

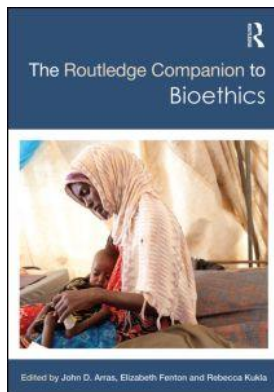
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REPRODUCTIVE TESTING FOR DISABILITY

Adrienne Asch and David Wasserman

Two developments in the 1970s and 1980s led to a striking contrast in public attitudes and policies toward having children with disabilities. On the one hand, the more routine character of prenatal genetic testing (and the availability of legal abortions) made it increasingly common, and perhaps expected, for parents to abort fetuses found to have “serious” disabilities. The termination rate for fetuses with one of the most common and easily detected conditions, Down syndrome, was estimated to be at or over 90 percent (e.g., Shaffer et al. 2006). On the other hand, those two decades saw the emergence of a strong disability rights movement and the reconceptualization of disability as a social phenomenon, the interaction of a physical or mental condition with an exclusionary environment. Informed by this social model, the disability rights movement played a major role in the passage of landmark disability discrimination laws in the United States in 1973 and 1990. As the abortion of fetuses with disabilities became routine, children and adults with disabilities became more visible and better integrated into educational and social activities. It was not long before proponents of the latter development observed a deep tension with the former.

As early as the mid-1980s, some scholars in bioethics and disability studies questioned the practice of prenatal selection against disability and the assumptions about disability informing it. In particular, they expressed concern about its ready acceptance by clinicians and the limited opportunity afforded prospective parents to reflect on its use. They argued that the speed at which testing became the standard of care for reproductive medicine, and the frequency with which positive results led to abortion, reflected and perpetuated harmful stereotypes about disability. This critique was independent of, and cut across, the abortion debate: It was not based on the moral status of the embryo or fetus, and many, though by no means all, of its proponents were pro-choice. Few sought special legal restrictions on disability-based termination.

These concerns have gained a greater hearing as it has become easier and less expensive to test early embryos and fetuses for an increasing number of health conditions. Selecting for sex and other “non-medical” traits has long been controversial, criticized by most bioethicists and reproductive professionals. In the past decade, some of these critics have recognized that selecting against disability also requires close examination. Routine disability testing is now coming under scrutiny from the media, healthcare professions, social sciences, philosophy, religion, and law. The issue of disability as a basis for selection became even more prominent with a recent controversy over selection *for*

disability, a controversy provoked by a highly publicized case in which a deaf couple sought to have deaf children (Mundy 2007).

A variety of concerns have been raised about the practice of disability selection and the exercise of selectivity by prospective parents: That decisions to test and terminate for disability are typically made without adequate information or opportunity for reflection (Asch 1989, 1999; Press and Browner 1997; Fine and Asch 1982; Asch and Wasserman 2009); that professional sponsorship of such testing demeans people with disabilities by assuming the lesser value or greater burden of disabled lives (Saxton 1998); and that the use of such testing by prospective parents to select against disability conflicts with the most attractive ideal of the parent–child relationship (Asch 2000; Asch and Wasserman 2005). These critiques differ in emphasis and in their reliance on normative and empirical claims. But all hold that routine prenatal selection against disability is incompatible, in theory or practice, with the social equality of people with disabilities and with their full inclusion in society (Reinders 2000; Asch 2003).

Many bioethicists and philosophers deny or downplay this conflict, arguing that prenatal selection against disability is compatible with full social inclusion. Some argue that the conflict can be avoided by distinguishing negative attitudes toward disability from negative attitudes toward people with disabilities (Buchanan et al. 2000; Steinbock 2000; Baily 2000; Nelson 2000). If that distinction is recognized, then prenatal selection should not be offensive; if that distinction is rejected, then it will also be offensive to prevent or treat disability. Some defenders of selection contend as well that the decision of individual couples to select against disability need not reflect a general view that it is undesirable or burdensome to have a child with a disability (Nelson 2000; Kittay and Kittay 2000). Finally, some defenders claim that the harms and costs of creating children with severe disabilities outweigh any damage to the inclusion of, or offense to, existing people with disabilities (Buchanan et al. 2000; Murphy 2011).

In the remainder of this chapter, we will consider the variety of concerns that have been raised about disability—those that are widely shared, and those that are held by only some critics. We begin by discussing the different ways disability is defined and conceptualized, because they provide a context for understanding the different critiques of prenatal testing.

What Is a Disability? What Are Its Causes?

Many different characteristics are considered disabilities. Paraplegia, deafness, blindness, diabetes, autism, epilepsy, depression, and HIV have all been classified as “disabilities.” The term covers such diverse conditions as the congenital absence or adventitious loss of a limb or a sensory function, progressive neurological conditions like multiple sclerosis, chronic diseases like diabetes or arteriosclerosis, the inability or limited ability to perform such cognitive functions as remembering faces or calculating sums, and psychiatric disorders like schizophrenia and bipolar disorder. There seems to be little about the functional or experiential states of people with these various conditions to justify a common concept; indeed, there is at least as much variation among “disabled” people with respect to their experiences and bodily states as there is among people who lack disabilities.

Two common features stand out in most official definitions of disability, such as those in the World Health Organization, the *U.K. Disability Discrimination Act*, and the *Americans with Disabilities Act*. There must be (1) an impairment (or a perceived impairment) and

(2) some personal or social limitation associated with that impairment. The notion of a limitation encompasses restrictions on such “basic” actions as moving one’s arms or legs (Nordenfelt 1997); on daily activities such as dressing and toileting; and on social activities, such as working. The classification of a physical or mental variation as an impairment may be statistical, based on the average in some reference groups; it may be biological, based on explicit or implicit theories of human functioning; or it may be normative, based on some understanding of what is good for human beings (Tremain 2006). Most often, it probably involves some combination of these.

The most controversial aspect of the definition of disability is the relationship between the two elements—between the impairment and limitation. At one extreme are definitions that imply, or are read to imply, that impairments are the sole causes of limitation. At the other extreme are definitions that appear to treat the physical and social environment as the sole cause of disability. Between these extremes are definitions that regard the impairment and environment as interacting to cause limitation. Thus, for example, an individual with a mobility impairment is limited in getting around by the interaction of his inability to move his legs and the lack of ramps and wide doors in the buildings he frequents.

These different understandings of the relationship of impairment to limitation inform two contrasting approaches to disability, often described as opposing models: The medical and social. The *medical model* understands a disability as both a physical or mental impairment and as the personal and social consequences of that impairment. It regards the limitations faced by people with disabilities as resulting primarily or solely from their impairments. In contrast, the *social model* understands disability as a social process or condition: The exclusion of people with certain physical and mental characteristics from important domains of social life. The exclusion is manifested not only by shunning and confinement, but also by a built environment and organized social activity that do not accommodate people with disabilities.

Two versions of the social model are embraced by disability scholars and activists. The minority group model sees people with disabilities as a “discrete and insular” group facing stigmatization and exclusion. The disadvantages they face arise from the discrimination they suffer, like racial, ethnic, or sexual minorities. The human variation model sees many of the challenges faced by disabled people as arising less from their exclusion as a stigmatized group than from a mismatch between their characteristics and society’s institutions. These two versions of the social model differ in emphasis, but their goals overlap, since discrimination has led to, and been expressed in the failure of society to accommodate the variations presented by people with disabilities. If one goal of social policy is to remove discrimination and its enduring disadvantages, another is to encompass the full range of human variation in the design of the physical environment and social practices.

In their extreme forms, the medical and social models serve to chart the space of possible relationships between impairment and limitation more than to reflect the actual views of individuals, groups, or institutions. The medical model is rarely defended, but often adopted unreflectively by health care professionals, bioethicists, and philosophers who fail to appreciate the disabling effects of environmental and social factors.

The medical and social models suggest (although they do not strictly imply) different views about the impact of disability on wellbeing, and different views about how disability is relevant to reproductive decisions, medical interventions, and social policy. Those who accept a social model of disability regard the association between

disability and wellbeing as highly contingent, mediated by a variety of environmental and social factors. They also tend to favor conceptions of wellbeing that do not give central importance to the exercise of the standard array of physical and mental functions. These two views are formally independent—one could regard the adverse impact of disability on wellbeing as substantial, but largely due to social causes; conversely, one could regard the adverse impact of disability as comparatively minor, yet largely attributable to the impairment itself.

The attribution of disadvantage to social causes may matter less for assessing prenatal selection. Even if the disadvantages associated with diagnosable impairments are primarily or solely attributable to social factors, there may be little that prospective parents can do to mitigate those disadvantages. What may be more important to their decision to test or terminate is the impact those disadvantages have on the overall wellbeing of the future child and its family. Critics of prenatal selection maintain that the adverse impact is greatly exaggerated by health professionals and mainstream bioethicists. Their disagreement is reflected in conflicting assessments of life with disabilities found in the bioethics and public policy literature on the one hand, and disability scholarship on the other.

Routine Termination for Disability Is Based on Unfounded Assumptions and Misinformation about the Difficulties of Disabilities for Children, Parents, and Families

Clearly, many health professionals, bioethicists, and laypeople believe that being born with a disability is almost always damaging and often disastrous for the child, her parents, and her siblings. Parents must give up other important life goals; non-disabled children are neglected as parents focus on the needs of the child with the disability; mothers especially must forsake or curtail other interests to “cope with” their child; resources of time and money are often strained to or past the breaking point (Wertz and Fletcher 1993; Botkin 1995). Despite parental commitment and increased social acceptance, life with a disability is almost always of lesser quality than life without one (Purdy 1995; Buchanan et al. 2000; Brock 2005; Green 2008). Research suggests that some of these views are shared by prospective parents who accept prenatal testing (Gottfreðsdóttir et al. 2009b).

But are these assumptions warranted? Chronic illness and disability are not equivalent to acute illness or sudden injury, in which an active disease process or unexpected change in physical function disrupts life’s routines. Most people with conditions such as spina bifida, achondroplasia, Down syndrome, and many other mobility and sensory impairments perceive themselves as healthy, not sick, and describe their conditions as givens of their lives—the equipment with which they meet the world. The same is true for people with chronic conditions such as cystic fibrosis, diabetes, hemophilia, and muscular dystrophy. These conditions include intermittent flare-ups requiring medical care and adjustments in daily living, but they do not render the person as unhealthy as most of the public—and members of the health profession—often imagine.

Like everyone else, people with disabilities are enmeshed in the details of everyday life. They are thinking about a traffic jam, a disagreement with a friend, which movie to attend, or which team will win the World Series—not just about their diagnosis. Having a disability can intrude into a person’s consciousness if events bring it to the fore: For example, if two lift-equipped buses in a row fail to stop for a man using a wheelchair; if the theater ticket agent insults a patron with Down syndrome by refusing to take money

for her ticket; or if a hearing-impaired person misses a train connection because he did not know that a track change had been announced.

Many proponents of prenatal testing and termination insist that critics ignore the fact that some conditions for which tests are available can be lethal in early childhood (Tay-Sachs), and can impair cognitive, physical, and sensory capacities to an extreme degree (Trisomy 13 or 18)—making it unclear how the child could have rewarding interactions in any environment. We acknowledge that given our knowledge of these conditions in 2013, medicine, education, and environmental design have not yet improved the potential for children with these conditions to have lives that most parents could conceive as satisfying. Nonetheless, the vast majority of diagnosable impairments are neither lethal in early childhood nor so capacity limiting. The availability of tests for such rare conditions hardly supports selection against all significant disabilities; it merely reinforces the case that prospective parents should make testing decisions based on a careful assessment of information about specific impairments and on how a child's particular condition will influence their family goals.

Most research on the wellbeing of people with disabilities relies on self-reports, and those reports do not confirm the grim views of third parties. Most people with disabilities report a quality of life similar to people without disabilities (Saigal et al. 1996; Albrecht and Devlieger 1999; Gill 2000; Goering 2008). However, the interpretation of self-reported wellbeing is complex and disputed (Menzel et al. 2002; Schwartz et al. 2007; Barnes 2009), and it raises the question about the extent to which appraisals of wellbeing should rely solely on subjective self-appraisal. This is not, or not entirely, an empirical question; it depends on the conception of wellbeing we regard as most appropriate in the context of procreation, where the individual in question is not (yet) capable of self-appraisal, desire formation, or the experiences of pleasure and pain.

There is a need for more empirical research, using a variety of methods, on the impact of children's disabilities on families. Existing studies of families paint a more complex picture than that found in most medical and bioethical literature. Many studies do find that parents of children with significant disabilities face considerable stress and hardship at various stages in their children's lives. Thus, Gerstein et al. (2009) note that "a wealth of research continues to suggest that families of children with ID [intellectual disabilities] face increased stressors Indeed, levels of stress have been found to be higher in parents of children with ID than in their typically developing counterparts." Eisenhower et al. (2009) find that mothers of children with developmental delays have poorer physical health outcomes, as well as the poorer mental health outcomes already shown in extensive research. The challenges may be especially great for parents of adult children with psychiatric disabilities, where "a body of research suggests that older parents of adults with serious mental illness experience on average, higher levels of burden and elevated health and mental health symptoms" (Aschbrenner et al. 2010).

Yet there is also considerable research, including some of the studies just cited, suggesting that these negative findings need to be qualified in several ways. First, the findings are not uniform. Some studies find that families of children with significant disabilities fare on average about as well as other families (Ferguson 2001; Walker et al. 1987). Some find that the additional challenges facing parents of children with disabilities are largely attributable to external factors like a lack of support services, or to pre-existing family, social, or economic circumstances (Hatton et al. 2010). And some find that although families with disabled children face additional challenges, they experience equal or distinct rewards. This is true even for parents of

adult children with serious psychiatric disabilities, “while later stages of the life course may involve unprecedented difficulties, they may also present unique opportunities for positive parenting experiences, including personal growth and a greater awareness of family strengths” (Aschbrenner et al. 2010).

A 2002 review of the existing research on families of disabled children noted that evidence of positive outcomes may have been overlooked because of the prevailing emphasis on negative ones. “If we ask negatively phrased questions, we are not very likely to get positive answers . . .” (Hastings and Taunt 2002: 117). Taking up this challenge five years later, Blacher and Baker (2007: 343) found that “the expression of common benefits across families with and without disability, despite differences in negative impact . . . tempers the exclusively negative perspective that has characterized earlier literature on family and disability.”

Prospective parents with disabilities have the personal experience enabling them to reject the exaggerated assumptions about disability held by many people without disabilities. They are often harshly confronted with those assumptions in deciding to have their own children. And yet, having experienced a variety of challenges related to their disabilities, from frequent hospitalization to pervasive stigma, they have a wide range of responses to testing and termination (Skotko 2005; Gottfreðsdóttir et al. 2009b). Some refuse testing, some use it only for preparation, some test and terminate, much like their non-disabled counterparts, and some choose not to reproduce (Kelly 2009; Boardman 2013; Walsh-Gallagher et al. 2012).

Yet even if we reject exaggerated assumptions about the hardships of disability, and attribute many or most to an exclusionary environment, the question remains of whether to regard disabilities, or the underlying impairments, as conditions it is better to live without. In their discussion of prenatal testing for disability in 2000, Parens and Asch noted that the most “contentious” issues in evaluating critiques of routine testing stem from the question of how much the disadvantage in having an “impairment” or being a person with a disability is socially constructed, and how much it is “intrinsic” to the condition itself, independent of any social environment (Parens and Asch 2000: 24). Should a disabling trait, an impairment, be differentiated from any other characteristic that a person will exhibit? Genetics professionals, bioethicists, and prospective parents all recognize that most normal variations will predispose an individual to some valuable experiences and make others harder to come by. Parents and others generally appreciate the pleasures of both the “mellow” and the “energetic” child, although they may later comment on how mellow children may stay close to home, may miss out on certain opportunities to discover new experiences and people; conversely, the energetic child may get into scrapes by barging into new territory and getting to know new people, without paying attention to cues that her more reserved brother might notice as reasons to stay away.

Most people who recognize the social contribution to disability and the flourishing of many disabled people, would still deny that impairments are merely “neutral” variations like mellowness. They hold that, on balance, in any imaginable world, an impairment is something it is better not to have. Why does this conclusion seem obvious, and should it? Even if further exploration reinforces the prevailing view, this question deserves to be taken seriously, and explored both conceptually and empirically.

Many (though not all) people with a wide range of disabilities articulate life’s benefits from their non-species-typical modes of being in the world. Even if we reject or qualify these claims after fuller investigation, it would be important to find out what lies behind

them, to endeavor to understand why these people with disabilities perceive their conditions as valuable. Hearing their voices would at least give pause to philosophers who “know” that disabilities preclude most reasonable life plans, make life harder overall, and must be treated as different from all other human variations that parents and society should expect to incorporate.

We ourselves find it plausible to regard disabilities, like many other characteristics and variations, as neither wholly positive nor wholly negative; rather, in some circumstances a disability, like a personality type, height, or the place one lives will promote some experiences and preclude others (Asch and Wasserman 2010). The question that needs further exploration is why disability, but not female sex, minority race, or rural residence, should be presumed to have a detrimental effect on wellbeing rather than being treated as one of many factors that contribute in complex ways to how well a life goes overall.

The Process and Content of Prenatal Health Care Should be Modified to Provide More Opportunity for Reflection and More Accurate Information about Living with a Disability

In one sense, prenatal testing and selective termination increase reproductive options. Before ultrasound, and chromosomal and genetic testing, women and couples faced an unconditional decision about whether or not to continue a pregnancy. Since the introduction of those technologies, that decision can be based on an increasing amount of medical detail about the fetus or embryo—even before implantation.

This increase in options may not, however, lead to an increase in reproductive autonomy if women are misinformed about the nature of the tests, and subjected to pressure to test and terminate in the face of “positive” results. Research over the past 15 years raises serious questions about whether consent to prenatal testing and selective abortion can be regarded as truly informed and voluntary.

It should not be surprising that many reproductive health professionals share the general views of non-disabled people about the overwhelming burdens of raising children with disabilities. Whether or not the mere offer of a prenatal test is itself directive (Clarke 1992; Wachbroit and Wasserman 1995), conveying the expectation that a prospective parent will terminate if the result is positive may make it more difficult for prospective parents to continue a pregnancy, especially if the result is accompanied by one-sided information about disability. Several studies suggest that when reproductive health professionals do talk to their patients about the reasons for prenatal testing and termination, they tend to focus narrowly on the medical issues associated with disability (Lippman and Wilfond 1992; Wertz 2000; Skotko 2005; Klein 2011). They emphasize “the array of potential medical complications and physical limitations that may occur in children with the condition” (Lippman and Wilfond 1992: 936). A 2011 literature review concluded that a high proportion of reproductive clinicians held extremely negative attitudes towards life with a disability, which they conveyed to their patients (Klein 2011). Other research suggests that such negative information has a significant impact on decisions about whether to terminate in the face of positive test results.

As reproductive testing becomes routine and comprehensive, issues of informed consent become more acute. In 1997, Press and Browner reported that women were being presented with prenatal testing as part of routine prenatal care, as “just another blood test.” Many were not told that the test concerned fetal health, not their own

health; nor were they told that the results would not help them or their doctor to manage their pregnancy or to improve the health of their fetus. The option of abortion after positive results was rarely mentioned. A 2009 study suggests a continuing failure to explain the implications of prenatal testing to pregnant women: “Approximately one half of the women surveyed who underwent both ultrasound and biochemical screening did not foresee that they might ultimately be confronted with the need to make the decision about whether or not to terminate the pregnancy” (Seror and Ville 2009). The introduction of non-invasive tests may further discourage reflection and discussion on the implications of testing. In a 2009 study, a woman explained her decision in these terms: “I just thought, well this is something you do when you are pregnant” (Gottfreðsdóttir et al. 2009a: 716). The frequent absence of clear communication and discussion should trouble conscientious health professionals, because it means that pregnant women are being led to obtain information they may not want to have, and to make decisions they may not want to make.

The solution does not lie in providing clinical detail about each of the conditions tested for. The sheer number of conditions that can now or soon be tested for, and the diagnostic and predictive limitations of many of those tests, make a comprehensive consent process virtually impossible. What is needed is not more detail, but a broader focus. It is important for clinicians to learn about the knowledge, attitudes, and values of pregnant women concerning reproductive testing, termination, and raising a child with a disability. And prospective parents must be able to obtain information about a subject they may know very little about, that is, what it is like to raise children with disabilities. This may also be a subject on which they are not expecting to reflect in a clinical setting. It would be helpful for reproductive health professionals to shift the focus from the clinical severity of the diagnosed condition to the expectations of the prospective parents in having a child: “What are you looking for in your experience of child-rearing and how do you think a child’s motor, cognitive, emotional, or sensory impairment might affect that experience?” If prospective parents have a chance to reflect on and respond to such questions, professionals may be in a much better position to discuss their concerns about the effect of impairments on parental goals and experiences (The Boston Women’s Health Book Collective 2008).

In 2008, the U.S. Congress took a major step in making that information available to pregnant women by enacting, with wide bipartisan support, the *Prenatally and Postnatally Diagnosed Conditions Awareness Act* (known as the *Kennedy–Brownback Act*). The Act requires the federal government to arrange for the collection and dissemination of evidence-based, up-to-date information about the conditions subject to diagnosis. This information encompasses “the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.” Such information should provide a powerful corrective to the “bad news” typically delivered to pregnant women whose fetuses are diagnosed with the tested conditions. The Act may have an even greater impact on prenatal decision-making if it helps reframe how those women and their partners view their choices after positive test results (Asch and Wasserman 2009). Information on the range of outcomes for individuals living with the diagnosed condition may help pregnant women and their partners see their decision as one about parenting a child who will have a disabling trait, not about preventing disability.

The Act, however, has a built-in limitation: It mandates better information only for women who have already been tested and received positive results, not for women deciding whether to obtain testing. The information the Act collects may come too late in the

process to be fully effective in reframing prenatal decision making. A woman who has already been led to regard such testing as a routine part of reproductive health care may have difficulty in seeing the testing as a prelude to a decision about what kind of child she is willing to parent. She might not want to make that decision, and, if she had understood the test's purpose before consenting to it, she might have refused to put herself in a position where she had to make such a choice.

Education about disability must begin much earlier, and for a much broader population of individuals contemplating having children, reproductive health professionals, and the general public. In order for this information to be meaningfully integrated into the decision-making of prospective parents, the processes by which prenatal testing is now offered them may have to be restructured. It will be a formidable challenge to incorporate the offer and provision of this information into an increasingly complex and congested informed-consent process.

The Practice of Prenatal Testing Is in Tension with the Social Equality of People with Disabilities, But Can Be Reformed in Ways that May Reduce this Tension

Unlike the difficult, complex, often confused decisions of individuals and couples, which need not “send a message” to others regarding the lives of disabled persons, official policies and practices can indeed send a message of inferiority. This would be obvious for race or sex. Imagine a state-funded research program to identify genetic variants associated with dark complexion or African ancestry, designed to enable prospective parents to terminate fetuses with those variants. Such research would rightly be denounced as eugenic and racist. The fact that there is no popular concern over similar research programs to promote selection against disability suggests that—even if there are important differences between disability and race as minority characteristics—the expressive significance of such practices and policies has been overlooked. Whether or not they identified with or celebrated their disabilities, people with disabilities might reasonably be troubled by state or professional sponsorship of programs that treated the birth of people with conditions like theirs as a highly undesirable outcome.

Two approaches have been proposed for weakening the expressive force of the connection between prenatal testing and selection against disability. First, prenatal testing can be used more frequently to arrange appropriate medical and social services for children expected to have disabilities. Although the dominant use of prenatal genomic testing is, and will remain, to decide about pregnancy termination or embryo selection, its clinical utility is not limited to those decisions. An early diagnosis of intellectual or developmental disabilities can significantly benefit prospective parents who intend to have the child regardless of the diagnosis. There is a growing recognition that prenatal diagnosis of these conditions can spare parents a painful and expensive diagnostic odyssey after birth. It can also facilitate early intervention, which can be helpful, even critical, in achieving better outcomes for some of the diagnosable conditions (Makela et al. 2009; Lopez-Rangel et al. 2008). Moreover, even when testing only yields probabilities, it may help identify environmental factors that increase risk or exacerbate symptoms. Thus, prenatal testing can be used to promote early intervention, heightened vigilance, improved treatment, and greater continuity of care. The professional and societal expectation that some parents will choose to bear children with diagnosed impairments, as well as the specific arrangements reflecting that expectation, may well

reduce the proportion of women and couples choosing to terminate after such a diagnosis (Le Dref et al. 2013).

A second, more controversial measure would be to allow prenatal testing for any genetically detectable condition or trait, whether or not it was associated with disease or disability. By permitting reproductive testing for any condition or trait, policy makers and professionals could support reproductive choice without singling out disability as a basis for selective embryo implantation or pregnancy termination (Asch 2003; Wasserman 2003; Gavaghan 2007). Such a policy would avoid the heightened stigmatization likely to result from the line-drawing, now widely advocated (Botkin 1995; Wertz 2000), to limit testing to more “serious” or “severe” disabilities. The more restricted the list of conditions subject to testing, the more stigmatizing testing will be for people living with those conditions.

The comparative virtue of this approach—of permitting any and all available testing—is that it would give no official or privileged role to disabilities in the determination of whether to offer testing or termination. Perhaps it would make little practical difference. Most prospective parents might well test only for disabilities (which would limit the costs of unrestricted testing), because they shared prevailing attitudes toward disability, and because there may be fewer reliable tests for characteristics besides sex and disability. But this is not all that matters in gauging the expressive significance of a prenatal testing regime. A policy that gave no special status to disabilities, that did not treat them as providing a presumptively stronger basis for selection than any other trait or variation, would emphatically disavow the exceptionalism about disability that has dominated prenatal testing since its inception. It would “send the message” that disability did not give prospective parents a privileged reason to screen out embryos or terminate a pregnancy, that disabilities were just some among the myriad variations that might be relevant to some prospective parents in deciding whether to bring a child into the world. At the same time, an unrestricted testing policy might well encourage a consumerist approach toward parenting; it might appear to endorse the treatment of embryos and fetuses, if not children, as commodities. To choose a policy of unrestricted testing is to treat this as a lesser evil than the heightened stigmatization of those disabilities subject to testing under a more restrictive policy.

An unrestricted policy would also permit selection *for* disability, a controversial issue in the recent bioethics literature. Most criticism of such selection concerns the welfare of the children chosen or its impact on aggregate wellbeing. Despite their skepticism about standard objections to creating children with disabilities, many disability advocates are reluctant to endorse their deliberate creation. Sometimes, the skepticism reflects doubts about “disability neutrality”—the view that there is nothing worse in having a disability than in lacking it (Asch and Wasserman 2010). But it may also reflect misgivings about the selection of a child based on any detectable trait—disability, sex, skin or eye color (Asch and Wasserman 2005; see next section).

Even if we adopt policies responsive to expressivist concerns about routine selection against disability, difficult questions remain. Can our society maintain a commitment to moral and political equality for people who are born with undiagnosable disabilities, or who acquire them later in life, while geneticists, reproductive health professionals, and bioethicists urge that families not knowingly bring to term fetuses who will have similar disabling traits? What grounds does a society have to demand that a teacher, employer, or business owner make provisions for someone with characteristics that the same teacher, employer, or businessperson was urged to treat as inimical to membership in her

family? On the other hand, how do we respond to arguments that prospective parents should avoid creating children they expect to be significantly worse off, for medical or social reasons, than some minimum level, thereby increasing inequality (Wilkinson 2010) or imposing further costs (for cost estimates, see Stabile and Allin 2012)? Or does a society lack the moral authority to criticize any procreative choice until it achieves a level of justice most societies fall far below?

Prenatal Selectivity Is Incompatible with the Most Attractive Ideal of the Parent–Child Relationship

One version of the disability critique—put forward by Asch (1989, 2000) and most fully developed by Asch and Wasserman (2005)—emphasizes an ideal of the parent–child relationship that is relevant to prospective parents. It distinguishes between the decision to not become a parent at this time (whether for the first time or not) and the decision to not become the parent of a particular child or kind of child—one with a diagnosable impairment. Although put forward earlier than many critiques of sex and other “non-medically” based selection, this objection is similar to some of these in drawing on a notion of parental acceptance (Wertz and Fletcher 1993; Sandel 2007; Herissone-Kelly 2007).¹

This critique has two parts. First, it maintains that prenatal selectivity is problematic in basing the decision to form a parent–child relationship on a single attribute of the future child—the diagnosable impairment. Selecting against disability involves a paradigmatic form of stigmatization—reducing the complex whole the future child would become to that single, disvalued part. Prenatal testing invites stigmatization because it makes that single part so salient. This does not imply that all parental decisions to terminate must be misinformed and stigma-driven; merely that stigmatization is a significant danger for prospective parents in the context of prenatal testing, a danger that reproductive health professionals and practices often exacerbate.

But even if the decision to terminate on the basis of a diagnosed impairment is not misinformed or driven by stigma, it involves a problematic exercise of selectivity. Choosing a future child of the basis of any trait—whether positive or negative—arguably falls short of what Asch and Wasserman call an ideal of “unconditional welcome.” This ideal is the counterpart for prospective parents of the ideal of unconditional love or commitment for actual parents. Prospective parents can hardly be expected to make an unconditional commitment toward an early-term fetus, let alone towards any or all of the embryos in an *in vitro* fertilization array. The ideal of unconditional welcome urges them to *anticipate* the commitment they would make on becoming parents by not conditioning their willingness to bear and raise a child on the expected presence or absence of virtually any trait (see also Herissone-Kelly 2007, 2009). Asch and Wasserman argue that this posture distinguishes prospective parents from prospective friends and lovers, who may and should exercise selectivity in choosing to form their intimate relationships. It also suggests a role for prospective parents continuous with that of actual parents, whose attachment to their children is expected to be even less dependent on the loss or acquisition of important traits than the attachment to a friend or lover.

Unlike Sandel (2007), Asch and Wasserman do not rely on the notion that children are “gifts.” They simply argue that prospective parents should recognize that their children, disabled or not, may differ greatly from their expectations in a host of ways. They should recognize that they exercise only limited control over who their children become, and should validate and foster their children’s unique characteristics. If disability is

understood as more similar to than different from other attributes in its impact on a child's and family's life, then a child's disability can be incorporated into the parent's appreciation of the child. Just as parents must accommodate a non-disabled child's interest in some favored family pursuits and aversions to others, so should prospective parents be willing to accommodate the different tastes and capacities of children with disabilities. This critique rejects the claim, made most cogently by Mary Ann Baily (2000), that the very fact that any child can pose unexpected challenges gives prospective parents a reason to "improve their odds." Asch and Wasserman counter that the attempt to do so by prenatal testing exaggerates the singular challenges of disability, mistakenly assuming that it is additive, and creates a false sense of security.

This version of the disability critique eschews parental selection *for* disability for the same reasons that it rejects selection *against* disability. Parents should recognize that disability is only one of a child's attributes, and that possessing or not possessing a disability does not in itself guarantee a child's potential for having a satisfying relationship with her parents or a rewarding and productive life outside the family. An impairment is just one source of possible affinity with parents who share it, just as it is only one source of possible lack of affinity with parents who lack it. In neither case should it be a basis for prenatal selection.

Thus, the ideal of unconditional welcome draws support from two insights. The first concerns parental attitudes that promote a child's sense of being loved and valued as a unique individual; the second concerns the limited role that any single trait, where an impairment like blindness or Down syndrome, or personality traits like extroversion or impatience, play a part in defining that individual. This hardly means that parents should accept any expression or manifestation of a trait in their child rather than attempt to control or modulate its expression. They should thoughtfully guide the development of any child, disabled or not.

This critique is not threatened by the claim (Nelson 2000) that the decision to terminate any pregnancy, for any reason, can be formally expressed as a refusal to bear a child with a particular trait—e.g., "our first/second/nth child." Why, Nelson, asks, is it objectionable to abort on the basis of an impairment, but not a "trait" such as being the fourth conceived? First, "traits" like the latter are not stigmatized—parents rarely decline to add an nth additional child based on birth-order stigma. Second, whether or not such relational characteristics qualify as traits—a question we leave to others—the decision not to have one's nth child is a decision not to enter a parent-child relationship with an additional human being. In declining to assume the role, one can hardly be held to an ideal specific to it.

Nor is this critique in tension with the social model, which understands disability as a relational characteristic (Kukla and Wayne 2011). It is doubtful that most health professionals and prospective parents involved in routine prenatal testing *see* diagnosed disabilities in relational terms, as conditions that are disadvantageous because of an unaccommodating environment. For those who do—for example, those who are successfully raising a disabled child but decline to have another child with the same disability because of realistically estimated costs—the critique would apply with lesser force, and the departure from the ideal of unconditional welcome would be less significant. In the extreme case of prospective parents living under a regime that killed those with significant disabilities, the critique would not apply at all.

A final concern is that the ideal of unconditional welcome is too narrow (Ruddick 2000) or too demanding—particularly on women (Gedge 2011). Ruddick argues that it is only one, i.e., the "maternal" model, of three reasonable models of

parenthood. It is not clearly superior to two others: The “familial”—where decisions about a child are based on its role in, and likely impact on the family as a whole; and the “projectivist” model, where decisions are based on whether the traits of a child are compatible with the goals or projects of its prospective parents. Asch and Wasserman (2005) argue that the familial model is rarely incompatible with unconditional welcome, which is an ideal both for parents and families. The perceived incompatibility, they argue, arises largely from exaggerated or unsupported beliefs about the adverse impact of children with significant disabilities on other family members. The projectivist model is indeed incompatible with our ideal, but it is arguably too inflexible and self-oriented, failing to recognize the limitations in treating the creation and rearing of a child as an individual “project.” It is important to recognize that a projectivist parent may be thwarted by a non-disabled child who turns out to be able but not willing to participate in valued family activities; who simply eschews the parents’ values and projects. Parents must be willing to support their children in their own pursuits, however little they resemble those of the parents, as long as those pursuits are respectful to others and not self-destructive. A child is not a “creation” like an artwork, but a separate person who may or may not express the values or vision of its creators.

There are at least two responses to the demandingness objection. The first, more general one, is that unconditional welcome is offered as an ideal, one to which prospective parents should aspire even if they will inevitably fall short (Wasserman and Asch 2007a, 2007b). For example, a couple may decide with deep misgivings not to have a child very likely to predecease them, or at risk of unemployment and institutionalization in surviving them. Such a decision may be unduly pessimistic, but if made with serious reflection and careful research, it is hardly one for which the couple should be criticized. The more specific worry, that the burden of welcoming will fall disproportionately on the mother, seems realistic as a practical concern but not as an objection. A moral ideal should not be rejected because of the likelihood that it would be abused or distorted by a sexist society.

In earlier writing, we extended Sara Ruddick’s (1995) conception of the work of mothers (or parents) to include not only protection, nurturance, education, and socialization, but also fostering an appreciation of the child as a unique individual, however much her characteristics diverge from those of her parents. Although we believe that such appreciation is a critical part of good parenting, it has not been seriously discussed in the literature—with the notable exception of Rosalind McDougall’s (2007, 2009) account of “acceptingness” as a core virtue for parents and prospective parents. We believe the parental role of appreciation, and the virtue of acceptingness, deserve further discussion, in the context of a broader examination of the goals of parenthood.

Related Topics

Chapter 17, “Ethical Issues in Genetic Research,” Dena S. Davis

Chapter 29, “Children, Parents, and Responsibility for Children’s Health,” Amy Mullin

Chapter 39, “Medicalization, ‘Normal Function,’ and the Definition of Health,” Rebecca Kukla

Note

- 1 It is striking that few opponents of sex selection extend their critique to selection against disability. Indeed, most would permit selection in the case of sex-linked disorders. Herissone-Kelly (2009) is one of the few to offer a critique general enough to encompass selection against disability.

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