

The Moral Implications of Prenatal Genetic Testing

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Abstract

The advance of medical technology now permits many genetic tests to be administered to a fetus in the womb. The goal of this testing is to determine the potential for genetically based disorders and disabilities. The use of these tests has major implications on the decision of a parent to abort a child based on what information they find in the prospective child's genes. Advocates of prenatal testing argue that it enables the families of these prospective children to make an informed decision when faced with the possibility of disability.

I argue that this choice is drastically limited by social coercion through a discriminatory and stereotyped perception of the disabled community. Permitting an uncontrolled barrage of prenatal genetic tests will further promote the stereotype of a disabled life, and thus hinders our societal goal to recognise and promote equality and individuality. Which disabilities to test for, or what genes to search for, is a judgement that should be made only through extensive consultation with members of the disabled community, including individuals who have suffered from or who have been directly associated with the disability which is to be tested.

Rapid advances in medical technology coupled with the recent completion of the Human Genome Project provide unprecedented insight into the genetic basis of many human diseases and disabilities. There are currently many technologies that allow early diagnosis and prediction of the probability of onset of particular diseases, malformations, defects and disabilities in an unborn child. As these technologies advance, the scope of accurate prenatal testing is seemingly limitless and has a future where the identification of any disorder or trait with a genetic basis becomes increasingly plausible. It is assumed that most

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prospective parents will be concerned with ensuring the birth of a healthy child and will likely adhere and succumb to the pressures of providing standard of prenatal care in order to be ensured of the fetus' good health. In the event that a genetic or potential genetic disorder is detected, prenatal diagnosis provides the prospective parents with several different options, including both mental and financial preparation for the birth of an abnormal child, the use of fetal treatments against the detected disease or termination of the pregnancy. Currently, the reality of prenatal testing is that the most widely used fetal treatment is the outright termination of the pregnancy. For the purposes of this discussion, I will assume that it is morally and legally acceptable that women have the right to terminate any unwanted pregnancies.

In this essay I address the problem posed by social influences that pressure parents toward a barrage of prenatal genetic tests, as well as what restrictions can be imposed upon the availability of these tests to counteract these pressures. In specific, I suggest that tests other than those that would identify a fetus with high probability of infant fatality, severe and chronic pain or severe cognitive impairment should be withheld from use.

One must assess what sorts of prenatal tests and genetic screening are currently available and what sorts will eventually be possible. Analysis of fetal genetic information or chromosomal abnormalities can be accomplished through procedures such as amniocentesis, chorionic villi sampling (CVS), maternal serum alpha-foetal protein assay (MSAFP), and preimplantation genetic diagnosis (PGD). Structural and anatomical abnormalities can be assessed through imaging techniques such as ultrasound, magnetic resonance imaging and fetal echocardiography (Cunniff, 2004, p.889). Ultrasound is currently the standard of care for health assessment in all pregnant women regardless of age, family history and health, while amniocentesis and CVS are utilized most commonly in pregnancies with woman over the age of 35¹, and as second round of testing when a disease is suspected. New medical genetic technology allows for identification of many genes known to be associated with particular abnormalities and provides the option of using the above procedures to screen for these particular genes. Although many diseases do indeed have a genetic component, the expression of these diseases does not

¹These tests are meant to follow an ultrasound diagnosis of potential problems, but are increasingly being used by many pregnant woman regardless of the potential for disease.

rely solely on the presence of the genes, but also on an interaction of the genes and the child's environment. In addition, many diseases and malformations result in factors completely unrelated to the genetic code; such as trauma incurred during pregnancy or birth, maternal drug use in early pregnancy or malnutrition in early development. It should be noted that in many cases, genetic tests identify only those genes that are associated with a particular disorder and in no way directly contribute to the development of the disorder.² The advancement of testing procedures, including a reduced cost and easier access will increase the number of tests routinely administered during pregnancy and will compromise a woman's autonomy in regards to which tests are necessary and which are desired.

The pressures placed upon expecting mothers are not necessarily imposed directly through coercion by the genetic counsellor³ or family, but generally through what is socially perceived to be an acceptable level of care required during pregnancy. It is assumed that parents are concerned with having a healthy child and ensuring the proper care for that child.⁴ As technologies advance, the meaning of proper care may encompass certain procedures that accomplish little more than to warn the pregnant woman of a potential for a fetal disability or abnormality. The perceived burdens of raising a disabled child pressures expecting parents to request a particular test (Lippman, 1991, p. 402). Should the fetus exhibit traits that promote a particular disability, the parents may seem to have little choice but to abort the pregnancy. The increased use of unnecessary tests will further perpetuate the unfounded societal belief that these tests are necessary to produce a healthy child and may subsequently perpetuate ignorance and discrimination toward the disabled community. People may start to wonder why these individuals were not identified and aborted, and would thus perceive them as reproductive errors or oversights. The perpetuation of these beliefs is ultimately detrimental to efforts in society to promote equality.

It is a disturbing perception that the disability is the primary defining feature of a disabled individual (Asch, 1999, p. 1653). Those women who receive prenatal tests only to discover that their child may be disabled tend to focus on the disability rather than the possibility of giving birth to a caring and loving child who will potentially develop their own personality and provide their own contributions to society.⁵ The point of emphasis is that the potential of a

² There are single genes that have been directly linked to disorders, such as the case for Huntington's disease and muscular dystrophy (Chan & Chan, 1997, p.173).

³ Genetic counsellors are in fact instructed not to provide any sort of direction in regards to decisions about termination of the pregnancy (Cunniff et al. 2004, p.889)

⁴ It is not through a concern for the health of the child that termination is considered, but rather a chance for the parents to produce a child with a socially acceptable level of health.

⁵ An infant or fetus can only be measured by its potential, although those affected by different levels of severity will show differing levels of social aptitudes as well.

disabled fetus is no different from the potential of an 'abled' fetus. The only difference arises from the ideals imposed in society as to what constitutes meaningful potential as a human being. For instance, emphasis is placed upon those who are intelligent, attractive and athletic. A disabled person may be none of those, but may be more caring, considerate, and thoughtful than an individual with the qualities above. Which qualities are more important and valued in society should be carefully assessed and reconsidered – although this is much easier said than done.

Many argue that prenatal testing enables the families of prospective children to make an informed decision⁶ when faced with the possibility of disability. Jeffrey Botkin, a proponent of prenatal testing argues that, "parents in this circumstance are not harmed by the suffering of the child... but rather by their time, efforts, and expenses to support the special needs of an individual with Down syndrome..." (Botkin, 1995, p. 36). Although Botkin acknowledges that the affected individual does not personally suffer from the disability, he emphasizes that a large burden is imposed upon the family. He defines a burden as the amount of time, effort and expenses provided by the family to support the child with a disability. Adrienne Asch (1999, p. 1653) argues that although the amount of support needed to raise a child who suffers from a particular disability is not questioned, it is interesting that the benefits received through this level of involved care are not assessed or weighed against the burdens. Caring for a disabled child is a difficult task, but such a difficult task must reap rather large emotional rewards. Additionally, Botkin does not address the dichotomy between those burdens imposed by gifted children and those imposed by disabled children (Asch, 1999, p. 1653). According to Botkin's criteria, a child who becomes interested in pursuing a career in professional hockey may impose much more of a burden upon their family than does a disabled child.⁷ The dichotomy lies in the appreciation society has of each of the two individuals. The fault is placed on a society that skews the perception of an ability and disability. Abby Lippman (1991, p. 404) argues that instead of creating additional social support programs to care and provide for those disabled persons, society expects to solve these 'problems' through medical and technological interventions. Interestingly, social programs that accommodate to the needs of gifted individuals are not difficult to come across.

An additional argument in support of prenatal genetic screening relates to the difficulties and pressures imposed upon the prospective disabled child. Proponents argue that

⁶ A decision in this sense would mean whether or not to abort a disabled fetus.

⁷ Supporting a child's interest in such an expensive sport and one of such high competition demands the investment of countless dollars and hours into providing expensive equipment, timely delivery to early morning practices and games, and the potential for lengthy hospital visits.

these difficulties would far exceed the benefits one may experience in such a life. By this description, it would be unfair to bring into the world a child who would outright be denied the “right of an open future” (Asch, 1999, p.1652). Numerous problems arise out of this argument, namely the distinction between a life with a disability versus no life at all, or non-existence. Differing levels of disability would undoubtedly generate different arguments. For instance, non-existence would likely be preferable to a life full of chronic, inescapable physical pain and anguish.⁸ Physical pain may be reduced through drug programs, but may not altogether eradicate it. A life dominated by drug use seems less than desirable, but is this sufficient to justify non-existence? Who, but the individual affected, can decide the value of a life? Here it is important to identify the difference between a life completely plagued by burdens and one perceived to be plagued by burdens.⁹ I argue that it is not the individual that determines dissatisfaction, but the structure of society in which the individual lives that ultimately determines the ability and willingness of an individual to live with his/her disability.

Mental anguish is essential in quality of life assessments, although the level of social contribution towards this anguish is difficult to illustrate and determine. Individuals with similar disabilities may report a wide range of personal experiences, depending upon their environment and subsequently their expectations of living with their disability. These expectations are constructed through social experiences with not only the individual’s parents and family, but through interactions with peers and the general public. Obvious physical abnormalities and mental retardation may be criticised in certain social environments, and such an individual may suffer low self-esteem and may consequently have negative expectations of living a life with his or her disability. However, if these individuals were raised in an environment where they are integrated and accepted regardless of their apparent disability, then these individuals would likely report a higher level of self-esteem and have more positive expectations of a life with a disability. Expectations would affect how an individual weighs the burdens of his or her life.

Considering the above arguments, there are certain foreseeable circumstances when a disability is not worth the life or risks associated with it to the mother and prospective child. If the chances for a live birth are slim, the fetus may be aborted in favour of the potential risks to the mother associated with carrying a severely defected child to term.¹⁰

A disease, which carries with it chronic and uncontrollable pain, or severely impaired cognitive development to those affected, may nullify the chance for an enjoyable life. These cases likely justify abortion of the affected fetus, and thus screening for these disorders may be permitted. The decision of which disabilities fit these criteria should only be made by those who have been personally affected by the disability in question.¹¹ It is only through consultation with the disabled community that the true quality of life associated with the disease may be assessed and a decision about whether or not to allow screening can be made. If individuals with the disorder cannot communicate the degree of their quality of life,¹² then the decision may pass to the parent, geneticist or obstetrician where a consensus can be made.

Variations in social experiences arise mainly due to what is considered normal¹³ in society. The public may regard individuals that are different as either inferior or as threats or may simply generalise to encompass a further difference in human characteristics such as thoughts, feelings and emotions. Thus, the problem arises from the general societal view that disabled is different, and different infers a level of difficulty and subsequent dissatisfaction in life. Here there must be a distinction made between what is dissatisfaction and what is difficulty. Certain difficulties are part of life for everyone and it is how people deal with these difficulties that determines the quality of their lives and their overall level of satisfaction. Indeed there are some people who do report that their lives may be complicated by disability, but these individuals consider it simply as a personal quality they must use to navigate throughout life. Additionally, the difficulties encountered by the disabled are largely socially rather than biologically imposed (Asch, 1999, p. 1653). Most disabled people report that their only dissatisfaction in life arises due to their unemployment and associated problems with income, and health insurance (US), encountered as a result of discrimination. A mother may feel pressured to abort an ‘abnormal’ fetus because it may encounter difficulties and discrimination as a result of his/her disability. The decision to abort a fetus with such a disadvantage thus completes the vicious circle. It will only compound the perception that disability is undesirable.

Several lines of research indicate that the ‘abled’ population perceives the quality of life of the disabled population as significantly less desirable than do those

⁸ However, this case represents one extreme end of a continuum.
⁹ Herein lies the fundamental problem of a perceptive reality, where an individual creates their reality based on their perceptions of what a particular life is to be. Such perceptions are based on social influences.
¹⁰ If such an action is so desired. Many woman suffer mentally even from aborting a doomed fetus due to the nature of abortion. Some prefer to let nature take its course rather than actively killing

¹¹ Understandably, the level of severity by which an individual suffers from the disability will affect his/her opinion on the morality of prenatal testing. An individual who suffers considerably from a particular disease would be more likely to support prenatal testing for it (Gollust et al., 2005, p.39).
¹² Inability to communicate entails an inability to comprehend due to severe cognitive impairment or early death resulting from the disease. It does not imply those with language disorders.
¹³ Definitions of normalcy vary, but may be considered as being those combinations of traits that are found in the majority of the population.

living with disabilities. A study performed by Ray & West (1984, p.83) indicated that individuals living with spinal cord injury reported an increase in positive self image after becoming disabled. Several other groups of disabled people seem to be satisfied with their lives and report the quality of life as being better than unaffected individuals perceive it to be. In fact, a certain group of deaf individuals have been reported to not only prefer having a deaf child, but would use prenatal screening to selectively terminate those fetuses that can hear (Dennis, 2004, p.894). Certain individuals maintain that their exclusion from the hearing world enables them to create closer, more intimate bonds between themselves and other deaf individuals, and prefer to share these experiences with their children. Although this is an extreme and seemingly isolated case, it clearly illustrates that certain disabled individuals do not lead difficult and painful lives but may in fact lead lives that they perceive as being superior to those without their 'disability'.

Aborting a disabled fetus solely due to a disability in which no valid or justifiable harm can be proven to the future individual may be considered a form of discrimination against individuals with the disability. Many individuals in the disabled community fear that uncontrolled genetic tests will eventually reduce the number of individuals in their population and thus create a higher level of discrimination (Gollust et al., 2005, p.37). Women who refuse prenatal tests or abortion after a positive test could be held financially responsible for their 'irrational' decisions. Support programs for a disabled child may not be as readily available if the option to avoid having the child is present. However, it must be kept in mind that many diseases do not have a genetic basis and the elimination of disability through prenatal screening is impossible. While screening would not eliminate disability, it would undoubtedly propagate the social stigma against the acceptance of those individuals. The propagation of negativity towards a certain group is always an undesirable consequence.

The goals of prenatal testing primarily intend to prevent the hardships and burdens of a life with disabilities for both the mother and the prospective child. Secondary to the benefits obtained from these tests are the moral implications that result on a society that is already distanced from, and discriminates against, the disabled community. This could then be considered a step in the wrong direction in a society that seems to want to promote equality. Widespread uses of prenatal testing will primarily affect and worsen the discrimination and distance which is already present in the disabled community. Providing a woman with a barrage of prenatal tests does not allow for a sufficient level of choice in regards to whether or not a disabled child should be carried to term, as social pressures drastically limit this choice. The only way to limit social coercion to abort a disabled fetus is to limit the use of prenatal tests and impose certain restrictions through consultation with members of the disabled community. 🧑🏻

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