

The Ashley Treatment: Creating an Inequality

J Steele, M Miceli

Citation

J Steele, M Miceli. *The Ashley Treatment: Creating an Inequality*. The Internet Journal of Law, Healthcare and Ethics. 2008 Volume 5 Number 2.

Abstract

In the latest in radical medical treatment for a child who has been diagnosed with a severe developmental intellectual disability, physicians have publicly argued that chemically controlling and surgically altering the natural development of Ashley - who is living with static encephalopathy - is an ethically acceptable option on the basis that her parents would be unable to continuously care for her as she continues to physically mature and that her disability would only lead to further medical complications later in life. After extensive and in-depth discussions with physicians and a thorough review by a Seattle Bioethics panel, which approved the request for the treatment, Ashley's parents and acting physicians decided that it was in the best interests of Ashley to have her growth stunted, uterus removed, and to remove any breast tissue that may cause discomfort to her in the future.

According to Clarke and Vasta (2007), one of the arguments put forward for removing her breast buds was that it would "mitigate her sexual appeal to possible predators." This logic was based on the contention that Ashley would become an easy target for abuse and rape as she continued to physically mature. Such a radical surgery was therefore meant to reduce, if not completely eliminate, such possibilities. Regardless of the evidence "that a female with disabilities is twice as likely to be a target of sexual abuse than a female without disabilities, and the risk increases with the more caregivers, attendants or physicians who are involved in treatment and care", it would seem that we now live in a world where we medically mutilate another person in order to prevent individuals capable of committing sexual abuse and other exploitative practices from pursuing their 'interests'. Kind of counterintuitive, isn't it?

From a disability perspective, the traditional approach of viewing disability has risen out of biomedical discourse which focuses on the individual aspects of bodily

functioning. Any deviation from the norm due to an underlying condition reduces the person's ability to function independently in society (Barnes, Mercer, & Shakespeare, 1999). As such, Western culture, in particular, "not only values physical ability and perfection; it devalues and discriminates against those who do not conform to the physical norm" (Morris, 1996, p. 43-44). This notion is evident when Clarke and Vasta (2007) point out that the parents have argued "that having Ashley be a size that is more appropriate to her developmental level makes her less of an anomaly to society and might assure her of the basic dignity and respect all persons deserve." Disability rights activists and their allies have continued to challenge such normative thinking and have argued that disability is not merely a medical or internal dysfunction rendering the individual disabled, but in fact it is equally, if not more, a product of one's physical, environmental, attitudinal and social context (Blackford & Israelite, 2003). It would appear that the attitudes towards Ashley's physicality were far more "disabling" than whatever limitations are inherent to her biology.

Proponents of this treatment have suggested it would provide the child with a better quality of life and the ability of Ashley's caregivers to provide the best possible care. Disability activists argue that healthcare personnel sometimes have an inaccurate impression when considering the 'quality of life' of persons living with disabilities since their perspective can mainly encompass a medical model approach. They arguably presume - in some cases - that it is a life of misery, worthy of pity and compromised by the disability itself. In Ashley's case, she was perceived to be the 'victim' of a personal tragedy and as someone who required continuous physical and personal care. It is certainly plausible that Ashley was in need of continuous care; however, such assumptions may have colored the manner in which treatments were administered.

The choice of Ashley's parents to pursue the procedures for their daughter was arguably not a free and informed choice, primarily because there continues to be both societal discrimination against people with disabilities, and lack of appropriate supports and services for them (Wasserman, Bickenbach, & Wachbroit, 2005). Yet, we can all agree that the intentions of Ashley's parents were benevolent and that they were merely acting out of concern for their child's well-being. However, altering Ashley's physicality and removing her ability to mature in such a manner does not serve any purpose other than to control for the innate fears that were felt over the notion of Ashley developing into a woman (and the lack of available social supports that were made available to her parents). It is this kind of thinking that will continue to damage the very core of what human rights activists have struggled to gain for so long – equality and the

respect for the quality of life for persons with disabilities as full members of society.

References

- r-0. Barnes, C., Mercer, G., & Shakespeare, T. (1999). Understanding disability. In *Exploring disability: A sociological introduction* (pp. 10-38). Cambridge: Polity Press.
- r-1. Blackford, K. A., & Israelite, N. K. (2003). Families and parents with disabilities. In L. Mairon (Ed.), *Voices: Essays on Canadian families* (pp. 141-148). Scarborough, ON: Thomson Nelson.
- r-2. Clarke, P.A., & Vasta, L. (2007). The Ashley treatment: An ethical analysis. *The Internet Journal of Law, Healthcare and Ethics*, 5(1),
- r-3. Morris, J. (1996). 'Lives not worth living'. In J. Morris (Ed.), *Pride against prejudice: Transforming attitudes to disability* (pp. 39-63). London: The Women's Press Ltd.
- r-4. Wasserman, D., Bickenbach, J., Wachbroit, R. (Ed.) (2005). *Quality of life and human difference: Genetic testing, health care and disability*. Cambridge: Cambridge University Press.

Author Information

Jason K. Steele, M.A., M.P.H. (candidate)

College of Medicine, University of Saskatchewan

Michael G. Miceli, Ph.D. Candiate

Critical Disability Studies Graduate Programme Office, York University