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Prenatal Testing and Disability Rights

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Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements

*Reading for
Wednesday*

The arguments raised by colleagues and friends during this Hastings Center project on the disability rights critique of prenatal genetic testing are important, serious, and sophisticated. They are made by scholars and health professionals with deep commitments to creating a more just, caring, and inclusive society for every child and family. The arguments raised against the disability rights critique and in support for the social practice of prenatal diagnosis are put forward by those who support the legal victories and societal changes that the disability rights movement has struggled to attain.¹ In what follows I will try to explain why, despite the challenges to this critique, I and others still believe that support for prenatal diagnosis and selective abortion contravenes the goals of people with disabilities for full acceptance and inclusion in our society, and why it also threatens cherished values in the parent-child relationship. I continue to view the practice of prenatal diagnosis followed by selective abortion as both misinformed about the true nature of disability and as problematic in what it connotes about societal and parental willingness to appreciate the many forms of human variation.²

I will not here review in detail the components of the disability rights critique, discussed in the opening chapter and in several other contributions to this volume. I am aware that many of my views are shared by others who espouse similar critiques; I do not present what follows as endorsed by all those with disability-based objections to prenatal testing.³

Throughout this project, we have discussed the contentions that prenatal diagnosis is "morally problematic" and "misinformed." I take up these arguments as they are discussed in the opening of this volume. Misinformation and misinterpretation about disability pervade the con-

struction of some moral arguments. Consequently, I address moral problems and misinterpretation throughout this discussion.

The "Message" of Prenatal Diagnosis and Selective Abortion

You are a professor in a philosophy department at a large urban university. In your class of fifty students, you notice that five students have pierced tongues and lips and that a few others have dyed their hair in unnatural colors. You have difficulty even looking at these students because of their style, and you ignore their raised hands when they want to participate in class discussion. Midway through the semester, a man with dyed hair comes to your office to raise questions about the work in the course, and you realize that he actually has some interesting observations to make about the class and find yourself chagrined at your avoidance of his raised hand, of which you were only half aware until he appears at your door. The characteristics of Down syndrome, spina bifida, cystic fibrosis, or hemophilia, you say, are not as trivial as piercings and dyed hair, and perhaps you are right, but recognize that prenatal testing gives only one piece of information about the embryo or fetus, that it carries a particular characteristic thought worthy of note by the medical profession. Prenatal testing is a clear case of first impression, and as with any such impression, it is an incomplete impression; when followed by selective abortion or by discarding an otherwise implantable embryo, that first impression includes a decision never to learn about the rest of who that embryo or fetus could become after its birth. Mary Johnson, the longtime editor of a major disability movement publication, writes in a similar vein when she says:

A decision to abort based on the fact that the child is going to have specific individual characteristics such as mental retardation, or in the case of cystic fibrosis, a build-up of mucus in the lungs, says that those characteristics take precedence over living itself, that they are so important and so negative, that they overpower any positive qualities there might be in being alive.⁴

Writing in 1987, another woman with a disability underscores how incomplete is the information provided by prenatal testing when she says:

I know that amniocentesis can't tell any parents what kind of child they will have. It can only tell what disability might exist in that child. Amniocentesis could never have told my mother that I would have artistic

talent, a high intellectual capacity, a sharp wit and an outgoing personality. The last thing amniocentesis would tell her is that I could be physically attractive.⁵

No matter how much we may find the previous self-description immodest, it is the description of someone who feels that she must justify the right of people with her disability to exist because she recognizes that its presence alone makes others ignore everything else about her and could make future parents reject a child they wanted once they learned of this unexpected characteristic through a prenatal test.

Those who object to the "expressivist argument"⁶ contend that prospective parents who terminate a pregnancy after a diagnosis of a disability may do so for many reasons that are not overtly prejudiced or hostile to people with disabilities. The prospective mother and her partner may feel that they haven't the financial or emotional resources to "cope" with the "extra" demands that a child with a disability would entail. Or they may already have a child with the same or another disability and feel stretched to their limit and want a child whose needs and demands will not be "special." Or, it is argued, the prospective parent may herself have a disability identical to the one diagnosed and may feel that to transmit that disability is to pass along a harsh and painful part of life to her child. All these claims do not refute the view that this one characteristic of the embryo or fetus is the basis for the decision not to continue the pregnancy or to implant the embryo. That decision still concludes that one piece of information about a potential child suffices to predict whether the experience of raising that child will meet parental expectations. In most cases of preimplantation genetic diagnosis or prenatal diagnosis, the woman or couple desires to be pregnant at this time; the termination of the process only occurs because of something learned about *this child*.

The Any/Particular Distinction

James Lindemann Nelson argues that this "any/particular" distinction as applied to the case of disability could be used to call any abortion into question. He claims that the fetus who would be the fourth-born child is also a "particular" fetus, and that *any* decision to abort is always a decision to abort a *particular* fetus at a *particular* time.⁷ However, Nelson errs in equating the fetus diagnosed with a disabling trait and the fetus that would become the fourth-born child in a family. As Nancy Press points out, the property of "fourth-bornness" does not inhere in

the fetus/child in the same way that disability does; the fourth-born child could just as easily have been the first or only child if adopted into another family.⁸ Moreover, being a fourth child, or even a family with four children, does not subject the child or the family to the invidious treatment that has marked the lives of people with disabilities. Fourth-born children have not been kept out of schools because of that trait; nor have they been subject to institutionalization, denied access to worship services with their families, or rejected by potential playmates for the characteristic of fourth-bornness.

What of other possible any/particular distinctions in prenatal testing? At least three other types of "selective abortion" present themselves for discussion: selecting for or against a fetus based on its sex; reducing the number of fetuses; or aborting a fetus if it is determined that Ted, rather than Jack, is the genetic father. Like most members of our project group, I am uncomfortable with using technologies to determine and select for or against a future child based on its sex, since it, too, uses one characteristic as determinative. Selective reductions, from triplets to twins or from twins to one for example, that are not undertaken to preserve the health or life of the mother or fetus/fetuses, pose some of the same moral dilemmas surrounding what prospective parents should be open to in undertaking a family that I will discuss shortly with regard to raising a child with a disability.

Abortion arising from uncertain or undesired paternity poses a challenge to those of us who distinguish between abortions based on fetal characteristics and those responsive to a woman's life circumstances. Ending a pregnancy because Ted, rather than Jack, is the genetic father of the baby a woman is carrying surely is a decision about a "particular" fetus and not "any" fetus; but the decision results from the woman's evaluation of the nature of the relationship with each of the men and what it means to her to imagine raising a child created out of a relationship with Ted or Jack. It may have little or nothing to do with any sense she has of wanting to carry on one man's genetic legacy but not the genetic characteristics of another. If she bears the child, her circumstances and those in which the child lives may be very much influenced by whether Ted, rather than Jack, is its father, but those intimate familial circumstances do not equate with membership in the category of "women" or "people with disabilities." Outside the circle of people who are aware of the child's origins, the child will not constantly have the badge "child of Jack" or "child of Ted"; for every day of the child's life, innumerable small and large occurrences will not be due to the world's regard for

"children of Jack" or "children of Ted" as they will be due to the world's evaluation of "how girls should behave" or "if I talk to the man in the wheelchair I might say the wrong thing and offend him." The child of Ted or of Jack is not a member of a historically discriminated-against class, such as people with disabilities have been. The mother may have different feelings about having become pregnant with Ted's child rather than Jack's, and her feelings may influence her relationship with and treatment of the child either positively or negatively; but the feelings are about her relationships with Jack and Ted and the meanings of having the child of one or the other in her body and for her life. A woman might say to herself, "I could never fully love a child of Ted," but that statement is not the same as saying, "I could never love a child who has brown hair, or is female, or has Turner's syndrome." Rather, it is a statement about the child as a reminder of Ted; if those same characteristics—brown hair, being female, or having Turner's syndrome—occurred in the child resulting from her relationship with Jack, they would not necessarily pose a problem for her. A woman planning to raise a child on her own may be less concerned with knowing who the genetic father is than would someone planning to raise a child in an ongoing relationship with Jack or Ted; thus, the paternity question might resolve into "Do I want to be a mother at all at this time?" changing the question from "Do I want a particular child with a particular father?" to "Do I want a child?" I argue that the any/particular distinction is important only when someone knows that she wants a child at a particular time, and that a conception or pregnancy is desired, but only if testing determines a particular characteristic (being female) or rules out a fetus or embryo based on one characteristic or property inherent, intrinsic, inevitable in the embryo/fetus/child-to-be.

Although Nelson contends that the any/particular distinction collapses because all abortions are abortions about particular fetuses at particular times in women's (or couples') lives, the reports of researchers who have studied women's experiences of these abortions following prenatal detection of disability indicate that the women view them as very different from previous abortions or from abortions for other reasons.⁹ Women who undergo prenatal testing typically are ending either a planned-for or very much desired pregnancy, based on their conviction that the disability in a future child will be gravely destructive for themselves and their families. Women are reported to think of the fetus as a baby they look forward to raising, and when they decide to end the pregnancy, they do so because they believe that the birth of a baby

with this characteristic will be heartbreaking, difficult, disappointing, and not the joyful experience they had anticipated in accepting this pregnancy.

The Selection/Prevention Distinction

In her contribution to this volume, Bonnie Steinbock argues that preventing the birth of a child who would have spina bifida is no different from taking folic acid to try to ensure the health of the developing fetus.¹⁰ For Steinbock, discarding the affected embryo or aborting the fetus determined to have spina bifida, like taking folic acid to protect the fetus against developing it, prevents someone from being born who will have this disability. To Steinbock or to Nelson, anyone who is pro-choice on abortion should not be troubled by the method of abortion if one accepts the act of prevention by taking medication. According to Nelson and Steinbock, I and others who differentiate among these actions must either have more concerns about the morality of abortion than we are acknowledging, or we must believe that disabilities are central, and desirable, aspects of identity. I reject both claims. Susan Wendell expresses views resembling mine when she writes:

I would be terribly sorry to learn that a friend's fetus was very likely to be born with ME [myalgic encephalomyelitis, the disability], but I would not urge her to abort it. In other words, many people with disabilities, while we understand quite well the personal burdens of disability, are not willing to make the judgment that lives like ours are not worth living. Every life has burdens, some of them far worse than disability.¹¹

Ending an otherwise desired pregnancy after learning of a diagnosis of spina bifida or cystic fibrosis says that this one fact trumps everything else one could discover about the child-to-be, and says that the woman (or couple) cannot accept into her intimate life a child with this characteristic when she planned to accept a child. A health report card becomes precursor to membership in the family, making the family rather like "the club" Leo Kittay describes in the discussion with his mother captured in her chapter in this volume.¹²

I will return to this matter of "family as club" and to the effects of prenatal testing upon concepts of parenthood later. For now, let me restate my conviction that women or couples should be free to reject becoming parents for whatever reasons they wish, and thus they should be able to use techniques like abortion to fulfill their familial goals. The conviction that a life with a disabling trait is so distressing that it should not be undertaken if it can be avoided is quite different from

saying that, if possible, one will try to aid the child one is now creating to be disability-free. Ending the process of becoming a parent because of a future child's likely disability, when one wished to become a parent at the time that the disability was discovered, in the network of relationships and amidst the life plans in which the disability was discovered, is saying that the disability is inimical to the life one wants for oneself, one's family, and one's child. The idea of a child's disability is so disturbing that it is best to delay parenthood or change the methods of parenthood (adoption, assisted reproduction with provided gametes) to avoid the child with the disability. Better to end any fantasy relationship begun with the child being created and to begin anew hoping for a different child at a different moment than to continue to nurture the life begun. (There is more on "parenthood," "nurturance," and "life" later.)

Undoubtedly, the prospective parents (whether with prior knowledge of disability or virtual ignorance of life with disability) sincerely believe that disability is best avoided by discarding affected embryos or delaying pregnancy after terminating the one with an affected fetus. Nelson, Steinbock, and others contend that this motive need express no devaluing of existing people with disabilities and no insult to anyone who might in the future be born with ones similar to those that can now be prenatally detected. Perhaps people who perceive insult do so because by expending substantial resources to determine the genes for some characteristics but not others, health professionals reinforce society's negative views about what disability means for a life. They endorse the idea that these traits are not acceptable if they can be avoided and that people should not be born with these traits if women and couples have the means to prevent their births. People with just the disabilities that can now be diagnosed have struggled against an inhospitable, often unwelcoming, discriminatory, and cruel society to fashion lives of richness, of social relationships, of economic productivity. For people with disabilities to work each day against the socially imposed hardships can be exhausting; learning that the world one lives in considers it better to "solve" problems of disability by prenatal detection and abortion, rather than by expending those resources in improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralizing. It invalidates the effort to lead a life in an inhospitable world.

Urging abortion if an otherwise wanted child is found to have the trait of hemophilia suggests that having hemophilia could destroy a good

life for a child and his family, rather than recognizing that hemophilia could occur to some people and that the society should consequently design its institutions to ensure that all members can participate. Prenatal testing and abortion suggest that perhaps it would be better if people with hemophilia didn't participate. "Don't participate at all if you will have a disability" differs markedly from "Let's do the best we can to make sure that all our future children avoid disability, but we will expect that people are born with and acquire disabilities, and we will include everyone no matter the disability." The first statement rejects potential people if they have the undesirable trait; the second acknowledges that the trait may be undesirable but rejects no existing or potential person who bears it.

Traits, Persons, and Disability Identity

Do people in the disability rights movement go beyond asserting the humanity of people who have disabilities, to actually valuing the trait of disability? Where does disability fit into a sense of personal identity? In a recent paper, Nelson suggests that the critique of prenatal testing springs from the place of disability in a sense of personal identity.

As scholars and activists in disability studies have helped make plain, many conditions regarded as disabling are also identity constructing in this social world. This is so, I think, in the sense that disability is a deep fact about a person's identity that does much to fuel the sentiments behind the [expressivist argument], the sense that some disability scholars and activists have that prenatal diagnosis and selective abortion threatens "our children."¹¹

Reportedly some Deaf community members and some people who have achondroplasia would like to use the technology to select for fetuses who would be deaf or who would have achondroplasia.¹¹

I, perhaps Wendell as quoted earlier, and others in the disability community would disagree with some or all of the ideas in the foregoing paragraph. Disability is not, and need not, be either a "deep" or a valued part of identity for everyone who shares the disability critique. And, as I will discuss, it is just as problematic to select for a disabling trait, thinking it guarantees something important about family life, as it is to select against it for the same reasons. Disability is not, and need not, be "central" for everyone who shares this viewpoint about prenatal testing.

Some people with disabilities clearly see themselves as part of a disability community and subscribe to the notion of a disability culture.

Increasingly surveys of people with disabilities learn that respondents identify themselves as belonging to a disadvantaged social minority.¹⁵ Recognizing membership in a numerical and disadvantaged minority group need not lead to assuming that the fact of disability is either central or positive, although it should be pointed out that a person could construct a sense of personal identity with disability central and positive, central and negative, or other combinations. During everyday life, people with disabilities do not think constantly about having a disability, but rather take necessary medications, use whatever methods they need to move, read, communicate, and get on with their lives of playing, studying, and working. A Chicago attorney lives with a woman who is one of the partners in their small law firm; together they travel to scenic parts of the world and enjoy exotic restaurants and foreign films. When the attorney is at home, she is involved in her local Episcopal parish and an urban neighborhood garden project. Muscular dystrophy affects her mobility, so that she must choose restaurants, theaters, and projects at her parish and with the garden group that she can negotiate on crutches or using a wheelchair. When the logistics work, she is more involved in thinking about the project or the next trip and what she wants to experience and learn; she factors in the crutches and the wheelchair as people who use glasses must factor them in.

Is muscular dystrophy central, positive, negative, or neutral to her sense of identity, and how does that influence her thinking about selective abortion to prevent others from having her disability? Like Wendell, she need not ignore the burdens imposed by trying to function in a world that is still not wheelchair-friendly.¹⁶ She might sometimes work with others interested in disability issues to promote greater access to city parks. Knowing that she enjoys wheelchair sports, she suspects that she might have become an avid hiker if she could walk longer and more easily. She can say, if asked, that having muscular dystrophy has sometimes impeded her because it has reduced her energy; neither has she enjoyed the intermittent hospitalizations. She may hope that any child she has will be free of the condition of muscular dystrophy so that her child might forego the hospitalizations and have the chance to enjoy hiking; however, she is confident that just as she has enjoyed her life, any child who had muscular dystrophy would similarly recognize the condition as a frustration or complication that could be managed along with other life complications. The attorney can acknowledge "might-have-beens" for herself and hope for them for any future child, just as I, a serious

amateur musician, might wish that perfect pitch would preclude me from singing sharp. She, or I, or anyone else can recognize that we lack capacities that others have (call them disabilities or traits) and appreciate the lives we have even without those enjoyable traits. Singing sharp keeps me out of certain music groups, and years of study and voice lessons haven't cured my musical problems. I must content myself with singing where and with whom I can, even though better pitch might give me more access to a much-loved activity.

Unlike the nonmusical Mary in Marsha Saxton's chapter in this volume, I needn't worry that "people like me" (without good intonation) will be told that the world would be better off if there weren't more people like us, when I am doing the best I can with the equipment I have in the world as it is.¹⁷ I can try to change myself to be a better musician; I can find places that will accept me with my mix of talents and problems as a musician; and I can enjoy the rest of life that includes many activities and people having nothing to do with music. I do not need to have an emotional investment in the fate of nonmusical people because it is not yet a characteristic that carries social stigma and occasions discrimination; prenatal testing does not yet announce to prospective parents that they might wish to learn of the musicality of their next child and prevent the birth of anyone with impaired intonation. Disability becomes central, or salient, when circumstances in the world around us compel us to make it salient or central. Put another way: those people within the disability rights movement who challenge prenatal testing do so in much the same spirit as they challenge other practices that have historically kept people with disabilities from being accepted as customers, students, coworkers, friends, and loved ones. They do so because they needn't celebrate nor even like certain facets of their impairments, yet they recognize that their lives—impairments and all—are respectable, acceptable ways to live.¹⁸

I have argued that disability moves from being one component of identity to being emotionally charged, and perhaps central, because it has been so consistently the occasion for institutional and personal rejection or segregation. All of these practices are part of what the movement adherents term "the social construction of disability," contrasted with the medical model that locates all problems of people with impairments in the impairments themselves and not in the social arrangements that impose needless hardships upon them. Fortunately, everyone in our project affirms that much of disability is socially

constructed; what has remained a contentious and painful divide has concerned just how much is "social," how much is irremediable, and how negative for child, family, or society those irremediable facets of disability turn out to be.

Challenges to the Social Construction of Disability

Australian philosopher Christopher Newell opposes prenatal diagnosis for much the same reasons as Saxton, Wendell, Kaplan, and I do: that it reifies disability as medical rather than social in its problems.¹⁹ He has a rich understanding of the social constructivist account of disability when he argues for the

social nature of disability, proposing that prenatal diagnosis and termination is a technology of oppression and control which serves to devalue the lives of people identified as having disabilities. . . . I suggest a social constructivist account, but this does not deny a physiological component. I have spent years of my life in hospitals and the symptoms were not just social! Rather, it is the social meanings given to "difference," "the disabled body" and the "disabled mind" which are important in terms of "social construction." Genetic conditions occur in a social context, and their meaning and impact are inherently social.²⁰

Opposing prenatal testing does not commit us to trying to avoid physical pain or to deny the biological realities of less energy, shortened life span, difficulty in breathing, need for mechanical devices and human assistance that might accompany impairments like cystic fibrosis, muscular dystrophy, or sickle cell anemia. Newell articulates that how people understand and interpret biological realities is crucial.²¹ Those realities can be viewed as only negative, destructive, and defeating of life's possibilities, or instead can be understood as an unenjoyable, but singular, part of a life that also contains many riches.

Although medicine, bioethics, and science imagine that physical pain, reduced life span, and other disability sequelae are the enemy and the problem, many people who live with the conditions themselves or as intimates of people affected by these conditions are able to incorporate them into the whole of a life, neither celebrating them nor having those difficulties overwhelm the rest of what life brings. To the surprise of social scientists, people with and families affected by cystic fibrosis and sickle cell anemia often reframed the experience of living with the condition. Describing one twenty-nine-year-old aspiring academic, the authors write:

Her biggest concern about health care is paying for her treatment. She told us she wanted to have free health care. "I want that even more than I want not to have CE."²²

Some project group members have less trouble understanding a social-constructivist account of disability when that account is limited to conditions without cognitive/emotional components. Most troubling to anyone who prizes the intellectual life is an impairment such as Down syndrome that precludes people from engaging in discussion of abstract ideas, or perhaps from discussion at all depending upon its severity. Parents of young people and adults with significant cognitive/communicative/physical impairments participated in our deliberations and tried to indicate that although some conditions limited life experiences in many ways, skillful teaching and care in creating supportive social arrangements provided people with multiple impairments—no verbal communication skills, hard-to-measure intelligence, limited physical mobility—with life opportunities that they and those around them found rewarding.²³

Illustrative is Dianne Ferguson's description of the life of her twenty-eight-year-old son, Ian:

The latest interpretation of self-determination for my husband and me came wrapped in a Christmas Eve invitation. Our son Ian invited us to his house for Christmas Eve. Although Ian has lived in his own home for almost 2 years, we have still spent holidays together in our home. At 28, perhaps Ian and we have reached the age when our children initiate that shift in relationship that sends parents to their children's homes for family celebratory rituals. What is hard to say is how this particular event occurred. Did Ian somehow arrive at the determination that it was time to shift our holiday celebrations to his own home? Did his housemates, Robin and Lyn, who had been helping him can fruits and vegetables, make jam and breads, and decorate and arrange baskets for weeks "support his choice" to invite us over or shape his choice on his behalf? Did they somehow teach him how and why he might want to request our presence at this holiday celebration?

. . . The challenge of Ian, and others with even more significant cognitive (and physical, and sensory, and medical) disabilities, is how close they seem to come to the absence of agency in key parts of their life. . . . It is not just that people's real and apparent passivity is enforced by limbs that do not move, or environmental and service barriers that trap them either physically, socially, emotionally, or politically. . . . [W]e cannot really conceive the social world of someone whose experience of concepts and communication is so uncertain and seems all too woefully

inadequate to warrant . . . characteristics of autonomy, self-regulation, empowerment, and self-realization.

. . . I do not know what Ian realizes about himself, although I would dearly love to know. . . . Yes, we are all interdependent, but the truth of the matter is that the balance of interdependence in Ian's relationships is disproportionate in most matters compared to my own. He is more dependent. He requires more care. He determines fewer things in the course of a day, week, or year than I do. Yet he does contribute in some very important ways to what occurs in his life. Does he choose? Sometimes. But, more often, he sort of indirectly influences events to end up being more okay than not okay from his point of view. . . . We want Ian to have a life that is more okay than not okay from his point of view most of the time.

. . . His contributions on this occasion were his ebullient renditions of carols, his energetic opening of gifts, his enthusiastic greeting when we arrived, and his just-controlled crabbiness about the finger-food supper.²⁴

I have quoted extensively because here we have a description of a life event imagined impossible by most in medicine and bioethics for someone with his array of cognitive, physical, and communicative impairments. His mother does not deny that his life differs in some important ways from that of adults his age without impairments; she describes him as a "co-author" of parts of his life, being more affected by his relationships with others than adults who can express and move more than he without others' help. Yet Ferguson emphasizes what makes Ian more like, than unlike, other people inviting their parents to their home for a holiday.

People with the impairments of Ian (and Sesha described in Eva Kittay's chapter in this volume) represent the largest challenges to the "social construction of disability."²⁵ Nelson, Steinbock, Ruddick, Botkin, Baily, and several others argue that these forms of human variation cannot be "constructed" so as to be neutral.²⁶ The heart of a "social construction of disability" is, perhaps, to appreciate what's more similar than different in the lives of people with the most significant departures from species typicality and to affirm the ways they benefit from and contribute to the world and the people around them. Increasingly, there are scholarly and personal accounts of people with these disabilities who live lives they and their loved ones consider more good than bad most of the time, and lives that enrich those they know. These writings also reveal stress and difficulty in trying to achieve the mix of indepen-

dence and support that leads to interdependence, and the complex imaginative leaps required for people with these disabilities to succeed in home, school, work, and community.²⁷

Philip M. Ferguson captures the social constructionist understanding of disability when he reminds us that under the right circumstances people with sensory impairments can enjoy beauty; those with mobility impairments can experience physical exhilaration; and people with cognitive disabilities can think and communicate about something they consider important.²⁸ That some people with "moderate" or "significant" impairments flourish does not mean that everyone does or will, any more than it indicates that every nondisabled child will grow into a productive, contributing adult. It does, however, demonstrate that people who depart in radical ways from species typicality can participate in what those of us who are typical define as "the human community." We can agree that our disabilities impose limitations we might sometimes wish were not there, and in that sense the trait of disability may not be neutral.

People with disabilities can also agree that to have their impairments is not to be "species-typical"; what they cannot agree to is that their impairments make them in Erving Goffman's words "less than human" or, to think again in terms of prenatal testing, less worthy than others of entering the world of humankind.²⁹

*Parenting and Disability: Nakhes, Tsuris, and Abortion*³⁰

Our Hastings Center project analyzed the disability critique of prenatal diagnosis principally in terms of the implications for family life. Sometimes people interpret the disability rights critics as "siding" with the disabled fetus against unthinking, unfair parents. The critique is focused principally on the professionals who advise parents, rather than on the parents themselves. Like Bruce Jennings, I am concerned about how genetic science suggests that people reimagine pregnancy, parenthood, and their future children; like Nancy Press, the critique is not so much with the choices made, but with the choices made available.³¹

I share much with those who have written eloquently about parental responsibilities and parental hopes. Along with Steinbock, I believe that parents should not bring children into the world if they do not feel they can help their children have rewarding lives.³² Like Ruddick, I believe that parents legitimately can have hopes and dreams for

themselves, as well as for their children, in creating families, and they can try to influence their children to adopt interests, goals, and values they hold dear.¹³

We differ primarily in whether we believe that a child's disability will deprive child or parent of a rewarding life. If I believed that disability in itself, now or in the future, thwarted parental dreams for themselves and their children, I would not be a critic. Since almost all people who have disabilities can give and receive love, contribute to others, appreciate the world around them, and make a social contribution, I am convinced that children and adults can have lives they and others will value without depriving parents of what they seek in family life.

Most project members believe that people with significant disabilities can have lives they experience as rewarding but worry that life with a disabled child would be more difficult than life with a child without disabilities. On this view, parents could or should not be expected to envision the family life that included a child with a disability as equivalent to family life where no children had disabilities. Skeptics about the research findings and interpretations summarized in this book by Ferguson, Gartner, and Lipsky suspect that the research reviewed does not tell the whole story and that a child with a disability poses substantial heartache, difficulty, and burden to families that far exceed in kind and degree the stresses modern parents typically face.¹⁴

Some members of the project recoil at unfettered parental selection because they share the tenet of the disability critique that urges parents to recognize the uniqueness of each individual child and to value the child for what that child is, rather than lamenting what a child is not. The parents' love and imagination should encompass people who will be tall or short, tone deaf, color blind, girls or boys, gay or straight, risk-takers or risk-averse. Disability strikes them as qualitatively different from all these other forms of human variation. They argue that even if the child can manage to have an acceptable life in this society with its inadequate set of supports for parents raising ordinary children, raising a child with a disability who requires anything "extra" is more than harried, frantic parents will or should want to do. Disability critics assert only that if society, and prospective parents, recognized how lives of people with disabilities and their families resembled other lives, they might decide that they could love, enjoy, welcome, and raise such a child.

The question for disability critics is what to make of the "extra burden" or "negative family impact claim." Families are indeed stressed

as it is raising ordinary children. The society is not set up for disabled children; there is no support—financial or otherwise—for extra expenses disability entails for families. Kittay echoes this message when she points out how fortunate she is that her family has the financial, personal, and social resources to help their daughter.¹⁵ She asks whether the disability rights critics of selective abortion shouldn't concentrate instead on changing health care, the educational system, and other social institutions so that existing disabled children and adults will live more easily and demand less parental sacrifice.

Disability rights critics, or at least this one, entirely support her social goals. The United States in the new millennium is hardly a perfect world for anyone regardless of disability, and the fight for social change must go on. It must be a fight that says, however, that the social arrangements for "ordinary" children should change to include the "special needs" of disabled children; since all children have special needs, but some of them don't have labels, some needs get met and others don't. All too often the children who have needs labeled by disability are still told that their needs are not ordinary and that ordinary school programs, after-school groups, baby-sitters, and daycare centers can't handle them. Only a fraction of children with disabilities have such complex and ongoing medical needs that those who care for them require specialized training. In manifold ways, the "extra burden" of raising a child who has a disability falls on family because the society still won't accept that children with disabilities are part of the human race and must be expected and planned for when we collectively create transportation, schools, housing, workplaces, or families.

I am heartened by data demonstrating that more families flourish than founder if they are raising disabled children, just as more families flourish than founder raising nondisabled children; yet I know that some families of both groups experience tremendous difficulty, upheaval, and stress. There are moving accounts of familial joy in disabled members, and wrenching stories of sorrow, anguish, rejection, and family dissolution.¹⁶ But the data showing family problems when there is a child with a disability should not be used against families trying to do their best any more than data about divorce rates should be used to convince people to eschew marriage. The information is at least as valuable for lessons we can learn about how to do things better, just as we use data about divorce to try to avoid pitfalls in our marriages. That many marriages fail does not make us abandon the institution but rather try

to find ways to help people survive and thrive. What does it say about our society that we are interested in abortion for disability, but we don't support divorce?

The wealth of empirical data about "the impact of the disabled child on the family" should not be used in the service of blaming the child with the disability for all problems or for saying that social arrangements are adequate because most families do well. Data about thriving or struggling families will not solve the moral question of what kind of society and family climate we want to create. If we learn enough about disability to locate problems in the interaction of biology with environment and not to view them as the inevitable consequence of impairment, we should put our professional institutions behind strengthening families; we should not use social resources to announce to prospective parents that a child's disability will ruin a family, because the data do not support these conclusions. Medical professionals and genetic counselors should learn about what works and why, as well as what is hard, and they should provide parents with the information. Program designers and policymakers should learn from the success stories and redesign services and laws to ameliorate problems when we can. We should work for funding and enforcement of a little-known federal law passed in 1994 that would increase the supports for families raising children with disabilities and better integrate that service network with the rest of the human service system.³⁷ Bioethics, medicine, and genetics must learn the lessons about the social nature of disability if they are ever to give wise guidance to people struggling to make hard decisions. Rather than giving up on societal acceptance and family appreciation of people with disabilities because some social institutions reject and some families abandon disabled members, I urge us to learn everything we can about what promotes inclusion and to stand behind laws, services, and innovations that promote that inclusion and enjoyment.

Mary Ann Baily argues that she and other decent parents expect to love any child they have, disability or no, but that they want to avoid whatever they can with selective abortion if they learn of a disability before a child is born.³⁸ She holds the view that if it is acceptable for women to end a pregnancy for any reason or no reason, the detected impairment of a future child is an excellent reason. Paraphrasing her metaphor: Why climb the Mount Everest of parenthood with problems I can predict and avoid if I have the chance to climb Mount Rainier: Mount Rainier will have its own twists and surprises!

I find the metaphor and attitude tempting but dangerous. It is dangerous because it again assumes that only the twists of detectable impairment are problems, that anything else is acceptable, but that disability is different, worse, unacceptable. It assumes that the attitude toward avoiding a detectable disability in a once-wanted child will not carry over into the attitude of rejecting or not appreciating the child who acquires a disability at two or twelve, the partner at twenty, the friend at forty, and parents when they are in their eighties. Why should playmates' parents, the neighbors, or the schools change to incorporate existing children with disabilities if families and professionals, government, insurance companies, and science work as hard as they do to avoid the births of people who will have these conditions? Where do we first learn justice, sharing, and cooperation, but in the family? If families are urged by their professional advisors and by experts not to welcome wanted children because those once-wanted children will now turn out to have disabilities, where will families learn for themselves and teach their existing disabled and nondisabled children to cooperate, to share, to respect difference, to see similarity within difference? I believe that disability is seen as a burden and only a burden because people forget that along with that negative characteristic of disability come hosts of other characteristics that are positive and negative, that enable people with very profound impairments to enrich the lives of those who discover the personality along with the impairment.

Let us grant that disability causes stress for parents and expense for them and for society. So does raising children with exceptional gifts. In June 1999, a family moved from Florida to Virginia so that their ten-year-old son could live at home while beginning his freshman year of college!³⁹ This family has spent extra money in finding him tutoring, a college that would accept someone usually in fifth grade, and in moving for the sake of his education; that may be more money and more disruption than disability occasions for many families. Studies of gifted children show that their families revolve around the children with those gifts and can experience marital stress and sibling difficulties resembling the ones blamed on the disabled child's presence in the family.⁴⁰ However, parents, siblings, and society tolerate the stress because they value the trait and the person with the trait, seeing the gift as offsetting the stress. The gifted child brings *nakhes* (joy) and makes up for the trouble (the *isuris*). In raising a typical child, parents count on joy and struggle and expect them to balance out in the years of family life. With the child who has a disability, professionals emphasize

negatives and burdens and often suggest that there will be no joy (no *nakhes*) and only trouble (*tsuris*).

If the majority continues to see disability as a form of human difference that is worse than other types of difference, it is no wonder that the majority will resist social changes that would incorporate people who have these negatively valued characteristics. The goal of the disability rights movement is to persuade the majority to recognize that people with those disabilities are not lesser than others because of those variations; they are not lesser in what they have to offer and what they can contribute to family and social life. If we truly believed that it was acceptable to have a disability, we would subsidize more disability-related expenses than we do as a society; even if parents paid some of their own money to help with making life easier for their son or daughter, professionals and the public would see it as neither better nor worse, nor different from the expenditures to help other children flourish.

Our society, as exemplified by medicine, science, education, and government, should do more than it does to help parents. It takes a village to raise every child, and perhaps that village needs to expand and change to include one described as having a disability.

If we want to create a society willing to include people with disabilities as well as accepting of parental decisions to avoid the births of disabled children, we must radically change how we offer prenatal diagnosis and selective abortion. In addition to the recommendations for a revamped counseling process endorsed by our project, we should change some other "messages." Professional literature should speak about the "possibility" or "likelihood" of having children with Down syndrome or spina bifida, rather than insisting upon using the word "risk" in discussions with prospective parents. Let parents themselves decide whether the possibility of having a child with one or another disabling condition is a risk to their hopes for family life. Similarly, spina bifida and other nonlethal disabilities should not still be described as "devastating defects" in professional literature or in materials given to parents contemplating offers of prenatal testing.⁴¹ We should eschew the temptation to accept some limits on testing for non-health-related characteristics, or for only what professionals decide are severe and burdensome conditions. Offered balanced, careful information about detected characteristics, parents should decide what they believe is in accord with parental and family goals. Saying that color blindness and tone deafness are too trivial,

but that blindness and deafness are serious enough to warrant testing and abortion, will not increase recognition of the humanity of people who are blind or deaf.

Although I commit myself to a trend toward much more selectivity than I would wish by respecting parental autonomy, I avoid the tendency to perceive disability as radically different from and worse than all other human difference. Because I oppose using selective abortion to avoid any traits, I oppose efforts of deaf parents or parents with achondroplasia to abort fetuses that would not share those particular traits. People with disabilities who seek such likeness in a child make the same mistake as those who reject children based on one characteristic—believing that the presence or absence of a trait predicts a satisfying life for a child, a fulfilling parent-child relationship, and a happy family life. Rather than wishing to make disability central to identity, I would like a world in which it assumed the moral, social, and professional significance that being fourth-born or nonmusical assume in this world.

I am convinced that professional limit setting based on a committee's list of "acceptable" and "unacceptable" disabilities or variations will erode what cooperation exists among people across disabilities. It will weaken those alliances being built between disability organizations and other political groups pressing for changes in how society handles new technologies, thinks about families, or deals with human difference.

I and others who take a critical view of selective abortion have been viewed as hard on parents and as holding out expectations that are too high. My concerns are much more with the professionals who set the tones that prospective parents hear than with prospective parents themselves. Ruddick is correct in saying that I would prefer all parents to imagine themselves able to welcome and nurture whatever children they have, and to see that the extras perhaps occasioned by some aspects of a child's characteristics may yield extras in human relationship.⁴² The hours spent in daily physiotherapy with a boy who has cystic fibrosis could be viewed as only a tragedy and chore, or they could come to be a special time for family or friend to help someone they care about, knowing that in other ways the boy gives to them in fun, love, and companionship. Ruddick is also correct that I think the process of parenting begins when a woman (or she and her partner) accepts the idea of a pregnancy as the beginning of a relationship with a child-to-be. I do agree with people who worry that making acceptance of parenthood contingent on a child's characteristics will fundamentally

change what is precious and unique in the love of parent for child and in family life. I recognize that prospective parents have their own limits and differences (call them disabilities?). If parents can make their choices about selective abortion after information that helps them to imagine a worthwhile life for child and family, I support parents in the decisions they make. There has been much searching and struggling in our project group. I have been moved and heartened by the words of Leo Kittay:

The argument you're making draws a major line between normal and retarded [sic] 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 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?

. . . What kind of message does aborting the retarded send to would-be siblings?

. . . 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.⁴¹

Thank you, Leo! You confirm my belief that there can be appreciation of people with disabilities, and of the disability critique of selective abortion.

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NOTES

1. I am profoundly indebted to Erik Parens for initiating the project, for permitting me to collaborate closely in its every stage, and for the countless discussions that have assisted me to rethink and perhaps clarify my beliefs. I would like to think that our collaboration has heightened my respect and compassion for people trying to do their best in difficult situations.

2. This project and this volume concentrate on prenatal diagnosis because it is the most frequent form of antenatal testing. For my purposes in evaluating the arguments for and against the merits of prenatal testing and abortion, I need not distinguish among types of procedures done on fetuses or embryos and whether the traits looked for are "genetic" in origin. I am concerned with the activity of seeking to use any method designed to select against the births of people with prenatally detectable disabling traits. My concern applies to preimplantation genetic diagnosis, or to any other procedure that could be devised, and it applies to people who seek testing to avoid the births of nondisabled, as well as disabled, children, such as are hypothesized about members of the Deaf community or of Little People of America.

3. For several other statements of the disability rights critique, see the articles by Marsha Saxton, "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion," in this volume; and Adrienne Asch, "Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy," *American Journal of Public Health* 89, no. 11 (1999): 1649-57, and the references they cite.

4. Mary Johnson, "Aborting Defective Fetuses—What Will it Do?" *Link Disability Journal* 14 August-September (1990), cited in Christopher Newell, "The Social Nature of Disability, Disease, and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick," *Journal of Medical Ethics* 25 (1999): 172-75, at 174.

5. Eileen Cronin-Noc, "'Thalidomide Baby' Grows Up," *Houston Chronicle*, July 26, 1987.

6. Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," in this volume; and James Lindemann Nelson, "The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies," in this volume.

7. Nelson, "The Meaning of the Act."

8. Nancy Press, "Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available?" in this volume.

9. Jeanne Menary, "The Amniocentesis Abortion Experience: A Study of Psychological Effects and Healing Process" (Ph.D. diss., Harvard University, 1987); and Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999).

10. Bonnie Steinbock, "Disability, Prenatal Testing, and Selective Abortion," in this volume.

11. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), p. 154.

12. Eva Feder Kittay with Leo Kittay, "On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son," in this volume.

13. James Lindemann Nelson, "Identity and Disability" (paper presented at the second annual meeting of the American Society for Bioethics and Humanities, Philadelphia, Penn., October 30, 1999).

14. Parens and Asch, "The Disability Rights Critique."

15. National Organization on Disability's 1998 Harris Survey of Americans with Disabilities, available at <http://www.nod.org/press.html#poll>, accessed August 29, 1999.

16. Wendell, *The Rejected Body*.

17. Saxton, "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion."

18. See Deborah Kent's essay discussing the difference between her own and her family's responses to the possibility that her child might inherit her genetic disability. Deborah Kent, "Somewhere a Mockingbird," in this volume.

19. Newell, "The Social Nature of Disability"; Saxton, "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion"; Wendell, *The Rejected Body*; and Deborah Kaplan, "Prenatal Screening and Diagnosis: The Impact on Persons with Disabilities," in *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994), pp. 49-61.

20. Newell, "The Social Nature of Disability," pp. 172, 173.

21. Newell, "The Social Nature of Disability."

22. Troy Duster and Diane Beeson, *Pathways and Barriers to Genetic Testing and Screening: Molecular Genetics Meets the "High Risk" Family* (Washington, D.C.: U.S. Department of Energy, October 1997), p. 47.

23. See also Fredda Brown, Carole R. Gothelf, Doug Guess, and Donna H. Lehr, "Self-Determination for Individuals With the Most Severe Disabilities: Moving Beyond," *Journal of the Association of Persons with Severe Handicaps* 23, no. 1 (1998): 17-26; Dianne L. Ferguson, "Relating to Self-Determination: One Parent's Thoughts," *Journal of the Association of Persons with Severe Handicaps*

23, no. 1 (1998): 44-46; and Michael Wehmeyer, "Self-Determination for Individuals With Significant Disabilities: Examining Meanings and Misinterpretations," *Journal of the Association of Persons with Severe Handicaps* 23, no. 1 (1998): 5-16.

24. Ferguson, "Relating to Self-Determination," pp. 45, 46.

25. Kittay, "On the Expressivity and Ethics of Selective Abortion."

26. Nelson, "The Meaning of the Act"; Steinbock, "Disability, Prenatal Testing"; William Ruddick, "Ways to Limit Prenatal Testing," in this volume; Jeffrey R. Botkin, "Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services," in this volume; and Mary Ann Baily, "Why I Had Amniocentesis," in this volume.

27. Brown, Gothelf, Guess, and Lehr, "Self-Determination for Individuals"; Ferguson, "Relating to Self-Determination"; Wehmeyer, "Self-Determination for Individuals"; and David Goode, ed., *Quality of Life for Persons with Disabilities* (Cambridge, Mass.: Brookline Books, 1994).

28. Philip M. Ferguson, personal communication, cited in Parens and Asch, "The Disability Rights Critique," note 51, in this volume.

29. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, N.J.: Prentice-Hall, 1963), pp. 5-6.

30. This title comes from an interchange during one of the meetings of our project group: "People are worried that the child with a disability won't give parents the 'nakes' they want from a child." Rejoinder: "It's not the 'nakes' I'm worried about; it's the 'tsuris.'"

31. Bruce Jennings, "Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability," in this volume; and Press, "Assessing the Expressive Character of Prenatal Testing."

32. Bonnie Steinbock and Ron McClamrock, "When Is Birth Unfair to the Child?" *Hastings Center Report* 24, no. 6 (1994): 15-21.

33. William Ruddick, "Parenthood: Three Concepts and a Principle," in *Marriage, Marriage, and Parenthood: An Introduction to Family Ethics*, ed. Laurence D. Houglgate (Belmont, Calif.: Wadsworth, 1999), pp. 242-51.

34. Philip M. Ferguson, Alan Gartner, and Dorothy K. Lipsky, "The Experience of Disability in Families: A Synthesis of Research and Parent Narratives," in this volume.

35. Kittay, "On the Expressivity and Ethics of Selective Abortion."

36. Zolinda Stoneman and Phyllis Waldman Berman, eds., *The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships: Research Issues and Challenges* (Baltimore, Md.: Paul H. Brookes, 1993); Myra Bluebond-Langner, *In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child* (Princeton, N.J.: Princeton University Press, 1996); and Meira Weiss, *Conditional Love: Parents' Attitudes Toward Handicapped Children* (South Hadley, Mass.: Bergin & Garvey, 1994).

37. Families of Children with Disabilities Support Act of 1994, P.L. 103-382 (October 20, 1994); Title 20, U.S.C. 1491 et seq.; U.S. Statutes at Large, 108, 3937.

38. Baily, "Why I Had Amniocentesis."

39. National Public Radio, "Nine-Year-Old Florida Boy Graduating from High School," *Morning Edition*, June 3, 1999.

40. Ellen Winner, *Gifted Children: Myths and Realities* (New York: Basic Books, 1996).

41. Martha M. Werler, Carol Louik, and Allen A. Mitchell, "Achieving a Public Health Recommendation for Preventing Neural Tube Defects with Folic Acid," *American Journal of Public Health* 89, no. 11 (1999): 1637-40.

42. Ruddick, "Ways to Limit Prenatal Testing."

43. Kittay, "On the Expressivity and Ethics of Selective Abortion."

Part Four



Making Policies, Delivering Services