The wrongness of growth attenuation is that it involves a failure to love and embrace the child with the characteristics and capacities she has. The mistake lies in making a child pay the price of medically unnecessary surgical modification for continued inclusion in her family’s everyday life.

These wrongs are no less wrong even if Ashley will never be aware of them. Most actions that we consider to be wrong are wrong whether or not the victim of the action is aware that it has occurred. In the case of People v. Minkowski, for example, a gynecologist was convicted of raping his patients after he had engaged in intercourse with them during vaginal exams without their consent, although they were not aware at the time that that was what he was doing. As Meir Dan-Cohen (1999) argues, it is coherent to state that they were raped—and therefore wronged—even before they realized that they had been raped.

When Diekema and Fost argue that growth attenuation is morally acceptable only if it is performed on a child who will never know what was done, they are arguing, in effect, that the intervention was morally acceptable because Ashley’s presumed cognitive impairment makes her different from most people. We argue, in contrast, that it is unacceptable because Ashley is the same as most people. She is the same in deserving to be accepted by and respected by and loved by her family for who she is and what she will become, with no modification required.

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alternative to the default process of parental choice, a process in which the child is represented by an advocate before a neutral third-party decision maker, and availability of intervention is limited by clearly defined criteria.

In response, Diekema and Fost take me to task for identifying deficiencies in the decision-making process at play in Ashley’s case when I was not a part of the process (“Ouellette even lists a series of important issues that the committee, in her view, did not discuss.” Ouellette’s claims “are speculative and quite simply wrong”). On one point, Diekema and Fost are quite correct. I was not there. That the committee considered issues they did not report on is a good thing, and I should have acknowledged more clearly that possibility in my earlier work. But as someone outside the room, someone looking at Ashley’s case as a kind of precedent for future cases (Gunther and Diekema 2006 even promoted the interventions as “A New Approach to an Old Dilemma”), I looked to public records released with the case to understand the decision-making process. The public record in this case consisted of the Gunther/Diekema paper and the ethics committee report. I stand by my criticism of the process reported in those documents. They focus exclusively on what Diekema and Fost continue to insist is the only “relevant question . . . whether the interventions were likely to be safe and effective in providing benefit to the patient and improving her quality of life” (Diekema and Fost 2010, 30). That limited inquiry does not require consideration of less restrictive alternatives (could we move the strap on the wheelchair instead of removing Ashley’s breasts?) or consideration of putting off the interventions. The process used did not guarantee that someone represented Ashley’s interests. Nor did it result in the legally required court review of the hysterectomy. To the extent the Gunther/Diekema paper and the ethics committee report represent blueprints for the next case, they are problematic.

Absent adoption of formal prospective rules, we cannot be sure that children whose parents seek growth attenuation, mastectomy, or hysterectomy to manage their child’s disabilities will receive even the same level of procedural protections provided Ashley. The process in Ashley’s case was voluntary. Ashley was lucky her parents and doctors were concerned only with her interests. She was lucky that the doctors insisted the ethics committee review the case. She was lucky the committee considered the issue from as many angles as reported by Diekema and Fost. But due process is not about luck. Due process is about legally required procedures that ensure against abuse and mistake. The greater the stakes, the more process the law requires. In the case of children whose parents choose growth attenuation, hysterectomy, and mastectomy to manage disability, the possibility of abuse or mistake is real and the stakes for children extraordinarily high. By requiring process—representation for the child, review and decision by a neutral third party based upon narrow and specific eligibility criteria—the law will protect children from abuse and mistake.

Diekema and Fost’s response to calls for additional process is confusing and contradictory. On the one hand, Diekema and Fost repeatedly emphasize the importance of ethics committee review and strict eligibility criteria in future cases. On the other hand, they suggest throughout the article that there is nothing special about the package of interventions used on Ashley. They compare them to appendectomies, surgeries to remove tonsils and tumors, the insertion of gastrostomy and tracheostomy tubes, fundoplication, spinal fusion, and tendon release. They say that as with ordinary medical interventions, “parents should be able to weigh [the] potential benefits and burdens and make a decision for their child in collaboration with qualified physicians” (30).

In this respect, it is hard to reconcile their positions. If growth attenuation, hysterectomy, and mastectomy are really the same as other medical procedures, why require ethics committee review? And if strict eligibility criteria are so important, why not impose them as a matter of law, or at least require the reviewing ethics committee to assess and apply the criteria? The answer to the first question, of course, is that the interventions used on Ashley were in some fundamental way different from other interventions used on children. They involved the elective disruption of a healthy growth process in and the surgical removal of healthy tissue and organs from a particularly vulnerable young child, who would not be subjected to the modifications were she not particularly vulnerable. Diekema and Fost may be able to find examples of other cases that are similar in one respect or another, but not one of their counterexamples involves all of the troubling factors at issue with the package of interventions used on Ashley. Diekema and Fost implicitly recognize that the interventions used on Ashley are different from appendectomies and the like by emphasizing the need for ethics committee review and the small category of children they would deem eligible for the interventions, but deny that difference is important enough to justify legal intervention for fear it “will reverse years of precedent in end of life cases, where the trend has been to move away from court review when there is agreement between the family and the medical team regarding the proper course of action” (Diekema and Fost 2010, 30). They need not worry.

Cases like Ashley’s, in which parents elect medical and surgical interventions for social, cultural, familial, or aesthetic reasons, raise a specter of abuse of power and the real possibility that the parent may subordinate the life, liberty, or body of the child for her or his own purposes that is simply not present when a parent elects or refuses medical treatment for a sick or injured child. Legal process can and should prevent parents from abusing their power. In a forthcoming paper, I question the assumption that parents have power over children’s bodies, which currently frames the paradigm for medical decision making for children (Ouellette forthcoming). I present an alternative that casts parents as trustees of their child’s welfare and uses principles of trust law to separate medical decisions that belong to parents, from decisions that belong to children and those
that should be made by a neutral third party. Under a trust-based paradigm, a parent seeking to modify a child’s body in the ways that Ashley’s parents did would be required to seek approval of a neutral third party—I suggest an institutional review board (IRB)-like structure—which would apply set and strict criteria designed to evaluate the child’s best interests. The interventions would be available if appropriate in a particular case, but the process would ensure full and fair consideration of each case before they could be implemented. Regardless of whether my trust-based construct takes, or whether we simply carve out special rules for growth attenuation, hysterectomy, and mastectomy in children, the interventions should be subject to additional process. The process adopted need not require court review. Due process is flexible. But sometimes there is good reason for the law to be in the room. ■

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The Limits of Parental Authority?

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Many of the arguments put forward, either in defense of the Ashley treatment or in questioning its legitimacy, rest upon the notion of “best interests.” In the target article Diekema and Fost (2010) argue that the interventions used in Ashley’s case were not contrary to her best interests, a claim supported by Singer in an opinion piece in the New York Times (2007). The authors outline the treatment options in a binary fashion: would Ashley’s interests be best served (or least infringed) by either (a) undergoing aggressive hormone therapy, hysterectomy, and excision of breast buds, thereby eradicating the possibility of breast and menstrual discomfort, and rendering her smaller and lighter so that she could be cared for in a loving family environment; or (b) remaining biologically “complete” but suffering regular discomfort, risk of developing breast cancer, and potentially growing too large and so needing institutional care? Presented like this, the choice is stark. However, there are problems with this presentation. First, it seems implausible that these are the only two options available, but I will return to this point later. Second, the choices offered indicate that should Ashley’s growth have been unrestricted, this would have made it “untenable” for Ashley’s parents “to care for their daughter at home.” However, this possibility is denied by Ashley’s parents in their own blog (2007). Third, it implies that Ashley’s “best” interests are sufficiently knowable to provide the basis for medical decision making. However, the fact is that the best interests of those who are incapable of expressing them are indeterminate. For example, in the case of choices (a) or (b) just listed, we will never know whether (b) would have turned out ultimately to be best for Ashley, because she underwent plan (a). Instead, the best interests of an incompetent person are simply speculative, and while greater weight may be attributed to the suppositions of those closest to the individual concerned, they still remain conjectural. Of greater concern is the fact that in any debate concerning decisions about the health care future of an incompetent person, this indeterminacy permits both sides to claim that their perspective best embraces the interests of that individual. Since two opposing care plans (e.g., to have a hysterectomy, or to not have a hysterectomy) cannot simultaneously represent an individual’s best interests, the use of this doctrine in moral debate is unhelpful. Instead, the decision-making process in the case of Ashley centers on the rights of her parents to make health care choices on her behalf. They proposed that it would be best if Ashley underwent a hitherto untested treatment plan. Ashley’s physicians and the health care ethics committee (HEC) approved. It is a standard legal and ethical principle that competent parents may make health care decisions on behalf of young or incapacitated children. In most states this includes the right to make serious choices, including end-of-life decisions for critically ill children. Allowing parents (rather than physicians or the state) to make these health

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