

Disability Rights and Selective Abortion

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Disability rights activists are now articulating a critical view of the widespread practice of prenatal diagnosis with the intent to abort if the pregnancy might result in a child with a disability. Underlying this critique are historical factors behind a growing activism in the United States, Germany, Great Britain, and many other countries, an activism that confronts the social stigmatization of people with disabilities.

For disabled persons, women's consciousness-raising groups in the 1960s and 1970s offered a model for connecting with others in an "invisible" oppressed social group and confirming the experience of pervasive social oppression. ("That happened to you, too?") Participants in such groups began to challenge a basic tenet of disability oppression: that disability *causes* the low socioeconomic status of disabled persons. Collective consciousness-raising has made it clear that stigma is the cause.

Effective medical and rehabilitation resources since the 1950s have also contributed to activism. Antibiotics and improved surgical techniques have helped to alleviate previously fatal conditions. Consequently, disabled people are living longer and healthier lives, and the population of people with severely disabling conditions has increased. Motorized wheelchairs, lift-equipped wheelchair vans, mobile

respirators, and computer and communication technologies have increased the mobility and access to education and employment for people previously ostracized because of their disabilities.

Effective community organizing by blind, deaf, and mobility-impaired citizen groups and disabled student groups flourished in the late 1960s and resulted in new legislation. In 1973 the Rehabilitation Act Amendments (Section 504) prohibited discrimination in federally funded programs. The Americans with Disabilities Act of 1990 (ADA) provides substantial civil rights protection and has helped bring about a profound change in the collective self-image of an estimated 45 million Americans. Today, many disabled people view themselves as part of a distinct minority and reject the pervasive stereotypes of disabled people as defective, burdensome, and unattractive.

It is ironic that just when disabled citizens have achieved so much, the new reproductive and genetic technologies are promising to eliminate births of disabled children—children with Down's syndrome, spina bifida, muscular dystrophy, sickle cell anemia, and hundreds of other conditions. The American public has apparently accepted these screening technologies based on the "commonsense" assumptions that prenatal screening and selective

abortion can potentially reduce the incidence of disease and disability and thus improve the quality of life. A deeper look into the medical system's views of disability and the broader social factors contributing to disability discrimination challenges these assumptions.

REPRODUCTIVE RIGHTS IN A DISABILITY CONTEXT

There is a key difference between the goals of the reproductive rights movement and the disability rights movement regarding reproductive freedom: the reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right *not to have to have* an abortion. Disability rights advocates believe that disabled women have the right to bear children and be mothers, and that all women have the right to resist pressure to abort when the fetus is identified as potentially having a disability.

Women with disabilities raised these issues at a conference on new reproductive technologies (NRTs) in Vancouver in 1994.¹ For many of the conference participants, we were an unsettling group: women in wheelchairs; blind women with guide dogs; deaf women who required a sign-language interpreter; women with scarring from burns or facial anomalies; women with missing limbs, crutches, or canes. I noticed there what we often experience from people who first encounter us: averted eyes or stolen glances, pinched smiles, awkward or overeager helpfulness—in other words, discomfort accompanied by the struggle to pretend there was none.

It was clear to me that this situation was constraining communication, and I decided to do something about it. I approached several of the nondisabled women, asking them how they felt about meeting such a diverse group of disabled women. Many of the women were honest when invited to be:

"I'm nervous. Am I going to say something offensive?" "I feel pretty awkward. Some of these women's bodies are so different!" One woman, herself disabled, said that she'd had a nightmare image of a disabled woman's very different body. One woman confessed: "I feel terrible for some of these unfortunate disabled women, but I know I'm not supposed to feel pity. That's awful of me, right?"

This awkwardness reveals how isolated the broader society and even progressive feminists are from people with disabilities. The dangerous void of information about disability is the *context* in which the public's attitudes about prenatal diagnosis and selective abortion are formed. In the United States this information void has yielded a number of unexamined assumptions, including the belief that the quality and enjoyment of life for disabled people is necessarily inferior, that raising a child with a disability is a wholly undesirable experience, that selective abortion will save mothers from the burdens of raising disabled children, and that ultimately we as a society have the means and the right to decide who is better off not being born.

What the women with disabilities were trying to do at the Vancouver conference, and what I wish to do in this essay, is explain how selective abortion or *eugenic abortion*, as some disability activists have called it, not only oppresses people with disabilities but also hurts all women.

EUGENICS AND THE BIRTH CONTROL MOVEMENT

The eugenic interest that stimulates reliance on prenatal screening and selective abortion today has had a central place in reproductive politics for more than half a century. In the nineteenth century, eugenicists believed that most traits, including such human "failings" as pauperism, alcoholism, and thievery, as well as such

desired traits as intelligence, musical ability, and “good character,” were hereditary. They sought to perfect the human race through controlled procreation, encouraging those from “healthy stock” to mate and discouraging reproduction of those eugenicists defined as socially “unfit,” that is, with undesirable traits. Through a series of laws and court decisions American eugenicists mandated a program of social engineering. The most famous of these was the 1927 U.S. Supreme Court ruling in *Buck v. Bell*.²

Leaders in the early birth control movement in the United States, including Margaret Sanger, generally embraced a eugenic view, encouraging white Anglo-Saxon women to reproduce while discouraging reproduction among nonwhite, immigrant, and disabled people. Proponents of eugenics portrayed disabled women in particular as unfit for procreation and as incompetent mothers. In the 1920s Margaret Sanger's group, the American Birth Control League, allied itself with the director of the American Eugenics Society, Guy Irving Burch. The resulting coalition supported the forced sterilization of people with epilepsy, as well as those diagnosed as mentally retarded and mentally ill. By 1937, in the midst of the Great Depression, twenty-eight states had adopted eugenics sterilization laws aimed primarily at women for whom “procreation was deemed inadvisable.” These laws sanctioned the sterilizations of over 200,000 women between the 1930s and the 1970s.³

While today's feminists are not responsible for the eugenic biases of their foremothers, some of these prejudices have persisted or gone unchallenged in the reproductive rights movement today.⁴ Consequently, many women with disabilities feel alienated from this movement. On the other hand, some pro-choice feminists have felt so deeply alienated from the disability community that they have been

willing to claim, “The right wing wants to force us to have defective babies.”⁵ Clearly, there is work to be done.

DISABILITY-POSITIVE IDENTITY VERSUS SELECTIVE ABORTION

It is clear that some medical professionals and public health officials are promoting prenatal diagnosis and abortion with the intention of eliminating categories of disabled people, people with Down's syndrome and my own disability, spina bifida, for example. For this reason and others, many disability activists and feminists regard selective abortion as “the new eugenics.” These people resist the use of prenatal diagnosis and selective abortion.

The resistance to selective abortion in the disability activist community is ultimately related to how we define ourselves. As feminists have transformed women's sense of self, the disability community has reframed the experience of having a disability. In part, through developing a sense of community, we've come to realize that the stereotyped notions of the “tragedy” and “suffering” of “the disabled” result from the *isolation* of disabled people in society. Disabled people with no connections to others with disabilities in their communities are, indeed, afflicted with the social role assignment of a tragic, burdensome existence. It is true, most disabled people I know have told me with certainty, that the disability, the pain, the need for compensatory devices and assistance can produce considerable inconvenience. But the inconvenience becomes minimal once the disabled person makes the transition to a typical everyday life. It is discriminatory attitudes and thoughtless behaviors, and the ensuing ostracism and lack of accommodation, that make life difficult. That oppression is what's most disabling about disability.

Many disabled people have a growing but still precarious sense of pride in an

identity as “people with disabilities.” With decades of hard work, disability activists have fought institutionalization and challenged discrimination in employment, education, transportation, and housing. We have fought for rehabilitation and Independent Living programs, and we have proved that disabled people can participate in and contribute to society.

As a political movement, the disability rights community has conducted protests and effective civil disobedience to publicize our demand for full citizenship. Many of our tactics were inspired by the women’s movement and the black civil rights movement in the 1960s. In the United States we fought for and won one of the most far-reaching pieces of civil rights legislation ever, the Americans with Disabilities Act. This piece of legislation is the envy of the international community of disability activists, most of whom live in countries where disabled people are viewed with pity and charity, and accorded low social and legal status. Disability activists have fought for mentor programs led by adults with disabilities. We see disabled children as “the youth” of the movement, the ones who offer hope that life will continue to improve for people with disabilities for generations to come.

In part because of our hopes for disabled children, the “Baby Doe” cases of the 1980s caught the attention of the growing disability rights movement. These cases revealed that “selective nontreatment” of disabled infants (leaving disabled infants to starve because the parents or doctors choose not to intervene with even routine treatments such as antibiotics) was not a thing of the past. In this same period, we also took note of the growing number of “wrongful birth” suits—medical malpractice suits brought against physicians, purportedly on behalf of disabled children, by parents who feel that the child’s condition should have been identified prenatally.⁶ These lawsuits claim

that disabled babies, once born, are too great a burden, and that the doctors who failed to eliminate the “damaged” fetuses should be financially punished.

But many parents of disabled children have spoken up to validate the joys and satisfactions of raising a disabled child. The many books and articles by these parents confirm the view that discriminatory attitudes make raising a disabled child much more difficult than the actual logistics of care.⁷ Having developed a disability-centered perspective on these cases, disabled adults have joined with many parents of disabled children in challenging the notion that raising a child with a disability is necessarily undesirable.

The attitudes that disabled people are frightening or inhuman result from lack of meaningful interaction with disabled people. Segregation in this case, as in all cases, allows stereotypes to abound. But beyond advocating contact with disabled people, disability rights proponents claim that it is crucial to challenge limiting definitions of “acceptably human.” Many parents of children with Down’s syndrome say that their children bring them joy. But among people with little exposure to disabled people, it is common to think that this is a romanticization or rationalization of someone stuck with the burden of a damaged child.

Many who resist selective abortion insist that there is something deeply valuable and profoundly human (though difficult to articulate in the sound bites of contemporary thought) in meeting and loving a child or adult with a severe disability. Thus, contributions of human beings cannot be judged by how we fit into the mold of normalcy, productivity, or cost-benefit. People who are different from us (whether in color, ability, age, or ethnic origin) have much to share about what it means to be human. We must not deny ourselves the opportunity for connection to basic humanness by

dismissing the existence of people labeled “severely disabled.”

MIXED FEELINGS: DISABLED PEOPLE RESPOND TO SELECTIVE ABORTION

The disability *activist* community has begun to challenge selective abortion. But among disabled people as a whole, there is no agreement about these issues. After all, the “disability community” is as diverse as any other broad constituency, like “the working class” or “women.” Aspects of this issue can be perplexing to people with disabilities because of the nature of the prejudice we experience. For example, the culture typically invalidates our bodies, denying our sexuality and our potential as parents. These cultural impulses are complexly intertwined with the issue of prenatal testing. Since the early 1990s, disability rights activists have been exploring and debating our views on selective abortion in the disability community’s literature.⁸ In addition, just like the general population’s attitudes about *abortion*, views held by people with disabilities about *selective abortion* relate to personal experience (in this case, personal history with disability) and to class, ethnic, and religious backgrounds.

People with different kinds of disabilities may have complex feelings about prenatal screening tests. While some disabled people regard the tests as a kind of genocide, others choose to use screening tests during their own pregnancies to avoid the birth of a disabled child. But disabled people may also use the tests differently from women who share the larger culture’s anti-disability bias.

Many people with dwarfism, for example, are incensed by the idea that a woman or couple would choose to abort simply because the fetus would become a dwarf. When someone who carries the dwarfism trait mates with another with the same trait,

there is a likelihood of each partner contributing one dominant dwarfism gene to the fetus. This results in a condition called “double dominance” for the offspring, which, in this “extra dose of the gene” form, is invariably accompanied by severe medical complications and early death. So prospective parents who are carriers of the dwarfism gene, or are themselves dwarfs, who would readily welcome a dwarf child, might still elect to use the screening test to avoid the birth of a fetus identified with “double dominance.”

Deafness provides an entirely different example. There is as yet no prenatal test for deafness, but if, goes the ethical conundrum, a hearing couple could eliminate the fetus that would become a deaf child, why shouldn’t deaf people, proud of their own distinct sign-language culture, elect for a deaf child and abort a fetus (that would become a hearing person) on a similar basis?

Those who challenge selective or eugenic abortion claim that people with disabilities are the ones who have the information about what having a disability is like. The medical system, unable to cure or fix us, exaggerates the suffering and burden of disability. The media, especially the movies, distort our lives by using disability as a metaphor for evil, impotence, eternal dependence, or tragedy—or conversely as a metaphor for courage, inspiration, or sainthood. Disabled people alone can speak to the women facing these tests. Only we can speak about our real lives, our ordinary lives, and the lives of disabled children.

“DID YOU GET YOUR AMNIO YET?”: THE PRESSURE TO TEST AND ABORT

How do women decide about tests, and how do attitudes about disability affect women’s choices? The reproductive technology market has, since the mid-1970s, gradually changed the experience of pregnancy. Some prenatal care facilities now present

patients with their ultrasound photo in a pink or blue frame. Women are increasingly pressured to use prenatal testing under a cultural imperative claiming that this is the “responsible thing to do.” Strangers in the supermarket, even characters in TV sit-coms, readily ask a woman with a pregnant belly, “Did you get your amnio yet?” While the ostensible justification is “reassurance that the baby is fine,” the underlying communication is clear: screening out disabled fetuses is the right thing, “the healthy thing,” to do. As feminist biologist Ruth Hubbard put it, “Women are expected to implement the society’s eugenic prejudices by ‘choosing’ to have the appropriate tests and ‘electing’ not to initiate or to terminate pregnancies if it looks as though the outcome will offend.”⁹

Often prospective parents have never considered the issue of disability until it is raised in relation to prenatal testing. What comes to the minds of parents at the mention of the term *birth defects*? Usually prospective parents summon up the most stereotyped visions of disabled people derived from telethons and checkout-counter charity displays. This is not to say that all women who elect selective abortion do so based on simple, mindless stereotypes. I have met women who have aborted on the basis of test results. Their stories and their difficult decisions were very moving. They made the decisions they felt were the only ones possible for them, given information they had been provided by doctors, counselors, and society.

Indeed, some doctors and counselors do make a good-faith effort to explore with prospective parents the point at which selective abortion may seem clearly “justifiable,” with respect to the severity of the condition or the emotional or financial costs involved. These efforts are fraught with enormous social and ethical difficulty. Often, however, unacknowledged stereotypes prevail, as does a commitment to a

libertarian view (“Let people do whatever they want!”). Together, these strains frequently push prospective parents to succumb to the medical control of birth, while passively colluding with pervasive disability discrimination.

Among the most common justifications of selective abortion is that it “ends suffering.” Women as cultural nurturers and medical providers as official guardians of well-being are both vulnerable to this message. Health care providers are trying, despite the profit-based health care system, to improve life for people they serve. But the medical system takes a very narrow view of disease and “the alleviation of suffering.” What is too often missed in medical training and treatment are the *social factors* that contribute to suffering. Physicians, by the very nature of their work, often have a distorted picture of the lives of disabled people. They encounter disabled persons having health problems, complicated by the stresses of a marginalized life, perhaps exacerbated by poverty and race or gender discrimination, but because of their training, the doctors tend to project the individual’s overall struggle onto the disability as the “cause” of distress. Most doctors have few opportunities to see ordinary disabled individuals living in their communities among friends and family.

Conditions receiving priority attention for prenatal screening include Down’s syndrome, spina bifida, cystic fibrosis, and fragile X, all of which are associated with mildly to moderately disabling clinical outcomes. Individuals with these conditions can live good lives. There are severe cases, but the medical system tends to underestimate the functional abilities and overestimate the “burden” and suffering of people with these conditions. Moreover, among the priority conditions for prenatal screening are diseases that occur very infrequently. Tay-Sachs disease, for example, a debilitating, fatal disease that affects primarily Jews of

eastern European descent, is often cited as a condition that justifies prenatal screening. But as a rare disease, it's a poor basis for a treatment mandate.

Those who advocate selective abortion to alleviate the suffering of children may often raise that cornerstone of contemporary political rhetoric, *cost-benefit*. Of course, cost-benefit analysis is not woman-centered, yet women can be directly pressured or subtly intimidated by both arguments. It may be difficult for some to resist the argument that it is their duty to "save scarce health care dollars," by eliminating the expense of disabled children. But those who resist these arguments believe the value of a child's life cannot be measured in dollars. It is notable that families with disabled children who are familiar with the actual impact of the disabilities tend not to seek the tests for subsequent children.¹⁰ The bottom line is that the cost-benefit argument disintegrates when the outlay of funds required to provide services for disabled persons is measured against the enormous resources expended to test for a few rare genetic disorders. In addition, it is important to recognize that promotion and funding of prenatal tests distract attention and resources from addressing possible environmental causes of disability and disease.

DISABLED PEOPLE AND THE FETUS

I mentioned to a friend, an experienced disability activist, that I planned to call a conference for disabled people and genetics professionals to discuss these controversial issues. She said, "I think the conference is important, but I have to tell you, I have trouble being in the same room with professionals who are trying to eliminate my people." I was struck by her identification with fetuses as "our people."

Are those in the disability rights movement who question or resist selective

abortion trying to save the "endangered species" of disabled fetuses? When this metaphor first surfaced, I was shocked to think of disabled people as the target of intentional elimination, shocked to realize that I identified with the fetus as one of my "species" that I must try to protect.

When we refer to the fetus as a *disabled* (rather than defective) fetus, we *personify* the fetus via a term of pride in the disability community. The fetus is named as a member of our community. The connection disabled people feel with the "disabled fetus" may seem to be in conflict with the pro-choice stance that the fetus is only a part of the woman's body, with no independent human status.¹¹

Many of us with disabilities might have been prenatally screened and aborted if tests had been available to our mothers. I've actually heard people say, "Too bad that baby with [x disease] didn't 'get caught' in prenatal screening." (This is the sentiment of "wrongful birth" suits.) It is important to make the distinction between a pregnant woman who chooses to terminate the pregnancy because she *doesn't want to be pregnant* as opposed to a pregnant woman who *wanted to be pregnant* but rejects a particular fetus, a particular potential child. Fetuses that are wanted are called "babies." Prenatal screening results can turn a "wanted baby" into an "unwanted fetus."

It is difficult to contemplate one's own hypothetical nonexistence. But I know several disabled teenagers, born in an era when they could have been "screened out," for whom this is not at all an abstraction. In biology class their teachers, believing themselves to be liberal, raised abortion issues. These teachers, however, were less than sensitive to the disabled students when they talked about "eliminating the burden of the disabled" through technological innovation.

In the context of screening tests, those of us with screenable conditions represent living adult fetuses that didn't get aborted. We are the constituency of the potentially aborted. Our resistance to the systematic abortion of "our young" is a challenge to the "nonhumanness," the nonstatus of the fetus. This issue of the humanness of the fetus is a tricky one for those of us who identify both as pro-choice feminists and as disability rights activists. Our dual perspective offers important insights for those who are debating the ethics of the new reproductive technologies.

DISENTANGLING PATRIARCHAL CONTROL AND EUGENICS FROM REPRODUCTIVE FREEDOM

The issue of selective abortion is not just about the rights or considerations of disabled people. Women's rights and the rights of all human beings are implicated here.

When disability rights activists challenge the practice of selective abortion, as we did in Vancouver, many feminists react with alarm. They feel "uncomfortable" with language that accords human status to the fetus. One woman said: "You can't talk about the fetus as an entity being supported by advocates. It's too 'right to life.'" Disabled women activists do not want to be associated with the violent anti-choice movement. In the disability community we make a clear distinction between our views and those of anti-abortion groups. There may have been efforts to court disabled people to support anti-abortion ideology, but anti-abortion groups have never taken up the issues of expanding resources for disabled people or parents of disabled children, never lobbied for disability legislation. They have shown no interest in disabled people after they are born.¹²

But a crucial issue compels some of us to risk making people uncomfortable by

discussing the fetus: we must clarify the connection between control of "defective fetuses" and the control of women as vessels or producers of quality-controllable products. This continuum between control of women's bodies and control of the *products of women's bodies* must be examined and discussed if we are going to make headway in challenging the ways that new reproductive technologies can increasingly take control of reproduction away from women and place it within the commercial medical system.

A consideration of selective abortion as a control mechanism must include a view of the procedure as a wedge into the "quality control" of all humans. If a condition (like Down's syndrome) is unacceptable, how long will it be before experts use selective abortion to manipulate—eliminate or enhance—other (presumed genetic) socially charged characteristics: sexual orientation, race, attractiveness, height, intelligence? Pre-implantation diagnosis, now used with in vitro fertilization, offers the prospect of "admission standards" for all fetuses.

Some of the pro-screening arguments masquerade today as "feminist" when they are not. Selective abortion is promoted in many doctors' offices as a "reproductive option" and "personal choice." But as anthropologist Rayna Rapp notes, "Private choices always have public consequences."¹³ When a woman's individual decision is the result of social pressure, it can have repercussions for all others in the society.

How is it possible to defend selective abortion on the basis of "a woman's right to choose" when this "choice" is so constrained by oppressive values and attitudes? Consider the use of selective abortion for sex selection. The feminist community generally regards the abortion of fetuses on the basis of gender—widely practiced in some countries to eliminate female fetuses—as furthering the devaluation of women. Yet women have been pressed to

“choose” to perpetuate their own devaluation.¹⁴ For those with “disability-positive” attitudes, the analogy with sex selection is obvious. Oppressive assumptions, not inherent characteristics, have devalued who this fetus will grow into.

Fetal anomaly has sometimes been used as a *justification* for legal abortion. This justification reinforces the idea that women are horribly oppressed by disabled children. When disability is sanctioned as a justification for legal abortion, then abortion for sex selection may be more easily sanctioned as well. If “choice” is made to mean choosing the “perfect child,” or the child of the “right gender,” then pregnancy is turned into a process and children are turned into products that are perfectible through technology. Those of us who believe that pregnancy and children must not be commodified believe that real “choice” must include the birth of a child with a disability.

To blame a woman’s oppression on the characteristics of the fetus is to obscure and distract us from the core of the “choice” position: women’s control over our own bodies and reproductive capacities. It also obscures the different access to “choice” of different groups of women. At conferences I’ve been asked, “Would I want to force a poor black woman to bear a disabled child?” That question reinforces what feminists of color have been saying, that the framework of “choice” trivializes the issues for nonprivileged women. It reveals distortions in the public’s perception of users of prenatal screening; in fact, it is the middle and upper class who most often can purchase these “reproductive choices.” It’s not poor women, or families with problematic genetic traits, who are creating the market for tests. Women with aspirations for the “perfect baby” are establishing new “standards of care.” Responding to the lure of consumerism, they are helping create a lucrative market that exploits the culture’s fear of disability and makes huge profits for the biotech industry.

Some proponents argue that prenatal tests are feminist tools because they save women from the excessive burdens associated with raising disabled children.¹⁵ This is like calling the washer-dryer a feminist tool; technological innovation may “save time,” even allow women to work outside the home, but it has not changed who does the housework. Women still do the vast majority of child care, and child care is not valued as real work. Rather, raising children is regarded as women’s “duty” and is not valued as “worth” paying mothers for (or worth paying teachers or day-care workers well). Selective abortion will not challenge the sexism of the family structure in which women provide most of the care for children, for elderly parents, and for those disabled in accidents or from nongenetic diseases. We are being sold an illusion that the “burden” and problems of motherhood are being alleviated by medical science. But using selective abortion to eliminate the “burden” of disabled children is like taking aspirin for an ulcer. It provides temporary relief that both masks and exacerbates the underlying problems.

The job of helping disabled people must not be confused with the traditional devaluing of women in the caregiver role. Indeed, women can be overwhelmed and oppressed by their work of caring for disabled family members. But this is *not caused by the disabilities per se*. It is caused by lack of community services and inaccessibility, and greatly exacerbated by the sexism that isolates and overworks women caregivers. Almost any kind of work with people, if sufficiently shared and validated, can be meaningful, important, joyful, and productive.

I believe that at this point in history the decision to abort a fetus with a disability even because it “just seems too difficult” must be respected. A woman who makes this decision is best suited to assess her own resources. But it is important for her to

realize this “choice” is actually made under duress. Our society profoundly limits the “choice” to love and care for a baby with a disability. This failure of society should not be projected onto the disabled fetus or child. No child is “defective.” A child’s disability doesn’t ruin a woman’s dream of motherhood. Our society’s inability to appreciate and support people is what threatens our dreams.

In our struggle to lead our individual lives, we all fall short of adhering to our own highest values. We forget to recycle. We ride in cars that pollute the planet. We buy sneakers from “developing countries” that exploit workers and perpetuate the distortions in world economic power. Every day we have to make judgment calls as we assess our ability to live well and right, and it is always difficult, especially in relation to raising our own children—perhaps in this era more so than ever—to include a vision of social change in our personal decisions.

Women sometimes conclude, “I’m not saintly or brave enough to raise a disabled child.” This objectifies and distorts the experience of mothers of disabled children. They’re not saints; they’re ordinary women, as are the women who care for spouses or their own parents who become disabled. It doesn’t take a “special woman” to mother a disabled child. It takes a caring parent to raise any child. If her child became disabled, any mother would do the best job she could caring for that child. It is everyday life that trains people to do the right thing, sometimes to be leaders.

DISABLED WOMEN HAVE A LEGITIMATE VOICE IN THE ABORTION DEBATE!

Unfortunately, I’ve heard some ethicists and pro-choice advocates say that disabled people should not be allowed a voice in the selective abortion debate because “they make women feel guilty.” The prob-

lem with this perspective is evident when one considers that there is no meaningful distinction between “disabled people” and “women.” Fifty percent of adults with disabilities are women, and up to 20 percent of the female population have disabilities. The many prospective mothers who have disabilities or who are carriers of genetic traits for disabling conditions may have particular interests either in challenging or in utilizing reproductive technologies, *and* these women have key perspectives to contribute.

Why should hearing the perspectives of disabled people “make women feel guilty”? The unhappy truth is that so many decisions that women make about procreation are fraught with guilt and anxiety because sexism makes women feel guilty about their decisions. One might ask whether white people feel guilty when people of color challenge them about racism. And if so, doesn’t that ultimately benefit everyone?

Do I think a woman who has utilized selective abortion intended to oppress *me* or wishes I were not born? Of course not. No more than any woman who has had an abortion means to eliminate the human race. Surely one must never condemn a woman for making the best choice she can with the information and resources available to her in the crisis of decision. In resisting prenatal testing, we do not aim to blame any individual woman or compromise her individual control over her own life or body. We *do* mean to offer information to empower her and to raise her awareness of the stakes involved for her as a woman and member of the community of all women.

A PROPOSAL FOR THE REPRODUCTIVE RIGHTS MOVEMENT

The feminist community is making some headway in demanding that women’s

perspectives be included in formulating policies and practices for new reproductive technologies, but the disability-centered aspects of prenatal diagnosis remain marginalized. Because the technologies have emerged in a society with entrenched attitudes about disability and illness, the tests have become embedded in medical “standards of care.” They have also become an integral part of the biotech industry, a new “bright hope” of capitalist health care and the national economy. The challenge is great, the odds discouraging.

Our tasks are to gain clarity about prenatal diagnosis, challenge eugenic uses of reproductive technologies, and support the rights of all women to maintain control over reproduction. Here are some suggestions for action:

- We must actively pursue close connections between reproductive rights groups and disabled women’s groups with the long-range goal of uniting our communities, as we intend to do with all other marginalized groups.
- We must make the issue of selective abortion a high priority in our movements’ agendas, pushing women’s groups and disability and parent groups to take a stand in the debate on selective abortion, instead of evading the issue.
- We must recognize disability as a feminist issue. All females (including teenagers and girls) will benefit from information and discussion about disability *before* they consider pregnancy, so they can avoid poorly informed decisions.
- Inclusion of people with disabilities must be part of the planning and outreach of reproductive rights organizations. Inclusion involves not only use of appropriate language and terminology for disability issues but also *involvement of disabled people* as resources. Women’s organizations must learn about and comply with the Americans with Disabilities Act (or related laws in other countries). If we are going to promote far-reaching radical feminist programs for justice and equality, we must surely comply with minimal standards set by the U.S. Congress.
- We must support family initiatives—such as parental leave for mothers and fathers, flex- and part-time work, child care resources, programs for low-income families, and comprehensive health care programs—that help *all* parents and thus make parenting children with disabilities more feasible.
- We must convince legislatures, the courts, and our communities that fetal anomaly must never be used again as a justification or a defense for safe and legal abortion. This is a disservice to the disability community and an insupportable argument for abortion rights.
- We must make the case that “wrongful life” suits should be eliminated. “Wrongful birth” suits (that seek damages for the cost of caring for a disabled child) should be carefully controlled only to protect against medical malpractice, not to punish medical practitioners for not complying with eugenic policy.
- We must break the *taboo* in the feminist movement against discussing the fetus. Getting “uncomfortable” will move us toward clarity, deepening the discussion about women’s control of our bodies and reproduction.
- In response to the imperative from medical providers to utilize reproductive technologies, we can create programs to train “NRT peer counselors” to help women to learn more about new reproductive technologies, become truly informed consumers, and avoid being pressured to undergo unwanted tests. *People with disabilities must be included as NRT peer counselors.*
- We can help ourselves and each other gain clarity regarding the decision to abort a fetus with a disability. To begin

with, we can encourage women to examine their motivations for having children, ideally before becoming pregnant. We can ask ourselves and each other: What needs are we trying to satisfy in becoming a mother? How will the characteristics of the potential child figure into these motivations? What opportunities might there be for welcoming a child who does not meet our ideals of motherhood? What are the benefits of taking on the expectations and prejudices of family and friends? Have we met and interacted meaningfully with children and adults with disabilities? Do we have sufficient knowledge about disability, and sufficient awareness of our own feelings about disabled people, for our choices to be based on real information, not stereotypes?

Taking these steps and responding to these questions will be a start toward increasing our clarity about selective abortion.

CARING ABOUT OURSELVES AND EACH OTHER

Here are some things I have learned while working to educate others on this issue. I try to be patient with potential allies, to take time to explain my feelings. I try to take nothing for granted, try not to get defensive when people show their confusion or disagreement. I must remember that these issues are hard to understand; they run contrary to common and pervasive assumptions about people and life. I have to remember that it took me a long time to begin to understand disability stereotyping myself. At the same time, I have very high expectations for people. I believe it is possible to be pushy but patient and loving at the same time.

To feminist organizations attempting to include disabled women in discussions of abortion and other feminist issues: for-

give us for our occasional impatience. To disabled people: forgive potential allies for their ignorance and awkwardness. At meetings we disabled people hope to be heard, but we also perceive the “discomfort” that nondisabled people reveal, based on lack of real information about who we are. *There is no way around this awkward phase.* Better to reveal ignorance than to pretend and thereby preclude getting to know each other as people. Ask questions; make mistakes!

I sometimes remember that not only have I taken on this cutting-edge work for future generations, but I’m doing this *for myself now*. The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are “too flawed” in our very DNA to exist; we are unworthy of being born. This message is painful to confront. It seems tempting to take on easier battles, or even just to give in. But fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality—we are indeed worthy of being born, worth the help and expense, and we know it! The great opportunity with this issue is to think and act and take leadership in the place where feminism, disability rights, and human liberation meet.

NOTES

1. *New reproductive technologies* is the term often used to describe procreative medical technologies, including such prenatal diagnostic tests as ultrasound, alpha fetal protein (AFP) blood screening, amniocentesis, chorionic villi screening (CVS, a sampling of a segment of the amniotic sac), and the whole host of other screening tests for fetal anomalies. NRTs also include in vitro fertilization and related fertility-enhancing technologies. The conference, “New Reproductive Technologies: The Contradictions of Choice; the Common Ground between Disability Rights and Feminist Analysis,” held in Vancouver, No-

- ember 1994, was sponsored by the DisAbled Women's Network (DAWN), and the National Action Council on the Status of Women (NAC).
2. David J. Kevles, *In the Name of Eugenics* (New York: Knopf, 1985).
 3. Not long after eugenics became a respectable science in the United States, Nazi leaders modeled state policies on their brutal reading of U.S. laws and practices. After their rise to power in 1933 the Nazis began their "therapeutic elimination" of people with mental disabilities, and they killed 120,000 people with disabilities during the Holocaust. See Robert J. Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York: Basic Books, 1986).
 4. Marlene Fried, ed., *From Abortion to Reproductive Freedom: Transforming a Movement* (Boston: South End Press, 1990), 159.
 5. Michelle Fine and Adrienne Asch, "The Question of Disability: No Easy Answers for the Women's Movement," *Reproductive Rights Newsletter* 4, no. 3 (Fall 1982). See also Rita Arditti, Renate Duelli Klein, and Shelley Minden, *Test-Tube Women: What Future for Motherhood?* (London: Routledge and Kegan Paul, 1984); Adrienne Asch, "The Human Genome and Disability Rights," *Disability Rag and Resource*, February 1994, 12–13; Adrienne Asch and Michelle Fine, "Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights," in *From Abortion to Reproductive Freedom*, ed. Fried; Lisa Blumberg, "The Politics of Prenatal Testing and Selective Abortion," in *Women with Disabilities: Reproduction and Motherhood*, special issue of *Sexuality and Disability Journal* 12, no. 2 (Summer 1994); Michelle Fine and Adrienne Asch, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (Philadelphia: Temple University Press, 1988); Laura Hershey, "Choosing Disability," *Ms.*, July/August 1994; Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth: How Genetic Information Is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators and Law Enforcers* (Boston: Beacon Press, 1993); Marsha Saxton, "The Politics of Genetics," *Women's Review of Books* 9, no. 10–11 (July 1994); Marsha Saxton, "Prenatal Screening and Discriminatory Attitudes about Disability, in *Embryos, Ethics and Women's Rights: Exploring the New Reproductive Technologies*, ed. Elaine Hoffman Baruch, Amadeo F. D'Adamo, and Joni Seager (New York: Haworth Press, 1988); Marsha Saxton and Florence Howe, eds., *With Wings: An Anthology by and about Women with Disabilities* (New York: Feminist Press, 1987).
 6. Adrienne Asch, "Reproductive Technology and Disability," in *Reproductive Laws for the 1990s: A Briefing Handbook*, ed. Nadine Taub and Sherrill Cohen (New Brunswick, N.J.: Rutgers University Press, 1989).
 7. Helen Featherstone, *A Difference in the Family: Life with a Disabled Child* (New York: Basic Books, 1980).
 8. To my knowledge, Anne Finger was the first disability activist to raise this issue in the U.S. women's literature. In her book *Past Due: Disability, Pregnancy, and Birth* (Seattle: Seal Press, 1990), which includes references to her earlier writings, Finger describes a small conference where feminists and disability activists discussed this topic. German and British disability activists and feminists pioneered this issue.
 9. Ruth Hubbard, *The Politics of Women's Biology* (New Brunswick, N.J.: Rutgers University Press, 1990), 197.
 10. Dorothy Wertz, "Attitudes toward Abortion among Parents of Children with Cystic Fibrosis," *American Journal of Public Health* 81, no. 8 (1991).
 11. This view must be reevaluated in the era of in vitro fertilization (IVF), where the embryo or a genetically prescreened embryo (following "pre-implantation diagnosis") can be fertilized outside the woman's body and frozen or can be implanted in another woman. Such a fetus has come to have legal status apart from the mother's body: for example, in divorce cases where the fate of these fetuses is decided by the courts.
 12. Many "pro-life" groups support abortion for "defective fetuses." Most state laws, even conservative ones, allow later-stage abortions when the fetus is "defective."
 13. Rayna Rapp, "Accounting for Amniocentesis," in *Knowledge, Power, and Practice: The Anthropology of Medicine in Everyday Life*, ed. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993).
 14. Suneri Thobani, "From Reproduction to Mal[e] Production: Women and Sex Selection Technology," in *Misconceptions: The Social Construction of Choice and the New Reproductive Technologies*, vol. 1, ed. Gwynne Basen, Margaret Eichler, and Abby Lippman (Quebec: Voyager Publishing, 1994).
 15. Dorothy C. Wertz and John C. Fletcher, "A Critique of Some Feminist Challenges to Prenatal Diagnosis," *Journal of Women's Health* 2 (1993).