

Forever Small: The Strange Case of Ashley X

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I explore the ethics of altering the body of a child with severe cognitive disabilities in such a way that keeps the child “forever small.” The parents of Ashley, a girl of six with severe cognitive and developmental disabilities, in collaboration with her physicians and the Hospital Ethics Committee, chose to administer growth hormones that would inhibit her growth. They also decided to remove her uterus and breast buds, assuring that she would not go through the discomfort of menstruation and would not grow breasts. In this way she would stay “forever small” and be able to be carried and handled by family members. They claimed that doing this would ensure that she would be able to be part of the family and of family activities and to have familial care. But the procedure has raised thorny ethical questions. I wish to explore these questions philosophically by bringing to bear my own experiences as a mother of a grown daughter with severe cognitive impairments.

PRELUDE

THE CASE

In 2002, the parents of a six-year-old girl with a condition that will require physical care throughout her life, and who had begun to exhibit signs of precocious puberty, requested, and were granted, permission to have high doses of estrogen administered to induce the premature closing of the long-bone epiphyses, thus maintaining the girl’s height at 4’5”. The intention was to facilitate her care by keeping her small. To reduce the uterine bleeding that accompanies the procedure, as well as the risk of uterine cancer, she underwent a hysterectomy prior to the estrogen treatment. To reduce the risk of breast cancer, of which her family had a history, and to prevent the growth of large

breasts, also a familial trait, her breast buds were removed. Surgeons also performed an appendectomy as a prophylactic, which was unrelated to the other procedures.

Given only this information, most will regard these procedures as ethically problematic, though some will suspend judgment until the condition is specified.

Now we add: this girl has severe cognitive disabilities from an unknown cause, static encephalopathy with marked global developmental deficits, rendering her profoundly intellectually limited as well as incapable of mobility, holding up her head, or doing anything at all for herself. Her physicians made this public in a medical journal, referring to the procedures in the title of their article as a “new solution to an old dilemma” (Gunther and Diekema 2006).

A near universal response is harder to predict now. Many think that parents who shoulder the burden of care should have great leeway in deciding on the treatment of their disabled child. Others will want to know: Are these caring and conscientious parents? Are there other options? Do the parents have an accurate prognosis and informed expectations? For still others, the procedures seem no less abhorrent because they are performed on a child with severe cognitive and physical disabilities.

Here are the remaining facts: This is the notorious case of Ashley. Following the scientific publication announcing the procedures, the case made the media rounds,¹ her parents set up a website to tell their story and to promote what they dubbed “the Ashley Treatment” (henceforth AT) for other children like Ashley.² By all accounts and as they appear in the website, her parents, middle-class and educated professionals, are loving and caring. They want to keep her small because this will permit them to care for her in their home for the longest possible time and allow her to participate in family events and in activities she enjoys, such as going to the beach. They justify the hysterectomy by arguing that their daughter will never be a mother. Without a uterus she will never become pregnant should she become a victim of sexual abuse—and as a woman with disabilities, especially cognitive disabilities, her risk is higher than that of other women. They justify the removal of the breast buds by claiming that large breasts will make the straps that keep her in place in a wheelchair uncomfortable, and will also reduce the likelihood that caretakers will sexualize her. In addition, surgery will guard against the slightly increased possibility of cancer in these sexual organs caused by the high-dose estrogen treatments. Despite all the criticisms, the parents actively defend and promote AT as a way to care for other “pillow angels,” as they call Ashley.

The Ashley case reveals views of human embodiment that have important ethical consequences, ones that are lived in the disabled body of a girl who is to remain forever small. I will argue against the acceptability of AT. For an issue as morally complex as this, no one argument is likely to be decisive.

Instead, I rely on the conjunction of four related arguments to make my case.

At stake are two questions: Did Ashley's parents, doctors, and the hospital act ethically? Should AT be made available to all parents of children whose prognosis is severe cognitive disability and non-ambulation (SCDN for short) at an age early enough to make AT effective, that is, when they are two to six years of age?³

The problem, as I diagnose it, is that AT is undertaken with a questionable set of assumptions, and in a context where the best alternative options are hard to come by. Although all acted to provide Ashley the best available care—no villains here—good faith does not guarantee that the actions are in fact caring ones. I may intend to care for a parched plant by watering it, but if, unbeknownst to me, the glass of clear liquid I pour in the plant contains vinegar, not water, most would agree that, despite my good intentions, I have failed to care for it. Ashley's parents surely intended to pour restorative water but, I contend, have poured vinegar instead. Moreover, had the available social supports been ready to hand, the option they conceived of might never have been considered.

A TALE OF TWO GIRLS AND A MOTHER'S JOURNEY

In the face of the extensive criticism directed at Ashley's parents, proponents responded that those who had not walked in their shoes ought not to judge them (Wilfond et al. 2010). Although I cannot presume to have walked in the shoes of Ashley's parents, I have long traveled in a similar pair.

My daughter, no longer a child but a woman of forty, is not quite a "pillow angel." She possesses some motor skills. She learned to hold up her head by the age of two years (instead of the typical age, two months). She did learn to walk—at age five after extensive physical therapy—but retained the wide gait of a toddler. For many years, however, as locomotion became too hazardous because of a seizure disorder and scoliosis of the spine, she has used a wheelchair. Like Ashley, she is very comfortable in bed, but we don't keep her there except to rest. Unlike Ashley, who requires a feeding tube, my daughter Sesha eats regular food (which she delights in), but she can at best finger feed.

Like Ashley, she does not toilet herself, speak, or turn herself in bed; she can do no daily tasks of living for herself, and she has no measurable IQ. Like Ashley, she is sweet, loving, and easy to love. A person with Sesha's disposition would easily be called "an angel," regardless of disabilities. Sometimes I wonder if Sesha is a special being sent to us from elsewhere, for there is an impossible-to-articulate sweetness, graciousness, and emotional openness about her—qualities we rarely find in others. I sense from the writings of Ashley's parents that Ashley too has these qualities. Still we try to refrain from referring to Sesha

as “an angel” since that has the unfortunate side effect of edging her out of the human community. To love Sesha as she is, it is of critical importance to us that, unlike an angel, Sesha has a body, and unlike eternal beings, she does age. Especially because it is hard for many to recognize and acknowledge people whose lives are significantly different, we need to reiterate the unqualified humanity of people with serious cognitive disabilities.⁴

On first consideration there appears to be a great difference between parents’ expectations and hopes for children with cognitive disabilities and those for their other children. As parents we don’t expect significantly cognitively disabled children to make us grandparents or have a thriving career, and we don’t hold them accountable for their actions. But on further consideration, we want the same things for all our children:

- that they live and stay as healthy as possible
- that they have a chance for happiness and joy; that malevolent forces do not disturb their lives
- that they contribute in some way to the lives of others.⁵

Despite the special qualities we parents find in our disabled children, and in spite of our curbed expectations, we share with most parents a deep love for our children, a commitment to their flourishing, and a desire to always have them in our lives.

As AT was her parent’s innovation, it was never presented to us as an option for Sesha. From my position as the mother of a grown woman, I recoil at the thought of doing this to my daughter. (Note the turn of phrase: “to my daughter” not *for* her.)

Might I have felt differently when Sesha was Ashley’s age and showed signs of precocious puberty? At six, Sesha was making progress physically and had started to walk. We could not envision a regression, and so we would have rejected any such suggestion. Could I say the same knowing, as I do today, that, as an adult Sesha would not walk independently? Could I say the same if confronted, as were Ashley’s parents, with a six-year-old who was developing breasts and sprouting pubic hair? I can certainly imagine being alarmed and fearing what the future held. Still, had I contemplated this option, I can say *today* that I would have been happy to have had someone talk me out of it.

When Sesha was very young, I recall thinking that her infancy and early childhood would probably be our best time with her. In fact, I could not imagine her grown—it was incongruous and, quite frankly, very disturbing. People then and now speak more easily and hopefully of *children* with developmental “delays” and mental retardation (MR).⁶ Adults with MR are rarely discussed except when they are victims of terrible abuse or when some poor fellow with “the IQ of a child” has committed a crime.

As I could not have the expectations of a woman for Sesha, there was nothing for my imagination to hang on. I was resigned to seeing myself wistfully recalling the halcyon days when Sesha was a child—when her mental age (whatever that was) more closely resembled her physical age. I was in the grip of what Tobin Siebers has called the “horizon of ability” (Siebers 2008).

But somehow her young years never strike me now as “halcyon days.” They were emotionally much more difficult. As Sesha has matured, we too have developed. The dominant “horizon of ability” has given way to a rich acceptance and full appreciation of who she is, of the lovely woman she has become. As much as I loved Sesha from the moment of birth, perhaps I love her still more today. She has acquired her own personality, her own mature beauty.

More important still, I have come to grow increasingly more humble in what I think I know about my daughter (just as, I may note, I have had to learn how little I know of and understand my *non-disabled* child). Sesha’s otherness is both more and less palpable today. The quality of containment, of mystery that we each present to each other, regardless of ability, is increasingly clear to me. We always see each other through a glass darkly, but when viewing a child with cognitive disabilities, the glass is darker still.

At the same time, I find more and more ways in which her disability is not as much of a difference as I had presumed. Her development will not show up on an IQ test, but she has become increasingly mature emotionally. As in the case of my adult son, the decades have altered her tastes, her understanding, and her responses to the world. All this, I hope to show below, is pressingly relevant in considering the ethical dimensions of AT.

A CARE ETHIC FRAMEWORK

Although many arguments against AT have been offered, some more effective than others, the argument that I make is based on an ethic of care. In the ethic of care that serves as my ethical framework,⁷ we care for another, in the normative sense of care, when we are motivated to concern ourselves with the well-being of another *for that other’s own sake* (Darwall 2002) and when such motivated actions contribute to the person’s flourishing.⁸ Below I briefly discuss the elements of an ethic of care that figure in the arguments I present.

ASYMMETRIES AND DEPENDENCIES

An ethics of care recognizes that our ethical life includes unequal and dependent parties. This immediately recommends it as the appropriate framework to consider the ethics of AT. For the procedure, beginning with a child diagnosed with SCDN who is incapable of consenting or entering the conversation, involves parties that are asymmetrical in power and dependency. The parents

who have the standing to provide a “substituted judgment” are themselves not fully equal and autonomous agents in medical situations. They are dependent on medical personnel for expertise in making the best choice for the child. An ethic of care would demand that the medical personnel recognize their asymmetrical power. In their role as carers, they have to listen to parents’ views and concerns. But because the new parent, if not herself disabled or already the parent of a disabled child, is likely to bring her own ableist biases to the situation, and as the physician is professionally liable to see disability as a medical condition only, a fully adequate response will require information from those better situated to provide a perspective from a life lived with disability.

THE TRANSPARENT SELF

A care ethics asks that *we make ourselves “transparent” to the needs of the other* (Kittay 1999, 51). That is, we promote the interests of the other as *that individual* experiences those needs—as best as we can ascertain them. As carers, our moral labor demands that we imagine the world from the perspective of the one cared for; that we respond to the cared-for in accordance with her *own* needs, desires, and interests; and that we attend to ways that our own needs, desires, and interests may color, obscure, or deflect those of the individual cared for. This is already hard when one is dealing with a still unformed person such as a young child, but is especially challenging when the person being cared for cannot be explicit in communicating needs and interests. In the case of a child like Ashley the difficulties seem insurmountable—we can at best get asymptotically close—but it is precisely for someone as vulnerable as Ashley that we need such stringent requirements. Within the constraints of a care ethics, all the carers, parents, physicians, and hospital review boards must be informed by the lived experience of disability. No doubt this is complex since those who can offer a view are by that fact alone not the target audience for AT. Nonetheless, from within the constraints of a care ethics, the fact that the judgment from the disability community is decidedly negative carries moral weight within an ethic of care, less because this third party might have an interest in the outcome of this case, (though this does matter) and more because people with disabilities help parents become more transparent to the needs of their child.

THE RELATIONAL SELF

The transparent self derives from the concept of the self as relational. On this view the boundaries between self and other are not impenetrable. It is this porosity that makes the transparency possible, but also challenging. The well-being of a child, assuming a loving family, is critical to the well-being of parents and siblings, just as their well-being is crucial to that of the child. This interdependency is at the heart of Ashley’s parents’ argument that AT is for Ashley’s

own sake and makes their argument persuasive to those who might otherwise oppose AT.

Yet the relational self is neither merged with, nor grafted onto, another self. Although each self is connected to others, it is distinct as well; otherwise there are no multiple relata to stand in relation to one another.⁹ To act caringly toward another is a mean between thinking of the other's interests as identical to our own and thinking of them as entirely distinct. When we give the family the power to act toward one another in ways that strongly contravene moral intuitions governing our actions toward one another, we are in danger of losing that mean. For example, a parent might know her child better than a third party and may insist on a right to *beat* sense into her. But severely beating children contravenes strong moral prohibitions, and we insist that a parent's power does not reach so far.

CARE ETHICS AS AN EMBODIED ETHICS

An ethic of care is an embodied ethics. We fail to care for another when we take an instrumental approach to the body. From an ethics of care perspective we cannot attend to the body without attending to the person, and we cannot care for a person without attention to their bodily integrity and well-being.

CONTEXT

An ethics of care is a contextual ethics that considers the particular actors, time, place, and circumstances as relevant to ethical deliberation. However, although the context of *this* child and *this family* matter, the context here goes beyond one family, not least because Ashley's parents have made a point of promoting AT. No evaluation of AT within an ethic of care can ignore broader contextual features of the case, especially as the population in question historically (and still today) is highly stigmatized, and as people with such disabilities have been (and continue to be) mistreated and abused.

Care "*Completed in the Other*". Care, as Nel Noddings has put it, has to be "completed in the other" (Noddings 1984, 4); or as Joan Tronto has stated, care needs to be received to be care (Tronto 1994, 106). This little noted consequentialist element of an ethic of care—that ministrations directed at the other are not care until they are taken up by the cared-for as care—perhaps plays the largest role in determining whether we should see AT as ethically permissible within an ethic of care. It justifies asking whether parents, even with the best intentions, care for their child in the best way possible. As we have yet to see how Ashley and other (unpublicized) cases of AT turn out, the final verdict remains uncertain. But, as we shall see, an ethic of care gives us many reasons to be doubtful, while it supports seeking alternate ways to care for children such as Ashley.

The contention of this essay is that despite good intentions, neither Ashley nor other qualified disabled children are well served by AT. Though it was done in the name of care, it does not foster flourishing in critical ways and thus falls short.

QUESTIONABLE PRESUMPTIONS

The mental exercise I proposed at the paper's outset engages four controversial presumptions. Each, as I will show below, is problematic.

1. The body, rather than being a constitutive part of who we are, has a *primarily* instrumental role.
2. AT claims to inhibit a body's development to make it more fitting to one who will always remain at the developmental stage of an infant.¹⁰
3. AT will avoid misuse by being limited to the severely cognitively disabled who are non-ambulatory.
4. AT solves the difficult problem of caring for Ashley in a way that keeps her close to the bosom of her family.

Presumption 1 sets off those who react to the initial description of AT with horror from those who withhold judgment. For the first group, such drastic bodily alterations are justified only if they are needed to preserve a child's life or vital functioning. For the second, many lesser justifications will suffice. This may be an unbridgeable difference. Yet I hope to show below that the second group's instrumental view of the body is inconsistent with deeply held moral intuitions and is incompatible with an ethics of care that treats persons as embodied.

Such intuitions normally constrain an unfettered use of biomedical technologies. Yet we might relax the constraints if we maintain Presumption 2, the belief that these disabled minds undergo no development, and Presumption 3, that if AT is limited to people with such disabilities we can avoid abuse of AT. These claims, I propose, underlie the judgment that Ashley's disability justifies AT. But Presumption 2, I contend, is belied by empirical facts, and Presumption 3 is discriminatory and unwarranted, not least because targeting an already stigmatized group runs the risk of their further stigmatization and mistreatment.

When assured that the family who requested the procedure was well meaning and loving, the last objection might be lifted for all but the most resistant group. Assured that AT would be limited to SCDN children (Presumption 3), they may grant that insofar as a loving family displays only the best motives, and as no good, socially available alternatives exist (Presumption 4), such families should have the final voice. Using an ethic of care, I reason that Ashley is better cared for, and we are all better served, if efforts are instead directed at

improving the supports, services, and equipment for the disabled and their families.

ARGUMENT 1. THE BODY “INSTRUMENTALIZED”

VIOLATING BODILY INTEGRITY

In an article meant to lay to rest the many criticisms launched at AT, Douglas Diekema and Norman Fost concede a right to bodily integrity, but claim it is a right that a physician may override in certain instances:

- 1) With permission given by the person or surrogate.
- 2) Without permission physicians should determine that “tumors, tonsils, and appendices” be removed.¹¹
- 3) In the case of children with disabilities when physicians “alter physical appearance,” insert “gastrostomy tubes and tracheotomy tubes,” and perform osteotomies (Diekema and Fost 2010, 34).

AT, they contend, is no different. Will this defense hold? I believe not.

1) Even an autonomous patient’s permission is not always dispositive. Our body is our own, but we are not thought to have an absolute right to violate it, or to permit others to do so. Ashley did *not*, because she could not, give her permission. In such cases the surrogate, usually the parent, decides¹²—for who is better equipped to determine and to care about the child’s best interests than a caring parent? (As a parent, I also do not want others to intervene.) But to determine what is in the child’s best interest, one’s beliefs need to rest on a solid foundation. New parents of a disabled child have little sense of the trajectory of that child’s life, so their decision rests on shifting sands. Furthermore, their decision is based on a physician’s assessment that their child will always “have the mind of a baby.” This, I argue below, is misleading.

2) Are the medical procedures that do not require permission appropriate comparisons? Tumors are removed because they are life-threatening or may interfere with bodily functioning. Tonsils are removed because they heighten susceptibility to infections. Appendices are removed when infected, or likely to become infected, and pose a risk to life. Where there is an imminent danger, physicians can proceed without permission if getting consent involves a risky delay. None of these conditions apply in Ashley’s case.

3) All the procedures enumerated by Diekema and Fost preserve life or ameliorate a health condition. They address specific ailments that need treatment whether or not the child is disabled. Those procedures carried out on disabled children that do not preserve life or affect function raise serious moral questions.¹³ However, the procedures involved in AT preserve neither life, health, nor function.

Can one retort that intrusions on bodily integrity are ultimately justified in Ashley's case because, like all those mentioned, they are procedures intended to promote the patient's flourishing? AT promotes parental care, and because such care is more important than height for her flourishing, the treatment is justified. Were Ashley's care impossible without it, then yes.

That we have to hire help or rely on equipment to do what parents' hands and arms can do is a loss; but although the ability to care for Ashley without such assistance may be lost, the ability to care for Ashley, and even to provide that care at home, is not. Learning what services and resources are available, advocating for more services, and adjusting to new people and equipment all take time and energy. And, surely, raising a child with severe disabilities is demanding enough: I know, I have been there. GA (growth attenuation) is a shortcut through these difficulties. But, as I will argue below, if these procedures would not be done but for the disability when these do nothing to cure or mitigate the disability, and if we believe that no reason justifies restricting the height of a person who otherwise would be within normal range to the height of a six-year-old, when that person does not have severe cognitive disabilities, then we should not avail ourselves of this procedure in the case of this disability.¹⁴

As one mother, Sue Swenson, put it: "Parents [of disabled children], too, need to operate within the bounds of society." As for the opportunities that open along with the difficulties, she writes:

It is difficult to care for a son who is legally blind, quadriplegic, non-verbal, autistic, profoundly intellectually disabled, six feet tall and 190 pounds. Heck, if you put it that way, it sounds impossible. . . . We have not been his sole caregivers since he was eleven. . . . Family support helped us learn to let go, and to recognize the man that emerged from behind the face of our baby boy. We needed information and training about raising a severely disabled child: how to position him so he could participate; how to transfer him without lifting; how to support his mobility and find useful equipment; how to figure out what he wanted; how to think about his rights. . . . We love our profoundly disabled son as we love our other sons. Like them, he is a strong, gentle, complex, and interesting person. He is his own man.¹⁵

THE INHERENT GOOD OF GROWTH

Diekema and Fost, note that growth *promotion* therapy is uncontroversial because people mistakenly think its point is to bring a child within a given norm,

whereas growth *attenuation* takes the child further from this norm. Instead, they argue, both procedures have nothing to do with norm heights but are manipulations of the body that make it more conducive for certain ends: In the case of growth promotion it is to make the child competitive in the job market and in social interactions. In the case of GA it is to make the child small enough to be cared for in the home (Diekema and Fost 2010, 34).

But GA is shaped entirely by contingent social values or perceived needs, whereas growth is what happens when a child is kept healthy and properly nourished. In the 1950s and 1960s a tall girl was at a distinct social disadvantage. The innovative “solution” to this socially constructed “problem” was GA using high dosages of estrogen. As we move toward gender parity, GA for tall girls has been cast into the wastebin of oppressive gender practices.

Critics have asked (rhetorically) if the aim of GA is to produce a size small enough to keep children like Ashley within the family orbit, why not just remove her legs? Diekema and Fost dignify this rhetorical question with a response, giving as one “nontrivial” reason against limb removal that it reduces the number of sites for intravenous access!¹⁶ Even if true, the response is grotesque. Removing healthy limbs is abhorrent, I suggest, because we value bodily integrity as a crucial intrinsic good. When deciding whether to remove a limb (or attenuate growth) we weigh not only risks and benefits, but also our values.

Imagine parents requesting GA for their talented prepubescent son who passionately wants to be a champion gymnast (or jockey or coxswain, where small size is necessary), and is willing to trade height for the realization of a dream. Surely the request would be denied. To accede to it, some may argue, would be to close the boy’s future options; but note that to refuse him, we foreclose an option for which he has demonstrated passion and talent. Instead, I venture, our moral intuition is that when we regard his body as merely instrumental to a specified ambition or goal, we also treat him as a mere instrument: our bodies *are* ourselves—what is done to our bodies is done to us.

SEXUALITY AND ORGAN REMOVAL

Diekema and Fost take an equally instrumental stance toward sexual organs. Surmising that the removal of the breast buds might reduce sexually pleasurable sensations, they promptly dismiss the worry since Ashley would never “experience sexual pleasure without being exploited or sexually abused” (Diekema and Fost 2010, 34).¹⁷ Asking “what it is about becoming a woman that would be of interest to Ashley,” they write: “Most of the usual features that distinguish a woman from a girl—the opportunity to marry, procreate, work, lead an autonomous life—would not have been available to Ashley with or without a uterus, fully developed breasts, or normal stature” (Diekema and Fost 2010, 34).

As the childishness in her face fades, Sesha's body has taken the form of a woman. I don't know if Sesha can rejoice in her breasts, if she notices them at all, if she would miss them, or if she compares herself to other girls. What I do know is only that I don't know. Nothing about Sesha—with all her profound incapacities—tells me that Sesha is incapable of these feelings. I can say that I, as her mother, delight in her womanliness. It is very much a part of Sesha, as she is now.

Its true that Sesha, like Sue Swenson's son, became harder to handle as she grew to be 5'4" and 120 pounds, and we had to make accommodations. At forty, she now lives away from us during the week and is at home with us only during the weekend not because she is too tall or too womanly, but because at this stage of her life, she has a more varied and fuller existence in the community where she is than she would if confined to our home. At a certain point we stopped taking her with us everywhere not only because she got bigger, but also because we felt that we needed time with our son, and he needed time to do things with us that Sesha could not share. Had Sesha been petite and skinny, some things would have been easier. What started to make it difficult to bring Sesha with us was the cumbersome wheelchair she needed to keep her well-positioned. Today there are umbrella strollers and beach buggies for strolls and water fun.

Do I regret at all that the "keep-her-small solution" was not available to us? No, emphatically not. We stand Sesha up and love that she is just a tad taller than me. "Sesha! You're bigger than Mommy!" Why? Why does anyone enjoy noting how tall one's child has become? We take pleasure and pride in our bodies as they grow and mature because . . . we do. Full stop. It needs no further justification. It is constitutive of a thriving life. That is *not* to say that one cannot thrive without breasts and without a uterus, or that short stature can only mean that we have not thrived. But height and the bodily changes of womanhood are among the ways in which human beings thrive, and ways to signal this thriving to others.

ARGUMENT 2. A BETTER FIT BETWEEN THE DISABLED BODY AND THE DISABLED MIND

Ashley's parents report: "Unlike what most people thought, the decision to pursue AT was not a difficult one" (Ashley's Parents' Blog). They go on to say that once they understood the options, the "right course was clear to us." What I believe happened is that once they understood that a child who was an eternal baby would grow into a woman, the course was clear to them.

They approvingly quote George Dvorsky: "The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby'. . . Ashley can continue to delight in being held in our arms and will be moved and taken on trips more

frequently” (Ashley’s Parent’s Blog). Professionals tell us: “She will *always* have the mind of a three-month-old infant.” The diagnosis and prognosis is *stasis*. It is just this idea that misleads us.

To have the mind of a baby and the capacities of a baby are not the same thing, for the disabled person may well have an understanding and a set of emotional responses that far exceed her *capacity to act*. The brain may be impaired, but it is not frozen. Synapses continue to be formed as they do in all brains. As the Board of the American Association for Intellectual and Developmental Disabilities writes: “The abundant evidence [is] that all children are able to learn and that the cognitive capabilities of children with severe motor impairments can be grossly underestimated . . .” (AAIDD 2007).

A young woman with Rett’s Syndrome with whom I am acquainted has no more capacities than a very young child, perhaps a baby of three months. But this young woman, when told that her father was dying, would be found by the caregivers sitting quietly shedding tears for weeks. This is not within the understanding of a baby. A dear caregiver joked in front of my daughter that the secret of her youthful appearance was that she had no worries, like paying taxes and bills. I countered by saying that Sessa has a lot to worry about, like not being able to scratch an itch, move out of an uncomfortable position, tell us what she wants, and so on. My daughter turned to face me, gave me an intense look, smiled broadly and reached out to hug me. I was startled, as were all who witnessed this response. Maybe she only grasped the tone, but it is no less possible, indeed plausible, that she understood the words. She has, after all, been listening to human speech for forty years.

What we know of are the capabilities that allow the brain to direct the rest of the body in certain ways. We do not yet know enough about what is actually going on in the (bodily) brain and the subjective world of people with severe cognitive disabilities. As Ashley will have hormones produced by intact ovaries, she may well experience the sensations of bodily maturation. What will it mean to her not to have breasts? Do we know? What will it mean to her to be a woman? Do we know? How will she experience bodily growth? Can we say? No, no, and no. It is the misleading image of a fertile, full-grown woman with the mind of a baby that makes us think we know something about which we, at the current time, have not a clue.

Diekema and Fost concede that “some rights claims raise troubling questions” among which are “that Ashley had been robbed of the right to sexual pleasure.” They grant that the removal of the breast buds might reduce sexually pleasurable sensations she might otherwise experience, but promptly dismiss the worry. Why? Because it is too worrisome to think of children like Ashley growing into sexual beings.

I deeply appreciate the worry and the fear that such a young woman might be exploited or abused, but removing breast buds and preventing breasts will

not guarantee or even reduce these possibilities. If one is perverse enough to sexually abuse such a girl, might he or she even be attracted by the strange history of a child who parents removed her breast buds? Who can say? Only careful screening, supervision, and respect for these girls and women can offer the needed protection.

Desiring AT for one's child makes sense if "she will always be a child mentally," as an adult body makes meeting her needs (the needs of a child) more cumbersome. Keeping Ashley forever small will, alas, not keep her forever young. Though difficult to grasp while the child is still young, one learns that in the case of disability, things don't just fit together in standard ways. Some cognitive skills are minimal, others may go through a relatively "normal development." Because one is incapable of holding up one's head, speaking, or walking does not necessarily mean that they cannot understand a slight. Because someone has had no apparent expressive speech does not mean that he or she cannot understand the thoughts of others as they are conveyed through language. The relationships among such capabilities are more complex and less predictable than in those who are species-typical.

From a position of an ethics of care, the caregiver needs to be able to understand the world, as far as possible, from the perspective of the cared-for. But this sort of understanding on the part of an able parent of a disabled child requires more than empathy, and more than love. It requires understanding and education. It requires time to grow with the disability as the child does. To short-circuit the project is ultimately not conducive to good care. Is Ashley, or Sesha, or another individual best cared for by always being kept close to Mom and Dad? Having moved through forty years of the life cycle, I have come to seriously question that proposition. A three-month-old may need only Mom or Dad or Grandma. But a severely cognitively disabled adult needs more, much more.

ARGUMENT 3. COGNITIVE DISABILITY AS THE (SOLE) INDICATOR FOR AT

Proponents recognize that there is always a risk of a misdiagnosis. Furthermore, I have offered reasons to question if the SCDN truly are incapable of all such understanding, even when the diagnosis is correct. Proponents respond that all medical procedures involve some uncertainty; there is always the risk that we are wrong. As in all medicine, we weigh doing the procedure against doing nothing. In the case of breast bud removal, Diekema and Fost ask if we had done nothing and "Ashley suffered frequent yeast infections under her breasts, recurrent biopsies, and fatal breast cancer due to a delayed diagnosis . . ." (Diekema and Fost 2010, 36), would that be preferable to having done nothing? But this retort is not compelling.

Yeast infections are a problem for large-breasted women, yet can be treated with over-the-counter antifungal cream, and often are preventable with good

care. As unpleasant as recurrent biopsies are, it is hard to imagine anyone choosing breast removal to avoid them. When there is a congenital risk of breast cancer, some women do favor preemptive mastectomy. But so far we have not suggested removing breast buds in all young girls where there is a family history of breast cancer. It is no more urgent in women with very severe cognitive disabilities.

The claim is that the risks are justification enough for the SCDN, as the individuals lack the awareness to understand the losses or engage in social interactions where the loss would be felt. Against the complaint that this looks like discrimination, proponents can answer that all medical procedures target limited populations. One prescribes antibiotics only to people with bacterial infections; anti-convulsives are limited to epileptics. Each medical intervention is targeted at particular ills that are dangerous to life, cause pain or ill health, or reduce function. Children with disabilities are subject to many invasive procedures that are limited mostly to people with disabilities. Diekema and Fost cite “tracheotomies to improve airway patency and enable suctioning, tonsillectomy to reduce airway obstruction, fundoplication to reduce gastroesophageal reflux, gastrostomy tubes to aid feeding, spinal fusions to prevent advancement of scoliosis, and tendon releases to reduce the effects of spasticity” (Diekema and Fost 2010, 36).

But all these are also carried out on children not otherwise disabled or they are directed to a specific medical disorder, not a class of persons *per se*. Tracheotomies are used for whoever needs this assistance for breathing; tonsillectomy and spinal fusions are carried out regardless of a person’s cognitive or physical capabilities; gastrostomy tubes may be more frequently administered to old and young whose cognitive function is impaired, but only because such impairment is coupled with conditions that impact swallowing and food intake. Severe cognitive disability is not an indicator for any of these or any other procedure save AT, for which it is the sole and necessary indicator.

AT is intended for ease in handling the person and preemptively treating sources of pain or discomfort. The disanalogy with all the other cases is that AT alone is not considered as a treatment for any other people whose size, or potential size, can pose equivalent difficulties in care or exclusion from family life—for example, an autistic boy who is likely to turn into a bulky six-footer and have violent tantrums that will require restraints.

The main reason for limiting the eligible population in this way is the supposition that these people alone will never know the difference—even if we cannot be sure this is true. But the treatment is not directed at their cognitive disability. It is directed at the difficulty of caring for them—a condition shared by many other populations. Then what else might we be able to do to this population on the supposition that they will never know the difference?

The long, cruel, and gruesome history of people with cognitive disabilities, especially when the disabilities are severe, are all justified on the supposition

that these people don't know the difference or can't feel the indignity—that they won't know the difference if a part of their brain is lobotomized, if they are deprived of clothing, if they are showered communally by being hosed down. The horrid shame of it all is made that much worse when some who are included are totally cognizant of their mistreatment. Yet we also have learned that once we stop supposing that “they don't know the difference anyway,” we find out that they were entirely capable of knowing, understanding, or at the least experiencing the treatment as mistreatment.

People with severe cognitive disabilities are often not told when a close family member dies because “they just wouldn't understand.” Yet the young women with Rett's understood all too well when told. So did another young man, diagnosed as severely cognitively disabled, whom I know. I myself witnessed his howling pain when told of his father's death. The uncertainty of us not knowing what they know is a great risk indeed. And the risk of further stigmatizing this group and discriminating against them—doing something to them that would not be done to anyone else—is also far too grave a risk to permit AT or even just GA to be routinely offered to parents of these children. We reopen a Pandora's box of well-intended salves that turn into nightmares when we allow severe cognitive disability to be the lone and sole indicator for a certain treatment.

In medical care as well as parental care we do balance risks and benefits. Caring is often a matter of making these difficult choices, but if we fail in our care when we do more damage than good, an ethic of care would suggest that some risks are not worth taking, no matter the benefits.^{18,19} The psychological pain expressed in some other cases where parents have intervened in their child's development while their child was very young and where there was not a medical necessity indicates that AT is not a risk worth taking, especially since the difficulty is ultimately less with the child's body and more with the social response, or rather *lack* of social response, to the needs of families of a SCDN child.

ARGUMENT 4. A SOCIAL FIX FOR A MEDICAL ILL

Jeffrey Brosco, a pediatrician and medical historian, in one of the best commentaries on the subject, writes sympathetically of the predicament faced by many parents of severely cognitively and physically disabled children. As a practical matter, Brosco points out that we do not know if AT will work. That is, “will the administration of high-dose estrogen to children with profound disabilities enable them to remain at home under the care of their parents for a longer period? And will this improve the quality of their lives?” (Brosco 2006, 1077–78)

His question is particularly relevant for an ethic of care because of its strong consequentialist element. Perhaps we would have to wait too long for the

Ashley case to provide evidence in either direction. But we have no evidence that smaller individuals are kept at home longer, nor that this is a factor in decisions to place children in out-of-home residences. We also lack evidence correlating smaller size with a better quality of life.

Most important, Brosco asks whether the proposed treatment does “justice to the scope of the problem?” His assessment is that the most morally troubling feature of the Ashley case is that it “fails to situate the plight of these parents struggling to care for their children, in the larger context of a societal failure to provide adequate social support in this most admirable of undertakings.” Instead it offers “simple technical fixes for seemingly intractable problems, which often combine biological and social aspects of human existence” (Brosco 2006, 1077–78).

Many hoped that the case would fuel demands for increased assistance. Equipment (often not user-friendly, reliable, or gainly) and caregivers (often untrained and inexperienced) are expensive and are only occasionally covered by health insurance. In communities where help can be obtained, parents have to scratch and claw their way into the appropriate programs. Although some strides have been made in making equipment easier to use, more reliable, sleeker, and less—well, let’s say it—ugly, most equipment is made for institutional, not home, use. Yet, as imperfect as it is, serviceable equipment does exist and contributes to improving the lives of people with disabilities and caregivers, and good non-familial caregiving is possible. The gains that have been made for people with severe cognitive disabilities have been hard won—and mostly by families who refuse to settle for an inferior life for their child.

The desire to keep Ashley forever small is quixotic even if doing so could help with very difficult problems of management that cry out for personal and social solutions. But the problems of care exist for those whose growth cannot be attenuated: those already past puberty, those who become disabled through disease, accident or war, those frail elderly no longer able to care for themselves. We cannot pare down their bodies to the leftover functional parts—not, that is, without creating a monstrous society. AT does fail “to do justice to the scale of the problem.”

Brosco’s appeal to the larger social problems that are the larger context for the Ashley case has an implicit appeal to the social model of disability. Disability activists who have largely decried AT abjure solutions that “fix the person” rather than alter the environment. Diekema and Fost (2010), along with other proponents, acknowledge the social problem, but ask why a family needs to sit around to wait for needed societal changes. If a family can make life better by altering the impaired body, why should an ideological construct such as the social model stand in the way?

If we dismiss the social model as mere ideology, we fail to see that because of it, disabled people have been able to reject the view of themselves as damaged

goods, and claim “the right to live in the world,” (tenBroek 1966, 842) and to do so as they are.

In order to see the world from the child’s viewpoint, a parent attempts to cultivate a “transparent self.” But as nondisabled parents who try to cultivate a transparent self of a care ethics, we must acknowledge our limited grasp of life lived with a disability. As much as we love our children, we are unlikely to see the world from their perspective, and we are likely to continue to harbor biases we retain from an “horizon of ability.” The caring physician too needs to acknowledge that it is an occupational hazard to favor a medical model. In the early years of our disabled children’s lives, we parents desperately want to believe that with an operation here, a treatment there, the right exercises, the right therapies, the problem will dissolve—our children will live “normal” lives. Parents have to tread a delicate line between refusing resignation and accepting the child as she is and as she will become. When there is no way to “normalcy” or increased function, a change in perspective is more than just “settling”—it is positively transformative.²⁰

When Sesha was six, I shared Ashley’s parent’s urge to freeze time, to keep her as the child she was then. But no medical intervention can suffice. We age and what was small when we were young is now not small enough. Siblings, too, mature and will want to do things without any siblings—disabled or not. Even if Ashley herself is cherished within the family, her future caregivers may well feel differently about the parent’s choice, disparaging the parents, the child, or both. As they grow older, will Ashley’s siblings see what had been done to her as the loving act of parents with a full acceptance of Ashley for who she is? Or will they wonder what conditions attach to their parents’ acceptance of them as they are?

The prototypes of the environmental fix that the social model of disability urges are alterations in the physical environment. As important as these are, still more important is the environment of inclusion: of welcoming many sorts of bodies and minds, seeing the world as enriched by this diversity, and embracing the possibilities as well as the challenges presented by those who diverge from the norm. If our actions with respect to our children belie the need to make the environmental transformations—creating a world for them to flourish even when we parents are no longer there for them—there is a generalized way in which we have not done well by them, have not *cared* as well for them as well as we might, had we instead worked to create an environment in which they could flourish.

NOTES

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1. See Burkholder 2007; Caplan, 2007; King 2007; Ritter 2007; Saletan 2007a; 2007b; Tada 2007; Tanner 2007; Verhovek 2007. See also Fitzmaurice 2008 for a bibliography of news commentary on the Ashley Treatment.

2. See Ashley's Parent's Blog.

3. Some agreed that the hysterectomy perhaps should have been subject to court approval. See Allen et al. 2008.

4. See for example Singer 2008.

5. These correlate with Sara Ruddick's discussion of a child's demands: preservative love, development of capacities, and social acceptance (Ruddick 1989).

6. The term "mental retardation," now is out of favor as "retard," has become a common slur. The preferred term is "intellectual (and/or developmental) disability."

7. For a summary of the features that I take to be essential, see Kittay 2007, 3–6.

8. The last of these is little remarked upon in care ethics. In Kittay forthcoming, I contend this consequentialism means that although the subjective state of the carer matters in judging whether an action is caring, unless the outcome does foster the flourishing of the one cared for, it is not care. If I helped, but minimally, the best that can be said is that I delivered poor care. But if my efforts harm rather than help, then the best that can be said is that I "tried to" care.

9. Carol Gilligan stresses this point (Gilligan 1982). An ethics of care may be thought of as an ethic directed at the tension between our necessary dependence on others and our distinct set of interests.

10. Liao et al. (2007) point out the absurdity of this proposition when applied to anyone who becomes cognitively disabled later in life. But there is another profound mistake that I call attention to above.

11. I assume that means without the consent of the non-autonomous person, but with the consent of the surrogate, or, in emergencies, without anyone's assent.

12. Surrogacy may be based on "substituted judgment" or "best interest." Substituted judgment supposes that the surrogate can know what the patient would have wanted, had the patient been able to choose. As Ashley could never make an autonomous decision, the "best interests" standard is likely to apply. See the *AMA Code of Medical Ethics*, Opinion 8.081: Surrogate Decision Making.

13. See arguments in Parens 2006. That we permit some questionable practices is a poor justification for permitting still others.

14. This, of course, then exempts dwarfs from consideration. Dwarfism is a human variation, which is not disparaged by objecting to GA.

15. Personal communication. See also Wilfond et al. 2010.

16. Additional reasons include morbidity, which is a risk of limb removal, and appearance, that is, the visual impression created by a person missing limbs. Neither is compelling as the reason to favor GA by high-dose estrogen. High-dose estrogen for very young children has not previously been tried, and hysterectomy and breast-bud removal

carry the risks of surgery. Either procedure will produce an anomalous appearance. But good cosmetic prosthetics are available for those missing limbs.

17. They do not consider the possibility of a spontaneous orgasm—assuming that is possible if one lacks breast and a uterus.

18. A utilitarian calculus may yield a different result.

19. See, for example, Dreger 1998; Chase 1999; Feder 2002.

20. See for example, AAIDD 2007 and ADAPT 2007. For an individual disability activist, see Peace 2007.

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