The Ashley Treatment

The Philosophy and Ethics of Growth Attenuation
Published on June 29, 2012 by Jennifer Baker, Ph.D. in For the Love of Wisdom

This guest post has been graciously provided by Robert Newsome, III, JD. His articles on this subject and others can be found in the journals Nursing Ethics, Nursing Philosophy, and the Journal of Nursing Law.

Ashley X was born in 1997 in Seattle, Washington. After the first month of life, she "began to display symptoms of hypotonia, feeding difficulties, choreoathetoid movements, and developmental delay". Consultation with all relevant specialties could identify no specific cause for her condition, resulting in a diagnosis of "static encephalopathy with marked global developmental deficits." In the ensuing years, her condition has, in many of these respects, remained unchanged. She is, and in the opinion of her physicians always will be, unable to sit up, roll over, grasp objects, or speak. She must be fed through a gastrostomy tube. Ashley is now 15 years old, and is experiencing life with the cognitive resources typically available to a 3-6 month old child (Diekema, 2010).

Shortly after her 6th birthday, Ashley began precocious puberty. Over a period of the ensuing 3 years, Ashley received high doses of estrogen, a growth attenuation treatment that has resulted in her remaining relatively small in stature, likely to never be larger that 4 feet 6 inches (1.37 m) tall, and weighing about 65 or 70 pounds (29–32 kg). Ashley also underwent a hysterectomy and breast bud removal (Diekema, 2010). This combination of medical interventions are now known, for good or ill, as "the Ashley Treatment".

The Ashley Treatment has been, and remains, controversial. It has been over 5 years since the Ashley Treatment was first described in a medical journal, but it remains a lively topic, for several reasons. One reason the controversy has not gone away is that the Treatment has not gone away; it is being administered in additional cases (at least 12 worldwide), and perhaps thousands of families around the world are exploring it. In the United States, The National Disability Rights Network has recently published a report which calls upon Congress, and State legislatures, to pass legislation which prohibits the Ashley Treatment.

Another reason for continued interest in the Ashley Treatment is the sheer number of issues it raises. Some of these issues are primarily legal in nature. Does the hysterectomy component of the Ashley Treatment constitute the involuntary sterilization of an incompetent, which if done without prior judicial approval is unlawful and a violation of the incompetent individual's constitutional rights? Should all highly invasive procedures require judicial approval before being performed on incompetent individuals, or should surrogate decisionmakers continue to enjoy broad discretion in such matters?

Other issues raised by the Ashley Treatment are more broadly philosophical. Even if, as I have argued elsewhere, surrogates may lawfully elect each component procedure of the Ashley Treatment without first obtaining judicial approval, and parents should continue to enjoy broad discretion in deciding what course of treatment is in their child's best interest, could choosing the Ashley Treatment EVER be in ANY child's best interest? It would seem that at least some commentators believe that the answer to that question is a resounding "No". What I wish to

suggest, in what follows, is that, whether or not the “Ashley Treatment” was, in fact, in Ashley's best interests, there may be cases where it could be in some child's best interests, and should therefore not be strictly forbidden.

Opposition to the Ashley Treatment comes from many different perspectives. Many of these objections have been addressed elsewhere (*see* Diekema 2010, Edwards 2011), and I have discussed some of them elsewhere (*see* Newsom 2007, Newsom 2009). However, there have been some objections raised to the Ashley treatment by very able feminist philosohers that I feel have, to date, been given insufficient attention.

Since my career as a nurse has been in skilled nursing/long term care, the broad topic of disability has been of particular personal concern to me. In my working nursing life I am a “Charge Nurse”, not a “Nurse Manager”; I take vital signs, wipe bottoms, bathe bodies, transfer patients from bed to chair, feed people who cannot feed themselves, give them their medicine, change their colostomy bags and the dressings on their wounds, etc. I am one of those people who, to quote Martha Nussbaum, does “all the work that extreme dependency requires” (one could say, I suppose, that I am part of Annette Baier's “moral proletariat”). Here, the contibution of feminist philosophers has been uniquely valuable. And no one book by a philosopher has meant more to me, on a personal and professional level, than “Love's Labor”, by Eva Fedder Kittay. If ever there was a book by a philosopher that was “for nurses”, it is “Love's Labor”. On the one occasion I met Dr. Kittay in person, and in brief e-mail correspondence with her, I have always felt it best to hold back my enthusiasm for this book, and my personal admiration for her as a philosopher and a person, lest she think she was dealing with a madman and an internet stalker.

Dr. Kittay has contributed to the conversation on the Ashley Treatment, but seems to have come to a different conclusion about it than I have. I find this troubling and not a little intimidating. In Dr. Kittay's case, I am truly reluctant to disagree with her about any matter of substance. I hope that, by examining our differences on the Ashley Treatment, I can add something new and constructive. So with GREAT trepidation, “here goes.”

There are many things that Dr. Kittay, and other philosophers like Dr. Adrianne Asch, say about disability in general, and Ashley's case in particular, with which I completely agree. First, Dr. Kittay writes movingly of “the extraordinary possibilities inherent in relationships of care with one who reciprocates but not in the same coin, one who cannot be independent, but repays with her joy and her love” (Kittay, 2011). That seems exactly right, and I shall have more to say along these lines at the end of this post.

Second, and specifically in regard to Ashley, Dr. Kittay writes that “The philosophers, however, have made the capacity for rational thought a criterion for dignity...Those creatures who don’t reach the mark are 'without dignity.' With one stroke, the Ashleys of the world...are placed below the line...we have learned the lessons that Ashley and our daughter Sesha have to teach those who create false idols of intellectual capacity: Life is precious; all individuals have intrinsic worth, the source of their dignity; and joy...” (Kittay, 2007). I think this is exactly right as well. Ashley's cognitive and other deficits do not diminish her dignity, or make her life less precious. My only reservation here is with the phrase “The philosophers”, as I think a number of philosophers in the western cannon have provided us with the resources to see things much as Dr. Kittay sees them (at least if read charitably).

Dr. Asch and Dr. Anna Stubblefield have written that “Ashley is the same as most people. She is the same in deserving to be accepted by and respected by and loved by her family for who she is and what she will become, with no modification required” (Asch). I think that is exactly (or at least mostly) right as well.

Each of these philosophers is committed to the claim every child should be loved and embraced with the characteristics and capacities that they have, whatever those might be, and whether or not those capacities include “the capacity for rational thought”. This claim is true, and I am truly afraid (very afraid) of anyone who does NOT accept it.

With so much agreement here, how can any disagreement arise? First, Dr. Asch and Dr. Stublefield point out that since very large people who have lost, or who have never had, the ability to ambulate, use their arms and hands, swallow, speak, etc, can nevertheless participate in family and community life with enough help, and enough “gear” (like the “hoyer lift”), the Ashley Treatment is not necessary (Asch). I think this claim is true, but does not establish that the Ashley Treatment might not sometimes beneficent, because we can, and should, perform many beneficent acts that are not “necessary”.

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Second, work by both Dr. Kittay and Drs. Asch and Stubblefield suggests that, since it is possible to be wrong about any individual's “cognitive abilities”, and future prospects for growth and development, the Ashley Treatment was approved based on assumptions about Ashley's future that no one is entitled to make (Asch, Kittay 2007). I will argue that this second claim needs to be very carefully evaluated and that, after doing so, it should be concluded that an assessment of our knowledge (and its limits) about Ashley's capacities, prospects and “inner life” do not support for the conclusion that the Ashley Treatment is always, and everywhere, wrong.

Third, Drs. Asch and Stubblefield claim that medically altering any characteristic or capacity a child might have violates our duty to “love and embrace” that child. I would argue that this claim is false, and think it is significant that Dr. Kittay stops short of making such a claim (Asch, Kittay 2007).

Considering these claims in reverse order, I conclude that we might fully love and embrace a child with whatever characteristics and capacities they have (or lack), and still conclude that their life might be, all things considered, better if one or more of those characteristics were altered. I don't, for example, think that parents who elect otoplasty for their child (a procedure that is NOT medically necesary) are failing to fully love and embrace that child, “no modification required”. Rather, they have simply decided that their child's life will be better if they are not nicknamed “Dumbo” by their peers during their formative years.

Parents have many duties that they owe to their children, of which the duty to “love and embrace, no modification required” is only one. Another duty that parents have is to make choices on behalf of their children which will, if all goes well, facilitate the best possible future for them. What is more, there are some reasonably clear cases where, in order to do so, medical intervention to modify growth will be something a parent should do, and we need look no further to illustrate this point than to examine the condition that brought Ashley to the endocrinologist,

Dr. Gunther, in the first instance.

While the background information about Ashley's lifelong care is sometimes frustratingly incomplete, it seems that Ashley's parents obtained an endocrinology consultation due to the onset of precocious puberty, as diagnosed by her pediatrician. Girls experiencing precocious puberty will have a "growth spurt" and, for a time, be taller than their peer group. However, since puberty will end for them at an earlier age than would otherwise be the case, they will be shorter, as adults, than they would have been if puberty had been delayed. They will, in other words, never reach their "full" potential height. What to do? Modify their growth by administering drugs called LHRH analogs — synthetic hormones that block the body's production of the sex hormones that are causing the early puberty. The precocious puberty stops (indeed, it sometimes reverses, so to speak – breasts become smaller, pubic hair disappears, etc.), and then puberty begins again at a more "appropriate" age.

Should a parent authorize medical intervention to "treat" their daughter's precocious puberty, which sometimes occurs for no identifiable reason? Yes. There are good reasons for parents to do so, even though they might "fully love and embrace" their precociously pubescent daughter. Some reasons are medical; for example, mounting evidence suggests precocious puberty significantly heightens the risk of breast cancer, and of mental health disorders. Other reasons are social; precocious puberty puts girls at a higher risk for teasing and bullying.

It thus seems that it is possible for a parent to fully love and embrace a child and nevertheless elect to medically "alter" that child, where a parent reasonably believes that in doing so they advance their child's interests.

The second claim, that the Ashley Treatment was approved based on assumptions about Ashley's future that no one is entitled to make, might seem plausible, since a) any medical diagnosis and/or prognosis might be erroneous, and b) we might think we never really "know" what the inner life of someone else is like. I think a) is true, but am unsure if knowing that it is true takes us very far when we make decisions about our health, or the health of our dependents. This is especially true in the case of prognosis, but can certainly be true with diagnosis as well. Consider the following simple example.

Wilm's tumor is a rare malignant tumor of the kidney which develops in childhood. There are clusters of signs and symptoms which lead physicans to suspect the presence of "Wilms tumor". However, it also possible that the diagnosis is mistaken; that "mass" showing up on the X-ray MIGHT be a begnin lump of tissue known as "metanephric adenofibroma". If it is, surgery is not a "medical necessity". Still, metanephric adenofibroma is an even more rare condition that Wilm's tumor, and the consequences of NOT surgically removing a Wilm's tumor are certain death. In other words, a diagnosis might be wrong, but it would nevertheless be a mistake NOT to accept it as true when deliberating upon what to do. The parent who decides to just HOPE that this is simply a case of metanephric adenofibroma would seem, at least to me, to be more than a little daft.

In the case of prognosis, we are similarly unlikely to obtain the degree of certainty that the village verificationist or annoying sophomore skeptic would say we need in order to justify a claim of "knowledge". Continuing on with the Wilm's tumor example, even if the tumor is excised while it is "stage 1", the patient is "cured" in over 90%, but less than 100%, of such cases. So, we might not want to say that we "know" the child in question is cured (at least when

certain epistemologists and sophomores are in earshot). We might want to say, instead, that we hope this child is cured, and that the hope is not a vain and fanciful one, but rather is based on evidence, and pretty good evidence at that. We would not think, given our collective experience, that a parent who hopes their child is cured is, under these circumstances, simply blinded by parental love and engaged in wishful thinking.

With Ashley, of course, matters are not as simple. A diagnosis of "static encephalopathy with marked global developmental deficits of unknown etiology" is an admission that there is a lot here that medicine does not know. No one has any published explanation that I have been able to find concerning what sort of massive insult Ashley's brain received, or when, exactly, it occurred. Some commentators have been, and are, suspicious of this diagnosis, and the prognosis accompanying it. Disability activist Anne McDonald remarked that in accepting the conclusion that Ashley will not significantly develop cognitively, ethicist Peter Singer "has accepted the doctors' eyeball assessment of Ashley without asking the obvious questions. What was their assessment based on? Has Ashley ever been offered a way of showing that she knows more than a 3-month-old baby?" (McDonald 2007).

I have two thoughts here. First, whence commeth the knowledge, on McDonald's part, that the physicians treating Ashley performed only an "eyeball assessment"? Was she there? Had she examined all of Ashley's medical records? Yes, there are reasons to think that historically medical science has, as Drs. Asch and Stubblefield have noted, often underestimated "the cognitive abilities of people who appear to be profoundly intellectually impaired" (Asch). This does not tell us that Ashley's cognitive abilities have been underestimated. Even more to the point, it does not establish that physicians and cognitive scientists are never entitled to make a prognosis like the one Ashley's physicians made, or that parents would always be wrong to accept such a prognosis and act upon it.

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This leads to consideration of b), above; how can we "know" what it is "like" to be Ashley, with these deficits, if we can reasonably conclude she has them, and always will? Here, I think, those of us who have argued that the Ashley Treatment might sometimes be beneficent have not been careful enough with our choice of words. I know that I have been guilty of saying, in the past, that Ashley probably has the emotional and cognitive life of a typical 3-6 month old child. What I SHOULD have said is that Ashley is a 15 year old girl who lives her life utilizing the cognitive capacities, or tools, available to a 3-6 month old child. There is a difference between those two statements.

What we find ourselves confronted with here with b) is a version of an old philosophical puzzle, the "problem of other minds", and a favorite of the aforementioned "sophomore skeptic", that wretched student sitting in the front row of my introduction to philosophy class who asks "how do you know that grass looks the same to you as it looks to me?" I have, so far, always been able to resist the temptation to strangle such an individual by reflecting on the fact that, in one way or another, the pernicious meme that my "mind", and yours, are "private" and accessible only to you and me, has found its way, like some lethal prion, in to the brains of people of true genius (and far better philosophers than me) on many occasions.

This isn't the forum in which to publish the dissertation I never wrote, so I will content myself with the bald assertion that “how grass looks to me”, and “what it is like to be Ashley” are not things that are “known”, if by “know” one means something like “able to select the correct answer on the multiple choice exam”. There are, however, MANY things I can justifiably BELIEVE and FEEL about life as Ashley lives and experiences it, and many other people for that matter, as well as non-human creatures great and small.

I have a well justified belief that Ashley is aware of her environment and responds to it. Moreover, I believe that her response to her environment today utilizes resources accumulated by her awareness of the environment in the past. For example, we are told that Ashley goes to school daily, and responds to arriving there with smiles, happy sounds and kicks. I have no reason to think Ashley forms the “rational” thought “I'm in school today, just like I was yesterday. This is great!”, but there is good reason to believe that her acquaintance with school, over time, causes her to, as William James once put it, “find it warm” . Using the term “knowledge” in the context of this “accumulation from acquaintance” would send any number of philosophers in to fits of rage, so I won't do that. But I do think we must conclude that something like it is a part of what it is to be Ashley. Ashley has feelings which are informed by her experience over time.

It may be that what Leplace said about the astrophysics of his day should be said about the cognitive science of today - “What we know is not much. What we do not know is immense.” However, “not much” is not the same as “nothing”. And, among those things that we do know, is that we should not dismiss the wisdom and value of feelings. For those who are inclined to do so, I recommend a dose of Martha Nussbaum's “Upheaval of Thought”, wherein Dr. Nussbaum makes an impressive case for understanding feelings (yours, mine and Ashley's) as judgments of the importance of what those feelings are about to our well being.

Why attribute this sort of very rich inner life to Ashley? One good reason to do so is that we need that hypothesis to understand what Ashley does. And, I might add, this illustrates why it is very important NOT to think of Ashley as “3-6 months old”. The “tools” she deploys to be aware of her environment may be the tools of a 3-6 month old child deploys, but those tools have been deployed for the last 15 years, not 3-6 months. What is more, there is every reason to believe that you and I use those tools also, and that how they shape and inform who we are is every bit as important as our “rational” life. Since we do deploy these same tools ourselves, we can therefore know at least something about what it is like to be Ashley. In fact, if we accept the descriptions of Ashley and her life today provided by her family (and I know of no reason not to), we know many things about what it is like to be Ashley, and, of course, her parents, siblings and teachers know many more.

We know, because of our capacity for what David Hume and Adam Smith called 'sympathy” (I think they had in mind what we call “empathy” today), what music pleases Ashley, what places Ashley likes to go, that she enjoys being picked up, cuddled and carried by her parents and grandparents, etc. In fact, this is a phenomenon that I have observed so often over the last 15 years of my life as a nurse that I have only recently begun to understand how significant it truly is, a purloined philosophy lesson hidden from me in plain sight.

In more cases than I can count, I have observed adults who have lost the capacity for rational thought, through Alzheimer’s Disease, nevertheless continue, for a time, to have a very rich

“inner life”, filled with love and caring. I have seen caregivers develop a deep and rich understanding of what that person's inner life is “like”, and respond to that person in truly remarkable ways as a result of that understanding. I have done so myself many, many times, without engaging in “rational” thought while doing so, or understanding the significance of what I had done. David Hume was right: “The *minds* of men are mirrors to one another.”

This leads, at long last, to the observation, by Drs. Asch and Stubblefield, that there is no NECESSITY to attenuate growth in order to facilitate good care (Asch). We do in fact lift, transfer and reposition even bariatric patients on a daily basis. For over a year one of my patients was a lady who weighed over 500 lbs, and she was up, dressed, eating lunch in the dining room and playing bingo every day, thanks to specialized equipment. She was also completely free of pressure ulcers thanks to a special bed. We hugged each other each time I came on duty. Ashley could, obviously, go to school, participate in family and community life, never get a pressure ulcer, receive hugs, and so forth, without growth attenuation.

But, matters do not end there. Caring feels most genuine and rewarding when it is unmediated by the mechanical and the non-human. There is more to caring than just transferring, repositioning, providing novel experiences, cleaning and washing. Consider this recollection of Ann McDonald's, describing life in the institution in which she was confined: “Nurses were discouraged from cuddling children. A crying child needed to be punished for its own good, so it would learn to accept the absence of affection and be happy. Punishment consisted of locking the crying child in a small dark store room” (McDonald, “14 years”).

One obvious thing to conclude from Ann's recollection is that some people who are nurses should be doing something else for a living, as they apparently lack a capacity (empathy) we are presently unable to supply upon demand. But the other thing we should conclude is that human touch is a critical component of human caring. It is comforting in ways that the mechanical is not. Ann's institution would have not been less of an absolute, shameful, hellhole if it had contained “hugging machines” to stick children in, instead of dark closets.

It is for this reason that I will confess that I don't like hoyer lifts. I do not like putting patients in a sling and lifting them, like a horse you are transferring from a ship to a barge, with the aide of a machine. What is more, most patients don't really like them either, and will tell you so if you ask. Those who are cognitively intact will tell you so in words; those who are not will let you know in other ways.

This not to say that hoyer lifts, and other assistive technologies, are not “good” things. One thing that is good about them is that, when the care of the fully grown adult is involved, they protect the caregiver. The fact that I do not like hoyer lifts, and did not use them as often as I should have (for my own good) early in my nursing career undoubtedly helps to account for the two ruptured discs in my back that cause me constant discomfort, have necessitated two emergency room visits, and may, in the not too distant future, place me in the ranks of the “disabled” as well. And, of course, many patients understand the wisdom of mechanical lifts; they are nice people who do not want their caregivers to sustain injuries. Sometimes a patient will INSIST that I, the nurse, use the lift because THEY have come to deeply care about me (one of the many rewards that nursing offers). Nevertheless, neither of us LIKE the damn things.

One big idea that seems to be distinctly feminist is Eva Kittay's observation that western philosophy has made a “false idol” out of the intellectual capacity for rational thought, singling it

out as the *sine qua non* for dignity, value and worth (Kittay 2007). Even if, as I maintain, there are historical figures in philosophy who were not utterly bewitched by "reason" (Spinoza, Shaftesbury, Hume and Smith come to mind), this feminist critique of the western philosophical cannon gets the "theme" right, starting with Plato and Aristotle, and with no clear end in sight.

If I am reading them accurately, Drs. Asch, Stubblefield and Kittay suspect that the defenders of the Ashley Treatment think growth attenuation is appropriate for individuals who do not have, and never will have, the capacity for "rational thought", and are, therefore, just repeating the same damn mistake old dead white men philosophers have made for the last 2,500 years (with, perhaps, a few honorable exceptions). Defenders of the Ashley Treatment, they suspect, are viewing those lacking "reason" as "less than" the rest of us, and so we can do things with them, and to them, that we cannot do with, and to, those possessed of reason (eat them, ride them, make them pull plows, lock them in cages, attenuate their growth, etc.). Perhaps defenders of the Ashley Treatment are, one might say, unjustifiably "privileging" reason over other ways of "being in the world". I, as one of those "defenders," plead "not guilty".

For surely, when we stop worshiping at the altar of the false idol of reason, we should become better able to value the role that the other, "feeling" way of "being in the world" plays in our life, and the lives of others. We should stop "thinking" that a crying child needs to be locked in a dark closet, and "feel" compelled to pick the child up and cuddle it instead. We should better comprehend what Ashley tells us, because Ashley does tell us things. Among many other things, Ashley tells us she loves tenors, school, and and being picked up, held and carried by those whose touch she finds comforting and warm. We might "feel" that, if the only way of "being in this world" for Ashley is the "feeling" way, then Ashley might be able to experience greater joy and love as a small woman than a large one when other factors, such as being unable to swallow, turn over, or grasp objects are also part of who she is. If so, helping Ashley be a small woman is not a failure of love and acceptance, but an act OF love and acceptance. In defending the availability of the Ashley Treatment, my intention is to privilege, not "reason", but "feeling", as a way of being in the world.

I want to think, even if Dr. Kittay cannot agree, that those who have elected the Ashley Treatment for Ashley have done so not because they worship a "false idol of reason", but because, instead, each time they pick her up in their arms and hold her, they experience, in a unique and special way, exactly what Dr. Kittay describes: "the extraordinary possibilities inherent in relationships of care with one … who cannot be independent, but repays with her joy and her love", and that Ashley does also. If so, they worship (if that is the word) at a different altar, one not consecrated to some jealous God called "reason"; and I see no compelling "reason" to forbid it.

Robert Newsome is a nurse, a lawyer, and a philosophy professor. As mentioned, his writing, on this topic and others, appears in the journals Nursing Ethics, Nursing Philosophy, and the Journal of Nursing Law.

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