Selection against Disability: Abortion, ART, and Access

Alicia Ouellette

A decade ago, Adrienne Asch asked: "Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities?"[1] She concluded that informed reproductive choice, including the use of pre-implantation genetic screening and selective abortion, could potentially coexist with respect for current and future people with disabilities, but that achieving such a balance would require substantial clinical and cultural changes in light of the social context in which decisions about disability-based selection are made.

This essay picks up where Asch left off, taking the position that renewed attention to the disability critique of both pre-implantation genetic selection and selective abortion is timely given new technologies that make detection of genetic traits common practice before and during pregnancy. It further urges that the increasing willingness of states to enact laws to constrain certain forms of pre-birth sex and race-based selection,[2] bring new urgency to issues raised by the disability community around disability-based selection. Although the laws against trait-based selection may be part of an agenda more broadly aimed at chipping away at the right to abortion generally, trait-based limitations are particularly troubling from a disability perspective, especially when considered together with new evidence that people with disabilities face significant barriers to exercising their own reproductive rights. This essay examines that connection and argues that although the disability critique suggests problems with the widespread use of disability-based selection, the answer is not to increase restrictions on reproductive and familial liberty. Societal and clinical reforms that improve decisionmaking, educate parents and providers, and expand access to reproductive healthcare will better promote respect for persons living with disabilities and otherwise mitigate the potential harm of disability-based selection.

A. Deciding against Future Children: Screening to Prevent Disability

For at least 40 years, potential parents have been able to use various forms of medical testing to investigate the health status, genetic makeup, or possible existence of a disability in a developing embryo or fetus.[3] Assisted reproductive technologies allow some pro-

Alicia Ouellette, J.D., *is Dean and Professor of Law at Albany Law School, and a Professor of Bioethics in the Union Graduate College/Icahn School of Medicine at Mount Sinai. She earned her A.B. at Hamilton College in Clinton, NY, and her J.D. from Albany Law School in Albany, NY.*

spective parents to screen embryos before a woman even becomes pregnant. When embryos are created through in vitro fertilization (IVF), some genetic conditions can be diagnosed through embryo biopsy, allowing prospective parents to select which embryos to transfer, and which to discard, based upon traits identified through genetic testing.[4] Once a woman is pregnant, ultrasound, blood serum tests, amniocentesis, and chorionic villus sampling all give prospective parents information about the health and genetic status of their developing fetuses.[5] Current technology can identify a number of traits including sex, neural tube defects, deafness, trisomy 13, anencephaly, adult-onset genetic disorders (e.g., Huntington's), Down syndrome, and an increased likelihood to develop certain cancers.[6] Advances in genetic and other prenatal testing appear likely to reveal even more information about developing fetuses, such as hair and eye color, skin pigmentation, and autism spectrum disorder.[7] Armed with such information, prospective parents can elect to terminate a pregnancy when it is discovered that a developing fetus has an unwanted trait, so long as the trait is detected prior to fetal viability, or earlier if so required by state law. New noninvasive maternal blood tests may give prospective parents genetic information about their developing fetus as early as five weeks into pregnancies when medical abortion, abortion caused by ingestion of prescription drugs mifepristone and misoprostol, remains an option, potentially expanding opportunities and feasibility of disability-based screening.[8]

> Although the laws against trait-based selection may be part of an agenda more broadly aimed at chipping away at the right to abortion generally, trait-based limitations are particularly troubling from a disability perspective, especially when considered together with new evidence that people with disabilities face significant barriers to exercising their own reproductive rights. This essay examines that connection and argues that although the disability critique suggests problems with the widespread use of disability-based selection, the answer is not to increase restrictions on reproductive and familial liberty. Societal and clinical reforms that improve decisionmaking, educate parents and providers, and expand access to reproductive health care will better promote respect for persons living with disabilities and otherwise mitigate the potential harm of disability-based selection.

Prenatal and pre-implantation screening gives physicians and prospective parents information that allows them to make decisions about whether a particular embryo or fetus should be brought to term. The information is powerful. Although exact statistics are not kept, some reports suggest that a positive test for Down syndrome results in an abortion in 85-90% of cases.[9] When genetic screening is used with IVF, embryos identified as carrying disabling genetic conditions are routinely discarded. As genetic testing becomes more available, less invasive, and more robust, questions arise about "which conditions can and should be tested for [before implantation and] prenatally…And as science evolves, we need to ask: should prenatal testing include autism, breast cancer risk genes, or even one's sexual orientation?"[10]

This is not to say that decisions to terminate a wanted pregnancy are easy, or even that prospective parents always elect to select against or terminate a pregnancy in which a disabling trait is detected in an embryo or fetus. Some prospective parents decline to seek the information in the first place and forgo prenatal screening and diagnosis. Others receive the information about the existence of a disability, and simply prepare to parent the child who is developing. In a handful of cases, prospective parents have sought to use technology to ensure the birth of a baby with traits such as deafness, Down syndrome, or achondroplasia.[11] Decisions to avoid screening or to give birth to a child with disabilities may meet some resistance, especially in the healthcare setting, where a principal goal is the birth of a healthy baby (a goal shared by most parents). Scholar Joan Rothschild explains, "[R]eproductive medicine characterizes the birth of a child with 'defects' as a tragedy, to be avoided by every means that science and technology can muster."[12] As a result, prospective parents report experiencing strong pressure by their healthcare providers to employ every means possible — including selective abortion — to avoid the birth of children with disabilities.[13] While many people follow that advice, some do not. Those parents who allow a disabled child to come to term report negative consequences for themselves and their children. Despite that these children are beloved members of the family, and children of choice, they are referred to and treated by others as "mistakes," "tragedies," and "burdens."[14]

Acknowledging that physical, developmental, and emotional impairments can limit life activities, disability scholars maintain that many of the limitations faced by individuals with impairments are socially constructed. In other words, it is often socially constructed barriers — in architecture, communication, education, attitudes, transportation, employment, and other social constructions — that make impairments disabling. Where such barriers are removed — through universal design in buildings and transportation, accommodating various means of communication, and accepting a wide range of human variation — many impairments are hardly limiting. Life with disability can be, and is, meaningful, productive, and worthwhile.

Unlike parents who feel pressure to select against disability, parents seeking to terminate pregnancies or select against embryos based on other traits — sex is the most common example — sometimes experience pressure in the opposite direction. Many providers refuse to participate in sex-based selection.[15] Professional organizations distinguish sex-based selection from selection against disabling traits, or using sex selection to avoid sex-linked diseases. Increasingly, state and international laws reflect this divide.[16] While many scholars, lawmakers, and advocates oppose selection based on traits such as race, sex, or eye color, all but the most committed to the preservation of all embryonic and fetal life would allow selection against "serious conditions" or for "medical reasons," categories that include a wide range of conditions.[17] On a practical level, then, disability-based selection appears to be here to stay (assuming abortion remains legal in the U.S.). The more immediate legal and ethical debate focuses on whether to adopt laws or policies that define as unacceptable other criteria for preimplantation and prenatal selection.

B. The Disability Perspective on Pre-Implantation and Prenatal Screening, Selective Abortion, and the Pressure to Avoid the Birth of Children with Disabilities

Many, even most, prospective parents do everything in their power to investigate and ensure the health of a future child.[18] Pregnant women take folic acid to avoid neural tube defects; they avoid alcohol and other substances that can cause problems for developing fetuses. Within medicine, prenatal screening during pregnancy is part of the standard of care, and pre-implantation genetic screening is an increasingly accepted part of the IVF practice, at least when the screening is for genetically linked disease or disability.[19] Despite its widespread use, debate continues about whether any legal limitations should be placed on the use of such screenings. For example, should prospective parents be given all available genetic information about embryos and fetuses, or should the information be limited? Should potential parents be allowed to abort a fetus for any reason at all, or should legal restrictions be placed on abortion chosen because of the sex or race or eye color of the developing fetus? Should the law treat trait-based screening through abortion differently from trait-based screening through IVF and PGD? Debates around these questions emphasize competing interests, including the importance of procreative liberty; individual choice; parental obligations to ensure the health of developing children; the prevention of pain, suffering, or fatal illness in future children; the unknown risks of creating designer babies; the loss of fetal life; the state's interest in prospective life; and the effect on family relationships.[20] To the extent they factor in the debate, disability-related issues are just one factor.

Nonetheless, practices that promote the intentional destruction of embryos and fetuses with disabilities raise serious concerns for the disability community that merit consideration in debates concerning limitations on the use of trait-based selection. Much work has been done by disability scholars, activists, and supporters to contest the myth that life with disability is inherently tragic. Indeed, a principal teaching of the disability community is that inclusion of people of different abilities in fundamental social institutions is not only possible, but valuable. Acknowledging that physical, developmental, and emotional impairments can limit life activities, disability scholars maintain that many of the limitations faced by individuals with impairments are socially constructed.[21] In other words, it is often socially constructed barriers — in architecture, communication, education, attitudes, transportation, employment, and other social constructions — that make impairments disabling. Where such barriers are removed — through universal design in buildings and transportation, accommodating various means of communication, and accepting a wide range of human variation — many impairments are hardly limiting. Life with disability can be, and is, meaningful, productive, and worthwhile. Moreover, disability scholars emphasize the many rich contributions that human variation provides in society. From the work of blind and deaf artists, to the various contributions of people with autism, to the joy brought to an individual family by the presence of a child with disabilities, the contributions are many. Even on a genetic level, traits thought to be disabling are sometimes found to come with profound advantages for those who carry them. For example, it was recently discovered that the same genetic condition that causes sickle cell disease also provides carriers with immunity against malaria.[22]

As such, disability scholars critique the use of reproductive technologies to prevent the birth of babies with disabling traits. They make four related arguments. First, the purposeful use of technology to prevent the birth of a disabled child expresses discriminatory negative attitudes about disabling traits and those who carry them.[23] Second, disability-based selection signals intolerance of human variation, which causes harm to parental relationships with children.[24] Third, selection against disability through pre-implantation screening and selective abortion is based on, and perpetuates, misinformation about the lived experiences of children with disabilities and their families.[25] Finally, selection reduces individuals with disabilities to a single trait, diminishing and eliminating their value as full human beings.[26]

The first claim, sometimes deemed the "expressivist argument,"[27] focuses on what selection against disability says about and means for persons living with disability. Explains one disability advocate, "The message...is the greatest insult: some of us are 'too flawed' in our very DNA to exist; we are unworthy of being born.... [F]ighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality — we are indeed worthy of being born, worth the help and expense, and we know it!"[28] This critique starts with recognition that "[c]ontinuing, persistent, and pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities."[29] Disability-based screening perpetuates that discrimination by broadcasting a potent message about life with disability: "the message implicit in the practice of abortion based on genetic characteristics is, 'It is better not to exist than to have a disability. Your birth was a mistake. Your family and the world would be better off without you alive.'"[30] Because the message is received and accepted by society — by policy makers, educators, employers, healthcare providers, and the public at large — prenatal screening perpetuates and validates existing discrimination.

The second claim against disability-based selection, that it signals intolerance of human variation that causes harm to parental relationships with children, is part of a broader critique of any form of genetic selection. The notion is that the world is made richer by human variation — whether the variation is in diversity of races, sexual orientations, or physical and mental abilities. The child with Down syndrome or autism adds to the rich tapestry of human experience as does the child with athletic prowess, superior intelligence, a unique racial background, or a minority sexual orientation. Selection allows parents to reject as inferior elements of human variation and reject an otherwise wanted child simply because of an expectation that the child's deviation from what the parent expected or hoped for will diminish their parental experience. Proponents of the disability critique argue that a familial construct that allows parents to assert their expectations to determine the very existence of a future child corrupts the parent-child relationship to one that resembles custom manufacture. The critique is similar to one Michael Sandel has aimed at genetic manipulation and sex selection.[31] Sandel explains that when parenting takes on the role of manufacture, "the problem lies in the hubris of the designing parents....

Even if this disposition did not make parents tyrants to their children, it would disfigure the relation between parent and child."[32] Sandel reflects on the teaching of theologian William May that parenthood, more than any other human relationship, teaches an "openness to the unbidden."[33] May's construct, says Sandel, "appreciate[s] children as gifts…as they come, not as objects of our design or products of our will or instruments of our ambition."[34] It recognizes that "[p]arental love is not contingent on the talents and attributes a child happens to have…[but on] acceptance of the child as he is."[35]

The third argument against disability-based selection is that PGS and selective abortion are based on, and perpetuate, misinformation about the lived experiences of children with disabilities and their families.[36] The critique addresses head-on the widespread belief that preventing the birth of babies with disabilities makes sense to ensure all children start life with open opportunities and full capacities. Proponents counter this assumption with studies that demonstrate the richness of life with difference, and the appreciation individuals who live with disabilities have for their own lives and their own methods of experiencing the world. Adrienne Asch, for example, acknowledged that disability limits some options, "relishing bird songs, experiencing the interaction of body and nature in a hike through the woods," but argued that

> [while] [h]aving capacities is good,…[no] capacity is an 'intrinsic' good. If typical capacities and health achieve value because they enable people to participate in facets of life, it is crucial to note how much of life is open, in today's society, to people with disabilities. Brief acquaintance with people who have disabilities and who work, play, study, love, and enjoy the world should demonstrate that very few conditions preclude participating in the basic activities of life, even if some conditions limit some classes of them, or methods of engaging them.[37]

Proponents of this argument tend often to support parental choice, even through genetic screening or selective abortion, but propose major changes in the delivery of test results, the training of health providers, and the culture in which such information is delivered.[38]

The final critique of disability-based selection, that selection reduces individuals with disabilities to a single trait, diminishing and eliminating their value as full human beings, is sometimes subsumed in the expressivist argument, and is equally applicable to selection based on traits other than disability, such as sex, race, or sexual orientation.[39] With respect to sex selection, for example, the argument is that it is "as if the parents were saying, 'We don't want to find out about 'the rest' of this fetus; we don't want a girl.'"[40] Such overt sex-based decisionmaking defeats sex-equality, diminishes inherent value in each sex, and denies the contributions the developing fetus could make to a family and society. The same critique applies to a fetus carrying a gene for deafness, autism, or other disabling characteristics. Such overt trait-based discrimination raises the specter of diminishment of the population of persons with valuable traits, such as is seen in some countries in which sex selection is common. Disability advocates point to the steep reduction in number of children with Down syndrome as proof that genetic screening can indeed have a population-wide impact.[41]

Although several threads of the disability critique apply to selection based on any trait, the specific concern in the disability community is what disability-based screening means for current and future people living with disabilities. Outside the disability community, screening against disability is widely accepted as self-evidently a good thing.[42] To the extent it is considered, the disability critique is sometimes dismissed in favor of individual autonomy and procreative liberty. Moreover, the disability critique is subject to strong counter arguments. The expressivist argument loses force, for example, when considered from the perspective of an individual making a decision about his or her own reproductive destiny; individual reproductive choices express nothing about the degree to which the person making choices respects persons living with disabilities. They are complex and personal, and "it is impossible to conclude just what 'message' is being sent by any one decision to obtain prenatal testing."[43] That is, it is perfectly possible for an individual to fully respect individuals living with disabilities while simultaneously deciding that he or she is not prepared to parent to a particular embryo or fetus. And the critique as a whole is itself subject to criticism for overbreadth to the extent it fails to acknowledge that not all disabilities are the same. Some disabilities are compatible with meaningful life, but others are uniformly fatal, or marked by a lifetime of extreme pain and deterioration.

Although vulnerable to counterargument, the disability critique of disability-based selection raises important concerns about the degree to which people living with disabilities and their families struggle for respect. Those concerns are heightened when one understands the context in which and the information upon which decisions about disability-based selection are made.[44] Laws that would define when prenatal selection is acceptable or not, such as state laws that prohibit abortions for sex selection but allow them to select against disability, compound these concerns.[45] "[B]y developing and offering tests to detect some characteristics and not others, the professional community is expressing the view that some characteristics, but not all, warrant the attention of prospective parents."[46] Disability-based concerns about line drawing take on additional weight when considered in the broader context of the barriers faced by adults with disabilities who wish to exercise their procreative liberty to become parents.

Among other things, negative attitudes toward people with disabilities by health care providers contribute to disability-based disparities in health care. Studies demonstrate that providers consistently underestimate the quality of life experienced by people with disabilities as compared with assessments made by the people who live with disabilities, largely because they make negative assumptions about the possible quality of life with disability that are simply inaccurate.

C. The Context for Medical Selection against Disability

Historically, legal and medical forces worked together to prevent both the birth of and reproduction by people with disabilities. [47] Indeed, the two were often linked. Based on the belief that disabling traits were heritable, eugenics laws allowed physicians to involuntarily sterilize those individuals deemed "defective" in order to prevent the birth of babies deemed "defective."[48] Justice Holmes's infamous pronouncement in defense of state-sponsored eugenics that "three generations of imbeciles are enough"[49] reflected questionable science, but accurately reflected the policies behind involuntary sterilization laws: if we can use science to prevent the birth of people with defective genes, we should. Of course, involuntary sterilization laws did not prevent the birth of all babies with disabilities, and history was not kind to survivors. Some babies with disabilities, including babies with correctable conditions, were simply left to die.[50] Others were taken from their families, institutionalized, and denied education, employment, and housing.[51]

With the abolition of eugenics laws, and adoption of the civil rights statutes that protect persons with disabilities from discrimination in housing, healthcare, education, and other public accommodations,[52] the lives of people with disabilities have dramatically improved. Nonetheless, disparities continue, including in the provision of healthcare services. A report published in 2009 by the National Council on Disabilities confirmed that people with disabilities experience significant healthcare disparities and barriers to care.[53] Specifically, the report indicates that people with disabilities are more likely to go without needed care; have more preventable emergency room visits and hospitalizations; experience a significantly higher prevalence of secondary conditions; and get less preventive care (e.g., pelvic exams, pap smears, prostate exams, weigh measures, prenatal care).[54] The statistics reveal a disparity issue similar to the disparity that is well recognized with respect to race and healthcare.[55]

Among other things,[56] negative attitudes toward people with disabilities by healthcare providers contribute to disability-based disparities in healthcare.[57] Studies demonstrate that providers consistently underestimate the quality of life experienced by people with disabilities as compared with assessments made by the people who live with disabilities, largely because they make negative assumptions about the possible quality of life with disability that are simply inaccurate.[58] A May 2012 report by the National Disability Rights Network details the ways in which the U.S. healthcare system fails to recognize the value of life with disability.[59] The report describes conversations between doctors and persons with disabilities and their families in which people with disabilities are "viewed as having little value as they are," and not "endowed with inalienable rights of liberty, privacy and the right to be left alone — solely because they were born with a disability."[60] Similar reports about the treatment of people with disabilities in the U.S. healthcare system feature prominently in disability studies scholarship.[61] The research documenting the barriers to healthcare encountered by people with disabilities explains the larger context in which specific decisions about disability and reproductive health are currently made.

D. Deciding against Future Parents: The Effect of Disability on Accessing Fertility and Other Reproductive Services

The problems faced by people with disabilities in accessing the healthcare system are especially acute when it comes to reproductive health. Despite legal requirements for accessibility, inaccessible medical equipment makes it difficult for women with mobility disabilities to get basic women's health services, such as pap smears, mammographic screening, and pelvic exams. Worse, providers often assume that people with disabilities are not sexually active and therefore do not need reproductive healthcare. As one scholar with physical disabilities explains, "There is an unfortunate stereotype that women with physical disabilities are asexual; we have no interest in sex, nor should we, heaven forbid, reproduce. This stereotype plays out in the assumption of some physicians that we are not sexually active and that if pelvic exams or mammograms are too much trouble because of inaccessible exam tables, they can be overlooked." Studies confirm that doctors are far less likely to ask women with mobility and other physical impairments routine questions about reproductive health than they are other women. Even explicit requests for routine reproductive health services like pap smears and mammograms are sometimes denied. For example, a woman with post-polio syndrome who uses a power wheelchair reported:

> My primary physician and several specialists I respect all practice at a major university medical center fairly close to my home. Recently, though, when I requested a gynecology referral there, I was told that I would not be seen unless I could bring my own assistants to help me get on the examining table. This is a huge world-renowned hospital. This is the era of [the] ADA. Still I am treated as though I don't belong with the other women who seek services in OB/GYN unless I can make my disability issues go away. This news makes me weary. I know it means once again that I can't simply pursue what I need as an ordinary citizen. I can't be just a woman who needs a pelvic exam; I must be a trailblazer.

It is in the context of a medical system that makes it difficult for women with disabilities to receive even basic women's health services, that adults with disabilities find themselves seeking medical assistance to become pregnant. Persons with disabilities seek fertility treatment and IVF for all the same reasons thousands of Americans seek such services each year, and in some cases, they have special needs for treatment specific to their own disabilities. For these individuals, access to reproductive technology is critical to biological reproduction. Unfortunately, disability-based discrimination is common in the fertility industry.

Disability experts explain that providers focus so intently on their patients' impairment that they disregard the possibility that their patients have more global needs.

It is in the context of a medical system that makes it difficult for women with disabilities to receive even basic women's health services, that adults with disabilities find themselves seeking medical assistance to become pregnant. Persons with disabilities seek fertility treatment and IVF for all the same reasons thousands of Americans seek such services each year, and in some cases, they have special needs for treatment specific to their own disabilities.[68] For these individuals, access to reproductive technology is critical to biological reproduction.[69] Unfortunately, disability-based discrimination is common in the fertility industry. A recent report by the National Council on Disability concludes, "Many prospective parents with disabilities encounter significant, and sometimes insurmountable, barriers to receiving assisted reproductive technologies (ART). Access to ART is often impeded by discriminatory practices against people with disabilities, as well as the growing costs of treatment combined with limited coverage by health insurance."[70]

The reasons for such discrimination are complex. The physician-patient relationship is a voluntary and personal one that the physician may choose to enter, or not, for a variety of reasons, such as excessive patient load, the person's inability to pay, or because the person is unlikable or uncooperative. Physicians cannot, however, refuse care for reasons deemed illegitimate under the law, such as the race, ethnicity, or disability status of a prospective patient. That is not to say that disability plays no role in legitimate medical screening. It is ethically and legally permissible for an ART physician to refuse to treat a patient when the ensuing pregnancy would compromise the health of the patient, or would constitute a "direct threat" to a third party, including an unborn baby that would not exist without medical treatment sought.[71]

Using these criteria, fertility doctors screen patients based on perceived ability to parent. The practice is both common and legally and ethically fraught. Fertility specialists screen potential patients based on their assessment of "both the welfare of the fertility patient or patients and the welfare of a future child prior to agreeing to help a patient achieve pregnancy."[72] Studies show that in screening patients, ART providers deny treatment to prospective parents with disabilities on the basis of their perceived inability to care for children, even when experience shows that parents with similar disabilities are effective, loving, and fit parents.[73] ART providers do not have special training in assessing parental fitness. Their judgments are not subject to judicial review. And judgments based upon biases against, or misunderstandings of, life with disability are frowned upon by professional ethics review boards.[74] Even so, they happen frequently enough that some experts go so far as calling the discrimination faced by persons with disabilities in their quest to become parents a new eugenics. For example, Judith Daar observed, "While the eugenicists of a century ago coerced the 'feeble minded' into surrendering their reproductive capacity through forced surgeries, today's practices act to deprive the disempowered of their capacity to reproduce by withholding the means necessary to produce a child."[75] It is important to remember that most individuals and couples without infertility problems need not satisfy any social criteria to implement a decision to have children. The disabled, as a group, face presumptions that they are incapable of parenting that have implications beyond the fertility clinic.

The use of disability as a proxy for parental fitness does not end when people with disabilities become pregnant and become parents. They face categorical questions about their ability to parent that do not apply to most potential parents.[76] Laura Rothstein has convincingly argued that there is "a judicial presumption of unfitness in many cases involving child custody for handicapped parents."[77] "Rothstein observes that this 'judicial presumption of unfitness' often manifests itself in different guises for different types of disabilities: deaf parents are thought to be incapable of effectively stimulating language skills; blind parents cannot provide adequate attention or discipline; and parents with spinal cord injuries cannot adequately supervise their children."[78] These assumptions do not survive scrutiny. With reasonable accommodations, many parents with disabilities can and do raise happy, educated, and healthy children.[79] Yet the presumption of parental unfitness is used, both in and outside the fertility clinic, to deny prospective parents with disabilities liberty and familial rights.[80]

E. Reconsidering the Disability Critique in Light of Selection against Parents: (Re)sounding the Call against Disability Exceptionalism in Reproductive Health Policy

The disability critique of PGS and selective abortion raises serious concerns about how selection against disability as currently practiced negatively affects equal treatment of and respect for current and future persons living with disabling traits. Individuals living with disabilities experience a healthcare system rife with disability-based inequalities and negative assumptions about life with disability. These affronts infect the decisionmaking process for prospective parents and affect the ability of adults with disabilities to become parents. To the extent policies and practices around disability-based selection have the effect of perpetuating discriminatory attitudes and negative experiences for people living with disabilities, the policies and practices should be revisited. This section explains the link.

Disability-based selection and disability-based denials of access to fertility treatment are part of the same culture of pernicious discrimination in medicine. It is in that culture that families selecting to carry to term an embryo with disabling traits face pressure to terminate, and experience disapproval from their medical providers if they do not. It is in that culture, that women with mobility disabilities cannot obtain reproductive services, and people with disabilities of all kinds are subject to judgments that they do not qualify for reproductive health services that would enable them to exercise their own procreative rights. It is that culture that needs changing.

It should be noted that the concern that disability-based selection perpetuates discrimination against persons currently living with disability is more acute with respect to laws[81] and professional policies[82] that distinguish disability-based selection from other kinds of trait-based selection, such as laws banning sex-based selection, than it is with individual choices. As discussed above, pre-implantation and prenatal screening gives potential parents information and control in deciding whether and how to exercise their right to reproduce. Individual parents make selections decisions based on their own values. Private decisions about reproduction need not harm or show disrespect to individuals living with disabilities. By contrast, laws and policies that define as unacceptable selection based on specific traits (sex or race, for example) differ from individual family decisions. Such laws send an official message that some forms of equality and respect have priority over others. Proposals to prevent sex-based selection in fertility treatment, for example, prioritize "women's equality at the expense of the equality of individuals with genetic diseases, conditions, and characteristics that are deemed 'undesirable.'"[83] Likewise, laws and policies that would deem selection acceptable for certain genetic or disabling traits (i.e., those that are especially serious or cause pain or reduce life expectancy), but not others, necessarily make a value judgment that some lives are valued over others.[84] A position statement by the American College of Obstetricians and Gynecologists implicitly makes this judgment, by deeming sex-based selection unacceptable, except when linked to disability status.[85]

Judgments that some lives are more valuable than others play out against adults with disabilities at the entryway to the fertility clinic. There, access is denied by the same providers who counsel patients that they can discard embryos because of disabling traits. These same providers have been shown, as a group, to underestimate the capacities of and quality of life experienced by their patients with disabilities, biases surely reflected in conversations with potential parents about the options for embryos and fetuses with disabling traits.

To be sure, selection based on sex is arguably different from selection based on disability. Some disabilities necessarily limit life opportunities in a way that sex need not. Some disabilities carry with them physical impairments and social and medical costs that can burden families. Some disabilities are uniformly fatal. Nonetheless, creating distinctions at law between sex and disability-based selection is not worth the cost. Laws and policies that carve out disability-based selection as appropriate (in contrast to other kinds of trait-based selection) tend to legitimize the discrimination and stigmatization that plagues adults with disabilities in the healthcare setting by confirming the belief that persons with disabilities are flawed, incapable, and unworthy of equal treatment. Moreover, the similarities between sex and disability-based selection are more important than the differences. Much of what is viewed as undesirable or unwanted about a child of a given sex or with a particular disabling trait is socially constructed. Indeed, some parents view sex as a kind of disability. They might see female children as inferior for cultural or social reasons, and view their life options and value to the family as more limited than males. Like parents selecting based on disability status, parents selecting for a particular sex, may make choices for family or social reasons. If one such choice is acceptable, similar choices should also be allowed. The law should leave such decisions to prospective parents.

Supporting parental choice while ensuring that individuals living with disabilities are afforded respect and equal treatment will require cultural and clinical changes. Cultural change is difficult. It takes work on many fronts. Steps worth exploring include charging health providers with taking a lead role in changing medical culture and clinical practice to better respect, understand, and include persons with disabilities as fully human. Medical schools should initiate steps to educate students about the value of life with disability. Perhaps they could require cultural competency in disability or other disability training by their graduates to ensure that all people, disabled or not, receive the message that they are worthy of full respect and equal treatment while under their care. Hospitals and clinics should ensure their buildings, programs, and equipment are accessible to persons with mobility disabilities.

More specific to prenatal and pre-implantation selection, changes should be made to clinical practice. It is unacceptable for providers to pressure potential parents to select for or against a potential child because of the presence of a particular trait, even a disabling one. Instead, the informed consent process should be reformatted to ensure potential parents are educated fully about all aspects, including the positives ones, of having a child with disabilities. Non-directive counselling should become the norm, and consideration should also be given to other proposals for reforming the informed consent process in reproductive medicine, including proposals to disaggregate information delivered at the time of screening from information given at the time of results.[86] More fundamentally, persons of all abilities would benefit if reproductive medicine in general reframed its goal from production of the perfect baby, to a more patient centered one: achieving the goals of the individual parent(s). Such a change would make as much room for decisions to parent a child with disabilities or any other trait, as there is room for decisions to select against disability, or any other trait. It could also translate, over time, into a culture in which persons living with disabilities could begin to achieve their own goals as potential parents.

Conclusion

In answering her own question, Adrienne Asch concluded, "As currently practiced and justified, prenatal testing and embryo selection cannot comfortably coexist with society's professed goals of promoting inclusion and equality for people with disabilities. Nonetheless, revamped clinical practice and social policy could permit informed reproductive choice and respect for current and future people with disabilities."[87] The statement holds true today. As currently practiced in the U.S., prospective parents have wide latitude to control their reproductive destinies, including by making decisions to select against various traits. Advocates who are uncomfortable with selection based on a particular trait often urge legal or practical bans on selection based on that trait. This paper argues that limitations on trait-based selection do more harm than good by preferencing one form of difference over another, in an arena in which such preferences can have devastating effects on the adults carrying those traits. They also limit reproductive liberties, which are critical to full inclusion and respect for adults living with disabilities.

From a disability perspective, the better approach is to change the culture in which potential parents make selection decisions by better educating healthcare providers and prospective parents, diminishing pressure by providers and others involved with counseling prospective parents to select against disability, and supporting inclusion of people with disabilities in all aspects of healthcare, including reproductive health. As others have argued, educating providers, disaggregating conversations about screening from delivery of testing results, incorporating non-directive counseling as part of reproductive care, disability training, and several other proposals for revamping clinical practice and culture will go a long way toward promoting choice and respect for people with disabilities.[88] Drawing lines between those traits serious or problematic enough to merit pre-implantation or prenatal selection will not.

Disability experts teach that a culture that devalues life with disability, devalues people with disability. To the extent possible, law and medicine should avoid taking positions that devalue life with disability. Instead the focus should be on recognizing the complexity of reproductive decisionmaking, educating parents and providers to understand and value all forms of human variation, and supporting individuals in achieving their own reproductive goals, whether those goals involve becoming a parent, or choosing to parent a child with a particular trait.

Acknowledgements

The author is grateful to Meredith Dedopoulos for her able research assistance on this article.

References

1. A. Asch, "Disability Equality and Prenatal Testing: Contradictory or Compatible?" *Florida State University Law Review* 30, no. 2 (2003): 315-342, at 315.
2. For example, some states prohibit abortions sought because of the sex of developing fetus. See, e.g., H.B. 2443, 50th Leg., 1st Sess. (Ariz. 2011), codified as Ariz. Rev. Stat. Ann. § 13-3603.02(A) (2014) (prohibiting the performance of an abortion on the basis of the unborn child's sex); 720 Ill. Comp. Stat. 510/6(8) (2014) ("No person shall intentionally perform an abortion with knowledge that the pregnant woman is seeking the abortion solely on account of the sex of the fetus."); S.B. 141, 85th Leg., Reg. Sess. (Kan. 2013) ("No person shall perform an abortion with knowledge that the pregnant woman is seeking the abortion solely on account of the sex of the unborn child."); S.B. 353, 2013 Gen. Assemb., 1st Sess. (N.C. 2013), codified as N.C. Gen. Stat. § 90-21.121 (2014) ("[N]o person shall perform or attempt to perform an abortion upon a woman in this State with knowledge, or an objective reason to know, that a significant factor in the woman seeking the abortion is related to the sex of the unborn child."); H.B. 1305, 63d Legis. Assemb., Reg. Sess. (N.D. 2013), codified as N.D. Cent. Code § 14-02.1-04.1 (2014) ("A physician may not intentionally perform or attempt to perform an abortion with knowledge that the pregnant woman is seeking the abortion solely...[o]n account of the sex of the unborn child."); S.B. 1890, 52d Leg., 2d Reg. Sess. (Okla. 2010), codified as Okla. Stat. tit. 63, § 1-731.2(B) (2014) (prohibiting the performance of an abortion solely on account of the sex of the unborn child); 18 Pa. Cons. Stat. § 3204(c) (2014) ("No abortion which is sought solely because of the sex of the unborn child shall be deemed a necessary abortion."); H.B. 1162, 89th Legis. Assemb., Reg. Sess. (S.D. 2014) (prohibiting sex-based abortions). North Dakota prohibits the provision of an abortion because the fetus has been diagnosed with either a genetic abnormality or the potential for a genetic abnormality. N.D. Cent. Code § 14-02.1-04.1 (2014). The constitutionality of these laws is subject to question. See, e.g., *MKB Management Corp. v. Burdick*, 954 F. Supp. 2d 900, 912 (D.N.D. 2013).
3. See J. Woo, *A Short History of Amniocentesis, Fetoscopy and Chorionic Villus Sampling*, *available at* <http://www.ob-ultrasound.net/amniocentesis.html> (last visited April 21, 2015); H. T. Greely, "Get Ready for the Flood of Fetal Gene Screening," *Nature* 469, no. 7330 (2011): 289-291, at 289-290.
4. See J. Malek, "Disability and the Duties of Potential Parents," *Saint Louis University Journal of Health Law & Policy* 2, no. 2 (2008): 119-134, at 121.
5. Judith Daar gives a clear explanation in lay language of what these various tests entail, and the information they reveal. See J. Daar, "One Small Step for Genetics, One Giant Leap for Genocide?" *Rutgers Law Journal* 42, no. 3 (2011): 705-724, at 707-711; see also J. S. King, "Not This Child: Constitutional Questions in Regulating Noninvasive Prenatal Genetic Diagnosis and Selective Abortion," *UCLA Law Review* 60, no. 1 (2012): 2-75.
6. See, e.g., J. S. King, "And Genetic Testing for All...The Coming Revolution in Non-Invasive Prenatal Genetic Testing," *Rutgers Law Journal* 42, no. 3 (2011): 599-658, at 600; Daar, *supra* note 5, at 709.
7. P. Sulman, et al., "Genetic Determinants of Hair, Eye and Skin Pigmentation in Europeans," *Nature Genetics* 39 (2007): 1443-1542, at 1443.
8. *Explosion of New Prenatal Genetic Testing on the Horizon, Greely Says*, University of Virginia School of Law (March 11, 2010), *available at* <http://www.law.virginia.edu/html/news/2010_spr/greely.htm> (last visited April 21, 2015); King, *supra* note 5; King, *supra* note 6.

9. S. D. James, *Down Syndrome Births are Down in the U.S.*, ABC News (November 2, 2009), *available at* <http://abcnews.go.com/Health/w_ParentingResource/down-syndrome-births-drop-us-women-abort/story?id=8960803#.T9Ki_FKxpul> (last visited April 21, 2015); R. Douthat, "Eugenics, Past and Future," *New York Times*, June 10, 2012, at SR12, *available at* <http://www.nytimes.com/2012/06/10/opinion/sunday/douthat-eugenics-past-and-future.html?_r=0> (last visited April 21, 2015).
10. C. Y. Johnson, "DNA Blood Test Can Detect Prenatal Problems," *Boston Globe*, February 26, 2014, *available at* <https://www.bostonglobe.com/lifestyle/health-wellness/2014/02/26/new-study-suggests-prenatal-genetic-tests-could-offered-all-pregnant-women/V1GQuRL4jkr1M6Oe1XcQCK/story.html> (last visited May 20, 2015).
11. See B. A. Fordham, "Disability and Designer Babies," *Valparaiso University Law Review* 45, no. 4 (2011): 1473-1528, at 1480 and note 33 (discussing cases); M. Spriggs, "Lesbian Couple Create a Child Who Is Deaf Like Them," *Journal of Medical Ethics* 28, no. 5 (2002): 283-285 (reporting the case of a lesbian deaf couple who used a deaf sperm donor to increase the likelihood that their son would also be deaf); M. Healy, "Fertility's New Frontier," *Los Angeles Times*, July 21, 2003, at 1, *available at* <http://articles.latimes.com/2003/jul/21/health/he-pgd21> (last visited May 4, 2015) (reporting the case of a doctor who refused a couple's request to use PGD to identify and implant an embryo with Down syndrome). In the reported cases, families make these decisions when someone in the existing family has the trait, and a child with similar traits is desired. With deafness, the parents may be member of Deaf Culture, and a deaf child will be particularly treasured. A child with achondroplasia might be desired by parents with achondroplasia for ease of care reasons. In the reported case of parents seeking a child with Down syndrome, the family sought a similarly situated sibling for an existing child with Down syndrome.
12. J. Rothschild, *The Dream of the Perfect Child* (Bloomington: Indiana University Press, 2005): at 105.
13. For individual stories relating such pressure, see National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* (September 27, 2012): at 214-215, *available at* <http://www.ncd.gov/publications/2012/Sep272012/> (last visited May 4, 2015).
14. See S. Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998): at 11.
15. See Daar, *supra* note 5, at 718, note 65.
16. See M. Darnovsky, *Countries with Laws or Policies on Sex Selection*, Center for Genetics and Society (April 2009), *available at* <http://geneticsandsociety.org/downloads/200904_sex_selection_memo.pdf> (last visited May 4, 2015); C. Feikert, *Sex Selection & Abortion: Australia*, Library of Congress (June 2009), *available at* <http://www.loc.gov/law/help/sex-selection/australia.php#f6> (last visited May 4, 2015); K. S. Nehra, *Sex Selection & Abortion*, Library of Congress (June 2009), *available at* <http://www.loc.gov/law/help/sex-selection/index.php> (last visited May 4, 2015).
17. See E. Parens and A. Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," *Hastings Center Report* 29, no. 5 (1999): S1-S22, at S16.
18. See Rothschild, *supra* note 11, at 71-92.
19. See Daar, *supra* note 5, at 709; K. R. Smolensky, "Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions," *Hastings Law Journal* 60, no. 2 (2008): 299-346, at 299, note 1.
20. See, e.g., King, *supra* note 5; E. W. Grant, "Assessing the Constitutionality of Reproductive Technologies Regulation: A Bioethical Approach," *Hastings Law Journal* 61, no. 4 (2010): 997-1034; K. E. Schiavone, "Playing the Odds or Playing God? Limiting Parental Ability to Create Disabled Children through Preimplantation Genetic Diagnosis," *Albany Law Review* 73, no. 1 (2009): 283-328, at 294-301; Malek, *supra* note 4, at 214; R. M. Green, "Parental Autonomy and the Obligation Not to Harm One's Child Genetically," *Journal of Law, Medicine & Ethics* 25, no. 1 (1997): 5-15, at 6.
21. See Parens and Asch, *supra* note 16, at S11, S13 (summarizing the social constructionist argument).
22. *A Mutation Story*, PBS, *available at* <http://www.pbs.org/wgbh/evolution/library/01/2/l_012_02.html> (last visited May 4, 2015).
23. See Parens and Asch, *supra* note 17, at S2.
24. *Id.*
25. See *id.*, at S7; see also M. Saxton, "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion," in E. Parens and A. Asch, eds., *Prenatal Testing and Disability Rights* (Washington, D.C.: Georgetown University Press, 2000): 147-164, at 148.
26. See Parens and Asch, *supra* note 17, at S2; Malek, *supra* note 4, at 126.
27. See Parens and Asch, *supra* note 17, at S2.
28. *Id.* (quoting M. Saxton, "Disability Rights and Selective Abortion," in R. Solinger, ed., *Abortion Wars: A Half Century of Struggle, 1950-2000* [Berkeley: University of California Press, 1997]: at 374-395, at 391).
29. See Asch, *supra* note 1, at 316.
30. See National Council on Disability, *supra* note 12, at 215 (citation omitted).
31. See M. J. Sandel, "The Case against Perfection: What's Wrong with Designer Children, Bionic Athletes, and Genetic Engineering," *Atlantic*, April 1, 2014, *available at* <http://www.theatlantic.com/magazine/archive/2004/04/the-case-against-perfection/302927/> (last visited May 4, 2015).
32. *Id.*
33. *Id.*
34. *Id.*
35. *Id.*
36. See Parens and Asch, *supra* note 17, at S7; see also Saxton, *supra* note 24, at 148.
37. See Asch, *supra* note 1, at 324.
38. See *id.*, at 337-41; also Parens and Asch, *supra* note 16, at S19-S20 (proposing reforms).
39. See Parens and Asch, *supra* note 16, at S2; Malek, *supra* note 4, at 126. Notably, current technology allows for identification of an embryo's sex. It does not allow identification of sexual orientation, which is a more complicated trait that may never be linked to a single genetic code.
40. See Parens and Asch, *supra* note 17, at S2.
41. See A. Harmon, "Prenatal Test Puts Down Syndrome in Hard Focus," *New York Times*, May 9, 2007, at A1, *available at* <http://www.nytimes.com/2007/05/09/us/09down.html?pagewanted=all&_r=0> (last visited May 4, 2015).
42. See Parens and Asch, *supra* note 17, at S1.
43. *Id.*, at S3.
44. See, e.g., Parens and Asch, *supra* note 17, at S2; D. Kaplan and M. Saxton, "Disability Community and Identity: Perceptions of Prenatal Screening," *Our Bodies Ourselves*, *available at* <http://www.ourbodiesourselves.org/book/companion.asp?id=31&compID=43&page=2> (last visited May 4, 2015); Saxton, *supra* note 24.
45. See King, *supra* note 5, at 40-41 (arguing against limitations on sex-based selection because such a limitation "prioritizes one form of equality significantly over another by protecting women's equality at the expense of the equality of individuals with genetic diseases, conditions, and characteristics that are deemed 'undesirable.' Such an approach would cast a dark shadow of eugenics over the states.")
46. See Parens and Asch, *supra* note 17, at S2 (citing N. Press, "Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available?" in E. Parens and A. Asch, eds., *Prenatal Testing and Disability Rights* [Washington, D.C.: Georgetown University Press, 2000]: at 214-233).
47. See, e.g., P. A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (Baltimore: Johns Hopkins University Press, 2008): at 45; R. K. Scotch,

“American Disability Policy in the Twentieth Century,” in P. K. Longmore and L. Umansky, eds., *The New Disability History: American Perspectives* (New York: New York University Press, 2001): at 375-392, at 377-378.

48. P. R. Reilly, *The Surgical Solution: A History of Involuntary Sterilization in the United States* (Baltimore: Johns Hopkins University Press, 1991): at 30-40.
49. “It is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind....Three generations of imbeciles are enough.” *Buck v. Bell*, 274 U.S. 200, 207 (1927). Questions existed about the heritability of conditions and whether the patients actually had the suspect conditions. For example, research indicates that Carrie Buck was not in fact mentally handicapped. See R. M. Berry, “From Involuntary Sterilization to Genetic Enhancement: The Unsettled Legacy of *Buck v. Bell*,” *Notre Dame Journal of Law, Ethics & Public Policy* 12, no. 2 (1998): 401-348, at 420-421; M. G. Silver, “Note, Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History,” *George Washington Law Review* 72, no. 3 (2004): 862-892, at 867.
50. See *Weber v. Stony Brook Hosp*., 467 N.Y.S.2d 685, 686 (2d Dep’t 1983). The “Baby Doe” cases were explored by a presidential commission, which issued a report in 1983 that would disallow denial of surgery to “an otherwise healthy Down Syndrome child whose life is threatened by a surgically correctable complication.” A. Asch, “Disability, Bioethics, and Human Rights,” in G. L. Albrecht et al., eds., *Handbook of Disability Studies* (Thousand Oaks: Sage Publications, 2001): 297-326, at 303 (quoting President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions* [March 1983]: at 6-7); see also D. F. Cantrell, “*Bowen v. American Hospital Association*: Federal Regulation Is Powerless to Save Baby Doe,” *Indiana Law Review* 19, no. 4 (1986): 1199-1218 (discussing a case in which a boy, born with Down syndrome and esophageal obstruction, died because his parents refused to consent to life-saving treatment); A. M. Antommaria, “‘Who Should Survive? One of the Choices on Our Conscience’: Mental Retardation and the History of Contemporary Bioethics,” *Kennedy Institute of Ethics Journal* 16, no. 3 (2006): 205-224 (discussing a film that “contains a dramatization of the death of an infant with Down syndrome as the result of the parents’ decision not to have a congenital intestinal obstruction surgically corrected.”).
51. See J. P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994): at 158-175 (discussing institutionalization and education).
52. See Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (2012); Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2012).
53. See National Council on Disability, *National Disability Policy: A Progress Report* (March 31, 2009): at 26-27, *available at* <http://www.ncd.gov/progress_reports/Mar312009> (last visited May 4, 2015).
54. See *id.*; E. Pendo, “Reducing Disparities through Health Care Reform: Disability and Accessible Medical Equipment,” *Utah Law Review* 4, no. 4 (2010): 1057-1084, at 1059-1060; K. Hwang et al., “Access and Coordination of Health Care Service for People with Disabilities,” *Journal of Disability Policy Studies* 20, no. 1 (2009): 28-34, at 29-30 (collecting results of population-based surveys); Office of the Surgeon General, U.S. Department of Health and Human Services, *The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities* (2005), *available at* <http://www.ncbi.nlm.nih.gov/books/NBK44667/pdf/TOC.pdf> (last visited May 4, 2015); Center for Research on Women with Disabilities, *Health Disparities between Women with Physical Disabilities and Women in the General Population*, Baylor College of Medicine (May 2005), *available at* <https://www.bcm.edu/research/centers/research-on-women-with-disabilities/?PMID=1331> (last visited May 4, 2015) (discussing the first national survey of women with disabilities on their experiences with women’s healthcare conducted in the years immediately following passage of the ADA).
55. See B. D. Smedley et al., eds., Institute of Medicine of the National Academies, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: National Academies Press, 2003).
56. These include equipment barriers and communication barriers. See J. I. Kailes, “The patient’s perspective on access to Medical Equipment,” in J. M. Winters and M. F. Story, eds., *Medical Instrumentation: Accessibility and Usability Considerations* (Boca Raton: CRC Press, 2006): 3-14, at 6; E. Pendo, “Disability, Equipment Barriers, and Women’s Health: Using the ADA to Provide Meaningfulness,” *St. Louis University Journal of Health Law & Policy* 2 (2008): 15-56, at 17-18 (describing barriers posed by inaccessible buildings and medical equipment); E. Pendo, “Shifting the Conversation: Disability, Disparities and Health Care Reform,” *Florida International University Law Review* 6, no. 1 (2010): 87-98, at 92 (noting that “twenty years after passage of the [ADA], many people with mobility impairments cannot get on examination tables and chairs, cannot be weighed, and cannot use x-ray and other imaging equipment.”); M. A. Schwartz, “Deaf Patients, Doctors, and the Law: Compelling a Conversation about Communication,” *Florida State University Law Review* 35, no. 4 (2008): 947-1002 (describing the difficulties experienced by deaf patients who are not provided sign language interpreters by their doctors).
57. See Pendo (2008), *supra* note 54, at 17-18.
58. See *id*., at 43; G. L. Albrecht and P. J. Devlieger, “The Disability Paradox: High Quality of Life against All Odds,” *Social Science & Medicine* 48, no. 8 (1999): 977-988; J. R. Bach and M. C. Tilton, “Life Satisfaction and Well-Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia,” *Archives of Physical Medicine and Rehabilitation* 75, no. 6 (1994): 626-632; S. Saigal et. al., “Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low-Birth-Weight Infants at Adolescence,” *JAMA* 276, no. 6 (1996): 453-459; National Council on Disability, *supra* note 51, at 57, 304; Kailes, *supra* note 54, at 5.
59. See D. Carlson et al., *National Disability Rights Network, Devaluing People with Disabilities: Medical Procedures That Violate Civil Rights* (May 2012), *available at* <http://disabilitylawva.org/wp-content/uploads/2012/10/Devaluing_People_with_Disabilities.pdf> (last visited May 4, 2015).
60. *Id*., at 5.
61. See, e.g., H. Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Alfred A. Knopf, 1992): at 212-213 (discussing the mistreatment of deaf patients in France); P. K. Longmore, “Medical Decision Making and People with Disabilities: A Clash of Cultures,” in P. K. Longmore, ed., *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003): 204-212 (describing conflicts between disabled persons and their healthcare providers); R. Whitaker, *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* (New York: Basic Books, 2010): at 71-72; S. Drake, *The Doctor Said It Would Be Better If I Didn’t Survive, Not Dead Yet* (March 30, 2012), *available at* <http://www.notdeadyet.org/2012/03/stephens_story.html> (last visited May 4, 2015); D. Coleman and S. Drake, *Disability Discrimination*, Hastings Center Bioethics Forum (July 11, 2012), *available at* <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5913&blogid=140> (last visited May 4, 2015); F. Vox, “The Cyclops Child’: Inhumanity in a 1960 Hospital,” *Atlantic*, July 14, 2012, *available at* <http://www.theatlantic.com/health/archive/2012/07/the-cyclops-child-inhumanity-in-a-1960-hospital/259810/> (last

visited May 4, 2015) (recounting Dr. Fredric Neuman's cruel treatment of a child with severe birth defects).

62. See *id.*, at 254.
63. See National Council on Disability, *supra* note 51, at 59. "[S]urveys of healthcare providers indicate that many providers believe that women with mobility disabilities are not sexually active, and are not or should not be mothers." See Pendo (2010), *supra* note 54, at 92.
64. M. A. Nosek, "Overcoming the Odds: The Health of Women with Physical Disabilities in the United States," *Archives of Physical Medicine and Rehabilitation* 81, no. 2 (2000): 135-38, at 136, *available at* <https://www.bcm.edu/research/centers/research-on-women-with-disabilities/?pmid=5300> (last visited May 4, 2015).
65. See C. J. Gill, "Becoming Visible: Personal health Experiences of Women with Disabilities," in D. M. Krotoski et al., eds., *Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being* (Baltimore: P.H. Brookes Publishing Company, 1996): at 5-16, at 8-9; B. F. Waxman, "Up against Eugenics: Disabled Women's Challenge to Receive Reproductive Health Services," *Sexuality and Disability* 12, no. 2 (1994): 155-171.
66. See Pendo (2008), *supra* note 54, at 16; Kailes, *supra* note 54, at 5.
67. See Gill, *supra* note 63, at 6 ("[W]omen with disabilities are stripped of our roles. We are not expected to be workers, romantic partners, caregivers, or mothers. Socially, we are in limbo––not quite children, but not adults; not men, but not real women either. It is difficult to get your bearings and struggle out from under that kind of unremitting yet subtle oppression, because it steals from you the very sense of self you need in order to fight.")
68. As Dave Shade notes, "[b]ecause disability has only a neutral or negative impact on fertility, people with disability who wish to have children are equally or more likely than the nondisabled population to experience infertility." D. Shade, "Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act," *Law & Inequality* 16, no. 1 (1998): 153-218, at 169.
69. Even non-biological reproduction is difficult for adults with disabilities. Adoption agencies balk at placing children with disabled adults. See National Council on Disability, *supra* note 12, at 188-193.
70. *Id.*, at 205.
71. *Id.*, at 210.
72. K. M. Mutcherson, "Disabling Dreams of Parenthood: The Fertility Industry, Anti-Discrimination, and Parents with Disabilities," *Law & Inequality* 27, no. 2 (2009): 311-364, at 316.
73. See National Council on Disability, *supra* note 12, at 216.
74. See *id.*, at 210.
75. J. F. Daar, "Accessing Reproductive Technologies: Invisible Barriers, Indelible Harms," *Berkeley Journal of Gender, Law & Justice* 23, no. 1 (2008): 18-82, at 73.
76. L. F. Rothstein, *Rights of Physically Handicapped Persons* (Colorado Springs: McGraw-Hill, 1984): at 185; see also M. A. Stein, "Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities," *Brooklyn Law Review* 60 (1994): 1069-1100 (documenting cases in which fit parents with physical disabilities have lost custody of children due to their disabilities); S. Stefan, "Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together," *Saint Louis University Journal of Health Law & Policy* 2, no. 1 (2008): 135-176 (documenting cases in which people with psychiatric disabilities have lost custody of their children due to their disabilities). For some remarkably moving narratives, see M. Wates and R. Jade, eds., *Bigger Than the Sky: Disabled Women on Parenting* (London: Women's Press, 1999).
77. See Rothstein, *supra* note 74, at 185.
78. See Stein, *supra* note 74, at 1083 (footnotes omitted) (citing Rothstein, *supra* note 74, at 185).
79. See National Council on Disability, *supra* note 12, at 239. To be sure, some disabilities, including some forms of developmental and mental illness, can affect an individual's ability to parent effectively. The difficulty with a presumption of unfitness is that it excludes capable parents without an individual determination.
80. See Daar, *supra* note 73, at 23 (arguing that "stigmatizing would-be parents by depriving them the opportunity to reproduce is dangerously reminiscent of our eugenics past, an era in which misguided judgments about parental fitness culminated in the involuntary sterilization of thousands of Americans.")
81. See, e.g., Ariz. Rev. Stat. Ann. § 13-3603.02(A) (2014) (prohibiting the performance of an abortion on the basis of the unborn child's sex); 720 Ill. Comp. Stat. 510/6(8) (2014) (prohibiting sex-based abortions); S.B. 141, 85th Leg., Reg. Sess. (Kan. 2013) (prohibiting sex-based abortions); N.C. Gen. Stat. § 90-21.121 (2014)(prohibiting sex-based abortions).
82. Position statement, American College of Obstetricians and Gynecologists, *available at* <http://www.acog.org/Resources_And_Publications/Committee_Opinions/Committee_on_Ethics/Sex_Selection> (last visited May 4, 2015).
83. See King, *supra* note 5, at 40.
84. *Id.*
85. Position statement, American College of Obstetricians and Gynecologists, *available at* <http://www.acog.org/Resources_And_Publications/Committee_Opinions/Committee_on_Ethics/Sex_Selection> (last visited May 4, 2015).
86. E.g., King, *supra* note 6, at 650-652 (proposing a two-step process for obtaining informed consent to conduct prenatal testing)
87. See Asch, *supra* note 1, at 315.
88. See, e.g., Asch, *supra* note 1, at 334-335 (emphasizing the need for non-directive counseling of potential parents); King, *supra* note 6, at 650-52 (proposing a two-step process for obtaining informed consent to conduct prenatal testing); Parens and Asch, *supra* note 16, at S19-S20 (suggesting improvements to education of professionals and providing disability-related information at specific points in the screening process).

Copyright of Journal of Law, Medicine & Ethics is the property of Wiley-Blackwell and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.