Karen Leitson

Personhood

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**Ethical Questions Raised by Growth Attenuation Therapy for Severely Disabled Children**

**Introduction**

Growth attenuation therapy for severely disabled children is a very controversial, very drastic intervention. Growth attenuation therapy (GAT) brings a plethora of ethical questions and concerns. Parents and health care providers offer several justifications for proceeding with growth attenuation for their children and patients. Some say they support growth attenuation to lessen their child’s discomfort because she spends so much time in bed, to limit bedsores that occur more often to larger people, to be able to “cuddle” with their child more easily, to be able to carry their child on hikes and around the house and be able to more easily bring their child to family events. Parents maintain that if their child remains small, she will overall, be more a part of the family structure. In the two cases below, the parents do not admit to forcing their child in to perpetual smallness in order to minimize their own pain and the hardship of raising a child with a debilitating disability.

I will describe and discuss the cases of Ashley, known as the Pillow Angel and Ricky Preslar (discussed in a recent NY Times Magazine article) in light of the principles of respect for autonomy and beneficence and human rights of people who are disabled. I will discuss the justifications for growth attenuation therapy from the parents’ perspectives while arguing for a society that accepts disability and assists parents and families in caring for their very difficult-to-care-for children.

**What is growth attenuation therapy?**

Growth attenuation is medical treatment targeted at limiting or stopping growth. Primarily, medication is given to close the epiphyseal plates or growth plates at the ends of long bones in order to diminish growth and ultimately limit adult size.In the 1950s, estrogen was given to tall girls so they would not have to cope with the anti-social aspects of tallness. Girls were not supposed to be taller than boys. Out of those experiences, came the research to prove that growth could be attenuated by the admiration of estrogen.

There are risks associated with administering such large does of estrogen. But, all medical interventions come with risk. A focus on the medical risks of growth attenuation is beside the point of this paper. Growth attenuation therapy for children with severe physical and cognitive disabilities is not rare. As of July 2015, close to 100 cases are documented (*Guardian* newspaper). Only a portion of these interventions were approved by ethics committees. In the cases of Ashely and Ricky, growth attention therapy included additional interventions, descried in their individual sections.

**Ashley**

Ashely was born with severe physical and brain injuries that her doctors said were beyond repair or improvement. Her diagnosis is “static encephalopathy of unknown etiology”. There’s really not much that Ashely can do. She can’t hold her head up, can’t sit up, she can’t roll over and she can’t feed herself. According to her parents, Ashley seems to enjoy television and listening to music. In fact, when she listens to music she moves her arms and smiles. She sometimes, but rarely, makes eye contact. Ashely doesn’t have additional illnesses that would compromise normal growth and a normal life span.

Because they want to care for Ashley at home, Ashley’s parents, who continue to go unnamed but go by the initials AM and AD (Ashley’s mom and Ashley’s dad), considered and moved forward with major interventions so that Ashely would not grow or develop sexually. AM and AD received approval to treat Ashley from Seattle Children’s Hospital and its bioethics committees to proceed with growth attenuation therapy. In 2004, At the age of six, Ashley underwent growth attenuation including high-dose skin-patch estrogen, hysterectomy to eliminate her menstrual cycle and its associated discomfort, and breast buds removal to avoid the development of expected large breasts, since in addition to a having a family history of breast cancer and fibrocystic disease, her mother has large breasts. Ashely parents believed monthly menstrual periods would be traumatic. The therapy reduced Ashley’s height by about 13”.

Ashely’s parents, refer to her as “Pillow Angel” because she “is so sweet and stays right where we put her- usually on her pillow” and, because “she’s an angel” (PillowAngel.org). The term “pillow angel” is now a coined term used to describe the disabled children who have undergone growth attenuation therapy. The growth attenuation regimen that Ashley received is known as the “Ashley Treatment.”

**Ricky**

Ricky’s story is similar to Ashley’s, but, being a boy, his growth attenuation treatment was different. Ricky Preslar, born with a form of cerebral palsy known as spastic quadriplegia with static encephalopathy (Smith, Genevieve). Similar to Ashley, Ricky can’t walk, talk, or feed himself. Ricky has permanent brain damage and very limited eyesight. Although he’s seven years old, he’s at the developmental stage of a six-month old baby. That won’t change.

Ricky’s parents, Matt and Cindy, first heard about growth attenuation treatment after reading about Ashley. After some discussion, when Ricky was four years old, they decided to go forward with growth attenuation therapy. The Preslar’s also thought that it would be easier to care for Ricky if he were smaller. Ricky’s medical team is in Colorado; the Seattle Children’s Hospital has since stopped doing GAT. For years Ricky, as did Ashley, received high doses of estrogen to close the epiphyseal plates. The intervention was successful. Although the Preslar’s were offered breast buds removal for Ricky, for cosmetic purposes, they declined. At 42 inches tall and 37 pounds, Ricky has stopped growing.

It’s been two years since Ricky’s GA intervention; his parents have no regrets. Cindy says that sometimes she sees “purposeful” movement; Ricky uses a communication assistive device to stop and start video games. When Cindy, Ricky’s mother recently strained her back, she said he was glad that Ricky was small.

**A few of the others**

At the age of eight, Tom, adopted from Vietnam, was the first boy to undergo growth attenuation therapy. His parents also, learned about the treatment from Ashley. Although Tom’s diagnosis is different from Ashley and Ricky’s –he has epilepsy- he is similarly physically and intellectually disabled. In addition to having the cognitive ability of a two-month old, Tom also could not walk, talk or feed himself. Fearful of a what it would be like to care for Tom as he aged, his parents elected growth attenuation therapy.

Anne Macdonald’s story is a both similar and different and is very significant. Hers is a story of “natural” growth attenuation. Anne’s brain damage was caused by her breech birth in 1961. Her diagnosis is static encephalopathy, the same as Ashley’s. When she was three years old and assessed to be severely retarded, Anne was admitted to a state institution in Melbourne, Australia. The conditions at this hospital were terrible; The institution didn’t provide Anne with a wheelchair so she lay in bed or on the floor for most of 14 years! She was starved in the institution. By the time Anne was 12 she hadn’t learned to walk or talk. When she was 18 years old, Anne weighed 35 pounds; she was 42 inches tall, had not menstruated and did not have breasts. Anne says her life changed when, at age 16, she learned to communicate with an alphabet board. She pointed to letters and two years later worked with lawyers who enabled her discharge from the institution. Now Anne still can’t walk, still can’t talk and still can’t feed herself. But, she began eating and grew an additional 18” to 5” and 120 pounds. Ann completed college, travels and wrote an article about her life. Anne is a fierce critic of growth attenuation therapy (MacDonald, 2007).

There is no indication of any motives that call into question the deep love, compassion and devotion that Ashley, Ricky and Tom’s parents have for their children. Ashley and Ricky’s parents didn’t choose to have their life altered and challenged so drastically. Most often I say, “the parent is usually right” and “people just don’t know what it’s like.” Although I believe that these parents acted out of love and that their actions came from a desire that their children have a better life, Ashley and Ricky were harmed. Their personhood was violated. Although I put a high value on parents’ choices and parents’ human and constitutional right to make medical decisions for their children, I think the parents overstepped.[[1]](#footnote-1)

But, as Eva Kittay reminds us In the face of the extensive criticism directed at Ashley’s parents, proponents responded that those who had not walked in their shoes ought not to judge them (Wilfond et al. 2010).

Notwithstanding the ethical and personhood questions that growth attenuation therapy poses, there remains lots of room for debate.

**Ethical and Personhood questions posed by Ashely and Ricky**

To determine if the Ashley Treatment is ethical, the principles of respect for persons, beneficence, no maleficence and justice will be applied to this treatment and its consequences.

Growth attenuation therapy for severely disabled and intellectual disabled children poses serious ethical concerns. Most have been posed and rebutted.

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In October, 2006, Ashley’s medical team, endocrinologist Dr. David Gunther[[2]](#footnote-2) and medical ethicist, Douglas S. Diekema, M.D., M.P.H. wrote about Ashley’s therapy in their article entitled, “Attenuating Growth in Children with Profound Developmental Disability” published in JAMA Pediatrics. Guntherand Diekema describe and defend growth attenuation therapy, both ethically and medically. The authors suggest that as a child’s extensive disabilities develop, carrying, dressing and carrying for her becomes extremely difficult. Growth attenuation therapy can ameliorate some of the problems and hardships. In a media interview, Doctor Diekema further explained why he agreed the procedures were in Ashley’s best interests:

When you look at the growth attenuation, the primary benefits are by being a smaller girl, it will be easier for people to lift her, and will allow her to receive a more personal level of care from her parents for a longer period of time. They really want to be able to pick up their daughter and give her a hug and put her in a chair. It will be easier for them to move her to the car and go on outings rather than thinking about leaving her behind with a caretaker when they go on vacation. As far as removing her uterus with a hysterectomy, there are many profoundly disabled children who are traumatized by menstruation. They don’t understand why there is blood coming from that part of their body, and it’s impossible to make them understand. Unlike a normal 11- or 12-year-old, you can’t explain to them this is a normal part of your development. The family wanted to spare Ashley that drama. Ashley’s a little girl who already had experienced being terrified of blood.

In my mind, Gunther’s and Diekema’s arguments are true but weak.

Why are they weak

Ashley and Ricky’s parents feel disenfranchised and alienated from the communities they have been a party of. The disability community said the ethics committees should include disabled people. That might be good way to mediate the discussion in an effort for both sides to understand each other. But, at the end of the day, it’s Ashley and Ricky’s parents who are home alone with their children.

Ashley’s father, in interview with Ed Pilkington said:

Ashley's most important human right is not to be blocked from receiving a treatment that her parents, doctors and ethics committee all agreed is of benefit to her. Depriving her of the treatment's benefits, thus causing her preventable pain and suffering, would be taking away from her human rights.

We find the suggested analogy to the forced sterilization of individuals with disability (eugenics) to be a shallow one. We see a deeper analogy that leads to the opposite conclusion: a collective policy to block the Ashley treatment from children independent of their individual needs has a deeper similarity to Eugenics. Both are misguided collective policies that harm the individual.

In defense of GAT and a response.

Ashley’s parents, and the ethics committee concurred that there is no hope for improvement. But, Ashely does attend school. I find this a bit of a contradiction. Her parents said, “She has been at the same level of cognitive, mental and physical developmental ability since about three months of age. Ashley’s “mental and physical abilities have remained and will remain those of an infant” (PillowAngel.org).

Tom hated having his hair cut. They posited that if Tom were permitted normal growth and development, he would need to have his beard shaved- causing “similar distress”!(McVeigh, Karen)!

The parents feel alienated from the disabled community that they once felt part of.

At the time of the initial publicity about growth attenuation, Ashley's parents wrote on their blog: "In our opinion only parents of special needs children are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or their caregivers." PIllowangel.org

Anne: communicatin therapy is the way to go

Issue of cerebral palsy vs static enephalooopy- outcry over cerebral pals

**My argument**

**DISPRECT for autonomy**

Karrie Shogren, co-director of the Kansas University Center on Developmental Disabilities, believes that growth-attenuation therapy is too often administered without consulting developmental specialists:

One of my major concerns is that places where this is being done might tend to be places that don’t have strong disability affiliations or support….There’s an inherent conflict between the Ashley Treatment and the current way of thinking about disability.

The current thinking is to presume competence. As we see from the story of Anne- how do we ever know what a person’s ultimate ability will be? Facilitated communication -discuss here Life changes, even for severely cognately disabled people, once they have a means to communicate. Research and empirical evidence shows that when people are given a means to communicate. Evidence reviewed in a recent study showed that 96% reported positive changes in communication for severely disabled people (Snell, 2011).

How is this different from eugenics? Eugenics selects for perfection or a to root out a person-type or non-person. Ashley most likely would never gotten pregnant so her sterilization was different than standard eugenics. But, this seems to me as just another side of the same coin. What is the moral value of a disabled person’s life? Tom Shakespeare says that living as “disabled person is a viable form of existence but that existing without any possibility of a real life is not living at all.” (Shakespeare, 20) That’s an interesting question and relegated to Ashley and Ricky, are they in this category? I don’t think so. He says that disabled people themselves should take up this debate. That makes sense. What do disabled people have to say about growth attenuation therapy for children with such severe disabilities as Ashely and Ricky have? This discussion is not about euthanasia, no one saying that Ashley and Ricky should not live. But, in a way, altering their bodies to such an extent is saying something about their right to live.

The drastic measures ‘done to” Ashely and Ricky presuppose that because they can’t communicate, they are not people. The

Ashley’s parents say that sterilization was a side-effect and not the intent of her growth attenuation therapy. But, it’s a side effect that could not be avoided, having removed her uterus. It seems just like word play to say that it was not intended.

Define and describe eugenics and compare

May be well-intentioned

Some of the arguments presented by Ashley’s parents and her doctors are very weak. Although Ashley’s parents say that that sterilization was an unintended consequence, her bioethicist said that a rationale for hysterectomy is to prevent pregnancy. They wanted to avoid menses, saying that Ashley would “not understand” her monthly cycle. What could she understand? I thought their argument was based on Ashley not having any degree of understanding.

I think we need to think about why parents find it so burdensome to raise a child with a serious disability. There is no question that parents prefer healthy children. That concept doesn’t require us to go that deep. We all have dreams and plans for our lives and they usually do not include carrying for a child with a disability or an illness. But, it happens. I can’t come up with a silver lining reasoning to say it’s all ok. But, our society has to find a way to support the parents of Ashely and help them and Ashley live the best life they can.

Ashley’s parents maintain that they attenuated her growth to make Ashley’s life better, so that she could avoid the trauma of menstruation and large breast. But, in their blog, they say that Ashley weight 65 pounds, just about the “max that they carry.” They admit that her small size makes their lives easier. They also say that the only people that have ever cared for Ashley are themselves and Ashley’s grandparents because they re unable to find quality caretakers. What will happen…..

They admit that they haven’t thought about the future. Ashley’s family is wholly lacking in support- all kinds of support- psychological, social and economic. Her parents say that in addition to AM and AD, only the grandparents have cared for Ashley because they’ve been unable to find qualified caretakers. “We tried hard and found it impossible to find qualified, trustworthy, and affordable care providers”. They continue, “we’re still young and able and perhaps naïve about the future- of course they are naïve about the future!! They said it. They are very naïve. Solutions are hard to come by but how can they not be thinking about the future when their parents will no longer be able to contribute t o Ashley’s care and they too, will age.

Caring for a child with a severe physical and cognitive disability is daunting. First there is the the supreme sadness that the healthy child hoped for is not to be. That’s a heavy adjustment adjustment. I’m sure that sadness does not go away despite the deep and limitless love the parents feel for their child. Then there is work. Lots of it. And, the work gets more difficult as the child becomes older and heavier. It is understandable that parents would consider all options to help make their child’s and their lives any degree less difficult. Many parents, also understandably, choose to move their severely disabled child to a group home or institution or some other placement where they will hopefully receive, quality care. Many parents have other children to care for and just can’t manage all the pulls on their emotional and physical strength. That being said, growth attenuation therapy is an unacceptable assault.

We must change, improve, modify our health care system. We must view disabled children as the children of our community.

Sure caregiving must be easier,

Rea d re disability org.

Field write: to begin to understand why a parent would choose to disrupt the growth of a child it helps to know what goes into caring for someone with severe disability.

How true.

Intentioned consequences?

(ethical theory here)

My opinion of Ashely and her treatment drastically changed when I saw her photos. It sure seems to me that Ashley can make eye contact. The photos on her web page showed a sparkle in her eyes.

Ashley’s parents maintain they took this drastic route to improve the quality of their daughter’s life. Their position statement says they did not proceed with growth attenuation therapy to mitigate their caretaking burden. But, in their testimonial, they report that Ashley’s current weigh of 65 pounds is the maximum they can lift. They contradict themselves. Ashley’s parents continually say she is bored. How does she experience boredom if she is so deprived of emotion? I’m not saying that growth attenuation therapy would be acceptable if AM and AD admitted they may not be able to lift Ashley as she grows or if she did not experience boredom. But, when their arguments are so baseless, it’s difficult to really respect their choices.

Ashley’s parents compare their intervention as that of parents who provide facial reconstructive surgery to their children with disfigured faces or chemotherapy to counter cancer.

**Counter argument**

There are many arguments supporting growth attenuation. Peter Singer, said that the “best interests” principle is in play here and that there is no reason why other parents of children similar to Ashely’s should not have access to the same surgery. He counters arguments that say Ashely should be treated with dignity:

But why should dignity always go together with species membership, no matter what the characteristics of the individual may be? ... Lofty talk about human dignity should not stand in the way of children like her getting the treatment that is best both for them and their families."p

This statement reflects Singer’s views that people with severe mental disabilities are not persons. But, who is to say that Ashley and Ricky do not experience pleasure, one of the hallmarks of personhood?

**Conclusion**

No empirical evidence that smaller people get better care at home

The pediatric bioethicist, Nikki Kerruish, a senior lecturer at the University of Otago in New Zealand, has analyzed the perspectives of parents who support GAT therapy and those who oppose it. (KL order this article\_

What kind of society do we want to build?

M\*\*\*\*ost important, Brosco asks whether the proposed treatment does ‘‘justice to the scope of the problem?’’ His assessment is that the most morally troubling feature of the Ashley case is that it ‘‘fails to situate the plight of these parents struggling to care for their children, in the larger context of a societal failure to provide adequate social support in this most admirable of undertakings.’’ In- stead it offers ‘‘simple technical fixes for seemingly intractable problems, which often combine biological and social aspects of human existence’’ (Brosco 2006, 1077–78).

It would be fool –hearty to suggest that the perfect society could totally relieve the emotional and physical toll caring for a child with severe disabilities. This intervention does not address the problems and inequities in our society for people with disabilities.

We must provide them with the supports and services they need to succeed in what Brosco and Feudtner rightly refer to as their “most admirable of undertakings.” However, growth attenuation of their children should not be included as an option. Under our law, parents are vested with the responsibility for making health care decisions for their minor children, but parental prerogatives are not absolute. Children have their own distinct rights and protections afforded them as individuals established in ethical principles and legal statutes. These rights should be of central relevance in the current situation, yet they did not seem to receive the attention they deserved (AAIID

We want a society that accepts and supports people with disability and their families. We need to educate society about disabilities, what they are, how to be inclusive

Currently our society views people with disabilities as a social and financial burden. People have to “fight’ for their rights and services. Getting a sig language interpreter at doctor’s office is an ordeal, let alone making a building accessible for a person with limited or no mobility.

Inclusive education

Civil rights

Disability Rights groups are overwhelmingly opposed to GAT. Some quotes:

This case marks a dangerous trend and a new low in the medical and ethical treatment of people with disabilities," wrote the Canadian Association for Community Living in a press statement. "It is tacit approval that people with disabilities, particularly those with significant disabilities, are not to be recognized as human in the same way others are. It is explicit approval that the bodies and lives of people with disabilities can be manipulated at others' will.

"We are saddened but not surprised by the fact that this was publicized and met with a great deal of public approval," said Diane Coleman, founder of the disability rights group Not Dead Yet, in press release. "The public is willing to sanction the murders of disabled children by their parents, so it’s hardly surprising they would rush to the support of parents and their medical partners in a matter like this.

ADAPT member Amber Smock of Chicago, Illinois, said: "I am angry that Ashley's parents, the medical establishment and society at large think it is acceptable to surgically and hormonally manipulate Ashley because the reality of her adulthood as a person with a disability is too 'grotesque' for them. With these drastic measures, her parents and doctors are physically reinforcing the disrespectful attitude held by many that people with disabilities are all 'childlike,' and can be treated like property or science experiments.

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Growth attenuation

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Growth Attenuation Therapy. Tom: the first boy to undergo procedure

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Alicia R. Oullette, J.D.

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GROWTH ATTENUATION, PARENTAL CHOICE, AND THE RIGHTS OF DISABLED CHILDREN: LESSONS FROM THE ASHLEY X CASE Alicia R.

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AAIDD Board of Directors

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1. The law recognizes that although parents may seek procedures without intending to inflict harm—parents seek procedures for cultural and religious reasons—their damaging physical, sexual, and psychological effects may make the procedure an unacceptable act of violence against women and children (Davis, Dena 2001). As this not a legal paper, I will not pursue this line of thinking. [↑](#footnote-ref-1)
2. A year after Dr. David Gunther co-published a paper about Ashley, he committed suicide [↑](#footnote-ref-2)