

Recommendations issued on controversial 'Ashley' procedure for disabled children

November 30 2010

(Garrison, NY) Should parents be able to use medical means to restrict the growth of profoundly disabled children to make them easier to care for at home? A working group convened to discuss the ethical and policy considerations of "growth attenuation" proposes some guidelines in an article in the [Hastings Center Report](#). Personal essays – including those of parents whose children cannot walk or speak -- accompany the article

Growth attenuation is the use of estrogen supplements to restrict a child's growth. Debate has raged since 2006, when the first case of the procedure came to light involving Ashley, a 6-year-old girl with profound developmental disabilities who underwent growth attenuation in Seattle Children's Hospital at the request of her parents.

The justification was that growth attenuation would enable Ashley's parents to more easily move her, dress her, and involve her in family gatherings. But the intervention drew strong criticisms, particularly from disability rights and family support groups, who compared it to involuntary sterilization and other horrific treatments inflicted on disabled people throughout history, ostensibly for both individual and social benefit.

The Seattle Growth Attenuation and Ethics Working Group consisted of 20 people, including Erik Parens, senior research scholar at The Hastings Center, as well as pediatricians, lawyers, and philosophers with diverse perspectives and experiences on disability issues. A few were directly involved in the Ashley case, and nearly half either have severely disabled

family members or are severely disabled themselves.

The group could not reach consensus, but it did reach a compromise: "growth attenuation can be an ethically acceptable decision because the benefits and risks are similar to those associated with other decisions that parents make for their profoundly [disabled children](#) and about which reasonable people disagree."

The group stressed the importance of having safeguards in place, such as eligibility criteria, a thorough decision-making process, and the involvement of ethics consultants or committees. Growth attenuation should be considered only for children who are nonambulatory and have persistent, profound developmental disabilities – about 4,000 such children are born each year in the United States. The decision-making process should begin with a competent evaluation of the child's condition by general pediatricians and various specialists, who can also assess the prospects for improvement.

In addition, clinicians should give parents information about the anticipated benefits and risks to the child, and about alternative options for including the child in family activities. As part of the information-gathering process, the group agreed "that parents should be given the opportunity to talk with other [parents](#) of profoundly disabled children in order to dispel any myths or assumptions about what life with a maturing child with profound developmental disabilities would be like."

Provided by The Hastings Center

Citation: Recommendations issued on controversial 'Ashley' procedure for disabled children (2010, November 30) retrieved 4 May 2024 from <https://medicalxpress.com/news/2010-11-issued-controversial-ashley-procedure-disabled.html>

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