

Shortening Ashley: Let's not rush to judgement

*Arthur Schafer*

It sounds truly awful: Doctors perform surgery upon and administer powerful hormones to a six year old girl in order to stunt her growth. When one adds that these drastic procedures were undertaken “for the convenience of the parents”, well, the Yuck factor becomes overwhelming.

But in this case, as in many ethically troubling cases, our final judgement is likely to be more clear-sighted if we consider all of the morally relevant facts. Without knowing in detail about Ashley's particular circumstances, we won't understand why the medical and surgical teams were persuaded to go along with her parents' request.

Ashley is profoundly and irreversibly impaired. Although she is now nine years old, her mental age will always be that of an infant. She will never be able to walk or talk. Indeed, her brain damage is so severe that she will never be able to sit in a chair or roll over in bed.

Thus, Ashley requires the highest level of care. As long as she lives, she will need to be diapered, bathed, and transported. Because she has no muscle tone, moving her is like moving a dead weight. If she grows to adult height and weight, meeting her needs at home might be impossible. Since most of her life will be spent in bed, if she is not shifted frequently her body will develop painful bed sores. Bed sores would impose an element of physical torment upon an existence which must, in any event, be a struggle.

Parents of children with severe developmental disabilities often find that they are unable to care for their children at home – they just don't have the emotional and economic resources. Once a child is fully grown, even the most dedicated parents can be defeated by the magnitude of the challenge.

Ashley's parents, however, were determined to raise her at home. The decision to treat her with high-dose oestrogen was intended to stunt her growth while she was still young and of manageable size. Pre-treatment hysterectomy will reduce the risk of thrombosis. The removal of her breast buds was done in part to avoid sexual abuse but primarily so that she would not experience discomfort when lying down.

To describe the choice made by Ashley's parents as motivated by “their own convenience” is a serious misrepresentation. The path of personal convenience would have been to place Ashley in an institution or group home. Even those who think the parents' decision was misguided ought to concede that they acted out of love and concern for Ashley's well-being, not their own self-interest.

Grant me this point, for the sake of argument, so that we can move on to consider whether the parents were nevertheless wrong-headed.

Disability rights advocates have alleged that, by trying “to freeze Ashley in time”, her parents “violated her human rights” and “undermined her dignity”. They have also expressed the fear that what was done to Ashley sets a dangerous precedent, one which puts us on the proverbial slippery slope at the bottom of which is a veritable snake pit existence for the disabled.

Frankly, most of these accusations make no sense to me – not in Ashley’s case, anyway. If keeping her small makes it possible for her to live a comparatively pain-free existence in the comfort of her family home then she will enjoy the only human right that could conceivably matter to her. As for “undignified”, what could that possibly mean in this context? She is incapable of self-awareness. The fact that she is much smaller than she would otherwise have been will not handicap her in either the employment or the romantic marketplace; it will mean, however, that she can accompany her parents on their family outings. More social interactions and fewer medical complications are bound to make her life a little easier. If people “infantilize” her because of her small body, well, that would be appropriate. She is now and will always remain (mentally) an infant. Her best interest, indeed her only interest, is to be kept comfortable and content.

There are, nevertheless, some reasons to be concerned: for example, the hormonal treatment may have unintended side-effects, such as epilepsy or thrombosis. That is, parents confronted with the dilemma of whether to follow the precedent set by Ashley’s family are going to have to weigh the potential medical risks against the potential medical and social benefits. There is no guarantee that the patient will benefit overall. Ashley’s parents and the medical team at their hospital decided that the risks were small and worth taking. In the circumstances, it wasn’t an unreasonable judgement.

Each case should be judged on its own merits. Treatment suitable for Ashley might not be suitable for moderately impaired children.

When a patient is incompetent to make her own decisions, the primary question for caregivers should always be: What’s in the best interests of *this* patient? Where the answer is unclear, the hospital’s ethics committee has a duty to ensure a good outcome. Our awareness of past horrors perpetrated against people with disabilities makes it urgent that there be safeguards in place to prevent abuse.

One additional moral concern should be flagged. If we as a society were willing to provide such families with a full range of personal care support services and equipment then medical intervention to stunt the patient’s growth might be less important. In societies where the prevailing mantra is “lower taxes”, social services for the disabled inevitably get short shrift. Once the needs of the disabled and their families are placed within this wider social context, we will surely find that for most disabled people there are better alternatives than drugs and surgery.

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