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Claremont McKenna College

Examining The Ashley Treatment: A Case Study of the Bioethical Implications
Associated with Growth Attenuation Therapy Through the Lens of the Capabilities
Approach

submitted to
Professor Alex Rajczi

by Allison Hill

for
Senior Thesis
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Next, I would like to thank Professor Rajczi for being the person who inspired me to write my thesis in the field of bioethics and specifically on growth attenuation therapy. Throughout this semester, my thesis took various shapes, but steadfast was Professor Rajczi's helpful advice and support. He was absolutely critical in the success of my thesis, and for that I am so grateful.

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Table of Contents

I.	Introduction.....	4
II.	Martha Nussbaum’s Capabilities Approach.....	7
III.	The Ashley Treatment.....	11
IV.	Wilfond et al. and Growth Attenuation.....	16
V.	S D Edwards’ Potential Objections to the Ashley Treatment.....	24
VI.	Conclusion.....	27
VII.	References.....	30

I. Introduction

In this paper, I will be addressing the questions: what is the capabilities approach? How does this framework help us to understand how altering our – and our children’s – bodies can assist in achieving equality for minorities? Or does it instead work against accomplishing this goal? How does this framework help us to understand how altering the bodies of people with disabilities can also protect those individuals’ dignity? Or does it do the opposite?

First, I will lay out the structure of Martha Nussbaum’s view of the capabilities approach, which is a normative framework used in assessing justice and equality, as well as quality of life and well-being. A normative framework is one that “[establishes]... a standard or norm, especially of behavior,”¹ and can be distinguished from a prescriptive framework, which is one that “[relates] to the imposition or enforcement of a rule or method.”² Nussbaum’s capabilities approach operates under the normative claim that quality of life can be best achieved through access to a certain set of capabilities, which can be understood as ways of being. If everyone has access to the ten basic capabilities she lays out, Nussbaum argues that equality will result. Because her approach is normative and not prescriptive, Nussbaum is not aiming to enforce this set of capabilities in society, but instead to enable discourse about equality and quality-of-life judgements in an effort to implement a new status quo that supports *everyone*. To cite Nussbaum, “[the Capabilities Approach] ascribes an urgent *task to government and public policy* – namely, to improve the quality of life for all people, as defined by their capabilities.”³

Next, I will examine the argument of philosophers Wilfond et al. in relation to their work

¹ “Normative: Definition of Normative,” Lexico Dictionaries, 2020.

<https://www.lexico.com/en/definition/normative>.

² “Prescriptive: Definition of Prescriptive,” Lexico Dictionaries, 2020.

<https://www.lexico.com/en/definition/prescriptive>.

³ Martha C. Nussbaum, “The Central Capabilities,” in *Creating Capabilities: the Human Development Approach*. (Cambridge: Harvard, 2011), 19.

on growth attenuation and the bioethical implications associated with this medical intervention. The specific case of growth attenuation that is presented in Wilfond's argument is what has been commonly referred to as 'The Ashley Treatment:' the medical intervention that consisted of a "hysterectomy [(or the surgical removal of the uterus)], the removal of 'breast buds' to prohibit growth of breasts[,] and treatment with high doses of oestrogen [in order to reduce final height]"⁴ on a six-year-old, profoundly developmentally disabled child named Ashley. The goal of this treatment was to stunt her overall height in order for her parents to take care of her more easily. Specifically, I will evaluate what pro tanto principles are at odds in Wilfond et al.'s argument, and reason through which principles should take precedence.

Pro tanto principles are necessary in everyday life to help us make our way throughout our days without being incapacitated by fear, helplessness, or frustration when it comes to making decisions. Pro tanto principles are "principles that tell us that we have strong reasons to do something, even though there might be circumstances where those reasons are outweighed or overridden by competing moral considerations,"⁵ and can help us make decisions as simple and easy as what to eat for breakfast in the morning. In fact, we reason through pro tanto principles and decide which ones take precedence in given situations quite often.

For example, one may hold the pro tanto principle that eating a healthy, balanced diet is important for overall good health, and also the pro tanto obligation that one shall not steal. Let me propose an example that will test these two pro tanto principles to see which is more important. Kelly walks into her kitchen in the morning and opens her fridge, ready to make some whole wheat toast with peanut butter for breakfast, which is both healthy and balanced and will fuel her with energy for the long day ahead. However, upon opening the fridge, which she shares with her two roommates, Kelly notices that she is out of bread for her toast; she finished her last slice at breakfast yesterday and forgot to pick up more at the grocery store after work. There is bread in the fridge, however; but it is one of her roommate's loaves and there is only one slice left. Here, Kelly sees two pro tanto principles in conflict with one another. The question in this case -- and in most cases which take pro tanto principles into consideration -- is: which principle takes precedence? Whichever does take precedence will impact Kelly's decision, as she will reason through which pro tanto principle she values more and will make the choice favoring which principle she chooses. Perhaps Kelly believes that her healthy diet is more important, and that she should take the slice of her roommate's bread so that she isn't hungry at work. Or maybe instead she thinks that stealing her roommate's last piece of

⁴ S D Edwards, "The Ashley treatment: a step too far, or not far enough?" *Journal of Medical Ethics* 34 (2008): 341–43.

⁵ Rajczi, "Conflicts Between Pro Tanto Principles," 1.

bread is cruel and selfish, so she would rather go to work hungry and without breakfast. Regardless of her decision, Kelly must reason through which principle she favors over the other in this case, carefully weighing the pros and cons of each (even if it seems to be a very quick decision in her eyes, and she does not even realize that she is in fact participating in such a philosophical process).

“Oftentimes the principle which takes precedence (or should take precedence) contributes to values that uphold morality.”⁶

I will then evaluate the arguments of Steven D. Edwards, who proposes five main objections to the Ashley treatment, which specifically propose why it could be deemed morally impermissible. While Edwards ultimately argues that four of the five objections are not compelling, his discussion surrounding the moral permissibility of the Ashley treatment is necessary to consider the argument for supporting the treatment. After positing the fifth and final objection, Edwards ultimately argues that “the most serious concern raised by the case is that it may set a worrying precedent if the moral principle employed in justification of the treatment is applied again to endorse it in similar circumstances.”⁷

An important distinction I must make is that in this whole paper, I will not be concerned with whether or not the Ashley treatment should be legal, or in any way associated with the law or policy. Instead, I will be presenting multiple arguments, then taking a stance on which argument I believe is more *morally permissible*. I will posit my opinion on this in the final section of the paper.

⁶ Allison Hill, “Weighing Pro Tanto Principles: Should Physicians Intervene in Patients’ Medical Decisions?” (Phil186 Essay, Claremont McKenna College, 2019).

⁷ Edwards, “The Ashley treatment,” 341.

II. Martha Nussbaum's Capabilities Approach

Renowned philosopher Martha Nussbaum is one of the original developers of the capabilities approach; however, Amartya Sen was the first philosopher to introduce the theory, and many other philosophers, political scientists, and ethicists have built their own conceptions of it. In this paper, I will adopt Nussbaum's interpretation, because I believe it is the clearest in establishing what is needed to achieve universal justice and better qualities of life. According to Nussbaum, "the Capabilities Approach can be provisionally defined as an approach to comparative quality-of-life assessment and to theorizing about basic social justice. It holds that the key question to ask, when comparing societies and assessing them for their basic decency or justice, is, 'What is each person able to do and to be?'" Another reason I will be utilizing Nussbaum's notion of the capabilities approach is that "[Amartya] Sen does not employ a threshold or a specific list of capabilities... nor does he make central theoretical use of the concept of *human dignity*."⁸

Nussbaum "[uses] the plural, 'Capabilities,' in order to emphasize that the most important elements of people's quality of life are plural and qualitatively distinct."⁹ Nussbaum's approach argues that having more capabilities – or access to more capabilities – will increase one's functionings. She defines a functioning as "an active realization of one or more capabilities."¹⁰ Functionings can best be categorized by things you can do: being warm, playing with others, and working. A capability, on the other hand, "answers... the question, 'What is this person able to do and to be?'"¹¹ Capabilities, therefore, are abilities to do or to be in certain states of functioning. There is a difference between having the capability of doing something and then

⁸ Nussbaum, "Capabilities," 19-20.

⁹ Nussbaum, "Capabilities," 18.

¹⁰ Nussbaum, "Capabilities," 25.

¹¹ Nussbaum, "Capabilities," 20.

actually pursuing that, through a functioning. According to Nussbaum, from a justice point of view, we should not care about how people are functioning (or choosing to function), but about their access to the capabilities associated with functioning. She places a strong emphasis on the *choice* of individuals; from a public policy or political point of view, governments and societies should not be concerned with *how* individuals choose to exercise their capabilities, as much as we should be concerned with whether or not individuals *have access to* securing basic capabilities.

Therefore, Nussbaum posits, injustice occurs when people do not have the capability to achieve certain valuable functionings that are necessary to achieve a fulfilling human life. For example, there are survival capabilities, like the capability to be sufficiently nourished and maintain a healthy temperature (by being warm *enough*), and then there are functionings which make life “plural and qualitatively distinct.”¹² You do not *need* these additional functionings to stay alive, but rather to both flourish as a human being and to uphold personal, everyday dignity.

Nussbaum’s definitive list of central capabilities serves as an addition to the bare minimum survival functionings that everyone should be able to achieve, regardless of disability or cognitive functioning. The ten capabilities she lists answer the question: “What does a life worthy of human dignity require?”¹³ They are: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; and control over one’s environment (both political and material).¹⁴ If someone is able to attain all of these capabilities, Nussbaum argues that they will have a better quality of life than someone who does not have access to them. Nussbaum also argues that until everyone has access to these

¹² Nussbaum, “Capabilities.” 18.

¹³ Nussbaum, “Capabilities.” 32.

¹⁴ Nussbaum, “Capabilities.” 33-34.

capabilities, we are living in an unjust society; however, once everyone is able to achieve access to the ten basic capabilities, we have reached equality (or at least *enough* equality).

In her book *Disability with Dignity: Justice, Human Rights and Equal Status*, Linda Barclay examines how best to preserve the dignity of people with disabilities (both as individuals and as a community). Barclay defines what she calls the “‘everyday concept’ of disability” by referring to fellow philosophers Guy Keohane and Julian Savulescu, who argue that such a definition should “[incorporate] both a descriptive and an evaluative component”¹⁵ in order to be as inclusive and accurate as possible. Keohane and Savulescu expand:

“Descriptively, the disabled are people with certain physical or cognitive features that lead to a loss of some function or ability that most people possess. Evaluatively, such people are said to *suffer* from disability; that to lack some function or ability that most people possess is a misfortune.”¹⁶ Whenever I use the word *disability* throughout the rest of this paper, I will be utilizing Keohane and Savulescu’s inclusive definition of the word.

In the book’s chapter titled “A Just Distribution of Capabilities,” Barclay uses Nussbaum’s Capabilities Approach to “[assess] whether the capabilities approach is a suitable theory of justice for disability.”¹⁷ Ultimately she argues that approaches like Nussbaum’s capabilities approach do, in fact, “propose the right kind of solutions to disadvantage.”¹⁸ This is why applying the capabilities approach to assessing justice of people with disabilities (compared to people without disabilities) is so important. Later, I will discuss how the Ashley treatment is a prime example of how Nussbaum’s capabilities approach can support people with disabilities to

¹⁵ Barclay, Linda. *Disability with Dignity: Justice, Human Rights and Equal Status*. (New York, NY: Routledge, 2019), 13.

¹⁶ Barclay, *Disability with Dignity*, 13-14.

¹⁷ Barclay, *Disability with Dignity*, 63.

¹⁸ Barclay, *Disability with Dignity*, 63.

uphold dignity and improve quality of life for people with disabilities.

III. The Ashley Treatment

To provide background information and context for the two arguments I will present – by Wilfond et al. and Edwards – I will explain who Ashley is, what ‘the Ashley treatment’ is, and why it was administered.

Ashley was a “severely intellectually and physically disabled child”¹⁹ whose disabilities were a result of her diagnosis of static encephalopathy. Static encephalopathy can be distinguished from progressive encephalopathy, in that with the static (and non-progressive) diagnosis, “although patients may have delayed motor milestones, they do not lose milestones, as they do in a progressive neurologic disorder.”²⁰ However, because of her profound developmental and physical disabilities, Ashley lacked the ability to participate in normal daily activities, since “her disabilities are such that she is unable to walk or talk, or even move herself to change position when lying down.”²¹ Ashley’s parents also cite that “her cognitive ability is similar to that of a 3-month old infant.”²² However, while Ashley’s disabilities are incredibly profound, her parents said that she “[enjoys] the lights and sounds of TV, music[,] and the company and embraces of her family.”²³ Because of her impairments, Ashley required constant care by her parents which included, but was not limited to, “feeding, dressing, toileting, and mobility assistance.”²⁴

Ashley’s parents began to realize when she was six years old that she began to put on weight rather rapidly and was “showing signs of premature onset of puberty, hence her

¹⁹ Edwards, “The Ashley treatment,” 341.

²⁰ “Static Encephalopathy.” Case Western Reserve University School of Medicine. Case Western Reserve University, July 17, 2006. <http://casemed.case.edu/clerkships/neurology/NeurLrngObjectives/CP.htm>.

²¹ Edwards, “The Ashley treatment,” 341.

²² Ibid.

²³ Ibid.

²⁴ Ibid.

secondary sexual characteristics were developing at an early age.”²⁵ As her primary caregivers, Ashley’s parents were responsible for moving Ashley, dressing her, feeding her, changing her diapers, and working to ensure the best quality of life for her on a daily basis. As a result of her rapid growth, Ashley’s parents began to grow concerned over how they would be able to care for her in the same way if she was much heavier, which would make their everyday duties much more difficult. However, they also believed that if Ashley was smaller and lighter (and did not continue to grow or develop through puberty), her “parents believed... [that participating] in more social and recreational activities”²⁶ would also be less of a difficulty; since Ashley was believed to have enjoyed such things, her parents wanted to ensure that their child’s well-being was maximized.

As a result of their growing concerns, Ashley’s parents sought out the opinions of medical professionals at Seattle Children’s Hospital²⁷ in order to discuss potential medical interventions to administer to Ashley. According to Ashley’s parents, the sole motivation behind this was to ensure that Ashley has the best quality of life possible. Because Ashley does not have the capacity to understand the medical interventions, or make medical decisions herself, Ashley’s parents serve as the proxy decision makers for her. As her parents, they are the people who best support Ashley’s autonomy in making medical decisions, since she is unable to do so.

This is a core principle of bioethics, and it is called autonomy. Philosophers Tom Beauchamp and James Childress state that “personal autonomy encompasses, at a minimum, self-rule that is free from both controlling interference by others and from certain limitations

²⁵ Steven D. Edwards, “The Case of Ashley X.” *Clinical Ethics* 6 (2011): pp. 39. <https://doi.org/10.1258/ce.2011.011007>.

²⁶ Wilfond et al., “Navigating Growth Attenuation,” 27.

²⁷ Wilfond et al., “Navigating Growth Attenuation,” 28.

such as an inadequate understanding that prevents meaningful choice.”²⁸ In the medical field, or from a healthcare perspective, autonomy is practiced when making decisions about one’s own medical care. Patients must always give doctors consent before proceeding with any kind of medical intervention (this includes everything from vaccines, to administering medicine, to more serious procedures like surgeries). And in order to give informed consent, there is a set of boxes that a patient must check off, like being competent to make a decision. According to Beauchamp and Childress, patients “are competent to make a decision if they have the capacity to understand the material information, to make a judgment about this information in light of their values, to intend a certain outcome, and to communicate freely their wishes to caregivers or investigators.”²⁹ To give some quick background, here is a brief summary of informed consent from the National Institutes of Health:

Informed consent is a process in which a health care provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention. The patient must be competent to make a voluntary decision about whether to undergo the said procedure. Informed consent is both an ethical and legal obligation of medical practitioners in the US and originates from the patient's right to direct what happens to his/her body. Implicit in providing informed consent is an assessment of the patient's understanding, rendering an actual recommendation, and documentation of the process. The Joint Commission requires documentation of all the elements of informed consent “in a form, progress notes or elsewhere in the record.” The following are the required elements for documentation of the informed consent discussion: (1) the nature of the procedure, (2) the risks and benefits and the procedure, (3) reasonable alternatives, (4) risks and benefits of alternatives, and (5) assessment of the patient's understanding of elements 1 through 4.³⁰

Unfortunately, because of some individuals states of being, informed consent is not possible because competency is not possible. Therefore, personal autonomy cannot be carried

²⁸ Beauchamp, Tom L, and James F Childress. “Respect for Autonomy.” *Principles of Biomedical Ethics*, 2009, 99–114. <https://claremont.illiad.oclc.org/illiad/pdf/556866.pdf>.

²⁹ Shah, Parth, Imani Thornton, and John E. Hipskind. “Informed Consent.” National Center for Biotechnology Information. U.S. National Library of Medicine, March 30, 2020. <https://www.ncbi.nlm.nih.gov/books/NBK430827/>.

³⁰ Ibid.

through as it would in a perfect-world setting, and Ashley is a prime example of this. However, there are still ways to respect and uphold Ashley's autonomy even though she is unable to make her own medical decisions. Beauchamp and Childress state that "mental incapacitation limits the autonomy of a severely retarded person,"³¹ but that proxy decision makers who can make medical decisions in the best interest of individuals can also respect individuals' autonomy (even if they are not themselves making a decision about their own bodies). And, in fact, this is more common than you may think: children under the age of eighteen are not, under law, deemed competent enough to give valid consent or make their own medical decisions. Therefore, more often than not, it is the patient's parents who act as their proxy decision makers to make an informed decision and give consent to act in their best interest. Of course, if there is a case where doctors sense that the proxy decision makers are not acting in the best interest of the patient, doctors have the ability to judge the situation and ask the court to rule the decision.

Ultimately, in an effort to uphold Ashley's personal autonomy and to maximize her quality of life and well-being, her parents made the medical decision to administer the medical intervention that has since been dubbed 'the Ashley treatment.' This consisted of "a hysterectomy, the removal of 'breast buds' to prohibit growth of breasts [,] and treatment with high doses of oestrogen"³² "to reduce her final height"³³ from "a predicted five feet four inches to approximately four feet six inches."³⁴

Ashley's parents' claim that their decision was strongly aligned with their vision for a better quality of life for their daughter: a life where she could be present in family activities, and

³¹ Beauchamp and Childress, "Respect for Autonomy," 54.

³² Edwards, "The Ashley treatment," 341.

³³ Wilfond et al., "Navigating Growth Attenuation," 27.

³⁴ Ibid.

to also “participate in more social and recreational activities”³⁵ outside of the home, like sledding in the snow or going down a slide at the playground. In addition, Ashley’s growth attenuation would assist her parent’s in “routine activities like dressing [her] and changing [her] diapers.”³⁶ While the entire treatment (cited earlier) is referred to as the “Ashley Treatment,”³⁷ Wilfond et al. focus their argument on assessing the ethicality of only the first step of the treatment, which was administering the estrogen patches.

Ashley’s case gained widespread media attention after its inception and publicity following a published blog post by Ashley’s parents. The public weighed in with various opinions about the moral permissibility of the treatment, and the argument amongst medical professionals, ethics boards, and philosophers continues to this day. Wilfond et al.’s article presents the majority opinion of “a twenty-person working group [who] convened to discuss the ethical and policy considerations of... ‘growth attenuation,’ and if possible to develop practical guidance for health professionals.”³⁸ The group was diverse, and consisted of medical professionals; members of the disabled community; and impartial spectators with individual, varying opinions of their own.

³⁵ Wilfond et al., “Navigating Growth Attenuation,”27.

³⁶ Ibid.

³⁷ Ibid.

³⁸ Ibid.

IV. Wilfond et al. and Growth Attenuation

“Navigating Growth Attenuation in Children with Profound Disabilities” by Benjamin Wilfond and Paul Miller is a bioethics article which analyzes the Ashley treatment and its moral permissibility. To provide context, I will begin this section by explaining what Wilfond et al.’s argument is, then examine which pro tanto principles are in conflict with one another, and which should take precedence after reasoning through them.

The authors then assert that some people believe – and as parents, raise their kids to believe – that we should “accept our... bodies as they are,”³⁹ while others believe – and as parents, raise their kids to believe – in “the moral importance of shaping our... bodies to advance our... interests.”⁴⁰ Ashley’s parents chose to pursue the latter option, given their circumstances. However, Wilfond et al. argue that for parents of children with profound developmental disabilities, it is exponentially more difficult to decide what to believe in this realm, and what to teach their children to believe. When there are options available to alter your child’s body in order to increase their quality of life, what is a parent supposed to choose? It must also be noted that there exist many parents – like Ashley’s – who themselves do not have disabilities, and therefore cannot exactly understand what it is like to live with them. Some may argue that this is an unfair judgement for able-bodied people to make on behalf of people with disabilities (as their proxy decision makers). However, Wilfond et al. argue that as a society, we should be more understanding of parents of children with profound disabilities, and that they should have the right to choose what is best for their children in the realm of what is best for their family, in the case that it is the parents who are the people who have raised their children for the entirety of their lives. From this experience, parents do, Wilfond et al. assert, have an understanding of what

³⁹ Ibid.

⁴⁰ Ibid.

is in the best interest of their children.

Next, Wilfond et al. believe that children with profound disabilities face more familial and social barriers in society than children without, partially due to the limits they face as their bodies grow, which makes their parents' efforts to help them participate in familial and social activities all the more difficult [due to their fully-grown adult size]. According to Martha Nussbaum's capabilities approach, children who have the capability to play – which can be defined as “being able to laugh, to play, [and] to enjoy recreational activities,”⁴¹ and which Nussbaum lists as one of the central ten capabilities necessary to live – will live a more “dignified or minimally flourishing life.”⁴² Living a life of dignity, according to Nussbaum, is directly correlated to a greater quality of life by having access to more capabilities, which ideally leads to increased functionings of those capabilities.

In the case of Ashley, growth attenuation ultimately “[reduced] the child's final adult height from a predicted five feet four inches to approximately four feet six inches.”⁴³ The connection between administering estrogen and increased capabilities lies in the caregivers (whether it be parents, guardians, or others) who are the intermediaries for children with PDDs to achieve these functionings. Growth attenuation can help these caregivers “lift and move [the child] more easily.”⁴⁴ Therefore, Wilfond et al. argue, children who are administered estrogen patches in order to fulfill the growth attenuation intervention – as is shown in the Ashley treatment – are more likely to be able to engage in familial and social activities with their families and friends, thus leading to increased capabilities, which therefore increases their quality of life.

Ultimately, Wilfond et al. conclude that while it should only be administered to in

⁴¹ Nussbaum, “Capabilities,” 34.

⁴² Nussbaum, “Capabilities,” 32.

⁴³ Wilfond et al., “Navigating Growth Attenuation,” 27.

⁴⁴ Ibid.

children with profound developmental disabilities, “growth attenuation [like in the Ashley treatment] can be morally permissible under specific conditions and after thorough consideration.”⁴⁵ The authors justify this by citing that “parents of children with profound developmental disabilities face a complicated set of challenges and should be afforded respect and considerable deference in making the complex and difficult decisions unique to their child’s care.”⁴⁶

Now that I have laid out Wilfond et al.’s argument, I will next analyze which pro tanto principles are conflicting in their article.

According to Alex Rajczi, professor of philosophy at Claremont McKenna College, pro tanto principles are “principles that tell us that we have strong reasons to do something, even though there might be circumstances where those reasons are outweighed or overridden by competing moral considerations.”⁴⁷ For example, most people place importance on the pro tanto principle of being honest, or of telling the truth. Generally, pro tanto principles are morally charged; however, because as humans we are all inherently different and therefore have different sets of morals, what happens when there are multiple pro tanto considerations at play? As Rajczi describes, “ethical controversies often arise when two or more pro tanto principles pull us in different directions.”^{48,49}

When reasoning through pro tanto principles, taking various important attributes of each principle into deep consideration is necessary. Rajczi describes a few main ideas to take into account when reasoning through these principles and making a decision about which ones take precedence over others. The first is “the degree of harm that will result from acting or not acting on each obligation.”⁵⁰ Next, Rajczi cites the “number of people harmed”⁵¹ as well as “mitigation of harm[– that is,] whether the harm to the people involved can be mitigated.”⁵²

⁴⁵ Wilfond et al., “Navigating Growth Attenuation,” 29.

⁴⁶ Ibid.

⁴⁷ Rajczi, “Conflicts Between Pro Tanto Principles,” 1.

⁴⁸ Ibid.

⁴⁹ Allison Hill, “The Importance of Dignity: How Does it Affect Individuals with Severe Cognitive Disabilities?” (Phil186 Essay, Claremont McKenna College, 2019).

⁵⁰ Rajczi, “Conflicts Between Pro Tanto Principles,” 3.

⁵¹ Rajczi, “Conflicts Between Pro Tanto Principles,” 4.

⁵² Ibid.

The first pro tanto principle that is at play in the Wilfond et al. argument is the moral obligation that we have as a society (and as humans in general) to value every human being equally. This includes children with profound developmental disabilities, and Wilfond et al. cite that they “are concerned that many people and institutions in society do not positively value people with profound developmental disabilities”⁵³ – that is, they do not believe that everyone treats these people with the same dignity and respect (or simply, equally) as they would anyone else without a disability. However, this is a tricky idea to implement, because there are many differences between people with profound disabilities – especially children – and people without. Some I discussed earlier in this chapter, like if people with such profound cognitive disabilities cannot be deemed competent enough to give informed consent about their own medical decisions. The issue here is that if we value every human equally, we fail to adjust for these large differences (e.g. disabilities). Would it be valuing every human equally to impose a universal government-funded education system that fails to provide resources for children with special needs or learning disabilities, because everyone should be given the same, equal resources? No; that would not be treating, nor valuing, every human being equally. Instead, it would be catering to the majority, or to the people without the need for such resources. Therefore, it is also important to take into account Ashley’s case, and distinguish that administering growth attenuation to a child without a profound developmental disability is *not* considered equal treatment to administering the same treatment to a child such as Ashley. However, it *does* result in valuing Ashley similarly to other non-disabled children, as the Ashley treatment adjusts for inequalities by helping bring Ashley’s quality of life up to a more equal level [to her peers]. This is why applying Nussbaum’s capabilities approach is so important; because if we view equality

⁵³ Wilfond et al., “Navigating Growth Attenuation,” 28.

through the lens of access to basic capabilities, it can be easier to understand how we can work to get people with disabilities to a similar quality of life as people without disabilities.

The next two competing pro tanto principles at odds in Wilfond et al.'s argument are: (1) "the moral importance of learning to accept our (and our children's) bodies as they are"⁵⁴ and (2) "the moral importance of shaping our (and our children's) bodies to advance our (and their) interests."⁵⁵ In the case of Ashley, her parents chose the latter, but not for reasons rooted in vain. Many others have engaged in this debate as well and posited their opinions as to which pro tanto principle here should take precedence; probably as a result of Ashley's case gaining so much public attention. For example, Wilfond et al. cite some people's "concerns about growth attenuation's adverse impact on... the disability community's progress in overcoming societal challenges."⁵⁶ That is, growth attenuation being a way that shaping one's body can advance one's own interest.

Let us break down these competing principles by giving a different kind of example, which does the exact opposite of growth attenuation. It is a medical intervention called growth hormone (GH) therapy, which delivers shots of testosterone to "children with GH deficiency and others with very short stature."⁵⁷ GH "rises during childhood, peaks during puberty, and declines from middle age onward,"⁵⁸ so it is easiest and most effective to initiate GH therapy in children and adolescents, since it "stimulates the growth of bone and cartilage."⁵⁹ What this intervention primarily works to achieve is increasing final adult growth height. While sometimes GH therapy

⁵⁴ Wilfond et al., "Navigating Growth Attenuation," 29.

⁵⁵ Wilfond et al., "Navigating Growth Attenuation," 29.

⁵⁶ Wilfond et al., "Navigating Growth Attenuation," 29.

⁵⁷ "Growth Hormone, Athletic Performance, and Aging." Harvard Health Publishing: Harvard Medical School, Harvard, May 2010, www.health.harvard.edu/diseases-and-conditions/growth-hormone-athletic-performance-and-aging.

⁵⁸ Ibid.

⁵⁹ Ibid.

is administered to children with other underlying or accompanying health issues, there are also those who use GH therapy solely to get their height up to scale with their peers. In this case, it seems as though the former pro tanto principle should take precedence. What is wrong with being below average height, if that person is not diagnosed with dwarfism – which, in addition to being a person of short stature, you also are subject to a wide array of accompanying health problems, which GH therapy can help mitigate – and that person’s parents simply want to administer the medical intervention in order for their child to fit in with their peers? This solution seems relevant, but does not really fall under the principle of accepting one’s body as it is, nor does it fall under the principle of modifying one’s body to advance their own interests, because the interests here are unclear. However, this is a common situation that is compared to growth attenuation. Therefore, in the case of Ashley, the reasons to modify her body are much clearer than with GH therapy: to increase her capabilities and therefore her quality of life, and for her parents to be able to more easily take care of her in order for Ashley to maintain her presence in familial and recreational activities. Because the harms of growth attenuation are slim after the initial intervention, the persons harmed are one in this case: Ashley. The degree of harm is also small, since the treatment would be only benefiting Ashley by decreasing her discomfort that would have been associated with puberty and growing.

This concern brings up another set of competing pro tanto considerations: a) the potential adverse impacts on Ashley individually versus b) the impacts of the disabled community as a whole. While it is clear that the relatively immediate effects of growth attenuation – specifically the Ashley treatment – are a shorter final adult height and the discontinuation of puberty, there did not exist extensive research on the lasting effects and implications of such an intervention at the time it was administered. This poses a significant risk to Ashley as an individual, and the

implications for her health and well-being down the line. In addition, the mitigation of harm would be very difficult since the treatment would have already be implemented years prior. While it would essentially only be one individual harmed if Ashley were in fact, to face harms from the treatment, the second consideration is the potential adverse impacts on the disabled community as a whole. The pro tanto consideration at play, therefore, would be preserving the disabled community's progress in bodily acceptance and "overcoming societal challenges."⁶⁰ Since this is a large group of people who have worked tirelessly for years to establish themselves as worthy and equal in society, there is a fair degree of harm associated with interfering with a disabled person's natural growth patterns and puberty in order to advance the interests of her caretakers. This is exactly the case with the Ashley treatment. Ashley's parents are not only two non-disabled people who made a life-altering decision on behalf of their daughter, but they also went against the principles that people with disabilities have worked so long to prove to society: that all bodies are okay as is and deserve respect. However, an important point that Wilfond et al. posit is their belief that "parents of children with profound developmental disabilities face a complicated set of challenges and should be afforded respect and considerable deference in making the complex and difficult decisions unique to their children's care."⁶¹ In this respect, I think that the pro tanto principle of valuing Ashley as an individual should take precedence over the disabled community as a whole.

Through the medical intervention that is the Ashley treatment, Ashley obtains more capabilities to function in ways that make her distinctly human (recall: Nussbaum's list of ten basic capabilities in Section II). Among this list is her ability to "participate in more social and

⁶⁰ Wilfond et al., "Navigating Growth Attenuation," 29.

⁶¹ Ibid.

recreational activities,”⁶² which is an example of play. According to Nussbaum’s capabilities approach, children who have access to the capability of play -- which can be defined as “being able to laugh, to play, [and] to enjoy recreational activities,”⁶³ and which Nussbaum lists as one of the central ten capabilities necessary to live -- will live a more “dignified or minimally flourishing life.”⁶⁴

Ashley’s treatment resulted in her growth attenuation, which ended up being ten inches shorter than her predicted final adult height. Because Ashley has profound developmental disabilities, her shorter height aided her parents (who, in this case, are also her caregivers) in “[lifting and moving Ashley] more easily.”⁶⁵ Therefore, as a child who received growth attenuation treatment, Ashley was more likely to be able to engage in in familial and social activities with their families and friends. From Nussbaum’s definition of play, this result leads to access to increased capabilities in the sphere of “play,” which increases quality of life.

⁶² Wilfond et al., “Navigating Growth Attenuation,” 27.

⁶³ Nussbaum, “Capabilities,” 34.

⁶⁴ Nussbaum, “Capabilities,” 32.

⁶⁵ Wilfond et al., “Navigating Growth Attenuation,” 27.

V. S D Edwards' Potential Objections to the Ashley Treatment

Edwards lays out “five main objections raised against the Ashley treatment,” and ultimately responds to each objection with reasoning through why each objection does not stand. In this section of the paper, however, I will focus on the counterarguments he posits to the moral permissibility of the Ashley treatment, and how his argument develops to form a conclusion.

The first reason Edwards presents as to why the Ashley treatment is not morally permissible is the “violation of Ashley’s rights [that] occurred, either her rights to bodily integrity or her rights to develop normally.”⁶⁶ Recall that since Ashley was not capacitated and therefore unable to give informed consent for her own medical decisions, her parents were left to be her proxy decision maker. While this is a normal practice in the medical field, and is generally upheld well, since families tend to have a good idea of what the patient might want, this was not the case for Ashley. Her parents made a decision to radically change her body, past the point of return, against its natural trajectory. “Furthermore, this [was done] without her consent,”⁶⁷ which directly violates one of Ashley’s rights cited in the *Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, that “every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”⁶⁸ By removing her breast buds, performing a hysterectomy at the age of six, and administering estrogen in order to stunt her growth, Ashley’s right to physical integrity “has plainly been violated,”⁶⁹ Edwards argues.

The next two objections that Edwards postulates are: a) that “the treatment involves using Ashley as a mere means to the ends of the parents; in other words that they were the main

⁶⁶ Edwards, “Ashley X,” 40.

⁶⁷ Edwards, “The Ashley treatment,” 342.

⁶⁸ Ibid.

⁶⁹ Ibid.

beneficiaries of the interventions and the purpose of the interventions was to benefit them as opposed to benefitting Ashley herself (If it is permissible to alter surgically disabled people for the convenience of their care-givers, this suggests that disabled bodies are objects)''⁷⁰ and b) that Ashley's parents chose to go through with the medical intervention for the sake of ease of their care for her, which would be appealing to Ashley's parents' best interests⁷¹, not her own. This is not only morally impermissible, but also dangerous, as it takes advantage of an individual who is part of a bigger community of vulnerable individuals. Disabled people are at higher risk for abuse, both in care facilities and in their own homes, at the hands of their caregivers. If the Ashley treatment were to be deemed morally permissible, it would set a dangerous precedent for other parents and caretakers of children with profound developmental disabilities, that it is okay to severely alter their bodies a) without their consent and b) to appeal to their own best interests.

The last objection Edwards posits is that it sets a precarious example that "it is justified to alter the body of a permanently incompetent person without their consent, providing it can be shown to be in that person's best interests'."⁷² This is a problem of a slippery slope. Questions that may be asked as a follow-up to the Ashley treatment are: What does the fact that the Ashley treatment was successfully, and legally, carried out mean for the disabled community as a whole? What other kinds of treatment on disabled persons will this open the door to in the future? The fact that the Ashley treatment was deemed ethically sound by Disability Rights Washington when they conducted an investigation into Seattle Children's Hospital (where the Ashley treatment took place) leads to certain implications about similar cases in which the precedent is set that "it is morally permissible to alter the bodies of non-autonomous disabled

⁷⁰ Edwards, "Ashley X," 41.

⁷¹ Recall their reasoning for pursuing the treatment in the first place; that growth attenuation would help them be able to move Ashley better; change her diapers; and strap her into her wheelchair easier.

⁷² Edwards, "Ashley X," 41.

individuals for the convenience of their carers.”⁷³ Humans are humans, and therefore deserve to be treated as so, regardless of disability. It is therefore even more important that the needs and rights of individuals with disabilities are protected against decisions that could harm them, which, according to Edwards, is an issue in the case of Ashley.

⁷³ Edwards, “The Ashley treatment,” 343.

VI. Conclusion

A common misconception of non-doctors in regard to modern Western medicine is that the Hippocratic Oath, which is the oath that medical students take before becoming physicians, includes the phrase “first, do no harm.” While this is an accurate translation from the original Hippocratic Oath, written in Greek, the phrase has been tailored and eventually omitted from the oath. Today, that part ceases to exist. While it is important for physicians to treat their patients well and not intentionally do harm to them, if present society and the medical community were going to live by this ancient rule today, doctors would not be able to give cardiopulmonary resuscitation (CPR) or even perform surgery without breaking the oath. These medical interventions are just a few of many that do, in fact, harm patients; however, they are necessary invocations of immediate harm or pain that lead to larger courses of treatment.⁷⁴ The case of Ashley and the medical intervention that was carried out in order to benefit her is no exception to this rule.

I support of the argument that Ashley’s parents’ decision to go through with the hysterectomy, removal of her breast buds, and administering estrogen patches, all in order to stop her from growing and from continuing on with puberty, is a morally permissible act. As discussed in previous sections, Ashley’s continued growth and puberty would have made it increasingly difficult for her parents to care for her – and their care is the source of Ashley’s well-being. In addition, not going through with this particular medical intervention would have most likely presented issues of discomfort for Ashley herself, since her weight gain from growing would have increased her risk of developing bed sores and ulcers; her breast development would have made it uncomfortable for her to be strapped into her wheelchair; and

⁷⁴ An example would be cutting someone open in order to perform open-heart surgery, which, while imposing immediate injuries, would ultimately save the patient’s life.

the onset of puberty would have caused discomforts from her menstruation cycle, including abdominal cramps.

Next, Ashley's parents' motivation seems genuine, if they were willing to go through the trials, tribulations, healthcare costs, ethics committee meetings, and public backlash from sharing Ashley's story on their blog, all in order to improve their daughter's quality of life. As Edwards points out, "if Ashley's parents did not really care about her, they could simply have arranged institutional care for her."⁷⁵ While it is unclear why they chose to take the former route as opposed to the latter, it is a well-known fact that institutions for disabled people are hot spots for abuse and neglect, and Ashley's parents likely knew this as parents of a disabled child. It is a position of much harder work and effort to be Ashley's caregiver than it would have been to admit her to an institution. Therefore, it seems as though Ashley's parents' motivation is genuine, and that the medical interventions that took place – that is, the Ashley treatment – were in fact in Ashley's best interest in terms of maximizing her access to capabilities through functionings.

While I believe that the Ashley treatment is morally permissible, that is not to say that there exist issues with the treatment itself. Wilfond et al. conclude in their paper that they "agreed to the compromise that growth attenuation can be morally permissible under specific conditions and after thorough consideration,"⁷⁶ and I agree. The overall principle of growth attenuation is okay with me, provided that it is working to increase the capabilities of an individual such that a better quality of life will result. I believe this to be true with Ashley's case. Ashley was able to continue to enjoy spending time with her

⁷⁵ Edwards, "Ashley X," 41.

⁷⁶ Wilfond et al., "Navigating Growth Attenuation," 29.

loved ones, participate in recreational activities of “play,” and even continue living with her family due to the ease of case. Let me be clear that I do not believe that every child with disabilities should be able to have access to the same treatment Ashley went through. However, growth attenuation allowed for Ashley’s quality of life to improve and for her to reach a level of justice otherwise unforeseen in her future, which was made possible by the Ashley treatment. Therefore, I elect that the Ashley treatment is in fact morally sound in its efforts, and am interested to see how medicine develops to adjust for people with profound developmental disabilities in the future to achieve the same goals.

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