

# The Disability Rights Critique of Prenatal Genetic Testing

## Reflections and Recommendations

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The international project to sequence the human genome was undertaken in the expectation that knowing the sequence will offer new ways to understand and treat disease and disability. If researchers can identify the sequences of genes that code for the body's building blocks, then, it is hoped, they can identify and correct the sequences associated with disease and disability.

So far, researchers have enjoyed only minimal success in using gene therapy to correct such conditions, and no researcher has yet even attempted to use gene therapy to correct genetic impairments in a fetus. Rather, the discovery of abnormal or incorrect sequences has led primarily to the development of genetic tests that can reveal whether a person, embryo, or (in the usual case) a fetus carries an abnormality or "mutation" associated with disease or disability. It is now possible to test for gene mutations associated with some 400 conditions, from those universally viewed as severe, such as Tay Sachs, to those that many might describe as relatively minor, such as polydactyly (a trait involving an extra little finger). The number and variety of conditions for which tests are available grows almost daily.<sup>1</sup>

Today we test for one trait at a time. In the future, however, with advances in biochip technology, it will

be possible to test simultaneously for as many traits as one would like. In principle, we will be able to test for any trait we wish that has been associated with any given allele. Not only will the cost of such testing likely decrease as the diagnostic technology advances, but advances in the technology will make it possible to do the testing earlier in the pregnancy. One such technology will isolate the very small number of fetal cells that circulate in the maternal blood. Insofar as these earlier tests will be performed on fetal cells obtained from the mother's blood (rather than from the amniotic sac or chorionic villi) they will be noninvasive. Thus it will be possible to do many more tests, at once, and with less cost to the pregnant woman in time, inconvenience, risk, or dollars, than is now the case.<sup>2</sup>

As the ease of testing increases, so does the perception within both the medical and broader communities that prenatal testing is a logical extension of good prenatal care: the idea is that prenatal testing helps prospective parents have healthy babies. On the one hand, this perception is quite reasonable. Though no researcher has yet even attempted to correct a genetic impairment with in-utero gene therapy, increasingly there are nongenetic approaches to such impairments. At the time of this writing, more than fifty fetuses have undergone in-utero surgery to repair neural tube impairments (myelomeningoceles).<sup>3</sup> Moreover, negative (or reassuring) prenatal test results will reduce the anxiety felt by many prospective parents, and this

in itself can be construed as part of good prenatal care. On the other hand, as long as in-utero interventions remain relatively rare, and as long as the number of people seeking prenatal genetic information to prepare for the birth of a child with a disability remains small, prospective parents will use positive prenatal test results primarily as the basis of a decision to abort fetuses that carry mutations associated with disease and/or disability. Thus there is a sense in which prenatal testing is not simply a logical extension of the idea of good prenatal care.

Logical extension or no, using prenatal tests to prevent the birth of babies with disabilities seems to be self-evidently good to many people. Even if the testing will not help bring a healthy baby to term this time, it gives prospective parents a chance to try again to conceive. To others, however, prenatal testing looks rather different. If one thinks for even a moment about the history of our society's treatment of people with disabilities, it is not difficult to appreciate why people identified with the disability rights movement might regard such testing as dangerous. For the members of this movement, including people with and without disabilities and both issue-focused and disability-focused groups, living with disabling traits need not be detrimental either to an individual's prospects of leading a worthwhile life, or to the families in which they grow up, or to society at large. Although the movement has no one position on prenatal diagnosis, many adherents of

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the disability rights movement believe that public support for prenatal diagnosis and abortion based on disability contravenes the movement's basic philosophy and goals. Critics contend that:

1) Continuing, persistent, pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities. Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.

2) In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.

3) When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely, "to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud."<sup>4</sup>

This document, the product of two years of discussions by a diverse group drawn from within and outside the disability rights movement, reshuffles what is contained in these criticisms and discerns in them two broad claims: simply put, that prenatal genetic testing followed by selective abortion is morally problematic and that it is driven by misinformation. The document elaborates and evaluates these two claims, turns to explore the prospects for distinguishing be-

tween acceptable and unacceptable testing, and draws out of the ongoing debate that it seeks to focus—not to put to rest—recommendations to guide professional providers of genetic testing through this difficult terrain.

### Understanding and Evaluating the Disability Rights Critique

**P**renatal Testing Is Morally Problematic. The disability critique holds that selective abortion after prenatal diagnosis is morally problematic, and for two reasons. First, selective abortion expresses negative or discriminatory attitudes not merely about a disabling trait, but about those who carry it. Second, it signals an intolerance of diversity not merely in the society but in the family, and ultimately it could harm parental attitudes toward children.

*The Expressivist Argument.* The argument that selective abortion expresses discriminatory attitudes has been called the *expressivist* argument.<sup>5</sup> Its central claim is that prenatal tests to select against disabling traits express a hurtful attitude about and send a hurtful message to people who live with those same traits. In the late 1980s, Adrienne Asch put the concern this way: "Do not disparage the lives of existing and future disabled people by trying to screen for and prevent the birth of babies with their characteristics."<sup>6</sup> More recently, she has clarified what the hurtful or disparaging message is:

As with discrimination more generally, with prenatal diagnosis, a single trait stands in for the whole, the trait obliterates the whole. With both discrimination and prenatal diagnosis, nobody finds out about the rest. The tests send the message that there's no need to find out about the rest.<sup>7</sup>

Indeed, many people with disabilities, who daily experience being seen past because of some single trait they bear, worry that prenatal testing repeats and

reinforces that same tendency toward letting the part stand in for the whole. Prenatal testing seems to be more of the discriminatory same: a single trait stands in for the whole (potential) person. Knowledge of the single trait is enough to warrant the abortion of an otherwise wanted fetus. On Asch's more recent formulation, the test sends the hurtful message that people are reducible to a single, perceived-to-be-undesirable trait.

This observation about letting the part stand in for the whole is surely enormously important. In everyday life, traits do often stand in for the whole, people do get looked past because of them. Indeed, one form of the expressivist argument has been regarded rather highly in another context. Many people who are concerned to support women's rights, have argued that prenatal sex selection is morally problematic because it embodies and reinforces discriminatory attitudes toward women.<sup>8</sup> The sex trait is allowed to obliterate the whole, as if the parents were saying, "We don't want to find out about 'the rest' of this fetus; we don't want a girl."

Marsha Saxton has put the expressivist argument this way:

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. . . . [F]ighting 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!<sup>9</sup>

And as Nancy Press has argued, by developing and offering tests to detect some characteristics and not others, the professional community is expressing the view that some characteristics, but not all, warrant the attention of prospective parents.<sup>10</sup>

For several reasons, however, there is disagreement about the merit of the expressivist argument as a basis for any public policy regarding prenatal diagnosis of disability. Individual women and families have a host of motives and reasons for seeking out genetic information, and as James Lindemann Nelson and Eva Feder Kittay argue, it is impossible to conclude just what “message” is being sent by any one decision to obtain prenatal testing.<sup>11</sup> Acts (and the messages they convey) rarely have either a single motivation or meaning.

Some prospective parents no doubt have wholly negative attitudes toward what they imagine a life with a disability would be like for them and their child; others may believe that life could be rich for the child, but suspect that their own lives would be compromised. Others who have disabilities perhaps see passing on their disabling trait as passing on a part of life that for them has been negative. Parents of one child with a disability may believe that they don't have the emotional or financial resources for another. The point is that the meaning of prenatal testing for would-be parents is not clear or singular. In any case, those sympathetic to at least some forms of prenatal testing point out that prospective parents do not decide about testing to hurt existing disabled people but to implement their own familial goals. In that sense, there is no “message” being sent at all.

To many in the disability rights movement, however, regardless of the parental motive to avoid the birth of a child who will have a disability, the parent may still be letting a part stand in for the whole. That prospective parents do not intend to send a hurtful message does not speak to the fact that many people with disabilities receive such a message and are pained by it.

A second criticism of the expressivist argument is that it calls into

question the morality of virtually all abortions. The argument presumes that we can distinguish between aborting “any” fetus and a “particular” fetus that has a disability—what Adrienne Asch has called the any-particular distinction. According to Asch, most abortions reflect a decision not to bring any fetus to term at this time;

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selective abortions involve a decision not to bring this particular fetus to term because of its traits. Prochoice individuals within and outside the disability community agree that it is morally defensible for a woman to decide, for example, that she doesn't want any child at a given time because she thinks she's too young to mother well, or because it would thwart her life plan, or because she has all the children she wants to raise. The question is whether that decision is morally different from a decision to abort an otherwise-wanted fetus.

But it is not clear that the distinction is adequate. Sometimes the decision to abort “any” fetus can be recast as a decision to abort a “particular” fetus. James Lindemann Nelson, for example, argues that if parents of three children chose to end a pregnancy that would have produced a fourth child, such parents would not be making a statement about the worthwhileness of other families with four children, or about the worth of fourth-born children as human beings.<sup>12</sup> Rather, they would be deciding what would be right for their particular situation. If, as Asch and others have argued, prenatal testing is morally suspect because it lets a trait stand in for the whole potential person, precisely the same argument would apply to aborting a fetus

because it was the fourth child. The trait of being fourth-born makes the prospective parents ignore every other respect in which that fetus could become a child that would be a blessing to its family and community. Nelson's example of the potential fourth-born child suggests one reason to doubt the merit of the any-particular distinction;

he thinks that the disability critics have failed to explain why traits like being fourth-born could be a legitimate basis for an abortion while disabling traits could not.

A third criticism of the expressivist argument is that it presumes that selective abortion based on prenatal testing is morally problematic in a way that other means of preventing disability are not. Such other means include, for example, taking folic acid to reduce the likelihood of spina bifida, or eschewing medication that is known to stunt the growth or harm the organs or limbs of a developing fetus. Such acts (or refraining from such acts) on the part of the pregnant woman are designed to protect the health of the developing fetus.

Disability critics hold, however, that abortion does not protect the developing fetus from anything. It prevents disability by simply killing the fetus. Proponents of this disability critique hold a strong prochoice position. Their objection is only to a certain way of using abortion.

But those from the mainstream prochoice community think of selective abortion in different terms. They do not see an important moral difference between selective abortion and other modes of preventing disability in large part because they do see an

## The Project: A Two-Year and Ongoing Discussion

Against a background of burgeoning medical discovery, rising consciousness of discrimination against people with disabilities, increasing attention to the disability critique of prenatal testing, and the societal debate about abortion, The Hastings Center undertook a two-year project that sought to create a sustained dialogue yielding both intellectual and policy benefit. The project was supported by a grant (RO1 HG01168-02) from the Ethical, Legal, and Social Implications section of the National Institute for Human Genome Research.

Not only has the widespread popular support of genetic testing largely failed to attend to the disability community's charge that such testing is discriminatory, but the disability community's critique has not met with sustained, respectful, but critical examination by the bioethics or medical communities.<sup>1</sup> In this project, we sought to ascertain whether a full discussion of the disability critique of genetic testing would substantially alter or be altered by the views of others, and we strove to find a framework to which all parties to this conversation could subscribe in distinguishing between acceptable and unacceptable testing. That is, we strove to find a way to distinguish between traits for which testing would and would not be appropriate, upon which genetics professionals, bioethicists, and members of the disability rights movement could agree.

The disability critique seeks to persuade prospective parents to examine the meaning of testing—the meaning of their and society's cumulative actions. Although many of those who voice this critique themselves live with disabilities or have close relationships with disabled people, many thoughtful people whose experiences are different are also persuaded by those arguments. The critique is made to persuade prospective parents

and medical professionals to re-examine stereotypes about life with disability and about what it means to be the parent of a child with a disability. Proponents of this critique seek to help professionals who develop and provide tests—and prospective parents who use tests—understand and criticize the assumptions that underlie testing. The arguments are intended to bring out the beliefs that testing assumes, in hopes that people will be persuaded to change these beliefs and decide on their own that they need neither to urge tests nor to use them.

Our group sought to understand both the logical moves made in the arguments from a disability perspective as well as the social and psychological context in which those arguments are made. Not only did we try to understand the logical moves and feelings of people in the disability community, but we also tried to understand the moves and feelings of the people in the majority community of the “temporarily abled.” No one in our group can any longer imagine having a view from nowhere. Those of us with disabilities appreciate that our particular experience of discrimination colors our critique of prenatal testing. Those of us who used prenatal testing before or during the project appreciate that this experience colors our responses to those critiques. Not surprisingly, those of us who are parents sometimes found ourselves justifying our own parental attitudes. Those of us who are not parents sometimes asked ourselves whether becoming parents might make us think differently about what constitutes an admirable parental attitude.

Though we came to the table with different experiences of both disability and parenting, we also came with a desire to think through a set of public policy questions about how best to manage an emerging tech-

important moral distinction between a born child with a disabling trait and an embryo or fetus with a disabling trait. They argue that parents of all born children have an obligation to love and care for those children—regardless of their traits. They also argue, however, that the pregnant woman (and her partner) are not “parents” before the child is born. Just as a woman or couple may decide during the first two trimesters of any pregnancy that becoming a parent to a first child, or to any child, is not in accord with their life plans, so may they make the

same decision on the grounds that the fetus has disabling traits. The woman may terminate the pregnancy and try again to become pregnant with a fetus that has not been identified as carrying a disabling trait. On this view, if it is reasonable to prevent disability in a developing child by adhering to a particular lifestyle, taking specified medications or refraining from taking others, it is equally acceptable to opt for abortion to prevent the birth of a child with a significant disability.<sup>13</sup>

Even if expressivist arguments will not dissuade all people from using tests

in making reproductive decisions for their own lives, policies that would in any way penalize those who continue pregnancies in spite of knowing that their child will live with a disabling trait must be avoided. Those prospective parents who either forgo prenatal testing or decide that they want to continue a pregnancy despite the detection of a disabling trait should not have to contend with losing medical services or benefits for their child, nor feel obliged to justify their decisions. Further, the availability of prenatal testing in no way reduces our societal

nology. We came with a desire to hear each other and to identify both those issues on which we could agree and those on which we could not. The group included people who live with and people who theorize about disabilities, scholars from the social sciences and humanities, medical geneticists, genetic counselors, physicians, and lawyers.

Over the course of our two-year project, we held five, two-day research meetings at The Hastings Center. The first four were devoted to paper presentations and discussion. A collection of essays based on those presentations will be published by Georgetown University Press in mid 2000.<sup>2</sup> The last of our meetings was to discuss the first draft of this summary of our deliberations. Between meetings we engaged in a lively group e-mail conversation. In addition, through a grant from the National Institute for Disability and Rehabilitation Research to the Society for Disability Studies, our project members gathered with members of the Society at its May 1997 meeting in Minneapolis. Four conference sessions were devoted to discussing the project's work in dialogue with many people who live with and study disability issues. This dialogue broadened our group's conversation by providing access to ideas from other interested and knowledgeable people. It also provided some members of the research group with their first contact—in a non-medical setting—with people who have disabilities.

Given the controversial nature of the subject and the diversity of our working group, it is not surprising that we could not reach consensus about all of the questions we took up. We did not reach consensus about what weight to give or how best to use the disability arguments about prenatal genetic testing in making public policy. We did not achieve unanimity on the major claims of the disability perspective—most

generally, that prenatal diagnosis is based on either morally problematic views about people with disabilities or on misinformation about the nature and consequences of disability. Critics continued to believe that as it now is practiced, prenatal testing reflects and reinforces the belief that a disability differs from and is worse than other attributes that a child might have. In their view the current practice constitutes a form of invidious discrimination. Supporters of prenatal testing continued to believe that it is one more method of helping prospective parents avoid problems for themselves and their children, much as other forms of prenatal care and health promotion seek to avoid the consequences of illness or disability.

None of us concurred more specifically about whether it is good public policy to draw lines between reasonable and unreasonable tests. Nonetheless, our project has achieved two important aims. First, we served the public purpose of airing and taking seriously the concerns of the disability community. Second, to the extent that we found merit in the claims made by scholars with that view, we have made recommendations about how to ameliorate some of the problems associated with the customary ways of providing prenatal testing. This document presents an account of what happened in our project—what we agreed and disagreed about and why.

## References

1. Though not devoted exclusively to the disability critique, an important antecedent of our work is *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994).
2. Erik Parens and Adrienne Asch, eds., *Prenatal Genetic Testing and the Disability Critique* (Washington, D.C.: Georgetown University Press, forthcoming).

obligations to those people who are born with or acquire disabilities. Even if prenatal diagnosis says nothing to or about existing or future disabled people, we should as a society vigorously enforce antidiscrimination laws and improve services and supports for disabled people and their families.

### *The Parental Attitude Argument.*

The second argument that prenatal testing is morally problematic we call the *parental attitude* argument. According to it, using prenatal tests to select against some traits indicates a problematic conception of and attitude

toward parenthood. Part of the argument is that prenatal testing is rooted in a "fantasy and fallacy" that "parents can guarantee or create perfection" for their children.<sup>14</sup> If parents were to understand what they really should seek in parenting, then they would see how relatively unimportant are the particular traits of their children.

The parental attitude argument also involves the thought that in the context of prenatal testing, a part, a disability, stands in for the whole, a person. The prospective parent who wants to avoid raising a child with a

diagnosable disability forgets that along with the disabling trait come other traits, many of which are likely to be as enjoyable, pride-giving, positive (and as problematic, annoying, and complicated) as any other child's traits. If prospective parents imagine that disability precludes everything else that could be wonderful about the child, they are likely acting on misinformation and stereotype. The prospective parent has made biology destiny in the way that critics of the medical model of disability consistently resist.

According to the parental attitude argument, prospective parents should keep in mind that the disabling trait is only one of a fetus's characteristics. The activity of appreciating and nurturing the particular child one has is what the critics of selection view as the essence of good parenting. Loving and nurturing a child entails appreciating,

dren, toward thinking about them and treating them as products rather than as "gifts" or "ends in themselves"? Is it making us as a society less resilient in the face of the inevitable risks that our children face, and less willing to acknowledge the essential fragility of our species? When members of our society are confronted with, for exam-

on or give rise to the same assumption. He suggests that some prospective parents may legitimately adopt a "projectivist" or "familial" conception of parenthood, and that either of these views is compatible with trying to assure that any child they raise has characteristics that accord with these parental goals. In the projectivist parent's understanding of child rearing, the child is a part of her parental projects, and, within limits, parents may legitimately undertake to ensure that a child starts out with the requisites for fulfilling these parental hopes and aims.

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enjoying, and developing as best one can the characteristics of the child one has, not turning the child into someone she is not or lamenting what she is not. If we were to notice that it is a fantasy and fallacy to think that parents can guarantee or create perfection for their child, if we were to recognize what is really important about the experience of parenting, we would see that we should be concerned with certain attitudes toward parenting, not with "disabling" traits in our children. Good parents will care about raising whatever child they receive and about the relationship they will develop, not about the traits the child bears. In short, what bothers those wary of prenatal diagnosis is what might be called "the selective mentality." The attention to particular traits indicates a morally troubling conception of parenthood, a preoccupation with what is trivial and an ignorance of what is profound.

Those who connect acceptance of disability to what is desirable in any parent-child relationship will worry that our attitudes toward parenthood and ultimately toward each other are changing as a result of technologies like prenatal diagnosis.<sup>15</sup> Do these technologies lead us, one might ask, toward the commodification of chil-

ple, sex selection or with the possibility of selecting for non-health-related traits like sexual orientation, concerns about the selective mentality come quickly to our lips. Indeed, those who want to reject the parental attitude argument in the context of disabling traits must recognize that they are criticizing an argument that they themselves may well want to use in the context of non-health-related traits. Certainly many worry about the cumulative effect of individual choices, about the technologization of reproduction, and about a decreasing cultural ability or willingness to accept the reality of uncontrollable events. These concerns trouble even those who profess to be comfortable with genetic testing and selective abortion.

Nonetheless, many find significant problems with the parental attitude argument. One of the most important is that it makes what William Ruddick calls the "maternalist assumption," namely, that "a woman who wants a child should want any child she gets."<sup>16</sup> Ruddick acknowledges that many women do hold "maternalist" conceptions of pregnancy and motherhood, out of which that assumption grows. But he points out that there are other legitimate conceptions of pregnancy and motherhood that do not depend

that projectivist parents could ignore a child's manifested commitments to things beyond the parents' life plans, but he is saying that, for example, the parent passionate about music may legitimately select against a future child whose deafness would make a love of some forms of music impossible. If a hearing child turns out to be tone deaf and enthusiastic about rock collecting and bird watching but not music, and if the parent views these activities as inimical to her parental values or projects, she need not support them, or (within limits) allow other people to do so.

Ruddick is not claiming that projectivist parents could ignore a child's manifested commitments to things beyond the parents' life plans, but he is saying that, for example, the parent passionate about music may legitimately select against a future child whose deafness would make a love of some forms of music impossible. If a hearing child turns out to be tone deaf and enthusiastic about rock collecting and bird watching but not music, and if the parent views these activities as inimical to her parental values or projects, she need not support them, or (within limits) allow other people to do so.

According to Ruddick, the "familial" conception of parenthood highlights a parent's vision of her child as herself a parent, sibling—a participant in a nuclear and extended family that gives central meaning to life. For example, parents whose dreams of child rearing include envisioning their own child as a parent would be acting consistently with their conception of parenthood if they decided not to raise a boy with cystic fibrosis, whose sterility and shortened life span might preclude either biological or adoptive parenthood. A child of such a parent might, of course, reject family life in favor of solitude or communal adult companionship, but in using available

technology to avoid raising a child who would never be able to fulfill a deeply cherished parental dream, the parent is acting in accordance with a legitimate conception of parenthood.

Although Ruddick is not alone in thinking that a selective mentality may be compatible with praiseworthy parenting, many share the disability community's worry that prenatal testing threatens our attitudes toward children, parenthood, and ultimately ourselves. Certainly, it would be to the good if we would think more deeply about our attitudes. If we want to be parents, why do we want to be parents? What do we hope it will bring for our children-to-be and for ourselves? And prospective parents would benefit from grappling with those questions in the context of prenatal diagnosis. However, such concerns could not undergird specific policies regarding prenatal testing for disabling traits.

**Prenatal Testing Is Based on Misinformation.** The second major claim of the disability critique is that prenatal testing depends on a misunderstanding of what life with disability is like for children with disabilities and their families. Connected with this claim is the question whether disability is one more form of "neutral" human variation, or whether it is different from variations usually thought of as nondisabling traits, such as eye color, skin color, or musicality.

There are many widely accepted beliefs about what life with disability is like for children and their families. Most of these beliefs are not based on data. They include assumptions that people with disabilities lead lives of relentless agony and frustration and that most marriages break up under the strain of having a child with a disability. Recent studies suggest, for example, that many members of the health professions view childhood disability as predominantly negative for children and their families, in contrast to what research on the life satisfaction of people with disabilities and their

families has actually shown.<sup>17</sup> One strand of this project, then, involved wrestling with what to make of conflicting perceptions about how people with disabilities and their families experience life. Three disability researchers in the Hastings Center group—Philip Ferguson, Alan Gartner, and Dorothy Lipsky—analyzed empirical data on the impact of children with disabilities on families.<sup>18</sup> Their review, surprising to many, concludes that the adaptational profiles of families that have a child with a disability basically resemble those of families that do not.

According to Ferguson, Gartner, and Lipsky's reading of the data, families that include disabled children fare on average no better or worse than families in general. Some families founder, others flourish. Ferguson, Gartner, and Lipsky do not deny that families are often distressed upon first learning that their child has a disability. And they acknowledge that families with children who evince significantly challenging behavior experience more disruption than do other families. But recent research on raising a child with a disability offers happier news for families than many in our society have been led to expect. In the words of one leading family researcher, "The most recent literature suggests that families of children with handicaps [sic] exhibit variability comparable to the general population with respect to important outcomes such as parent stress, . . . family functioning, . . . and marital satisfaction."<sup>19</sup> Studies of family adaptation have begun to recognize the prevalence of positive outcomes in many families.<sup>20</sup> Indeed, one recent study found that parents of disabled adolescents reported more positive perceptions of their children than do parents of nondisabled adolescents.<sup>21</sup>

In a 1995 study intended to learn how a child's disability affected the work lives of dual career families, the authors found that the needs and concerns of families with and without children with disabilities were "strikingly similar." They did, however, observe:

What seems to distinguish families of children with disabilities from other working families is the intensity and complexity of the arrangements required to balance work and home responsibilities successfully. For example, parents of children with disabilities, particularly those with serious medical or behavioral problems, find it more difficult to locate appropriate, affordable child care. . . . Similarly, these families are more dependent upon health insurance policies with comprehensive coverage.<sup>22</sup>

This same study reminds us of a point that both Ruddick and Kittay made: a child's disability may sometimes alter the customary parent-child life cycle, in which parents gradually relinquish daily guidance and caretaking and—if they are fortunate—see their children take on adult productive and caretaking roles. Depending on the impairment and on the social arrangements that parents help a growing child construct, some people with disabilities may require their parents' help through adulthood in securing shelter, social support, and safety. Increasingly, adults with disabilities such as muscular dystrophy, spina bifida, cystic fibrosis, Down syndrome, and other conditions do not stay "eternal children," as they were once thought to do. Nonetheless, some, albeit small, portion of the population of disabled people will be more vulnerable for longer than others, and more in need of what Kittay (borrowing from Sara Ruddick) described as "attentive, protective love."<sup>23</sup>

While it is important to demolish the myth that disability entails relentless agony for the child and family, there is still considerable disagreement about what conclusions to draw from the literature on the family impact of a child with disability. In the view of

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the disability community, this literature suggests that prenatal testing to select against disabling traits is misguided in the sense that it is based on misinformation. That is, if prospective parents could see that families with children who have disabilities fare much better than the myth would have it, then parents would be less enthusiastic about the technology.

However, recognizing that there are erroneous beliefs that need to be dispelled may not show that the desire for prenatal testing stems from misinformation alone. The first problem with the argument from misinformation has to do with the difference between retrospective and prospective judgments. It is one thing to look back on a stressful but ultimately rewarding experience and say, I'm glad I did that. It is another to look forward to the possibility of a stressful and perhaps ultimately rewarding experience and say, I'm glad to give it a try. To appreciate that many families respond well to stress does not commit one to thinking that it would be a mistake for families to try to avoid it. It may be true that, as one of the studies of working families points out, the concerns of working parents with disabled children very much resemble the concerns of any working parent—ensuring that children are safe, happy, stimulated, and well cared for at home, at school, and in after-school activities. But that study also acknowledges that working parents of children with special medical or behavioral needs find that meeting those needs takes more time, ingenuity, and energy than they think would have to be spent on the needs of nondisabled children. To appreciate that many families emerge stronger, wiser, and even better as a result of such an experience may not suggest that it is unreasonable or morally problematic to try to avert it. As Mary Ann Baily put it, child rearing is already like mountain climbing.

That I want to climb Mount Rainier doesn't commit me to wanting to climb Everest. I appreciate that the rewards of climbing Everest might be extraordinary, beyond my wildest dreams, but I'd settle for Rainier.<sup>24</sup>

The disability researchers and theorists did not persuade everyone in the

But does that imply that having a characteristic like cystic fibrosis or spina bifida is of no more consequence than being left-handed or being a man who is five feet, three inches tall? According to the disability rights critique of prenatal testing, if people with disabilities were fully inte-

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project group that raising a child with a disability is not more demanding than raising a child without this condition. As a specific type of life challenge, raising a child who has a disability may provide one individual of a particular aptitude or orientation with a life experience of great reward and fulfillment, perhaps with a positive transformation. For a different individual, who possesses a different character or aptitude, the overall experience may be negative. Parents may examine themselves and conclude that they are not choosing against a child's specific traits; they may be making an honest and informed acceptance of their own character and goals.<sup>25</sup>

*Disability in Society.* Perhaps the most fundamental and irreconcilable disagreement over the argument from misinformation has to do with just what having a disability is "really" like for people themselves and for their families. Just how much of the problem of disability is socially constructed? Is it reasonable to say that in a differently constructed social environment, what are now disabling traits would become "neutral" characteristics?

Undoubtedly, more of the problem of disability is socially constructed than many people generally believe.

grated into society, then there would be no need for the testing. In the world they seek to create, if a given health status turned out to be a handicap, that would be because of societal, not personal, deficits; the appropriate response would be to change society so that the person could live a full life with a range of talents, capacities, and difficulties that exist for everyone. In a society that welcomed the disabled as well as the nondisabled, there would be no reason to prevent the births of people with traits now called disabling.

In this project, those sympathetic to at least some forms of prenatal testing were struck by the fact that, for reasons that seem to be complex, members of the disability community speak at different times in different modes about the nature of disability. Sometimes, members of that community are clear about the fact that disabling traits have a "biological reality" or are not neutral. Adrienne Asch writes, "The inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options."<sup>26</sup> At other times, however, and this is the mode usually emphasized in critiques

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of prenatal testing, those in the disability rights movement speak as if those traits indeed are inherently neutral. Thus Deborah Kent writes: "I premised my life on the conviction that blindness was a neutral characteristic."<sup>27</sup> In this other mode, the disability community argument often is that, different from what prospective parents imagine, these so-called disabling traits are not, to coin a term, "disvaluable" in themselves; they are disvaluable because of the way they are socially constructed.

Nora Groce's work illustrates the point about how social arrangements shape whether a characteristic is disabling.<sup>28</sup> In Martha's Vineyard in the 19th century, Groce argues, being unable to hear was not disabling because everyone spoke sign language. Groce's work establishes that much of what is difficult about having a disability stems from manifold facets of society, from architecture to education to aesthetic preferences. In choosing how to construct our societies, we do, as Allen Buchanan puts it, "choose who will be disabled."<sup>29</sup> We could choose differently than we have, and if we were to choose differently, what's disabling about what we now call disabilities would be largely eliminated. Plainly, then, the social constructionist argument is powerful. The objection concerns, rather, what appears to be a correlative claim of the disability position: that so-called disabling traits are neither disabling nor "disvaluable," but neutral.

Trying to delineate, understand, and come to consensus over this claim is perhaps the most contentious and difficult part of thinking about prenatal testing in the context of the disability critique. It is worth restating what Asch, Saxton, Lipsky, and others do and do not mean by the "neutrality" of disability. Adherents of the disability critique acknowledge that some characteristics now labeled disabilities are easier to incorporate into today's society, or into a reconstructed society, than are others. Thus, no one would

deny that disabling traits—departures from species-typical functioning—foreclose some options, or that some disabilities foreclose more options than others. A child with Down syndrome may never climb Mount Rainier because his strength, agility, and stamina may preclude it; he may also never read philosophy because he does not have the skills to decipher abstract material. Granting that people who can climb mountains and read abstract papers derive enjoyment and meaning from such activities, then being foreclosed from them, not by one's own choice, is regrettable. The lack of possibility is widely seen as disvaluable. In addition, these lacks of capacity stem from the characteristics of the individual who is not strong enough or agile enough to climb, or who is unable by any teaching now known to us to grasp complex abstract discourse. In that sense, disability community critics acknowledge that these facets of some disabilities are "real," inherent in the characteristic itself and not an artifact of any interaction with the environment. Even if all traits are to some extent "socially constructed," that is irrelevant to the fact that the existence of these traits forecloses for those who have them the opportunity to engage in some highly desirable and valuable activities; not being able to engage in those activities is disvaluable.

Disability community critics of the medical model of disability acknowledge that they would be going too far if they claimed that society should not value activities that some of its members cannot engage in; it is harmless to value the capacity of sight that permits people to behold Rembrandt's masterpieces, sunsets, or the faces of family members and friends. It is not offensive to prize intellectual accomplishment, athletic prowess, or the ability to appreciate visual beauty and to regret that not everyone we know can enjoy them. To the extent that spina bifida, Down syndrome, blindness, or cystic fibrosis currently preclude peo-

ple from undertaking some parts of life that people who do not have those traits might experience, the disability critique acknowledges that disability puts some limits on the "open future"<sup>30</sup> people seek for themselves and their children.

As Bonnie Steinbock argues, if we really thought disability "neutral," we would not work as we do to maintain, restore, and promote health in ourselves and others. We use medicine in the hope that it will cure or ameliorate illness and disability. We urge pregnant women to refrain from activities that risk harming the fetus. If we thought that disabilities were "neutral," then we could tell women who smoke or drink during pregnancy to rest easy, for developmental delay, low birth weight, and fetal alcohol syndrome would all be just "neutral variations," of no consequence to the future child.<sup>31</sup>

While disability community critics acknowledge that some disabilities foreclose some opportunities, they also hold that calling attention to the foreclosure obscures two important points. The first is that rather than dwell on the extent to which opportunities to engage in some activities are truncated, we should concentrate on finding ways for people with disabilities to enjoy alternative modes of those same activities. Philip Ferguson puts it this way:

The point is not so much whether . . . a blind person cannot enjoy a Rembrandt. . . but whether social arrangements can be imagined that allow blind people to have intense aesthetic experiences. . . . People in wheelchairs may not be able to climb mountains, but how hard is it to create a society where the barriers are removed to their experiences of physical exhilaration? . . . Someone with Down syndrome may not be able to experience the exquisite joy of reading bioethics papers and debating ethical theory, but . . . that person can experience the joy of thinking hard about

## The Context *continued from page 12*

disability critique; the motivation for the disability critique is the reality of using prenatal testing and selective abortion to avoid bringing to term fetuses that carry disabling traits. Thus the issue we examined concerns a special way of using abortion: namely, to select against disabling traits.

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something and reflecting on what he or she really believes. . . . The challenge is to create the society that will allow as many different paths as possible to the qualities of life that make us all part of the human community.<sup>32</sup>

The second fundamental point is that rather than concentrate on the truncation or loss of some opportunities, our society generally—and prospective parents in particular—should concentrate on the nearly infinite range of remaining opportunities.

Indeed, every life course necessarily closes off some opportunities in the pursuit of others. Thus while the disability critics of prenatal diagnosis acknowledge that disability is likely to entail some amount of physical, psychological, social, and economic hard-

ship, they hold that when viewed alongside any other life, on balance, life is no worse for people who have disabilities than it is for people who do not. No parent should assume that disability assures a worse life for a child, one with more suffering and less quality, than will be had by those children with whom she or he will grow up.

The claim then is that overall, there is no more stress in raising a child with a disability than in raising any other child, even if at some times there is more stress, or different stress. In that sense the disability community claims that disability is on balance neutral. Even here, however, many find that the terms “neutral” and “normal” are either inaccurate characterizations of disability or are being used in confusing ways. Specifically, some worry that these terms are used sometimes only to describe or evaluate traits and at other times to describe or evaluate persons.

*Evaluations of Traits versus Evaluations of Persons.* As already mentioned, the disability community itself sometimes speaks about the descriptive and evaluative senses in which disabling traits are not neutral, not normal. Legislation like the ADA could not exist without a recognition that in some sense disabling traits are neither neutral nor normal. Indeed, the societal provision of special resources and services to people with disabilities depends on noticing the descriptive and evaluative senses in which disabling traits are not neutral, and how the needs of the people who live with them are, descriptively speaking, not normal. Yet the recognition of the obligation to provide those special resources is rooted in a commitment to the fundamental idea that the people living with those traits are, morally speaking, “normal”; the people bearing the traits are evaluatively normal in the sense of deserving the normal respect due equally to all persons. Unequal or special funding expresses a commitment to moral equality. Recognizing

the non-neutrality of the trait and the “ab-normality” of the person’s needs is necessary for expressing the commitment to moral equality and equal opportunity. There is nothing paradoxical about appreciating the descriptive sense in which people with disabling traits are abnormal while also appreci-

and evaluative claims about the trait do not bear a necessary logical relation to evaluative claims about the person who bears it. As an evaluative or moral claim about the person, it makes perfect sense to say that a person who is blind is normal; she is normal in the sense that she deserves the normal,

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**Families that include disabled children fare on average no better or worse than families in general. Some families founder, others flourish.**

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ating the evaluative or moral sense in which they are normal.

Some who are sympathetic to prenatal testing worry that people in the disability community (as well as others) often conflate descriptive claims about traits and evaluative or moral claims about persons, as for example when Deborah Kent, who is blind, writes:

When I was growing up people called my parents “wonderful.” They were praised for raising me “like a normal child.” As far as I could tell, they were like most of the other parents in my neighborhood, sometimes wonderful and sometimes very annoying. And from my point of view I wasn’t like a normal child—I was normal.<sup>33</sup>

What does Kent mean when she says that she “was normal”? As a descriptive claim, it is not reasonable to say that the trait of blindness is normal. Statistically speaking, it is not. Also, as an evaluative claim, insofar as the trait can make it impossible to enjoy some wonderful opportunities, it does not seem reasonable to say that the trait is neutral. The trait may indeed seem neutral and insignificant when viewed in the context of the whole person; but that is a claim about the person, not the trait. On the view of those sympathetic to testing, the descriptive

usual, equal respect that all human beings deserve.

But if it is easy to notice the difference between the descriptive and evaluative claims about traits and the evaluative claims about persons, why do people in the disability community (and others) keep slipping between the two? Erik Parens suggests that there may be an important reason for this seemingly imprecise slipping. Discrimination against people with disabilities often involves a tendency to allow the part to stand in for the whole; Parens’s suggestion is that members of the disability community sometimes succumb to a similar, equally problematic error. The majority community sometimes uses the trait to deny the moral significance of the person; the disability community sometimes uses the moral significance of the person to deny the significance of the trait. The majority community slips from an observation about a trait to a claim about a person; the disability community slips from an observation about a person to a claim about a trait. At important moments, both groups fail to distinguish evaluations of traits from evaluations of persons. While such slippage may be easily committed in both communities, and particularly understandable on the part of the disability community, it may be equally counterproductive in both.

In the end, for all of the project group's disagreements about the appropriateness of employing selective abortion to avoid raising a child with a so-called disabling trait, and about the aptness of the distinction between aborting any fetus versus aborting a particular fetus with a disability, at least these disagreements forced the group to grapple with what many think is disvaluable or undesirable about these traits. Albeit uneasily, the majority of the working group seems to think that disabling traits are disvaluable insofar as they constrain or limit some opportunities. To say that a disability is disvaluable is only to say that, in the world we now inhabit and in the world we can imagine living in any time soon, to have a given trait would make it impossible or very difficult to engage in some activities that most people would want themselves or their children to have the option of engaging in. For this reason, then, the majority seems uneasily to think that traits are disvaluable insofar as they preclude what many find precious. This view was held "uneasily" because many are keenly aware of how limited our ability is to imagine alternative social constructions—as well as of the extent to which traits once thought unreconstructable are now thought to be nearly infinitely plastic. We are keenly aware of the extent to which the trait that is sex was constructed in the past in arbitrary and pernicious ways, as well as of past arguments that sex could not be constructed much differently. And we recognize how paltry our ability is to imagine what the experience of others is like. Few of us would have believed before the project meetings began that conjoined twins would report feeling about their lives pretty much like people with "normal" bodies report feeling about theirs.<sup>34</sup>

It is important to remember that the disability community arguments are not intended to justify wholesale restrictions on prenatal testing for genetic disability. Rather, they are in-

tended to make prospective parents pause and think about what they are doing, and to challenge professionals to help parents better examine their decisions. They are intended to help make our decisions thoughtful and informed, not thoughtless and automatic. In his book about his son who has Down syndrome, Michael Bérubé attempts to steer a path much like the one ultimately adopted here. He writes:

I'm . . . not sure whether I can have any advice for prospective parents who are contemplating what course of action to take when they discover they will bear a 'disabled' child. Obviously I can't and don't advocate abortion of fetuses with Down syndrome; indeed, the only argument I have is that such decisions should not be automatic.<sup>35</sup>

To some, the advice that such decisions shouldn't be automatic may seem wishy-washy and disheartening. But to those who, like Hannah Arendt, think that evil can arise from thoughtlessness, it seems neither.

### Recommendations to Professional Providers

These reflections lead to a question that defied our efforts at consensus: is there a helpful and rational way to distinguish, in light of the needs and interests of families, between tests that providers should routinely offer and those they should not?

From the beginning of this project, it was agreed that using tests for conditions like Tay Sachs is reasonable. Families have a morally defensible interest in avoiding the stress and sorrow associated with having a child who has a uniformly fatal condition such as this. And at least in the beginning, many also agreed that it would be unreasonable for medical professionals to offer tests for non-health related traits such as, say, eye color. Many agreed that medical resources should not be used to help individuals satisfy narcis-

sism or gain advantage. Further, many agreed, at least initially, that when it comes to prenatal testing to avoid disability, arguably is consistent with the goals of medicine, prenatal testing to produce advantage is not. As James Lindemann Nelson points out, just as most reject what might be called the unconditional demand to welcome the prospect of a child with Tay Sachs, so most reject what might be called the unconditional demand for the so-called perfect child.<sup>36</sup> A desire for what has no conditions or constraints seems to be at work in both, and in both seems unreasonable.

If one thinks there are reasons to draw lines between reasonable and unreasonable tests, then the question becomes, How many and how clearly can and should such lines be drawn? Jeff Botkin has made one of the most sophisticated attempts to draw lines.<sup>37</sup> To undergird that attempt, Botkin offers the general principle that when inquiring about the traits of the fetus, parents should be able to get information "designed to prevent harms to parents that are approximately the same magnitude as the harms of an unwanted pregnancy" (p. 36). The reasoning goes something like this: we assume that the prospective parent's conception of the harm associated with an unwanted pregnancy is realistic and appropriate. And we recognize that beyond the abortion itself no other scarce medical resources, such as prenatal testing and genetic counseling, are required. However, according to Botkin, we should worry that the prospective parent's conception of the harm associated with some disabling traits is neither realistic nor appropriate. "The disappointment parents may feel [in circumstances where the condition is minor] is real, but disappointment from unrealistic or inappropriate expectations need not be considered a harm worth preventing" (p. 37). That is, we should develop criteria to help determine when the harm associated with a disabling trait is realistic and appropriate enough to

such ignorance is one of the primary sources of the discrimination suffered by people with disabilities. Our outrage at that discrimination is rooted in our fundamental commitment to the moral equality of all persons. Out of that same respect for persons grows our belief that prospective parents should have the liberty to make decisions about the uses to which they will put prenatal information about genetic disability. As those in the disability community have argued since they first launched their campaign to get medicine and bioethics to examine the assumptions behind prenatal diagnosis, those decisions will be truly informed—those exercises of liberty will be authentic—only when people in our society come to learn what disability really does and does not mean for individuals and their families.

Although the group as a whole does not accept even claim in the disability community's critique of prenatal testing, we do wholeheartedly endorse its central commendation to reform how prenatal genetic information is communicated to prospective parents. Even with the best information about the meaning of disability to various individuals and families, and even if that information is made available to prospective parents many weeks before they must make any decisions about parenthood, many (perhaps most) will choose to forego raising a child with a disability. But if prospective parents comprehend what is possible given a disability, if they carefully ask themselves hard questions about what they want and will appreciate in a future child, then they and any future children they raise have a better chance for fulfillment and for mutual, rewarding family life. And if genetics professionals learn more about what raising disabled children can mean, rethink their approach to parents, and help those parents better imagine what a child's disability might mean for their family, then some progress will be made in honoring the disability rights move-

ment's central message that our society must be able to value people and lives of many different kinds. Only as we take that message seriously can we be confident that our prenatal decisions will improve familial and communal life.

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