is almost impossible to imagine what a just version of that would look like. This book serves as my attempt.)

Thus my desire for crip futures is, as Heather Love puts it, "a hope inseparable from despair."97 I feel this hope—and the hope has the fierce intensity that it does—because it is birthed out of and coexists with this despair about our impoverished imaginations. What I need is to follow some of these longings out, even if they put me in the realm of fantasy. Changing our imaginations, suggests Judith Butler, allows us to change our situations. Fantasy carries a "critical promise," she argues, "allow[ing] us to imagine ourselves and others otherwise."98

This intermingling of recognition and absence, of despair and hope, renders my desire quite queer. Queer in that my want, my longing, my pleasure intensifies with nonrecognition. Queer in that my intimate desires are entwined with queer desire. Queer in the sense that to pursue my desire is to harbor a potential for what is unimaginable and out of the realm of possibility. Queer in that my desire makes the possibility of watching and publicizing the presence of disabled people in public, perhaps—does not guarantee acceptance or inclusion, especially for those not already privileged by race and class.99 As feminists from Minnie Bruce Pratt to Bernice Johnson Reagon to Chandra Talpade Mohanty have cautioned, the desire for home, for familiarity, often leads to naive evocations of community.100 Thus, in naming and experiencing this desire, I am likely misreading and misrecognizing the bodies and practices of others. I am, in other words, finding both disability and desire where they don't necessarily belong—surely a potentially queer and crip move.

This desire, these imaginings, cannot be separated from the crip presents surrounding us; indeed, these very pasts and presents are what make articulating a critical crip futurity so essential. To put it bluntly, I, we, need to imagine crip futures because disabled people are continually being written out of the future, rendered as the sign of the future no one wants. This erasure is not merely absence; it is also a potential for violence. Disabled people, particularly those with developmental and psychiatric impairments, too often face discrimination, segregation, and institutionalization; denial of equitable education, health care and social services; violence and abuse; and the withholding of the rights of citizenship. Too many of these practices continue, and each of them has greatly limited, and often literally shortened, the futures of disabled people. It is my loss, our loss, not to take care of, embrace, and desire all of us. We must begin to anticipate presents and to imagine futures that include all of us. We must explore disability in time.

2 At the Same Time, Out of Time

Ashley X

The stories of women with disabilities must be told, not as stories of vulnerability, but as stories of injustice.

—Sherene Razack, "From Pity to Respect"

In thinking about crip futurity, I find myself haunted by Ashley X. Born in 1997, the girl known as Ashley X was diagnosed with "static encephalopathy" a few months after her birth. "In the ensuing years," doctors note, "her development never progressed beyond that of an infant," and her doctors held no hope that her cognitive or neurological baseline would improve. "At the age of 6 years, she [could not sit up, ambulate, or use language]." Concerned about their daughter's long-term future, Ashley's parents met with doctors in 2004 to discuss the potential effects of puberty and physical growth on their ability to care for her at home. 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. According to her parents and doctors, these interventions were necessary for Ashley's future quality of life: they would reduce her pain and discomfort (by removing the possibility of her menstruating or developing breasts) and would enable her parents to continue caring for her at home (by keeping her small enough to turn and lift easily). Her parents worried that, without the Treatment, Ashley would become too cumbersome for them to lift safely, and, as a result, her participation in social and recreational activities would decrease dramatically. Ashley's doctors took this concern a step further, expressing fear that caring for her at home might eventually become "untenable" and that Ashley's parents would need to place her "in the hands of strangers."
From the moment this case became public, in late 2006, it has garnered widespread attention. Both Ashley’s doctors and Ashley’s parents have written extensively about the case, carefully articulating their respective positions on the appropriateness of the Treatment. Bioethicists, disability rights activists, pediatric specialists, parents of disabled children, policy makers, disability studies scholars, legal experts, bloggers, and journalists have joined the fray, debating the ramifications of this case in particular and of growth attenuation/sterilization in general. Critics of the Treatment have condemned the hospital for violating sterilization regulations, challenged the parents’ presumption that they know what is best for their daughter, and debated the appropriateness of reshaping children’s bodies without their consent. Supporters of the Treatment have stressed the difficulties of parenting severely disabled children, the noble intentions of the parents, and the alleged benefits of growth attenuation and sterilization. Rather than rehash that work here, parsing the legalities of the case or determining the proper decision-making authority or debating the moral permissibility of surgically shaping children, I want to take a different tack, rereading Ashley’s case through the lens of time and futurity.

As becomes clear in both parental and medical justifications of the Treatment, the case of Ashley X offers a stark illustration of how disability is often understood as a kind of disruption in the temporal field. Supporters of the Treatment frame Ashley’s disability as a kind of temporal disjunction; not only did she fail to grow and develop “normally,” but her mind and body were developing at different speeds from each other. According to this logic, Ashley’s body required intervention because her body was growing apart from her mind; physically, her body was developing rapidly, but mentally, her mind was failing to develop at all. As a result, she was embodied asynchronously; her mind and body were out of sync. By arresting the growth of Ashley’s body, the Treatment could stop this gap between mind and body from growing any wider. In order to make this argument, Ashley’s parents and doctors had to hold her future body—her imagined future body—against her, using it as a justification for the Treatment. Without intervention, the asynchrony between mind and body would only grow wider; Ashley’s body would become more and more unbearable to her, to her parents, and to those encountering her in public. This future burden, brought on by the future Ashley, could only be avoided by arresting the present Ashley in time. Adding to the future framing of the case is the fact that both parents and doctors have offered the Treatment as a template for other children; they have expressed the hope that the Treatment will, in the future, become more widespread. The Ashley case, in other words, is shot through with temporal framings of the mind/body, especially the disabled mind/body, and with rhetoric about the future.

Before examining the temporal framing of the case, I will first present an overview of the Treatment and its legal aftermath, as well as a summary of how Ashley’s parents and doctors explain and justify the Treatment. The bulk of the chapter reads the case through a temporal framing, focusing on the ways in which Ashley was cast, and cast as, out of time; from the beginning of the case, she has been represented as temporally disjointed, as an eternal child, and as threatened by her future self. In addition, I explore the gendered dimensions and assumptions of the Treatment, detailing how Ashley’s feminality, or future feminality, rendered her asexual temporality particularly grotesque. As this story makes painfully clear, not all disability futures are desirable; in other words, the problem is not only the inclusion of disability in our futures but also the nature of that inclusion. I conclude the chapter, then, with a brief reflection about how to imagine desirably disabled futures.

A Case History of the Ashley Treatment

Ashley’s surgery took place under the direction of Dr. Daniel Gunther in July of 2004, at Seattle Children’s Hospital; the procedure, which was “uneventful,” included a hysterectomy, a bilateral mastectomy, and an appendectomy. For the next two and a half years, Ashley received high doses of estrogen in an attempt to stunt her growth. Estrogen accelerates the “maturation of the epiphyseal growth plates,” which means one’s bone plates fuse quickly, arresting growth. At the conclusion of the estrogen regimen, Ashley’s size was about average for a nine-year-old girl: fifty-three inches tall and sixty-three pounds. Three years later, in January 2010, her parents reported that her size had remained virtually unchanged (fifty-three inches tall and sixty-five pounds). X-rays of her hands revealed that the gaps between her finger bones had fused, indicating that she had indeed reached her maximum height. By her doctors’ and her parents’ measure, the Treatment was a success.

For many disabled people and disability activists, however, the Treatment was nothing to celebrate. As the case became public, disability rights organizations, disability activists, and disability studies scholars spoke out against the hospital’s actions, and the Washington Protection and Advocacy System (WPAS) launched an investigation. In January 2007, WPAS issued their report on the case, finding that “[t]he sterilization portion of the ‘Ashley Treatment’ was conducted in violation of Washington State law, resulting in violation of Ashley’s constitutional and common law rights.” According to WPAS, the hospital should have sought a court order before moving forward with the sterilization; state regulations mandate judicial review prior to the sterilization of patients who do not or cannot consent.

Although the hospital’s own ethics committee had noted in regard to the hysterectomy that “there is need for a court review of this aspect of [the] proposal,” no such review took place. Instead, after the ethics committee issued its report, Ashley’s parents consulted with attorney Larry Jones about the sterilization. In a June 2004 letter to Ashley’s father, Jones asserts, “It is not necessary to have a court hearing on sterilization when the object of the medical procedure is not sterilization, but to obtain another medically necessary benefit.” Rather, sterilization would be “merely a byproduct of surgery performed for other compelling medical reasons,” namely the prevention of bleeding associated with estrogen therapy and the cessation of menstruation. Since
sterilization was not the main goal of the Treatment, Jones argued, a court order was unnecessary. Moreover, he explained, the sterilization policies were intended to protect those patients who might develop or regain the capacity to raise children; Ashley would never have the ability to make child-bearing decisions, so there was no need to protect her from the permanence of sterilization. Ashley's father sent the letter to Ashley's doctors, who later told WPAS that they had accepted the letter as a form of "court review" and acted accordingly.

The Washington Protection and Advocacy System disagreed with this logic, arguing not only that the parents' consultation with Jones did not qualify as judicial review, but that his legal opinion "is not supported by a reasonable interpretation of pertinent law." They explained that existing policy clearly required the hospital to safeguard Ashley's interests through a thorough judicial review. Seattle Children's Hospital accepted the findings in the WPAS report, agreeing that they had acted inappropriately in not following their own ethics committee's push for a court review. According to a joint statement signed by both parties in May 2007,

[Seattle] Children's [Hospital] agrees with the finding in the report that Ashley's sterilization proceeded without a court order in violation of Washington State law, resulting in violation of Ashley's constitutional and common law rights. Children's deeply regrets its failure to assure court review and a court order prior to allowing performance of the sterilization and is dedicated to assuring full compliance with the law in any future case.

Dr. David Fisher, the medical director of Seattle Children's Hospital, issued a statement supporting the WPAS findings, admitting "an internal miscommunication which resulted in a violation of the law" and taking "full responsibility." In their joint statement with WPAS, Seattle Children's Hospital agreed to obtain a court order before permitting growth attenuation or sterilization procedures on other disabled children; they also pledged to develop stronger oversight and monitoring programs over their sterilization practices and policies. Finally, the hospital consented to the addition of a disability rights advocate to their ethics committee.

Although the case of Ashley X is "closed"—WPAS has released their findings; Seattle Children's Hospital has apologized and issued new guidelines per their agreement with WPAS—the Ashley Treatment remains an open question. Ashley's doctors and parents continue to write (separately) about the Treatment, presenting it as a viable course of action for other families. The University of Washington held symposia devoted to the case in 2007 and 2009; in late 2010, the Seattle Growth Attenuation and Ethics Working Group (SWG), an offshoot of the first symposium, published a position paper on growth attenuation. In that report, they argue that "growth attenuation can be morally permissible under specific conditions and after thorough consideration"; one of those conditions is that the patient be neither ambulatory nor communicative. Although most of the twenty-person group were able to agree to this compromise position, two participants wrote brief dissents, spelling out continued points of disagreement among some members. These points of dissonance, combined with the report's call for additional research, suggest that more debates and reports lie ahead.

Documenting the Ashley Treatment

The details of the Ashley Treatment became public almost two and a half years after her surgery. In October 2006, two doctors centrally involved in the case—Dr. Daniel Gunther, a pediatric endocrinologist, and Dr. Douglas Diekema, a pediatric bioethicist—published the results of the growth attenuation therapy in the Archives of Pediatric and Adolescent Medicine. Several months later, Ashley's parents launched a blog called The 'Ashley Treatment': Towards a Better Quality of Life for "Pillow Angels." As these titles suggest, both texts took a future-oriented approach; they presented the Ashley Treatment as a new tool in the care of disabled children, one that other parents and doctors might choose to replicate. Before addressing this future-orientation, or analyzing the rhetoric deployed in each text, I first offer a brief summary of each document.

In their initial article, which focused primarily on the growth attenuation therapy, Gunther and Diekema argue that Ashley will benefit both physically and emotionally from her smaller size:

A child who is easier to move will in all likelihood be moved more frequently. Being easier to move means more stimulation, fewer medical complications, and more social interaction. Personal contact between parent and child is likely to be more direct and personal without the need for hoisting apparatus or other devices. Being easier to move and transfer also makes it more likely that the child will be included in family activities and family outings.

Gunther and Diekema frame the growth attenuation therapy as essential to Ashley's future quality of life; without it, they claim, her parents would eventually be unable to care for her at home or to include her in family events.

Gunther and Diekema's article is as interesting for what it excludes as for what it includes. While the WPAS report stressed the hysterectomy, discussing it at length, the two doctors limit discussion of the procedure and its ramifications to a single paragraph. "A word here about hysterectomy is probably appropriate," they concede, casting discussion about the hysterectomy—and, by extension, the hysterectomy itself—as a mere side issue to the more important topic of growth attenuation. The hysterectomy is apparently so trivial, or so incidental, as not to merit extensive analysis on its own; they do not even use the word "sterilization" in regard to Ashley, thereby avoiding that conversation altogether. In downplaying the hysterectomy, Gunther and Diekema echo the stance of attorney Larry Jones: as Jones argued in his letter to the family, the hysterectomy and resultant sterilization were only byproducts of treatment done for other reasons. The hysterectomy was performed not in order to sterilize Ashley but to mitigate the risks of uterine bleeding (a side effect of the estrogen regimen) and the anxiety and discomfort of menstruation. Since Ashley would never develop
the ability to raise children, preserving her reproductive health was not an issue; she had no need of her uterus, so there was no need to discuss it.

Effectively rendering Ashley's breasts as even more expendable than her uterus, Gunther and Diekema do not mention the bilateral mastectomy at all—nor does Diekema in an interview with CNN a few months later.27 When eventually pressed about this silence, Gunther and Diekema argue that the mastectomy was irrelevant to growth attenuation and high-dose estrogen therapy; there was nothing to discuss.28 Although Diekema has addressed the mastectomy in more recent articles, he seems to do so only in response to criticism, not because he sees the mastectomy as anything meriting attention in and of itself.29

Ashley's parents, however, understand the mastectomy differently, representing it on their blog as an essential component of "the Ashley Treatment"; for them, the hysterectomy, mastectomy, and estrogen regimen are all of a piece. The mastectomy, or, to use their language, "breast bud removal," was necessary for three reasons.29 The primary reason for the "removal" was that any breast development was likely to cause Ashley pain and discomfort. Breasts would make lying down unpleasant for Ashley ("large breasts are uncomfortable lying down with a bra and even less comfortable without a bra") and would "impede securing Ashley in her wheelchair, stander, or bath chair, where straps across her chest are needed to support her body weight." Those straps would then compress Ashley's breasts, causing further pain and confusion. Butressing this rationale for the procedure were two "additional and incidental benefits": the bilateral mastectomy would eliminate the possibility of breast cancer or fibrocystic growth, two conditions present in the family; it would also prevent Ashley from being "sexually" according to Ashley's parents, the mastectomy "posed the biggest challenge to Ashley's doctors, and to the ethics committee," but the parents ultimately convinced them of the benefits of the procedure.30

Ashley's parents launched their blog on January 2, 2007, not long after Ashley completed her estrogen regimen, and it was this text that generated worldwide attention. Such attention seemed to be the parents' goal, as they started the blog "for two purposes: first, to help families who might bring similar benefits to their bedridden Pillow Angels; second, to address some misconceptions about the treatment and our motives for undertaking it."31 The blog covers much of the same terrain as Gunther and Diekema's article, although more informally; it discusses Ashley's medical history and diagnosis, the details of the Treatment, and a point-by-point justification for the procedures. These pieces are supplemented by family photographs of Ashley (with her parents' and siblings' faces blurred for privacy), "testimonies" from other parents of "pillow angels," letters of support, and excerpts from sympathetic editorials and commentaries.32 The blog also offers definitions for two key terms that did not appear in the original article by Gunther and Diekema: "the Ashley Treatment" and "Pillow Angel." "The Ashley Treatment" refers to the combination of growth-attenuating estrogen regimen, hysterectomy, and "breast bud removal," while "Pillow Angel" signifies people with a cognitive and mental developmental level that will never exceed that of a 6-month old child as well as associated extreme physical limitations, so they will never be able to walk or talk or in some cases even hold up their head or change position in bed. Pillow Angels are entirely dependent on their caregivers.33

Given the intent of the blog, it is not surprising that Ashley's parents see the Treatment as an unmitigated success. As they told CNN in 2008, "Ashley did not grow in height or weight in the last year, she will always be flat-chested, and she will never suffer any menstrual pain, cramps, or bleeding."34

Out of Line, Out of Time

Always flat-chested, never menstruating, finished growing: for Ashley's parents, the Treatment was undeniably about arresting Ashley's development so that they might continue to lift and carry her without difficulty. Mention of Ashley's flat chest and hysterectomy, however, suggests that more than weight was at stake in their decision. They were also concerned about the developmental disjunction taking place as her body, which was developing more typically, grew further away from her mind, which "stopped growing . . . when she was a few months old." They understood Ashley's body as en route to "adulthood," even though her mind was permanently mired in "childhood," and this disconnect required intervention. Doctors and bioethicists following the case echoed this concern; the Treatment was necessary to keep Ashley's cognitive self and physical self aligned. The Ashley Treatment thus enacted a circular temporal logic: Ashley's disabilities rendered her out of time, asynchronous, because of this developmental gap between mind and body; her development needed to be arrested to correct this mind/body misalignment; this arrested development then cast her further out of time, more befitting her permanent cognitive infancy.

From the beginning, the Treatment was described as a way to correct the disjunction between Ashley's body and mind. "When you see Ashley," Dr. Diekema tells CNN, "it's like seeing a baby in a much larger body,"35 Without the Treatment, this disjunction would only become more pronounced, as Ashley would eventually become not only a baby in a much larger body, but a baby in an adult's body. What was needed, as her parents put it, was to bring Ashley's "physical self closer to [her] cognitive self."36 As John Jordan argues, "Despite her otherwise healthy prognosis, Ashley's body had to be articulated as 'wrong' in such a way that the Treatment could be recognized as the best way to make her 'right.'"37 This "wrongness" was framed in terms of a temporal and developmental misalignment between mind and body, "the brain of a 6-month-old in the body of one much older; to the extent possible, the Treatment corrects that disjunction.38

In this desire for mind and body to align, what we see is a temporal framing of disability dovetailing with a developmental model of childhood. In classical child development theory, children move through a defined sequence of stages toward adulthood, a one-way and linear march "upward." Children can be seen in this framework as
"unfinished" adults, or as people who have yet to move through the necessary stages of growth and development. What this understanding of childhood often means is that disabled people, particularly those with intellectual disabilities (or "developmental" disabilities, as they are often known), are also cast as "unfinished" adults. Diekema's description of Ashley as a "baby in a much larger body" reflects an extension of this logic: regardless of how old Ashley is chronologically, she will always be a "baby" developmentally. (Similar logics are at work when Jerry Lewis refers to adults with multiple dystrophy as "kids" or when Christopher Reeve describes paralysis as having "suddenly transformed [him] into a forty-two-year-old infant." Reeve aligns physical dependence with infancy, and Lewis frames disability as inherently infantilizing.)

The linkage of intellectual disabilities with childhood has a long history. Licia Carlson, explaining that people classified as "idiots" in the late nineteenth and early twentieth centuries were seen as "remaining at an early stage of development," notes that superintendents of state institutions often referred to their wards as "man-baby," "woman-baby," and "child-baby." Within this framework, there is no room for the adult with intellectual disabilities: if adulthood is about independence, autonomy, and productivity, then adulthood becomes both unachievable and inconceivable in relation to profound intellectual impairment like Ashley's.

In their initial defense of the Treatment, Gunther and Diekema stress that Ashley faces a future of no future: she is "an individual who will never be capable of holding a job, establishing a romantic relationship, or interacting as an adult." Within the logics of normative time, adults work, marry, and live independently; but according to Gunther and Diekema, disability renders too many of such practices impossible. As a result, the interventions can do no harm; she is already prohibited by her disabilities from having romantic relationships (or children), so her breasts and uterus are easily removed.

Notice, too, in their description the conflation of adulthood with productivity; interacting as an adult is paralleled with holding a job. Disability, then, is defined as a lack of productivity; in a move that brings the word closer to its roots, being disabled means being unable to work. Bioethicist Norman Fost makes plain this perspective in his summary of the case: "It [the Ashley case] reminds [me] of the scandal some years ago when it was discovered that some Cadillacs had Chevrolet engines." In positioning Ashley as "a Cadillac with a Chevrolet engine," Fost not only references the "deceptive" nature of her imagined future appearance—a child in an adult's body—but reveals the degree to which we view normal adulthood as a time of, and as defined by, productivity. We are all to be smoothly running engines, and disability renders us defective products. Ashley does not merit the protections offered adults or other children because she will never be an adult.

The term "pillow angel" both reflects and perpetuates this linking of disability with infancy and childhood. Ashley's parents explain that they "call her our Pillow Angel since she is so sweet and stays right where we place her—usually on a pillow." This phrasing paints a picture of infant-like dependency and passivity; it makes it difficult to imagine Ashley as a teenager or a woman-to-be. Thus, much as the estrogen therapy and mastectomy make Ashley look like the permanent child she allegedly is, the "pillow angel" label names her as such. Within this schema, her body, mind, and identity all line up perfectly.

Such alignment is necessary not only to ensure that people treat Ashley "in ways that are more appropriate to [her] developmental age," but also to protect those around her from disruptions in their temporal fields. Dr. Norman Fost, a bioethicist who has often written about the case, echoes Diekema's concerns about the problem of mind/body misalignment:

[H]aving her size be more appropriate to her developmental level will make her less of a "freak." . . . I have long thought that part of the discomfort we feel in looking at profoundly retarded adults is the aesthetic disconnect between their developmental status and their bodies. There is nothing repulsive about a 2 month old infant, despite its limited cognitive, motor, and social skills. But when the 2 month baby is put into a 20 year old body, the disconnect is jarring.

In invoking the image of an adult body with a baby's brain, and assuming such an image prompts repulsion, Fost enters the realm of the grotesque. He positions Ashley as the embodiment of category confusion, of "matter out of place": the imagined Ashley blurs infancy and adulthood together, troubling cultural understandings of the normative life course. We are to imagine an adult that looks like "us" but can never function or think like us, and this collision of sameness and difference makes us uncomfortable. George Dvorský, another bioethicist commenting on the case, makes explicit this link to the grotesque. Writing in support of the Treatment, he too praises its ability to "endow her with a body that more closely matches her cognitive state—both in terms of her physical size and bodily functioning." He then goes on to argue that 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." The disjunction between mind and body is apparently all the more jarring, all the more grotesque, because of Ashley's gender. Within this framework, Ashley's imagined future body is held against her present body and deemed excessive and inappropriate: too tall, too big-breasted, too fertile, too sexual, too adult for her true baby nature. The Treatment was thus necessary to prevent this imagined big and breasty body—this grotesque, fertile body—from coming into being. Dvorský makes clear the unspoken reason why the growth attenuation had to be combined with a hysterectomy; without the latter, Ashley would remain grotesquely fertile.

The definitions that Ashley's parents provide on their blog reveal their own anxieties about the too-big, too-fertile body to come: they describe the hysterectomy as the "removal of tiny uterus" and the mastectomy as "breast bud removal: removal of almond sized glands." Both procedures must be done quickly, they argue, before "rapid
growth of breasts and uterus” begins. Of course, any such “rapid growth” would be caused, at least in part, by the estrogen regimen itself, but the rhetoric has the effect of depicting Ashley’s body as out-of-control; it is as if the imagined future Ashley, with her large breasts and uterus, is going to take over, to consume, the angelic pillow angel with her “almond sized breast buds.” The Treatment is positioned as a cure for adult womanhood as much as adult disability.

Feminists have long challenged the reduction of women to their reproductive capacities, and the case of Ashley X reveals how disability both complicates and enables that reduction. On the one hand, despite the surgical focus on her reproductive organs, Ashley is understood to be completely removed from the realm of reproduction. What makes the bilateral mastectomy and hysterectomy permissible is the underlying conviction that Ashley will never need or use her breasts and uterus. Her parents explain that the only reason to forgo the “breast-bud removal” is if child-bearing and breast-feeding are in Ashley’s future; since they are not, her breasts can be removed without any problem. They present the hysterectomy in similar terms. In their diagram describing the treatment, the hysterectomy is placed next to the appendectomy, suggesting that for Ashley, her uterus is an appendix: useless, unnecessary, and expendable. Thus, Ashley’s disabilities prevent her from being reduced to her reproductive organs; unlike nondisabled women, she is not to be understood in those terms.

At the same time, however, the Treatment reveals the extent to which the female body is always and only framed as reproductive. Dvorsky’s anxieties about Ashley’s fertility suggest that disability only renders such fertility more threatening, more in need of containment and intervention. Furthermore, her parents’ presentation of her breasts and uterus as irrelevant and unnecessary testifies to the persistence of a reproductive use-value understanding of female bodies. The only purpose of these body parts is reproductive; if reproduction is not in one’s future, then these parts can be shed without ethical concern. The centrality of reproductive frameworks to our understanding of what constitutes a woman or a female is what made the mastectomy and hysterectomy possible or imaginable. Ashley’s breasts and uterus were never going to serve their real purpose, so they could be dismissed.

Indeed, a dismissive attitude toward mastectomy and hysterectomy pervades Gunther and Diekema’s original article. Their approach makes sense, in that to focus on the hysterectomy qua hysterectomy might prompt questions about state sterilization protections. But their discussion of the procedure makes clear that they had no real concerns about it; sterilizing someone like Ashley takes on the appearance of common sense. Indeed, they acknowledge concerns about forced sterilization only to brush them away:

Hysterectomy in children, particularly in the disabled, is controversial and invariably associated with the negative connotations and history of forced “sterilization.” But in these profoundly impaired children, with no realistic reproductive aspirations, prophylactic hysterectomy has several advantages as an adjunct to high-dose estrogen treatment. Placing “sterilization” in scare quotes suggests that Gunther and Diekema do not see it as a real concern, almost as if it were not an accurate description of a hysterectomy. The history of forced sterilization apparently has no bearing on cases of such profound impairment. Nor, apparently, do feminist critiques of sterilization, as the procedure is completely degendered in this passage. They describe hysterectomy in children, as if boys also have hysterectomies, as if there were no gendered dimension to such procedures. Or, perhaps, the use of “children” is an indication that Diekema and Gunther do not recognize disabled children as gendered at all; they cannot be boys or girls because both categories presume an able-bodied/able-minded norm. The Treatment is thus a surgical manifestation of the conceptualization of Ashley as a permanent child. As a child, Ashley has no need of reproductive organs; as a disabled person, she has no sexuality. Maintaining her small size and keeping her flat-chested and infertile ensures that her physical appearance matches her cognitive functioning, and that both reflect the lack of sexuality befitting a disabled person/baby.

At first blush, it makes no sense to describe Ashley as cured or the Treatment as a kind of cure for her condition. The Treatment did not improve her cognitive or physical functioning nor was it intended to do so. Yet it is undoubtedly a curative response to disability. Ashley had to be cured of her asynchrony, at least to the fullest extent possible. She also had to be freed of the specter of her future body, the full-sized, large-breasted, menstruating and fertile body to come. Ashley had her imagined body held against her, and held against her in both senses of the phrase; it was this imagined body that justified the Treatment, and it was this imagined body that became grotesque when compared to her present body.

“Towards a Better Quality of Life for ‘Pillow Angels’”

Ashley’s parents and doctors are concerned not only about Ashley’s future (and future body), both real and imagined, but also about the futures of other disabled children. The very fact of their writing proves as much, with each publication geared toward presenting the Treatment as effective, morally permissible, and ethically appropriate for others. Blogging enables Ashley’s parents to communicate with other families worldwide and generates press coverage to further their message; publishing in medical journals is a way for Gunther and Diekema to gain peer validation, approval, and, ultimately, adoption of a new treatment beyond the featured case.

One need look no further than the title of Gunther and Diekema’s article for proof that they see the growth-attenuating estrogen therapy as having an application beyond Ashley: “A New Approach to an Old Dilemma.” “The old dilemma” is how best to care for children with severe disabilities, particularly how to keep them out of nursing homes and state institutions; the “new approach” to this problem is growth attenuation (and its accompanying surgeries). Indeed, they frame their whole article in terms of the struggle against institutionalization. The first sentence of the article sets this tone, noting that the “American Academy of Pediatrics recently endorsed the goal of
Healthy People 2010 to reduce the number of children and youth with disabilities in congregate care facilities to zero by the year 2010. For Gunther and Diekema, such an ambitious goal both requires and justifies bold new approaches such as growth attenuation; it also requires other doctors to take up the practice with their own patients.

Throughout the piece, Gunther and Diekema stress the efficacy of high-dose estrogen treatment in order to make the case for its use with other disabled children. Quite simply, their goal is to make an argument for the careful application of such a treatment strategy in nonambulatory, profoundly impaired children. We believe that foreshortening growth in these children could result in a positive benefit in the quality of life for both child and caregiver, and we propose that in situations in which parents request such an intervention, it is both medically feasible and ethically defensible.

As this passage suggests, Gunther and Diekema see the Treatment as more appropriate for some children than others ("nonambulatory, profoundly impaired children"), but they refrain from setting out strict or definitive criteria, opening the door for even wider applicability. Aware that the Treatment might be controversial, they suggest the formation of a decision-making board to determine the appropriateness of the Treatment in particular cases; this recognition of the need for outside observers proves that they imagined the Treatment as having a life beyond Ashley.

Similarly, Ashley's parents imagine their blog as a resource for other parents seeking such treatments for their children: the subtitle of the blog makes this desire plain: "Towards a Better Quality of Life for "Pillow Angels."" The plural "angels" makes clear that they do not see Ashley as a unique case. "It is our hope," they explain, "that this treatment becomes well-accepted and available to such families, so they can bring its benefits to their special needs child if appropriate and at an optimal age in order to obtain the most benefits." They insist that the blog is not a defense or justification of the Treatment but rather a place to "share their learned lessons." To that end, they offer a one-page summary of the Treatment—"The Ashley Treatment" for the well-being of "Pillow Angels"—that breaks down each component of the Treatment in terms of its primary and secondary benefits to Ashley. They urge other parents interested in the Treatment to contact them for advice and assistance, stressing that the Treatment is not limited to girls; in fact, they suggest, "it even makes more sense in [boys'] case, since boys tend to grow taller and bigger."

Ashley's parents claim to have heard from "about a dozen" families who have successfully acquired the Treatment for their children (both boys and girls). Other families have apparently tried to do so, but without success; the blog mentions a family whose request was denied at the last minute, not by the ethics committee but because of "PR concerns." More promisingly, from Ashley's parents' perspective, is the growing acceptance of growth attenuation by pediatric specialists. On their blog, they mention a packed session on growth attenuation at the 2008 Pediatric Academic Societies Meeting; according to a doctor present at the session, "half of the room said they had been approached by a family seeking growth attenuation, and about a dozen hands were raised when asked if they had offered it to a family." Moreover, the recent report by the SWG proves that Ashley's parents and doctors have been successful in getting the medical and bioethics communities to take the Treatment seriously; the group's finding that growth attenuation is morally permissible under certain conditions and guidelines suggests that the practice may very well become more common.

Even when the Treatment first made news, and the voices of critics were more prominent, many observers saw the procedures as acceptable. A 2007 MSNBC poll, for example, found that 59 percent of respondents supported the decisions by Ashley's parents.

Reading the "testimonials" and "letters of support" posted on the parents' blog drives home how persuasive Ashley's parents and doctors have been in making their case. Countless medical professionals, caregivers, and parents of disabled children have written to voice their support and, often, their wish that the Treatment had been available to the people in their care. Many of these responses illustrate the slippery expansiveness of categories like "pillar angel" and "severely disabled." While Ash­ley's parents, her doctors, and ethicists have all offered guidelines for the degree of impairment required for the Treatment to be appropriate (the most common criteria are "nonambulatory" and "noncommunicative"), those parameters are not universally accepted. One parent writes, for example,

I am the father of a child (now 16) born with Spina Bifida. Whitley is paralyzed [sic] from the waist down. We were talking about your daughter and the treatment that you were giving Ashley. . . . Whitley agrees with me that if she was much smaller the effort she would need to "get around" would be much easier. She weighs about 120 lbs and is 4'11" tall. She is a handful to lift. God bless you and Ashley and keep up the good work for her, God is guiding you in a good direction."

Whitley and her father would perhaps not get their wish for the Treatment; not only is she likely too old to benefit, an ethics committee might not approve its use with someone of her level of impairment. She is able not merely to communicate, but to evaluate her situation and express her own desires; she may not be able to walk, but she is able to "get around." She is not impaired enough. In other words, to qualify for the Treatment, at least according to the criteria recommended by the SWG. But, according to her father, she is sufficiently impaired. His comments reveal that the attempt to draw bright lines between classes of disability is rarely successful; one person's "severe" may be another's "moderate" or "mild." Supporters of the Treatment insist that it is to be used only in rare cases, cases of "profoundly impaired" children, and that concerns of its being expanded to cover ever-broader categories of disability are overblown. They
may be right; yet, as Whitley's father makes clear, defining "profound" impairment constitutes contested, and slippery, terrain.

The Future Will Be Privatized: The Ashley Case in Context

Discourses surrounding the Ashley Treatment serve as a template not only for future medical interventions or standards of care but also for how to view the place of disability and caregiving in the early twenty-first century. The future invoked by the Ashley treatment is a wholly privatized one: disability and disabled people belong in the private sphere, cared for by and within the nuclear family; and the nuclear family should be the sole arbiter of what happens within it. This is not to say that such cases have no bearing on the public sphere, but rather that the public sphere is to have little bearing on such cases. Even as the case is debated in public, it is repeatedly cast by supporters of the Treatment as a private matter. We can see traces of this position in the family's insistence that there was no need for judicial review in this case. In their response to the WPAS investigation, they go so far as to suggest that judicial oversight should never play a role in private, familial deliberations involving children like Ashley:

While we support laws protecting vulnerable people against involuntary sterilization, the law appears to be too broadly based to distinguish between people who are or can become capable of decision making and those who have a grave and unchanging medical condition such as Ashley, who will never become remotely capable of decision making. Requiring a court order for all hysterectomies performed on all disabled persons regardless of medical condition, complexity, severity, or prognosis puts an onerous burden on already over-burdened families of children with medical conditions as serious as Ashley's.68

This rejection of judicial oversight dovetails with long-standing cultural presumptions about the objectivity and authority of Western medicine. Within this framework, doctors and scientists are objective observers of the truth of the body, uniquely able to read, interpret, and understand the mind and body. Logically, then, medical experts are better able to evaluate and adjudicate questions of medical ethics because they can bracket their own political or emotional investments and focus only on the case at hand. They are able, as Donna Haraway puts it, to perform the "god trick of seeing everything from nowhere," making decisions free from bias or subjective opinion.69 Dr. Diekema's response to the WPAS recommendations serves as a case in point. Challenging the WPAS demand for the addition of disability advocates to hospital ethics committees, Diekema asserts that "ethics committees are not for people with political agendas."70 With this claim, Diekema positions people living with disability—family members, disability advocates, and disabled people, i.e., those constituting community members within the framework of the WPAS report—as political actors in ways that doctors and bioethicists are not. Such professionals apparently have no such "political agendas" and therefore are the only proper members of ethics committees. Families—such as Ashley's parents—play an integral role in medical decisions, but only in terms of their own families' cases; their agendas turn political if directed outward, beyond their individual situations. Noteworthy is Diekema's depoliticization not only of doctors and bioethicists but of the whole decision-making process. Both disability and decisions about disability are private concerns rather than political ones.

Thus, parents, with guidance from doctors, are the only ones with standing in such cases. As Ashley's parents explain on their blog, "In our opinion, only parents with special-needs children are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or their caregivers."71 Leaving aside for the moment their assumption that parents are always the best—and only—spokespeople for disabled children, I want to focus on how their rhetoric excludes all other voices from this debate. Parents are not only the ultimate arbiters but also the only ones with any right to speak or reflect on the case; both decision making and debate belong only within the realm of the family. As a result, outside observers are invited to participate only within the terms of the parent-child relationship. Many editorials, commentaries, and blogs personalized and thereby privatized the debate by phrasing it exclusively in terms of familial questions: What would you do if this were your child? Who would you want caring for your child? How would you feel if the state/the medical establishment/disability activists took away your right to determine your child's care? What would you do if an ethics committee refused you access to a treatment you knew was in your family's best interest? The very phrasing of the questions reveals how pervasive this private framing is.

One of the main themes running throughout critiques of the Ashley Treatment is the need for more social support for parents of disabled children. Supporters of the Treatment counter that such services are currently unavailable and that to "abandon" Ashley's parents to "these harsh social and economic realities" would be cruel; "Ashley does not live in a utopian world," Sarah Shannon notes in Pediatric Nursing, and to focus on the need for accessible houses or in-home attendant care is a "utopian view of care."72 Shannon's read of current realities is unfortunately accurate, but calling any and all talk of social supports as utopian and therefore unreasonable denies the possibility of different futures and different presents. As Adrienne Asch and Anna Stubblefield explain, there are already-existing practices and technologies that make home care easier, such as mechanized lifts that can assist with transfers. Moreover, many "full-size" adults live successfully in independent settings and receive care outside of institutions, even without the kind of growth-stunting interventions that the Treatment involves.73 Completely brushing aside frank talk of social supports renders these kinds of options invisible, such that the Treatment appears as the only real choice parents can make for their children.

Thus the dilemma described by Ashley's doctors is a choice between the Treatment and institutionalization: if we let her imagined grotesque body come into being, then the only possible future that can await her is the one of the institution, or what
Harriet McBryde Johnson calls the “disability gulag.” Ashley must be protected, then, from that future location and the future body that would put her there; the Treatment is her only hope for a future away from the institution. That this is a false choice—for surely these are not the only two options, and the Treatment by no means guarantees that she will never be institutionalized—does not take away from the rhetorical power of this justification for the Treatment.

Supporters of the Treatment make a compelling case, and its power is one of the reasons why this story is essential to an analysis of crip futures. The doctors involved in the case, Ashley’s parents, their supporters: all draw on rhetoric and ideas nourished and developed from within disability rights movements, but to far different effects. In their initial article, for example, Gunther and Diekema stress the importance of moving as many disabled children as possible out of institutions and other long-term care facilities, keeping them with their families and in their communities. Ashley’s parents and their supporters similarly tout the importance of keeping Ashley at home, allowing her to grow up with her siblings and surrounded by people who love her rather than isolated in an institution. (Indeed, they assert that they would never place Ashley in an institution, Treatment or not.) These are undoubtedly goals shared by, and long advocated by, disability rights and independent living movements.

The use of these arguments to justify growth attenuation, sterilization, and mastectomy— as if such practices were necessary to stave off institutionalization—requires those of us concerned and invested in these movements to challenge this appropriation of language and ideology. We need to be much more vigilant and aware of the risks inherent in touting the importance of family involvement and family care. Too easily, those calls can be reinterpreted to mean that the only care worth supporting is that provided by relatives, inadvertently demonizing and pathologizing the use of paid attendants. This is not to say that family members who provide attendant care for their disabled relatives should not themselves be compensated for their work; indeed, I support consumer-directed attendant services that allow disabled people to hire their own attendants, including family members. But, as Laura Hershey explains, 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. This attitude, in turn, leads to the continued devaluation of caregiving; abysmal wages and working conditions are justified on the basis that family members—almost always women—would be doing this work anyway and therefore any compensation, no matter how meager, is sufficient. Moreover, casting disability as a private, familial problem, one properly confined to the home, makes it possible to remove caregiving—regardless of whether it is provided by a relative, regardless of whether it is compensated—from the political realm of public policy. This attitude suggests that the only thing that matters is having a loving relative by one’s side, rather than attending to the resources, support, and training that a loved one might need to make such caregiving sustainable over the long term.

The Ashley Treatment has been presented as necessary to Ashley’s quality of life. Ashley will be “better off” as the result of these interventions, the story goes; her parents and doctors had to intervene in order to protect her from future harms. “Quality of life” is a familiar refrain in discussions of disability, as the term has often been used as a measure of the worth of disabled people’s lives. “Measure” is perhaps too precise a term, as the meaning or criteria of “quality” of life are often taken to be common sense. Many people, regardless of disability, may use the term to examine their own experiences, but disabled people often find their own quality of life described by others as if it were self-evident in their appearance or diagnosis; such discussions almost always include descriptions of the disabled person’s (assumed) level of function and pain. Yet accurately evaluating function is not as easy as it might seem. If a disabled person has never been given any kind of adaptive therapy or training, or if someone has no access to adaptive equipment (or only to substandard equipment), then one’s function might be much lower than one’s ability. Quality of life, then, is affected by one’s access to resources and bodies of knowledge rather than a necessary fact of the body/mind. Indeed, descriptions of another’s pain and suffering often rely more on assumption than fact, as do presumptions about what level of function is required for a good quality of life.

As a result, analyses of other people’s lives, ones intended to demonstrate a certain quality of life (or lack thereof), are often ambiguous and contradictory. Descriptions of Ashley are no different, rife with inconsistencies about the nature of her life. Ashley’s doctors and parents describe her as having the cognitive functioning of an infant, but her parents also talk about her experiencing confusion, feeling bored, and having musical preferences (she reportedly waves her arms along with music that she likes). Reading each of these reactions in relation to each other suggests that Ashley’s cognitive abilities might be more advanced than justifications for the Treatment assert; or, perhaps, her family is reading more into her behaviors than others can see. In either case, the combination of observations suggests that function and quality of life are not as straightforward as some analyses might claim. Given someone like Ashley, who “cannot communicate,” these questions of quality of life become all the more complicated; she cannot tell us what she thinks about her life.

The issue of communication is itself complicated. According to her parents and doctors, Ashley is unable to communicate and will always remain so. This lack of communication was one of the factors used to justify the Treatment (and one the SWG extended, casting “noncommunicative” as one of the criteria used to evaluate the appropriateness of growth attenuation). But, again, as I note above, if Ashley’s parents are able to track boredom, confusion, and musical preferences in Ashley’s experiences, but disabled people often find their own quality of life described by others as if it were self-evident in their appearance or diagnosis; such discussions almost always include descriptions of the disabled person’s (assumed) level of function and pain. Yet accurately evaluating function is not as easy as it might seem. If a disabled person has never been given any kind of adaptive therapy or training, or if someone has no access to adaptive equipment (or only to substandard equipment), then one’s function might be much lower than one’s ability. Quality of life, then, is affected by one’s access to resources and bodies of knowledge rather than a necessary fact of the body/mind. Indeed, descriptions of another’s pain and suffering often rely more on assumption than fact, as do presumptions about what level of function is required for a good quality of life.

As a result, analyses of other people’s lives, ones intended to demonstrate a certain quality of life (or lack thereof), are often ambiguous and contradictory. Descriptions of Ashley are no different, rife with inconsistencies about the nature of her life. Ashley’s doctors and parents describe her as having the cognitive functioning of an infant, but her parents also talk about her experiencing confusion, feeling bored, and having musical preferences (she reportedly waves her arms along with music that she likes). Reading each of these reactions in relation to each other suggests that Ashley’s cognitive abilities might be more advanced than justifications for the Treatment assert; or, perhaps, her family is reading more into her behaviors than others can see. In either case, the combination of observations suggests that function and quality of life are not as straightforward as some analyses might claim. Given someone like Ashley, who “cannot communicate,” these questions of quality of life become all the more complicated; she cannot tell us what she thinks about her life.

The issue of communication is itself complicated. According to her parents and doctors, Ashley is unable to communicate and will always remain so. This lack of communication was one of the factors used to justify the Treatment (and one the SWG extended, casting “noncommunicative” as one of the criteria used to evaluate the appropriateness of growth attenuation). But, again, as I note above, if Ashley’s parents are able to track boredom, confusion, and musical preferences in Ashley’s reactions, then she does not sound completely noncommunicative. Perhaps she could eventually develop a means of communicating with others; in their analysis
of the Ashley case. Adrienne Asch and Anna Stubblefield remind us that "there is a long history of experts underestimating the cognitive abilities of people who appear to be profoundly intellectually impaired." Some parents of children with "severe" or "profound" disabilities have reported seeing changes in behavior or capacity over time, despite the fact that their children were given static, unchanging prognoses. They report that their children changed in their ability to interact with the world even if the world remained unable to recognize their interactions as communication or intent. Ashley may never develop the ability to speak or interact in a normative fashion, but perhaps her "reactions" could be extended or enhanced through technologies such as assisted communication. Assisted communication—which often involves an aide helping a disabled person point toward letters, words, symbols, or pictures on a communication board (or, increasingly, electronic device)—remains controversial, but it does at least raise the question of whether Ashley's noncommunicative status is permanent or complete. There certainly are examples of people who claim to have received similar diagnoses and yet eventually learned ways to communicate with others. Given that possibility, why engage in such an extensive medical intervention based in part on the fact of her noncommunication? Is there not a possibility that new technologies could enable some form of communication in the not-too-distant future?

I cannot know the answer to that question, and asking it seems only to raise a whole other set of problems and complexities. Stressing that Ashley might "get better" either through technological interventions or therapy (or both) suggests that it is the "getting better" that renders the Treatment offensive or inappropriate. And if that is the case, then the Treatment is appropriate as long as we make sure we are getting the "right" children, the ones who do not have a chance of improving their function. But drawing lines between levels of impairment is notoriously difficult and, as Eva Kittay points out, suggests that some people are more deserving of ethical concern and consideration than others.

Rather the key seems to be on the unknowability inherent in the case. There is no way to know for certain whether the Treatment improved Ashley's quality of life. We have no baseline of "quality" by which to measure, for Ashley or for any of us. Supporters of the Treatment claim medical evidence for their assertion that the Treatment had a positive effect, but they are extrapolating from other cases or other situations. Ashley's parents' long-term quality of life likely improved, given that Ashley will remain easier to lift, and Ashley's quality of life is bound up in her parents' lives; if they are doing well, the odds are higher that she is doing well. But, again, we cannot know, not for certain, whether the Treatment benefited Ashley's quality of life.

Were the interventions a success in terms of reducing Ashley's pain? I don't know. I can't know. The surgery itself likely resulted in pain both physical and psychological, but perhaps that pain has faded from Ashley's memory. Perhaps that pain, now passed, is less significant than the constant pain of compressed breasts or the recurring pain of menstrual cramps. Or perhaps not. We cannot know the answers to these questions, but they are presented in Treatment-supportive discourses as self-evident. The claim that the Treatment reduced Ashley's pain is taken as fact.

Missing from this discussion of Ashley's quality of life is the possibility of pleasure—how might the Treatment have foreclosed upon a range of potential sites and sources of pleasure? It is possible that Ashley would have developed the large breasts that reportedly run in her family, and it is possible that she would have experienced discomfort from them. It seems equally possible, however, that she would have experienced pleasure from those large breasts: the sensation of her shirt moving against her skin, or of her skin moving against her sheets, or of her own arms brushing against her breasts. Even the tight chest straps holding her in her chair could have been sources of pleasure: perhaps she would enjoy the sensation of support, or take pleasure in the alternation between binding and release as she was moved in and out of her wheelchair. The inability or unwillingness to imagine these pleasures is a manifestation of cultural approaches to female sexuality and disability. It is seemingly inconceivable to imagine Ashley's body—her disabled female body—as the source of any sensation other than pain. We have few tools for recognizing female sexuality, particularly disabled female sexuality, as positive; nor can we recognize the potential for a self-generated and self-directed sexuality.

Ashley's parents see the mastectomy as offering an "additional benefit to Ashley" beyond its elimination of imagined future pain; according to them, the mastectomy will also prevent "sexualization towards [her] caregiver." Their syntax is odd here. To what does the "towards" refer? Is it meant to imply the possibility of a caregiver taking sexual liberties with Ashley, so that the mastectomy prevents caregivers from sexualizing her? Or does it refer to the possibility that Ashley might feel sexual when touched by her caregiver? In either case, it is a troubling rationale for the surgical removal of her breast buds. A lack of breasts does not render one safe 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. Or, if their concern is more about Ashley feeling sexual (and it is profoundly unclear what they would imagine that to mean, given their positioning of her as a noncommunicative infant), then the surgery has been justified, in part, on the need to diminish Ashley's access to pleasurable sensations. Maybe Ashley experiences pleasure from being held or hugged, from being bathed in warm water or towelled off, from nestling into a fresh bed or feeling the sun on her face. And if we can recognize those physical sensations as human pleasures to which even the disabled are entitled, then why deny her the future possibility of feeling the sensations of her breasts? The Treatment foreclosed on some of the ways Ashley might experience, or understand, or interact with her own body. Her inability to describe such interactions or even to understand them intellectually does not necessarily translate into an inability to feel them.
At the Same Time, Out of Time; or, Looking for Ashley among Crips and Queers

"Out of time": I choose this phrase for its multiple meanings. First, Ashley's being "frozen in time" is a casting out of time; the development of her female body has been arrested, removing her from expected patterns of female development and aging. Second, the use of Ashley as a "case study" only exacerbates this frozen-ness, as scholars and activists—including myself—continue to focus on what happened to Ashley in the past, as if the intervening years never happened, as if she weren't continuing to live beyond the dates of our analyses. Third, the Treatment itself was justified on the basis of Ashley's being always already out of time: her mind and body were so asynchronous that medical intervention was necessary to prevent her from falling further out of time. Finally, Ashley has run out of time. We are too late to stop the Treatment, too late to interrupt this representation of her as endangered by her future self or as embodied asynchrony.

To return then to where I started: In thinking about crip futurity, I find myself haunted by Ashley X. Of course, Ashley is not the only one doing the haunting. Ashley's parents suggest that there have been other pillow angels who have undergone the Treatment, and, if so, their stories remain unknown; I am haunted by that unknown. I think also of those disabled children who were altered in more traditional but no less invasive ways, children whose stories have not been seen as worth remembering, let alone preserving or disseminating. Perhaps the interventions in their bodies were considered a matter of course, a part of the standard of care, and therefore not prompting judicial review or public response; or maybe they were children who were seen not as figures in a sentimental narrative but as the inevitable and unremarkable casualties of poverty, violence, and inequality. Perhaps the details of their lives were unable to capture the public imagination in the same way a white pillow angel could. Sentimentality has historically and culturally been linked with white middle-class femininity, and Ashley's representation as a "pillow angel" calls to mind these racialized discourses of domesticity and passivity. As Patricia Williams points out, the "pillow angel" label held sway in public discussions of the case in no small part because of Ashley's race and class. Williams doubts, and with good reason, that "a poor black child would have been so easily romanticized as a 'pillow angel.'" Williams uses the case as a reminder that we are more concerned with the quality of some lives than others (even as the steps ostensibly taken to "ensure" that quality reveal profound ableist and misogynist anxiety).

I draw on this language of haunting to mark the difficulty of this case, to recognize the power with which it hit. In the years since this story first broke, conversations about the Ashley case have repeated and repeated themselves, a citational frequency that reveals the emotional toll the case took—and continues to take—on disabled people. I know that I continue to feel a mixture of anger, shame, and betrayal about the Ashley case: betrayal that mainstream feminists largely kept silent about the case, perhaps seeing it as only a "disability" issue; anger that these medical and surgical interventions were allowed to happen and will likely happen again; and shame that we could not save her, that we cannot reach her.

Yet supporters of the Treatment argue that disability activists have no bearing on this case because Ashley is too severely disabled to be considered a disabled person. Ashley's parents, for example, refer to her as "permanently unable" in order to distinguish her from other disabled people; "unable" is a "new category" that includes "less than 1% of children with disability." Although she does not argue for this kind of new terminology, Anita J. Tarzian argues that it might be a "mismiser" to call Ashley disabled. Both disability rights and people-first or self-advocacy movements are concerned with individuals who "have some level of cognitive capacity," she explains, which means that these movements do not have the tools or the rhetoric to address those with "severe neurological impairments."

Predominant models of disability studies and activism too often do skim over such people, and Ashley's situation is not, and never has been, similar to most of us working in disability studies. How, then, are we to understand the differences between our experiences even as we name us all as disabled? Or, to move in the other direction, how might such an identification—we are all Ashley X—work to trouble the binaries of functional/nonfunctional, physical/developmental, or moderate/severe disability? What work are we enabled to do by placing Ashley in the center of disability scholarship and activism, or by positioning her as part of disability communities and movements? If crip theory and critical disability studies remind us to attend not only to the experiences of disabled people but also, and especially, to the ways in which disability and ability work in the world, then we need to contest this representation of some minds and bodies as beyond the reach of disability analysis and activism.

I want to caution, then, against viewing Ashley as exceptional or her case as a spectacular anomaly. After all, there remains a very real possibility that growth attenuation (and its attendant surgeries) will be performed on other disabled kids, which means that we cannot dismiss the case as a one-time event. More to the point, Ashley herself is not wholly unlike the other disabled people inhabiting the pages of this book or the movements and scholarship discussed here. To see her differently, to accept the representation of her as "unable" rather than "disabled," is to accept an ableist logic that positions impairment—if "severe" enough—as inherently depoliticizing; "unability" becomes the category that allows "disability" to separate itself from those bodies/minds that remain in the margins.

We will remain haunted by the Ashley case, in other words, if we refuse to look for her among crips and queers, if we refuse to recognize her as part of our work. How might we imagine futures that hold space and possibility for those who communicate in ways we do not yet recognize as communication, let alone understand? Or futures that make room for diverse, unpredictable, and fundamentally unknowabl-
experiences of pleasure? If, as I discussed in the previous chapter, queerness entails nonheteronormative approaches to temporality, then how might we learn to approach asynchronous bodies and minds as something other than grotesque or pathological?

Reading Ashley through the lens of temporality is likely going to require changes to both our theories of disability and our approaches to queer/crip futurity. As we intervene in the representation of Ashley as abnormally asynchronous or grotesquely fertile, as we interrupt the depiction of her as developmentally and temporally other, we must take care, as feminist disability scholars and crip theorists, not to write Ashley out of our own desirably disabled futures.

3 Debating Feminist Futures

Slippery Slopes, Cultural Anxiety, and the Case of the Deaf Lesbians

The fear that lesbians and gay men will start to fabricate human beings, exaggerating the biotechnology of reproduction, suggests that these "unnatural" practices will eventuate in a wholesale social engineering of the human... But it seems a displacement, if not a hallucination, to identify the source of this social threat, if it is a threat, with lesbians who excavate sperm from dry ice on a cold winter day in Iowa when one of them is ovulating.

—Judith Butler, Undoing Gender

The pervasiveness of prenatal testing, and especially its acceptance as part of the standard of care for pregnant women, casts women as responsible for their future children's able-bodiedness/able-mindedness; prospective parents are urged to take advantage of these services so as to avoid burdening their future children with any disabilities. This notion of "burdening" children finds an echo in the debate over same-sex marriage, with LGBT couples cast as selfish parents, placing their own desires over the physical and mental health of their children (and, by extension, of all children).

Moreover, according to Timothy Dailey of the Family Research Council, homosexual parents often "recruit" children into the homosexual lifestyle by modeling "abnormal sexuality." The possibility that same-sex parents might produce queer children is one of the most common reasons given for opposing such families, a reasoning that takes for granted the homophobic worldview that queerness must be avoided at all costs.

It is in the literature of reproductive technologies and their "proper" use that heterocentrism and homophobia intersect powerfully with ableism and stereotypes about disability. These stories reveal profound anxieties about reproducing the family as a normative unit, with all of its members able-bodied/able-minded and heterosexual. At sites where disability, queerness, and reproductive technologies converge, parents and prospective parents are often criticized and condemned for their alleged misuse of technology. Assistive reproductive technologies are to be used only to deselect or prevent disability; doing otherwise—such as selecting for disability—means failing to properly reproduce the family.