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Features

Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability

Lisa Freitag and Joan Liaschenko

ABSTRACT

The controversy over the so-called Ashley Treatment (AT), a series of medical procedures that inhibited both growth and sexual development in the body of a profoundly intellectually impaired girl, usually centers either on Ashley's rights, including a right to an intact, unaltered body, or on Ashley's parents' rights to make decisions for her. The claim made by her parents, that the procedure would improve their ability to care for her, is often dismissed as inappropriate or, at best, irrelevant. We argue, however, that caregiving is a central issue in the controversy, as Ashley's need for caregiving is a defining characteristic of her life. In this article, we analyze the ethics of the Ashley Treatment within the context of family caregiving. Through the physical and emotional work of caregiving, families participate in the formation and maintenance of personal identity, a process that Hilde Lindemann recently called "holding." We argue that, in an intellectually disabled person such as Ashley, who depends on her family for every aspect of her care, the family's contribution to identity is an essential source of personhood. We believe that the treatment can be justified if it is indeed an instance of appropriate family "holding" for Ashley.

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BACKGROUND

In 2004, the parents of a six-year-old, profoundly intellectually delayed girl requested from doctors at Seattle Children's Hospital a series of procedures for their daughter, Ashley, that they felt would help them manage her long-term care. None of the procedures was new, but the constellation of medical interventions in a multiply disabled child was unprecedented. Doctors, in consultation with ethicists, agreed with the parents, and the procedures were done.

Both parents and doctors, believing that they had developed a procedure that might benefit other families with similar caregiving burdens, were willing to make the process public. The parents began a blog, and the doctors published an analysis of the growth attenuation aspect of the procedure in the *Archives of Pediatric and Adolescent Medicine*.¹ Both expected controversy, but were stunned at the explosion of responses, many of which were deeply negative.

The girl came to be known as Ashley X, and the set of interventions called the Ashley Treatment. The treatment was comprised of several procedures whose intent was to limit her eventual body size. First were two simultaneous surgical procedures: removal of breast buds and hysterectomy. The final procedure was the administration of high-dose es-

trogen to cause early fusion of bone growth plates, effectively attenuating her growth. The stated medical reason for the surgery was to abate the unknown long-term risk of high-dose estrogen, including the possibility of rapid breast enlargement, severe uterine bleeding, and an undetermined risk of breast cancer. The medical risk/benefit ratio of the triple procedure has been much discussed elsewhere,² and we feel the evidence is, so far, insufficient to either support or oppose the procedure on medical grounds.

Additional benefits to Ashley of the three procedures, stated by her family and doctors, included preventing the discomfort of menstruation, avoiding difficulty in positioning that might result from large breasts, and completely ending the possibility of pregnancy. To her caregivers, however, the largest benefit was that keeping Ashley small would make it possible to continue their caregiving, as they had done since birth, in their home.³ The most important part of this was the ability to physically hold and carry Ashley, easing the burden of caregiving for both Ashley and her parents. We believe that growth attenuation in support of family caregiving is perhaps the most significant aspect of the procedure, although it has taken the least importance in the ensuing discussions.

With the complexity of this case and its numerous divergent ramifications, it is difficult to discuss the AT as a whole. The different components of the procedure have different implications, both legal and ethical. The initial article defending the procedure defended the ethical implications and medical risk of only the growth attenuation phase of the procedure. The inclusion of hysterectomy in the AT also adds the factor of involuntary sterilization, and the legality of this without a court order has been questioned.⁴ There have been objections to the use of surgery to address a nonmedical problem,⁵ discussions of the meaning of altering a “natural” child’s body,⁶ and even controversy over the possibility of surgical pain.⁷ Others, speaking for the disability community, question the undesirability of “stunting” normal growth, preventing the achievement of a sexually mature body, and “infantilizing” Ashley’s body.⁸

The discussion has also questioned Ashley’s parents’ right to decide for the procedure. Parents are, of course, called on to make medical and surgical decisions for their children who are incapable of consent. However, some believe that, in obtaining the procedure, Ashley’s parents exceeded their authority and caused her actual harm, particularly by an infringement of her right to her own healthy,

intact body.⁹ Whether the procedure is seen as a net burden or net benefit—whether it was something that was “done to” Ashley, or “done for” her—is integral in deciding if the procedure was in Ashley’s best interest. That the procedure was done at least partially in order to ease her parents’ caregiving, for some, constitutes a further wrong,¹⁰ despite claims that the procedure has likely also made life easier for Ashley.

The ethical controversy over the AT persists in the pages of pediatric, ethics, and disability studies journals. Although there are many supporters, the hospital no longer offers the procedures. The parents shield their faces online, and screen all potential members of the chat room the father still runs. Ashley, meanwhile, has never developmentally exceeded two months old, and remains completely unaware of the controversy.

Our evaluation will center not on the medical burdens or benefits, or an analysis of parental rights, but on a different aspect of the procedure: the way in which it contributes to, or detracts from, Ashley’s identity. We will describe the ways in which Ashley’s identity and personhood are constructed in the context of family caregiving. We maintain that allowing the family to continue to hold her physically also supports their holding her in personhood as a valued, though profoundly intellectually disabled, individual.

PHYSICAL HOLDING AND EARLY FORMATION OF IDENTITY

Ashley’s parents’ stated intent in seeking the procedures was to keep her small, so that they would be able to continue to hold and carry her. Ashley was, and continues to be, non-ambulatory, and, at age six, it was already beginning to be difficult to move her. Her parents were expected to perform routine caregiving tasks such as bathing and diapering. They also wanted to be able to carry her with them, so that she could continue to be physically present for family activities. They were able to envision a time when Ashley’s size would prevent her from being included in some activities, as well as a time when they would be physically unable to care for her.

There is some disagreement as to the importance of Ashley’s parents’ ability to hold and carry her. Detractors of the AT have indicated that the desire to keep her small is largely for the parents’ own benefit. It has been suggested that the procedure was done merely “for the convenience of her carers.”¹¹ Ouellette affirms the seeming selfishness of this ben-

efit: "Ashley's parents had much to gain by changing Ashley's body. Simply put, their lives would be made better if they modified Ashley. They would be relieved of the burden of caring for a profoundly needy adult-sized being."¹² It is indeed true that the burden of caring for Ashley might be eased somewhat by keeping her small, but caring for her will never be trivial.

It is also true that there are other ways in which the parents' caregiving burden might be relieved somewhat. A lift could be employed to move Ashley's body from bed to wheelchair, for example. But is this truly a better option for Ashley? Few would deny that there is an intimacy in physical holding and carrying. We carry infants in our arms, or in slings that keep them near our own bodies, and no one doubts that this contact benefits the infant as well as the parent. Psychoanalytic theories support our view that the physical contact inherent in caregiving is essential, not just in meeting bodily needs, but in laying the groundwork for psychological development.

According to the psychoanalyst D.W. Winnecott, physical holding—defined as all parts of meeting the needs of an infant, including, but not limited to, actual cradling in the mother's arms—is an integral part of the maternal-child bond. He writes that the formation of a rudimentary sense of self begins within the physical contact that is necessary for care. In the earliest, infantile stage of development, dependency is so complete that the infant can perceive no separation, either physically or emotionally, between mother/caregiver and self.¹³ So, in this stage, an infant's selfhood is derived from the caregiver. In psychoanalytic theory, a stable holding relationship in this stage is essential, and is the basis upon which individual selfhood is formed.

The need for physical holding in the context of caregiving declines as we grow up, but does not go away. Park MacArthur, who developed a form of late-onset muscular dystrophy, wrote about her father's assistance with transfers, which were at that point done without mechanical assistance. She states, at age 26, "This caring labor is also affirming. Because it resembles a hug, the lift that allows a caregiver to transfer . . . me from one seat to another makes the caring aspects of assistance tangible—the lift literally looks like an expression of love."¹⁴ This sort of contact is not present in a mechanical lift. We maintain that, for Ashley as well, there is a benefit and a beauty in being physically held and carried.

Ashley will likely remain totally dependent on others to meet all of her bodily and psychological needs. She likely will remain in the infantile psy-

chological state, without the ability to develop a sense of her own separate self. In this early developmental state, her sense of self will continue to be derived from her parent's holding. Her family, through the caregiving process, can sustain her in personhood by holding her physically.

HOLDING IN PERSONHOOD

Physical holding begins the process of emotional development and identity formation. Families not only hold a physical place for a child to grow in personhood, they also hold an emotional place, an identity for a child's personality to form around. For Ashley, who cannot actively uphold her own identity, the identity provided for her by her family is of the utmost importance.

Lindemann has recently proposed that one of the important functions of families is "holding" an identity for each of their members. According to Lindemann, families provide, essentially from birth, a ready-made identity, which will become the basis for each individual's unique personhood. It is with this initial identity that a family member's personhood is established. The "holding" becomes a mutual, interactive process as a child develops and begins to participate in the process by expressing her or his own self and desires, and accepting or rejecting the identity the family has given him or her. The identity is constructed from narrative, essentially a collaborative storytelling effort, as members share experiences and repeat them to each other. Together, the network of narratives about the family creates and upholds each other's identities and calls new members into personhood.¹⁵

This network can sustain its members through difficult times, such as when a family member's personal identity is threatened by serious illness or dementia. A family can "hold" members with Alzheimer's, for example, by remembering for them what they did, how they lived, and who they were, preserving their identity even though they can no longer participate in the process. Lindemann calls this "the practice of holding the individual in personhood," and it is done "by constructing or maintaining an identity for her when she cannot, or can no longer, do it for herself."¹⁶ The family's holding supports both maintaining an identity and upholding personhood.

Creating and holding an identity for a typical infant is perhaps more difficult than maintaining an adult in an identity that is fading or being threatened. An infant cannot express as much as an adult, although parents report that each infant can indeed

express a unique personality from birth. An infant, however, cannot remember and tell stories for herself or others, at least initially. The infant's narrative therefore is constructed by others, and told from a third-person point of view. It is formed around very little data; a smile, a cry, a reaction to a toy, the timing and content of first words. Over time, the child's story can be honed and refined, as the child becomes an active participant in the stories told by and about her or him.

A child such as Ashley poses an even more difficult problem. Ashley cannot and likely will never be able to participate in more than a minimal way in the construction of her own identity. However, this does not prevent the formation of an identity by her caregivers. Indeed, one of the main points of Lindemann's theories is that personhood can be constructed, by families or other close social groups, for a human being who is never able to participate in the process. Lindemann claims that this account of identity formation as a social practice "allows for the possibility that a personal identity could be constructed from a purely third-person perspective."¹⁷ This practice can be performed by a family or any other close social group.

Lindemann's observations of the role of family in identity formation were formed in part from the care of a sibling who, much like Ashley, had a profound intellectual disability. Her sister, Carla, had hydrocephaly and never developed the ability to express herself. She could not swallow, or smile, or speak. Lindemann points out that Carla did not meet the philosophical definition of personhood. Carla was not self-aware or capable of rational self-expression. She could not express, nor did she likely have, second-order desires. Nor did she possess an autobiographical narrative; she could not participate in the telling of her own story.

Carl Elliott has pointed out that there is a good bit of ambiguity in the way in which modern philosophy and ethics talk about such profoundly impaired children. Carla, and others with profound intellectual disability, fill none of the criteria usually used to distinguish persons, and never will. Yet, our gut feeling is that Carla is a person, and that is how we think, talk, and write about her. We call her "she" and not "it," and give her a name rather than a number.¹⁸ According to Lindemann, this social practice of habitually thinking about, interacting with, and caring for Carla in the same way that persons are treated identifies her in personhood. By recognizing and responding to her as a person, her family members engaged in the "social practice of personhood."¹⁹

Like Carla, Ashley does not meet the philosophical definition of personhood. She will never develop moral agency; the available medical facts indicate that she will never function above the level of an infant. However, neither Ashley's nor Carla's personhood has ever really been in contention. Both the detractors and supporters of the AT seem to agree that Ashley is a person, if not a fully competent, decisional one. The ethical discussions about Ashley assume that she is a person, but rarely examine the source of that personhood. We do not wish to question Ashley's personhood here. We want instead to focus on the ways in which that personhood is derived and bestowed upon her by her caregivers.

We agree with Lindemann that the identity, and therefore personhood, of Carla was derived from the "third-person" narratives constructed around her. Lindemann, and her parents and siblings, wove Carla into the story of their family, even though Carla could participate only minimally in the process. Carla's identity was thus "constructed entirely from the third-person point of view. We who were her family, along with friends, neighbors, and the many health professionals she encountered in her short life, gave her all the identity she had."²⁰ They envisioned her and treated her as a daughter, sibling, or even playmate, creating a narrative for her. In this way they constructed and held for her an identity as a person.

Ashley's family has also given her an identity, and is holding her in personhood by that identity. She has been given the role in her family story of valued daughter and sibling. As it was for Carla, this is the source of her personhood. Ashley's family has an additional burden, or joy, in that her story is much longer than Carla's. Carla died at age 18 months, and her family's "holding" continues only in memory. Ashley's family has cared for her and held her in personhood for 20 years now.

CREATION OF IDENTITY AND CAREGIVING

We have stated that personhood is constructed in part through the cooperative, narrative work of a family or social group, and that this process can be performed for a human being who cannot participate in it. We wish now to discuss how the narratives essential for holding an infant in personhood are created by, and told in, the context of caregiving.

We turn to Lindemann again for a description of how the social practice of identity construction is done by the families of profoundly intellectually disabled children. Lindemann states that, for the

process of narrative construction of personhood to work, there must be at least some response from the individual. She believes that a family cannot hold in personhood an infant who is anencephalic or in a persistent vegetative state, in which the absence of any higher brain activity precludes the possibility of reaction. However, Carla was given her identity as daughter and sister at (or before) birth. That identity grew to include not only her diagnosis, but also other stories about her, that were based upon very minimal reactions. We believe that Lindemann, in requiring some response, has underestimated both her own ability to interpret cues from Carla and the narrative creativity of many parents.

All infants must be constantly monitored to provide for their bodily needs, and the information received from the infant is never complete. Much of the parental response is based on supposition (“it’s been three hours, the baby must be hungry”) and physical evidence (“time for a new diaper”). From this data, parents begin to form an idea of who their infant is becoming. For Carla, also, most of the family narratives, like those told about any infant, revolved around the basic activities of feeding, bathing, carrying, and comforting.

Parents caring for intellectually disabled children frequently engage in a somewhat inventive process of determining a response to care, even if no response is present. A parent can form a complex relationship based on such minimal clues as eyes opened or closed, the appearance of discomfort, or even the timing of bowel movements. Carla did not really provide much feedback. It was likely from the close monitoring required for meeting her bodily needs that Lindemann and her family based their ideas about her personality.

Likely Ashley’s family also began to “hold” her before birth, by giving her a place in the family as a daughter and sibling. Perhaps they had to alter those stories, adjust their hopes and expectations for her, as they learned of her diagnosis. Likely they have formed opinions about her personality, or at least her temperament, based on their observations of what she seems to like, or what seems to cause her discomfort, or what she seems to respond to. Certainly they have to interact with her physically: give her feedings, change her, bathe her, and move her from room to room. Her identity would have to be constructed largely from her reactions to this care given to her body.

Ashley can tell us what she wants through her response to care, and only in the most basic way, crying or seeming comfortable. She can tell us who she is only through the interpretations her caregiv-

ers form around those responses. Since she will remain verbally noncommunicative, the only way to interpret her identity/personhood is through the physical act of caregiving. Her family holds her in personhood through meeting her physical needs.

Through the enormous and ongoing task of caregiving, the parents of intellectually disabled children become inextricably bound with the lives of their children. If a child can never take over the process of identity formation, the parents become life-long interpreters of their child’s needs and personhood. As they enact this social practice of identity construction, parent-caregivers are responsible for creating the narrative of their child’s life.²¹ Thus, claims that they make about their child’s needs and personality should not be taken lightly. Their children are called into and sustained in personhood almost entirely by the fact of their care.

We wish to note that there is another set of narratives told about Ashley, the story told by the decade-long academic discourse about her. This narrative clearly also establishes her in personhood by thought and attitude. However, the participants in the discussion do not have any actual contact with Ashley, and have constituted her as a generalized other, rather than as a particular person. It should be noted that the identity thus constructed for her has no contribution from Ashley, unlike the one given to her by her parents.

THE PILLOW ANGEL

The creation and maintenance of identity through caregiving is certainly a moral act, particularly if there is minimal participation from the person being cared for. Lindemann agrees that family holding can be done well or badly. We believe that disagreement about the proper identity for Ashley is at the core of much of the arguments over the AT. The accusations of infantilization, denying sexuality, and stunting growth are essentially arguments for a different identity for Ashley than the one her parents have given her. The parents stand accused of forming Ashley’s body into their image of her as an infant, thus enforcing a wrong identity for her.

It is clear that Ashley’s family does not consider her merely as a body to be hauled around, kept clean, and fed. In attitude and treatment, she is treated as a person, both as an individual to be cared for and as an integral part of her family. The responsiveness inherent in good caregiving will enforce her identity as a person to be included in activities, and whose desires, if discernible, are very important. Her parents report that Ashley is seemingly happy, lay-

ing motionless on her pillow as the activity of her family revolves around her. This is the identity in which they have chosen to hold her.

Ashley's family describes her as their "pillow angel," a title that is still used on the public portion of their website. This identity, presumably repeated in family stories, implies that she is, at the very least, a cherished member of the family. The addition of the word "angel" implies a kind of holiness or innocence, although we do not know if her family intends a religious meaning here. They may mean merely that she never gets into trouble, not surprising as she is unable to move. She certainly is cherished.

However, it is true that the family also identifies her as an infant. By asking for the surgery, they requested that her body be made more in keeping with her mind, which would never advance developmentally out of infancy. No one, that we know of, has criticized her family for identifying Ashley as an angel, but there have been many objections to their treating her as a perpetual infant. Indeed, the image of Ashley being carried helpless from room to room on her pillow implies an eternal infancy. However, the ongoing necessity of bathing, feeding, and diapering her, as well as the level of emotional attentiveness she needs, is similar to the caregiving required by infants.

In asking for the AT procedures, Ashley's parents asked her doctors to reform her body in line with the care that she needs and that they are providing. By questioning their judgement, we also question the identity they have given her through this care. We have to ask, then, if holding Ashley in an identity as an infant is inappropriate for her, and if altering her body to hold her physically and emotionally in that identity constitutes a wrong.

Lindemann admits that identities can indeed be constructed inappropriately. A family who "holds well" will preserve an identity while allowing each of the individual members of the family to find their own way. They will, perhaps, hold an open future for a child, so that the child has the widest possible identities to choose from when she or he is able to do so.²² A family that "holds badly" will forget or fail to acknowledge its members or, worse, enforce its own agenda for its' members' identities. They can restrict their child's future autonomy by making desirable choices impossible, or insisting on or refusing to recognize certain qualities.

Few families are totally correct in the identity they bestow upon their child. We don't usually question the identity that parents have given their child, but we do expect children to be able to refute it, to

some extent, as they mature and begin to tell their own story. If Ashley's family has constructed an inappropriate identity for her, she will never be able to refute it. If, by consenting to the AT, her parents do force her to remain in a static and inappropriate identity, that would be a great wrong. We maintain, however, that the identity of a perpetual infant is not inappropriate for Ashley.

It is true that her parents have not held open for her the possibility of becoming a full-grown, sexual woman. This is indeed an immense loss, but, along with many other privileges of adulthood, it was not taken from her by the surgery. The circumstances of her birth had already made many futures impossible. At the time of the surgery, she did not suck or swallow, did not say any words, and had minimal spontaneous movement. Her best possible developmental outcome did not allow for the emergence of the ability to take care of her own body, nor the ability to recognize her physical losses.

Some commenters on the procedure fear that Ashley's development might eventually become more advanced than anyone could predict at age six. There is an idea that she will some day come to miss those things that the surgery stole from her, particularly sexual maturity and fertility. Those who suggest this are seemingly unaware of the consequences of profound intellectual disability. Even if she makes unexpected developmental progress, it is likely that she will remain totally dependent on her caregivers. There is no possible developmental outcome that would allow Ashley the maturity to engage in consensual sexual activity. If her parents came to a fertility clinic requesting that she be artificially inseminated in order to bear them a grandchild, we would find that ethically outrageous.

Some of the detractors feel that holding Ashley as an eternal infant will ultimately result in holding her back from any development at all. The lack of ability to mature sexually is felt to contribute to that inability to mature emotionally. However, proper family holding allows for the possibility of change. In being responsive to her bodily needs, the family must monitor her emotional moods, and thus will become aware of any change in attitude or preferences. Holding her well will not hold her back from all change. In fact, attentiveness to her physical needs will lead to the recognition of any change in personality she might express.

Ashley's parents have not limited her future or her identity in any way by having the procedure done. Her impairments had already done that. Essentially the growth attenuation and surgery merely formed Ashley's body in keeping with the only iden-

tity her parents could give her. She will continue to need to be cared for as an infant, although she is, in fact, a good deal larger than a baby, despite the growth attenuation. By having the surgery, Ashley's parents insured that it will be possible to continue to care for her. Assuring her continued care is perhaps the only way they can guard her future. She is, and will remain, their pillow angel, a personality constructed through the responsive meeting of her bodily needs.

The reality of Ashley's disability is that she must be cared for as an infant; she will continue to require feeding, bathing, diapering, and comforting. As part of that caregiving, her parents will interact with her and respond to her moods, while attending to her physical needs. She will also quite probably remain at an infantile level of psychologic development, in which she benefits from the intimacy of close physical holding. Because of the surgery, she can for now continue to be held in personhood and identity as a cherished member of a family.

Being held in an identity as an infant is not inappropriate for Ashley. It is likely that it is impossible to hold her in any other way.

CONCLUSIONS

Ashley represents a level of disability rarely acknowledged in medical or ethical literature, but unfortunately not unheard of in pediatric medicine. Ian Brown, the father of a severely intellectually and physically disabled boy, says of his son and others like him, "Until twenty years ago, children this medically complex didn't exist. They didn't survive. High-tech medicine has created a new strain of human beings who require superhuman care. Society has yet to acknowledge this reality, especially at a practical level."²³ Perhaps it is no surprise that there is controversy over the proper way to envision a person such as Ashley. She may well be a new type of person, one we are just beginning to see value in, and care for.

Ashley's parents, and those of similarly disabled children, understand what it means to care for a child who will remain intellectually an infant. Through caring for profoundly delayed children as cherished persons, these parents establish for their children an identity and a life narrative. Since much of the story of Ashley's life is encompassed in the act of bodily caregiving, the way in which she is cared for is central, not only to her physical comfort, but to her psychological well-being.

Within the act of caregiving, Ashley's family is holding her in personhood and identity. Because she

will never be able to participate in her story or object to its contents, the identity thus formed can never be confirmed or refuted. This does not mean that her identity is static, however. Holding well includes being responsive to changing needs and potential for growth.

It is possible that the debate over the Ashley procedure can be reframed as a debate about who, exactly, we envision Ashley to be. Perhaps Ashley has been given one identity by her parents, and an utterly different one in the ongoing discussions about her. We maintain that, because of the relationship between Ashley and her parents as responsive caregivers, the identity they have given her takes precedence. We must be careful not to impose our own identities on Ashley and her body.

We believe that the identity constructed by Ashley's family, as an eternal infant and beloved pillow angel, is not inappropriate for her. By allowing her parents to choose the growth attenuation and surgery, we have not only eased the burden of caregiving, but validated her family in holding her well. We support the procedure because it was done in accordance with an appropriate identity constructed by her caregivers.

NOTES

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