

**A Statement of the Governance Board of Directors of the
National Catholic Partnership on Disability (NCPD) in response to
“Attenuating Growth in Children with Profound Developmental Disability:
A New Approach to an Old Dilemma”¹**

Executive Summary

Last fall, doctors at the University of Washington reported on a treatment they hoped would enable parents to continue caring for their profoundly disabled children at home. Known as "Ashley's Treatment," after the non-ambulatory girl with severe cognitive impairments who was the procedure's subject, the proposal involves injecting young patients with large doses of estrogen over time to attenuate their normal growth. Small in stature, such children would arguably prove easier for parents to lift, bathe, and transport, as they grow older—thus, making it easier to continue caring for them at home.

“Ashley’s Treatment” is not a morally acceptable medical procedure. The presence of a disabling condition does not negate the right of persons to have the integrity of their remaining healthy bodily functions respected. "Ashley's Treatment" violates this principle. It would stunt skeletal growth as the direct means of preserving home care. Though ultimately aimed at benefiting the child, the immediate goal of the procedure is undeniably the convenience of the caregivers. As Ashley’s doctors concede, “[t]he primary benefit offered by growth attenuation is the potential to make caring for the child less burdensome and therefore more accessible.”² Furthermore, there is no indication that moral alternatives were considered by Ashley’s doctors before embarking on growth attenuation.

The eugenics movement of the past century and its massive violation of disabled persons’ human dignity require that any regimen that may involve impairing a disabled person’s healthy bodily functions meet a high threshold of professional scrutiny. The proposed procedure, with its known and unknown risks, falls far short of the mark since it has never been subjected to any rigorous clinical trials.

The threat of a slippery slope is no mere abstraction here. Once a decision was made to compromise Ashley's growth, it became easier to elect to remove her healthy uterus and breast-buds. Moreover, parents whose disabled children pose other management risks might also be drawn to this treatment option. Widespread availability of “Ashley’s Treatment” would undermine efforts to make resources more available for home care by providing an expedient alternative for society to address the basic needs of profoundly impaired individuals.

The dilemma faced by this family exposes not only the lack of societal supports which could have negated the use of the procedure, but the vulnerable desperation felt by many parents who care for family members. The concerns are real, but should be addressed by providing appropriate supports rather than violating an individual’s rights and dignity. Undoubtedly, the most selfless sacrifice parents of children with disabilities make is to overcome their fears and accept their children for the persons they are and will become. “Ashley’s Treatment” is a surrender to fear and a denial of the dignity of the human person.



415 Michigan Avenue, NE, Suite 95, Washington, DC 20017
202-529-2933 (v); 202-529-2934 (tty); 202-529-4678 (fax); www.ncpd.org

¹ Daniel F. Gunther and Douglas S. Diekema, *Archives of Pediatric & Adolescence Medicine* 2006; 160: 1013-1017.

² Gunther and Diekema, 1016.