

Managing Attitudes Towards Defective Newborns

The Reverend Charles McConnell

Charles McConnell is pastor of Salem Bible Fellowship Church in Allentown, PA. He and his wife are the parents of seven children, the sixth of whom was a Down Syndrome (trisomy 21) girl with an imperforate anus and a complete atrioventricular canal defect. She died at nine months of age following open heart surgery.

It is two o'clock in the morning. The exhausted yet exhilarated father has just arrived home from the hospital after witnessing the birth of one of his children - a girl. To all appearances at delivery, both mother and child are doing well. But now the phone is ringing, at two in the morning. The night-duty pediatrician identifies the alarmed father. "I'm sorry to have to tell you this," he says, "but your daughter has some problems." With care and sensitivity the pediatrician explains from the mother's bedside that the baby girl delivered less than two hours ago was born with an imperforate anus. Permission is needed for a colostomy for the bowel anomaly. The baby girl is also Down Syndrome.

What happened? What went wrong? The causes of birth defects can be divided into four groups.

4 GROUPS OF CAUSES FOR BIRTH DEFECTS

First, there are single-gene diseases (diseases with Mendelian inheritance). "There are approximately 3,000 different diseases in the single-gene-disorder group, all of which are caused by different abnormal (mutant) genes."¹ In single-gene disorders, there has been a chemical change in the structure of the gene that has produced a corresponding defect or defects. Examples of single-gene disorders are Tay-Sachs disease and muscular dystrophy.

The second group of birth defects are those caused by chromosomal disorders. By that is meant "Wither one chromosome too many or one too few is present in each body cell . . . The most common chromosomal problem in the population is Down Syndrome, or

trisomy 21."²

Third group: Most of the common birth defects, such as congenital heart defects, cleft lip and palate, and open spine defects (neural tube defects) classify under the third group of birth defects called multifactorial (polygenic) diseases. "These disorders are not associated with chromosomal problems and are not due to a single abnormal gene. In this group of disorders, the precise nature of the genetic component is not clear. Apparently, both genetic and environmental nongenetic factors play a role in etiology. These disorders are thus said to have multifactorial inheritance because both genetic and nongenetic factors are involved."³

The fourth group of birth defects is diseases caused by teratogens - Substances or factors inducing birth defects. X-ray radiation is a widely known teratogen. Atypical effect of maternal heavy radiation is microcephaly, which in most cases causes mental retardation. Alcohol is an important teratogen when consumed in heavy amounts.

However, regardless of their etiology or frequency of occurrence in the general population, every birth defect is a disturbing, unsettling experience for both parents and physicians. "The birth of a (defective) child has a profound effect on the family. Parents go through some of the stages of grief: shock, denial, sadness, anger, self-pity, adaptation, and reorganization."⁴ The physician's attitude towards the defective newborn is critical at this point. His attitude is critical from the standpoint of how rigorously he decides to treat the child, and his attitude is critical from the standpoint of how he will affect the parent's attitude towards, and

acceptance of, their defective newborn.

Will the physician communicate an attitude that the child's quality of life is of such negligible value that even a modicum of treatment would be fruitless and a waste of his time and energy; or, will he communicate that this is a special child, uniquely created by God as he or she is, and for that reason is worthy of treatment and the parents' time and energy in caring for and helping the child to achieve its maximum potential? As Dr. C. Everett Koop has said, "It is impossible for the physician not to influence the family by innuendo alone; how much more if he counsels: "If this were my child . . ."

Both parents and physicians may have questions in their minds as to why a loving and merciful God would allow a newborn baby to be born with congenital anomalies. When such questions arise, with their associated feelings, remember the Word of the Lord in Isaiah 55:8-9, " `For my thoughts are not your thoughts, neither are your ways my ways,' declares the Lord. `As the heavens are higher than the earth, so are my ways higher than your ways and my thoughts than your thoughts.' " God tells us that His ways are inscrutable and unsearchable. That being so, we may not assume the posture of the clay addressing the potter, "Why have you made me this way?" (Rom. 9:20, Is. 29:16, 45:9) No parent and no physician may be so arrogant and presumptuous as to ask the God of heaven and earth such a question as that.

However, that does not preclude discerning His purpose. While we must be careful not to question God and His wisdom, we can address the difficult matter of defective newborns from the standpoint of purpose. What could God accomplish through such an act of seeming unkindness or cruelty? What might His purposes be in allowing a defective child to be born whose physical, emotional, and spiritual needs are going to consume the energy and resources of many people in both his family and community?

It is the purpose of this article to explore some purposes of God in allowing newborn children to be

born with congenital anomalies. Lest the presumptuousness and arrogance that physicians and parents are warned against in this article be engaged in by the author, let it be clearly understood that what follows is only by way of suggestion. It will be helpful to let these suggestions be viewed from the perspective that all human beings are abnormal.

ALL HUMAN BEINGS ARE ABNORMAL

If we look at all mankind in the light of God's Word, Paul tells us in Romans 3:23 that "all have sinned and fall short of the glory of God." In other words, all human beings are abnormal - spiritually abnormal. The fact that most human beings have enough outward physical characteristics and features to constitute them as being in a very large class of people known as "normal" does not in any way diminish the fact of their spiritual abnormality. In reality, our outward normality only conceals a grotesque spiritual abnormality that is all too visible to our holy, omnipresent, omniscient God. In fact, close examination of physically "normal" people can almost always turn up a physical abnormality. It is estimated, moreover, that the average "normal" person carries several genes for severe disorders, which would be expressed if that person conceived a child by someone else who also carried the same deleterious gene.

Therefore we may say that physical abnormalities are only relative to the larger and universal abnormality of human sinfulness. To understand the presence of physical anomalies, we must go back to the fall of man as recorded in Genesis 3. Adam and Eve sinned in the garden of Eden and departed from God's standard of holiness by eating fruit forbidden to them. God had commanded our first parents to be perfect through obedience. When they disobeyed God, Adam and Eve plunged the entire human race into spiritual abnormality, of which congenital anomalies are only one result.

The biblical doctrine of the fall of man, and the consequent pronouncement of a curse upon the entire human race by God, should lead us to one inescapable conclusion with respect to congenital anomalies: we

should expect abnormal children to be born. Paul makes clear in Romans 8 that the whole creation is groaning and travailing together until Christ comes and creates the new heavens and the new earth wherein dwells righteousness and bodily perfection (Rom. 8:18-23).

When Paul says in Romans 8:22 that "the whole creation has been groaning as in the pains of childbirth right up to the present time," that includes not only earthquakes and aging, but also the birth and lives of abnormal children. The wonder, then, is not that abnormal children are born, but that so few are born relative to the total number of births in any given year, and relative to the doctrine of the fall of man and God's curse upon the human race!

Now, the reality of congenital anomalies ought not to cloud the fact that God in His grace can have definite purposes in mind when He allows an abnormal child to be born. It is these purposes that can bring hope and comfort to both the suffering child and to the medical community and the child's parents. Perhaps the psalmist expresses it best: "The Lord is righteous in all His ways and loving towards all He has made" (Ps. 145:17).

THREE PURPOSES POSSIBLE FOR DEFECTIVE NEWBORNS

I would like to suggest three purposes that the Lord might have in mind when He allows the birth of a defective newborn.

a) A defective newborn is a unique medium with which to be creative not a problem to be solved.

One purpose God might have in allowing abnormal children to be born is to give to those children and their parents a unique medium with which to be creative. This means that abnormal children should be looked upon not as problems to be solved but as unique media out of which both the children and their parents have a responsibility to be creative; just as people who are ugly, shy, paraplegic, poor, or locked in a concentration camp in Soviet Russia have a unique medium with

which to be creative within their limitations.

The first recorded activity of God in the Scriptures is that of creating. Because man is made in the image of the creator God, man naturally desires to create. However, there is a difference between God creating and man creating. God created the heavens and the earth out of nothing. Man must create out of what exists, which includes not only the earth's natural resources but also his circumstances, opportunities, and responsibilities. This include ugly countenance, imprisonment for one's faith, shyness, poverty, childlessness, and defective newborns.

Think about this further by looking at two passages in Genesis I and 3. In Genesis 1:27-31 we see a passage of Scripture that is called the cultural mandate, or the dominion charter. It is a mandate from God commanding man to be creative, to take what exists and to work with what is. Genesis 3:14-19 records the curse of man after he sinned against God in the garden of Eden. Nowhere in Genesis 3, nor anywhere else in the Word of God, does the fall and subsequent curse of man cancel out the dominion charter of Genesis 1:27-31. What the curse of man does is to change the nature of both the man and the materia

l out of which he is to create, or with which he is to be creative. Now man has a sinful nature in need of redemption, and the earth is now corrupt and subject to futility. Now man has to create with thistles and thorns to impede him, and sweat to make him uncomfortable, and drudgery to make him tired and break his back, and abnormal children to break his heart. Yet still man is to be creative with what is - including abnormal children.

A defective newborn is not the material with which most people would choose for themselves but because there are defective newborns, they are a unique medium with which both physicians and parents can be creative, especially if the child is viewed in this light. Many people have outdated and frightening ideas about defective newborns. "They need to know the truth about their child's capabilities and how much influence they can have in their child's life. They need to know

where they can go to get comprehensive and sensitive care for their child. They should be told about Public Law 94-142 (1975), which states that all handicapped children have a right to special services and resources, in a reasonable amount of time, and in an unrestricted environment that will promote the maximum development of the child. ¹¹⁶ Parents need to be told about the abundance of community support groups that affirm the rights, dignity, and worth of the child, such as Easter Seal Society, United Cerebral Palsy, and local chapters of Parents of Down Syndrome.

Now what this highly unique medium does is to teach the principle that human worth is not predicated on physical or mental wholeness.

b) Every defective newborn can teach the principle that human worth is not predicated on physical or mental wholeness.

Human worth is often predicated on physical or mental wholeness. This should not be the case at all, but it is. And because it is, a defective child can teach the principle, so desperately needed to be learned, that human worth ought not to be predicated on physical and/or mental wholeness.

The birth of a defective child is a concentrated learning experience for many people affected by that birth: physicians, nurses, family, neighbors, and friends of the family. An abnormal child teaches the people involved with him to stretch their love beyond the dimension of wholeness so that it begins to cover fragmentation, incompleteness, ugliness, deformity, permanent helplessness, and so on.

Every abnormal child is an added dimension to its physician, parents and their friends and loved ones. Abnormal children teach us that all people are precious and as deserving of love as any other human being. An abnormal child is a seed sower, sowing seeds of love, tolerance, and understanding in the lives of those closest to him. He is one who keeps nurturing those qualities day after day.

c) God allows defective newborns to be born in

order that "the work of God might be displayed in (that child)" John 9:1-3

Jesus healed a man who was born blind in order that "the word of God might be displayed in his life." In the case of this man, the work of God being displayed was the power of Christ to restore sight so that men might see His power and believe in Christ for salvation. In the case of defective newborns, the work of God being displayed is a fresh affirmation of the sanctity of human life and the continued expression of that affirmation by loving, helping and enabling that child to develop his or her God-given potential, however low or high that might be (and in many instances it is, comparatively speaking, abysmally low).

But, comparative levels - abysmal, immeasurable, and qualitatively low or high - are not the point at all. The point is that the work of God is being displayed in defective newborn care. It is not so much that these children must be made whole, although every reasonable effort to make them whole should be expended; but rather, the point is the development of each defective child's fullest potential through love, care, attention, and even sacrifice. And by such means the sanctity of human life is reaffirmed, upheld maintained.

Just as the man born blind was allowed to be born that way so God's specific purposes for salvation might be accomplished when Jesus restored his sight, so does God allow defective newborns to come into world: to press us to adjust to the reality of the fallen world in which we and to uphold the sanctity of human life that each person, and especially those trained and licensed in the healing arts, ought to uphold and protect at all cost.

God is perfect and does all things well, including allowing defective newborns to come into the world. While that may be hard to accept, it is nevertheless true. Still, there are cases so tragic, so traumatic, so devastating in their anomalousness that the above considerations bring no comfort, or even offend. Perhaps such instances fall under this rubric: there are times in life, and especially in medical practice, when we have to be content with the words of Deuteronomy

29:29, "The secret things belong to the Lord our God, but the things revealed belong to us and to our children forever that we may follow all the words of this law." God has revealed in Word a great deal about what should do - far more than enough to consume our energy and mental capacity. The secret things we will leave to Him when His purposes are not clear.

References

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