

**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**

*In October of 2006, doctors at the University of Washington reported in the **Archives of Pediatrics & Adolescent Medicine** on a treatment protocol they hoped would enable parents to continue caring at home for their daughter diagnosed with static encephalopathy with marked global developmental deficits. The girl is non-ambulatory and has severe, combined neurological and cognitive impairment. The procedure 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. The doctors further argued that such children would suffer less discomfort and could benefit longer from integration in a loving family environment. After outlining numerous safeguards, they concluded that “In the presence of those safeguards, we suggest that such treatment is both ethical and feasible and should be an option available to parents.”² In a subsequent internet “blog” published in January 2007, the patient’s parents explained their motivation for agreeing to what they called “Ashley’s Treatment” and promoted its availability for parents in similar situations.*

Treating Every Person with Dignity

The procedure described by Doctors Gunther and Diekema as *Growth Attenuation* raises considerable moral and ethical questions, and must not be considered an acceptable treatment option as presented.

It is an established principle of professional practice that those with developmental disabilities should live in as normal a setting as possible—that is, one that closely approximates a family environment. Thus, the professional objective of *Growth Attenuation* is understandable since it aims at keeping such persons at home, as well as mitigating other developmental issues that are the reality for persons with severe developmental disabilities.

However, no matter how praiseworthy a treatment goal, it cannot be achieved by immoral means that violate the dignity of a person. In this protocol, dignity is violated when the person’s bodily integrity is compromised. More specifically, bodily integrity is violated when a healthy bodily function, such as skeletal growth, is sacrificed for the convenience of others. Missing in Gunther and Diekema’s justification for such therapy is a consideration of the moral alternatives available that do not involve unnatural modification and violation of bodily integrity.

As the doctors themselves observe, the eugenics movement of the past century and its massive violation of disabled persons’ human dignity, through involuntary sterilization programs among other outrages, requires that any regimen that may involve impairing a disabled person’s bodily integrity meet a high threshold of ethical scrutiny. The violations of the past, and present attempts to justify such protocol only reinforce the necessity of understanding the moral consequences of *Growth Attenuation*.

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

² Gunther and Diekema, 1017.

We must affirm and uphold a long-held principle: the presence of a disabling condition does not negate the right of persons to respect for the integrity of their remaining healthy bodily functions.

Clearly, *Growth Attenuation* violates this principle. It stunts skeletal growth, a healthy bodily function, as the direct means for preserving home care. Though ultimately aimed at benefiting the child, the immediate goal of the procedure stated by Gunther and Diekema is undeniably the convenience of the caregivers: “[t]he primary benefit offered by growth attenuation is the potential to make caring for the child less burdensome and therefore more accessible.”³

Weighing Risks

In addition to the moral issues presented by this protocol, nothing in the current scientific literature provides any clear assurances that the benefits outweigh the potential risks. *Growth Attenuation* has never been applied to a young, disabled population. The risk of thrombosis and seizure, associated with increased estrogen levels, not to mention the unknown risks from stunting normal growth, have not been subjected to rigorous clinical trials. Although weight as well as height is a critical factor in the hypothesis that limited growth will enhance the ability of parents to continue home care, the doctors have provided no evidence demonstrating a correlation between decreased weight and high-level estrogen treatment. Potential weight gain in proportion to shorter stature could pose additional health risks to individuals undergoing this protocol.⁴

The permanence of *Growth Attenuation* is another concern. This experimental procedure presupposes that no significant functional improvement is likely, despite the remarkable advances in the habilitation of people with developmental disabilities that have occurred in the past decades.

Finally, the threat of embarking on the slippery slope to unethical medical practice is by no means a mere abstraction in this case. Once a decision is made to compromise the growth of a person with severe developmental disabilities, it becomes easier to decide to remove a healthy uterus, as was done in the case reported by Gunther and Diekema, not only to avoid the excessive menstrual bleeding that would result from the treatment, but to avoid any discomfort that would result from a normal menses in the future, and to avoid any speculative risk of pregnancy if rape occurred. Further, as explained by the parents, it was then decided to remove the breast-buds, which would develop as a result of the treatment, even though there was no indication that such development would be abnormal, because mature breasts might cause her some discomfort and might increase the possibility for sexual abuse.

An additional danger posed by this procedure involves its application to other individuals. While the doctors cautioned against extending the procedure to other than non-ambulatory, profoundly developmentally disabled patients, clearly some parents whose disabled children pose different management risks—violent behavior or extreme hyperactivity, for example—might also be drawn to this treatment option, and may be successful in persuading ethics committees of such a perceived

³ Gunther and Diekema, 1016.

⁴ See Jeffrey Brosco and Chris Feudtner, “Growth Attenuation: A Diminutive Solution to a Daunting Problem,” *Archives of Pediatric & Adolescent Medicine* 2006; 160: 1077, where precisely this point is made. Brosco and Feudtner believe the practice is ill advised at present.

necessity.⁵

Considering Alternative Supports

NCPD recognizes the profound moral, as well as societal issues raised by the use of the *Growth Attenuation* protocol. The debate invited by Gunther and Diekema's disclosure of the procedure in the *Archives of Pediatrics & Adolescent Medicine* demands a thoughtful response. The dilemma faced by this family serves to expose 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 are now caring for such family members. The concerns are very real, but should be addressed by providing appropriate supports rather than violating the rights and dignity of an individual with profound disabilities.⁶ Widespread availability of the *Growth Attenuation* protocol, as advocated by Gunther and Diekema, would undermine efforts to make family support resources more available for home care by providing an expedient alternative for society to address the basic needs of these individuals.

Parents often make heroic efforts to care for and protect their children with disabilities. But undoubtedly their most selfless sacrifice is to overcome their fears and accept their children for the persons they are and will become. *Growth Attenuation* is a surrender to fear and a denial of the dignity and worth of the human person.

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⁵ The Board of Directors of the American Association on Intellectual and Developmental Disabilities, (AAIDD), the oldest multi-disciplinary association in the United States representing professionals in the field of intellectual and developmental disabilities, makes this very point in their statement condemning this treatment in “Unjustifiable Non-therapy: A response to Gunther and Diekema (2006) and to the issue of growth attenuation,” at http://www.aamr.org/Policies/board_positions/growth.shtml.

⁶ The AAIDD board in “Unjustifiable Non-Therapy,” makes this point as well.