

Growth Attenuation

A Diminutive Solution to a Daunting Problem

SHOULD HORMONE THERAPY BE USED TO MAKE children with profound impairment smaller? This question—having within it the key elements of a modern tragedy—needs to be handled with supreme care regarding both the predicament it addresses and the treatment it proposes.

Consider the predicament: among the many extraordinary problems confronted by parents of children with profound cognitive and physical disabilities, figuring out how to provide care as the child grows into an adult is among the most difficult to solve and distressing to contemplate. When parents age and face disability themselves, many find increasingly difficult the tasks of bathing, diapering, and transferring their adolescent and adult children, who have grown larger, heavier, and perhaps stronger. Additionally, as the child transitions from the pediatric into the adult system of medical and social services care, parents often have less access to personal care aids or to useful but expensive devices such as mechanical lifts. Having devoted much of their lives to meeting the basic daily needs of their child, many parents find themselves forced to find out-of-home placements for their son or daughter.

See also pages 1013 and 1035

Now examine the proposed treatment: in this issue of the ARCHIVES, Gunther and Diekema¹ offer a medical solution to families who will likely face the harrowing choice of what to do when their child becomes too big to care for at home. Specifically, the authors suggest that high-dose estrogen could be used to attenuate the growth of children with profound developmental disabilities (which they characterize as a combination of severe neurologic and cognitive impairment). They present a case study and some historical context and describe the risks and benefits of treatment with high-dose estrogen. Gunther and Diekema conclude that growth attenuation may be appropriate “when parents request it.” They urge caution in the wider implementation of growth attenuation, suggesting that a developmental specialist and an ethics committee be involved in each case.

Combined together, the predicament and the proposed intervention raise 4 central questions.

First, quite practically, will the treatment work? More precisely, will the administration of high-dose es-

trogen to children with profound disabilities enable them to remain at home under the care of their parents for a longer period? And will this improve the quality of their lives? The answers to these pivotal questions are unknown, which underscores the highly speculative aspect to the medical strategy proposed by Gunther and Diekema. While there are data that high-dose estrogen treatment will make extremely tall-for-age (but otherwise normal) girls shorter as adults, this effect may be different in the population of children with severe disabilities. More needs to be known. What is the typical velocity of linear growth over time and final adult height in this population? When in a child’s growth trajectory would estrogen have to be given to achieve a clinically significant reduction in height but without making them excessively short? What is the correlation between final adult height (which might be reduced by high-dose estrogen treatment) and weight (which may not be limited by this treatment), since weight is likely as important a factor as height with regard to the physical burdens of care? Furthermore, given the association between low-dose estrogen therapy and seizures, consideration of potential adverse effects of high-dose therapy should be studied in this population that is predisposed to or has epilepsy. And ultimately, the motivating hypothesis—namely, that young adults with profound impairment who are shorter and lighter stay at home longer and are (on their own terms) happier than their taller and heavier peers—should be tested through a randomized controlled trial or other rigorous methods with adequate follow-up.

Second, more generally, is manipulating nature in this heavy-handed manner acceptable? Some readers might recoil from the idea of “shortening” people, feeling that it seems just plain wrong to so dramatically change a person’s physical stature. In truth, though, American society is fairly accepting—even encouraging—of other forms of medical therapy that seek to enhance one’s existence. If in the pursuit of a more perfect appearance, adults and even teenagers can readily enlist plastic surgeons to fix noses or augment breasts—and there is no moral outrage over this unnatural modification—then perhaps we should be more circumspect about decrying the treatment proposed by Gunther and Diekema as unnatural or abnormal. Indeed, as Lee and Howell² point out in this issue of the ARCHIVES, estrogen has long been used to attenuate growth in girls destined to be taller than average. Furthermore, if what of-

fends us is simply the idea of a small adult, we are wise to recall the lessons of the late 20th-century disability rights movement in the United States: there is value in every human life regardless of how closely any of us approximates average size, function, or appearance.³ Persons with a medical or genetic condition that results in severe short stature typically reject the idea that they are any less “normal” than average-sized persons, and exceedingly few opt for surgical fixes to lengthen limbs and appear taller. Is it right to reject the Gunther and Diekema plan simply because the potential results—a smaller adult—strike some of us as odd? Not if we truly believe that the worth of a person goes deeper than his or her physical appearance.

Third, somewhat speculatively, might the treatment be misused? Given the history of persons with disabilities over the past 100 years—as mentioned by Gunther and Diekema—concern on this front is warranted. The eugenic movement of the first half of the 20th century, although now routinely castigated, was at the time championed by mainstream scholars and societal leaders across the political spectrum.⁴ Well-meaning eugenic advocates hoped to eliminate pain from disease and inequity in US society by allowing “defective” infants to die, encouraging certain couples to marry, and discouraging others from parenthood. Because they believed that persons with mental retardation could not be trusted to understand the wisdom of eugenics, many states passed laws that led to the involuntary sterilization of adults with mental retardation. Upheld by the US Supreme Court in their 1927 *Buck v Bell* decision, such laws resulted in more than 60 000 individuals being sterilized. Although eugenics was viewed with mounting disdain after World War II, sterilizations of persons with mental retardation continued in the United States through the 1960s, and it was still routine practice in the 1970s to allow a child with Down syndrome to die of lack of surgical correction of duodenal atresia. In this historical context, the proposal to radically alter the growth patterns of a child with severe disabilities demands the utmost scrutiny and, if implemented, the most thorough safeguards and protections.

Finally, and most broadly, does the proposed treatment do justice to the scope of the problem? American society in general, and the medical community in particular, has traditionally sought simple technical fixes for seemingly intractable problems, which often combine biological and social aspects of human existence.⁵ In the end, what might be most distressing about attempts to shorten children with profound disabilities and thus lighten the load on their parents is not only that it might not work or cause undesired adverse effects or be misused; no, more distressing is how this solution fails to situate the plight of these parents, struggling to care for their children, in the larger context of a society failure to provide adequate social support in this most admirable of undertakings. Without this broader reframing of the core predicament, high-dose estrogen therapy to prevent out-of-home placement simply creates a new Sophie’s Choice for parents to confront, where neither letting the child grow unchecked nor imposing shortness is without peril. If we as a society want

to fundamentally revise the nature of the harrowing predicament that these parents face, then, in the end, more funds for home-based services, not more medication, is what is called for.

As Lee and Howell argue in their recounting of the history of hormone therapy for attenuating growth in tall girls, judgments regarding the appropriateness of medical therapy reflect broad appraisals of social and political values as well as specific individualized assessments of health risks and benefits. Treating girls who had idiopathic tall stature with high-dose estrogen arose as a practice in the mid-20th century in the United States, conforming to then prevailing expectations that adult women would fulfill certain gender roles, and declined starting in the 1970s with the rise of the feminist movement. Similarly, the appropriateness of attenuating growth in children with profound developmental disabilities will be judged not only in the privacy of clinical offices or within the confines of institutional review boards but also in the social-political context of both the disability rights movement and the woefully impoverished options for high-quality long-term residential care of children or adults with profound developmental disabilities.

Although we believe that attempts to attenuate growth are ill advised, we applaud Gunther and Diekema for publishing this case report. By focusing on a critical issue and beginning the debate, they help to advance our ethical dialogue as we struggle to define our core values in words, laws, and deeds. If high-dose estrogen treatment is on the right track, the collective community response will bestow general approval on growth attenuation; if not, the criticism may suffice to proscribe this mode of treatment. Only with further research and public discussion will we learn whether attempts to attenuate growth run with or against our fundamental values in caring for children with profound developmental disabilities.

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