

## **Scrutinizing Ashley X: Presumed Medical “Solutions” vs. Real Social Adaptation**

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*“This case was about making one little girl’s life and one family’s experience a little better. We were not trying to set precedent or policy” - Douglas Diekema (2008)*

At the end of 2006 Daniel Gunther and Douglas Diekema published “Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma” in the *Archives of Pediatric and Adolescent Medicine* that caused a storm of controversy. Ill prepared for the spotlight and intense media interest, Ashley X’s parents complicated matters in January of 2007 by posting a blog about their daughter and children like her deemed “pillow angels”. It is our belief that Diekema, Ashley X’s parents, and proponents of the Ashley Treatment, now referred to as growth attenuation, are disingenuous. On the one hand they collectively argue the Ashley Treatment was about one profoundly cognitively and physically disabled child and yet simultaneously promote the treatment for other “pillow angels.”

Predictably, disability rights scholars, disability activists, and those who work directly with children and adults with profound cognitive and physical disabilities were outraged. Diekema, Seattle Children’s hospital and Ashley’s parents were stunned at the fierce reaction. The hospital was investigated by the Washington Protection and Advocacy System (WPAS), which published a detailed report that concluded Seattle Children’s hospital illegally sterilized Ashley X (Carlson and Dorfman 2007).

Since 2007 the debate between those advocating for and those against the Ashley Treatment remains unusually ill-tempered. A nuanced discussion has proven elusive. Of central importance, in our estimation, are the personal narratives of parents and care givers that are responsible for the day to day care of those who are entirely dependent upon others yet discussions, debates, and analyses of the Ashley treatment have consistently dismissed this narrative as “anecdotal.” By default, Ashley’s parents’ narrative viewpoint is the only one considered in relation to growth attenuation. It is our contention that in this discussion it behooves the academic community to access the perspectives of *other* parents similarly involved in the care of an individual with severe disabilities, many of whom find the Ashley Treatment to be abhorrent and Ashley’s

parents to be misguided. These alternative life narratives present a powerful counterpoint to the detached dialogues of “experts”.

### **Cognitive Dissonance**

The scholarly literature from 2007 to the present pertaining to Ashley X is substantial, as is the reaction by disability studies scholars and activists. A few facts remain consistent. Ashley X was diagnosed with static encephalopathy of unknown origin. She is described as having the cognitive capacity of a three month old infant, capable of making sounds but without use of language. She responds to outside stimuli, but her parents are not certain she recognizes them or her siblings. She is completely dependent upon others for all tasks of daily living. At her parents’ request, when Ashley was six years old, she had surgery to remove her uterus and breast buds (her appendix was removed as well). Dubbed the “Ashley Treatment” by her parents, Ashley was also prescribed high dose hormones for three years to prevent typical growth.

Outside of these basic facts, however, the Ashley X case has become extremely convoluted. It is difficult enough to have two mutually hostile perspectives, but add in Ashley X’s parents’ blog that is subject to periodic revision, multiple and contradictory public statements, an insistence their identity remain anonymous, and it is no wonder the discussion surrounding the ethics of the Ashley Treatment is heated. Lost in this debate is perhaps the most important issue that growth attenuation raises: the failure of American society to adequately support children and adults with profound disabilities.

The effort to infantilize Ashley, render her small forever, proponents would argue is not relevant. Diekema and others are convinced that size for a person, such as Ashley, with severe cognitive and physical disability has no value. Gunther and Diekema (2006) concluded, “in the end it was obvious the bond and love that exists between Ashley and her parents convinced [us] it was the right thing to do” (1017). The justification for attenuating Ashley’s growth rests upon an emotional assessment—the bond of love between parent and child—but proponents such as Diekema and others note practical reasons and unsubstantiated physical benefits for attenuating the growth of Ashley. Second, the Ashley Treatment was never about one little girl in Seattle and the wide latitude all parents are given when it comes to making health care decisions. The Ashley Treatment was and remains about all “pillow angels” whose proponents argue can benefit from growth attenuation. The parents made this clear in early 2007 shortly after Gunther and Diekema, at their urging, published about what had been done to their daughter.

In their original blog, Ashley’s parents wrote glowingly about the Ashley Treatment performed at Seattle Children’s Hospital. They freely speculated about the larger implications for all pillow angels. The blog and its contents, however, have undergone numerous revisions and updates. Success, as defined by the parents, has been constantly revised leading to much confusion. One thing, however, remains consistent: Ashley’s parents and proponents of growth attenuation collectively fail to grasp why the vast majority of people with a disability reacted with shock and hostility (Kuusisto 2007; Olson 2007; Peace 2007a, 2007b, 2010). Simply put, a fundamental cultural disconnect

exists between those for and those opposed to the Ashley Treatment. For such a procedure to exist and to have been given approval by an ethics committee at a leading children's hospital is by itself evidence of considerable cognitive dissonance regarding the Ashley Treatment and disability in general. To create and permit such a treatment option causes great anxiety on the part of people with a disability given the long history of disability based oppression. Forced sterilization and eugenics spring to mind, treatments that were justified as being for the greater social good and in the best interests of a person with a disability. In fact some of the grossest cases of abuse in medical history were created under the guise of helping disabled people. Thus S.E. Smith's observation that "many of the arguments in favour of the Ashley Treatment come dangerously close to the core of the problem with it: they position people with disabilities as less than human" (Smith 2012). Smith notes that Peter Singer and, we might add, other utilitarian philosophers such as Jeff McMahan, Julian Savulescu, and Dominic Wilkinson are all too quick to accept that hospital ethics committees ensure adequate protection for children and non-competent adults. However, the fact Ashley was involuntarily and illegally sterilized is evidence ethics committees are inadequate and fail to protect vulnerable people like Ashley. In "The Growing Power of Healthcare Ethics Committees Heightens Due Process Concerns," Thaddeus Mason Pope concludes with a relatable and cogent warning: "State legislatures, courts, and agencies are increasingly delegating adjudicatory and gate-keeping roles to Health Ethics Committees (HECs). As HECs get more power and authority, the quality and integrity of their decision-making processes should improve...But this has not happened. The fairness and legitimacy of HEC procedures has not improved. HEC decisions are at substantial risk of making decisions tainted by corruption, bias, carelessness, and arbitrariness. Given the stakes (often life and death), the risk of error is too great" (Pope 2013, 23). Clearly, the legal implications are vast and cannot be so easily waved aside. Though it is beyond the scope of this paper to fully address the issue, considerable other literature has been produced on the profound legal implications of the Ashley Treatment and growth attenuation in the U.S. David Carlson of Disability Watch Washington, author of the 2007 WPAS report remains actively involved in the legal implications of the Ashley Treatment. Most recently in Canada, Malhotra and Neufeld (2013) have argued convincingly that the legal lens must be polished to take into account the social model of disablement in judgments relating to disability. Furthermore, they argue that the Ashley X case reflects "deeply embedded social ideas about women and female bodies...(and) present an extremely limited idea of what a woman might be. Ashley does not and cannot conform to such an embodiment of a woman" (Malhotra and Neufeld 2013, 107). These unexamined biases can play significantly against girls and women with disabilities in the legal arena (Malhotra and Neufeld 2013).

Limiting the Ashley Treatment to children with profound cognitive and physical deficits suggests these people are somehow different, less human. What proponents of the Ashley Treatment underestimate, if not outright dismiss, is the insidious and unquestioned impact of ableism within and outside of the confines of a clinical setting. Smith notes:

"Ashley and other children are subjected to this treatment because they live in a

world where people with disabilities are undervalued and their parents fear their capacity to care for them and move through public spaces with them. Their approach to this problem focuses on violating their integrity, rather than confronting society around them to demand full rights and access for people with disabilities. Keeping people in a forcible state of underdevelopment for convenience would be condemned if procedures of this nature were performed on non-disabled children, and rightfully so—it would be viewed as an utter violation of humanity. Disabled children are not, apparently, accorded the same respect. The Ashley treatment is never ethically permissible, except under a framework that truly believes disabled people are not human" (Smith 2012).

What is not in question is that children with profound cognitive and physical disabilities and the adults they become are in desperate need of social supports, for this population challenges ideas that are sacrosanct: foremost among them autonomy. In health care, autonomy forms the bedrock of concepts such as informed decision making, the right to refuse treatment, advance directives, patient confidentiality, and end of life decisions. Multiple professional organizations in the health sciences have expressed respect for autonomy in codes of ethics and standards for practice. Bluntly put, autonomy is revered and the loss of it is feared, particularly among the elderly and disabled. In Oregon and Washington, where assisted suicide is legal, the loss of autonomy and ability to do things that make life enjoyable are the prime reasons people seek out a lethal dose of medication. Similar thoughts exist in neonatal centers where severe disability is perceived to be an outcome worse than death and where physicians struggle with what they identify as "lethal anomalies" (Koogler, Wilfond, and Ross 2003; Lam 2009). What many overlook is that lethal anomalies such as trisomy 13 and 18, for instance, are in some cases treatable. Such conditions become lethal because physicians choose not to treat infants with a poor neurological prognosis (Janvier et al. 2012).

The sort of decision making strategies involved in treating the young and elderly involve a highly normative view about quality of life and in many ways mirror the social isolation and abuse too many people with cognitive disabilities experience. While this paper is not concerned with life and death decision making strategies, it is clear to us that growth attenuation has far reaching implications that extend well beyond people with severe cognitive and physical disabilities. The narratives associated with the lives of individuals who will never be fully autonomous shed light on how we define humanity and personhood. We do not question that people who are profoundly disabled and unable to articulate their wishes are human beings. Thus we recoil when, at a scholarly conference, scholars Peter Singer and Jeff McMahan unfavorably compared Eva Kittay's daughter Sesha, a severely disabled adult, to a pig (Kittay 2010). This is a shocking and demeaning statement. In reply, Kittay stated: "I just reject the idea that you should base moral standing on a list of cognitive capacities, or psychological capacities, or any kind of capacities. Because what it is to be human is not a bundle of capacities. It's a way that you are, a way you are in the world, a way you are with another. And I could adore my pig; I could dote on my pig. It would be something entirely different" (Kittay 2010, 408). Kittay also noted that "in all their writings about

people with significant cognitive impairments, philosophers such as Singer and McMahan presume to know the cognitive capacities of the people they write about, when, as I have attempted to demonstrate, they know virtually nothing at all. And they fail to acknowledge their ignorance...nor do they appear to take any concrete steps to rectify the situation, because they presume that they have nothing to learn that is of moral significance” (Kittay 2010, 405). We maintain that proponents of growth attenuation suffer from the same lack of “epistemic modesty,” to use Kittay’s expression.

A radical reassessment of autonomy is needed in part because many assume life has no value if one is not autonomous. Autonomy, as currently understood is, in our estimation, an illusion. We are all dependent to certain degree. Autonomy is fluid—over a life span it will ebb and flow like the tides. Stephen Kuusisto has written, “able bodied assumptions about physical catastrophe depend upon emotional extravagances” (Kuusisto 2009). Rather than observe what a person such as Ashley X or Kittay’s daughter can do, proponents of growth attenuation see only physical and cognitive limitations. This utter lack of imagination, to see what is possible, undermines what people with profound disabilities contribute to society. The contribution they make is not easy to assess because it defies traditional norms. Any time a person with a disability is compared to sociocultural norms (work, family, marriage, career, friendships etc.) the person with a disability will inevitably fail and occupies a space apart from the mainstream. Thus Kuusisto told “a group of artists and advocates for people with disabilities at the Kennedy Center for the Arts in Washington DC that the mainstream is one of the great, tragic ideas of our time. No one is physically solid, reliable, capable as a solo act, protected against catastrophe; there is only the stream in which each one of us must find solace in meanings” (Kuusisto 2009).

It is well established that the mere presence of a person with an obvious and profound disability upsets routine social interaction (Goffman 1959). Many assumptions are made on the part of the normate, to use the term created by Rosemarie Garland-Thomson in 1997, which refers to the constructed identity of those who by way of bodily configuration and cultural capital assume they can step into a position of authority and wield the power it grants them. Foremost among the misconceptions associated with disability is that all disabilities involve a loss of autonomy and independence. This may or may not be true. A person who is paralyzed, such as Peace, is perceived within the disability community to be autonomous and has a privileged body in part because he participates in adaptive sports. In contrast, Roy’s daughter Sophie needs significant assistance in her activities of daily living and is without question entirely dependent on others. Regardless of the disability and degree of assistance required, Carolyn Ells has written “The presence of disability can make apparent the extent to which people are interconnected. Just how much one’s life is wrapped up in the lives of others is readily apparent when others are needed to prepare one’s food, wipe one’s bottom or, more generally, to enact the decisions one makes” (Ells 2001, 603).

When one combines physical and cognitive deficits that limit one’s ability to be autonomous with the penchant for non-disabled others to assert their power, it is no wonder people with a disability are socially isolated and stigmatized. Ells maintains, the

challenge for those with a disability is to retain, regain, or re-configure substantial autonomy despite autonomy loss brought on by the conditions of impairment or the condition of one's social situation... This struggle often involves grappling with barriers in housing, transportation, employment, rehabilitation, technology, education and the physical environment that interfere with acting independently" (Ells 2001, 606). The efforts of people with a disability to be autonomous will always fail if they are expected to aspire to be typical, specifically by using bipedal locomotion and without cognitive deficits. It is thus more empowering to reject accepted beliefs associated with autonomy (the struggle for independence) and instead embrace situated autonomy. The fact is all people with a disability can be independent to a degree within the confines of one's socially constructed space. When one situates autonomy in a socio-cultural context, many possibilities are created that are not usually associated with autonomy. Ells has observed that "Access to social spaces and services and empowering relationships makes autonomy possible. In other words, situated independence is necessary to achieve the control necessary for governance" (Ells 2001, 606). The concept of situated autonomy is at odds with the larger social perception of autonomy as defined by Tom Beauchamp and James Childress (1994) in health care. As we understand Beauchamp and Childress, an autonomous person is one who freely acts in accordance with a self-chosen plan. Thus autonomy is the personal rule of the self that is free from controlling interferences by others and from personal limitations that prevent meaningful choice.

Widely accepted sociocultural norms typically associated with autonomy are unobtainable for people with profound cognitive and physical disabilities. Autonomy as defined by Beauchamp and Childress (1994) is not relevant to the day-to-day life of people with profound disabilities. Narrowly defined, autonomy empowers society to dismiss decision making strategies that form an important part of life for people with profound cognitive and physical disabilities. This also can be applied more broadly. For instance, when a person who is deaf asserts that he or she is not disabled but rather merely a variation of humanity he or she is deemed an extremist or simply dismissed. Similarly, Peace acknowledges his impairment, spinal cord injury, but rejects the belief his life is diminished in any way. Susan Wendell in *The Rejected Body* details the extent to which social and cultural factors create and sustain disability. Building on Wendell's work, Ells maintains, cultural attitudes about people and the body frequently favor certain representations, thereby explicitly or implicitly denying or ignoring the experience of people who do not conform to those representations. It becomes necessary, therefore, to be clear that our conception of disability as something lived will allow for variation in one's experience and one's environment" (Ells 2001, 601).

Self-governance or autonomy for people with a disability can be quite different from the norm. A person with a disability may or may not be able to perform typical tasks associated with autonomy and yet be quite capable of self-governance. At issue is what, exactly, represents "meaningful choice" for a person with a disability? Are people with a profound physical and cognitive disability all that different from typical bipedal humans? We think not. If one accepts the idea of situated autonomy, a person can to a degree self-govern and have agency. The concept of situational autonomy is critically important

because it calls into question what autonomy means. Autonomy cannot be measured nor is it the result of a set of definable human capabilities as some utilitarian philosophers maintain. Autonomy is gained and lost over a lifespan: it is ever changing. Peace and Sophie (Roy's daughter) cannot walk and as a result use wheelchairs. Peace and Sophie's respective wheelchairs make life possible. A wheelchair to them is empowering technology. Yet for others, life with disability, paralysis or cognitive deficits, is something to be feared and some would prefer to be dead than disabled (Atreus nd).

When one combines a stereotypical or normative conception of autonomy with a medical model of disability the results can be deadly. In a clinical setting autonomy has been replaced by the term "patient centered care". This refers to activities of daily living and a person's ability to live independently or with minimal assistance. In 2010 Peace was critically ill and wrote about his experience in which a hospitalist suggested his pain could be alleviated and that aggressive use of life saving antibiotics be discontinued (Peace 2012). At issue was the knowledge that Peace's recovery would be long and arduous. Patient-centered care, in this instance, was the suggestion death was preferable to a grim future—a future of unemployment, institutional care, bankruptcy, social isolation, and physical dependency. Would such a suggestion be made to a typical man? Not a chance. In reply to Peace's essay, Kuusisto (2012, 4) wrote that it:

"...offers a study of fear, stigma, alienation, and the social politics of physical difference—a slumgullion of inhumane circumstances that should properly make the reader as sick as the narrator. A man with a severe postsurgical infection who happens to be a wheelchair user is counseled in the utilitarian art of ending his life, not because his pain is unendurable (though it's vastly unpleasant) and not because his prospects of recovery are impossible, but because the "hospitalist" can't imagine why life with a disability is worth fighting for. Accordingly, an educated man with a disability who has labored to transcend that category finds himself at the intersection of medicine, health insurance, and efficiency experts. (One wants to add: *And all without leaving his bed*, for he's trapped, in excruciating pain, for the time being incapable of flight.)"

### **A Narrative of Severe Disability**

If any benefit is derived from the literature about the Ashley Treatment it is that the subject matter sheds light on the daily experiences of those with profound cognitive and physical disabilities. There are practical reasons this population remains among the most socially isolated groups in the nation. The Seattle Working Group concluded their *Hastings Center Report* essay on growth attenuation with the following words:

"It is clear that these families need greater social support. To date, there has been insufficient public discussion about how to provide that support and improve the lives of people with profound disabilities. Further, the issues facing this population have not been a primary focus for many health care professionals. We hope that engaging in questions and discussions about growth attenuation will, if nothing else enhance public and professional awareness about children with

profound disabilities and garner greater appreciation for the value of these most dependent members of our society” (Wilfond et al. 2010, 39).

We believe the Seattle Working Group’s attempt at a moral compromise falls far short of protecting or empowering people with profound cognitive and physical disabilities. There remains within it the lack of genuine commitment to viewing the rights of people with disabilities—of all people with disabilities, regardless of severity—as inalienable civil rights. The Working Group’s assertion that families caring for severely disabled children need more services seems hollow when, ultimately, they indicate support for the use of growth attenuation. That such services are in fact the real “solution to an old dilemma” can be seen in how Roy has navigated the world with her daughter Sophie. Roy’s daughter Sophie suffered a brain stem stroke in May 2000 at the age of six. By the end of the day, MRI scans indicated that the damage was so extensive she was deemed clinically brain dead by both the hospital pediatric neurologist and neurosurgeon. Roy and her husband were, in fact, approached by medical staff about donating her organs.

In the night, before life supports were removed, Sophie began to show signs of life. At that point the medical team pressed forward with vigorous interventions to support her, though the head neurologist insisted her prognosis was still death or permanent vegetative state, PVS. Sophie, in spite of these multiple, *expert* opinions to the contrary has not only survived but also thrived. She is now 20 years old and severely disabled. In the early years post-stroke, she spent considerable time in her bed like Ashley. Indeed, in many ways, they are alike. Sophie requires full assistance for all activities of daily living. She cannot walk, nor even voluntarily move her legs, and requires a wheelchair that fully supports her trunk. She has limited use of her right hand and none of her left. She needs a shunt to drain fluid from her brain, and a g-tube to supplement her daily water intake. She has severe scoliosis, and her feet, left arm, and both legs are locked in a bent position. She has a seizure disorder. Significant portions of her brain tissue washed away when she suffered from hydrocephalus, and other portions retain an abnormal shape. Though she can talk and answer simple questions, she cannot converse or express herself fully. Sophie wears diapers, must be turned at night during her sleep, and requires supervision at all times. Her sense of time is not typical. As with Ashley, how she perceives herself, as a young woman, is not fully known, because she does not have the ability to express it.

This description of Sophie’s significantly compromised body and brain by no means describes the young woman—the person—that Sophie is today. In Ontario, Canada, where Roy and her daughter Sophie live, and in sharp contrast to the United States, she qualified for the many supports that are available to the severely disabled. She was at one time in school and supported one on one both with a nurse and a teacher’s aide. She received home care as well as occupational, physical, and speech therapy. Currently, under pediatric services, there is enough support to have care in the home for six to nine hours, seven days per week. The Assistive Devices program provided all necessary enteral feeding supplies, a personal mechanical lift, and every five years will pay for a new wheelchair, with a custom seating insert.



Over the years, Sophie was provided with as much physical and intellectual stimulation as possible, thanks to engaged parenting and the many support services available. Though she rests in bed periodically throughout the day, she spends more of her time in her wheelchair. Her caregivers are all well trained and well paid, with considerable government oversight, and take her development to heart. She is provided with daily educational programming, arts and crafts, and physical therapy. She is also taken on outings in the community several times a week.

It is the availability and quality of supports and the respite they provide that have allowed Sophie to progress to the young woman she is, her significant physical and intellectual deficits notwithstanding. The six-year-old girl first pronounced brain dead, then given a prognosis of death or PVS by expert physicians based on advanced brain scanning and standard neurological testing, has indeed changed and grown. Though she may test at the primary level academically, this is by no means an indicator of the breadth of her personality or of her actual understanding of the world around her. Sophie is continually given opportunities for self-expression, choices that provide a degree of autonomy. For example, every day she is offered a simple choice as to what she would like to wear, what she would like to do, where she would like to go, and she has clear preferences in all of these things. She selects a very particular style of clothing, enjoys number work over reading and writing, and always picks shopping over outdoor walks. She tends to ogle handsome young men her age that she sees at the mall. Even her musical tastes have changed over the years. She is now much more interested in music people her age typically enjoy.

Her interactions change with different people. With her older sister, she has a typical sibling relationship. She understands many subtle jokes and laughs when people slip up in their words. She can also be offended. Some years ago, a particular nurse would treat then 15 year old Sophie like a baby. The nurse spoke to her in a sing-song tone and would ask insulting questions. Finally, one day, when asked to count to three by the nurse, Sophie responded by counting to ten, in French, (which Roy had taught her) and then in German (taught by another caregiver). Out of respect for Sophie's dignity, Roy fired the nurse.

Proponents of growth attenuation, like Ashley's parents, Diekema, Fost, and others maintain that individuals with limited cognitive and physical abilities are so fundamentally different that growth attenuation is ethically permissible (Allen et al. 2009; Diekema and Fost 2010; Mims 2007; Spriggs 2010). They justify singling out this population because their cognitive skills are severely limited and go as far as to suggest their brains are static. Diekema and Gunther asserted the following about Ashley: "Static encephalopathy with marked global developmental deficits eventually was diagnosed. In the ensuing years, her development never progressed beyond that of an infant" (Gunther and Diekema 2006). In January of 2007, the parents stated, "our daughter stopped growing mentally and intellectually years ago, when she was a few months old" (Ashley's Blog January 13, 2010). In March of 2012, Ashley's father noted: "Her capability level is essentially that of a newborn's. In all medical probability, Ashley will never develop beyond early infancy level" (Pilkington 2012).

Information about Ashley, including about her intellectual capabilities, is limited, unclear, and contradictory. In the “Ashley Treatment: Towards a Better Quality of Life for Pillow Angels,” the parents describe six-year-old Ashley as follows: “Ashley is alert and aware of her environment; she startles easily. She constantly moves her arms and kicks her legs. Sometimes she seems to be watching TV intently. She loves music and often gets in celebration mode of vocalizing, kicking, and choreographing/conducting with her hands when she connects with a song (Andrea Bocelli is her favorite – we call him her boyfriend) (Ashley’s Blog). These abilities are dismissed as insignificant. They also point out that “It is common for Ashley to be uncomfortable or to be bored”. One might question how a child with no potential for brain development becomes bored. Interestingly, in his 2012 interview with the *Guardian*, Ashley’s father downplays her abilities:

“Ashley’s life may be very limited, but like any baby, novelty attracts her attention” (Pilkington 2012). Ashley’s father provides no further detail and instead redirects the conversation to a description of her physical abilities alone. “She cannot talk, although she vocalizes, as she did five years ago. She does not track and follow with her eyes, point at or grip a toy...We’d love for Ashley to be able to do more. The kind of developments that we’ve observed with her along the years include: being able to hold her head up, stick her thumb in her mouth, and touch her hair behind her ear.” Almost in the same breath, however, Ashley’s parents make the case for her own situated autonomy: “We do all we can to provide her with experiences that seem to make her happy, give her a good life, and cheer her into expressing delight through vocalization and kicking” (Pilkington 2012).

Clearly, Ashley, like Sophie and many other individuals, has distinct preferences, which she communicates to those around her.

It is not uncommon, however, for those inexperienced with life around people with disabilities to equate physical ability with intellectual ability; in other words, they believe one reflects the other. Kittay writes, “To have the mind of a baby and the capacities of a baby are not the same thing for the disabled person may well have an understanding and a set of emotional responses that far exceeds her capacity to act. The brain may be impaired, but it is not frozen” (Kittay 2011). Stories like those of Anne McDonald (2007), Christy Brown, author of *My Left Foot*, and Jean-Dominique Bauby, author of *The Diving Bell and Butterfly*, have vividly proven that those with severe physical limitations are not necessarily equally affected intellectually. If Ashley is as profoundly physically disabled, as her parents assert, how can they appropriately assess her cognitive level? Many will point to brain imaging as an indicator of cognition. Consider, then, that Roy’s daughter was given a prognosis of death or PVS, by experts in the field of neurology, based on MRI brain scans and standard neurological testing. Given this wildly inaccurate conclusion, the ability to correctly assess any severely disabled young child’s actual cognitive function comes into serious question. Even more difficult to accept would be the prediction of future abilities of a person who has no reliable or volitional physical means of expression. As Kittay (2013) pointedly asserts, “We have no

access to or knowledge of the subjective life of people with the disabilities that Ashley has. How can we presume to act on the supposition that we do?"

The categorical assertion that there can be no development whatsoever in a living brain exposed to stimulation goes directly against the latest research of Joseph Fins (2012) and his forthcoming book *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*. Norman Doidge (2007), asserts that scientists studying the brain discovered that "children are not always stuck with the mental abilities they are born with; that the damaged brain can often reorganize itself so that when one part fails, another can often substitute; that if brain cells die, they can at times be replaced; that many "circuits" and even basic reflexes that we think are hardwired are not" (Doidge 2007, xix).

Most importantly, however, is the simple fact that children just like Ashley change over their lifespan. Their minds "progress" and change though not necessarily in a typical fashion. For example, Sophie, at 19, while eating lunch at a mall food court, expressed her significant interest in a young man walking past by gaping and dropping her fork in admiration. This is not the behavior of a little girl or remotely like infant behavior. Many other parents of children even more compromised than Roy's daughter report similar growth on the Life with a Severely Disabled Child blog (July 26, 2013):

"My daughter ...is...severely disabled from a refractory seizure disorder. She is non-verbal and needs assistance with nearly everything, including walking, feeding, changing, diapers, etc. However, I have seen change... she might be attracted to something, a toy or object for months or even years. Over time, she grows tired of it, doesn't pay any attention to it, resists or ignores it. When something new is introduced, she goes for that. She listens to music differently than she did when she was younger and is better able to express herself, particularly when she dislikes something or has no interest. She has an "attitude" that she didn't have in the past."

"My little one (14 years old) is severely disabled and is non-verbal. He has most definitely made progress over the years... He started using an iPad (with eye gaze) a few years ago and that has changed everything and allowed us to have a much better way to see that progress. We have learned that he can read ...and understands far more than [sic] we thought. Also now that he is a teen we have the attitude thing to, [sic] lol. No need for words when he can say it so well with eye roll and facial expression."

Ian Brown, in his book, *The Boy in the Moon* felt similarly about his son: "Intellectually, he's an infant, always will be; he reminds me what it's like to be with a baby. But while I think Walker will never change, he changes all the time...I never expected to see him become independent, to have a life of his own, but he has and does" (Brown 2009, 247).

The proponents of growth attenuation and some utilitarian philosophers draw an

imaginary line in the sand whereby a certain level of cognitive ability, questionably assessed, gives parents and the medical community the moral freedom to decide the fate of a child with severe disabilities; in the Ashley X case it was to surgically and chemically alter her body. The definition of what they deem to be sufficiently disabled to “benefit” from the treatment is not clear. Ashley’s own parents assert that the Ashley treatment would be “shockingly inappropriate” (Ashley’s Blog January 9, 2007) for individuals with different disabilities. Ashley’s parents quote Diekema’s vague references to “carefully selected patients who might also benefit” (Ashley’s Blog January 13, 2010). Ultimately, in “Growth-Attenuation Therapy: Principles for Practice,” Diekema explained that “Consideration of growth-attenuation therapy should be restricted to non-ambulatory children with a diagnosis of profound cognitive disability, confirmed by a physician who is experienced in the assessment of children with cognitive disability, with a near certain prognosis for no significant improvement in cognitive function. Children who are aware of their social environment or who have the capacity for social achievement may suffer from the stigmatization that often accompanies extreme short stature” (Allen et al. 2010). The criteria Diekema outlines fail to clearly define “profound cognitive disability,” and it includes the necessity to predict the future since it is recommended that parents receive counseling for growth attenuation when the child is three years of age. The attempt to predict even a typical child’s social awareness at three years of age or their future scholastic ability without considering the impact the social environment might have on their development is decidedly without merit. In fact, such an effort would be met with stiff resistance by most parents and educational professionals. Yet proponents of growth attenuation are prepared to do just that for severely disabled children. This indicates to us a clear cultural bias against individuals with severe intellectual disabilities. The unrelenting focus is on what such individuals cannot do instead of what is possible.

Proponents for growth attenuation believe it is acceptable to physically alter a child’s body if they think the child would not notice or care about the difference. In this vein, Ashley’s parents quote transhumanist George Dvorsky at length: “If people have concerns about Ashley’s dignity, she will retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development” (Ashley’s Blog 2007). Dvorsky also stated: “If the concern has something to do with the girl’s dignity being violated, then I have to protest by arguing that the girl lacks the cognitive capacity to experience any sense of indignity.” This line of thinking is so dangerous as to lead one to conclude, then, that it would be acceptable to provide minimal care in unattractive surroundings and devoid of privacy to individuals diagnosed with dementia, because they have no sense of what is going on. Harriet McBryde Johnson (2003) described this environment in her widely read essay “The Disability Gulag.” Kittay (2011) has also expressed this eloquently: “The long, cruel and gruesome history of people with cognitive disabilities, especially when the disabilities are severe, are all justified on the supposition that these folks don’t know the difference or can’t feel the indignity...The horrid shame of it all is only made that much worse when some who are included are totally cognizant of their mistreatment. Yet we also have learned that once we stop supposing that “they don’t know the difference anyway,” we find out that they were entirely capable of knowing, understanding, or at the least experiencing, the

treatment as mistreatment.”

Ashley’s parents’ insistence that they are doing everything in their daughter’s best interests alone is misleading. Growth attenuation could also be used to address the very same problems Ashley’s parents worry about with children who have severe physical disabilities. The anonymous Huahima who maintains the blog *Mysteries and Questions Surrounding the Ashley X Case* wrote:

"Growth attenuation is, in fact, all about physical disabilities, not cognitive disabilities. Profound cognitive disability is only an alibi, a magic they use to turn something that would be regarded as unethical if applied to physically disabled children without profound cognitive disability. That's why they have to include physical disabilities in their definition of profound cognitive disability 'for purpose of this therapy'. But I doubt that will keep physically disabled children without cognitive disabilities safe from the therapy once it becomes standard medical practice. The article authors don't forget to add 'at the present time' when they suggest that growth attenuation should be limited to children with profound disabilities"(Huahima June 20, 2009).

The reference here is to Gunther and Diekema (2006). They did appear to originally defend a wider application of growth attenuation in the future.

The reality remains that Ashley's parents violated their daughter's human rights because she is intellectually disabled. The response of Ashley's parents over the years to the fact that the Seattle Children’s Hospital was found guilty of violating their daughter's civil rights by allowing if not insisting on a hysterectomy without first obtaining a court order has always been one of denial and justification. “(Our lawyer’s) conclusions disagree with those of the authority. Sterilization is a side effect of the treatment, not its intent” (Pilkington 2012). Medicalizing her disabilities was also an effective tactic: “While we support laws protecting vulnerable people against involuntary sterilization, the law appears to be too broadly based to distinguish between people who are or can become capable of decision making and those who have a grave and unchanging medical condition such as Ashley, who will never become remotely capable of decision making” (Ashley’s Blog). It is interesting to note here that Ashley’s parents, prior to this legal confrontation, had assessed Ashley as very healthy and stable. “Ashley is a beautiful girl...She is expected to live a full life and was expected to attain a normal adult height and weight. Ashley’s health being in a stable condition is a blessing” (Ashley’s Blog January 13, 2010). Ultimately in Ashley’s parents’ estimation, judicial oversight for children like Ashley is an inconvenient roadblock to their loving good intentions. “As responsible and loving parents, deeply concerned for the wellbeing of our child, we provided a better quality of life for our Ashley, who is doing very well under our love and care. We hope that other families of the many children like Ashley will likewise be able to care for and benefit their children without undue obstacles” (December 31, 2007). In our estimation, however, as Alicia Ouellette noted, “the law failed Ashley. It allowed her parents to alter her body profoundly and permanently for social, not medical, reasons without adequate process or oversight. The lack of process

was unacceptable given the magnitude of potential harm to Ashley, the potential conflict of interest faced by her parents, and the potential for abuse of the proposed interventions" (Ouellette 2008).

It is with a decidedly paternalistic gaze and in genuine opposition to the facts that proponents of growth attenuation put forth their rationale for radically altering the bodies of children with severe disabilities. There is a clear bias here, a denial of the value of the lives of these individuals, simply because their physical and intellectual capabilities do not fall under acceptable—and we add arbitrary norms.

Limiting growth attenuation to a specific population is in our and others' estimation a form of discrimination. Kittay, in dissenting from the compromise reached by the Seattle Growth Attenuation and Ethics Working Group wrote: "I do not believe that growth attenuation is ethically or medically appropriate, even when limited to children with profound developmental and intellectual impairments... The problem is that the limitation is itself already an abuse. If growth attenuation should not be done on children without these impairments, then it should not be done on any children. To do otherwise amounts to discrimination" (Wilfond et al. 2010). Kittay's point cannot be dismissed by asserting medical interventions by design target specific bodily deficits and as such no discrimination exists. This line of reasoning conveniently ignores the long history of abuse experienced by children and adults with cognitive disabilities as exemplified by the ugly laws, eugenics, and horrific abuses at institutions such as the notorious Willowbrook School. Carey, in *On the Margins of Citizenship*, noted that people with intellectual disabilities continue to be marginalized and that "segregation continues to dominate both the provision for public education for children and adult "programming" such as sheltered workshops and day activity centers" (Carey 2009, 3). In spite of 40 years of progressive legislation designed to empower people with a disability, the denial of fundamental human rights remains commonplace. Justice Oliver Wendell Holmes, Jr. in the 1927 *Buck v. Bell* case denied people with cognitive disabilities the right to privacy, parenthood, and bodily integrity famously writing, three generations of imbeciles is enough." Many of the justifications Holmes used remain in place today. Those with cognitive disabilities remain "manifestly unfit" and as such lack the ability to reason, cannot be independent or autonomous, and as dependents of the state's largesse were considered "lesser citizens".

Via their blog and lack of a nuanced understanding of disabilities in the past and present, Ashley's parents have done a terrible disservice to all children with severe disabilities. As Carey (2009) and other scholars have demonstrated, an atmosphere of fear still exists surrounding what it means to grow up with severe disabilities. Ashley's parents consider their own child's disabled body as problematic in every way, simply a conduit for forms of continual discomfort, unless surgically altered. They show a marked ignorance about the nature of sexual violence with their defense for removing Ashley's breast buds and performing a hysterectomy, preferring to blame the victim, as it were (Malhotra and Neufeld 2013). Ashley's parents continue with a dismissal of the benefits of in home mechanical supports via inaccurate portrayals of their appearance and function. Consider their description of a patient lift, likely a Hoyer lift used in hospitals,

rehabilitation centers, and homes for the last 50 years: “Currently, one person can carry Ashley, versus requiring two people or a hoisting harness and ropes, should she have grown larger.” Peace and Roy who have spent decades with profoundly disabled people have never seen a patient lift that uses a “harness” and “ropes.” The parents further imply that appropriate respite services and in home care givers are impossible to find: “Other than her Mom and Dad the only additional caregivers entrusted to Ashley’s care are her two Grandmothers, who find Ashley’s weight even more difficult to manage. We tried hard and found it impossible to find qualified, trustworthy, and affordable care providers” (Pilkington 2012). They never counterbalance their perspective by citing credible outside voices, like other parents with children or adults similar to Ashley. They also clearly have nothing but disdain for disability activists or “the disabled community.” They categorically dismiss each and every legitimate critique with a shockingly simplistic viewpoint:

“From reviewing the reaction of the disabled community in detail, it is clear to us that not enough attention was given to Ashley’s unique condition and needs, and how the treatment brings her significant and direct benefits... the disabled community objected to changing the individual rather than focusing on changing society so that disabled people could function more easily in society: accommodations such as curb cuts for wheelchairs, mainstreaming in school, and beeping crosswalks. These are all great things and we support them. Society needs to provide for everyone, especially those with special needs, paying attention to the specifics of the need and the person” (Pilkington 2012).

## **Conclusion**

Parents new to the life of caring for a child with severe disabilities are woefully unprepared for a complex health care system and the Byzantine world of disability they did not know existed. Clinicians underestimate the great deal of time required to adapt and learn what is and is not best for a child with a severe disability. An entire medical lexicon must be learned by parents who are exposed to largely negative views of their child’s future. QALY/DALY and other statistics are wielded by health care professionals many of whom, such as Dominic Wilkinson, who openly question whether death is preferable when certain thresholds cannot be met by a newborn (Wilkinson 2013). “New parents of a disabled child have little sense of the trajectory of that child’s life, so their decision rests on shifting sands. Furthermore, their decision is based on a physicians’ assessment that their child will always have the mind of a baby” (Kittay 2013). This is misleading. Proponents of growth attenuation give a dark scenario and dismal depiction of the future. They do so for good reason—all acknowledge social supports for families with a profoundly disabled child in the United States are inadequate. The solution to this supposedly new take on an old dilemma, to use the subtitle to the Gunther and Diekema (2006) article, is to surgically alter a child as young as three years old to maximize the benefit. But the benefits of the proposed treatment are not clinically proven. No efforts toward support or education are made. The problem is perceived to be singularly unusual and unique. No consideration is given to decades of disability studies scholarship that calls into question societal and medical assumptions about disability. It is simply assumed that such children are a burden to be

mitigated in some way, not human beings to be supported and provided with choices.

Brown muses that “The struggle to do that—to treat the intellectually disabled as individuals, as equal and contributing members of society, no matter how subtle or small their contribution is, and how reluctant we are to understand what it might be—is the unresolved struggle in the history of intellectual disability” (2009, 268). He continues, referencing his profoundly disabled son Walker, “I have begun simply to love him as he is, because I’ve discovered I can; because we can be who we are, weary dad and broken boy, without alteration or apology, in the here and now” (Brown 2009, 285). Brown reminds us we are embedded in our respective cultural milieu and historic place in time. In another era Ashley, Roy's daughter, Brown's son, Peace, and others like them would have been classified as handicapped, insane, idiotic, feeble minded, freaks, retarded, or crippled. Proponents of growth attenuation appear to be content with a rigid and seemingly predetermined life associated with severe disability. It is as though Ashley's parents and proponents of growth attenuation have a crystal ball that has empowered them to gaze into the future. We reject this “clairvoyance.” The real life experiences of all people who have a disability are as rich and unpredictable as the normate and of equal value. It is our hope our words shed some light on lives worth living that are all too often relegated to obscurity and darkness.

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