

The Inadequacy of “Choice”: Disability and What’s Wrong with Feminist Framings of Reproduction

Alison Piepmeier

WHEN I WAS INTENTIONALLY PREGNANT, I experienced a complex reproductive decision: whether to undergo prenatal testing. Our cultural expectation is that pregnant women have prenatal testing performed so that they can make the choice to terminate pregnancies with “defects.” Down syndrome is a condition for which much prenatal screening and testing are done, and up to 90 percent of fetuses identified as having Down syndrome are terminated. I didn’t want to be faced with that choice, and so I did not have an amniocentesis. I am now the happy parent of a daughter with Down syndrome.

I shared this experience in a March 2012 article on the *Motherlode* blog on the *New York Times* website. The *New York Times* is aimed at a thoughtful audience, many of whom identify as liberal. Given this readership, it wasn’t surprising that many of the more than 170 online comments made about the article accepted abortion as an available option. What did surprise me is the eugenicist use to which many of these readers would put abortion. They offered the choice of abortion as a way to avoid what they saw as an unacceptable situation, having a child with a disability. Here are several of the comments:

A condition that brings with it guaranteed cognitive disabilities is not something I’m willing to inflict on another human being, much less my own beloved child.

Knowingly giving birth to a special needs child is a crime against the child.

I resent having to pay for children who are going to be a huge drain on society, financially and resource wise, if the parents knew in advance that they were going to have a special needs child.

I was raised to believe that knowingly giving birth to a severely disabled or mentally retarded baby was a sin—a really terrible sin—because it harmed not just the baby (who would never have a normal life) but also the family (including siblings who would be pressed into caring for an aging disabled brother or sister, no longer “cute” in their 50s) and society (stuck with enormous bills for a lifetime). I still feel that way. Hopefully in time, that 92% [of fetuses with Down syndrome that are terminated] will become 100%.¹

The comments as a whole were quite diverse, but these comments here were not rare. They are examples of the ignorant, troubling, and offensive narratives that surround reproduction, disability, and parenting in our culture. For instance, readers described giving birth to a person with a disability as an act of “harm” or cruelty, even as a “crime”—deeply stereotypical framings that individuals with disabilities might well dispute. People with disabilities were being defined principally as “a huge drain on society.” The term “normal life” was used as though it were an unambiguous goal, without acknowledging the extent to which “normal life” here is a narrowly imagined construct that does not embrace the diversity of human existence. The final comment here concludes with the clearly eugenicist hope that 100 percent of fetuses with Down syndrome will be terminated. The world, presumably, is a better place if people with Down syndrome or intellectual disabilities aren’t in it.

Such opinions are not just a feature of the open comments section of *Motherlode*. They crop up—albeit in more nuanced ways—in feminist writing as well. The fact is, most feminist conversations haven’t gone beyond the level of this online commentary. This isn’t simply an observation about feminist understandings of disability; it’s about feminist framings of reproduction. The narrative of “choice” that surrounds and defines US reproductive rights discourse is simply inadequate. During my pregnancy, when my partner and I were deciding

whether to have an amniocentesis and, presumably, an abortion if the fetus had Down syndrome, I discovered that feminist texts had little to offer me. My story isn't one that many feminists are talking about—or if they are talking about it, it is in ways that I found troubling rather than helpful. Feminist writing offers a number of reductive and stereotypical narratives about reproduction and disability. These problematic narratives are particularly visible in (rare) feminist discussions of prenatal testing and abortion. These discussions are often built around stereotypes—stereotypes of people with disabilities, of parenting people who have disabilities, and of what “choice” means and how it functions.

These feminist conversations about disability and abortion are indicative of broader problems within feminist discussions of reproduction. Reproduction should not be defined by “choice,” a concept that is individualized and ignores the broader societal contexts that shape reproduction, parenting, and our understanding of children. For feminist scholars to address reproduction in a meaningful way, they must become resistant to stereotyping narratives that perpetuate oppression and instead listen to a different set of narratives, those told by pregnant women and by parents who exist at complex intersections. We need scholarly and activist feminist conversations about reproduction that embrace, rather than fear, the complexity of reproductive decision making.

This project emerged in part from my desire to hear the stories of other individuals' decision-making processes. I've conducted a series of interviews with parents of children with Down syndrome and with pregnant women. What I've learned from these conversations is that the process of reproductive decision making is far more complex than mainstream feminist narratives suggest. Prenatal testing and selective abortion were the starting point for my conversations, but this isn't an argument exclusively about prenatal testing, or about Down syndrome or disability. The narratives emerging from decisions about prenatal testing and whether or not to terminate a fetus can serve as case studies for ways that feminist discourse around reproduction needs to change. This essay will present both activist and scholarly feminist conversations around disability as examples of inadequate feminist discourse. I will then look to parents' narratives as a site for the complexity that feminists need to engage with. Finally,

I'll turn to reproductive justice framings that allow for far more complex understandings.

FEMINIST NARRATIVES

The gap between reproductive rights and disability rights has been problematic for some time. As early as 1984, Marsha Saxton was articulating her ideology as a feminist who supports reproductive rights and also “question[s] the practice of systematically ending the life of a fetus *because it is disabled*.”² In 1998 she more thoroughly articulated the divide involving reproduction: “The reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right *not to have to have* an abortion. . . . We must actively pursue close connections between reproductive rights groups and disabled women’s groups with the long-range goal of uniting our communities.”³

In 2007 and 2008, Generations Ahead convened a series of meetings in which disability rights and reproductive rights and justice advocates gathered.⁴ These meetings were necessary because, as Sujatha Jesudason noted, “The disability rights and reproductive rights communities have often been at odds.” Because reproductive rights are continually under threat, “some reproductive rights advocates . . . strategically argued for the need for abortion in the cases of rape, incest and disability as a way to undermine their opposition and win undecided voters to their side.”⁵ By rhetorically equating disability to rape and incest, reproductive rights advocates participate in the dehumanization of people with disabilities, presenting disability not only as inhuman but as an act of terrorism. This equivalence between disability and rape is damaging, and it highlights the ways that feminist strategies are distorting and stereotyping an important public conversation about reproduction.

Naomi Wolf and Amy Richards offer two dramatic examples of popular but problematic feminist narratives. Their books—Wolf’s *Misconceptions* (2001) and Richards’s *Opting In* (2008)—are thoughtful memoirs, each using the author’s personal experience of pregnancy to frame a larger feminist conversation about reproduction and motherhood. Both were written during a decade when feminist disability studies scholarship was emerging, and despite the counternarratives available to the authors, both make essentially the same point:

that parenting a child with a disability would be a kind of martyrdom that the authors couldn't tolerate.⁶ They utilize the same stereotypes — that parenting a child with a disability would be an act of suffering and sacrifice and that children with disabilities aren't fully human — and don't recognize them as stereotypes.

Wolf offers a brief discussion of prenatal testing in which she shares her own results from an early prenatal screening.

When my husband and I got our abnormal AFP test, I was paralyzed with fear and indecision. Like women everywhere, I prayed. I respected and admired women who could give their lives over to caring for a severely disabled child, but I knew I could not do it myself. In an obsessive mental video of caring for such a child, I watched the things I loved in my life be stripped away; I witnessed vivid scenes detailing the exact nature of my own callowness.⁷

While Wolf's fear is understandable, she doesn't then reveal to the reader that her fears were based on stereotypes that were inaccurate and hurtful. She doesn't offer an interpretation of her "obsessive mental video" as one created by a culture with skewed, dehumanizing views of disability. Instead, this statement of fear stands as an unchallenged, presumably accurate, description. Readers are supposed to feel relieved when Wolf reveals that her fetus has no disabilities.

While Richards didn't receive any results that worried her, she offers a very similar description of her own thinking around testing.

I opted for the tests, and while I would like to think that I was open to any result, in reality I most likely would have terminated the pregnancy if there was a strong likelihood of a fetal abnormality. I could argue that I was doing this "for the baby's sake," not wanting "it" to be challenged from the get-go, but the truth is that I didn't want the hardship of parenting a child with serious health issues.⁸

Similar to the commenters on the *Motherlode* website, both Wolf and Richards characterize parenting a child with a disability as a "hardship" or as the requirement to "give their lives over." Even more dramatically, Wolf's fear paints this parenting as losing "the things I loved in my life." While such a fear is certainly comprehensible given the poor information available in mainstream media and even in medical settings about parenting a child with a disability, the fact that neither

Wolf nor Richards chose to investigate their fears strikes me as troubling.⁹ It is as if they had no curiosity about whether their fears were even accurate. They are understandably voicing a feminist resistance to the notion that women should be martyrs to parenthood, but they fail to recognize the way that stereotypes about disability are affecting their interpretations. In books that they expected to reach large readerships—some feminist readers, some not—the fact that they allowed their fear-based depictions of parenting to stand unchallenged helps bolster unhelpful stereotypes.

Another mainstream feminist text, *Choice: True Stories of Birth, Contraception, Infertility, Adoption, Single Parenthood and Abortion* (2007), offers a different framing of prenatal testing, but one that is equally problematic. In the introduction, the editors, Karen Bender and Nina de Gramont, ask, “Instead of banning late-term abortions, why not create a test for genetic abnormalities that will detect problems earlier in pregnancies, so that women can learn about the health of their fetus earlier and make the choice that is right for them?”¹⁰ In this section of the introduction they are offering a list of ideas for making reproductive rights less controversial. This suggestion to make late-term abortions less likely follows a suggestion that sex education be more widely available and precedes another suggestion about including contraception on healthcare plans—fairly common reproductive rights stances. They seem to be presenting early testing as common ground, as if controversy would dissipate if fetuses with disabilities could be terminated in the first trimester.

Notice that their reframing suggests that parents be able to “make the choice” earlier, which implies abortion. They don’t, for instance, argue for different ways to understand the potential personhood of a fetus with “genetic abnormalities” as anything other than as defective goods. In what is overall a very thoughtful, nuanced book on reproduction, these authors reinforce stereotypical thinking about prenatal testing and disability that impacts the broader feminist conversation about reproduction. At the time they edited this book, no early prenatal tests existed, but in recent months several have entered the market, and these tests are triggering the very conversations about prenatal testing that these authors seem not to anticipate.¹¹

Problematic narratives appear as well in scholarly texts specifically addressing prenatal testing. In 1986, sociologist Barbara Katz

Rothman wrote the groundbreaking book, *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*, which effectively critiques the notion of “choice” but still replicates a number of stereotypes, including the ideas of mothers as “victims” and Down syndrome as a tragedy. In discussing how painful this individualized “choice” is, she says, “In choosing between the tragedy of a disabled, defective, damaged, hurt, ‘in-valid’ child, and the tragedy of aborting a wanted pregnancy, a woman becomes responsible for the tragedy of her choice.” Later in the same chapter she notes, “While the abortion calls forth pain and grief, so too does the experience of mothering a child with Downs Syndrome [*sic*].”¹² Rothman frames the “choice” presented by prenatal testing as a Hobson’s choice: either option is a tragedy. This framing of Down syndrome as a tragedy, one that automatically “calls forth pain and grief,” is echoed in the comments to my article on *Motherlode*.

This is not the only place Rothman connects Down syndrome to tragedy. Earlier in the book she offers a lengthy (nearly two-page) description of an adult with Down syndrome that is heartbreakingly awful; in it, a woman describes her sister-in-law and ends by saying, “There is *no* solution to this sort of retardation other than *prevention*.” This narrator sees cognitive disability as so horrifying that she thinks we should have a nationwide mandate of amniocentesis and abortion. Rothman offers an alternative narrative—the stories of two women who have children with Down syndrome and describe them as “a complete joy.” Rothman notes that “neither was unwilling to accept another Downs Syndrome [*sic*] child,” but these two women have shorter quotations included, and their more positive perspective on disability is muted.¹³

Dena S. Davis is a feminist bioethicist whose book, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children’s Futures*, replicates similar problems. Davis claims that this is a study that gives a “fresh look” at prenatal testing. She does put prenatal testing into a social context, addressing the ways in which certain disabilities gain meaning because of available testing.

For the woman who would not contemplate abortion, or for whom Down syndrome is one acceptable (if not desirable) outcome of pregnancy, the existence of this technology can be oppressive. Women

speak of the “rituals” and routines of genetic testing within pregnancy, and of the real difficulty they experience in fighting the momentum of those routines and assumptions if they decide that testing is not right for them. Now that the choice exists whether or not to have a baby with, for example, Down syndrome, the decision to go ahead and have that baby may actually be much harder to make.¹⁴

In other words, she observes that the availability of a test for Down syndrome can change the meaning of Down syndrome (which she inaccurately calls a “disease”): “Indeed, as testing becomes more and more routine, the disease being tested for becomes ever more dreaded, ever more unthinkable.”¹⁵ This is an acknowledgement of the social construction of disability; that the test itself creates meaning by being available. Having the test isn’t a neutral situation; it can create and contribute to fear.

At the same time, some of Davis’s core arguments are quite troubling. Her book emphasizes the ways in which children and potential children are affected by parents’ choices. Davis ultimately argues that having a child with a disability is deliberately making a decision “to substantively constrain the ability of their children to make a wide variety of life choices when they become adults.”¹⁶ It is, she suggests, being an irresponsible parent to have a child with a disability, since, according to Davis, disability—and not the larger set of social contexts that establishes our understanding of and approaches to disability—constrains an individual’s life choices.

She doesn’t blame parents for every challenge when she assesses children’s quality of life; she understands that certain limited choices are created by societal context. For instance, she explains that she isn’t

criticizing people who have children under less than optimal conditions because of societal injustice, for example, members of oppressed minority groups. In that case, the appropriate criticism is directed at the oppressors, and one of the worst evils of oppressive societies is precisely the way in which they constrain the future of the minority children who are marginalized.¹⁷

Although she understands the significance of societal injustice and its effects on children, she explicitly does not consider people with disabilities members of an “oppressed minority group.”

This is a serious and seemingly intentional omission, because disability studies scholars had been making compelling arguments about the social construction of disability for nearly two decades at the time her book was published. In her foundational essay, “Integrating Disability, Transforming Feminist Theory,” Rosemarie Garland-Thomson made an explicit comparison between our understanding of race, gender, and disability, arguing that

disability is a pervasive cultural system that stigmatizes certain kinds of bodily variations. . . . The informing premise of feminist disability theory is that disability, like femaleness, is not a natural state of corporeal inferiority, inadequacy, excess, or a stroke of misfortune. Rather, disability is a culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender.¹⁸

Davis understands that race is a socially constructed category, “a culturally fabricated narrative of the body,” but sees disability as far more biologically grounded and stable in its meaning. She doesn’t demonstrate a feminist skepticism for narratives of bodily inferiority, accepting the stereotypes of disability and bodily inferiority as accurate.

The writings of Wolf, Richards, Bender and de Gramont, Davis, and Rothman offer a glimpse at some of the problems in feminist framings of prenatal testing and disability. Not recognizing the complexities that define reproductive decision making in regard to disability means that feminist conversations are limiting and are distorting an important public conversation about reproduction. As Alison Kafer argues, “Making disability do the work of defending abortion may be effective in securing abortion rights in the short term, but it does so by trafficking in discriminatory stereotypes about disability. Moreover, its long-term effectiveness is doubtful, as it opens the door to a continued interrogation of individual women’s reasons and decisions.”¹⁹

The aforementioned texts are not meant to comprise a literature review.²⁰ They are instead meant as samples of troubling feminist narratives that are not substantially different from the comments posted on the *Motherlode* blog. The problems in this feminist discourse should motivate us to question what else may be insufficient in this conversation.

Listening to the narratives of pregnant women and parents shows us not only where feminist rhetoric is wrong about prenatal testing

and disabilities, but also how we do a poor job discussing reproduction altogether. A reproductive rights approach to reproduction is so skewed that it makes it almost impossible for us to address what Generations Ahead calls “difficult questions about how to simultaneously ensure reproductive autonomy while valuing people with disabilities.”²¹ To find a different set of narratives, I talked to parents and potential parents.

PARENTAL STORIES

In summer 2011, I began interviewing parents of children with Down syndrome, having conversations with them about their pregnancies, their prenatal testing, and their parenthood. These were semi-structured qualitative interviews, each lasting between one and three hours. These interviews were intended to be “conversations with a purpose”: I am interested in these individuals’ narratives of their reproductive decision making.²² Although I went into every interview with a list of questions, I discovered that I only had to ask one: “Did you have prenatal testing when you were pregnant?” Almost every conversation has taken off from that single question and has needed very little encouragement from me.

I primarily advertised among parents involved in local and national Down syndrome organizations. My invitation was for parents of children with disabilities, particularly Down syndrome. The invitation stated, “I’m interested in talking with parents who decided to have prenatal testing as well as those who decided not to.” I interviewed twenty-nine parents of children with Down syndrome. I interviewed fifteen of these individuals in the Charleston, South Carolina, area, and all of these interviews were done in the parents’ homes, as was their preference. I conducted phone interviews with fourteen additional people who live across the country, including in Vermont, Connecticut, New York, Maryland, Georgia, Ohio, Missouri, Utah, and California.²³ I also interviewed seven women who were pregnant at the time of the interviews, asking them about what tests they were considering (or had had performed), why they were considering them (or had them done), and what they planned to do with the results with which they were presented. These pregnant women weren’t the population I was seeking out; each of them contacted me when they learned about the research project and asked if

they could take part. Everyone I interviewed signed an informed consent document that explained that their participation was completely voluntary, and they could stop the interview at any time; in addition, at the beginning of each interview I reminded the individuals that they could stop the conversation, refuse to answer any question, change their minds about being interviewed at all, ask me any questions they wanted, or suggest a new direction for the conversation.²⁴ The vast majority of the people I interviewed were white, although I sought out women of color and talked with four African American women.²⁵ Virtually all the people I spoke with were middle class, and class strikes me as a particularly significant variable here: these were people with access to prenatal medical care and access to second trimester abortion services, even if those services would mean they had to leave the state.

The narratives these parents and potential parents shared did not fit within any of the reductive models our culture offers; indeed, there's no way to make sense of these stories within the framework of the familiar narratives about reproduction and disability because these stories are neither about choice nor tragedy. They do more than challenge our cultural stereotypes and misunderstandings of Down syndrome; they challenge our conventional feminist understanding of reproductive decision making. Parents talked with me about how their experiences exceeded standard cultural frameworks, as several of the mothers were supportive of abortion and yet did not terminate their pregnancies. They grappled with the distinction between a "fetus" and a "child," a distinction that they found unclear and shifting. They addressed the fact that the pregnant woman was the decision maker, and they experienced this as isolating rather than empowering. Ultimately, the interviews highlighted the inadequacy of the narrative of "choice."

A familiar cultural narrative is that people who don't terminate pregnancies when fetal disability is identified are people who are opposed to abortion for ideological or religious reasons.²⁶ My interviews challenge that explanation. Some of the women I interviewed chose not to have testing because of their religious beliefs. They believed that the reason to test for anomalies is because you might choose to terminate, and because they had religious objections to termination, they did no screening. Other women made the same set of decisions

without religious foundations. One woman I interviewed identified very strongly as religious but did have an initial screening performed. When the screening reported that she had a higher-than-average possibility of having a child with Down syndrome, she decided to do no more testing. Many other women I interviewed characterized themselves as “pro-choice,” but their narratives demonstrate that the concept of “choice” is far too limited a term to explain their experiences. Tricia expressed a sentiment I heard repeatedly: “I’m pro-choice, but it’s awfully complex when it’s close to home.”²⁷ At least three of the women I interviewed had had abortions in the past, but in the case of the pregnancies with fetuses identified as having Down syndrome, they did not terminate.

Elizabeth had had an abortion in college and felt devastated by the decision. She wasn’t opposed to abortion (indeed, she was an activist for women’s rights in many areas, starting in college and continuing into adulthood), but she said, “After that time, I knew I would never have another abortion if I became pregnant unplanned. I would find a way to manage whatever the situation.” In discussing her pregnancy with her daughter who had Down syndrome, she said,

With Rachel . . . she was so wanted by me. I planned her and did everything I could to get pregnant short of *begging* Dan for another child. The heart defect and then the Down syndrome were overwhelming pieces of news, and sometimes during the pregnancy I wondered if the baby might die before birth and all would be better for her. I attached these feelings to the heart defect (not Down syndrome) because we were unsure of the severity and how she would manage once born. I was so scared she would die shortly after birth. Never once considered terminating after we got the Down syndrome news.

Elizabeth’s story reveals her complex mixed feelings; on the one hand she thought that the prenatal death of the fetus “would be better for her,” but then Elizabeth was “so scared [the baby] would die shortly after birth.” She was certain that she wouldn’t terminate the pregnancy, but she wasn’t certain what would be the best decision for the child.

Others grappled with the possibility of abortion more directly. Leanne had had two abortions earlier in her life, when she wasn’t ready to be a parent. When she was pregnant with her second child,

amniocentesis revealed that this fetus had Down syndrome, and she explained,

I was just kind of shell-shocked. I really actually went through the process of deciding whether or not to go through with [an abortion] or not. I had another ultrasound, and I was almost sure I couldn't do it. That I couldn't go down the path of terminating. So, I would set up little things for myself. I would have an ultrasound where they're really going to look at the heart. If anything was wrong, I wasn't going to go through with [the pregnancy] because it wasn't worth it for the child. When really, they could have surgery, you know. So, I said that that will make my decision, because I didn't really want to make that decision myself. I wanted something to determine it for me. If the heart's okay ... then the heart was okay.

Interviewer: Was that a relief, or like, "Damn it, decision still not made"?

Leanne: Yeah, it was kind of like that.

For Leanne, the diagnosis of Down syndrome and the decision of whether to continue with the pregnancy were somewhat traumatic experiences. She wasn't opposed to abortion in general terms, and she didn't perceive her earlier abortions as devastating, as Elizabeth did. For this particular pregnancy, however, there was no easy decision. Leanne's thought process mirrors some of the comments from the *Motherlode* piece; she was evaluating her decision making by considering what would be "worth it for the child," an impossible line of questioning. Even four years later, discussing this with me, Leanne was quite emotional. She is delighted by her daughter. Her emotion wasn't grief at having a child with Down syndrome; it was sadness at remembering how painful the decision-making process was. Note that Leanne was grappling with a familiar, limited narrative, trying to use it to help her make sense of a complex situation.

As Leanne's story shows, the notion of "choice" doesn't always apply to the experiences pregnant women have. Leanne "didn't really want to make that decision myself," so she looked for reasons to terminate: "If anything was wrong, I wasn't going to go through with it." She was searching for a way out of "choice"—for validation or for

some kind of assistance. Another woman I interviewed, Diane, also resisted the framework of individual choices. Like Leanne, although to an even more dramatic extreme, Diane wasn't sure what to do, and she wanted external guidance. As she progressed in her pregnancy, she discovered that she kept moving the line to determine whether or not she would have an abortion.

Diane became pregnant unexpectedly. Before the testing even began, Diane and her partner weren't sure that they wanted to continue with the pregnancy.

I was already kind of in a situation where we were trying to decide—because it was such an unplanned thing and my boyfriend and I weren't together very long—whether he and I were even going to keep the baby regardless of what the testing told us. So we're still kind of, “Do we even want to have the baby at all, regardless of whether it's Down syndrome, special needs, or whatever?”

The prenatal testing became a way for her to try to gather information to make a decision about whether or not to have an abortion. She initially thought that if the fetus had a disability, she'd terminate. When Down syndrome was identified, she decided that Down syndrome was acceptable, but if the fetus had anything else, she'd terminate. Then when a significant heart condition was diagnosed, she decided that as long as the child could have a meaningful life, she would continue, but if the child's life was in danger, she'd terminate. When testing revealed that the child's life was in danger, she discovered that she still wasn't ready to terminate.

Part of the uncertainty was that there was no clear line between this entity being a fetus-which-isn't-yet-a-person and being a child.

We got to the point of the amnio. We had already named him, I had already seen him a couple of times, and you know, he was my son. And regardless of whatever issues he had, he was still my child, and I was going to go through with it. And if that meant, you know, a long, hard road for me, then that's what it was going to have to be. But I still got thinking in my head, *just Down syndrome*. When we get to something else, that's like hitting another brick wall and I had to start all over again.

Here Diane reports knowing that this was her son, her child, a person who already had a name. She felt ready for whatever challenges his life might pose for her. She didn't frame her experience using an easy binary of "tragedy" versus "bliss"; instead, she identified parenthood as "a long, hard road." And yet even in that space of having identified the fetus as a person, Diane still wasn't certain that she would or should continue the pregnancy. It was never intuitively obvious to her, since each new diagnosis required "start[ing] all over again." Diane explained of the heart diagnosis, "His heart defect made things more complicated, more and more complicated—as if it could get any more complicated."

Not knowing, not being able to decide, seemed to characterize much of Diane's experience of being pregnant with Chase: "I think I probably had a general idea of where I wanted to go, and that meant keeping the baby. But I didn't want to make a decision yet. I wanted to keep my options open and just really get more information before I made such a serious decision." Keeping options open is, of course, an impossible solution for a pregnancy. After the amniocentesis identified the fetus as having Down syndrome and a cardiology visit identified a very serious heart defect (the cardiologist characterized the fetus as having a 20 percent chance of survival), she and her boyfriend had different opinions—he wanted to terminate, she wanted to have "her baby." So, she said, they "compromised": she'd carry the pregnancy to term, but then they wouldn't do surgery. They'd wait and let the baby die. Her son did not die, and at the time of our interview was eighteen months old and healthy.

In our conversation, Diane revealed the complexity of this sort of thought process. There were no easy narrative frameworks for explaining her experience. A feminist assertion of Diane's right to make a "choice" doesn't help her figure out what "choice" means in her individual context. She knew that she had a "choice," but she wanted something more: guidance, information, real options, meaningful support. One helpful circumstance was her relationship with her boyfriend's father and stepmother, who was pregnant at the same time. Their support and sympathy for her challenging situation—their offer of food as well as their offer of in-utero comparisons—made the process easier for her.

The difficulty with choice might be related to another pattern that emerged in these conversations: for most of my interviewees, the decision of whether to terminate was made by the woman. This is, of course, legally appropriate, but it spoke to a pressure that the women felt they had to bear alone. Several women said that they and their partners had different opinions about abortion. While Diane was trying to decide what to do, her partner was scheduling an abortion. Diane explained, "I think that's really where he thought we were going to go, and I wasn't saying no at that point. I was just saying, 'I don't know, I don't know, I don't know.'" The difference of opinion between the potential father and mother was very clear to many of the women with whom I spoke. A woman who was pregnant at the time of our interview had an older child with Down syndrome, and she had just recently had an amniocentesis for this second pregnancy. She was discussing whether she would terminate if the results showed that the fetus had Down syndrome, and she knew that she would be alone in her decision because her husband had a very different opinion.

Interviewer: So, did this really feel to you like your decision?

Julia: Yes, which made it so much harder because I knew he would never do it.

Interviewer: He would never terminate the pregnancy?

Julia: No.

Many of the women were very aware of the decision making being their obligation. For instance, Leanne disagreed when her husband Stefan said they'd made the decision together. She reminded him that after the amniocentesis he began identifying the fetus as a child, and he agreed.

Another woman had an amniocentesis, but she realized that by the time the test results returned, she wouldn't terminate in any case. She explained that she went into the testing without a clear agenda, because "this was the next thing to do, whatever." She then felt certain she would terminate if the results showed a fetus with a disability. When the results returned, her pregnancy was at eighteen weeks,

she and her husband knew the fetus's gender, and her feelings had changed: she didn't want to terminate. She said that she thought she could approach the issue "rationally," but then realized, "No. No way." Her husband was much more open to the question of terminating, but she wasn't at all.

Pregnant women can feel pressure from partners and family members who don't want an abortion and those who do. Many women expressed surprise at the extent to which they felt, if not pressure to terminate, an openness to termination from people who they had understood to be explicitly opposed to abortion. For instance, Leanne's parents said they would support her whatever she decided, and she seemed to feel this as a slap in the face.

Leanne: I thought, excuse me? I just didn't expect that from my parents. My mother's a solid Christian, and my dad's a retired pastor.

Interviewer: So you felt like they were saying that if you decide to terminate, that it's okay?

Leanne: Yeah. Maybe even more for my mother.

By articulating that the decision was all hers, one that they would support, Leanne felt that her parents were giving her the message that she should terminate, thus adding to her feeling of isolation. At this moment she was eager for a different kind of support, a family community that would help her navigate having a child with a disability.

An emphasis on individual choice is pervasive in much feminist writing about reproductive rights, but these interviews demonstrate that individual rights and responsibilities don't solve all problems or even explain them. These women didn't discuss the individualized decision-making process as empowering, with meaningful options available to them. Instead, they felt frightened and pressured, as if those around them had unpredictable agendas that had to be negotiated and manipulated.

These stories illustrate the complexities that can characterize reproductive experiences, complexities that need to appear in feminist discussions of reproduction. Women who are supportive of reproductive rights, even those who have had abortions, may still decide to have a child with Down syndrome. These narratives suggest that

“choice” needs to stop being used as a universal, easy answer, because reproductive decision making is messy, sometimes painful, and often involves negotiations, which the term “choice” doesn’t suggest. “Choice,” as used in feminist rhetoric, generally refers to the availability of abortion, but this wasn’t the focus for these parents and potential parents. While resting on an individual woman, reproductive decision making often demands support from family, community, and medical services. Certainly these narratives are partly about our cultural understanding of disability, but these mothers’ stories do more than challenge our cultural stereotypes and misunderstandings of Down syndrome; they challenge our feminist understanding of reproductive rights.

This is where a reproductive justice approach offers more useful tools. Mainstream reproductive rights conversations are politically strategic; they are defensive and “safe.” Reproductive justice offers a different model, one that “emphasize[s] the relationship of reproductive rights to human rights and economic justice.”²⁸ There are no pat slogans that oversimplify difficult decisions. Reproductive justice makes room for messier questions and concerns. It emphasizes social justice, which removes this decision from an individualized space and makes it part of a broader set of community priorities.

REPRODUCTIVE JUSTICE

Reproductive justice is a scholarly and activist framework that expands conversations around a host of questions relating to reproduction. Rather than framing the central issue as “choice,” which is unrealistically and unproductively individualized, reproductive justice demands that we recognize how social context shapes reproduction and how community opens and closes particular possibilities. Reproductive justice demands that we understand how stigmas and stereotypes are created and perpetuated, so that we can recognize how these narratives play a role in reproductive decision making. It demands attention to “a much wider set of concerns. Access to resources and services, economic rights, freedom from violence, and safe and healthy communities are all integral to [this] expanded vision.”²⁹ Perhaps more to the point of this article, it acknowledges the complexity of reproduction.

Reproductive rights discourse generally addresses the legal right to have an abortion, and this tends to be a framework that's individualized. Of course, legally it's a very important right for an individual woman to decide about her own reproduction.³⁰ But this is a limited model. My interviews have revealed that parents and potential parents may resist this individualized expectation. They recognize that decision making happens in an intimate as well as a societal context. They want a *we* framework, not an *I* framework, and they resist the simplistic notion of "choice" because they recognize that they are making a decision that's far more complex than the rhetoric of "choice" suggests.

Reproductive justice asks scholars to view reproduction as something that extends far beyond the individual. Legal scholar Dorothy Roberts makes this point clearly.

Reproductive liberty must encompass more than the protection of an individual woman's choice to end her pregnancy. It must encompass the full range of procreative activities, including the ability to bear a child, and it must acknowledge that we make reproductive decisions within a social context, including inequalities of wealth and power. *Reproductive freedom is a matter of social justice, not individual choice.*³¹

Roberts's emphasis on social justice is similar to Rothman's argument that the social system "fails to take collective responsibility for the needs of its members, and leaves individual women to make impossible choices. We are spared collective responsibility, because we individualize the problem. We make it the woman's own. She 'chooses,' and so we owe her nothing. Whatever the cost, she has chosen, and now it is her problem, not ours."³² Both scholars, like many others in this vein, identify reproductive decision making as extending beyond simple, individual choice.³³ Reproductive justice scholarship also stresses the importance of the community for reproductive decision making.³⁴ As Kafer notes, reproductive justice offers the tools for a "cross-movement analysis" to bring together reproduction and disability.³⁵

My conversations with potential parents and parents demonstrated again and again how inadequate "choice" was as a way to describe their experiences. These people were in a sense having to pretend to be individuals, making individual choices, but they

were—as Roberts says—operating “within a social context.” This social context is multilayered, from the intimate to the institutional, which Roberts describes as “including inequalities of wealth and power.” That social context plays a large role in dictating the value of the fetus, the rational decision, the right thing to do. It generates stigma and stereotypes that have effects not only on individual beliefs but on educational and financial support. Mapping this larger social context is part of the work that feminist disability studies scholars are doing. Feminist scholars more broadly, as they examine the rhetoric, legal and physical structures, and economic practices that create and perpetuate oppression, should be aware of how disability plays into this mix. Most of the individuals I talked with brought up the social context and the effect it had on their decision making.

There are also more intimate social contexts in which parents and potential parents are operating, and these intimate contexts were part of every interview I conducted: parents and potential parents were eager for community. One part of this community is a family that often has multiple opinions, a family that may have a large part to play in the life the child lives. Most interviewees shared stories of their families’ responses and how important they were. They also discussed the broader community responses, from their friends and coworkers to the people they encounter daily. My conversation with one parent I call Aasha gave a clear example of the ways in which these community contexts can work to affect decision making. Aasha, a single mother, described how she negotiated within family, friend, and broader social contexts.

After she’d had the amniocentesis that let her know her fetus had Down syndrome, she gathered her entire family together to tell them the results of the testing. She wanted them to help her make her decision. She reports that her mother said, “Have an abortion,” while most of the rest of the family felt that she should “bear her cross” (remain pregnant, but do so with an awareness of the tragedy). Then she shared, “One of the turning points in that family meeting was my stepmother. . . . She just started crying in the meeting, and she could barely get it out, but she said to the group, ‘Just have the baby and I will raise her.’” Her stepmother’s offer and her emotional reaction were significant: by offering to raise the child, she humanized her, framing her not as a “cross to bear” but as a child with a

valuable life. Aasha continued, “Her statement to me and the family was one of the deciding factors for me to take abortion off the table.” It didn’t matter *why* her stepmother made her statement; it only mattered *that* she said it. By voicing her desire for the “baby” to live, she activated a possibility that changed Aasha’s thinking.

Aasha explained how important it was that she gain the explicit support of her family.

I also knew that I had everybody’s [support]—at least their verbal commitment to this process—because I told them all, I said, (you know, at the time I was finishing my doctorate degree and I was working full-time and my family didn’t live in the immediate area). . . . I just needed them to know I will need all of [their] support to make this happen. And they gave me their word, their commitment. So I—it brought me comfort.

One family member identified the value of Aasha’s child, and then all her family committed to helping her raise her child. These demonstrations of family support helped make her decision possible.

At the same time that she was having this conversation with her family, Aasha was also engaging with the broader community context in ways that helped with her decision making. Shortly after her amniocentesis, she met with a friend at work who was a social worker.

And I told her that, you know, my baby’s going to have Down syndrome. And we’re riding up the elevator and she was just quiet. Then, all of a sudden . . . she starts rattling off resources. And I said to her, “Did you hear what I just said? I just said, you know, it’s the end of the world. I just said I’m going to have a baby with Down syndrome and you’re already talking about resources.”

Aasha describes herself as believing and voicing the stereotyped perspective about having a child with a disability, the perspective that appeared in the *Motherlode* comments as well as in much feminist writing: she saw herself facing “the end of the world.” Her understanding of what parenting a child with Down syndrome would mean was shaped by societal distortions and misunderstandings.

Notably, her friend disagreed, viewing Aasha’s situation not as a tragedy but as a need for support and resources.

And she was like, “Well, I’m a social worker so my thing is if you’ve got a ‘problem,’ let’s start talking about how we can address the problem. . . . You know, what supports do you need?” Like, she just went on this whole thing about how can I get support in all kinds of forms? You know, monetary, social support, physical, medical support, all of that. She just looked at it from a different perspective than I did and she came at it different than anyone else had. And that was also a turning point for me, that why does she not see it so negatively? . . . It was something I will always remember because she was the first person who didn’t say, you know, something like “Oh, Aasha, that’s terrible,” or “Oh, I feel so bad for you.” She didn’t say that at all. It was, “Okay, well, we’ve got some work to do.” You know, so she really helped me kind of reframe my situation where it wasn’t total doom and gloom.

Aasha’s culture had provided her with a series of negative narratives about having a child with Down syndrome, and most of the people she encountered endorsed those narratives, offering her comfort in the face of what they understood to be a tragedy. When this friend offered a different narrative, it was significant. Her friend framed the child not as a terrible event but as a person for whom varieties of support could be gathered. The reframing this friend offered helped undo what disability studies scholar Adrienne Asch identifies as the “sin of synecdoche.” That sin, Asch explains, “is to allow a single known characteristic of the future child to so overwhelm and negate all other hoped-for attributes that the prospective parents no longer desire the coming-into-being of that child,” or, to put it more plainly, “prenatal testing yields only a first impression.”³⁶ The friend did not let Down syndrome become the only significant characteristic of the child. Significantly, this friend recognized that Aasha was not an individual, but a member of a community, and she identified levels of support (“monetary, social support, physical, medical support”) that Aasha and her child would need in order to thrive.

Aasha said that after she decided that she was going to have her daughter, her pregnancy was “wonderful.” She described an even broader social context, her baby shower, to which eighty people came. She said, “It really was a celebration in my mind of people committed to support, you know, in their own individual way—but it was just this sense of community rallying around not me, but this baby.”

Interviewer: So you really did, then, feel like you had—you had a community. Like she was being born into a place where people were excited about her and were going to love her and support her.

Aasha: Yeah. Absolutely. And, like, I felt like I could just relax and just—literally just deliver her. I felt very comfortable. Because I think for me it was just about the loneliness of it all. Like I just knew I couldn't do this by myself. You know. And maybe I said it enough times to where people said, "Okay. Okay. We will help you."

Aasha's story demonstrates the importance of community as a component of reproductive decision making, and the layers of social context that are involved. It is noteworthy that Aasha framed these conversations, these community connections, as turning points for her. She didn't make her decision alone, even though she, as a single mother, could be seen as operating in a more individualized context than people who are partnered. Her decision was complex and was grounded in community, in a *we*.

Aasha's story makes an important point for feminist conversations about reproduction. Although she's discussing pregnancy with a child with a disability, her experience isn't limited to that population. No parent is actually an *I*—we are always a *we*. Some find this objectionable: a reader of the *Motherlode* blog argued, "I resent having to pay for children who are going to be a huge drain on society." Some resent the *we*, the fact that they're part of a community helping to support people with disabilities. And yet parenting a child always requires a community. Kimala Price explains that the reproductive justice movement's "three core values" are "the right to have an abortion, the right to have children, and the right to parent those children."³⁷ Price argues that if we really want women to have control over their reproduction, that doesn't merely mean that they are able to choose not to be pregnant. It also means that they are able to choose to have children *and* parent children—a very meaningful aspect of the narrative for the parents I interviewed and an aspect of the narrative that many feminist scholars of reproductive rights have overlooked. Perhaps even more pointedly, Generations Ahead, echoing several reproductive justice advocates from the global South, calls for "a framing away from the right not to have children to a right to have children, and a framing away from creating a self-sufficient,

productive individual to re-shaping society to provide for the needs of all people, regardless of gender, race, ability, sexual orientation, citizenship status and class.”³⁸ The need for community support may be more visible when parenting a child with a disability, but dependence is part of the human condition, as Garland-Thompson has noted.³⁹ A continued emphasis on the individual can perpetuate what Aasha described as “the loneliness of it all.” Parenting is never something a person can do entirely alone.

Public discourse about reproduction in recent years has demonstrated that familiar feminist approaches are under stress. Current conversations about reproduction aren’t simply about the availability of abortion; they’ve become much more invasive. In 2012 contraception became a controversial issue among certain political groups, and several states succeeded in making abortions less attainable, requiring lengthier waiting periods or transvaginal ultrasounds, and are dispensing inaccurate medical information. In general the only voices discussing prenatal testing publicly have been deeply conservative, such as presidential contender Rick Santorum, a candidate emphatically opposed to abortion, contraception, and reproductive justice. Feminists aren’t talking with those who are considering the relevance and ethics of prenatal testing and abortion, and this has important consequences for the lived experiences of women and their families. The conversation about reproductive decision making requires that feminist scholars offer narratives and frameworks that respond to and respect the complexity of the decision-making process. We not only need to respect the humanity of people with disabilities; we also need to help create communities that make decisions possible.

NOTES

1. Comments to Alison Piepmeier, “Choosing to Have a Child with Down Syndrome,” *Motherlode* (blog), *New York Times*, March 2, 2012, <http://parenting.blogs.nytimes.com/2012/03/02/choosing-to-have-a-child-with-down-syndrome>.
2. Marsha Saxton, “Born and Unborn: The Implications of Reproductive Technologies for People with Disabilities,” in *Test-Tube Women: What Future for Motherhood?* ed. Rita Arditti, Renate Duelli Klein, and Shelley Minden (London: Pandora Press, 1984), 302, italics in original.

3. 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), 375, 389, italics in original.
4. According to their mission statement, "Generations Ahead was the only organization in the United States that worked with a diverse spectrum of social justice stakeholders—including reproductive health, rights and justice, racial justice, LGBTQ, and disability and human rights organizations—on the social and ethical implications of genetic technologies." It closed in January 2012.
5. Sujatha Jesudason, "Executive Summary," for Generations Ahead, *Bridging the Divide: Disability Rights and Reproductive Justice Advocates Discussing Genetic Technologies* (Generations Ahead report, 2008), 1, 4, http://www.generations-ahead.org/files-for-download/articles/GenAheadReport_BridgingTheDivide.pdf.
6. One of the most important studies of prenatal testing—Erik Parens and Adrienne Asch, *Prenatal Testing and Disability Rights* (Washington, DC: Georgetown University Press, 2000)—which contains a number of feminist explorations of selective abortion, was published before both Wolf's and Richards's books.
7. Naomi Wolf, *Misconceptions: Truth, Lies, and the Unexpected on the Journey to Motherhood* (New York: Anchor, 2001), 40. The "AFP test" is an alpha-fetoprotein screening that uses maternal blood to screen for neural tube conditions and chromosomal conditions, including spina bifida and Down syndrome.
8. Amy Richards, *Opting In: Having a Child without Losing Yourself* (New York: Farrar, Straus, and Giroux, 2008), 112.
9. For examples of information that potential parents are given during prenatal testing, see Brian G. Skotko, Susan P. Levine, and Richard Goldstein, "Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers," *American Journal of Medical Genetics Part A* 155, no. 10 (October 2011): 2335–47; and Brian G. Skotko, Priya S. Kishnani, and George T. Capone for the Down Syndrome Diagnosis Study Group, "Prenatal Diagnosis of Down Syndrome: How Best to Deliver the News," *American Journal of Medical Genetics Part A* 149A, no. 11 (November 2009): 2361–67. One woman I interviewed said that her older child's pediatrician told her that children with Down syndrome are routinely institutionalized. That has not been true for forty years, and yet she made her decision to terminate based in part on shockingly inaccurate information from a medical professional.
10. Karen Bender and Nina de Gramont, *Choice: True Stories of Birth, Contraception, Infertility, Adoption, Single Parenthood and Abortion* (New York: MacAdam / Cage, 2007), 12.

11. In fall 2011, a maternal blood test was introduced that offers genetic information about the fetus in the first trimester of pregnancy, without a risk of miscarriage. As of January 2013 there are three such tests on the market in the United States.
12. Barbara Katz Rothman, *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood* (New York: W. W. Norton, 1993), 180, 187.
13. Rothman, *The Tentative Pregnancy*, 61, 75, 76.
14. Dena S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Oxford University Press, 2009), 17.
15. *Ibid.*, 19.
16. *Ibid.*, 84.
17. *Ibid.*, 84–85.
18. Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," *NWSA Journal* 14, no. 3 (2002): 5.
19. Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013), 167.
20. Other popular books give either inaccurate or no information at all about prenatal testing: Krista Jacob, *Abortion Under Attack: Women on the Challenges Facing Choice* (Emeryville, CA: Seal Press, 2006); Jessica Valenti, *Full Frontal Feminism: A Young Woman's Guide to Why Feminism Matters* (Emeryville, CA: Seal Press, 2007); and *1 in 3: These Are Our Stories* (Washington, DC: Advocates for Youth, 2013).
21. Generations Ahead, *Bridging the Divide*, 2.
22. B. L. Berg, *Qualitative Research Methods for the Social Sciences*, 4th ed. (Boston: Allyn & Bacon, 2007), 89. Anthropologists Rayna Rapp and Faye Ginsburg offer an excellent explanation of the work that I hope these parent narratives do: "The cultural activity of rewriting life stories and kinship narratives around the fact of disability . . . enables families to comprehend (in both senses) this anomalous experience, not only because of the capacity of stories to make meaning but because of their dialogical relationship with larger social arenas. . . . In other words, the way that family members articulate changing experiences and awareness of disability in the domain of kinship not only provides a model for the body politic as a whole but also helps to constitute a broader understanding of citizenship in which disability rights are understood as civil rights." Rayna Rapp and Faye Ginsburg, "Enabling Disability: Rewriting Kinship, Reimagining Citizenship," in *Going Public: Feminism and the Shifting Boundaries of the Private Sphere*, ed. Joan W. Scott and Debra Keates (Urbana: University of Illinois Press, 2004), 189.
23. These interviews amounted to 287,433 words of transcribed data.
24. College of Charleston Institutional Review Board approval code GJJQ-05-02-2011.

25. I identified some women of color through online communities of bloggers who are parents of children with Down syndrome. Others came to me via a graduate student, Michael Owens, who spent two semesters doing independent studies about people of color who are parents of children with disabilities. He let parents know about my research, and several were willing to talk with me. All of the women of color with whom I spoke said that the other parents of children with Down syndrome with whom they interact are white.
26. As Sujatha Jesudason and Julia Epstein note, “feminist disability advocates end up feeling shut out of reproductive rights conversations because they assume their pro-choice counterparts believe any questioning of pregnancy termination to be anti-choice.” Sujatha Jesudason and Julia Epstein, “Disability and Justice in Abortion Debates,” Center for Women Policy Studies, in *Reproductive Laws for the 21st Century Papers*, no. 2 (February 2012), http://www.centerwomenpolicy.org/news/newsletter/documents/REPRO_DisabilityandJusticeinAbortionDebates_JesudasonandEpstein.pdf. Kafer makes a similar observation in her *Feminist, Queer, Crip*, 163.
27. Some names of the people I interviewed have been changed, based on their preferences. The names of all the children have been changed.
28. Jael Silliman, Marlene Gerber Fried, Loretta Ross, and Elena R. Gutierrez, *Undivided Rights: Women of Color Organize for Reproductive Justice* (Cambridge, MA: South End Press, 2004), 4.
29. *Ibid.*, 6.
30. I align my political views with those of Kafer: “Abortion for any reason and under any circumstance must then be accompanied by accessible and affordable prenatal care for all women, as well as reliable and affordable child care, access to social services, and the kind of information about and supports for disability mandated in the Kennedy Brownback Act.” Kafer, *Feminist, Queer, Crip*, 167.
31. Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Pantheon Books, 1997), 6, italics in original. Reproductive justice was a term that emerged after her book was published, so she uses the terms “reproductive liberty” and “reproductive freedom.”
32. Rothman, *The Tentative Pregnancy*, 189.
33. For instance, well-respected abortion scholar Rickie Solinger argues, “I am convinced that choice is a remarkably unstable, undependable foundation for guaranteeing women’s control over their own bodies, their reproductive lives, their motherhood, and ultimately their status as full citizens.” Rickie Solinger, *Beggars and Choosers: How the Politics of Choice Shapes Adoption, Abortion, and Welfare in the United States* (New York: Hill and Wang, 2001), 7. In January 2013, Planned Parenthood gave up the “pro-choice” label to characterize their work.

34. Kafer explains, "Both reproductive justice activists and disability rights activists interrogate the rhetoric of choice found in reproductive rights movements. . . . The language of choice fails to account for the ableist context in which women make decisions about pregnancy, abortion, and reproduction in general." Kafer, *Feminist, Queer, Crip*, 162. Andrea Smith critiques the "pro-life versus pro-choice advocates who make their overall political goal either the criminalization or decriminalization of abortion," noting that reproduction depends not only on individuals but also on communities. Andrea Smith, "Beyond Pro-Choice Versus Pro-Life: Women of Color and Reproductive Justice," *NWSA Journal* 17, no. 1 (2005): 120. Jesudason argues that advocates must "recognize the relationship of individual lives to larger social, political, and economic factors, and the intersectional and contextual nature of individual and family decision making. They appreciate that the difficult decisions that women and people with disabilities make must be understood in terms of structural and pervasive inequality, mistreatment, and bias." *Generations Ahead, Bridging the Divide*, 5.
35. Kafer continues, "Even if reproductive justice movements do not always live up to this promise in terms of disability (as when a major reproductive justice text relegates disability to a single footnote), the possibilities remain." Kafer, *Feminist, Queer, Crip*, 162.
36. Adrienne Asch and David Wasserman, "Where Is the Sin in Synecdoche? Prenatal Testing and the Parent-Child Relationship," in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. David Wasserman, Jerome Bickenbach, and Robert Wachbroit (New York: Cambridge University Press, 2005), 182, 174.
37. Kimala Price, "What Is Reproductive Justice? How Women of Color Activists Are Redefining the Pro-Choice Paradigm," *Meridians: Feminism, Race, Transnationalism* 10, no. 2 (2010): 43.
38. *Generations Ahead, Bridging the Divide*, 116.
39. "Our bodies need care; we need assistance to live; we are fragile, limited, and pliable in the face of life itself. Disability is thus inherent in our being: What we call disability is perhaps the essential characteristic of being human." Rosemarie Garland-Thomson, "The Case for Conserving Disability," *Bioethical Inquiry* 9, no. 3 (September 2012): 342.