no reason to suppose that it is a mistake that the Supreme Court of Washington, or any other court, would make. There is, therefore, *pace* the WPAS, reason to doubt that the Hayes "Laundry List" for sterilization is the proper instrument with which to

measure the permissibility of performing hysterectomies on those who are legally incompetent, and reason to doubt that the courts of Washington, undoubtedly consisting of sensible people who would not be inclined to discourage beneficent acts, would so hold.

Growth Attenuation and Breast Reduction

There is more to the Ashley Treatment than hysterectomy; it also includes the surgical reduction of breast tissue and growth attenuation by means of hormone treatments. Must a parent of a child in Ashley X's condition obtain judicial approval in order to authorize these interventions on behalf of his or her child? Should such approval ever be granted under these, or similar, circumstances?

The WPAS clearly thinks judicial approval must be sought, and should not be granted. The report acknowledges that U.S. Supreme Court cases, such as *Parham v. J.R.*, clearly vest parents with wide discretion in making medical decisions on behalf of their minor children, since such discretion is an integral part of the liberty and privacy rights parents exercise in determining how they will raise their children. However, the report also notes that other cases, decided by the same court, such as *Prince v. Commonwealth*, have held that the scope of parental decision making is not "unfettered" (Carlson, 2007, p. 18). This is well put, and bids fair to be hornbook law. It is also singularly unenlightening. The contentious question is what sorts of decisions fall within the bounds of this wide, but not unfettered, parental discretion.

The WPAS report surveys Washington law, and concludes that, at least in the state of Washington, "even guardians cannot make certain decisions, and judicial intervention is required before these medical treatments can be provided or procedures be performed" (Carlson, 2007, p. 17). In cases where the guardian is the parent of a minor child, WPAS argues that parents cannot consent, without court approval, to "highly invasive and/or irreversible medical treatment" (Carlson 2007, p. 18).

Limitations on Parental Discretion

The WPAS report cites Washington cases, and/or legislation, that require judicial review of parental decisions to allow involuntary inpatient psychiatric treatment, electro-convulsive therapy (ECT), lobotomy, abortion, and sterilization, as underwriting their conclusion that judicial approval is required for highly invasive and/or irreversible medical treatments. But none of the cases they cite contain such a general rule.

The case the WPAS does cite as authority for the principle that court review is necessary in the case of medical treatments that are "similarly invasive" to involuntary commitment, lobotomy, ECT, abortion, and sterilization is an extremely interesting choice. The case chosen is a 2006 Washington Court of Appeals case, *State v. Baxter* (Carlson, 2007, p. 19). In *Baxter*, the evidence at trial disclosed that a father, one E. B. Baxter, after spending several weeks pondering the 17th chapter of Genesis, concluded that God wanted him to circumcise his 8-year-old son, "E.N.B." E. B. Baxter then attempted to circumcise E.N.B. with his hunting knife, resulting in severe bleeding, a call to emergency medical services, a trip to the emergency room, several stitches, an interesting scar but no permanent "impairment," and a charge against E. B. Baxter of second-degree assault on a child (*State v. Baxter*, 2006, p. 591).

The *Baxter* court did not hold that circumcision is an exclusively medical treatment, but acknowledged its status as a religious ritual as well (*State v. Baxter*, 2006, pp. 599–600). The *Baxter* court did not even contemplate, much less suggest, that parents cannot elect to have minor sons circumcised, or that they must obtain court approval in order to do so, or that only physicians can perform the procedure. Rather, the court simply, and correctly, held that an adult who attempts to circumcise an 8-year-old boy "in a dirty bathtub, with no medical training, using a hunting knife and animal wound cauterizing powder as his tools," commits assault (*State v. Baxter*, 2006, p. 600). It is thus difficult to see how *Baxter* stands for the proposition that parental election of all highly invasive, irreversible medical treatments, which are similar to abortion, lobotomy, ECT, and involuntary commitment, require judicial approval.

Plausibly, the reason that the WPAS report cites no case that clearly and squarely holds that all highly invasive, irreversible medical procedures performed on minors require judicial ratification of parental consent is because no such case can be found. Such a rule, if interpreted literally, would require court review of most surgery, including some of the most beneficent acts physicians perform. Surgery is, by its very nature, highly invasive and irreversible. Removing a Wilms' tumor, or an inflamed appendix, is highly invasive and irreversible, but surely the WPAS is not advocating judicial review of all parental authorizations of such procedures.

General Scope of Parental Discretion

Although often criticized by scholars (see Rosato, 2000), the general rule in the United States concerning the scope of parental decision-making authority in medical (and other) contexts is simple; parents may consent,

or refuse to consent, to medical procedures (including organ removal) on behalf of a child when they believe it is in the child's best interest to do so, and their decision can be set aside only in instances where the parents' decision constitutes neglect, provides no benefit to the child, or threatens the child's life or permanent well-being (see, generally, Ouellette, 2008, p. 2; Wadlington, 1994, pp. 312–314). The U.S. Supreme Court has summarized the general deference to be afforded parental discretion, as a matter of constitutional law, in this language: "there will normally be no reason for the State to inject itself into the private realm of the family to question the ability of that parent to make the best decisions concerning rearing of that parent's children" (*Troxel v. Granville*, 2000, p. 68).

Some scholars argue that courts are generally moving away from a position of paying such great deference to parental wishes, and towards one where the child's "best interests" are held to justify judicial intervention in a wider range of cases than in the past (see Wadlington 1994, p. 331). In a thought-provoking article in *Temple Law Review*, Jennifer Rosato has argued that the traditional policy (and the case-by-case exceptions to it that the WPAS report identifies) provides both too much, and too little, deference to parental discretion (Rosato, 2000, p. 3). Rosato urged that the "rights"-based discourse upon which current doctrine is founded be abandoned, and that an alternative, "bioethics" discourse be adopted instead (Rosato, 2000, p. 3).

THE OUELLETTE ANALYSIS

Alicia R. Ouellette has examined the question of the scope of parental discretion in the specific context of the controversy surrounding Ashley X (Ouellette, 2008). While not contending that the Ashley Treatment was necessarily contrary to Ashley's best interests, Ouellette argues that the case is illustrative of a pressing need to change current parental discretion doctrine.

Ouellette argues that: (1) Ashley's body was "altered profoundly" for "social, not medical, reasons without proper process or oversight," and that (2) proper process and oversight was needed because (a) the Ashley Treatment constituted a potential harm to Ashley of great magnitude, (b) Ashley's parents faced a "potential conflict of interest," and (c) the Ashley Treatment consists of interventions that have a "potential for abuse" (Ouellette, 2008, p. 25).

Consideration 2a, that the Ashley treatment constituted a potential harm of great magnitude, is open to question. Ouellette asserts that the procedures caused Ashley "actual harm" (Ouellette, 2008, p. 28). These

alleged harms consisted, per Ouellette, of (a) being confined to the hospital for 4 days; (b) being "sliced open"; (c) being anesthetized; (d) having normal "growth functioning" impaired; and (e) suffering the loss of her breasts and uterus (p. 28). Indeed, Ouellette sees these harms as "comparable to female circumcision or genital cutting" (p. 28).

To characterize these features and consequences of the Ashley Treatment as harms on a par with female circumcision, in the case of a patient like Ashley X, is a rather sweeping case of begging the question. A hospital stay, accompanied by anesthesia, tissue removal, and incisions, is not generally thought to be a harm in instances where the goal is a beneficial outcome for the patient. Indeed, these are features of nearly every surgical intervention. In a similar vein, impairing Ashley's normal growth function might not constitute a harm to her if she is, all things considered, deriving some special benefit from being an unusually small woman with unusually small breasts.

Moreover, while it seems correct to say that the Ashley Treatment constitutes a significant alteration of the patient's body, Ouellette's conclusion that this alteration took place for social rather than medical reasons assumes that a sharp division between social and medical reasons can be easily drawn, and that social reasons are suspect when offered as justifications for surgical intervention. This set of assumptions deserves examination.

Clearly some common medical procedures are performed that are not, strictly speaking, medically necessary, but that are widely held to be beneficent nonetheless. One example would be otoplasty. Children who are deemed excellent candidates for otoplasty can usually hear adequately, and there exists no pathophysiological reason to alter the appearance of their ears. Still, it is common wisdom that children with unusually large ears are in for a tough time from their peers past the age of six, and that the cumulative effect of being called "Dumbo" by schoolmates during their formative years is bad enough to merit prevention by surgical intervention (see Janis, Rohrich, & Gutowski, 2005).

There are also conditions that cry out for surgical correction for both medical and social reasons, any one of which would justify surgical intervention. One example of such a condition would be cleft lip and palate. Cleft lip and palate can certainly lead to medical complications, such as increased frequency and severity of ear infection, and can produce speech defects, but it is also a condition that negatively affects the patient's acceptance by peers when adolescence is reached (see generally Damiano et al., 2005). While non-surgical

interventions can often address the speech defects and additional ear infections the condition occasions, only surgical repair will address the peer acceptance difficulties as well.

It therefore seems that a good case can be made for saying that surgical interventions can be, and in fact are, justified by social as well as medical reasons. However, those who question the propriety of the Ashley Treatment might want to argue that the social benefits justifying otoplasty, or corrective lip and palate surgery, are benefits to the patient, whereas in the Ashley X case, there were no benefits to Ashley, but only to her parents.

This objection leads naturally to consideration of a concern that Ouellette articulates, that Ashley's parents might have a potential conflict of interest. Ouellette writes:

Ashley's parents had much to gain by changing Ashley's body. Simply put, their lives would be made better if they modified Ashley's body. They would be relieved of the burden of caring for a profoundly needy adult-sized being. They would no longer need to strain to carry Ashley. They would not have to deal with her menstrual blood . . . and (would) avoid the guilt and loss felt by many parents who have to institutionalize their children.

(Ouellette, 2008, pp. 28-29)

Ouellette does not deny that it might be the case that the Ashley Treatment was, all things considered, in Ashley's best interests, or argue that consideration of social benefits, and benefits to the extended family, are always inappropriate (Ouellette, 2008, p. 29). Her point seems to be, rather, that the benefits conferred upon the parents in Ashley's case are so great as to call in to question the default presumption that they were acting in their daughter's best interests.

Ouellette's argument against unreviewed deference to parental decision in cases such as Ashley's rests on an assumption that the situation presented by the circumstances of Ashley X and her family are appropriately analyzed in the moral, as well as legal, dimension by referring to rights, and in effect treats the parent/child relationship as analogous to the fiduciary model of trustee and beneficiary. But perhaps even couching the discussion in terms of rights, when the subject is the welfare of children living in families, is the wrong way to think about children and families. It has been argued that thinking in terms of rights and interests in this context both fails to capture what is unique, and uniquely good, about families, but also threatens to undermine them (see Schoeman, 1980). Philosophers advocating this approach are arguing, as David Archard reads them, that:

the ascription of rights to children is inappropriate because it displays a misunderstanding of what childhood is, what children are like, or what relationships children stand in to adults . . . (and because) notwithstanding their lack of rights, children can be assured of adequate moral protection by other means.

—(Archard, 2006, p. 7)

Archard goes on to note that these philosophers view relationships within a family as “marked by an especial intimacy and deep, unconditional love,” which are “dispositions and attitudes” that can be destroyed by claims of “right or rule” (Archard, 2006, pp. 9–10).

Philosophers subscribing to this view are often classified as “critics of children’s rights” (Archard, 2006, p. 6). In addition to arguing, as above, that ascribing “rights” to children is to misunderstand, and indeed to threaten, the role of families in the lives of children, these philosophers argue that: (a) children are not fully capable of being bearers of rights, and (b) that although children lack rights, they do indeed have “interests,” which deserve to be and can be protected by assuring that adult obligations to protect and further those interests are fulfilled (see O’Neill, 1988, pp. 459–463).

Not every philosopher considering these issues sees matters in this way. “Child liberationists” seem to assert what Critics deny, and argue that, for various reasons, children are appropriately viewed as bearers of rights. Some of their objections to the Critic position can be set aside for purposes of this discussion, since in the end critics and liberationists frequently commend the same practical policies concerning the care of children, and the protections to be afforded them, with Critics seeing matters in terms of the enforcement of adult obligations, and Liberationists seeing them in terms of a vindication of rights.

One defense of the Liberationist position regarding children is, as Archard notes, that it serves a “political or rhetorical function by reminding us of what must be done for them” (Archard, 2006, p. 10). But Critics are not precluded from agreeing that people need to be reminded of what must be done on behalf of children. It is, after all, possible to advocate on behalf of animals, or the environment, without insisting that puppies and trees have rights. And, many Liberationists would agree that children do not possess all of the rights that adults do (see Brennan and Nogge, 1997).

Structuring the discussion in terms of adult obligations to further the interests of children, instead of the vindication of the rights of children, captures the relationship that actually exists between children and their adult carers in the best of circumstances—a relationship of love, dependency, responsibility, and need.

Tamar Shapiro articulates the adult/child relationship in the following way:

The picture is of children as emerging persons—as human beings who are in the process of liberating themselves from the rule of instinct, but who have not yet completed this task, and who are therefore to some extent at the mercy of a blind and alien form of rule. If children are already in a condition which prevents them from governing themselves, then by “liberating” them from adult authority, we merely hand them over to the arbitrary governance of nature. An implication of this, however, is that adults only earn their right to govern children by governing them better than nature would. They do this by safeguarding children’s interests, including their distinctively human interest in achieving autonomy.

—(Shapiro, 2003, p. 592)

On this view, the fundamental questions are not whether the Ashley Treatment violates some putative right possessed by Ashley X, but whether it actually furthers some interest, or interests, she possesses, and who should decide whether or not it does so.

Ouellette seems to view the Ashley X case as a sort of *reductio* argument against parental choice as the appropriate decision-making model. She argues that it is an example of parental choice operating well, while exhibiting a number of deliberative failures on the part of those involved (Ouellette, 2008, p. 31).

Specifically, Ouellette concludes that Ashley’s parents: (a) were in no way abusive, unfit, or neglectful; (b) “acted at every step with good faith, with love and with good intentions”; (c) researched many options for their daughter and consulted with excellent physicians; and (d) voluntarily sought ethics committee review (Ouellette, 2008, p. 31). Ouellette also concedes that the consulting ethics committee (a) was free of any conflict of interest; (b) debated the proposed interventions; and (c) made a thoughtful and careful decision (p. 31).

In spite of these favorable observations, Ouellette finds the process actually employed in Ashley’s case “inadequate.” Per Ouellette, the committee: (a) “failed to put everything on the table that was at stake for Ashley”; (b) inadequately explored less invasive options; (c) failed to consider that the Ashley Treatment might disturb Ashley’s “human essence” and that other interventions (or none at all) might better “advance Ashley’s right to an open future”; and (d) left the ultimate decision on whether to proceed in the hands of Ashley’s parents, “despite the real possibility that their interests were not identical to Ashley’s” (Ouellette, 2008, pp. 31–33).

It is of course true that Ashley’s interests and her parents’ interests are not identical. But this is a trivial truth. For that matter, the interests of the WPAS and Ashley’s interests would not necessarily be identical.

A court's interests and Ashley's interests would not necessarily be identical. Identity of interest is not necessary in order for one person to act responsibly on behalf of another, even in circumstances where bonds of love and affection are not present; if it were, there could be no such thing as a bank trust department.

The real question is not whether Ashley and her parents (or anyone else) have interests that are identical, but whether the circumstances were such that Ashley's parents were incapable of acting in their daughter's best interests, and whether there is any reason to believe that better outcomes would somehow be assured by substituting someone else's judgment in the place of the judgment of (admittedly) loving, well-informed and well-intended parents who act in good faith, and act only after consulting with an (admittedly) thoughtful, unbiased panel of well-informed physicians and ethicists. In fact, the deliberative process actually followed in the Ashley X case is notable for how well it addressed many of the very real concerns feminist (and other) philosophers have raised for some time about informed decision making in health care contexts.

Thoughtful scholars have expressed concern that the existing conception of informed decision making is often inadequate: individual patients or their surrogates are sometimes unaware of their health care options, are unduly deferential to physician recommendation due to lack of education, and lack the social support and financial resources necessary to make choices from among alternative interventions that are genuine possibilities for them (see Donchin, 2008, pp. 11–12). When one or more of these circumstances is present, it is difficult to say that choices are being freely and advisedly made. Yet, this is precisely not the picture the Ashley X case presents. Ashley's parents went to great lengths to inform themselves, as Ouellette notes, and there is every reason to think that the sort of genuine consent that is sometimes absent from "real life" decision-making processes was actually present in Ashley's case.

Moreover, the actual deliberative process that was followed in Ashley's case suggests a way to at least begin to address Rosato's desire, noted above, to see discussions of rights give way to bioethics discourse. Reliance on parental discretion, when parents are informed by the deliberations of ethics committees, at least introduces bioethics discourse in to the process, even if it does not entirely replace considerations of right and rule.

One commentator has characterized the idea that there might be some better advocate and surrogate for children than loving parents as "magical thinking" (Goldstein, 1977, p. 650). This out-of-hand dismissal

fails to address a concern Ouellette raises, that the decision-making process utilized in Ashley's case failed to assure consideration of the treatment's effects on her human essence and her right to an open future.

It is difficult to determine how the Ashley Treatment could affect Ashley's human essence, absent some specification of exactly what human essence is supposed to be. Are we dealing with something residing in Plato's Realm of Forms when contemplating human essence, or the less metaphysically spooky but still somewhat suspect idea of a collection of characteristics necessarily shared by all "real" *Homo sapiens*? If it is the former, there is little to say, and nowhere to turn for guidance; dyed-in-the-wool Platonists of the right sort are in short supply these days.

If some collection of putatively necessary characteristics is what is meant by human essence, then it hard to see which of any such possible characteristics were altered by Ashley's treatment, or left unexamined by the ethics committee. How the Ashley Treatment could cause diminished human essence is a mystery, unless all other unusually short women with small breasts who have undergone a hysterectomy suffer from diminished human essence also.

A similar difficulty confronts concerns about limiting Ashley's right to an open future. Presumably a right to an open future, if there is any such thing, is something along the lines of what Shapiro alludes to; the "distinctively human interest in achieving autonomy" (Shapiro, 2003, p. 592). Unfortunately, this is an interest Ashley does not, and never will, possess. Nor is it an interest that the Ashley Treatment deprived her of. Nothing her parents, the ethics committee, or her medical providers did or did not do, or considered or failed to consider, affected this putative right or interest; Ashley lacked, and always will lack, an open future thanks to Kant's "niggardly stepmother, nature."

Indeed, it is precisely because Ashley does not have an open future in the relevant sense, and because it is beyond the ability of medical science to provide her with one, that Ashley's parents considered the medical interventions they ultimately authorized, and sought the counsel of the ethics committee in the first instance. If Ashley had an open future there would have been no Ashley Treatment, and this is surely so blindingly obvious that it is hard to see why an ethics committee would have needed to specifically mention it in their deliberations.

CONCLUSION

None of this is to say that medical providers must unquestioningly provide whatever interventions parents

request for their minor children, or that some requirement that parental decisions be reviewed by neutral third parties would not be wise. As Ouellette observes, the court in *Parham* specifically commended a careful review by a neutral party or parties of the propriety of some parental medical decisions (Ouellette, 2008, p. 38; *Parham v. J.R.*, 1979, p. 610). This is what, in fact, occurred in Ashley's case. What the *Parham* court did not require or commend was what the WPAS and other critics of the Ashley Treatment would like to see occur, "an adversary contest to ascertain whether the parents' motivation is consistent with the child's interests."

The court in *Parham* reached the conclusion it did for reasons similar to those advanced here. The *Parham* court was concerned that formal, adversarial court review would: (a) be at odds with the presumption that parents are acting their child's best interests; (b) constitute a distressing confrontation that would interfere with intimate relationships and adversely affect the ability of parents to continue to care for their child; and (c) be placing reliance on a sort of procedure that, in medical contexts, offers benefits that are "more illusory than real" (*Parham v. J.R.*, 1979, pp. 608-611). Indeed. And, nothing in the facts and circumstances of the Ashley X situation provides any reason to conclude that the *Parham* court was wrong.

In the best of all possible worlds, no child would be afflicted with static encephalopathy. Ours is not that world, and the only possible response to the fact that our world is not that world is to provide children like Ashley, and the families that care for them, with interventions that can make their lives better, and their burdens lighter, all things considered. This seems to be the result achieved in Ashley's case, and there is therefore good reason to reproduce, rather than to alter, the process that produced it.

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