his series of books, published by The Hastings Center and Georgetown University Press, examines ethical issues in medicine and the life sciences. Established in 1969, The Hastings Center, located in Garrison, New York, an independent, nonprofit, and nonpartisan research organization. The work of the Center is mainly carried out through research projects, the publication the Hastings Center Report and IRB: A Review of Human Subjects Research, and numerous workshops, conferences, lectures, and consultations. The Hastings Center Studies in Ethics series brings the ongoing research of The Hastings Center to a wider audience.


34. Blumberg, "Eugenics vs. Reproductive Choice."

35. Asch, "Reproductive Technology and Disability."

36. Ibid.

37. Blumberg, "Eugenics vs. Reproductive Choice."


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My daughter, Sesha, now twenty-seven years old, lives at home with us. It is sometimes easiest to describe her in the negative, what she is not and does not do, for these are the well-defined capacities: she doesn’t talk, she walks only with assistance, she is not fully toilet trained, she can’t feed herself, and so on. But what she is is so much more. She is a beautiful young woman with a winning smile, an affectionate nature, and a love for music, water, food, and the joys of physical affection. I had never before written of her or our relationship and had not used my knowledge of living with a disabled person directly in the service of my professional writing.

I was about to undertake the first of such writings when I was invited by The Hastings Center to participate in a project on prenatal testing for genetic disability. I had wanted my first forays into writing philosophically about my daughter to be about her and what her life means and has meant to me. I had to be persuaded to join the project, for it meant that instead I would have to reflect on the hypothetical of her nonexistence, and worse still, of the hypothetical of having had to choose whether or not she was to come into the world.

During the course of the project, I was asked to consider whether selective abortion for disability “sends a message” that devalues the life of the disabled. When some initial discussions on the question revealed differences between me and my twenty-one-year-old son, Leo, who has an undergraduate degree in philosophy, I chose to write a chapter by conducting a dialogue with my son. We carried on our conversation through e-mail over a period of a few months while my son was working at a ski resort. This article records our dialogue.
From My Diary

I want to get some thoughts on paper before the intensity of this, the first of the four Hastings meetings, evaporates.

10/22. Reflecting now on one participant's memory of when her pediatrician told her that he didn't know if her underweight baby would be all right, and her recalling this as the most terrible moment in her life, I thought what I would answer had someone asked me, "was the moment you learned that Sesha was retarded the most terrible moment in your life." I would have answered, "No." The most terrible moment in my life was when I thought Sesha would die. The next most terrible moment was when my mother insisted (or tried to insist) that Sesha be institutionalized and that I give her up.

I was asked if my mother has changed her attitude toward Sesha, I said, "Yes," and said that had happened because she initially thought that keeping Sesha would ruin my life. She's seen that it hasn't ruined my life.

10/23. Wednesday morning I awoke feeling sore internally, somewhat nauseated, somewhat as if I were recovering from a physical torture. Tuesday evening, as I tried to cram the articles on psychological experiments on metaphors and idioms into my head for the upcoming class I teach, a dam burst and the floodgates came undone. I sobbed—deep, deep sobs from the interior of my soul. I cried, I cried for Sesha. I felt the hurt for her impairments, for the profound limits of the life she could experience, for the multiple aspects of life she could never know or even know that she couldn't know. I wept for Sesha—not for me, not for Jeffrey [my husband], not for Leo, but for her, her sweetness, her limitation, and the pain of knowing what a small aspect of human life she could inhabit. She, my daughter—the child I had brought into the world and the child I had raised and worked to nourish and protect. It is a hurt that doesn't dare to be felt, almost all the time, and it is a hurt that cannot be felt in her sunny presence. But it is there and at moments like post-Hastings it floods in.

Now what is this mysterious pain? Mysterious because who is hurt? I don't think Sesha is aware of her limitation. It is not like the sorrow for another's pain, because pain is felt by its bearer. So do I cry for myself and my expectations of the child I wanted to raise? That is not what those sobs were about—I know—I've had that cry as well. I need to think more about this mystery.

In debriefing Jeffrey and Leo on Tuesday, I spoke of the question posed at the conference: Whether aborting after learning that the fetus is impaired sends the message that a disabled life is not valuable. I asked Leo: If I had aborted a fetus based on disability, would it have sent the same message to him as would the message he'd receive if we had institutionalized Sesha. He said, "No." It wouldn't have sent the same message, but he did think that the message of an abortion would have been that the disabled shouldn't exist. I asked him, "Even in the face of Sesha and our life with her?" He answered that it still would, although it wouldn't be as strong as the message would be if I had aborted an impaired fetus in the circumstance that Sesha was not part of our life.

This surprised both me and Jeffrey. But it is information I must take seriously.

Dear Leo/ Dear Mom

EFK's Letter #1
Dear Leo, I've been asked to address the question of expressivity of a woman's decision to abort a fetus that has been diagnosed with a disability following amniocentesis or other prenatal testing. The question of expressivity is the question of whether such a decision signals the devaluation of the life of a person with disabilities. I thought I would send you excerpts of the letter I sent to Erik Parens when he first invited me to participate in the Hastings Center project. Tell me what you think.

Much love, Mom

Dear Dr. Parens:
I have a severely retarded daughter who also has cerebral palsy. As much as I value my daughter—she, together with my well son, constitute the single greatest joy in my life—I do not agree with the negative appraisal of prenatal testing that you say has been articulated by some members of the disability community. I believe that our society does not provide the conditions that make raising and caring for a severely handicapped child, while otherwise living a full and fulfilling life, possible for most parents, and I am skeptical about the possibilities of any society reaching such an ideal state in the foreseeable future. To undertake to care for a child with severe disabilities has been a difficult and painful course, and yet to abandon such a child to the care of strangers was and continues to be, for both me and my husband, unthinkable. We have...
garnered tremendous joy and learned more than one can imagine from our daughter, and yet the decision to have a child with such severe and multiple handicaps is not one I could easily endorse. I think it is terribly cruel to burden a couple with the responsibility for a severely handicapped child when prenatal testing can determine in advance the condition of the fetus. Furthermore, as a feminist, I must underscore that the responsibilities normally fall to the mother, as fathers not uncommonly abandon the family with the advent of a severely disabled child, and in most instances the mother provides the daily care.

On the other hand, prenatal testing does not eliminate the tragedy of a child who is severely impaired, for I can also envision the agony of making a decision either to abort or not to abort. Rather, the testing shifts the tragic moment and the decisions to be made. But if the decision is made to go to term, even in the face of the impairment, at least there is a conscious choice, made with the possibility of a truly informed understanding of what such a decision requires of the future parents. Moreover, the availability of the technology to avert some of the consequences of genetic disabilities does not absolve the society at large of mitigating the difficulties of raising and caring for disabled persons. In any case, such is the line that I would take based on my own personal reflections.

Sincerely, Eva Kittay

Leo's Letter #1

Mom,

If we are to take the position that giving birth to a retarded child should be a choice in years to come, that is to say, that all parents will have their fetuses tested, and that the only fetuses to reach full gestation will be those whose parents have expressly chosen to raise them, then we must also be sure that some other changes are made. To begin with, it must be made public that raising a retarded child is equally, albeit less so, fulfilling, Mom, it is probably because we just expect it to be less so. Without such increased exposure to those different joys, sheer ignorance will cause the retarded population to become extinct. Anyone with the option would decide to abort a disabled fetus because they would not be able to imagine that the incredible burdens of raising a retarded child could be outweighed by the joys.

Why is this bad? Actually this is a hard argument to make. Social Darwinists might say that this is fine. This is a sort of "preemptive" survival of the fittest argument. However, a survival of the fittest argument is applied to fetuses or children only with difficulty. All babies are weak, and they tax parents and society. It might seem that we would all do better for ourselves in a world without the dependent young, but we all know such a world would be short-lived, if not absurd. Even Social Darwinists must take into account the dependents. They could argue that eventually "normal" children will grow big and strong. But, while many disabled children do not become strong and independent, some "normal" children do not either. This leads me to my next point. The argument you're making draws a major line between normal and retarded children, based on the difficulty of bringing them up. But beware the slippery slope, Mom. Are not all children a burden?

If, someday, we could determine that a fetus will develop into a hyperactive child, or into one with recurring ear infections, will these children's births also have to be expressly willed? Children are a burden. But it is incredibly important to keep making them and tolerating them. No, Mom? No human child is fit for survival without the help of elders. To start drawing the line about how much help they should need is extremely problematic. Some groups of children will start vanishing. And we do not even want a single species of animal to disappear. They are all intrinsically valuable. How do we show others how wonderful it can be to raise a retarded child, and how important and valuable her existence is? It is difficult! Especially if fewer retarded persons are being born.

What kind of message does aborting the retarded send to would-be siblings? I can only guess at this, Mom, because Sesha was born. But here are two different messages I could conceive of receiving:

1. The love my parents have for me is a condition of my being mentally and physically sound, not just of being a child of theirs. Rephrasing this: The only reason my parents want me is that I'm relatively smart and fit.

2. My parents chose me and therefore must really care about me. Again rephrasing: My parents wouldn't just love any child they might have, they love me because I possess the desirable properties or characteristics that make me who I am.

What I am trying to say is that the family starts to seem more like a club, and less like a family. In a club the members are selected based on one characteristic or another. This leads one to believe that if, for some reason, that characteristic is no longer attributable to the individual, or if anyone in the club comes to believe that this characteristic never applied, the membership in the group and the "love" that results can vanish. If a fraternity guy stops playing football well, he might be

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afraid he would not be wanted in the fraternity anymore. He was aware, after all, that his ability to play football allowed him entry into the club. If a child believes his membership in the family is contingent on not being retarded or otherwise disabled, he might at first value his place in it more highly because it was earned. (This goes hand in hand with the belief that those who are retarded or disabled are worth less. I think immediately of children who use the word "retard" on those they wish to insult and how this insult always seems to be underscored by the desire of the one doing the insulting to differentiate him- or herself from those who are retarded.) But the positive feeling that love has been earned can subside, and the child might instead feel a constant pressure to prove himself to be worthy of his place in the family. He will not view his family’s love for him as unconditional love.

I hope these thoughts are helpful.

Love, Leo

EFK's Letter #2

Dearest Leo,

You raise many points, each of which is crucial and each of which I want to explore. My assignment was to consider the expressivity of prenatal testing with respect to disabilities generally, but you speak primarily of retardation. I will move from the one case to the next with some fluidity, although I will try to address the larger perspective of disability.

Parenthetically, let me say that in reading your letter, I realized why I have tended to speak of Sesha as "handicapped" rather than "disabled"—a designation for which I was called to task at the first meeting of The Hastings Center project on prenatal testing. Sesha’s disabilities are so severe that in speaking of my child as disabled I think that I will be failing to communicate the particular condition that is Sesha’s. That is, to speak of her as disabled puts her in the same category with persons with relatively mild disabilities, disabilities that do not prevent them from leading very independent and productive lives. By whatever our standards for independence and productivity, Sesha doesn’t now and never will meet those. I feel more comfortable speaking of Sesha as "seriously disabled," although someone like Stephen Hawking is, by any standards, seriously disabled, and again by any standards is productive, though not independent. I recognize, of course, that "independence" too is a slippery notion because in some very important respects no one is independent.

The Americans with Disabilities Act speaks of a disability as “a physical or mental impairment that substantially limits one or more of the major life activities.” Disability activists speak of handicaps as the consequence of a disability, where environment limits an individual with a given disability.9 Many of these handicaps can be overcome with social interventions and modifications of the environment. It takes a social and political will to structure the environment so that it responds to the needs of those who are disabled. But Sesha’s condition is such that most of her disabilities remain handicaps even with environmental modifications. In Sesha’s case handicap and disability are nearly coincident. I think the distinction is nonetheless a very important one and speaks to the importance of how we express ourselves with respect to disability. I want to make it clear at the outset, that nothing I have to say is meant to deny the importance of how we speak with respect to the disabled. I think that Michael Bérubé is correct when he speaks of how representations of the disabled figure in their treatment and life prospects.5

Let me now summarize what I think are your main points. I will then address them.

First, you speak of the need to expose people to the joys and fulfillment of raising a child who is retarded (or severely disabled). Second, you address the possibility that with advances in prenatal testing all cases of retardation (and other serious disabilities) will be eliminated. You then ask us to consider what would be lost if we no longer had persons with mental retardation. Third, you point to the problem of arguing from the difficulties and burdens imposed in raising a seriously disabled child, and the slippery-slope problems connected to such a position. Finally, you address the message that the sibling gets if the family chooses to abort a fetus diagnosed with a disability.

I will start with the second point, the speculation that with advances in prenatal testing all cases of retardation (and other serious disabilities) will be eliminated. Most cases of retardation are not genetically based. Most cases of retardation result from something going wrong during the pregnancy itself or immediately after birth. This was probably the case with Sesha. Such cases could not be picked up in prenatal testing, which depends on examining genetic material. Even if all retardation or other disability were picked up prenatally, there would still be problems that occur during birth and immediately after birth. Then, of course, there is disease and trauma that leave children (and adults) disabled (and sometimes mentally retarded)—some of the children in
Sesha's early intervention program, for example, were casualties of car accidents or gunshot wounds. However, certain populations, such as those with Down syndrome and spina bifida, are likely to be diminished by selective abortion following prenatal testing.

Among fetuses diagnosed with Down syndrome upon results from amniocentesis, it has been said that 90 percent are aborted. However, that figure has to be looked at more carefully. Prenatal testing, although increasingly available, is not available to large numbers of women—and even when it is available, not all women avail themselves of it. So when we get the 90 percent figure, we get the percentage of women who have taken the test, often having already concluded that they would abort if the results are that the child has a severe disability. The literature indicates that the reasons for aborting—whether or not they are well informed—are various and complicated. But we can discuss that later.

My point now is only that I do not believe we will ever see a world without persons with disability, without serious disability, without mental retardation, or even without persons with Down syndrome or spina bifida—even though there may well be fewer of the latter individuals, and we can certainly talk about the extent to which this would be undesirable.

Now you go on to ask what would be lost if it became the case that populations of significantly retarded persons and others with serious disabilities would be eliminated or significantly diminished through selective abortion. Let us confine this question to the case we know well, mental retardation. And qualify that case to include not all mental retardation, just all mental retardation that occurred before or even at the moment of birth. Well, I agree that the world would be a poorer place without persons with Down syndrome or other sources of retardation, without people like Jamie Bérubé, or Sesha. Our household has been immeasurably enriched by Sesha. People like Jamie, Sesha, or Abbie [our neighbor's little girl], force us to think much more profoundly about what it is to be human, what our obligations are to others, why we have these obligations, what the source of human joy and human sorrow is. I haven't begun to plumb the depths of these questions with respect to Sesha, but they are my measure of the truth, and the value, of all philosophical theories. If they cannot include Sesha in their universe, they are at best incomplete, at worst faulty. And that is not because Sesha is so different from us, or even because she is so much like us, but that at the very core, we are so much like her. We understand so much more about who we are and what moves us, when we see what moves Sesha. I understand so much more of what it is to be a parent and love a child like you, when I know what it is to love Sesha. (But, of course, there are also limits to that. If I kissed you as much as I kissed Sesha, you would have been gone from this house much sooner!)

And yes, Bérubé is right. Sesha's value, like Jamie's value, is not in what they teach us. They are of value in and of themselves, in the same way that you are of value in and of yourself. Perhaps the world is always diminished when that which has value in and of itself, intrinsic value, is lost to the world. Perhaps Wittgenstein was wrong when he wrote, "The world is the totality of facts." Perhaps he ought to have said, "The world is the totality of intrinsic value." Because our world—our lived world—does not consist of facts, but of our understanding of facts and the value those facts have in our life.

Now, if I choose to abort a fetus that would grow into a child with disabilities, have I diminished the world? That is a painfully difficult question. Yet I cannot see that it is necessarily a very different question from the question: "If I abort have I diminished the world?" For to abort any fetus will be to abort a being that would have intrinsic value in this world. Perhaps I deviate from some feminists in thinking that a decision to abort is itself a difficult one; often, psychologically painful and ethically problematic (not necessarily wrong, but not easily right.) Yet I do not deviate from the feminist position in believing that the moral choice must be the woman's to make. I remain convinced that the same must be said, though perhaps with more poignancy (and you will be right to ask why), when the phrase "with disability" is inserted. Let me end this letter for now. Perhaps you want to reply before I move on to the other points. Hope the skiing continues to be wonderful.

All my love, Mom

Leo's Letter #2

In response, Mom:

I think that your summary doesn't highlight my point that it is only through exposure to actual retarded people that anyone can really appreciate how much they contribute to our lives, at least with the most severely "disabled." (Here I don't include Stephen Hawking because we can measure at least some of his value on the same scale that we measure the abled.) Not all disabled people are wonderful, though, and we would not want to put together an argument that is based on that premise. (Bérubé makes this point, his most memorable in my opinion. The story of My Left Foot also contains wonderful examples of this, when the disabled protagonist is often less than charming.) We could argue
that severely disabled persons are pivotal to our world because they
too add to it. Yet evil people, boring people, everyone adds to a culture
in some way, and probably in some positive way to boot. No one tries
to suggest that we attempt to abort these groups. You are right though,
Mom, when you say we will never have the choice, or at least not in
the conceivable future, of whether or not to allow disabled people to
exist. So I don't know if this is an interesting line of argument at all.
Two possibilities might result if there were fewer retarded persons.
The first is that fewer people will know what joys can come from being
around someone like Sesha. More ignorance, and this is never a good
thing. But here is another way of looking at it: a smaller population of
this minority would be less threatening socially, politically, and economi-
cally (like the single African American child in an all-white school, or
the sole Jewish family in a town of Christians). Sometimes it is easier
for a minority to prosper under these conditions. But I tend to buy
the first result more readily. The second feels too artificial and, in
circumstances like these, the danger of stereotyping remains substantial.

You point out that I would want to consider why you say that
aborting a disabled child is more poignant. I think it is because it feels,
for a moment, to be an easier question than that of aborting a normal
child. We fear that it will not get the same weight as the other question;
that our system of values weighs the death, or (sorry) the lack of life,
of one as less meaningful than the other. I think the way we will have
to argue this point is to equate the value of the disabled with that of
the normal. Maybe this is obvious to you, but it is not to me. Just as
you are arguing that there is no difference between aborting a normal
fetus and aborting a fetus with a disability, so we have to say that Sesha
is not special—she is equal. Yes, she takes more money, more time,
more patience maybe, but these needs should only be an adjustment in
the mental figuring of the would-be parents. This is and must be separate
from any appraisal of the child's worth.

Love, Leo

**EFK Letter #3**

Dearest Leo,

I want to respond to the point that people need exposure to disabled
persons if they are to understand that the value of disabled people is,
as you say, equal to the value of those not impaired. But I want to start
by addressing the equally serious matter of the slippery slope argument.

You write that the argument I'm making draws a major line between
normal and retarded (and other seriously disabled) children, "in the
sense of them being difficult to raise." And while you acknowledge that
this may be the case, you argue that we have to watch out for slippery
slope arguments that would have us ask if, whenever detectable, other
conditions which make a child more difficult to raise would make such
conditions eligible for selective abortion as well. So if a child has a con-
dition which would, for example, lead to recurring ear infections, that
would be a condition for which parents may choose to abort. And you
ask, "Are not all children a burden?"

A slippery slope problem is always hard. One doesn't even need
to move into science fiction to face some of these dilemmas, since,
although most genetic disorders detectable by prenatal testing today are
potentially severely disabling, the tests cannot tell us how severe these
disorders will be. In the language of genetics, test results cannot tell
us the degree of expressivity of the genetic anomaly. Some conditions,
such as Turner's syndrome, can result in a life that is little different
from the life of persons without this disorder, except that the individual
cannot bear a child.

Then again, women are already free to abort a fetus irrespective
of any manifestations of disability. Some disability rights activists, who
consider themselves to be feminists and pro-choice, argue against selec-
tive abortion on the grounds that there is an important distinction to
be made between "aborting any fetus" and "aborting this fetus." That is,
they maintain it is one thing to determine that you do not want to have
a child, or to have a child at this time, or even with this man (that is,
abortion simpliciter), and another to say that you do not want to have
this particular child because it manifests such and such a trait (that is
to say, selective abortion). Perhaps this is the argument you would
like to endorse?

Well then, here is my question. Why do women choose not to
have a child? Or not to have a child at a particular time? Or not to
have the child of a particular man? Well, for many reasons. But whatever
the reasons (unless the decision is that they do it for ideological reasons—
for example, "I do not believe it is right to increase the population of
an already overcrowded world, but I will adopt and raise a child already
born" or "I will not raise cannon fodder for a war state," or "I think
this is too evil a world into which to bring new life"), the reason to
abort involves some decision not to assume the burden, yes, burden of
raising a child, now or under the current conditions of the woman's life. For yes, my dearest son, children are a burden.

Children, however, even in terrible times, under terrible conditions, are also a source of the deepest joy and satisfaction imaginable. Even under slavery, many women had their babies and raised them in spite of the near certainty that these children would be slaves, as abject as they themselves. Harriet Jacobs was a young slave woman who wrote of an old slave woman who chided her for shedding tears over her children: “Good old soul! She had gone through the world childless. . . . No sweet little voices had called her mother; she had never pressed her own infants to her heart, with the feeling that even in fetters there was something to live for.”

We can add that even where a child is as profoundly disabled as Sessa, there is so much to treasure. Does my assertion that “I think it is terribly cruel to burden a couple . . . with the responsibility for a severely disabled child when prenatal testing can determine in advance the condition of the fetus” belies the value of a child like Sessa, a child who requires very extensive resources, material and emotional, to survive and thrive, whose care is so burdensome, even as it has such special rewards? Children are a burden, but we each engage in numerous decisions about when and how to assume the burden, responsibility, and privilege of raising a child. We choose a mate or defer or decide against marriage (or cohabitation); we engage in or avoid sexual intercourse; we refuse or use contraception; we choose whether or not to take the pregnancy to term, when abortion is a choice; we commit to raising the child, or have family members raise the child temporarily or permanently, or give it up for adoption, and so forth.

Women have been thwarted in making such choices at various points along the way. As in all matters, we make choices but circumstances foil us and we are faced with unanticipated consequences of our actions or the actions of others. At each fork in the road, we have to decide. And when the matter is the care of a child, well or sick, able-bodied or disabled, we have to think if and how we can assume that burden and if the sacrifices required, at this time in our life, under these life circumstances, and given our current estimate of what our capacities are, what resources we can muster (remember how Bérubé quotes Janet declaring to him, “We can do this”), and what this child will require to survive and thrive. Rayna Rapp, an anthropologist studying women who have refused amniocentesis or who sought (or submitted to) it, and then based on a fetal diagnosis decided to abort, writes of the different decisions women make. They are based on the women’s perceptions and understandings, both of their circumstances and of the kind and extent of the disability.

The choices are enormously complex. An unmarried woman in her late thirties, whose pregnancy is “an accident” but who is delighted to be pregnant, chooses not to have amniocentesis because she knows that she will not have another opportunity to have a child. She knows she can welcome the child, whether or not there is a disability, as long as she has the support of the church she once left, the Seventh Day Adventists. Another woman, in her forties and with two sons and a daughter, chooses to abort a fetus diagnosed with Down syndrome because she is concerned about having a child with a disability at her advanced age. She fears that she will not live long enough to care for the child as the child ages. She is further concerned that such a major and unending responsibility will fall to her daughter alone. Another family, which includes a cousin with Down syndrome, in learning that the child will have a disability that may result in the child’s being “slow,” but outwardly normal in physique, decides to bring the pregnancy to term. They would have aborted if the child had Down syndrome because they were witness to the exertions on the part of their family in caring for the physical aspect of the disability of their cousin.

Many of these decisions are inflected by experience of race and the history of racial oppression. One African American family, whose fetus was diagnosed with Down syndrome, was told of farm communities where adults with Down are cared for and where they can participate in farmwork. The father’s response was, “Sounds too much like slavery to me.” They decided to abort. Many urban white families, in contrast, find the thought of a rural life for their Down syndrome children a comforting notion.

So yes, all children are a burden, and maybe you are quite right to say that to argue for the permissibility of abortion when the fetus is diagnosed with a severe disability on the grounds that a disabled child presents greater burdens is untenable, since the question of where we draw the line is an inevitable and unavoidable one. Perhaps the best rejoinder (if there is one) is to say that because having a child, any child, is a great burden and a great responsibility, our obligation as a society and as prospective parents is to go into that great adventure with our eyes open and with as much forethought as we can muster about whether we can assume that burden in a responsible way. Because a disabled child poses special burdens and responsibilities, a mother and
a family must know that it is a challenge that they are prepared and willing to meet, when, that is, foreknowledge of an impairment is an option.

In fact, judging from the accounts that Rayna Rapp has accumulated, it is just such thinking that does, in fact, predominate. These thoughts and these facts have a great bearing on the question of the expressivity of selective abortion, which I would like to sort out in a future letter. But for now, I want to mention two things. First, the stigmatization of the disabled. Doesn't that play a big part in the decision making of families and in their thinking of what they can and cannot handle (and so, argue those opposed to selective abortion, permitting such abortions only reinforces the very stigmatization that is a causal factor in the decision). If so, the question you raise, whether stigmatization increases or decreases with a greater or lesser population of the disabled, is pertinent.

Second, a very important part of the decision making around testing and abortion has to do with the resources that the society itself makes available. For many women, the idea of raising a child with disabilities is weighed against her own ambitions, the ambitions she has for her other children, the prospects for her disabled child when she can no longer care for her. Perhaps it is more appropriate to question how the larger society values or devalues the disabled life—by looking at the resources it withholds or devotes to children with disabilities and their families—than to impute a disregard for the value of the life of disabled persons to the pregnant woman who tests for and aborts a fetus with impairments. I want to talk more about this social dimension later.

Must go now. Call us tonight, and let us know if you are going to remain in Taos.

Much love as always, Mom

EFK's Letter #4

Dearest Leo,

I am now going to try to respond to the first point, which you have been pressing throughout: The need to expose people to the joys and fulfillment of raising a child who is retarded (or severely disabled).

And you want to add, rightly, that not all who are disabled are wonderful nor that anyone who is disabled needs to be wonderful or sweet or whatever positive attribute we want to put in, in order to be valued. Again, I have no argument. I also have no argument with the need to expose all of us to more persons who are disabled, whatever the disability. That educating ourselves and others about differences in abilities, in the rewards of raising a severely disabled child, is crucial if women are to make a well-informed and genuine choice. Perhaps it is especially important to become aware of those who are severely cognitively impaired, and of their presence as being crucial to enriching all of our lives. Increasing such awareness is vitally important if we want those who have had no intimate contact with disability to open their hearts and devote resources to improving the lives of the disabled and their families.

I think few things are as difficult for humans to face as disabilities they themselves do not have; few “differences”—not race, not gender, not sexuality—are as threatening to a person’s notion of self. Most characteristics that put us in a relatively privileged position are ones that it is difficult for us to imaginatively transmute. A man won’t turn into the devalued woman; the white into the devalued black; the Christian into the devalued Jew. But the able-bodied can in fact turn into the devalued disabled at the next turn in the road. You would think therefore that prejudice against the disabled would be contained, confined, because, after all, at any time “I” could turn into “them.” But, instead, such a possibility only increases the prejudice, the avoidance, and the stigma.

I don’t know how to get past this, except to show people our love for Sessa, to recognize the difficulty others have with Sessa and simply, by our example, help them past this. But does this mean I have gotten past all my prejudices concerning the disabled? No. The first thing is to recognize them, know where they come from, and then relate to the person and not the disability, except as you can be of service or learn from the person who has had to engage in struggles you yourself have not faced. I think that all the kids in your high school who watched your friend’s sister participate in high school performances and athletics will have more understanding about what it means to have the Down syndrome that marked her as “different.” They will not automatically respond to a pregnancy with, “If there’s Down, we’ll abort.” But I also am sure that among special education teachers, who have a deeper knowledge of what retardation and severe disability mean, there will be those who decide that, while they value every one of their students, they themselves cannot take on the challenge and responsibility of raising a child with a severe disability. In fact, among the women in one of Rapp’s studies, there were two women who were special education teachers who chose to abort.
Rayna Rapp cites another woman, on the other hand, who upon receiving the diagnosis visited a group home for the mentally retarded and chose to bring the pregnancy to term. Knowledge is crucial. I agree. And the time to get informed is not just when you are facing the decision. We need to be active in integrating persons with disabilities into every aspect of life, to seeing that our society devotes the resources that can facilitate such integration and facilitate the lives of disabled persons and their families. Only when this is the case will people have the exposure to children such as Sesha and Jamie Bérubé that will permit prospective parents to truly understand what is involved in raising a child with severe impairments.

However, when that is the case, raising a child like Sesha will also be different. Raising a child with developmental delays and deficits today is so very different than it was when Sesha was born. What was available to Jamie was not available, or only becoming so, when Sesha was born. “Early intervention” was an entirely new concept then. New York City sidewalks didn’t have a cut in their curbs that made using a wheelchair so much less cumbersome—an improvement that helps not only the disabled but also every parent who has an infant or toddler in a carriage and every shopper with a shopping cart.

Still, we live in a society without guaranteed health care for every child, much less every adult. How would Janet and Michael Bérubé have paid for Jamie’s care if they didn’t have generous insurance plans through their employment? During Sesha’s recent back operation, her surgeon alone cost $25,000, paid for through the generous health care plan my job provides. One professor I know who has a severely disabled child has an ongoing battle with his university because they set a one-million-dollar limit on her medical insurance, and in the time he has exceeded the limit! So our society has done little to provide for even basic health care for the disabled. While this is also a difficulty for families with unimpaired children, for families with a disabled child, where medical emergencies are so much more frequent, having to consider cost can be devastating. The story that Bérubé tells of Jamie’s early years is about par for the course—for some it’s better, for some it’s worse.

Then there is the question of the daily care of the severely disabled. There are now some respite programs that provide care for a disabled child so that a parent may have some time away from her disabled child, but these are woefully inadequate, as are the facilities for the severely retarded once they “age out” of the mandated school programs. If we want to speak of acts that are expressive of the devaluation of the life of the disabled, then to direct our attention to selective abortion is to direct us away from acts that are most egregiously expressive of this devaluation. The devaluation of the disabled life is expressed over and over again in the failure of our society to provide adequately for the disabled and their families. A woman who decides that she must make what is an excruciatingly difficult choice to abort (see Rapp’s account of her own decision) may not be expressing that devaluation except in a secondary sense. She acts thus because she is faced with Hobson’s choice—this or not at all: To raise a child with disabilities with only minimal social support (this) or to abort (not this child at all). It is an act motivated in part, at least, by the difficulties created in a society that fails to accord full humanity and citizenship to the severely disabled.

This isn’t to say that in a utopian society not a single fetus will be aborted because of disability. Society can make available certain material resources, but individual emotional resources will vary from family to family. Perhaps some people shouldn’t be parents at all, and some shouldn’t be parents to disabled children, at least when that situation can be foreseen. Some parents cannot love unconditionally. I have heard parents say that their love for a child was diminished because the child wasn’t as smart as they wanted their child to be. How sad for that child, I think. How much more devastating for a child not to get the love and the special love that she needs to sustain the illnesses, the pain, the loneliness that so often accompany a disability.

People who come into our house say Sesha is lucky to have parents who love her so much. And our standard response is that we are lucky to have Sesha whom we can love so much. But, in truth, they are right. As lovable as Sesha is, not every family may have allowed themselves to find out how wonderful she is. It’s hard to imagine since she touches your soul so, but I just know it’s true. To be able to love her so, to find it hard to imagine that anyone couldn’t love her so, is to be touched by a bit of grace, and it has been our good fortune to be granted that grace. But what would her life be like if she didn’t have people to love her as we do?

That, my dear, is the most painful thought—the thought of what happens to her when we are no longer around. No, these are things no one has any right to tell a family—no one has a right to say to a family: You must take this on and if you don’t you are immoral, you don’t value a life that is disabled.
Finally, I am ready to address some of your concerns as a sibling about the expressivity of the act of abortion in the case of disability. I’ll write this tonight and tomorrow and e-mail you tomorrow night.

Love, Mom

**EFK’s Letter #5**

Dearest Leo,

You ask, “What kind of message does aborting the retarded send to would-be siblings? And you say that there are two possibilities to consider. The first is a negative message, that parental love is conditioned on “soundness” and accomplishment, or as you put it: “The love my parents have for me is a condition of my being mentally and physically sound, not just of being a child of theirs.” And you provide an alternative formulation of this idea, that “the only reason my parents want me is that I’m relatively smart and fit.” I see your alternative formulation as one that has to do not with the infant when born (a time when we cannot assess intelligence or athletic ability, but only good health and absence of anomalies) but has rather to do with the child’s realization of the potential that good health and soundness make available.

The other possible message seems at first more positive, but contains a hidden explosive that can shatter a child’s sense of well-being. This is a very disturbing message that we need to explore. You suggest that the message received might go something like this: “My parents chose me and therefore must really care about me.” Or, “My parents wouldn’t just love any child they might have, they love me because I possess the desirable properties or characteristics that make me who I am.” But this seemingly positive message becomes just another statement of a conditioned love. For then, as you say, “the family starts to seem more like a club, and less like a family,” in which the members are selected based on some desirable features. But if a person starts to fall short of the desirable characteristics, she knows that she is no longer welcome in the club. In a family, this would lead a child to feel “that if I don’t toe the line and exhibit the desirable characteristics, I’ll no longer be valued.”

You take your example of a club, and less like a family, “the family starts to seem more like a club, and less like a family,” in which the members are selected based on some desirable features. But if a person starts to fall short of the desirable characteristics, she knows that she is no longer welcome in the club. In a family, this would lead a child to feel “that if I don’t toe the line and exhibit the desirable characteristics, I’ll no longer be valued.”

You see your alternative formulation as one that has to do with the infant when born (a time when we cannot assess intelligence or athletic ability, but only good health and absence of anomalies) but has rather to do with the child’s realization of the potential that good health and soundness make available.

First, however, we need to think a bit about what it means to send a message. You are asking about the kind of message the act of selective abortion based on disability sends to the sibling. Opponents of this sort of selective abortion ask, “What kind of message does it send to society about the value of the life of persons with disabilities?” Many opponents of selective abortion (see, for example, Saxton) claim that something is communicated in the decision to abort selectively for disability—that we say we want a child, but we do not want this child. They ask us to consider the claim that aborting a life sends the message that a disabled life is not one worth living; very much the way feminists have claimed that selective abortion for gender, which is generally a choice against having a girl, is a statement devaluing the life of females. They ask us furthermore to consider the impact of this sort of message on those who are female, in the one instance, and disabled, in the other instance. In focusing on the message that the sibling receives, your point is more specific, yet some of the considerations are the same. Some others, I’ll try to show, are different.

The first thing we have to consider is whether the act of selective abortion is a “saying.” Is it an act of communication at all? What are we committing ourselves to when we claim that it is? Can we base an ethical evaluation of the act of selective abortion on the claim that the message sent is a devaluation of the life of those possessing the properties that determined the choice to abort?

When we say things, we are generally thought to mean what we say. I say, “It is raining,” and mean by it that it’s raining. Sometimes we speak of something meaning something when there is no one who is speaking, or when someone is not speaking but doing something. For example, we can say that lightning means thunder, or that a bear’s paw prints mean that a bear has been here recently. Philosopher of language H. P. Grice makes the distinction between “natural meaning,” as in “thunder means lightning,” and “nonnatural meaning,” as in $U$ meant something by uttering $x$. Now if we have an agent that is capable of meaning something, then we can ask what that agent meant by her action, even if that action was not a piece of verbal behavior. Let’s say this is a case in which $U$ meant something, by doing $a$. So, if the footprints are those of a person and not of a bear, we might wonder if the person meant something by leaving those footprints. But the person may have meant nothing at all by leaving footprints. In that case, we can legitimately conclude nothing more from those footprints than what we can from a bear’s prints. Nonetheless, when we have an agent
who has intentions we are tempted to ask about a given act a if U meant something by act a.

Now if we take the term “utterance” to include acting as well as saying, then the utterance x could be an action. Grice goes on to analyze nonnatural meaning of utterances as follows:

“U meant something by uttering x” is true if and only if:

1. U intended, by uttering x, to induce a certain response in A
2. U intended A to recognize, at least in part from the utterance of x, that U intended to produce that response
3. U intended the fulfillment of the intention mentioned in (2) to be at least in part A’s reason for fulfilling the intention mentioned in (1).

So if in uttering the words “It is raining,” U intended A to believe that it is raining (condition 1), and U intended A to recognize that U intended A to believe that it is raining, at least in part from U’s utterance “It is raining” (condition 2), and finally that U intended A to believe that it is raining because of A’s recognition that it is what U intended (condition 3), then we can say that U meant that it is raining when he said it is raining. Otherwise, for example, U could simply have been reading a script in which the words “It is raining” appeared. In other words, for U to mean something by the utterance x, U must have the intention of communicating that something, of so communicating by that very utterance, and to be communicating to someone who would understand both the utterance and the intention with which it was uttered. Otherwise it falls short of nonnatural meaning.

Now when we say that an action “sends a message,” do we mean that this is a communication, and so a form of nonnatural meaning, or do we mean that it is something that has meaning in the sense that thunder means lightning. Well, if we are going to say that an action is unethical or immoral because it sends a certain message, I take it we mean that the action has meaning in the nonnatural sense, for if the action is to be either moral or immoral then it must be carried out by those who intentionally carry it out. Can we say of those who choose abortion following a diagnosis of fetal anomaly that they mean that the life of the disabled is not worth living? Not in the Gricean sense of nonnatural meaning. The utterer, in this case the woman, would have to intend to induce in another the belief that the life of the disabled is not worth living; she would have to intend to communicate this, in part at least, by aborting her impaired fetus; and she would have to intend her interlocutor to believe that she intended to produce that belief, in part at least, by aborting her impaired fetus. I don’t think we need dwell on this point further than to note that none of those conditions are met in the case of most women who abort a fetus with disabilities.

Nonetheless, someone could deduce from this situation a conclusion: that a woman aborting a fetus (because it has an extra 21st chromosome, for instance) doesn’t value the life of one with Down syndrome. But this would be a conclusion drawn not from a message sent but something inferred from an action taken. And then we could ask, are we correct in concluding this? Well, we’d have to ask the woman why she chose to abort and then, if Rapp’s studies are indicative, we can see that there are many reasons women abort under these circumstances, few of which are that they believe that disabled persons shouldn’t have the opportunity to live a life.

One could argue that the woman does not deny that she is aborting the fetus because it has this anomaly, so why then can we not conclude that her action itself bespeaks a devaluation of the life of the disabled—regardless of what else she says? Because this causal “because” need not express the meaning of the act. Let us say, for example, that I have ten dollars to spare today, and that I tell you that I am going to the movies because I have ten dollars to spare. However, this does not allow you to conclude that what it means to me to have a spare ten dollars is that I go to the movies.

Perhaps using the Gricean model puts too strong a set of constraints on what we can call a communication. Communication, nonnatural meaning, is perhaps too tightly connected to intentional acts. Is there another model? The great early modern linguist Roman Jakobson spoke about what it means to send a message or to communicate something in our use of semiotic systems. Perhaps we can adapt his analysis to the case of communicating by an action. He identified six elements described in a communication. The first requirement is an addressee or speaker. The second is an addressee. A third is an open channel of communication between the addressee and addressee. When, for example, we establish eye contact with a potential interlocutor, we open a channel for communication. The fourth requirement is a “message” (we’ll call it an “utterance”) that the addressee sends to the addressee. Fifth, we need the “context” in which the message was sent, and sixth, we need a “code”—that is, a medium in which the message is encoded and which is understood by both the addressee and the addressee. The
code, as Jakobson understood it, is normally a language or some system of signs (e.g., semaphores). If we want to include complex acts such as an abortion, we will need to consider the code as a set of conventions or social practices that are widely shared and by means of which such acts carry a commonly understood meaning.

While on a Gricean account we cannot say that an act of selective abortion sends a message, if we mean by that “means something in a nonnatural sense,” we might find this looser notion of communication—one that does not rely so heavily on the intention of the addresser—a more apt model. But, in Jakobson’s model, what we have is at best (as people in information theory would say) a “degraded” form of communication. If selective abortion is an act of communication in which the message arrives in a degraded form, then I fail to see how it can provide grounds for any ethical judgments or moral (much less legal) prescriptions.

First, in the case of selective abortion, we identify the addressee as the woman who decides to abort the fetus and the addressee as society in general (alternatively, the disabled community). Now, it is not clear that a contact is ever established between addressee and addresser. A woman rarely says: “Listen, world. I am having an abortion based on a diagnosis of fetal abnormality and I am about to tell you why I choose to abort a fetus with such an abnormality.” (There are, of course, exceptions.) When we learn that someone had such an abortion, we may not be in a position to query that decision, and the woman may not be in a position to query the addressee about the correctness of the “message” received.

Second, there is no established code by which to decipher the “meaning” of such an act. That is, there is no established code or convention or practice to which both addressee and addresser can appeal when determining the meaning of that act. When I tell you, “It is raining,” you (if you speak English) know how to understand that statement, and I know that you know. There is a common code that allows us to communicate a statement such as that. But such codes are not always available. If, given the conventions of foot apparel, I wear one green sock and one blue sock, you don’t know how to interpret that action. Perhaps I dressed before dawn in the dim light and failed to discern the colors of my socks. Perhaps I lacked a clean pair of matching socks. Perhaps I was engaging in a flight of fancy. Or costumed myself for a play. Or dressed according to a preestablished code, thereby signaling to a comrade the start of a revolution.

The failure to discern a univocal—or indeed any—meaning of the act of selective abortion partakes of the ambiguity of all those actions which fail to be situated in practices that have an agreed upon meaning. (The same may be said about abortion itself, an act whose meaning remains contested.) I may already spend my life caring for persons with disabilities. I may decide to adopt a retarded child once I have health insurance. I may feel that I can take on the care of a healthy child now, but a disabled child only at a later time in my life. Or I may think that even a limp makes life not worth living. There is no established code by which you can interpret my action and so understand what my abortion means to me, nor by which I can discern what my action might mean to you.

Third, we have to consider the extent to which the context influences the act of communication. If I am in a drought-stricken area, the statement “It’s started to rain” carries an emotional charge very different from one carried by the same utterance in a flood-torn area. Context will affect the cognitive meaning or emotive charge of an utterance. The newspaper headline announcing the crash of Hemingway’s plane, when the writer was assumed dead, ran: “Hemingway Lost in Africa.” When it was learned that he was still alive but missing, the headline remained, but with a different meaning. The less developed the code, the more ambiguity the code itself permits, the more the context will determine meaning. Because codes concerning acts of abortion and selective abortion are so underdeveloped and so contested, context is virtually, though not entirely, determinative. In the case of selective abortion, the context includes both the particulars of the individual lives affected by the decision and the larger social setting in which the decision is made. Most contestations over this new technology and the decisions people make with it are struggles over how to understand and determine the context that, in turn, contributes to the meaning of the act. For many in the disability community, the context is one in which disability is stigmatized and persons with disabilities are devalued. That context, they argue, inevitably means that we interpret the act of selective abortion as another sign of the devaluation of a disabled life. That is to say, they believe society in general (the addressee) interprets the “utterance” of selective abortion in the context of the stigmatization of disability and that the message sent is that a child with disabilities will not be welcomed into a family. Therefore, they argue that the act of communication that results is that the disabled life is not worth living.
In response, we have to ask, “If we alter the context, is it the same message or not?” If we utter, “It’s raining,” to folks in a sodden Seattle and make them more miserable, is it the utterance (and what that utterance refers to, the fact that it is raining) or the context in which it is uttered that is the source of the misery? If we issue the same utterance to drought-stricken East Africa, are we uttering a message that makes people miserable? No.

If we are concerned with the devaluation of the life of the disabled (and that is something we should each be concerned about, regardless of whether we ourselves are disabled or have a disabled family member or if disability has never personally touched our lives), then we need to fix on, and fix, the context, not the utterance. Still, you might argue, to abort fetuses with disabilities is itself to further devalue the disabled. But that can’t be the reply, because that is exactly what is at issue. What I will grant is that it is reasonable to infer that if many persons choose to abort fetuses with a particular characteristic, it is fair to make a hypothesis that those characteristics are devalued. But that is again, at best, a conclusion hypothesized about the causal factors that lead to the abortion and not a message that is sent out by the abortion. Only further questioning of actual motives can establish whether this woman aborted because she devalues disabled life. But even so, we should not confuse a message sent with a causal determinant of an action.

Now you may want to respond, “Look, Mom, it is only through exposure to actual retarded people that anyone can really appreciate how much they contribute.” With selective abortion, “fewer people will know what joys can come from being around someone like Sesha. More ignorance, and this is never a good thing.”

But if we could fix those conditions in utero, if we could have Sesha without the retardation, would we balk, even for one moment? And maybe, probably, Sesha wouldn’t have the incredible sweetness she now has, a sweetness that is perhaps, in part, the result of her not encountering conditions that most of us encounter—an innocence of intentional evil, of senseless nastiness and stupidity that humans are capable of, of corrosive ambition, of frustrated dreams, of biting competition, and so on. What of it? Would we hesitate one moment to exchange her for a Sesha with all her mental faculties intact. Although every day I lay eyes on her, Sesha melts my heart with the purity of her joy, her laughter, I would not hesitate. Truly, I wouldn’t hesitate.

Sesha’s condition isn’t just a difference, only it is that too. Sesha’s condition is an impairment. If I can contemplate a Sesha without her impairments, or another child in her place, does this mean that I think that a disabled life is not worth living—that Sesha’s life is not worth living? Absolutely not.

My life is worth living. Nonetheless there are conditions, ones that those I love would have rejoiced in, under which I would not have been born. Had my mother left Poland before the war and been spared the horrors of Auschwitz, I would not have been born. Does this mean that I cannot wish with all my heart that she had married the man from Toronto who had betrothed her and sent her the papers to leave Poland before the war? The fact that she didn’t, of course, says nothing about the value she placed on my life. She could know nothing of what that life would have been like. But if she had had a crystal ball, and had foreseen it all—yet had no idea of what awaited her if she went off with the beau from Toronto—foreseen both surviving Auschwitz and me and would still have chosen Toronto, could I blame her? Could I say she devalued my life—could I blame her for not choosing this child? But these are fantasies, and she could never know.

We can know no more of the life we do not conceive or the life we choose to abort. Would I have aborted Sesha if I had known of her condition? I don’t know. It might depend on the level of attachment I felt at the time I learned that the fetus had some problem. If it was already my child in my heart and mind, I may not have. I may have thought just as I did once Sesha was born—our own version of Janet Lyon’s “We can handle this.” But maybe that is not what I would have said. Maybe I would have investigated further, learned something of the lives of the retarded. Our decision (because both Dad and I would make this decision) may well have depended on where our investigation led us: to a home like the Bérubé’s or to a day treatment program like the one Sesha is currently in? These considerations reinforce some of the powerful points Bérubé makes with respect to the representation of the disabled. But it is also a confirmation of what I have wanted to underscore—namely the importance of the commitment of the society in general to the disabled.

So maybe we would have decided that there is joy enough for us here, and that we can make a good life for ourselves and our child. Maybe, and it is hard to think of it, I would have aborted. And we would never know Sesha. And that loss seems unimaginable. But I may have given birth to another child, whose nonexistence would seem equally unfathomable, and I would have wondered about the child I aborted. I would have stopped every time I saw a mentally retarded
child or adult and wondered, with tears in my eyes. Just as now, with tears in my eyes, I think about the young woman of twenty-seven who might be a graduate student like my wonderful graduate students, or be thinking about marriage, or be out on the ski slopes with you. In each case there is a loss. It is a human tragedy.

No one can judge the choices of another in these cases based on what is at best a degraded form of communication. No one can make a moral evaluation based on this incomplete communicative situation. There is no singular utterance enunciated through a clear channel in an accepted code, in a nonambiguous context. It is a moral wrong to utter the word "nigger" in speaking of or to a person of African descent. It is a moral wrong to produce degrading and demeaning portrayals of women as sex toys for men. It is a moral wrong to reduce services for the disabled poor (doubly wrong). All these send vile messages that some people do not possess the value that others possess.

But to selectively abort because the fetus I carry is likely to develop into a child with profound disabilities does not send any clear and unambiguous message. And the morality of that choice must be weighed in the conscience of the woman who makes that choice. She alone can know just what her act meant and if it was carried out as a consequence of moral sloth and uncaring, or through a responsible choice.

Now, at last, we get to your point about the message that the sibling receives. First, let's consider this situation of communication with the six factors that Jakobson delineates. The situation here is quite different than that of an undefined audience, "society in general." Why? First, because in this case one can establish that channels of communication are open, and second, because one can adopt a code by which to interpret this utterance. Furthermore, we can delimit the context, or at least specify the relevant contextual features. Put more simply, one can discuss the matter through an exchange, not unlike the exchange you and I are now having. I wonder, however, if such exchanges do take place. Were I an empirical scientist, I would like to conduct a study in which to ask this question. But I think it is a parental duty to explain to one's child why one makes, or why one has made, such a decision. Otherwise, all sorts of misinterpreted, unintended, or garbled messages are an inevitable outcome.

Let's take the first scenario you envision. The sibling assumes that the parent's love for him is conditioned on his sound mind and body and is concerned that if anything should happen to him that would cause him to be disabled, the parent would want to discard him, as, once before, she had aborted his disabled unborn sibling. The first distinction I would want to put into place is the distinction between a born child, and the commitment a parent has to a child that has been born, and an unborn fetus. I believe that the concern you raise is a concern a child might raise in the case of any abortion. If the reason for the abortion is "I can't afford another one," a child may wonder, "What if we have less money than we have now? Will my parents want to be rid of me, too?" If the reason is, "I have my hands full with the children I have now," the child may wonder, "If I'm more trouble than I am now, will my parents want to be rid of me, too?" I think you see how it can go.

Remember, without discussion, with only the act of the abortion itself, we have not a true act of communication but a very degraded one. Once we have the distinction between the commitment to the born child and the tentative commitment to the unborn fetus, we are able to develop other features of the code and the context. We can make the case that the decision to abort was in significant measure a question of the parent's commitment to children already born, or to the other children the parents were likely to have. If there is a decision to bring the fetus to term, there is also considerable parental input that is demanded. A child may view any sibling as a rival, but a sibling that requires the additional attention a disabled child does may raise the level of resentment and jealousy. It is the job of the parent to open the channels of communication, to explain the decision (or the fate, as the case may be), and to integrate the normal and disabled siblings into one cohesive, caring family.

Too often we think that the message is obvious. We needn't check with our addressee if the intended message has been received. Your dad and I thought that it was obvious that our love for Sesha would give you the clear message that we love our children, unconditionally, irrespective of achievement. You might have gotten the unconditional part, but I'm not so sure about the "irrespective of achievement" part. Instead, you thought the message was that you had to compensate for the fact that Sesha would never have accomplishments, as those are normally tallied. Because we presumed the message was clear, we never made the effort to be certain that it was being received. (How dangerous to make moral judgments based on such bad communication channels.) I recall how as a four-year-old you mistook our affectionate responses to Sesha as a sign that we loved you less. We had to explain to you
that Sesa understands only kisses and hugs—it is our sole means of communicating with her—whereas we could play and talk with you. Again, how careful we have to be in explaining our messages.

Now let's move to the second case: the sibling who first bathes in the love garnered for his particular characteristics and then comes to fear that such love is too unstable—that the family based on such love is more like a club than like a family. Here too one can invoke the distinction between commitment to the unborn and commitment to the born. But here I think the important point is that a family must not be like a club, whose membership is based on a set of desirable features. That is not how a family nurtures. We need a place where love is unconditional, where our mistakes are forgiven, where our imperfections are accepted and even cherished. We need such a place if we are to be emotionally whole. If the “message” that selective abortion for disability sends is that a disabled child is of less value, then it cuts into the sanctity of such a space and is corrosive. So here we have to be very clear. But once again, clarity comes from how we treat those with disabilities and not with a family’s (and especially a woman’s) decision to bring a fetus, any fetus, or this fetus to term. If we treat persons with disabilities with care and respect; if we attend to need when we see it and listen to the voices of those who wish to speak; if we treat all persons as moral equals, irrespective of ability or accomplishment; and if a household reflects this in all that it undertakes, then no child should think that it is valued only for having certain desirable traits.

There is only one problem, Mom. No child is consistently under the impression that the above condition is the case. In fact, no person for that matter thinks that his or her family is always treating him or her in such a way all the time. Even a family as wonderful as ours, n'est-ce pas? This passage does help me answer one thought that has been plaguing me throughout our discussions. Even though you did not abort Sesa, I remember experiencing every feeling that we have discussed a would-be sibling goes through as a result of a selective abortion. Just because you had Sesa and raised both of us honestly, better than I can imagine, I still managed to feel quite frequently and strongly throughout childhood, and even during many of my most formative moments, that Dad's and your love for me is a condition of my physical and mental abilities. Without these, I often felt, on some level, that I would not command your love and respect.

But when you break down the manner in which these messages get communicated in the case of an abortion, it helps me to see how this message could have been communicated so countintuitive in the case of the elected birth, Sesa. It was in those moments in my upbringing when I felt treated as more than equal, when I got more attention than Sesa, or alternatively when I did not feel treated with the same care and respect as Sesa, that my young mind sometimes interpreted this unequal treatment in terms of the inequalities and not the equalities. I thought I must be getting more attention than her because I can do more, or that I was getting less because she needed more. I think to some extent this phenomenon exists between all siblings, even between a child and a parent's career, between a child and the other spouse, whenever a parent's energies have to be distributed fairly. Anytime a child feels his status change, he is constantly searching for the cause of the change. Only a completely open line of communication continually sending a message of equally high value to all can truly do away with a mixed message. So, yes, Mom, I think you have hit on the secret of how not to send the wrong message to one's children when one decides to abort. I think it also happens to be a secret of parenting in general.

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Abort a disabled fetus will convey a harmful message of conditional love to the sibling unless the following condition is met: "If we treat persons with disability with care and respect; if we attend to need when we see it and listen to the voices of those who wish to speak; if we treat all persons as moral equals, irrespective of ability or accomplishment; and if a household reflects this in all that it undertakes, then no child should think that it is valued only for having certain desirable traits."

Leo's Letter #3

Mom,

Yes, the lines of communication must be open. And this is incredibly difficult. As open and honest as our family is, only in my twenty-first year have you and Dad and I discussed at any length many of the more painful, difficult aspects of having Sesa in the family. I have not even allowed a healthy dialogue to take place in my own head about Sesa until recently. Tremendous issues of anger and guilt have been lurking within me regarding Sesa, and coming to grips with them has been a big part of my postcollege soul searching. You said that the act of
This leads me to my final thought. Let me say I do fear that allowing abortion based on prenatal screening will result in many abortions that are decided more quickly and based on less information than is ideal. Some women will even elect to have an abortion because they think less of disabled people, or because they want their children to be perfect. But, and this is my thought, parents make lousy decisions all the time. Some spend their money irresponsibly, some raise their kids to think they’re worthless, others raise their kids to think they’re worth more than everyone else, some beat their children. While sometimes I think it would be great to make laws that put a stop to such behavior, I know that in general that would not be a good idea. To insist that parents have children they are not thrilled about doesn’t strike me as the best way to give children a great start in life. After all, the great burden of deciding whether or not to abort the child is small compared to the burden of raising the child. And if someone is not going to handle the decision responsibly, I would hate to see how they would handle the child.

Might they become thrilled before the nine months are up? Might having the child shatter their prejudice against the disabled? Yes, but it also could take longer. And what messages would be sent out meanwhile?

Love, Leo

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**NOTES**

1. This chapter was prepared for The Hastings Center project, “Prenatal Genetic Testing for Genetic Disability,” funded by the National Center for Human Genome Research of the National Institutes of Health, grant 1-R01-HG116801A2. It is a revised version of a chapter in *Norms and Values: Essays on the Work of Virginia Held*, ed. Joram G. Haber and Mark S. Halton (Lanham, Md.: Rowman and Littlefield, 1998).

2. These diary entries were written prior to the correspondence that follows them.

3. Erik Parens, personal correspondence to Eva Feder Kittay, Briarcliff Manor, N.Y., May 21, 1996.


6. Bérubé, *Life as We Know It*, p. 76.

7. Bérubé, *Life as We Know It*.

8. See Elizabeth Spelman, *Inessential Woman: Problems of Exclusion in Feminist Thought* (New York: Beacon Press, 1988), who speaks of the practice of saying about some people who are viewed as Other “but they are just like us” as “boomerang perception,” one in which we only can see the other as “just like us,” and never see ourselves as “just like them.”


17. Rapp, “The Ethics of Choice.”


19. Bérubé, *Life as We Know It*. 