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The Effects of the Ashley Treatment on Society and the Individual

Bailey R.M. Sims

Throughout history there have been many examples of the medical model of disability in everyday life. These cases are usually faced with backlash, especially from the disability community. This was the case with the Ashley Treatment. The Ashley Treatment combined a series of medical surgeries and procedures with an end goal of realigning Ashley's cognitive mind with her physical body. This treatment is the embodiment of the medical model of disability. It uses medical intervention to cure Ashley and rid her of her disability. Although the Ashley Treatment was performed out of love for Ashley and wanting to give her the best life possible, there are many negative sides to the procedure. The Ashley Treatment promotes the privatization of health care cases, stripped Ashley of her biological femaleness, and falsely claimed to improve Ashley's quality of life.

Shortly after her birth, Ashley was "diagnosed with 'static encephalopathy'" which caused her mental development to stay "at that of an infant" (Kafer 282). Due to this condition, Ashley did not have the strength to hold her head or body up without support, and she was unable to communicate effectively (Shannon 175). Worried about Ashley's future, her parents and doctors developed a treatment using estrogen and different surgeries to stall her growth and puberty transformations. "Together they crafted a two-pronged plan: 'attenuate' Ashley's growth by starting her on a high-dose estrogen regimen; and, prior to the estrogen treatment, remove Ashley's uterus and breast buds in order 'to reduce the complications of puberty' and mitigate potential side effects of the estrogen treatment" (Kafer 283). With love in their hearts and good intentions the parents decided to go through with the procedure. However, when news of this new treatment was released, the Ashley Treatment was faced with much controversy.

To see the positives of the Ashley Treatment one must look at the different health benefits the procedures caused and view the decision-making process from the parents' perspective. The removal of Ashley's uterus had many additional health benefits. The hysterectomy allowed "the high dose estrogen therapy to be administered without progesterone," it "avoids future hormone therapy to control menses, and "a hysterectomy removes the cervix alleviating the need to do routine PAP smears for health maintenance" (Shannon 176). The mastectomy Ashley received helped to "eliminate the possibility of breast cancer or fibrocystic growth, two conditions present in the family" (Kafer 287). Also, if Ashley's breast were to develop to their full size, she would most likely experience discomfort and skin irritation and breakdown when using a chest strap to support herself (Shannon 176). Although these medical and health benefits were very persuasive in choosing

to go through with the treatment, they were not the main reasons for the parents' decision.

Due to Ashley's condition, her parents feared that without the treatment Ashley would become too big and "cumbersome" for them to continue to take care of her, forcing them to place her in the care of a stranger or have to institutionalize her (Kafer 283). One of the main reasons why Ashley's parents went through with the treatment was because they wanted to find a way to slow and stop "Ashley's development so that they might continue to lift and carry her without difficulty" (Kafer 287). This goal was achieved through the estrogen regimen that Ashley was put on. This process kept Ashley at a small size, making it easier for her parents to take care of her and move her around when needed. Due to this treatment, Ashley is now able to be cared for at home by her parents, siblings, and even grandparents, and she is able to "be moved around the home to hear and watch family activities" (Shannon 177). Also, Ashley's parents were able to share their experiences and knowledge about the treatment through the creation of their blog. Through their blog they displayed "the Treatment as effective, morally permissible, and ethically appropriate for others" (Kafer 291). This allowed other parents to find comfort in knowing that there was something they could do to help their own children. This shows that the Ashley Treatment did not only have a positive effect on Ashley's family, but many others that were able to gain access to similar treatments for their children. However, the Ashley Treatment still faced much backlash from many people, including the disabled community.

One of the main drawbacks of the Ashley Treatment is that it promotes privatizing health care. As described above, one main factor in proceeding with the Ashley Treatment was to keep Ashley small enough for her parents and family to always be able to take care of her. In doing this, the family removed the need for an outside trained caregiver. The parents and doctors also viewed the treatment as a way to keep young children with disabilities out of institutions and other care facilities, which in turn "require[ed] and justify[ed] bold new approaches such as growth attenuation" (Kafer 292). By promoting the Ashley Treatment through the blog and medical journals, it comes off like "the only care worth supporting is that provided by relatives, inadvertently demonizing and pathologizing the use of paid attendants" (Kafer 295). However, "seeing attendant care as something best provided by a family member too easily perpetuates the idea that disability is a private problem concerning the family that has no place in the public sphere" (Kafer 295-296). This creates many problems within the disability community as they continue to fight for equality, accessibility, and more governmental support. Although the Ashley Treatment had negative effects on the general community, it also negatively affected Ashley as an individual.

The removal of Ashley's uterus and breast buds through the treatment stripped Ashley of her biological femaleness. One of the assumptions that persuaded the parents to go through with the treatment was that Ashley would never be able to carry and give birth to any children, which meant that she did not really need her uterus (Savage 176). However, many viewed this procedure as forced sterilization. The Washington Protection and Advocacy System examined Ashley's treatment and found that the sterilization of the treatment was "a violation of Ashley's constitutional and common law rights" (Kafer 284). However, Ashley's parents and doctors claimed that the sterilization, mastectomy, and hysterectomy were all byproducts of the overall goal of the treatment, making them legal and ethical (Kafer 285). Another justification for removing Ashley's uterus and breast buds is that their removal could prevent Ashley from being sexually assaulted and sexualized by others. However, this is not the case because "a hysterectomy will protect against pregnancy but not molestation, rape, or sexually transmitted diseases" (Savage 176). Also, removing Ashley's breast buds does not protect her from "sexual assault or abuse, and many would argue that such assault is more the result of a desire for power and control than of sexualization" (Kafer 298). By removing Ashley's uterus and breast buds based off these assumptions the parents and doctors falsely stripped her of her biological femaleness at a young age. However, it was not just Ashley's biological femaleness that was taken from her.

Another major reason why Ashley's parents and doctors proceeded with the treatment was because they believed it would improve Ashley's quality of life. However, there is no way to tell if Ashley's quality of life improved because her mental development stopped at that of an infant, so she could never truly communicate with her parents or doctors. Nevertheless, her parents have claimed that they could sense confusion and boredom from Ashley, as well as her music sense (Kafer 296-297). Due to these examples of emotion, Ashley could have developed ways of communication if given the time to develop them. With advances in technology and the medical field, it is highly possible that Ashley could have one day developed a form of communication (Kafer 297). However, now that she has undergone the treatment no one may ever know if her quality of life has improved or worsened. Ashley's parents and doctors were also concerned about the separation of Ashley's cognitive and physical development. Both Ashley's parents and doctors claimed that the developmental gap between her body and mind needed to be corrected, and the way to do this was through the Ashley Treatment (Kafer 288). Due to the treatment, Ashley's parents perceive her as a baby and have even coined the term "Pillow Angel" for her to perpetually link the idea and image of an infant to Ashley (Kafer 289). Bioethicist Dr. Norma Fost even said that "having her size be more appropriate to her developmental level will make her less of a freak" (Kafer

289). However, through the treatment, Ashley was thrown into “crip time” (Samuels 189), trapped in a body that will never change even as she grows older. “Crip time” is defined as not forcing people with disabilities to live by the “normal” clock, but instead bending time to fit with the lives of people with disabilities (Samuels 189). By keeping Ashley from growing and developing, her parents bent the clock of normality to fit her disability. She was forced into medical intervention because it was seen as the only thing that could keep her from falling further out of time with her own self.

Due to all the negative sides of the treatment, it is clear to see that even though the parents acted out of love for their daughter, the Ashley Treatment was not the best solution for their situation. The Ashley Treatment promoted the privatization of health care cases, stripped Ashley of her biological femaleness, and claimed to improve Ashley’s quality of life. This case shows how the medical model of disability is still active today. No matter how much the disability community works to remove themselves from the medical model of disability, cases like these remain, mitigating all the disability community’s efforts.

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