The disability rights movement has come of age in the 1990s with the passage of the Americans with Disabilities Act and with increased public attention to disability concerns. Persons with disabilities have made great advances in moving social policy away from two different models of thought on disability: the “charity” approach, which presumes that the best we can do is to provide welfare and charity toward primarily custodial services for persons with less social value, and the “medical” approach, which applies a medical framework toward social problems presented by disability and assumes that the best outcome is for a medical cure of the disability. A new approach, based on integrating persons with disabilities into society and accepting disability as a predictable aspect of life, has emerged during the past two decades.

Prenatal screening is inherently concerned with the existence, or avoidance, of disability in society and individuals. Are the social goals of those who have worked for the widespread use of prenatal screening consistent with those of the disability rights movement? As persons with disabilities have moved into significant policy-making positions throughout society, their views and experiences are becoming difficult to ignore.

The purpose of this chapter is to examine some of the policy implications of prenatal screening from a disability perspective. That perspective is based on the life experiences of persons with
disabilities who have attained academic, scientific, and social roles that provide them with an opportunity to present a new way of looking at the value of living with a disability. This chapter also reviews some of the most commonly given reasons for prenatal screening and extracts potential research topics from an analysis of those reasons.

Why Do We Engage in Prenatal Testing?

The most frequently given reason for utilizing prenatal testing is that we are trying to prevent or ameliorate medical or disabling conditions that are genetically based. Once a genetic syndrome or condition is diagnosed in a fetus, there are three types of prevention that can be pursued:

1. Prevention of the birth through abortion. Although new testing procedures sometimes permit this to take place during the first trimester of pregnancy, many such abortions still occur during the second trimester.

2. Prevention or amelioration of the disability using methods such as treatment through dietary changes or supplements for the mother or infant; prenatal treatment of the fetus through pharmaceutical or surgical interventions; other forms of treatment or therapy for the infant that occur after prenatal diagnosis.

3. Prevention of family disruption through prenatal preparation by family members. This can entail obtaining information about the diagnosed condition and its consequences through reading or through talking to families who have children with similar disabilities or to adults who live with the disability themselves. It may also include such means as finding out about available public or private resources or forms of assistance, purchasing equipment, or making home modifications.

From the perspective of persons with disabilities, the second and third types of prevention are not terribly controversial, although there are some disability groups who might object to
some forms of prenatal medical intervention. For example, some deaf families who do not regard deafness as a negative characteristic might reject prenatal cochlear implants, were such interventions available. For many persons with disabilities, though, the most disturbing type of prevention is the first: abortion. There are two reasons relating to this.

The first reason coincides with the general public controversy over abortion. People with disabilities take positions on both sides of this issue, for reasons that apply to the general populace as well as for those that are specific to persons with disabilities. On the one side, some persons with disabilities are anti-abortion for primarily disability-based reasons, including the very personal point that they might never have been born had their parents had access to prenatal screening and a legal abortion. Anecdotal accounts from adults with disabilities who were told as much by their parents validate those fears.

On the other side of the issue, many in the disability rights movement hold a strong belief in individual autonomy and support the concept of a woman's right to control her own body. Among other reasons, some disabled women and men are in favor of legal abortions because women with particular types of disabilities and medical conditions may be more likely to require late abortions of wanted pregnancies because of medical risks associated with those disabilities (Fine & Asch, 1988).

A unique disability perspective exists on both sides of the broader social debate that is largely unappreciated by the general public and by the media. It is frustrating and difficult for persons with disabilities to understand why their varied points of view on this issue are so often ignored, discounted, or simply unreported, especially when part of the debate focuses on the quality of their own lives (Morris, 1992; Saxton, 1984a, 1984b).

The other reason often cited for the widespread use of prenatal testing is due to a clash in values or beliefs about the value of life with a disability. Many in the disability rights movement and the disabled community hold a different view than does the majority of society on the effects of disability on individuals and families. The prevalent belief in many cultures is that the existence of a disability is overall a negative trait (Degener, 1990). One doesn't need to look very far to find negative images of
disability in both fiction and nonfiction. Horror movies are chock-full of crazed killers who have one form of disability or another. Even fairy tales and classics read by children contain disabled villains such as Captain Hook or pathetic, helpless figures such as the little girl who can't walk until Heidi befriends her.

Generally, of course, the prevailing attitude doesn't hold that disabled people themselves are bad but that the experience of the disability contributes to a lower quality of life for the individual. This often results in a widespread assumption that if a person with a disability is experiencing difficulties, those difficulties must surely be caused by the disability and not by other factors. It also results in the disability becoming elevated to that person's predominant characteristic, as opposed to one feature out of many that define a personality.

However, people with disabilities are finding that, with advances in the availability of assistive technology, accessible environments, and appropriate social services, those widespread negative assumptions do not necessarily hold true. For many persons with a variety of disabilities, their own experiences in terms of quality of life are positive. Persons with very significant disabilities now attend regular schools, attend colleges and universities where they receive advanced degrees, find challenging jobs, get married, and live fairly normal lives.

The emerging disability rights movement is built upon the shared belief that many of the problems experienced by persons with disabilities are caused not by the disability but by the barriers that exist in society, whether they are architectural, technological, legal, or attitudinal. This is easier to see in retrospect. For example, a person who uses a wheelchair is not "confined" to the wheelchair in an accessible environment. The wheelchair is a tool, much like a pair of eyeglasses, that enables people with mobility limitations to move about wherever they please. However, until wheelchair users had the opportunity to go places freely and without assistance, a wheelchair did feel like a confining piece of equipment.

The advances in the legal rights of persons with disabilities that have taken place during the past two decades have permit-
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ted persons with disabilities to gain this new perspective about their lives. Until children with disabilities could go to their local schools and obtain the services needed to fully benefit from an education, it was easier to assume that the disabilities were the cause of the educational inequality experienced in those children's lives. Now, with a federal law mandating equality in access to education, it no longer makes sense to perceive the disability as the problem.

Why Do We Want to Prevent the Birth of Fetuses with Disabilities?

The most frequently given reasons for wanting to prevent the birth of fetuses with disabilities are to avoid negative consequences in the following areas:

- economic impact on families
- economic impact on society
- disruption of families
- quality of life of person with a disability
- notions of "perfection"

It is possible to identify areas that are ripe for further inquiry by conducting an analysis of each reason. More information is needed to determine whether the assumptions behind the reasons are actually valid.

Economic Impact on Families

It is widely believed that there are disability-related costs that must be assumed by families with disabled children. While plenty of anecdotal evidence exists to support this notion, it is unclear exactly what those costs are and how predictable they are.

Some research has been conducted on the costs of raising a child with a disability. This work needs to be collected and examined to determine what the costs are associated specifically with raising a child with a disability that are not associated
with raising nondisabled children. Similarly, what costs are higher for a child with a disability needs to be determined. For those special costs, what sources of support are currently available for families? Which costs must currently be borne by the families?

**Economic Impact on Society**

Some have pointed with alarm to the large amounts of money allocated by the government for social programs catering to persons with disabilities. The inference commonly drawn is that "prevention" through abortion will decrease those expenditures and therefore reduce public expenditures associated with disability.

The nature of public expenditures for disability needs is changing, however. In large part due to the advocacy of persons with disabilities, the purposes of many public programs are under examination. Persons with disabilities are challenging the custodial nature of many public programs and have advocated for program redesign, with the goal of providing incentives and support for employment and self-sufficiency as much as possible. Thus, new program priorities could be viewed as creating a social investment, which is paid back by the person with a disability later in life through income taxes and other types of contributions to society, both financial and other.

In addition, legislation like the Americans with Disabilities Act will have a significant impact on the American landscape, resulting in an environment with permanent fixtures that enable persons with disabilities to function like other people. It is unclear to what extent those changes will reduce the need for public expenditures that had previously served to compensate for social and architectural barriers reducing the functioning abilities of persons with disabilities.

Given the caveats above, little evidence exists to validate the assumption that abortion-based prevention will significantly reduce disability-related social costs. Research needs to be conducted to examine the following questions: To what extent are social program resources used by persons with genetic conditions? Of that group, what percentage has been reduced in recent years through genetic testing? To what extent are savings
offset by public expenditures related to prenatal screening? How much money has truly been saved?

Disruption of Families

While the assumption prevails that the addition of a child with a disability to a family will be disruptive, there are anecdotal accounts supporting both sides of this question. There are accounts of families who say they have been weakened by the presence of a disabled child, as well as of those who report to have been strengthened or enriched. Presumably, there are also families who report little or no significant impact. Beyond anecdotal information, however, little solid evidence can be found either to support or refute the common view.

Without solid research into this issue, we cannot determine the impact across the many different types of families in our society. What demographic factors account for any differences in familial experiences? What other factors exist? For example, of particular importance to women is information about the extent to which mothers of disabled children are expected to disrupt their own lives in order to meet the needs of their children. Anecdotal accounts suggest that mothers assume this role far more often than do fathers.

Quality of Life

There are several possible sources of information about a person with a disability's quality of life: health and helping professionals, parents and other family members, and persons with disabilities themselves. Since quality of life is such a subjective concept, it makes sense to get information from primary sources as much as possible. This means that research into this issue should use subjects who are themselves disabled.

There is a distinction that needs to be drawn between the quality of life of the person with a disability and that of others such as family members. Many of the concerns voiced about the quality of life of family members are reflected above, and possible areas of research have been suggested. However, it is important to recognize that the experience of the person with a disability may be different than that of the other family members.
Allowing family members to report on the quality of life of the person with a disability may be misleading, because their perceptions may, at worst, be wrong or, at best, be biased by their own experiences. Thus, it is surprising and alarming that the impressions of professionals and family members have been given great credence in this regard, without any acknowledgment of their distance from the subject matter.

Little existing research refers to this subject. Further research needs to examine the subjective feelings of persons with genetically based disabilities. Subjects should be questioned about major facets of their lives (such as social life, employment, family relationships, and recreation), while persons with no disabilities should serve as a control group, responding to the same set of questions. The results of such a survey would give us much-needed information about how persons with disabilities regard their own lives.

Notions of “Perfection”

It is difficult to know whether to consider this notion seriously. However, although the goal of guaranteeing “perfection” in an offspring is not usually the stated reason for obtaining prenatal testing, it cannot be ignored. To a certain extent, this concept of perfection is tied to our notion of normalcy.

Potential research questions include: To what degree does a desire for a “normal” child factor into the decision to seek prenatal screening? What are the ethical implications of those goals? What do we mean by “perfect” or “normal”? What cultural factors contribute to different perceptions about normalcy? Are some disabilities acceptable to some groups and not to others?

The Quality of Life Dilemma

The most appealing and satisfying reason for permitting abortions based on genetic characteristics is a kind of altruism: we believe we are saving potential children from pain and harm. Other justifications, based on the economic or social interests of the family, or general societal norms, may also be present, but they do not sound as benevolent. Perhaps it is this justification that is most troublesome to disability rights activists.
What would happen to the level of social acceptance for this technology if quality of life research revealed that persons with disabilities don't share the view that the quality of their lives is significantly reduced because of their disabilities? Are the economic or social interests of others sufficient to sustain support for the technology? What would be the policy result if it were found that persons with disabilities do not report a negative subjective experience of their lives?

It is noteworthy that some of the most insistent voices questioning the rationale for prenatal screening are persons with disabilities—those whose voices most certainly deserve our attention. Persons with disabilities and their leaders are, more and more, questioning the use of prenatal screening as a response to social problems that could be resolved through other policy initiatives.

Public Perceptions of Disability

Many leaders of the disabled community (and again I emphasize persons with disabilities, as opposed to family members or professionals who often speak “for” disabled persons) have expressed concern that the widespread use of genetic testing and prenatal screening has a tendency to promote overall negative attitudes about disability. They worry that those negative attitudes result in public policies or practices that foster such problems as job discrimination, barriers to obtaining health insurance coverage, and cutbacks in public support programs (Wang, 1992).

Prenatal testing has come about during a time in which persons with disabilities and their organizations have undertaken major efforts to remove attitudinal barriers to social acceptance. They fear that the availability of prenatal testing encourages negative attitudes in several ways:

1. A general social expectation has developed that we will be able to reduce funding of programs for persons with disabilities, whether or not the actual number of persons with disabilities decreases. Prenatal screening has been promoted as beneficial because it will lead to
a reduction in the number of persons with disabilities in society. To what extent have public policy makers, under increasing pressure to make budget cuts, seized upon this idea to rationalize their actions?

2. A subtle shift in perception about the causes of disability, at least in the case of genetic disabilities, results in the blaming of parents who “caused” a disability either by not having been screened or by having chosen to carry a pregnancy to term after screening revealed the existence of a targeted genetic trait. To what extent has this led to family difficulties or breakups, social ostracism, or other negative results?

3. There may be an increase of negative attitudes in general. In part this fear comes from language or terminology frequently used in the medical field: “bad” genes, “bad” babies, “defective” genes, “defective” babies. Do these terms extend to describe or define persons with disabilities? Are they “bad” people? “Defective” people? They are not terms, certainly, that disabled people use to describe themselves. To what extent are negative images of disability related to those expressions?

4. The ability to predict the existence of a genetic condition before birth could cause increased difficulties in obtaining adequate medical insurance coverage for persons with disabilities. Do prenatally diagnosed conditions become “preexisting conditions”? Under current economic conditions, insurance companies are using a wide range of tactics to deny coverage to individuals who previously had no trouble in obtaining health insurance. To what extent has the availability of prenatal screening resulted in more exclusive medical insurance practices?

Underlying these concerns is a message that many disabled leaders believe is implicit in the practice of abortion based on genetic characteristics: It is better not to exist than to have a disability. This concept is soundly rejected by the disability
rights movement, which is promoting a very different message: Most of the problems experienced by persons with disabilities are the result of intolerance, poorly conceived social programs, and environmental or communication barriers that can be removed by changes in social policy (Deegan & Brooks, 1985). These are two profoundly different perspectives on disability.

It should be pointed out that prenatal testing will never have a very significant impact on the number of persons with disabilities in the United States. It is estimated that in this country there are more than 42 million persons with a variety of disabilities—most are caused by trauma and age; relatively few are genetic in nature. Any public expectation that prenatal testing will lead to a meaningful reduction in the rates of disability in our society is quite misplaced.

Another factor that complicates the discussion is the fact that "disability" is a relative concept, as is "genetic condition." All human beings have genetic characteristics that differentiate them from other people. As our base of genetic information increases, are we at risk of creating new genetic conditions with new social stigma attached to them? Are we contracting (as opposed to expanding) the category of normal?

Where is the line drawn between a genetic characteristic and a genetic condition? At what point does a mere characteristic become an imposing condition? In a preliterate society, learning disabilities probably had much less impact on the ability of the individual to function or succeed. In a physical environment that is fully wheelchair-accessible, with low-cost and lightweight sports wheelchairs commonly available, we might not be so prone to describe wheelchair riders as "wheelchair bound" or "confined to a wheelchair." Prenatal screening cannot predict the severity of most genetic conditions, or society’s perceptions of the severity, which adds further complication.

It is important to weigh these potential negative results of the availability of prenatal screening against known benefits. Thus, the benefits from prenatal screening can be more clearly defined and measured. It is also important to evaluate whether the means that are currently used to promote prenatal screening such as public service announcements, brochures, and the training of medical personnel tend to promote unacceptably negative
messages about disability. If that is the case, alternative means or messages should be explored (Wang, 1992).

The varying perceptions of disability may partially explain the different points of view that abound regarding the validity of prenatal screening as a tool of public policy. If persons with disabilities are perceived as individuals who encounter insurmountable difficulties in life and who place a burden on society, prenatal screening may be regarded as a logical response. If, on the other hand, persons with disabilities are regarded as a definable social group who have faced great oppression and stigmatization, then prenatal screening may be regarded as yet another form of social abuse.

Conclusion

In order to evaluate the effectiveness of prenatal screening, we must first be clear about what goals we are trying to achieve. If we are using prenatal screening in order to attempt to protect future human beings from experiencing a terrible quality of life, we must be sure that there is a valid relationship between predictable genetic conditions and a negative life experience.

If we are using prenatal screening in order to attempt to resolve economic or social disadvantages that are associated with genetic disabilities, we should first explore whether this goal can be achieved through alternative methods and examine those alternatives. The disability rights movement certainly agrees that there are economic and social disadvantages associated with disability. However, the fact that so many persons with disabilities are engaging in ordinary lives with satisfying jobs, happy family situations, and involvement in a variety of community roles suggests that those disadvantages can be eliminated without eliminating persons with disabilities.

Disability leaders have attempted to eradicate these problems through advocacy for civil rights protections, legislation to eradicate barriers found in the environment, programs to promote and make available adaptive technology, and more effective social support programs. Prenatal screening as a widespread social practice appears to be at odds with some of the
disability rights movement's goals, and many prominent disability leaders question its value and ethical basis (Finger, 1984).

At a minimum, prenatal testing strikes some as a technology that is proceeding without a firm basis in social policy. There are many questions about how we should proceed in an era in which proliferating information about human genetics makes matters more and more complex. We surely need to include the perspectives of the disabled community more fully in our research and exploration of policy options. The disability community is willing to join in the dialogue.

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