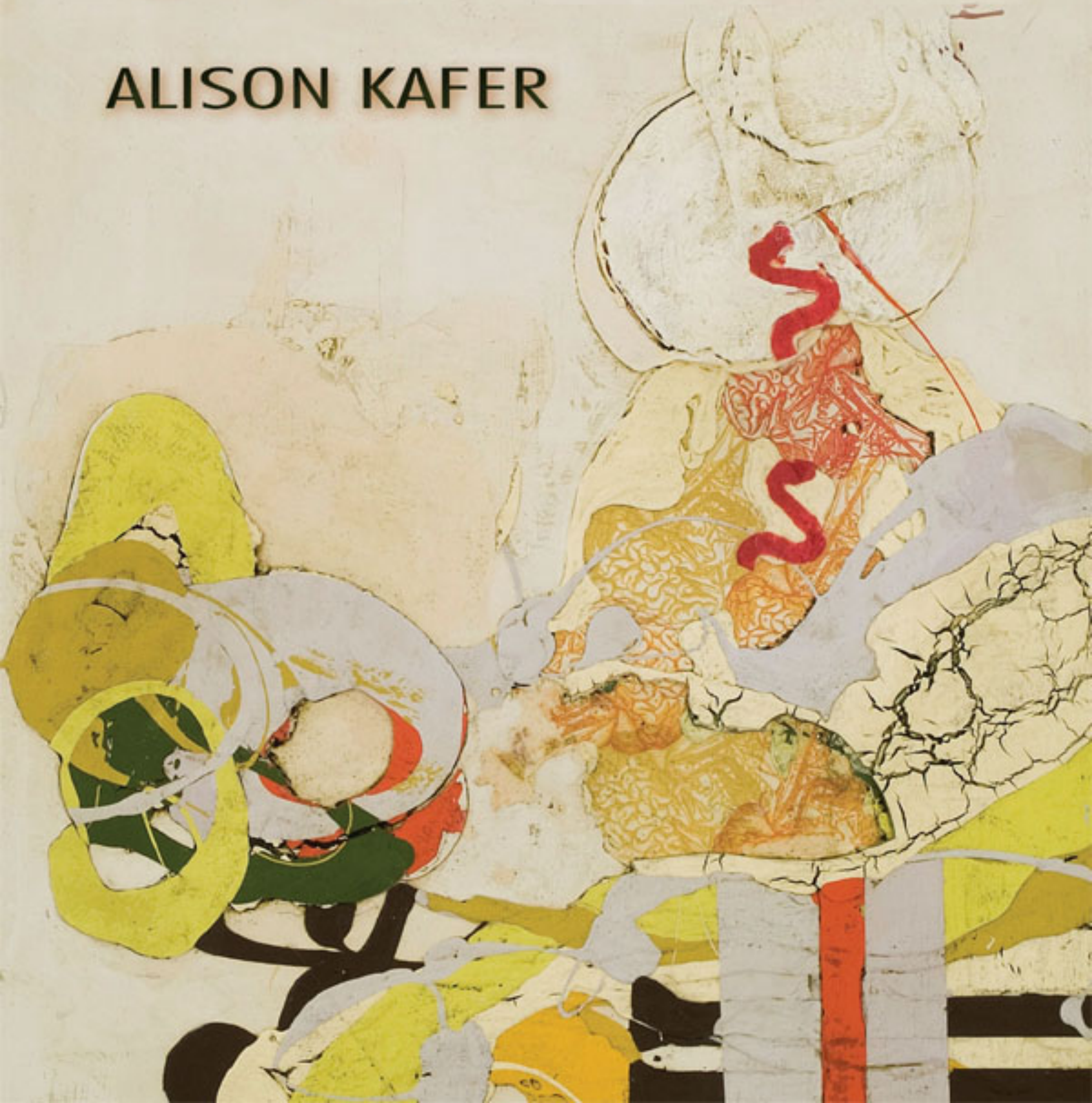
FEMINIST QUEER CRIP

ALISON KAFER



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For Dana

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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.[1] 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.”[2] 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.

In this chapter, I explore one such story in which ableism and heterocentrism combine, a situation in which parents were widely condemned for failing to protect their children from both disability and queerness. Sharon Duchesneau and Candace McCullough, a deaf lesbian couple in Maryland, attracted publicity and controversy for their 2001 decision to use a deaf sperm donor in conceiving their son. What most interests me about their story, and what I focus on here, is the consistency with which cultural critics and commentators took for granted the idea that a better future is one without disability and deafness. In order to illustrate this dimension of the story, I frame their account with an analysis of Marge Piercy's influential utopia, *Woman on the Edge of Time*.[3] In that novel, as in the responses to McCullough and Duchesneau, "common sense" dictates that disabled minds/bodies have no place in the future, and that such decisions merit neither discussion nor dissent. Both stories, in other words, center around the proper use of assistive reproductive technology and the future of children.

This is What the Future Looks Like: Reproduction and Debate in *Woman on the Edge of Time*

In 2001, I served as a teaching assistant in an introduction to women's studies course at a liberal arts college in Southern California. One of the assigned texts was Marge Piercy's novel *Woman on the Edge of Time* (1976), chosen by the professor in order to spark discussion about feminist futures. Published over three decades ago, the novel continues to be popular among feminists for its representation of an egalitarian society. Students responded enthusiastically to Piercy's book, finding its imagined utopia hopeful, enviable, and desirable. As a disability studies scholar, however, I found the novel troubling for its erasure of disability and disabled bodies, an erasure that is never debated or discussed in the novel. With the marked exception of mental illness, an exception to which I will return, *Woman on the Edge of Time* simply assumes that a feminist future is, by definition, one without disability and disabled bodies.

Woman on the Edge of Time is a feminist utopia/dystopia that chronicles the experiences of Connie Ramos, a poor Chicana woman who has been involuntarily institutionalized in a New York mental ward. The novel moves back and forth among three settings: mental institutions and Connie's neighborhoods in 1970s New York; Mattapoisett, a utopian village in 2137; and a future, dystopic New York City inhabited by cyborgs and machines in which all humans have been genetically engineered to fulfill certain social roles.[4] While incarcerated in the violent ward of a mental institution in 1976, Connie develops the ability to travel mentally into the future, interacting with a woman named Luciente who lives in the utopian Mattapoisett community. During one attempt at mental travel, Connie's attention is diverted and she finds herself in the dystopic future Manhattan, but the rest of her time travels involve Mattapoisett.

Piercy lovingly describes Mattapoisett. She has clearly thought a great deal about difference in constructing this world, trying to envision a thoroughly feminist, antiracist, socially just, and multicultural community. All sexual orientations and identities are present and respected in her vision of Mattapoisett, everyone possesses equal wealth and resources, and all have access to education according to their interests. People in Mattapoisett have developed harvesting and consumption patterns intended to redress the global imbalance of wealth, resources, and consumption wrought during Connie's era. The world is viewed holistically, with Mattapoisett's inhabitants aware of how their actions affect others both within the borders of their community and beyond.

Luciente explains to Connie that Mattapoisett's communal harmony has been achieved through radical changes in the system of reproduction. All babies are born in the "brooder," a machine that mixes the genes from all the population's members, so that children are not genetically bound to any two people. Three adults co-mother each child, a task that is undertaken equally by men and women. Through hormone treatments, both men and women are able to breast-feed, exemplifying the community's belief that equality between the sexes can be engineered through technological intervention and innovation. By breaking the traditional gendered nature of reproduction, explains Luciente, the brooder has eliminated fixed gender roles and sexism within the community. It has also eradicated racism by mixing the genes from all "races," thereby rendering everyone mixed-race and making notions of "racial purity" impossible to maintain. Cultural histories and traditions have been preserved, but have been separated from the concept of "race." Luciente's friend Bee tells Connie that the community has recently decided to create more "darker-skinned" babies in order to counteract the historical devaluation of people of color, resulting in a village inhabited by people of all skin tones: "[W]e don't want the melting pot where everybody ends up with thin gruel. We want diversity, for strangeness breeds richness."[5]

All decisions concerning the community are publicly debated during open meetings. Decisions are made on the basis of consensus, and every community member is allowed and expected to participate. People volunteer to serve as representatives to intercommunity meetings at which decisions affecting a larger population are debated. No decisions are made for other people by other people. Every person has the right to speak out on issues that affect him or her.

To illustrate the way this participatory democracy works, Piercy gradually introduces Connie, and the reader, to a conflict currently being played out in Mattapoisett. The "Mixers" and the "Shapers" are involved in a heated disagreement about the next direction the brooder should take, with the Shapers advocating a more aggressive stance. The Mixers would prefer to maintain the status quo: the brooder currently screens out genes linked to birth defects and disease susceptibility, thereby preventing "negative" characteristics from being passed down to children. The Shapers, however, want to program the brooder to select for "positive" traits as well, ensuring that children will have the traits most desired by the community. Luciente and her friends are on the side of the Mixers, arguing that it is impossible to know which traits will be necessary or valued in the future. Piercy makes it clear that Luciente's perspective mirrors her own; the genetically engineered inhabitants of her dystopian New York suggest the logical, and undesirable, result of a Shaper victory. Piercy refuses, however, to simply impose a Mixer victory on Mattapoisett; she depicts a continuing process of respectful dialogue and public debate between the two groups, creating a vision of a feminist community in which all people participate equally in the decisions that affect them. The Mixers-Shapers debate is never resolved in the novel, illustrating Piercy's notion of the importance of open-ended dialogue and group process.

It is this description of democratic decision making, of a community debating publicly how it wants technology to develop in the future, that has made *Woman on the Edge* such an attractive text to feminist scholars of science studies and political theory. Decades after its initial publication, the novel continues to inspire feminist thinkers with its image of an egalitarian future in which all people's voices are heard, respected, and addressed. A quick glance at the women's studies syllabi collected on Internet databases reveals the continued popularity of the book in conversations about "feminist futures," "feminist utopias," and "ecofeminisms"; *Woman on the Edge of Time* is often taught in introductory women's studies classes to initiate discussion about feminist worldviews.[6]

Similarly, several feminist political theorists and science studies scholars cast the book as a vital exploration of political and technological processes influenced by feminist principles. José van Dijck, for example, praises Piercy for depicting science as "a political and democratic process in which all participants participate," a depiction that recognizes genetics "as a political, rather than a purely scientific," practice. Political theorist Josephine Carubia Glorie shares van Dijck's assessment, noting that Piercy's novel features a society in which all community members are able to engage in social critique. Even those who disagree with Piercy's pro-genetic engineering and pro-assisted reproduction stance, such as ecofeminists Cathleen McGuire and Colleen McGuire, find *Woman on the Edge of Time* to be a compelling vision of a world without social inequalities.[7] As these comments suggest, over thirty years after its initial publication, *Woman on the Edge of Time* remains a powerful, productive text for feminist theorists concerned with the role of technology in the lives of women and committed to envisioning an egalitarian, just world. Piercy's articulation of the "Mixers vs. Shapers" debate—should we breed children for desired traits?—seems prescient in the early twenty-first century as bioethicists and geneticists debate the morality and feasibility of allowing prospective parents to create or select embryos on the basis of such traits as sex, hair color, or height.[8]

What has gone unnoticed in these praises of Piercy's novel, however, is the place of disability, and specifically disabled bodies, in her imagined utopia. In a world very carefully constructed to contain people of every skin tone and sexual orientation, where people of all genders and ages are equally valued, disabled people are absent.

This absence cannot simply be attributed to oversight or neglect; it is not that Piercy forgot to include disability and disabled people among her cast of characters and life experiences. On the contrary, the place, or rather the absence, of disability in Piercy's utopia is at the heart of the Mixers-Shapers debate: both the Shapers and the Mixers agree on the necessity of screening the gene pool for "defective genes" and "predispositions" for illness and "suffering." It is taken for granted by both sides—and by Piercy and (presumably) her audience—that everyone knows and agrees which genes and characteristics are negative and therefore which ones should be eliminated; questions about so-called negative traits are apparently not worth discussing. Thus, disabled people are not accidentally missing from Piercy's utopia; they have intentionally and explicitly been written out of it. Mattapoisett, an influential feminist fictional utopia, has wiped out congenital disability. The apparent lack of any physically or cognitively disabled inhabitants of Mattapoisett, coupled with the genetic screening of all congenital disabilities, suggests that even disabilities acquired through age, illness, or accident are lacking in this utopia; presumably medicine has advanced to such a degree that all impairments can be cured or prevented.

At first glance, mental disability seems to be an exception to this absence. Not only is the novel highly critical of the institutionalization of people with mental disability, it also casts "crazy" as a diagnosis more likely to be attached to poor women of color and to those who refuse to adhere to cultural norms. Unlike the stigma and forced institutionalization Connie faced in 1970s New York, the inhabitants of Mattapoisett recognize mental disability as part of a normal course of life, with people "dropping out" of their communities as needed to tend to their mental and emotional needs. But this requirement to drop out, to separate oneself from the community until one's functioning returns to "normal," enacts another version of this erasure of disability. People with disabilities have no place in this feminist future. Indeed, it is their very absence, whether permanent or temporary, that signals the utopian nature of this future.

Neither Piercy, writing in the mid-1970s, nor theorists such as van Dijck and Glorie, writing in the late 1990s, seem to have noticed that the entire Mixers-Shapers debate rests on profound assumptions about whose bodies matter. Van Dijck and Glorie praise Piercy for articulating a vision of science as a democratic process in which all voices are heard, yet the assumptions underlying the Mixers-Shapers debate ignore the perspectives of an entire class of people, those with congenital disabilities. Never once do the nondisabled members of Mattapoisett debate the decision to eliminate ostensibly defective genes, never do they question how one determines which genes are labeled "defective" or what "defective" means. Van Dijck highlights Piercy's recognition that genetics is political—contested and contestable, subject to debate and disagreement—but fails to realize that screening the gene pool for allegedly negative traits is also political. In both the novel and interpretation of the novel, it is assumed that disability has no place in feminist visions of the future, and that such an assumption is so natural, so given, that it does not merit public debate.

What does it mean that disability appears in Piercy's utopia only as an unwanted characteristic in a debate over genetic engineering, a debate itself used to illustrate her ideas about democratic science? What does it mean that feminists writing and teaching about the United States in the 1990s and 2000s use this novel, and specifically the Mixers-Shapers debate, as an example of ideal democratic decision making and public critique, of a political community grounded in feminist principles of egalitarianism and democracy? What can be inferred about disability from the fact that contemporary feminists highlight a debate in which both parties assume from the beginning that "negative" traits are self-evident, natural, and therefore outside the scope of discussion? What can a feminist disability studies reader learn from the fact that feminist theorists have offered no critique of a debate in which disabled people do not participate because they have already been removed from this supposedly diverse, multicultural, egalitarian landscape?

I suggest that Piercy's depiction and, more importantly, feminist theorists' praise of it mean that disability in the United States is often viewed as an unredeemable difference. Disability and the disabled body are problems that must be solved technologically, and there is allegedly so much cultural agreement on this point that it need not be discussed or debated. Disability, then, plays a huge, but seemingly uncontested, role in how contemporary Americans envision the future. Utopian visions are founded on the elimination of disability, while dystopic, negative visions of the future are based on its proliferation; as we will see below, both depictions are deeply tied to cultural understandings and anxieties about the proper use of technology.

I turn now to one particular case of the alleged misuse of technology, moving from Piercy's fiction to the stories we tell ourselves about others' reproduction. The story of Sharon Duchesneau and Candace McCullough, a deaf lesbian couple who selected a deaf sperm donor for their pregnancies, has been presented to the public almost exclusively in terms of what the future can, should, and will include. Whether warning of a slippery slope, of other disabled people "manufacturing" disabled children, or of "unnatural" lifestyles, commentators see the couple's selection of a deaf sperm donor as a sign of a dangerous future. I am less interested in arguing for or against these women's decision than in detailing how critics of the couple utilize dystopic rhetoric in their condemnations, presenting deafness and disability as traits that obviously should be avoided. As with *Woman on the Edge of Time*, a world free of impairment is portrayed as a goal shared by all, a goal that is beyond question or analysis, a goal that is natural rather than political.

Deaf/Disabled: A Terminological Interlude

For most hearing people, to describe deafness as a disability is to state the obvious: deaf people lack the ability to hear, and therefore they are disabled. For some people, however, deaf and hearing alike, it is neither obvious nor accurate to characterize deafness as a disability and deaf people as disabled. Rather, Deaf people are more appropriately described as members of a distinct linguistic and cultural minority, more akin to Spanish speakers in a predominantly English-language country than to people in wheelchairs or people who are blind.[9] Spanish speakers are not considered disabled simply because they cannot communicate in English without the aid of an interpreter, and, according to this model, neither should Deaf people, who rely on interpreters in order to communicate with those who cannot sign, be considered disabled. Drawing parallels between Deaf people and members of other cultural groups, supporters of the linguistic-cultural model of deafness note the existence of a vibrant Deaf culture, one that includes its own language (in the United States, American Sign Language [ASL]), cultural productions (e.g., ASL poetry and performance), residential schools, and social networks, as well as high rates of intermarriage.[10] As Deaf studies scholar Harlan Lane explains, "[T]he preconditions for Deaf participation [in society] are more like those of other language minorities: culturally Deaf people campaign for acceptance of their language and its broader use in the schools, the workplace, and in public events."[11] This linguistic-cultural model of deafness shares a key assumption of the social model of disability—namely, that it is society's interpretations of and responses to bodily and sensory variations that are the problem, not the variations themselves.

Everyone Here Spoke Sign Language, Nora Groce's study of hereditary deafness on Martha's Vineyard from the early eighteenth century to the mid-twentieth century, provides an example of this perspective. Groce argues that genetic deafness and deaf people were so interwoven into the population that almost every person on the island had a deaf relative or neighbor.[12] As a result, "everyone [there] spoke sign language," a situation that proves it is possible for hearing people to share the responsibility of communication rather than simply expecting deaf people to lip-read and speak orally or alleviate their hearing loss with surgeries and hearing aids.[13] Groce's study challenges the idea that deafness precludes full participation in society, suggesting that the barriers deaf people face are due more to societal attitudes and practices than to one's audiological conditions. For those who subscribe to this worldview, deafness is best understood as a distinct culture in which one should feel pride, rather than as a disability.

Although some Deaf people are averse to the label "disabled," either because of their immersion in Deaf culture or because of an internalized ableist impulse to distance themselves from disabled people, others are more willing to explore the label politically. This kind of exploration is based on making a distinction between being labeled as "disabled" by others, especially medical or audiological professionals and the hearing world in general, and choosing to self-identify as disabled. Many Deaf people who choose to take up the label of disability do so for strategic reasons. For some, the decision stems from a desire to ally themselves with other disabled people. They recognize that people with disabilities and Deaf people share a history of oppression, discrimination, and stigmatization because of their differences from a perceived "normal" body. As a group, Deaf and disabled people can work together to fight discrimination, and they have done so since the birth of the modern disability rights movement in the late 1960s. Thus, while some Deaf people may be opposed to (or at the very least ambivalent about) seeing deafness as a disability, they may simultaneously be willing to identify themselves as disabled or to ally themselves with disabled people in order to work toward social changes and legal protections that would benefit both populations.[14]

Recognizing this affinity between disability and deafness is particularly important in an analysis of cure narratives and utopian discourse, because it is precisely the image of deafness as disability that animates these narratives. What makes the actions of parents who express a preference for a deaf baby—the case under consideration here—so abhorrent to the larger culture is the refusal to eradicate disability from the lives of their children.

Reproducing Cultural Anxiety: The Case of the Deaf Lesbians

In November 2001, the same year that I taught Piercy's novel, Sharon Duchesneau and Candace (Candy) McCullough, a white lesbian couple living in Maryland, had a baby boy named Gauvin, who was conceived by assisted insemination. Both Duchesneau, the birth mother, and McCullough, the adoptive mother, are deaf, as is their first child, Jehanne. Jehanne and her new brother Gauvin were conceived with sperm donated by a family friend, a friend who also is deaf. Duchesneau and McCullough had originally intended to use a sperm bank for the pregnancies, but their desire for a deaf donor eliminated that option: men with congenital deafness are precluded from becoming sperm donors; reminiscent of the eugenic concern with the "fitness" of potential parents, deafness is one of the conditions that sperm banks and fertility clinics routinely screen out of the donor pool.[15] Several months after he was born, Gauvin underwent an extensive audiology test to determine if he shared his parents' deafness.[16] To the delight of Duchesneau and McCullough, the diagnosis was clear: Gauvin had "a profound hearing loss" in one ear, and "at least a severe hearing loss" in the other.[17] Duchesneau noted that they would have accepted and loved a hearing child, but a deaf child was clearly their preference. "A hearing baby would be a blessing," Duchesneau explained, "a Deaf baby would be a special blessing."[18]

Liza Mundy covered Duchesneau and McCullough's story for the *Washington Post Magazine* in March of 2002, and her essay provided a detailed explanation of these women's reproductive choices. Although the piece acknowledged the criticisms lodged against Duchesneau and McCullough, it was largely sympathetic; Mundy took care to explain the women's understanding of Deaf identity and to situate them within a larger understanding of Deaf culture and community. She also, of necessity, mentioned the women's lesbian relationship, but it was not a central component of the piece. For Mundy, it was the women's deafness, and their decision to have deaf children within a larger Deaf community, that made their story newsworthy.[19]

The piece made quite a splash, and the story of the Deaf lesbian couple was picked up by other newspapers and wire services. Papers across the United States and England ran versions of and responses to the story, and cultural critics from across the ideological spectrum began to weigh in. The Family Research Council, a Washington-based organization that "champions marriage and family as the foundation of civilization," issued a press release with comments from Ken Connor, the group's president at the time. Describing Duchesneau and McCullough as "incredibly selfish," Connor berated the pair for imposing on their children not only the "disadvantages that come as a result of being raised in a homosexual household" but also the "burden" of disability. Connor linked disability and homosexuality, casting both as hardships that these two women "intentionally" handed their children. The Family Research Council's press release closed with a quote from Connor that not only continued to link homosexuality with disability but also depicted both as leading toward a dystopic future: "One can only hope that this practice of intentionally manufacturing disabled children in order to fit the lifestyles of the parents will not progress any further. The places this slippery slope could lead to are frightening."[20] The use of the term "lifestyles"—a word frequently used to refer derisively to queers and our sexual/relational practices—effectively blurs deafness and queerness, suggesting that both characteristics are allegedly leading "us" down the road to ruin.[21]

Indeed, the queerness of this future had everything to do with its portrayal as negative and imperfect. Although Ken Connor and the Family Research Council probably would not celebrate the use of a Deaf sperm donor by a heterosexual couple, it is highly unlikely that they would have condemned it as aggressively or as publicly as they did here, casting such a move as the first step on a slippery slope into the unknown. (They have not gone on record, for example, condemning Deaf heterosexuals who have children.) The case of the Deaf lesbians acquired the mileage that it did because of its evocation of a queer disabled future; heterosexism and ableism intertwine, each feeding off and supporting the other.

The Family Research Council was not alone in discussing these women's desire for a Deaf baby in the context of their sexuality. Indeed, even some queer commentators found something troubling, and ultimately dystopic, about the idea. Queer novelist Jeanette Winterson seemed to suggest that it was precisely these women's queerness that made their decision so anathema:

> If either of the Deaf Lesbians in the United States had been in a relationship with a man, Deaf or hearing, and if they had decided to have a baby, there is absolutely no certainty that the baby would have been Deaf. You take a chance with love; you take a chance with nature, but it is those chances and the unexpected possibilities they bring, that give life its beauty.[22]

It is worth noting that Winterson appears concerned only about the loss of some possibilities, namely the possibility of having a hearing child. Screening out deaf donors from sperm banks *also* removes the chance of "unexpected possibilities," at least in terms of genetic deafness, but apparently the denial of that chance does not trouble her.

Winterson condemned Duchesneau and McCullough for removing the element of "chance" from their pregnancy and guaranteeing themselves a deaf baby, a guarantee that could not happen "with nature."[23] However, her remarks obscure the fact that the women's use of a deaf donor provided no such guarantee, a fact made clear in Mundy's article.[24] Duchesneau, McCullough, and their deaf donor; Winterson's hypothetical deaf heterosexual couple: both groups would have exactly the same odds of having a deaf child, yet Winterson found no fault with the imagined heterosexual conception. She appears to believe that it is acceptable, if perhaps regrettable, for heterosexual deaf couples to have deaf children because such an act is "natural"; bearing deaf children becomes "unnatural" and thereby dangerous when it is done outside the bounds of a "normal, natural" relationship—an odd position for a queer writer to take and one that has certainly been influenced by dominant ableist culture.

Winterson clearly took for granted that "everyone" views these women's behavior as reprehensible; for her, it was a "simple fact" that life as a deaf person is inferior to life as a hearing person. Duchesneau and McCullough's refusal to accept this "simple fact," and their insistence that deafness is desirable, has made them the targets of criticism from across the political spectrum. Winterson echoed Connor's "slippery slope" rhetoric when she suggested that these women's actions will lead to other, allegedly even more troubling futures. "How would any of us feel," she asked, "if the women had both been blind and claimed the right to a blind baby?" The tone and content of Winterson's essay answers this question for her readers, making clear that "we" would feel justifiably outraged.[25] It is perhaps no accident that Winterson referred to "blind women" rather than "blind people," again implying that it might be "natural" for a heterosexual blind couple to reproduce, but not a lesbian one. She even drew on this image for the title of her essay, "How Would We Feel If Blind Women Claimed the Right to a Blind Baby?"[26]

This rhetorical move—shifting from an actual case involving deafness to a hypothetical situation involving a different disability—is a popular strategy to convince a disabled person that her decision to choose for disability, either by having a disabled child or by refusing technological fixes, is misguided, illogical, and extreme. By decontextualizing the situation, removing it from a Deaf person's own sphere of reference, it is assumed that the Deaf person will be able to recognize her error in judgment. This practice suggests that some disabilities are worse than others, that eventually one can substitute a particular disability that is so "obviously" undesirable that the disabled person will change her mind. Cross-disability alliances are presumed to be nonexistent; it is assumed that all Deaf people believe it would be best to eliminate the birth of "blind babies" or people with X disability.

This story is complicated by the fact that Winterson's stance is not without basis. In the *Washington Post* story, McCullough does express a preference for a sighted child. According to Mundy,

> If they themselves—valuing sight—were to have a blind child, well then, Candy acknowledges, they would probably try to have it fixed, if they could, like hearing

> parents who attempt to restore their child's hearing with cochlear implants. "I want to be the same as my child," says Candy. "I want the baby to enjoy what we enjoy."[27]

McCullough and Duchesneau's position that Deaf babies are "special blessings" does not mean that they are not also simultaneously implicated in the ableism of the larger culture; their desire for deafness does not necessarily extend to a desire for any and all disabilities. Deaf and disabled people are not immune to the ableist—or homophobic—ideologies of the larger culture. (It is worth noting in this context, however, that McCullough does not express a desire for genetic testing and selective abortion).

Indeed, even some disabled queers mirrored the blend of heterocentrism and ableism circulating through mainstream responses to Duchesneau and McCullough's reproductive choices. A participant on the QueerDisability listserv, for example, found the couple's decision to choose a Deaf donor troubling, partly because of the hardships and social barriers their children would face, partly because of the alleged financial burden their children would place on the state. Echoing Winterson, the listserv member drew a distinction between the "naturally" Deaf children who result from heterosexual relationships and the "unnaturally," and therefore inappropriately, Deaf children who result from queer relationships. We are left to wonder how this community member would view the choice by an infertile heterosexual Deaf couple to use a Deaf sperm donor, whether that choice would be deemed more natural and therefore acceptable.[28] Her comments lead me to believe that she would, like Winterson, find less fault with the imagined heterosexual couple than with the real homosexual one: either deafness or homosexuality in isolation would be permissible, but the combination is too abnormal, too disruptive, too queer, even for some gays and lesbians and people with disabilities.

These kinds of responses to the use of assisted insemination by Deaf queers support Sarah Franklin's argument that, while reproductive technology "might have been (or is to a limited extent) a disruption of the so-called 'natural' basis for the nuclear family and heterosexual marriage, [it] *has instead provided the occasion for reconsolidating them*."[29] With few exceptions, Franklin explains, the state has taken little action to guarantee queers and/or single parents equal access to assisted reproductive technologies, and prominent people in the field of reproductive medicine have been outspoken in their belief that these technologies should not be available to same-sex couples or single parents.[30] As sociologist Laura Mamo points out, "[A]ccess to reproductive technologies in the United States is from the outset a class-based and sexuality-based phenomenon, and the institutional organization of these services enacts the reproduction of class and sexuality hierarchies by assuring the survival and ongoing proportionality of middle-class (usually white) heterosexual families."[31]

Mamo details the ways in which lesbians and (single heterosexual women) are disadvantaged within the medical system. Insurance policies, for example, require a diagnosis of infertility before they agree to cover assistive technologies, yet such a diagnosis is difficult to make in the absence of heterosexual sex. Many lesbians want to use sperm donated by a friend or family member, yet some clinics forbid the use of sperm from a known donor unless the woman is married to the donor.[32] Dorothy Roberts and Elizabeth Weil note that many fertility clinics require proof of a "stable" marriage before initiating treatment, an open-ended requirement that has been used to block the treatment of queers, women of color, and poor people. California prohibits discriminating against queers in fertility treatments, but, as Elizabeth Weil argues, such discrimination can hide under other names. Guadalupe Benitez lost her case against the North Coast Women's Care Medical Group when they argued that they had refused to treat her not because she was a lesbian but because she was unmarried; in an earlier case, which the clinic lost, Benitez was able to prove that treatment had stopped because of her status as a lesbian.[33] Assisted insemination may make it easier for queers to bear children, thereby "unsettling the conflation of reproduction with heterosexuality," but heterocentric/homophobic attitudes may prevent, or at least hinder, their use of this technology.[34]

Dorothy Roberts notes that racism also plays a role in access to assisted reproductive technologies, as doctors are far less likely to recommend fertility treatments for black women than for whites.[35] Although clinics cannot legally discriminate against potential patients on the basis of race, they can neglect to inform people of color about all possible treatments.[36] Ableist attitudes pose similar barriers to disabled people's use of assisted reproductive technologies. Many disabled women report being discouraged by their doctors and families from having children, a fact that suggests that they might not receive all the fertility assistance they need.[37] The policing of these technologies serves to reinforce the dominant vision of a world without impairment and to perpetuate the stigmatization of the queer, disabled, nonwhite body.

The case of Kijuana Chambers deserves attention here, as her experience with a Colorado fertility clinic illustrates the kind of policing reconsolidation to which Franklin refers. In 1999, Chambers went to the Rocky Mountain Women's Health Care Center (RMWHCC) for assisted insemination. After three cycles of treatment, the clinic informed Chambers that they could no longer work with her because they had "concern[s] about her ability to safely care for a child." Chambers is blind, and the clinic believed that her blindness posed a direct threat to the welfare of any future child.[38] Until she could provide an assessment from an occupational therapist attesting to her ability to raise a child, the clinic would no longer treat her. Chambers sued the RMWHCC under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, claiming that the clinic illegally discriminated against her on the basis of her disability. Sighted women, her supporters noted, were not required to provide documentation of their ability to childproof their homes or raise their children. In November 2003, a US District Court jury in Denver found in favor of the defendants, deciding that the clinic behaved appropriately in questioning Chambers's fitness. The US Tenth Circuit Court of Appeals decided in the summer of 2005 not to rehear her case, letting the lower court's decision stand.

Chambers's race (African American) and her sexual orientation (lesbian) may well have factored into the clinic's decision, but the clinic's spokespeople and legal staff, and the media, have focused primarily on Chambers's status as a single disabled woman. An article in the *Denver Post*, for example, makes no mention of Chambers's race or sexual orientation, and other news reports on the case followed suit. Given the long history of disability being seen as more medical than political in this country, the exclusive focus on Chambers's blindness guaranteed that this case would be understood by the public as a matter of common sense and child protection rather than discrimination. This is not to suggest that race played no role in Chambers's treatment; during the hearing, she was portrayed in almost animalistic terms, with witnesses testifying to her dirty underwear, disheveled appearance, and emotional outbursts, claims that at least implicitly drew on histories of racist claims about Africans' and African Americans' allegedly primitive and uncivilized nature. (Contrast this portrayal with the depiction of Duchesneau and McCullough, white, middle-class, professional women, as "selfish." The condemnation of these women varied dramatically by their racialized positions.[39]) Rather, I want to suggest that discrimination on the basis of disability, in this case blindness, is often not seen as discrimination at all, and therefore not considered as having a place in the political arena. It is assumed to be self-evident that blind women cannot parent safely or appropriately, and there is nothing discriminatory or political about asking them to prove otherwise to a medical expert (as Chambers was required to do).

In her analysis of the case, disability rights activist Laura Hershey argues that the clinic drew on

> contradictory notions about disability and help. . . . On the one hand, Chambers felt confident she could raise a child largely by herself, yet because of her stubborn refusal to prove this to anybody, she was denied treatment. On the other hand, if Chambers sometimes did ask for assistance—perhaps with finding her clothes in an unfamiliar environment, for example [as happened during an appointment at the clinic]—this was viewed as reason enough to doubt her competence.[40]

Chambers challenged the clinic's assertion that medical professionals were the best judges of her ability to raise a child, and she disputed their suggestion that an occupational therapist could provide a more accurate assessment of her assistance needs than she herself could. The jury agreed with the clinic's position, however, that clinic staff were justified in requiring "expert" documentation of Chambers's parenting abilities. Unfortunately, explains Carrie Lucas of the Colorado Cross-Disability Coalition, presumptions of incompetence are common for parents and potential parents with disabilities: "[T]he public believes we [people with disabilities] must prove ourselves before we are allowed to do the things nondisabled people consider their right."[41] The Chambers case provides a powerful example of how the use of reproductive technologies by certain people—such as disabled people, queers, single parents, people of color, or, as in this case, a disabled queer single parent of color—is patrolled and restricted, with "nontraditional" users brought under strict surveillance. This surveillance is cast, then, not as a political decision, or a potentially discriminatory one, but as an obviously necessary step toward a better life.

None of the articles tracing the reproductive choices of Sharon Duchesneau and Colleen McCullough questioned the assumption that a future without disability and deafness is superior to one with them. As in Piercy's fictional debate between the Mixers and the Shapers, no one recognized the screening out of deaf sperm donors as a political decision; indeed, it was not recognized as a decision at all because no other possibility was even conceivable. The vast majority of public reactions to these women's choices tell a story about the appropriate place of disability/deafness in the future; it is assumed that everyone, both hearing and Deaf, disabled and nondisabled, will and should prefer a nondisabled, hearing child. Thus the future allegedly invoked by the couple's actions is dangerous because it advocates an improper use of technology; technology can and should be used only to *eliminate* disability, not to *proliferate* it. Such a goal is *natural*, not *political*, and therefore neither requires nor deserves public debate.

Open to Debate? Disability and Difference in a Feminist Future

This idea that disability is best conceptualized as a problem to be eradicated brings us back to how Marge Piercy addresses disability and other differences in *Woman on the Edge of Time*. In her utopian vision of a future Mattapoisett, diversity is highly valued, with the village's inhabitants rejecting the idea of a "thin gruel" in which everyone is the same. I want to suggest, however, that the community is actually founded on an *erasure* of difference. Sexism is rooted out not through the passing of antidiscrimination laws or a changing of attitudes but by erasing reproductive differences, rendering both sexes able to breast-feed and neither able to give birth. Similarly with racism: Mattapoisett uses the brooder to mix races together; different skin tones may result, but the practice is founded on the idea that racism can never be eliminated until everyone is, essentially, the same. Piercy removes the stigma of mental disability but only on the grounds that those who are unwell voluntarily remove themselves from the community, dropping out of society until they are back to "normal." Other disabilities she eliminates entirely from her vision of the future. In Piercy's utopia the problem is not ableism, the problem is disability itself, and it can best be solved by segregating people with mental illnesses and eradicating "defective" genes from the brooder. Moreover, this elimination of disability can take place without debate or discussion; the whole community apparently supports it. In Mattapoisett the problem of disability is best solved through its eradication, segregation, and erasure.

As illustrated by *Woman on the Edge of Time*, and as manifested in the furor surrounding McCullough and Duchesneau's reproductive choices, disability is often seen as a difference that has no place in the future. Disability is a problem that must be eliminated, a hindrance to one's future opportunities, a drag on one's quality of life. Speaking directly about the Duchesneau and McCullough case, bioethicist Alta Charo argues, "The question is whether the parents have violated the sacred duty of parenthood, which is to maximize to some reasonable degree the advantages available to their children. I'm loath to say it, but I think it's a shame to set limits on a child's potential."[42] Similar claims are made in opposition to same-sex parenting; critics argue that children raised in queer households will have a lower quality of life than children raised in heterosexual ones.[43] However, in both of these situations, it is assumed not only that disability and queerness inherently and irreversibly lower one's quality of life but also that there is only one possible understanding of "quality of life" and that everyone knows what "it" is without discussion or elaboration.

In *The Trouble with Normal*, Michael Warner condemns the use of "quality of life" rhetoric, arguing that this terminology masks dissent by taking for granted the kinds of experiences the term includes. Although he is challenging the use of "quality of life" arguments in public debates about pornography and public sex, Warner's argument resonates with cultural constructions of disability, as becomes clear when we substitute "disability" for "porn":

> The rhetoric of "quality of life" tries to isolate [disability] from political culture by pretending that there are no differences of value or opinion in it, that it therefore does not belong in the public sphere of critical exchange and opinion formation. When [people] speak of quality of life, [they] never acknowledge that different people might want different qualities in their lives, let alone that [disability] might be one of them.[44]

Susan Wendell suggests that living with disability or illness "creates valuable *ways of being* that give valuable perspectives on life and the world," ways of being that would be lost through the elimination of illness and disability.[45] She notes, for example, that adults who require assistance in the activities of daily life, such as eating, bathing, toileting, and dressing, have opportunities to think through cultural ideals of independence and self-sufficiency; these experiences can potentially lead to productive insights about intimacy, relationship, and interdependence. "If one looks at disabilities as forms of difference and takes seriously the possibility that they may be valuable," argues Wendell,

> it becomes obvious that people with disabilities have experiences, by virtue of their disabilities, which non-disabled people do not have, and which are [or can be] sources of knowledge that is not directly accessible to non-disabled people. Some of this knowledge, for example, how to live with a suffering body, would be of enormous practical help to most people. . . . Much of it would enrich and expand our culture, and some of it has the potential to change our thinking and our ways of life profoundly.[46]

To eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence.

To be clear, no policy decisions have been made as to which "defects" should be eliminated or about what constitutes a "defective" gene; with few exceptions, assisted reproductive technology remains largely unregulated in the United States. But the proliferation of prenatal testing and the increasing availability of pre-implantation genetic diagnosis certainly send a message about the proper and expected approach to disability. Public discussions of these technologies have lagged far behind their use and development, and they rarely include the perspectives of disabled people. As H-Dirksen L. Bauman argues, "Presumptions about the horrors of deafness are usually made by those not living Deaf lives."[47] The Prenatally and Postnatally Diagnosed Conditions Awareness Act (2008) is a step in the right direction, mandating that women receive comprehensive information about disability prior to making decisions about their pregnancies, but it remains unclear how well this policy will be funded or enforced. Moreover, as the debate surrounding Duchesneau and McCullough's reproductive choices makes clear, selecting for disability remains a highly controversial position, and hypothetical disabled children continue to be used to justify genetic research and selective abortion. "Curing" and eliminating disability—whether through stem cell research or selective abortion—is almost always presented as a universally valued goal about which there can, and should, be no disagreement.

I want to suggest that stories of Deaf lesbians intentionally striving for Deaf babies be read as counternarratives to mainstream stories about the necessity of a cure for deafness and disability, about the dangers of nonnormative queer parents having children. Their stories challenge the feasibility of technological promises of an "amazing future" in which impairment is cured through genetic and medical intervention, thereby resisting a compulsory able-bodied/able-minded heterosexuality that insists upon normal minds/bodies. It is precisely this challenge that has animated the hostile responses these families have received. Their choice to choose deafness suggests that reproductive technology can be used as more than a means to screen out alleged defects, that disability cannot ever fully disappear, that not everyone craves an able-bodied/able-minded future, that there might be a place for bodies with limited, odd, or queer movements and orientations, and that disability and queerness can indeed be desirable both in the future as well as now.

The story of the Deaf lesbians, Candace McCullough and Sharon Duchesneau, is only one among many. An ever-increasing number of memoirs, essays, and poems about life with a disability, as well as theoretical analyses of disability and able-bodiedness, tell other stories about disability, providing alternatives to the narratives of eradication and cure offered by Marge Piercy in *Woman on the Edge of Time*. There are stories of people embracing their bodies, proudly proclaiming disability as sexy, powerful, and worthy; tales of disabled parents and parents with disabled children refusing to accept that a bright future for our children precludes disability and asserting the right to bear and keep children with disabilities; and narratives of families refusing to accept the normalization of their bodies through surgical interventions and the normalization of their desires through heterocentric laws and homophobic condemnations. These stories deserve telling, and the issues they raise demand debate and dissent.

It is not that these tales are any less partial or contested than the others in public circulation; they, too, can be used to serve multiple and contradictory positions. Indeed, Lennard Davis argues that we need to question whether these kinds of reproductive decisions—choosing deafness and disability—are "radical ways of fighting against oppression" or "technological fixes in the service of a conservative, essentialist agenda."[48] I would only add that the two are not mutually exclusive; the same choice can serve both agendas. Just as selecting for girls can be as problematic as selecting for boys, with both choices potentially reliant on narrow gender norms and expectations, selecting for disability has the potential to reify categories of able-bodiedness as much as deselecting disability does.[49] What is needed then are examinations of how particular choices function in particular contexts; what does it mean for lesbian parents to choose deafness in this context, or a single mother to refuse to terminate a pregnancy after receiving a Down diagnosis in that context? Such explorations are impossible as long as selecting for disability remains largely inconceivable, as long as we all assume—or are assumed to assume—that disability cannot belong in feminist visions of the future and that its absence merits no debate.

http://www.seattlepi.com/opinion/319702_noangel17.html. See also Jeremy L. Brunson and Mitchell E. Loeb, eds., "Mediated Communication," special issue of *DSQ: Disability Studies Quarterly* 31, no. 4 (2011); and Nirmala Erevelles, "Signs of Reason: Rivière, Facilitated Communication, and the Crisis of the Subject," in *Foucault and the Government of Disability*, ed. Shelley Tremain (Ann Arbor: University of Michigan Press, 2005): 45–64.

82. Kittay, "Discrimination against Children with Cognitive Impairments?" 32.

83. Asch and Stubblefield make a similar point, stressing that neither the supporters nor the critics of the Treatment can know for certain how the interventions have affected Ashley or what her experiences of them were. They explain, "Ashley's parents and doctors decided to proceed with her growth attenuation with good intentions in circumstances of uncertainty about how Ashley experiences herself and the world. Our objection to performing growth attenuation procedures on children like Ashley is also based on good intentions in identical circumstances of uncertainty. So the acceptability of this intervention cannot be decided based on which side has better intentions or on which side has more certain knowledge of what life is like for Ashley." Asch and Stubblefield, "Growth Attenuation," 46–47.

84. Ashley's Parents, "AT Summary."

85. For more on violence against people with disabilities, see, for example, Mark Sherry, *Disability Hate Crimes: Does Anyone* Really *Hate Disabled People?* (Burlington, VT: Ashgate, 2010); and Dick Sobsey, D. Wells, R. Lucardie, and S. Mansell, eds., *Violence and Disability: An Annotated Bibliography* (Baltimore, MD: Paul H. Brookes Publishing Company, 1995).

86. I refer here only to the kind of sensations I mentioned above: the binding and release of her seat belts; the feel of her clothes rubbing across her skin; warm bathwater. To be clear, I am not in any way condoning or encouraging sexual acts with someone unable to consent. Urging for a recognition that Ashley might feel pleasure in her body, through her skin, is significantly different from encouraging others to take pleasure (or power, or control) in her body.

87. Ashley is not the only child to have had her body medically and surgically altered through interventions that were cast as necessary to her quality of life. Children born intersexed or with "ambiguous" genitalia have faced all kinds of surgical interventions intended to normalize them without regard to their pain, sense of self, or relation to their bodies. Other children have endured limb-lengthening or limb-straightening procedures or have been made to wear braces and splints that often led to chronic pain and no real increase in function.

88. Williams, "Judge Not?" 9.

89. Anita J. Tarzian notes that a similar phenomenon and critique happened with the Terri Schiavo case: disability rights activists, organizations, and scholars treated the case as a disability issue (even as they disagreed about the proper course of action), while critics disputed the relevance of the case to disability rights. Anita J. Tarzian, "Disability and Slippery Slopes," *Hastings Center Report* 37, no. 5 (2007): c3.

90. Ashley's Parents, "AT Summary."

91. Tarzian, "Disability and Slippery Slopes," c3.

Chapter 3

1. A wide range of feminist studies and disability studies scholars have addressed the issue of prenatal testing and selective abortion, analyzing the impact these practices have on women and disabled people and deconstructing the assumptions about gender, pregnancy, and disability that underlie them. For examples of this work, see, among others, Adrienne Asch, "A Disability Equality Critique of Routine Testing and Embryo or Fetus Elimination Based on Disabling Traits," *Political Environments* 11 (2007): 43–47, 78; Dena S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Routledge, 2001); Anne Finger, *Past Due: A*

Story of Disability, Pregnancy, and Birth (Seattle: Seal Press, 1990); Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights* (Washington, DC: Georgetown University Press, 2000); Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999); Janelle Taylor, *The Public Life of the Fetal Sonogram: Technology, Consumption, and the Politics of Reproduction* (New Brunswick, NJ: Rutgers University Press, 2008); Karen H. Rothenberg and Elizabeth J. Thomson, eds., *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* (Columbus: Ohio State University Press, 1994); Marsha Saxton, "Disability Rights and Selective Abortion," in *Abortion Wars: A Half-Century of Struggle: 1950–2000*, ed. Rickie Solinger (Berkeley: University of California Press, 1998), 374–93; and Tom Shakespeare, "Arguing about Genetics and Disability," *Interaction* 13, no. 3 (2000): 11–14. See also Generations Ahead, *Bridging the Divide: Disability Rights and Reproductive Rights and Justice Advocates Discussing Genetic Technologies,* July 2009; and Generations Ahead, *A Disability Rights Analysis of Genetic Technologies: Report on a Convening of Disability Rights Leaders,* March 2010, http://www.generations-ahead.org/resources.

2. Timothy J. Dailey, "Homosexual Parenting: Placing Children at Risk," *Insight* no. 238, accessed November 8, 2006, www.frc.org. See also Caryle Murphy, "Gay Parents Find More Acceptance," *Washington Post,* June 14, 1999, A1.

3. Susan Merrill Squier makes a case for literature, specifically science fiction, in analyses of biomedicine and reproductive technology. Fascinated by representations of reproductive technology in feminist fiction, she urges cultural critics to attend to the "ideological construction . . . being carried out through the production and dissemination" of these texts. Susan Merrill Squier, *Babies in Bottles: Visions of Reproductive Technology* (New Brunswick, NJ: Rutgers University Press, 1994), 19; Susan Merrill Squier, *Liminal Lives: Imagining the Human at the Frontiers of Biomedicine* (Durham, NC: Duke University Press, 2004).

4. Piercy's utopian village shares its name with a small town in southeastern Massachusetts that was incorporated in 1857. According to the town website, the town's "name is said to come from an old Indian word meaning 'a place of resting.'" "Mattapoisett," accessed November 7, 2011, http://www.mattapoisett.net/Pages/index. Piercy does not specify the year of the dystopic New York, suggesting only that it is another possible future, an alternative to the one found in Mattapoisett.

5. Marge Piercy, *Woman on the Edge of Time* (New York: Fawcett Crest, 1976), 96.

6. WMST-L, a women's studies teaching and research listserve, has featured several discussions over the years about teaching the book to undergraduate women's studies students. Searching Google for "syllabus" and "Woman on the Edge of Time" produces multiple links to individual courses and women's and gender studies departments/programs that include the novel in their curricula. For a (dated) collection of such courses, see "Women's Studies Syllabi," University of Maryland, last modified July 24, 2002, http://www.mith2.umd.edu/WomensStudies/Syllabi.

7. José van Dijck, *Imagenation: Popular Images of Genetics* (New York: New York University Press, 1998), 86, 87; Josephine Carubia Glorie, "Feminist Utopian Fiction and the Possibility of Social Critique," in *Political Science Fiction*, ed. Donald M. Hassler and Clyde Wilcox (Columbia: University of South Carolina Press, 1997), 156; Cathleen McGuire and Colleen McGuire, "Grassroots Ecofeminism: Activating Utopia," in *Ecofeminist Literary Criticism: Theory, Interpretation, Pedagogy*, ed. Greta Gaard and Patrick D. Murphy (Urbana: University of Illinois Press, 1998). See also, for example, Patricia Huckle, "Women in Utopias," in *The Utopian Vision: Seven Essays on the Quincentennial of Sir Thomas More*, ed. E. D. S. Sullivan (San Diego: San Diego State University Press, 1983), 115–36; and Kathy Davis, "'My Body is My Art': Cosmetic Surgery as Feminist Utopia?" in *Embodied Practices: Feminist Perspectives on the Body*, ed. Kathy Davis (Thousand Oaks, CA: Sage, 1997), 168–81. Even feminist theorists who take a more critical stance toward Piercy's vision of utopia, finding fault with its use of violence or its reliance on small communities, praise Mattapoisett's system of participatory democracy, particularly its embodiment in the Shaper/Mixer

debates. See, for example, Erin McKenna, *The Task of Utopia* (Lanham, MD: Rowman and Littlefield, 2001).

8. For discussion of these issues, see, among others, Lori B. Andrews, *Future Perfect: Confronting Decisions about Genetics* (New York: Columbia University Press, 2001); Glenn McGee, *The Perfect Baby: Parenthood in the New World of Cloning and Genetics* (Lanham, MD: Rowman and Littlefield, 2000); and Dena S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Routledge, 2001). Some entrepreneurs have hoped to profit from this desire to breed "the perfect baby," establishing sperm banks that accept sperm only from "successful" men. Perhaps the most notorious of these projects was Robert K. Graham's Repository for Germinal Choice, formed with the intent of collecting sperm from Nobel Prize winners and other high achievers in order to increase the number of intelligent and creative people in the population. Because of Graham's racist and explicitly eugenicist views, the company was widely reviled in the media and had difficulty attracting donors of the desired caliber. It eventually closed in 1999, after almost twenty years in existence (and after creating over two hundred children). Although the Repository for Germinal Choice is the most well-known "genius sperm bank," other companies share its mission to collect sperm from successful, healthy, and intelligent men. Heredity Choice, based in Nevada and run by former Graham employee Paul Smith, is one such example. David Plotz, "The 'Genius Babies' and How They Grew," *Slate,* February 8, 2001, http://www.slate.com.

9. The use of "Deaf," with a capital "D," emerged in the late twentieth century as a way to signal pride in one's identity and in the cultural practices and historical traditions of deaf people. Deaf with a capital letter is thus a way to draw attention to a cultural deaf identity, whereas Deaf with a small "d" simply connotes being unable to hear or hard-of-hearing. This use is not universally accepted, however, with some deaf people and deaf studies scholars moving away from the "big D/little d" convention. For a recent reflection on this question, and on larger questions of deaf identity, see Brenda Jo Brueggemann, *Deaf Subjects: Between Identities and Places* (New York: New York University Press, 2009); for discussion about the limitations of American discourses of deaf identity, see Susan Burch and Alison Kafer, eds., *Deaf and Disability Studies: Interdisciplinary Perspectives* (Washington, DC: Gallaudet University Press, 2010).

10. Carol Padden and Tom Humphries, *Deaf in America: Voices from a Culture* (Cambridge, MA: Harvard University Press, 1988); John Vickrey Van Cleve and Barry Crouch, *A Place of Their Own: Creating the Deaf Community in America* (Washington, DC: Gallaudet University Press, 1989).

11. Harlan Lane, "Constructions of Deafness," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 1997), 161. Lane acknowledges that there are differences between Deaf people and other linguistic minorities. He notes, "Deaf people cannot learn English as a second language as easily as other minorities. Second and third generation Deaf children find learning English no easier than their forbears, but second and third generation immigrants to the United States frequently learn English before entering school. . . . Normally, Deaf people are not proficient in this native language [sign language] until they reach school age. Deaf people are more scattered geographically than many linguistic minorities. The availability of interpreters is even more vital for Deaf people than for many other linguistic minorities because there are so few Deaf lawyers, doctors, and accountants, etc." Lane, "Constructions of Deafness," 163–64.

12. Nora Ellen Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard* (Cambridge, MA: Harvard University Press, 1985). For a more recent discussion of deafness on Martha's Vineyard, see Annelies Kusters, "Deaf Utopias? Reviewing the Sociocultural Literature on the World's 'Martha's Vineyard Situations,'" *Journal of Deaf Studies and Deaf Education* 15, no. 1 (2010): 3–16.

13. Unfortunately, there is an extensive history of requiring Deaf people to do precisely that: to learn to lip-read, speak orally, and abandon signing, and to undergo painful surgeries and medical treatments in order to "correct" their hearing loss. Scholars of Deaf studies have documented

histories of Deaf people being punished, often brutally, for engaging in sign language, and of the campaigns waged against residential schools and Deaf communities. In spite of such treatment, the Deaf community continued to use and fight for sign language. Robert M. Buchanan, *Illusions of Equality: Deaf Americans in School and Factory, 1850–1950* (Washington, DC: Gallaudet University Press, 1999); Susan Burch, *Signs of Resistance: American Deaf Cultural History, 1900 to World War II* (New York: New York University Press, 2002).

14. For one example of these kinds of coalitions, see Corbett Joan O'Toole, "Dale Dahl and Judy Heumann: Deaf Man, Disabled Woman—Allies in 1970s Berkeley," in *Deaf and Disability Studies: Interdisciplinary Perspectives*, ed. Susan Burch and Alison Kafer (Washington, DC: Gallaudet University Press, 2010): 162–87. For a recent discussion on whether deaf equals disability, see H-Dirksen Bauman, ed., *Open Your Eyes: Deaf Studies Talking* (Minneapolis: University of Minnesota Press, 2008). For some Deaf studies scholars, deaf/disability coalition requires not seeing deaf as disability; Lane stresses that recognizing the "great common cause" between culturally Deaf people and people with disabilities means respecting the "self-construction of culturally Deaf people" as not disabled. Lane, "Constructions of Deafness," 165.

15. Deafness is not the only trait screened out of the gene pool. Sperm banks exclude male donors who have family histories of cystic fibrosis, Tay-Sachs, alcoholism, and other conditions deemed problematic or undesirable. Under guidelines established by the FDA, most sperm banks forbid gay men and men who have had sex with men in the last five years from donating. For discussion of the politics of sperm banks and sperm donation, see Cynthia Daniels, *Exposing Men: The Science and Politics of Male Reproduction* (New York: Oxford University Press, 2006); and Laura Mamo, *Queering Reproduction: Achieving Pregnancy in the Age of Technoscience* (Durham, NC: Duke University Press, 2007).

16. Indeed, Gauvin's deafness was not a given. There are many different genetic combinations that result in deafness, but the trait is recessive; two congenitally deaf parents will not automatically or necessarily produce deaf children.

17. Liza Mundy, "A World of their Own," *Washington Post Magazine,* March 31, 2002, www.washingtonpost.com. Sadly, Gauvin died suddenly and unexpectedly from an inherited condition (unrelated to his deafness). In sharp contrast to his birth, his passing was met with very little news coverage or public reaction.

18. Mundy, "A World of Their Own."

19. MJ Bienvenu makes a similar point, although she more optimistically attributes the lack of focus on their lesbianism to the "strides made by the L/G community." "Queer as Deaf: Intersections," in *Open Your Eyes: Deaf Studies Talking*, ed. H-Dirksen Bauman (Minneapolis: University of Minnesota Press, 2008), 270.

20. Family Research Council, "*Washington Post* Profiles Lesbian Couple Seeking to Manufacture a Deaf Child," PR Newswire Association, April 1, 2002. There are strong parallels here between Connor's warning and the eugenic tracts in wide circulation in the late nineteenth and early twentieth centuries. Alexander Graham Bell, for example, worried about the development of deaf culture and any related rise in deaf populations. See his "Memoir Upon the Formation of a Deaf Variety of the Human Race" for one iteration of these fears. I thank Susan Burch for pointing me in the direction of this text.

21. In tying together the women's sexuality with their deafness, and presenting both as if they could, and should, be eliminated, Connor seems to be yearning for (his understanding of) a better world; his preference for households that do not bear the burden of disability or queerness supports Robert McRuer's contention that the "dream of an able-bodied future is . . . thoroughly intertwined with the heterosexist fantasy of a world without queers." Robert McRuer, "Critical Investments: AIDS, Christopher Reeve, and Queer/Disability Studies," in *Thinking the Limits of the Body*, ed. Jeffrey Jerome Cohen and Gail Weiss (Albany: State University of New York Press, 2003), 154–55.

22. Jeanette Winterson, "How Would We Feel If Blind Women Claimed the Right to a Blind Baby?" *Guardian* (UK), April 9, 2002.

23. For feminist and queer deconstructions of nature rhetoric, particularly uses of "nature" to proscribe gender and sexuality identities and practices, see, for example, Catriona Mortimer-Sandilands and Bruce Erickson, eds. *Queer Ecologies: Sex, Nature, Politics, Desire* (Bloomington: Indiana University Press, 2010); and Noël Sturgeon, *Environmentalism in Popular Culture: Gender, Race, Sexuality, and the Politics of the Natural* (Tucson: University of Arizona Press, 2009).

24. Winterson is not alone in this exaggeration. Although Mundy's original article made it clear that the use of a Deaf sperm donor only increased the women's chances of having a Deaf baby to 50 percent, wire reports and stories in other papers consistently described the women as manipulating nature and technology to "guarantee" a Deaf baby, a misrepresentation of the facts that depicts the women as meddling with the future. Even essays in medical journals followed this pattern, referring to the use of the donor as "guaranteeing" and "ensuring" a Deaf child. (I do not mean to suggest that criticisms of the couple would have been justified if the use of a Deaf donor had increased the odds to more than 50 percent, and I doubt that critics would have left the women alone if the odds had been less than 50 percent.) Critics condemned these women for failing to do everything in their power to prevent disability, a failure that, in the ableist worldview, sentenced their children to a negative, imperfect future. See, for example, a set of essays in the *Journal of Medical Ethics*, both of which determined the women to have acted inappropriately: K. W. Anstey, "Are Attempts to Have Impaired Children Justifiable?" *Journal of Medical Ethics* 28 (2002): 286–89; and N. Levy, "Deafness, Culture, and Choice," *Journal of Medical Ethics* 28 (2002): 284–85.

25. Winterson refers to McCullough and Duchesneau's decision as "a bad joke," a sign of "psychosis," "paranoid," and a form of "genetic imperialism."

26. For an essay on a blind woman reflecting on her desire for a blind child, see Deborah Kent, "Somewhere a Mockingbird," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch (Washington, DC: Georgetown University Press, 2000). Kent movingly describes her internal struggles in realizing that her parents and her husband, all sighted, do not share her understanding of blindness as a "neutral trait" and are concerned about the possible blindness of her future children.

27. Mundy, "A World of Their Own."

28. These comments were not left unaddressed by other members on the listserv, however. Participants questioned the assumptions about the "burdens" caused by disability and about the inappropriateness of Deaf women choosing a donor that reflected their own lives, a choice nondisabled couples make regularly. They also challenged the contention that Deaf children pose a financial strain on the state, arguing that economic arguments about the "strain" caused by people with disabilities have often been used to justify coerced and forced sterilization, institutionalization, and coerced abortion.

29. Sarah Franklin, "Essentialism, Which Essentialism? Some Implications of Reproductive and Genetic Technoscience," in *If You Seduce a Straight Person, Can You Make Them Gay? Issues in Biological Essentialism versus Social Constructionism in Gay and Lesbian Identities*, ed. John P. DeCecco and John P. Elia (Binghamton, NY: Harrington Park, 1993), 30; italics in original.

30. Patrick Steptoe, known as the "father of in vitro fertilization," remarked that "it would be unthinkable to willingly create a child to be born into an unnatural situation such as a gay or lesbian relationship." Quoted in Franklin, "Essentialism, Which Essentialism?" 31.

31. Mamo, *Queering Reproduction*, 72.

32. Ibid., 134.

33. Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage, 1998); Elizabeth Weil, "Breeder Reaction," *Mother Jones* 31, no. 4 (2006): 33–37.

34. Franklin, "Essentialism, Which Essentialism?" 29.

35. Roberts, *Killing the Black Body,* 254. In her more recent work, Roberts notes that fertility clinics are increasingly including *elite* women of color in their campaigns; even as these technologies become available to a wider range of women, their availability mirrors the unequal distribution of health care in this country. See, for example, Dorothy Roberts, "Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?" *Signs: Journal of Women in Culture and Society* 34, no. 4 (2009): 783–804.

36. This trend is only the latest in a long history of marginalization, discrimination, and abuse; disabled, African American, Latina, and Native American women have undergone forced and coerced sterilization, medical experimentation, and coerced abortion at the hands of medical professionals and government employees who deemed them unfit. See, for example, Elena R. Gutiérrez, *Fertile Matters: The Politics of Mexican-Origin Women's Reproduction* (Austin: University of Texas Press, 2008); Jennifer Nelson, *Women of Color and the Reproductive Rights Movement* (New York: New York University Press, 2003); Nancy Ordover, *American Eugenics: Race, Queer Anatomy, and the Science of Nationalism* (Minneapolis: University of Minnesota Press, 2003); and Roberts, *Killing the Black Body*.

37. Jo Litwinowicz, "In my Mind's Eye: I," in *Bigger than the Sky: Disabled Women on Parenting*, ed. Michele Wates and Rowen Jade (London: Women's Press, 1999).

38. Jim Hughes, "Blind Woman Sues Fertility Clinic: Englewood Facility Halted Treatments after Questions about Her Fitness as a Parent," *Denver Post,* November 7, 2003.

39. In her influential study of amniocentesis in the United States, Rayna Rapp notes that "selfishness" is a key lens through which white middle-class couples, and especially white women, understand their reproductive decisions. Rapp, *Testing Women*, 136–42.

40. Laura Hershey, "Disabled Woman's Lawsuit Exposes Prejudices," *The Ragged Edge,* accessed December 2003, http://www.raggededgemagazine.com/extra/hersheychamberstrial.html.

41. The Colorado Cross-Disability Coalition filed suit in Chambers's behalf. Hershey, "Disabled Woman's Lawsuit."

42. Quoted in David Teather, "Lesbian Couple Have Deaf Baby by Choice," *Guardian* (UK), April 8, 2002, http://www.guardian.co.uk/world/2002/apr/08/davidteather.

43. Glenn Stanton from Focus on the Family scolds, "[A] wise and compassionate society always comes to the aid of children in motherless or fatherless families, but a wise and compassionate society never intentionally subjects children to such families. But every single same-sex home would do exactly that, for no other reason than that a small handful of adults desire such kinds of families." Same-sex households are to be discouraged, in other words, because they "subject" children to situations in which they will need "aid" and rescue. Quoted in McCreery, "Save Our Children/Let Us Marry," 196.

44. Michael Warner, *The Trouble with Normal: Sex, Politics, and the Ethics of Queer Life* (New York: Free Press, 1999), 183. Ellen Samuels examines the limits of substitution, rightly noting that there is often an imprecision in meaning and an effacement of specificity when "disability" is used in place of "sexuality" (or "porn," in my example). In this case, however, my substitution points to important parallels between disability and queerness: both queerness and disability have been cast as entities to be avoided and as drains on a child's quality of life; moreover, as I have argued here, their *combination* has proved especially threatening. Ellen Samuels, "Critical Divides: Judith Butler's Body Theory and the Question of Disability," *NWSA Journal* 14, no. 3 (2002): 58–76.

45. Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia: A Journal of Feminist Philosophy* 16, no. 4 (2001); 31, emphasis in original.

46. Wendell, *Rejected Body*, 69.

47. H-Dirksen L. Bauman, "Designing Deaf Babies and the Question of Disability," *Journal of Deaf Studies and Deaf Education* 10, no. 3 (2005): 313.

48. Lennard J. Davis, "Postdeafness," in *Open Your Eyes: Deaf Studies Talking*, ed. H-Dirksen Bauman (Minneapolis: University of Minnesota Press, 2008), 319.

49. For an analysis of sex selection and "family balancing," see Rajani Bhatia, "Constructing Gender from the Inside Out: Sex Selection Practices in the United States," *Feminist Studies* 36, no. 2 (2010): 260–91.

Chapter 4

1. The Foundation for a Better Life, February 7, 2010, http://www.values.com/.

2. All of the billboards can be viewed on the foundation's website, which also features "inspirational stories," "good news stories," and short vignettes about specific values. See the Foundation for a Better Life, February 7, 2010, http://www.values.com.

3. The image of the Tiananmen Square protestor has been removed from the organization's website, but I am unsure as to when it disappeared. It was still on the site in 2007, but by 2010 it was gone, and there is no mention of it on the organization's website.

4. Of course, as any disability studies scholar (or social services gatekeeper) will note, determining who is and who is not disabled is easier said than done. For the purposes of this discussion, I have focused only on those figures who are widely recognized as disabled, who have publicly identified as disabled, and/or whose illnesses and disabilities are highlighted in the campaign itself.

5. The italicized words are the values highlighted in each billboard; on the billboard, the value is in white bold capitals, inside a red text box. The phrases in quotation marks are the captions on the billboards.

6. The Foundation for a Better Life, "About FBL," June 30, 2004, http://www.forbetterlife.org/main.asp?section=about&language=eng.

7. Amy Vidali offers a useful analysis of the relationship between vision and knowledge, critically examining the assumption that "knowing is seeing." Amy Vidali, "Seeing What We Know: Disability and Theories of Metaphor," *Journal of Literary and Cultural Disability Studies* 4, no. 1 (2010): 33–54. See also Georgina Kleege, *Sight Unseen* (New Haven: Yale University Press, 1999). Both the FBL billboards ("VISION") and the stylistic conventions of footnotes (e.g., "see Kleege") rely on this history of representation and this epistemology.

8. It is useful here to read the FBL's representation of Muhammad Ali in light of Anna Mollow's discussion of overcoming. Mollow rightly notes that a story of overcoming illness or disability does not have to be "a denial of political realities" but can instead be "an assertion of personal strength amid overwhelming social oppression." In the case of the FBL, however, their overcoming narratives do not highlight "individuals' power in relation to oppressive political and economic structures"—Mollow's criteria for understanding overcoming narratives differently—but rather deny that such oppression exists at all. Anna Mollow, "'When *Black* Women Start Going on Prozac': Race, Gender, and Mental Illness in Meri Nana-Ama Danquah's *Willow Weep for Me*," *MELUS* 31, no. 3 (2006): 89, 68.

9. Foundation for a Better Life, "Our Mission Statement," accessed February 7, 2010, http://www.values.com/about-us/mission-statement.

10. The FBL's Internet domain name is registered to the Anschutz Exploration Corporation, an oil and gas exploration company owned by Anschutz. See Nathan Callahan, "Corporate Vulture: Philip Anschutz Tries to Thread His Way into Heaven," *OC Weekly* 8, no. 35 (2003), accessed September 18, 2004, http://www.ocweekly.com/ink/03/35/news-callahan.php; Stuart Elliott, "A Campaign Promotes Noble Behavior," *New York Times*, November 9, 2001; Colleen Kenney, "Lincoln Receives Several Messages of Hope from Up Above" *Lincoln Journal Star*, February 5, 2004; Jeremy David Stolen, "Foundation for a Better Life," Portland Independent Media Center, accessed July 4, 2004, http://portlandindymedia.org/2002/02/7617.shtml; and Jeremy David Stolen, "Big Money behind 'Inspirational' Billboard Campaign," accessed April 15, 2006, http://www.theportlandalliance.org/2002/april/billboard.html. See also Sandra Thompson, "Billboards Marketing Virtues We Can Use Now,"