

## **IF "Growth Attenuation" is the Answer... What is the Question?**

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### **Abstract Text**

**AIM:** In 2007, AAIDD and many other organizations took a strong, public stand in opposition of what was called in the literature the "growth attenuation" of a girl with disabilities. In fact, far beyond attenuating her growth, she was un-sexed – mutilated by the surgical removal of her ovaries and her breasts. The issue of Ashley is well known, however, we do not have in one place a summary and synthesis of the actions and issues involved in this landmark case.

**METHOD:** Today, many parents across the country are still reported to be requesting the "Ashley Treatment©" for their children. Many associations and famous individuals from ethicist Peter Singer to Self Advocates Becoming Empowered took stands on this case. This presentation will provide a time-line of the events before and after the "treatment".

**RESULTS:** The session will synthesize a perspective of what happened and how it could have ended differently.

Who joined AAIDD in opposing this procedure?

Who failed Ashley?

What does it tell us about our society and our service system safeguards?

If "Growth Attenuation" or the so-called "Ashley Treatment©" is the answer, what is the question?

Special thanks to Disability Rights Washington, formerly Washington Protection and Advocacy Services for their excellent report that was a significant source of the material in this paper.

The Archives of Pediatric and Adolescent Medicine, (Gunther & Diekema, 2006) published a startling article titled: "Attenuating growth in children with profound developmental disability: a new approach to an old dilemma." This journal, published by the American Medical Association, is an old and established medical journal that traces its origins back to 1911. The current mission statement of the journal says (in part) that the journal is:

**"...for physicians and other health care professionals who contribute to the health of children and adolescents".**

So, what exactly was the "old dilemma" and how did the family come to this particular "new approach", and what has become of the issue, the physicians, Ashley and her family?

Gunther & Diekema are both affiliated with the Department of Pediatrics at the Children's Hospital and Regional Medical Center at the well respected University of Washington School of Medicine. In their 2006 article, they use the phrase "growth attenuation", and do not name the individual who has since become known as "Ashley-X" (Her parents have consistently withheld the family name while disclosing great amounts of other personal medical information about their daughter, leading to wild speculation about who the family might be.) In the article, Gunther and Diekema argue that the young girl presented with such a complex constellation of disabilities that a "solution" of this magnitude was warranted.

The physicians recount their assessment of her present condition and her future as well, stating that the combination of her profound disability, including the fact that she is non-ambulatory, means that:

**"...all the necessities of life must be provided by caregivers, usually parents, and that these tasks become more difficult as the child grows to adolescence and adulthood" (pg 1013).**

They go on to say that:

**"...after proper screening and informed consent" (presumably the consent of the parents) "...growth-attenuation therapy should be a therapeutic option available to these children should their parents request it." (Pg 1013).**

In fact, they cite the American Academy of Pediatrics goal of "Healthy People 2010" quoting:

**"...belief that all children, regardless of the presence of disability, belong in families" (pg 1013).**

Armed with the apparent medical certainty that she will always be non-ambulatory, experience severe cognitive impairments, and certain that growth and maturation will only increase her dependency on others, that the procedure will result in greater quality of life, the need for the "treatment" was clear to them. The objectives for the "therapy" were for her to be shorter, to weigh less, and to be easier to care for than if she achieved her normal height. Based on this medical appraisal, with the informed consent of the parents, as well as with the express approval of the hospital ethics committee, the "therapy" was begun.

This initial article describes "high-dose estrogen treatment" to "arrest growth" and to "bring about permanent attenuation in size..." (pg 1013) as well as to **"...reduce the long-term complications of puberty."** (Pg 1014).

In addition, a "pretreatment hysterectomy" was performed and the surgery was described as "uneventful" (pg 1014).

The article presents a lengthy description of the risks of the treatment, which begins with the following sentence

**"Because we have no direct experience with high-dose estrogen treatment in young children, the possible adverse effects and risks are difficult to assess with certainty." (pg 1015).**

Although there was no record in the medical literature of this procedure being used in this way, the physicians reviewed the known complications from similar procedures performed on teenagers with growth disorders. The risks with other patients in the past have included nausea, headache, weight gain, uterine bleeding. One might assume that Ashley, based on their description of her functioning, is apparently unable to communicate her discomfort from nausea or headache, and weight gain would seemingly defeat the purpose of the "treatment". Other risks include thrombosis, including deep vein thrombosis.

The physicians conclude:

**"These risks do not appear to be unreasonable and are not out of line with the risks of other medical interventions these children undergo" (pg 1016-17).**

Frankly, this initial discussion of the situation was more than enough to draw the concern of individuals and groups across the US and beyond. However, in subsequent months, additional information became available about the treatment and the decision-making process.

Immediately, the Board of Directors of the American Association on Intellectual and Developmental Disabilities (AAIDD) became concerned, along with a host of other disability organizations. At our December 2006 leadership retreat, we took a formal position in opposition to the concept of what the authors called "growth attenuation" and immediately wrote the journal asking for the opportunity to publish a reply. In the May 2007 issue, our letter was published with the title "Growth Attenuation: Unjustifiable Non-therapy" (Bersani, 2007). Within the editorial constraints of the journal (including a limit of 500 words) Bersani, writing on behalf of the Association stated:

**"...we endorse policies and actions that help families to rear their children at home, and we applaud the efforts of the many professionals who provide extraordinary care to children with intensive and pervasive support needs. However, we view growth attenuation as a totally unacceptable option." (pg 521)**

In that same issue, Drs. Gunther & Diekema (2007) replied:

**"Dr Bersani strongly objects to the proactive measures we have taken to attenuate the growth of our profoundly developmentally disabled patient, which we believe has improved the quality of her life and that of her family."**

**"...he insists that 'both law and ethics demand that these rights be protected'; this is simply assertion without content. To argue that our actions have violated some right without defining what that right might be is simply rhetoric, not a reasoned argument. It is unclear to us how our patient, with an infant mind, insisting on an adult body protects her interests or dignity."**

**“The attitude that the disability advocates know best does a disservice to parents caring for these profoundly disabled children by minimizing their devotion and challenges and by presupposing that a disability advocate is somehow better positioned to judge what is best for a particular child than the parents who care for that child everyday.”  
(pg 522)**

The group Disability Rights Washington (DRW) the protection and advocacy entity for the state of Washington was able to procure documents from the hospital and the following quotes (unless otherwise noted) have come from that report, available on-line. In those documents, Ashley is described (in May of 2004) as:

**“A 6-3/4 year old female who has static encephalopathy of undetermined etiology with:  
Profound developmental delay/mental retardation  
Global hypotonia with a  
Virtual absence of voluntary movements,  
Absent coordinated swallowing  
Heel cord contractures  
Scoliosis  
Possible reflux  
Possible seizures  
Precocious puberty...”**

One can not help but note that although this litany does indeed describe a girl with serious disabilities, the surgeries and treatments she received fail to address any of these specifics. Even if growth attenuation is achieved, and there is the sought after relief from the “long-term complications of puberty”, she would presumably continue to have static encephalopathy, profound developmental delay, global atonia, with an absence of voluntary movements. She will continue to lack coordinated swallowing, experience heel cord contractures, scoliosis, possible reflux, and possible seizures. The treatment - if successful - may arrest (but not reverse) the precocious puberty.

Clearly aggressive therapy is warranted, but to what end growth attenuation? Surgeries for the heel cord contractures, adaptive equipment (and possible surgery) for the scoliosis, augmentative communication devices, special education all seem warranted. None of them depend on her growth being attenuated or her weight minimized.

Also in May of 2005, the hospital Ethics Committee report stated:

**"...the consensus of the committee members was that the potential long term benefit to Ashley herself outweighed the risks and that the procedures/interventions would improve her quality of life..."**

The Ethics Committee stated that the benefits of the hysterectomy include:

**"to avoid the menstrual cycle..., physical discomfort..., hygienic issues, and...the anxiety in an individual unable to understand what is going on and... to totally exclude the possibility of the patient being sexually assaulted and impregnated".**

It is important to note here, that to get permission to sterilize a child is a legally daunting feat in this day and age. However, in June of 2004, Larry Jones, Ph.D., J.D. wrote a letter to Ashley's father with an important legal opinion. In that letter (obtained by DRW) Attorney Jones states:

**"It is not necessary to have a court hearing on sterilization when the object of the medical procedure is not sterilization, but to obtain another medically necessary benefit."**

Thus, by listing medical benefits, the family can seek a medical procedure of a total hysterectomy, which just so happens to have the side-effect of sterilization, without the burden of a court decision in support of sterilization.

Let's return to the list of reasons for the hysterectomy. The first three: to avoid the menstrual cycle...physical discomfort..., hygienic issues, can be accomplished in this manner. One can also argue that such symptoms can be dealt with in other ways, and are not seen as a reason for radical surgery in the general population.

However, note the final two reasons: "the anxiety in an individual unable to understand what is going on", and "...to totally exclude the possibility of the patient being sexually assaulted and impregnated".

Certainly her ability to understand what is going on is not addressed with this treatment, and in fact, the treatment presents additional difficult situations far beyond menstruation for her to be anxious about (and again the anxiety can be managed in other ways).

Finally, the hysterectomy (the non-sterilization sterilization) is warranted by the hospital Ethics Committee to:

**“...totally exclude the possibility of the patient being sexually assaulted and impregnated”.**

Certainly the Ethics Committee of the Medical School at the University of Washington does not think that a hysterectomy offers protection from sexual assault. So presumably this is a poorly crafted sentence intended to convey that if she should somehow be sexually assaulted, (while under the total care of her parents) she would not get pregnant. Remember that the purpose of the “treatment” is to keep her at home and out of care facilities where abuse might happen.

I am willing to concede that avoiding pregnancy for Ashley is a sound idea, however, I fear worse consequences for her following a sexual assault (post traumatic stress syndrome, sexually transmitted disease, physical trauma), and it must be pointed out that the surgery offers no protections from these possibilities. In fact, one might argue that the combination of not speaking, and not being able to conceive might paradoxically increase her risk for sexual assault by making her a safer “target” of a predator.

One of the troubling themes in this case study is the level of certainty of the physicians, parents, and the Ethics Committee. They seem unaware of the vagaries of determining at age 6 or 7 what the quality of life will be for an adult with severe disabilities, especially one for a family such as Ashley’s who possess substantial emotional as well as economic resources. Physicians can (usually) accurately predict the sequelae of a specific disease. They are not experts in the future outcomes of people with disabilities, or the effectiveness of non-medical interventions.

### **Some relevant dates/events**

**January 2, 2007.** Ashley’s parents began a blog to describe the medical interventions they sought for their daughter (<http://ashleytreatment.spaces.live.com>). One of the early postings on the blog states:

**“We call it Ashley Treatment because...As far as we know she is the first child to receive this treatment. We wanted a name that is was to remember and search for. The name applies to a collection of procedures to improve her quality of life – more than just “growth attenuation”**

In fact, they have reportedly copyrighted the term "Ashley Treatment"© and so I have used the © in conjunction with the term in this paper. The blog describes the "Ashley Treatment©" as including: Sterilization (total hysterectomy), Dual Mastectomy (Breast bud removal), High dose estrogen therapy (to promote growth attenuation by fusing the growth plates of bones) and a prophylactic appendectomy.

On the blog, the parents state the goals of the Ashley Treatment© as limiting final height (and therefore weight). The perceived benefits of these procedures include:

**Avoiding menstruation and cramps**

**Limiting growth of breasts**

**Protect against the 5% chance of appendicitis  
with "no additional risk"**

**Sterilization is a "side effect" of the treatment, not its intent**

The blog also begins to refer to Ashley and others like her as "Pillow Angels". A group calling themselves "Friends of Pillow Angles" posts information on the "Ashley Treatment" to the web. <http://pillowangel.org/AT-Summary.pdf>

The website describes the surgery as taking about "two hours" and as being **"About as risky as a tonsillectomy"**. They also point out the radical surgeries and hormone treatment dramatically reduces her risk for several cancers.

**January 12, 2007.** Dr. Diekema was interviewed on Larry King, says of the Ethics Committee:

**"I can tell you that there was no one in the room who disagreed with the decision".**

This may be one of the most disturbing statements to me – this level of uncertainty is not common among those of us with decades of experience in the daily lives of people with such complex disabilities.

**May 8, 2007.** After a lengthy review, the Washington Protection and Advocacy Services office (which then became Disability Rights Washington) found that hospital that performed the surgery violated the law by not having a court order.

**September 30<sup>th</sup>, 2007.** Dr. Daniel F. Gunther died from toxic asphyxia from inhaling car exhaust.

**October, 2007.** The journal *Intellectual and Developmental Disabilities* published the position statement of AAIDD on the issue (Bersani et al, 2007). At about the same time, other groups respond including: L'Arche Canada, the National Catholic Conference on Disability, and UCP & the Arc issue a joint statement.

### **Comments/Questions**

**Growth attenuation or unsexing?** The list of Ashley's disabilities may be true, but they are not addressed by the "treatment". They serve, rather, to differentiate Ashley and other "Pillow Angels" from "us" to make more palatable the experimentation and mutilation being proposed. Only the medical "problems" of puberty and pregnancy are resolved by the course of "treatment". This can only be called "unsexing".

### **If the goal is limiting weight and height...**

Given the "medical certainty" that she will never walk, and by a logical extension of the physicians' argument, one could conclude that better height/weight control could be obtained by prophylactic dual amputation of her legs. This would also reduce the known risk of decubitus ulcer, and would minimize the possibility of deep vein thrombosis in the legs which is a risk that actually increased with the procedure that was used. Clearly a "Pillow Angel" has no need of legs.

### **Parental Judgment without question?**

Drs. Gunther & Diekma seem to imply that professionals can not use their expertise and training to question the requests of a parent. One needs to ask if doctors, when observing an abusive situation, have an obligation to bring their professional training & ethics to bear on a situation, or merely defer to the parents who "care for that child every da."

### **Treatment or Experimentation?**

I believe one has to ask: Is it honest to describe this as treatment when in fact it reads much more like an experiment? (One in which the scientists admit no direct experience)? They are so certain about her prognosis without the "treatment", but admit they can not be certain about the possible adverse effects and risks of the treatment. The fact that the physicians admit that they have "no direct experience with high dose estrogen treatment in young children" and that "adverse effects and risks are difficult to assess" seem to argue that this is in fact an experiment, rather than a treatment.

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