

PROCREATION ETHICS SERIES

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God's work. Our hands.

Genetic Screening and Counseling James Childs

[1] One of the relatively new developments in modern medical science is our expanded knowledge of hereditary illness. We now know that many children born with birth defects suffer these disorders because one or both of their parents carry defective genes. Scientists today have identified over 3,000 such genetic disorders. Recent figures tell us that one or more of these defects appear in over 200,000 infants out of a total of 3 million born each year in the United States. Two to three percent of that total display a major congenital disease. It has been further estimated that genetic disorders account for 30 percent of the children and 10 percent of the adults in our nation's hospitals.

[2] Along with our growing knowledge of the nature and extent of genetic disease we have increased our ability to detect the presence of defective genes in those who are potential parents. This has led to programs of screening and testing people to discover those who carry genetic traits that may cause problems for their offspring. For example, it is possible to screen people for the presence of those genes which can cause sickle cell anemia or Tay-Sachs disease. Both of these diseases are fatal. Sickle cell anemia is a blood disorder which usually kills its victims by age 40. A child born with Tay-Sachs disease will suffer progressive brain deterioration and die by the age of five. Both of these diseases are called recessive disorders because both of the parents must carry the trait for the child to be afflicted. When both parents are carriers of the defect, there is a one in four chance that their offspring will actually have the disease. There is a 50 percent chance that their children will be carriers of the trait even though they do not suffer from the disease itself. Other diseases like Huntington's chorea, a disorder of the central nervous system occurring later in life, are dominant genetic illnesses. In the case of dominant genetic defects, only one parent needs to carry the gene that causes the disease. Usually that parent suffers from the genetic disorder as well. Through screening for problematic genetic traits, parents can learn whether or not they are in danger of having a child with birth defects, and the extent of their risk.

[3] To assist people in dealing with this new information, a new profession called genetic counseling has grown up. People who have already had one child with birth defects may seek the help of a counselor. Others seek genetic counseling when they suspect a problem because of some incidence of genetic disease in their family; Genetic counselors also work with people who have been identified in a screening program as carriers of defective genes. The counselor provides information about the

degree of risk that parents face if they decide to go ahead with a pregnancy. The counselor also helps them understand the severity of the disease should it occur in their child, and the therapy that might be available, if any. With the information which the counselor provides, parents can then make an informed decision whether or not they should go forward with their plans to have a child.

[4] All this new knowledge promises marvelous benefits for the prevention of birth defects. However, it also raises serious theological and ethical questions which must be faced.

[5] One of the first concerns is whether or not our knowledge of genetics and our use of that knowledge in screening and counseling is an interference with God's plan. Should we not steer clear of trying to unlock the mysteries of life itself, accept the will of God if we have a defective child, and care for it in a loving and responsible way? Certainly we recognize God's presence in the miracle and mystery of life. There are times when it appears that human beings have gone too far in their search for knowledge and in their ability to control life itself. However, we are created in God's image, and have been endowed with the responsibility of caring for our own lives and our environment. God has given us our reason that we may gain knowledge of the orderly patterns of the creation. God has not commanded us to remain ignorant but to use our knowledge in loving obedience to God's will. And that will for us is wholeness and health. Jesus in his ministry went about healing the sick. In this healing he foreshadowed the ultimate healing of the whole person, which is the promise of the resurrection victory. The promise of perfect wholeness is part of the promise of the future kingdom of God. When we use our knowledge in medicine and in genetics to prevent disease and to reduce suffering, we anticipate that promise as a testimony to the hope that is within us. In so doing we show our care for the quality of life as well as for its sanctity, even as God has cared for the whole of life through the ministry of Jesus Christ, our Lord. Thus, responsible use of our genetic knowledge in screening and counseling for the prevention of unnecessary suffering is in accord with God's purposes.

[6] However, even if we agree that God has created us with reason for the purpose of gaining knowledge and using it responsibly and lovingly, in genetics as well as in other areas of life, the questions raised by genetic screening and counseling are not fully answered. It is also possible and even likely that sinful human beings will misuse the knowledge they gain or be misguided in their application of that knowledge. Thus, it is not surprising that ethical concerns have been raised both in connection with public screening programs and personal decisions in the counseling situation.

[7] Sickle cell anemia and Tay-Sachs disease are examples of genetic disorders which occur almost exclusively in special populations. Sickle cell anemia is predominantly a disease among Blacks, and Tay-Sachs occurs almost entirely among people of Eastern European Jewish extraction. Because these diseases are specific to those populations, it has seemed possible and even desirable to establish public screening programs for members of those groups in an effort to detect whether individuals are

carriers of the disease. The hope is that through public screening programs of these populations, potential parents will be alerted to the risks they may take if they should marry and have children with a person who also carries the genetic trait.

[8] On the surface it would seem that such a public screening program benefits not only those who are at risk, but the public health as well. Nonetheless many in the Black community and some in the Jewish community have been critical of these programs because of the problem of stigmatization. That is, minority populations are set apart in this connection from the rest of the population and branded as people who are genetically flawed. There is a fear that this kind of public attention will tend to confirm and deepen long-standing prejudices against such groups.

[9] A great deal can be done to overcome the threat of stigmatization through good public education concerning genetic screening programs and genetic disorders. However, public screening programs also raise other fears which are not so easily dealt with. Many are concerned that successful screening programs will lead society towards a policy of making screening for genetic disorders mandatory. This could easily lead to additional legal restrictions on marriage in cases where couples are detected as having genetic problems. While mandatory screening and restrictions on marriage may promise certain benefits for the public health, these measures would also constitute an invasion of the right to privacy and a denial of the right to reproduce freely. Furthermore, such attempts to control our destiny through genetic knowledge could lead us to be less and less accepting of those who are afflicted with birth defects, and more and more prideful concerning our ability to control the future. Even though fears of this kind may sometimes seem a bit exaggerated, they should nonetheless be taken seriously.

[10] Christians who understand that God wills our wholeness will recognize that we cannot pursue physical health measures without also being concerned for the human spirit. If the church has sometimes neglected physical well-being because of a preoccupation with spiritual things, the community of medical science has sometimes overlooked the things of the human spirit through preoccupation with the physical. Thus, as we do battle with genetic disease using the weapons of medical science, Christians remember that we are always also at war within ourselves, our sinful inclinations continually threatening to distort the good we mean to do. In view of this caution, we do well to be concerned about public programs such as genetic screening, that they do not perpetuate discrimination through stigmatization, that they respect our freedom to make responsible decisions about procreation, and that the right to privacy is protected. Moreover, our Lord's commitment to all who suffer, mandates our commitment to the weak and afflicted. Care about these matters is care about dignity of the human spirit and the worth of every person in God's eyes. Human beings can, indeed, intrude into God's plan, not because we gain forbidden knowledge of genetics, but because use of that knowledge can threaten the rights and dignity of our neighbors - which God would have us safeguard.

[11] Though we may feel it necessary to oppose mandatory public screening in order to protect freedom of choice in procreation, it does not follow, morally speaking, that this freedom can be exercised without restraint. Christian love is self-sacrificing and accepting. It can lead us into caring wholeheartedly and faithfully for a child afflicted with genetic disease. Many have reported great blessings in their lives through such circumstances, despite all the pain and suffering. Yet love also requires that we take responsibility to prevent suffering when possible. This means that couples who go for genetic counseling and discover a possible problem have the need to consider with utmost seriousness whether it is right for them to risk having a child.

[12] Deciding on whether or not to risk a new pregnancy is often difficult because the counselor will usually be able to give a couple only the odds of the possibility of genetic defect. The counselor cannot offer certainty. Is a one in four chance sufficient risk to hold back on having a child? What about a 50-50 chance? Parents who seek genetic counseling will sometimes find to their relief that the chances are remote, but often they must deal with these terrible odds.

[13] Of course, the severity of the disease at risk enters into the decision as well. Whether or not there are promising ways of treating the disease is another consideration. Diseases which promise pain and eventual death such as sickle cell anemia or cystic fibrosis pose a different problem from the threat of bearing a child with PKU, an enzyme deficiency leading to retardation that can be treated by diet in the early years. Although the latter is a severe problem, it is not a hopeless one.

[14] St. Paul teaches us that "love does not insist on its own way" (I Cor. 13:5). Christian couples facing the risk of severe genetic disorders in their children need to consider their obligation to forego the freedom to procreate, and not gamble with the odds in order to prevent unnecessary suffering.