

# THE BRINK: THE PARENT-CHILD BOND IN THE GENETIC REVOLUTION

JOHN FLETCHER

*Interfaith Metropolitan Theological Education, Inc., Wash., D.C.*

NEW DISCOVERIES in human biology have already begun to affect the way parents, with their physicians and genetic counsellors, make decisions about parenthood and childbearing. While a storm of debate swirls about the morality of futuristic proposals<sup>1</sup> for making "better" babies—in the genetic sense—some members of the first generation of parents in history are already crossing a borderline of decision-making, venturing out to use the knowledge obtainable from prenatal diagnosis of genetic disease in their unborn children. I refer specifically to the parents who enter genetic clinics and receive the technique of amniocentesis, which will be described fully below.<sup>2</sup> The first stage of genetic medicine is already being institutionalized, insofar as amniocentesis for diagnostic purposes is no longer considered as "experimental," and a number of genetic clinics with supporting counselling units have been in operation for several years. James Sorenson has recently published the first results of his exploratory studies of the sociological factors which influence parents and genetic counsellors.<sup>3</sup> The point I want to make in this introduction is that whereas genetic counselling has been primarily a verbal transaction based upon the analysis of pedigrees and the risks following the birth of genetically handicapped children, parents have begun to enlist in significant numbers as patients under the care of physicians who use more precise methods for detecting disease or abnormalities in the unborn fetus. The first installment of genetic medicine is upon us. Very grave ethical

<sup>1</sup> By futuristic proposals I refer to the issues involved in cloning and *in vitro* fertilization of an ovum for eugenic purposes. The issues in the debate emerge clearly by comparing four authors: Leon Kass, "The New Biology: What Price Relieving Man's Estate?" *Science* 174 (1971) 779-88; *id.*, "Making Babies—The New Biology and the 'Old' Morality," *The Public Interest*, no. 26 (1972) 18-56; *id.*, "Babies by Means of In Vitro Fertilization: Unethical Experiments on the Unborn?" *New England Journal of Medicine* 285 (1971) 1174-79; Joseph Fletcher, "Ethical Aspects of Genetic Controls," *New England Journal of Medicine* 285 (1971) 776-83; Paul Ramsey, *Fabricated Man* (New Haven: Yale Univ. Press, 1970); Karl Rahner, "Experiment: Man," *Theology Digest* 16 (Feb. 1968) 57-69.

<sup>2</sup> The best collection of informed opinion on the technique of amniocentesis is found in Maureen Harris, ed., *Early Diagnosis of Human Genetic Defects: Scientific and Ethical Considerations* (Fogarty International Center Proceedings 6; Washington, D.C.: U.S. Govt. Printing Office, 1972).

<sup>3</sup> James R. Sorenson, *Social Aspects of Applied Human Genetics* (Social Science Frontiers Series; Russell Sage Foundation, 1971).

questions, made sharper by the availability of reliable knowledge, press in upon these parents and their advisers in ways for which the traditions of parenthood and the morality surrounding it are not totally prepared.

The purpose of this article is an analysis of the ethical issues involved in the relations of parents to their children, born and unborn, when parents are involved in prenatal diagnosis and genetic counselling. I will use as my primary data interviews with twenty-five couples who received this test in a genetic counselling center in Washington, D.C.<sup>4</sup>

The argument which I advance through the article, on the basis of my experience with these couples and in the light of my own moral analysis, is that when prenatal diagnosis reveals a severe and untreatable genetic abnormality, some parents may responsibly (though not necessarily) elect to abort the fetus with the view either to attempt once more to bear a less handicapped child or to cease childbearing altogether. A hypothesis is advanced which needs much more testing, namely, that the experience of parents in prenatal diagnosis and genetic counselling does not lessen the affection they bear for their children, already born or to be born, even though that relationship is permanently altered by the character of the experience of genetic counselling and amniocentesis. The effects of amniocentesis and genetic counselling on public social policy should be held, in the eyes of legislators, physicians, and parents, as an interim and temporary measure, affording them some space in the long-range task of discovering treatment to genetic disease *in utero*. This view, in my opinion, is fundamentally compatible with the central values guiding the way the relation between family life and the progress of biomedical science should be regulated. At the same time, great care should be taken in the counselling of parents and in the public support of biomedical science to assure that treatment, not abortion, of genetically handicapped children is our ultimate goal.

#### PARENTS IN GENETIC COUNSELLING

My primary interest in research is the dependency relationship in all of its forms, especially where the dependent person relates to an "expert" who controls highly significant or risk-laden knowledge, technique, or processes. On the basis of an investigation into the morality of informed consent in human experimentation,<sup>5</sup> and due to

<sup>4</sup> My thanks go to the Fogarty International Center, NIH, for funding the study, and to Cecil Jacobson, M.D., and the George Washington University Medical School for allowing me to work in the genetics-counselling unit.

<sup>5</sup> John Fletcher, "Human Experimentation: Ethics in the Consent Situation," *Law and Contemporary Problems* 32 (1967) 620-49.

the great interest generated by the application of amniocentesis to prenatal genetic diagnosis, it seemed mandatory to initiate an action-research project to investigate the moral problems actually experienced by parents who seek genetic counselling supported by amniocentesis.

Withdrawal of amniotic fluid from a pregnant woman, for therapeutic purposes, has been practiced in medicine for over a century.<sup>6</sup> The use of amniotic fluid for diagnostic purposes relating to Rh-factor was first done by Bevis in 1952.<sup>7</sup> Fuchs was the first physician to withdraw amniotic fluid for purposes of examination of sex chromatin in the nuclei of cells in the fluid.<sup>8</sup> In cases of sex-linked genetic disease, Fuchs and his colleagues were able to identify fetuses at risk and inform the parents. Since 1965, much progress has been made in improving the technique of karyotyping the cells of the fetus which float in amniotic fluid, for the purpose of diagnosis of genetic disease. The cells can be cultured and pictures taken of the arrangement of chromosomes for the inspection of physicians and genetic counsellors. The pregnancies for which amniocentesis is applicable are (1) patients who are definite carriers of a chromosomal translocation which results in repetition of multiple chromosomal anomalies, e.g., Down's Syndrome, (2) carriers of a Mendelian gene for which a reliable heterozygote test is available, (3) patients who have had significant exposure to radiation or virus infections, (4) patients with a poor reproductive history of recurrent fetal anomalies and early abortion.<sup>9</sup> Thus, parents who have had one child with Down's Syndrome, Tay-Sachs disease, or Lesch-Nyhan Syndrome, plus many other genetic diseases, upon becoming pregnant the second or third time, enter genetic counselling and receive amniocentesis. Between the fourteenth and eighteenth week of pregnancy, when a fetal heartbeat is detected, amniotic fluid is extracted by needle-puncture, analyzed, and diagnosed. Parents who, through tests, are determined to be carriers of such genetic diseases can also receive amniocentesis during their first pregnancy.

A study was designed to develop hypotheses about the structure of moral problems of parents in one genetics counselling unit. I interviewed a series of twenty-five couples and the counsellor at crucial points in the counselling process: (1) after their meeting with the counsellor, (2) with the counsellor after the initial counselling session,

<sup>6</sup> Fritz Fuchs, "Amniocentesis: Techniques and Complications," in Harris, *op. cit.*, p. 11.

<sup>7</sup> D. C. A. Bevis, *Lancet* 1 (1952) 395.

<sup>8</sup> P. Riis and F. Fuchs, *Lancet* 2 (1960) 180.

<sup>9</sup> Cecil Jacobson and Robert H. Barter, "Intrauterine Diagnosis and Management of Genetic Defects," *American Journal of Obstetrics and Gynecology* 99 (1967) 797.

(3) with the couple after the report on the results of amniocentesis, (4) with the couple following birth or abortion. In addition to these interviews in the immediate process, a follow-up interview was conducted six months to one year after birth or abortion in order to identify their central perceptions and feelings as parents. The results of these latter interviews are most pertinent to the substance of this article, although the previous interviews form an introduction to a discussion of the morality of prenatal diagnosis and its relation to the ethics of parenthood.

For the purposes of this study, a "moral problem" was defined within the framework of two types of human conflicts. The first is when a person or group is perceived by others to be in fundamental violation of responsibilities to the welfare of a significant human community. The important feature of this situation is that the moral problem is defined in collective terms. The collective poses the question of basic loyalty to the decision-maker. "Are you with us or against us on this matter?"<sup>10</sup> A Catholic mother who decided on abortion of a genetically defective fetus would be judged by the norms of a significant segment of the Catholic community, whether she felt guilty or not.

The second situation finds a person confronting sharply conflicting responsibilities, divided within himself, and making a decision which expresses the conflict. This situation has been described as the "conflict of rule situation."<sup>11</sup> For example, some genetic counsellors allow couples to believe that each contributes to a particular genetic disease, when in fact one is the carrier. Robert Murray reported a case involving his response to possible nonpaternity in a couple seeking genetic counselling for sickle-cell anemia. He commented that "it was explained to them that an egg from the mother containing a sickle cell gene was fertilized by a sperm in which a fresh mutation also producing a sickle cell gene had occurred. It was *not* pointed out that mutations are extremely rare."<sup>12</sup> Caught between a concern for the marriage and a concern to give accurate information, the counsellor may be untruthful and hence suffer some remorse. The most intense moral suffering may occur when these two situations firmly coalesce into one. Most "everyday" moral problems are situations which have elements of demands of collectively defined loyalty and the individuals who are objects of these demands confronting decisions which express conflicts of loyalty. This definition of a moral problem guided our study of

<sup>10</sup> Talcott Parsons, *The Social System* (New York: Free Press, 1951) p. 97.

<sup>11</sup> Frederick S. Carney, "Deciding in the Situation: What is Required?" *Norm and Context in Christian Ethics*, ed. Outka and Ramsey (New York: Scribner, 1968) p. 13.

<sup>12</sup> Robert F. Murray, Jr., "Problems behind the Promise: Ethical Issues in Mass Genetic Screening," *Hastings Center Report* 2 (April 1972) 12.

parents in genetic counselling. What the patient, couple, or counsellor said about the experience of violating standing in a significant community or an inner conflict of loyalties was the datum to be studied in collecting data for the moral problems of these parents in genetic counselling. A full discussion of the significance of these problems for the ethics of human parenthood will follow my report.

The results of our study with this small sample of parents showed three major periods or phases of decision-making within which "clusters" of problems collected: (1) motivation to seek genetic counselling and a decision about amniocentesis, (2) decision following amniocentesis and learning the results of the diagnosis, (3) postabortion, sterilization, or postbirth decisions. The following diagram (Figure I) outlines these phases. On the first line are listed the major events prior to, in, and after the genetic-counselling relationship. On the second line are listed the major moral problems experienced by parents and the genetic counsellor within the time frame of the events on the first line.

*Phase 1: Decision about Amniocentesis*

The twenty-five couples' experience confirms many research findings about genetic counselling. At certain important points, however, their experience was divergent. All of the couples interviewed were expecting a new baby. All but one of the couples were from the middle class or above, and the majority had graduated from a four-year college. Twenty-four couples were white (Sorenson, 1971).

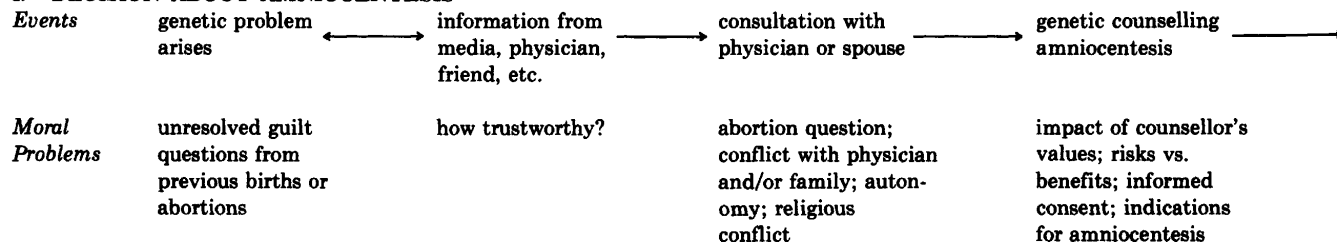
The religious affiliation of the couples broke down as follows:

Protestant (both)	11
Jewish (both)	4
Catholic (both)	2
Mixed religious marriages	5
No religious affiliation	3
	<hr/> 25

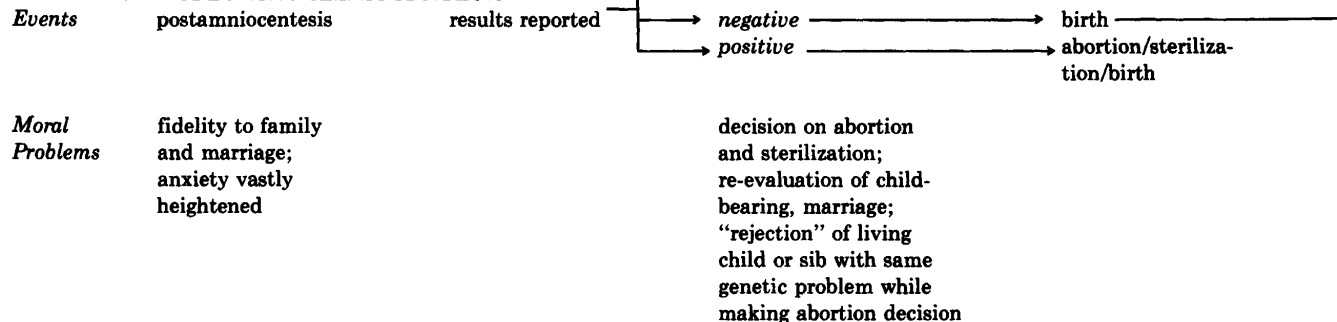
Thirteen couples came to the unit due to a previously defective child and were now pregnant again. Ten couples were motivated by the "age factor" and its relation to occurrence of Down's Syndrome. These latter couples discovered the risk ratio largely through reading or the media. One couple sought counselling due to a sibling or twin who had a defective child; one requested counselling because her three brothers had a genetic disease, muscular dystrophy. Recent research done at Princeton on motivation for genetic counselling showed that 80 percent of all cases are parents with a defective child.<sup>13</sup>

<sup>13</sup> James R. Sorenson, "Decision Making in Applied Human Genetics: Individual and Societal Perspectives" (Bethesda: Fogarty Center for Advanced Study in the Health Sciences, in press).

I. DECISION ABOUT AMNIOCENTESIS



II. DECISION FOLLOWING AMNIOCENTESIS



III. POST ABORTION STERILIZATION BIRTH

*Moral Problems* justification of decision; cosmic doubts; self-rejection; decision about future birth; fidelity to marriage

Figure 1

More than half of the couples (14) were self-referred to the center. Within this group four couples were "repeaters," having had amniocentesis previously in this center. Three of the four repeating couples had chosen abortion following positive diagnoses of Lesch-Nyhan Syndrome, Patau Syndrome, and sex factor related to muscular dystrophy. Twenty-two fetuses were negatively diagnosed and twenty-two normal babies have now been delivered. Eleven couples had been referred by either a gynecologist or through a program for parents of retarded children.

### *Unresolved Guilt*

Parents with one defective child were quick to express their reasons for seeking counselling and amniocentesis when asked. Since the defect had been, for the most part, a shock to them, many acknowledged that though they had learned to live with it, the effect had not worn off. There is often an unusual sense of shame and guilt associated with genetic disease which I came to call a "cosmic guilt." Other investigators have documented this particular form of guilt or sorrow.<sup>14</sup> Having no previous choice over being parents of a defective child, several parents voiced their gratitude at finally being able to do something about the new pregnancy. The sense of being isolated from the community of the "normal," evident in illness generally, is much more in evidence in these particular parents. "I don't know why fate singled me out, but it did," said one mother. The great expense and personal difficulty in adjusting to a defective child was often mentioned. Parents bring their previous problems to the counselling situation in expectation of the relief of information and the partial freedom that it brings. The relief may stem from a sense of having conquered in part the previously arbitrary fate assigned to them as carriers.

The couples, especially the wives, who were "repeaters" with earlier abortions still bore vivid memories of their disappointment and sense of failure. Later interviews with these couples underlined their need for support and counselling at the time of therapeutic abortion and the deep depression suffered at the time. Each declared an intention to make this "the last time."

### *Conflicts with Physicians or Family Members*

In five cases, serious conflicts with obstetrician-gynecologists or with family members had preceded their entering genetic counselling. In

<sup>14</sup> Among the best studies of this problem are Pauline Cohen, "The Impact of the Handicapped on the Family," *Social Casework* 43 (1962) 137-42; Samuel Olshansky, "Chronic Sorrow: A Response to Having a Mentally Defective Child," *Social Casework* 43 (1962) 190-93; David G. Langsley, "Psychology of a Doomed Family," *American Journal of Psychotherapy* 15 (1961) 531-38.

the couples' opinion, the physicians had been motivated by either a religious objection to the option of abortion or by a poor opinion of the indication for amniocentesis. One 40-year-old mother of three reported that when she consulted her obstetrician about her intention to seek amniocentesis because of her age, he informed her that her "mental, not physical, health needs attention," and strongly advised her against this course of action. As he had delivered her three children, she felt his words deeply, and she showed considerable ambivalence in counseling. A 26-year-old Catholic mother, carrier of Lesch-Nyhan Syndrome, with one affected child, said that the physician she first consulted "as much as called me a murderer when I said that I wanted a test." Another couple reported opposition from their physician because he thought this an "expensive, unnecessary gimmick which some people are using to build up their reputation."

In twenty-five interviews I detected no substantial disagreement between spouses as to the justifications for seeking help in prenatal diagnosis. Two women told of arguing with family members who strongly disapproved of their actions. One told of her mother-in-law, who herself had given birth to a defective child and kept him at home, attempting to shame her for "taking the easy way out." To the casual observer such conflicts may seem easily dismissed as projection and "sour grapes"; to those who are on the receiving end of them, however, they assume serious proportions. Such is especially true of conflict with physicians.

### *Prior Consent to Abortion*

When asked, each of the twenty-five couples answered that they were agreeable to abortion, if indicated by diagnosis, as a morally acceptable means of managing a genetic problem. Judging by content analysis of tapes and notes, the abortion question was the *prevailing moral problem* faced by these parents during the process. More time, energy, and reasoning were expended on explaining their positions on this issue than on their reasons for seeking counselling. Why is this so? My hypothesis is that (a) the structure of the situation calls for a readiness to be committed to abortion as the means of managing a positive diagnosis; (b) being parents strongly motivated to have children and to go to extraordinary lengths to exercise responsible parenthood, these parents are "sensitized" to the abortion question in considerably more depth than other parents. Therefore, wanting another child (sometimes desperately) and being explicitly committed to abortion constitutes a tension of severely conflicting loyalties and is perceived as a moral problem. Some parents showed signs of what I came to call "moral suffering" of the highest order as they struggled with their



conflicts, duties, and changing perception of parenthood. I shall define moral suffering more precisely and discuss it fully in the second major section of this paper.

In this genetics-counselling center the policy was *not* to elicit a firm commitment of the couple to abortion as a prior condition for undergoing amniocentesis. Here we note a difference from what has been reported as the prevailing practice by counsellors and physicians.<sup>15</sup> Such an opinion was emphatically offered by Littlefield when he stated: "Of course amniocentesis should not be undertaken unless the family is committed to subsequent intervention if appropriate."<sup>16</sup> Fuchs, a pioneer in the field, takes the precommitment position because of the risk factor in amniocentesis:

It is virtually impossible to give a reliable estimate of the risks to fetus and mother. The risk of abortion due to infection or trauma may be of the order of one to two percent. It is certainly large enough to contra-indicate amniocentesis in cases where the risk of a particular genetic disorder is less than two percent. In addition, it is certainly large enough to contra-indicate the procedure if the patient and her physician are not prepared to interrupt the pregnancy if a positive diagnosis of a particular disease is made. While it is the experience of several investigators that a patient may change her mind between the amniocentesis and the completion of the fluid analysis, it is imperative that the problems and the risks be thoroughly discussed before the amniocentesis and that a firm decision is made to interrupt the pregnancy if the suspected disorder is proven by the amniotic fluid examination.<sup>17</sup>

As the counselling relationship unfolded, the couples' opinion on the acceptability of abortion was usually revealed, but the counsellor was careful to point out that only the facts were relevant to the decision and deciding on subsequent action should be postponed until after the final report.

The guiding motives for abortion in these parents were largely between the "on demand" and "never" extremes. They explained their own views most often in terms of sufficient reasons for abortion: serious genetic defects, among other reasons (rape, incest, injury to mother), justified abortion. There were many echoes of the theme struck by one mother: "I am nervous about abortion solely for psychiatric or economic reasons, but if my child is seriously affected, I would agree to it."

The parents were almost universally serious about the moral responsibility in being willing to opt for abortion. A father put it: "We

<sup>15</sup> Charles J. Epstein, "Medical Genetics: Recent Advances with Legal Implications," *Hastings Law Journal* 21 (1969) 35-49.

<sup>16</sup> John W. Littlefield, "The Pregnancy at Risk for a Genetic Disorder," *New England Journal of Medicine* 282 (1970) 627-28.

<sup>17</sup> Fuchs, *op. cit.*, p. 14.

have discussed it at length . . . we only want an abortion if we have to for medical reasons . . . it is not an easy decision to make, since you are talking about a life. It is a moral issue." Only one couple approved "abortion on demand." Only one couple gave evidence of coming to genetic counselling on the pretext of having genetic problems but wishing for an abortion of an unwanted child. This couple was not accepted for amniocentesis.

The "moderate" position on abortion held by the great majority of these parents probably stems from their *parental* values as modified by the success of the technique of amniocentesis. They deeply desire children, but they are willing to allow an intervention to test for genetic defects and to act on the consequences. As a mother said, "These days you have a choice about having a healthy baby." While this statement is not exactly true, it reveals a willingness to employ the *technical* utility of prenatal diagnosis while holding firmly to a yearning for children. As the first generation of parents who have had an informed choice about abortion for genetic reasons, as indicated by amniocentesis, they did not consciously suppress affection for the fetus or deny that there was a human life at stake. "When the baby is inside you, you start loving it," said a mother carrying Lesch-Nyhan Syndrome. "When you feel movement, you feel ashamed about contemplating abortion," said another mother. These statements indicate a deep moral problem perceived while in the process of amniocentesis. Follow-up interviews after birth showed even deeper reflections on this problem later. These will be reported in a separate section. Caught between a loyalty to the life of their child and a loyalty to the norm of "healthy" life (as expressed in children with no severe or handicapping genetic defects), there was considerable suffering expressed. It is my hypothesis that the forces assisting these parents in justifying their decision to accept abortions were (1) experience with genetically defective children which led them to believe that the child's life would be unfulfilled, and (2) belief in the values of health and intelligence which their life-style requires for a sense of adequacy and success. Given the choice of accepting a genetically defective child or resorting to abortion, and being informed by their own largely middle-class values, they would choose the latter, even though they suffered from the thought of being responsible for ending the life of their child. Our culture and its preferences tend to reinforce each belief of these parents.

### *Reasons for Seeking Genetic Counselling*

In seeking to identify the deeper reasons, a pattern of justification, for the need for genetic counselling, the parents most often offered an

argument based on their understanding of parental responsibility to provide for the health of their children and the security of their families. The same mother who spoke of her resistance to abortion for strictly economic or psychiatric reasons said: "It is not fair to it [the child], to the family, to society, or to me to bring another child like the one I have into the world." The concept of "fairness" was often used for justification. Parents with one defective child reasoned from their experiences of psychic and economic loss most often to reflect on their responsibility. The important note in their reasoning was that they included genetic concern as part of parental responsibility. None of these parents could be described as proactive eugenicists, and only a tiny fraction reasoned solely on the basis of individual convenience. In extended conversation about the underlying justification for genetic counselling, it became readily apparent that population problems, genetic responsibility, and parental values were interwoven in the social ethics of the majority of couples. For example, a Catholic father said: "We have an obligation to our children before they are born; you can't turn your back on the future." Another father said: "I couldn't go through it again . . . it is not doing anything for the child or for society just to be born so sickly . . . it will not make society better for it to happen again."

Several parents, but not a majority, mentioned the concept of a "right to good mental life." In a discussion with one father about this concept, he said that "everyone has a right to live, but each should have a right to a good life, mentally." When I pressed him to try to take the concept to some logical conclusions as applied to society or individual cases, he admitted that he would not want to have rigid standards about "intelligence" or "mental ability" used in screening who would be born. Given the choice, however, between having a child as retarded as his own and abortion, he would choose the latter. He realized that if the majority of people reasoned in a similar manner about all children, a "tyranny of the majority" could develop, aided by an exclusive value on "intelligence" and having little tolerance for weakness or sickness. He made a distinction between those whose mental potential had been drastically destroyed by genetic disease and those who did not have this particular problem, saying that abortion ought only be available on proof of the former. "Medical reasons for genetic betterment are safer than social reasons," he declared.

Parents who sought genetic counselling because of the "age factor" cited social and economic reasons for their inquiry, just as did parents who had defective children. "I have two children and did not intend to get pregnant again," said a 42-year-old mother, "and I must do

everything possible to see that my child is healthy. The world has enough problems, I don't want to add to them."

### *Autonomy*

Throughout the counselling process, in all three of its phases, these couples showed a consistent reliance on their own authority in decision-making. Only two couples had consulted a nonmedical person for advice, and these advisers were personal friends, not a clergyman, counsellor, or lawyer. Even though the majority perceived moral conflicts in the process of making up their minds, there was no sufficient cause for official moral "counsel," since they considered their own parental roles the primary source of moral authority for childbearing and family matters. As the previous section illustrated, however, couples freely talked of what "society" had a right to expect, but they did not see society's claims as overriding their own autonomy as parents. They sought medical advice freely, often consulting other physicians. Parents saw no need to consult an authority or helper outside of the medical world for the problems they faced with amniocentesis. Yet there were signs of need for counsel in the moral dimension of their decisions.

At this point I would hypothesize that the time and energy given by the vast majority of the parents to interviews and telephone discussions indicates a need for ventilating their concerns and receiving informed "moral counsel." Parents were extremely diligent in keeping appointments and giving time to the interviews. Several indicated that they enjoyed our discussions, and four relationships of "moral counselling" developed in which the interviewer, on the suggestion of the genetic counsellor, invited couples to discuss their most difficult decisions with him. These discussions suggested to me that alongside an attitude of moral autonomy in these parents may lie a need to establish a sense of moral direction with the larger community. They are not "individualists" and as such found fulfilment in reflecting on their social commitments. I felt that it was striking that the two couples who consulted friends were Catholic, and that the two friends were cited as being very "religious" and knowledgeable about religious matters. Both Catholic couples also asked the genetic counsellor about religious conflicts with their possible course of action. One would normally expect the greatest religious and moral conflict regarding abortion in Catholic couples, or where one spouse is Catholic. In a unique study of parents of retarded children, Zuk found Catholic mothers greatly more accepting of their retarded children than non-Catholic mothers.<sup>18</sup> One

<sup>18</sup> G. H. Zuk, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," *American Journal of Mental Deficiency* 64 (1959) 139-47.

Catholic father in a mixed marriage said: "All of my childhood training has suddenly come back to haunt me." He felt that he had achieved a high degree of autonomy in the development of his conscience—until this decision.

### *Phase 2: Decision Following Amniocentesis*

The period following amniocentesis to the report on the results of the tap found the parents in considerable anxiety, and whatever problems existed in their marriage or family relationships were exacerbated. The average time between test and reporting in 25 cases was 20.9 days. The physician told each couple that normally the time lapse was three weeks. Telephone calls to the physician by parents were numerous, and his staff often counselled a spouse over the telephone to tell them of the status of their case.

On looking back at process with the couples, they described "toughest" time as the anxiety in waiting for a report on amniocentesis. "We shouted at each other and fought like tigers," said one husband. Another husband who sought marriage counselling in this period stated that the long wait had made him angrier at his wife for being a carrier, and that he wanted out of the relationship more than ever. Several couples testified to the fact that only their strong marriage relationship sustained them and that without it they would be without support and comfort. "I don't know what I would do without his being with me, since I get so depressed," said a mother carrying Down's Syndrome.

If a marriage is troubled, the strains will most likely break forth in this period, testing to the limits the capacity of the couple to face their problem and make plans. I saw this trouble more often in younger couples than in the older parents. One husband in particular acted out his feeling trapped in a marriage to a carrier partner by making homosexual liaisons. After intensive counselling and some psychotherapy more realistic assessments were made by the parents.

### *Decisions Following Positive Diagnosis*

The most acute personal suffering followed a positive diagnosis. In each of three cases the couples decided for abortion and sterilization by hysterotomy. A great deal of grief and self-condemnation followed these procedures. Following the report it was as if the whole decision had to be made anew. One might expect that significant preparation had been made which would lessen the burden. Possibly because the couple had so hoped for a normal child, a set of expectations heavily weighted in that direction formed and were shattered.

The reasons offered for the step to be taken were uniformly personal and related to the emotional strain the parents had been under. "I just

can't go through this again," said a mother. "If they can't tell me that my child is not normal, I don't want to try again. I have three brothers with muscular dystrophy, and I am not going to take a chance on it." "No one who knows me would say that I don't want children, but I have had enough," said the third mother. The counsellor, sensitive to the profound disappointment of the parents, advised caution in their decision, especially towards sterilization, but none preferred to remain able to bear children.

The three mothers who elected sterilization, and the fathers as well, suffered deeply from guilt and a sense of failure. Added to the guilt associated with being a carrier of genetic disease was their realization that their experiment to get a healthy child had failed, and there would be no more children of their own. I was particularly interested in the plight of the women. One of them stated:

I am just crushed and disappointed. I had so hoped to give my husband a healthy baby, and now I know that I will not. You spend all your life looking at pictures of pretty babies and their mothers and growing up thinking that will be you. It is pretty gruesome when you are the one who is different.

When asked about vasectomy as one option open to them, each mother rejected it vehemently. "It is my fault, why should he have to pay for it?" said one. "He may want to marry again, if anything happens to me, and he should be able to have his own children," said another.

Two mothers electing hysterotomy had living children or family members suffering from genetic disease. They were acutely aware that aborting a fetus affected by the same problem amounted to a type of "rejection" of the relative. One mother talked of her child:

He knows what's going on. I wonder what he thinks about the baby. He could think . . . they want to put me out of the way, too. And he could think, no one should have to suffer the way I do. I suppose it would be more the second.

Neither mother felt strongly enough about the meaning of abortion to a living person suffering the same disease to choose against it. Several parents with living children remarked that one of the forces driving them against amniocentesis itself was the effect an abortion might have on the security of a child at home with the same problem. One mother gave voice to her sense that an already affected child felt threatened by her visit to the center when she found him hiding in the closet upon returning. Follow-up interviews found parents still concerned about the implied threat to an existing child and finding ways to explain to the new healthier child how it could happen that they once contemplated his destruction if a diagnosis compelled them.

*Phase 3: Reflection after Action*

An interview was held with parents following childbirth or the termination of pregnancy. No parent regretted using amniocentesis. Parents who could look forward to having a "normal" child said they were greatly eased by the knowledge and that the latter part of pregnancy was easy.

Parents who elected abortion and sterilization were still troubled, but they were also taking other steps to help themselves. Two couples made plans for adoption and a third decided to move to a farm.

Parents electing abortion and sterilization took particular pains to justify their decision and to put the decision into a framework which made sense to them. A Catholic couple alone attempted to place the event in a religious framework, but one which no longer satisfied them morally or intellectually. "Why does God give so many terrible things to children?" queried the mother. She then told of several years of religious doubts due to the birth of a previous child and her rejection by a priest when she earlier sought amniocentesis. "I have a very hard time believing in God any more. I have prayed to God this time for his protection and for a normal baby, and you see nothing has happened." As she talked she cried openly. Feeling that she was reaching for a form of faith which would help interpret suffering without condoning magic, I offered her help in examining the religious views she had been holding. First, she made no distinction between nature and God. "God" was the source of good and bad genes. Secondly, she lived in a universe with a very small margin of moral freedom, if any at all. God determined everything, including one's choices. Thirdly, her anger and cosmic resentment were clearly unacceptable in the eyes of such a God. I reasoned that God was at least as gracious to us as we are to our own children. "Would you always keep your child penned up in the backyard, even when he was older?" I asked. She got the point quickly and began to talk more about her unsatisfactory religious beliefs and fear of the church.

*Following Abortion*

Each mother revealed an element of "cosmic doubt," even though the Catholic mother alone cast her doubt in a strictly religious perspective. "You try to understand how things like this happen," said a Jewish mother, "and there is a scientific explanation... but... I feel like the fickle finger of fate pointed at me."

"I lie awake nights damning God, even though I don't believe in a God," a third mother with no particular religious persuasions stated. The experience of genetic disease and ending a pregnancy may lead

people to the "borderline" question about the meaning of human existence. These questions are of their nature religious questions, since people attempt to come to terms with their fate and a profound sense of isolation from the roles of parenthood. Even if religion is not used as a last line of defense against the arbitrariness of life, parents probably will seek to make some ultimate sense out of these events, and seek some ultimate security in their insecurity.

Following the birth of children, couples who had undergone genetic counselling re-examined their role as parents thoroughly. It was as if the process made them ever more serious about childbearing and parental responsibility. Parents who knew that their children were carriers of a defective gene resolved to instruct them about their problem and to do everything possible to assist them in controlling their marital future. No parent even considered seriously the eugenic possibility of aborting a child who was a carrier. Amniocentesis or another technique would be open to them in the future. .

### *Additional Reflections*

Discussions with parents at the conclusion of the process provided a good format for inquiry into their attitudes about sex determination and genetic surgery. Only one of the twenty-five couples preferred not to learn the sex of their child. Those who preferred to know gave pragmatic reasons for wanting to know. "It takes some of the mystery out of it, but it helps to prepare us," said a father. Only the parents with sex-linked genetic diseases felt that sex determination was advisable. None of these couples felt that it was wrong to predetermine that a male or female be born if genetic disease could be avoided. Medical indication for sex predetermination was the predominant justification for this step when it becomes feasible. One mother stated: "It wouldn't be a good idea to let everyone select the sex of their children. There would be too many problems. But in our case . . . Fabry's disease . . . it would be a blessing."

In discussing concepts of genetic surgery, these parents were wary of prenatal interventions. None preferred to be the first to allow genetic surgery unless there were good reasons to hope for success. Attitudes of these parents were distinctly conservative in this regard. Yet the same parents had no doubts about the technique they were using. After the birth of a child I asked parents if the possibility of "technical failure" (false negative) had worried them prior to birth. With one exception, a dental surgeon, the answer was "It crossed my mind, but I did not seriously consider it." The exceptional person said that he was not truly at ease until the baby had been examined by a pediatrician.



Thus, the power of technology and the credibility of physicians combine to produce incredible trust in couples using amniocentesis.

None of the mothers who were in a position to discuss "surrogate parenthood" would have chosen this alternative of having a child rather than adoption. Each mother was a carrier of a deleterious gene and would (in surrogate parenthood) have to be the recipient of a donated ovum fertilized by her husband. The husbands preferred to have children either by adoption or when "it is my sperm and her egg."

#### THE ETHICS OF PARENTAL CARE AND PRENATAL DIAGNOSIS

Will the use of prenatal diagnosis by parents in increasing numbers diminish the sense of care, love, or affection parents must show to their children for the maximal psychic and ethical development of children? More precisely, does the procedure itself, because it inclines the parents to contemplate the abortion of the fetus before they are fully informed as to the results of the test, erode that "basic trust" which is so fundamental as to lead Erik Erikson to assert that "the firm establishment of enduring patterns for the balance of basic trust over basic mistrust is the first task of the budding personality and therefore first of all a task for maternal care"?<sup>19</sup> When evaluated from a Christian ethical perspective, does the use of this technique and its accompanying awareness of elective abortion subvert the deputyship of parents, who as representatives of the love of God for the child are called to represent a love which inspires the confidence that "whatever is, is good," and is no "respector of persons"?<sup>20</sup>

In preparing answers to these questions, I determined first to interview each of the couples again, more than six months to one year after the birth of a healthier child or after abortion following a positive diagnosis. Four families were not interviewed because of distance and one was unavailable. Twenty couples gladly accepted follow-up interviews.

In my interviews I developed questions around three general areas for the purpose of formulating hypotheses. The areas were: (1) the way they perceived their relationship with a "healthier" or "normal" child born after amniocentesis compared with their perceptions about their relationship with previously born children whether healthy or genetically handicapped; (2) eliciting their feelings about any possible damage to the "trust" dimension of their role as parents caused by the contempla-

<sup>19</sup> Erik Erikson, "Growth and Crises of the Healthy Personality," *Psychological Issues* 1 (1959) 63.

<sup>20</sup> Others have remarked on the affinity between Erikson's researches into "basic trust" and this description of H. R. Niebuhr's of the moral dimension of radical monotheism: *Radical Monotheism and Western Culture* (New York: Harper, 1960) p. 32.

tion of abortion; (3) gathering any further moral or ethical reflection they had done as parents at a distance from the birth of the child.

Because the results of the interviews were so uniform, and in the interest of space for further discussion, I shall furnish details of one interview and simply indicate the results of the remainder.

Mr. and Mrs. C. had a Mongoloid daughter, age 4, when Mrs. C. became pregnant the second time. They learned of amniocentesis through a program for parents of the retarded and sought help. She is Protestant, he is Catholic. Following amniocentesis and a negative diagnosis for Down's Syndrome, a son was born over a year ago.

In answer to the first set of questions, the following statements were made by Mrs. C.:

*It is really different, I think, from the experience of parents who do not know if their babies are well before they are born.*

*I know I feel different about S. [the son] than other mothers do their children. I feel this way about it . . . he is fortunate, it is like adoption, we planned and chose him, we have given him a good gift. Other mothers seem casual about expecting a child, I could never be casual again.*

*The difference between the way I feel about S. [son] and E. [daughter] is that we knew him a lot longer [italics mine].*

*I feel that there is a "miracle type attitude" around my relationship with S. We worked very hard to get him and went through a lot of terrible worry.*

Mr. and Mrs. C. acknowledged having discussed how they would explain later to their son when he was old enough to understand the circumstances of prenatal diagnosis. Both were aware of the possibility of having to answer his questions about "what if you had found that I was like E.?" Mr. C. outlined a future discussion with his son as follows:

*We did what we did because of your sister. If she had not been sick, we would not have done what we did with you. We owed it to her not to risk having another child like her, since we [the parents] couldn't have survived it. We had a hard enough time taking care of her, and if a second had come along, it would have crushed us for sure. In spite of the risk we ran in having you tested, it was worth it to know that you were really healthy.*

Mr. C. acknowledged that he had suffered considerable guilt over the thought that he might have had to decide to abort his own child, "especially since my belief is that the fetus is a life from the earliest stage." He stated that there was "no good way to explain to your own child that you might have had a part in deciding the end of his life." But neither parent felt that the total value of amniocentesis was overshadowed by the possible pain or loss to a son who would one day learn

of their decision. They did not think that this knowledge would threaten their son, rather he "will be grateful for being born healthy." They both emphasized the *known* risk involved in their having a healthy child.

In order to stimulate discussion of their later reflection on the morality of elective abortion following amniocentesis, I introduced the facts of the "Baltimore Case"<sup>21</sup> and asked them to compare the morality of what they might have decided with that case. In that case a Mongoloid was born to a couple and needed simple surgery for relief of an internal blockage. They instructed the physician not to operate and to allow the child to die. No food was administered to the child, and it took fifteen days for the child to die.

Mr. and Mrs. C. and each of the other couples interviewed felt strongly that the decision made by the Baltimore parents was "terrible," "wrong," or "immoral." Mrs. C., pointing out the difference between her husband's beliefs and her own, stated: "If a child is born, you must do everything you can to help it. That is different from our decision." When asked *how* it was different, she said:

We would have found out the problem early enough. . . . I do not believe that it would have been wrong in our circumstances to have decided for an abortion . . . especially since we already had E. . . . We had already decided to keep her, no matter what, but we just couldn't risk having another child with the same problem. The difference, though, when you look at it, is really that we could know so much earlier. We were having such a tough time with E. . . . and when we heard that there was a way to find out about the next one, it was the only thing to do. We first were under the impression that we might have twins, which would have made it that much harder. We had to find out the facts in order to save our family. I am thankful that we were able to know. The only difference between the Baltimore people and us is that we knew earlier . . . plus the fact that the doctor supported us.

In order to move into the third area of inquiry, their sense of the ethics of parenthood, I pointed out to them the difference between the arguments they were using, based upon the prediction of certain consequences to them and E. if another Mongoloid child was born, and an "idea of parenthood which accepted the consequences of the birth of children as part of your responsibility." Mrs. C. countered with the assertion:

It would not have been responsible of us not to go to the doctor . . . not to find out . . . if there was a way. . . . If you can know for sure, and the doctor

<sup>21</sup> This case was the focus of a symposium, "Choices on Our Conscience," sponsored by the Joseph P. Kennedy, Jr. Foundation, Oct. 15-17, 1971, in Washington, D.C. The case was subsequently reported in the press: Harold M. Schmeck, Jr., "Parley Discusses Life-Death Ethics," *New York Times*, Oct. 17, 1971, p. 52; Stuart Auerbach, "Doctors Ponder Ethics of Letting Mongoloid Die," *Washington Post*, Oct. 16, 1971, p. A1.

told us there was every chance we could find out...then we would have been adding to our troubles to avoid it. We couldn't pretend that we didn't know about the test. We even discussed having the child if we found out it was to be like E. But I was already decided not to do that. If you can be sure that you can have a healthy child, why shouldn't you find out? I can't tell you what a relief it was to know.

Mr. C. added:

I know what you are getting at. I feel it when I am with my own parents and the way they look at me. The fact is that medicine has discovered this test and we needed it. The only other way would have been for us not to have any more children. Given the choice between that and having one normal child...I wanted to do what we could. As it happened, we were lucky...the worst didn't happen. We love E. very much and are taking care of her ourselves. Having S. gives us everything we ever wanted.

My questions then turned to wider consequences of decisions of parents like them for society, such as the hypothesis that less concern might be shown for Mongoloid or retarded children as a result of widespread use of prenatal diagnosis and elective abortion. Neither parent agreed with this idea, and their answers were supported by most of the other couples questioned. Mrs. C. said that she felt that

more people have become aware of the problems of retarded children since amniocentesis has been used. If there are fewer children like E., the ones who are living might have more of a chance to be helped than before. They might get more care when people have more choice. People have told me that what we did might eventually lead to us trying to breed a super-race, but I don't believe that. Maybe it will even lead to a cure for what is wrong with E.

Mr. C. stated:

It is a tremendous thing which we did, when you stop to think about it. I feel good about it now, but I was really worried when it was going on. I was raised Catholic, and all my childhood teachings hit me hard. We went around here screaming at each other. Then, when we sat down and figured out the ways the test would help us and the ways it wouldn't, the first was obvious. For us, with one retarded child at home, it was the right thing. It helped us know and to plan.

I questioned Mr. C. about his concept of the morality of abortion at this stage in his thinking. Was he aware of changing his concept? He answered:

I still *feel* the same way. I was petrified at the thought of having to choose to abort my own child. I would have done it, though, for the sake of saving my

family. I am...like...of two minds on the subject...my feelings take me one way and my mind another.

Having concluded that they both felt that this decision was right for them as a family and that the consequences had borne out the fittingness of their decision, I asked about their preferences for social policy on prenatal diagnosis. Should it be required of parents who have one child with Down's Syndrome? Should regulations be passed covering high-risk groups? At this point, one of the most interesting results of the interview emerged. Mrs. C. took a "hard line" and said yes to every social proposal for screening, detection, and prenatal diagnosis. Mr. C. was adamant in the other direction, stressing that only voluntary methods could be used with families in need of genetic counselling. He stated:

I can't see how you can successfully force people to make these decisions. Having the test available and teaching about it was some pressure on me, but I chose to do it. My wife has become a "crusader" about it, but I disagree.

Analysis of the answers of Mr. and Mrs. C. reveals that they do perceive their relation to their second child to be permanently altered due to amniocentesis. It is "different," according to Mrs. C., when parents "know" the child "a lot longer." Descriptions by other couples bore out this perception. Knowing the sex of the child and being reassured of its health bring the couple into a more active relation with the child. "It takes the mystery out of it," said one father, "but it also took the terror out of it." The primary *difference*, in these parents' relation to their tested children, seemed to lie in the fact that active roles as parents began earlier in the course of pregnancy. It was as if the test and its results speeded up activities which most parents begin only after birth. "Most parents may be hoping for a boy, but not knowing," said one mother; "we started to fix up his room as soon as we knew the results of the test." Assurance of the health of the child releases parental care, planning, and symbolic activity usually reserved for birth.

Insofar as Mr. and Mrs. C. already felt enough pressure to begin to construct explanations for later use with their son as to why he was tested, I would make a tentative deduction that they do feel some sense of threat to the type of caring which had characterized the parental roles they had learned. Mr. C.'s remark that "there is no good way" to tell a child that a parent once was partially resigned to its abortion appears to me as evidence of an underlying awareness of threat. When asked, other couples acknowledged having reflected on the task of telling the child about the intervention, though none were

as articulate as Mr. C. about an already composed answer. The couples tended to rely on the assurance that the child would be so grateful for being born healthy that no real threat would be perceived. This idea underestimates, in my opinion, the power of the human mind to imagine and enlarge on reasons for rejection. Sidney Callahan, in commenting on the Baltimore case and its possible effect on existing parent-child relations, wrote: "Knowing one's parents let your little brother die because he wasn't 'normal' or was 'sick' would create deep insecurity. 'Will I be done in if I don't measure up? or if I get sick?'"<sup>22</sup> My questions to the parents revolved around their impressions of the feelings of living children where amniocentesis is being used on a fetal sib. Do they worry about their own security? Or did they think that a *tested* child would later grow morbid over the idea that its parents once had him or her tested with a predilection towards abortion? The couples did not know the answers to these questions, nor do I. They showed signs of discomfort at being asked about these possible psychic consequences: Their answers, at this time, revolved around justifications based on the known risk of their having more children and the promise of early knowledge of health in their child. They tended, like the C.'s, to imagine that their tested children would be grateful, not resentful, when they learned the facts with which the parents were faced. Much more study needs to be done of the families of the first generation of parents in amniocentesis to find harder answers to these questions. My conclusions about this small sample of parents would support a hypothesis that parents are aware of some alteration in the formation of trust in their relations to tested and untested children, due to the abortion issue; further, this alteration is seen as justified in the light of known risks about their childbearing.

The moral reasoning of the parents was distinctly along consequentialist lines informed generally by the norm of parental protection. I interviewed no parents who came at their roles from highly conscious norms or principles about parenthood and unconditioned caring. This is not to say that there is not evidence in their discussion of their having internalized such norms, as Mr. C.'s discussion shows. Parents like Mr. C. will show some signs of "moral suffering" as they attempt to come to terms with the impact of genetic counselling on their roles and perceptions of morality. I define moral suffering as the state of being threatened by normlessness, even as one is caught between two forces or principles, both of which are right. Moral suffering is not the direct effect of *anomie*, relative cultural normlessness, on the individual con-

<sup>22</sup> Sidney Callahan, "Choices on Our Conscience," Symposium on Human Rights, Retardation, and Research, *op. cit.*, Morning Plenary Session: "Who Should Survive: Is Survival a Right?" p. 20.

cerned, but rather the opposite, as when a person is caught in a dilemma between two goods. Moral suffering occurs when highly motivated parents who desire children intensely, even desperately, are caught between the rightness of protecting their families from the great strains which genetic disease may place upon them, and the rightness of unconditional caring for the life of their conceived child. In more formal terms, these parents find themselves suffering actively in the process of making society, even as that society and its products "feed back" upon them to introduce new choices into the parent-child relationship. Whether or not this moral suffering will lead to "ethical tragedy," as this term is employed by Henry D. Aiken,<sup>23</sup> depends upon whether the conflict between rights is ethically soluble. It is my position that prenatal diagnosis, taken in the context of the therapeutic goals of genetic medicine and its relation to the circumstances of particular families, does not introduce a permanently insoluble moral conflict in the ethics of parental caring. The remainder of this essay is devoted to this argument.

### *Amniocentesis and the Morality of Abortion*

The most compelling reasons for elective abortion following prenatal diagnosis combine the certain severity of a genetic indication with evidence of potential damaging stress to the family involved. Abortion of a genetically deformed fetus is not "treatment," as Paul Ramsey has so ringingly made clear.<sup>24</sup> When related strictly to the therapeutic goals of genetic medicine, amniocentesis is morally difficult to justify, since there are no basic gene therapies available, and if the medical literature is an indication, genetic therapy will be very difficult to achieve for some time to come.<sup>25</sup> According to Robert Murray, Howard University geneticist, regulating the products of genes will precede any wholesale treatment of defective genes.<sup>26</sup> For example, he predicts that scientists will understand how hemoglobin is synthesized and thus be able to regulate the product of the sickle-cell anemia gene long before they will be able to introduce therapies for the sickling gene itself. Amniocentesis is also difficult to justify morally in relation to studies of the products of genes, unless one wanted to argue that the sacrifice of the genetically deformed fetus is a necessary contribution to the research for a fuller understanding of the genetic problem under consideration. It is not morally right to recruit abortions strictly for re-

<sup>23</sup> Henry D. Aiken, *Reason and Conduct* (New York: Knopf, 1962) p. 80.

<sup>24</sup> Ramsey, *op. cit.*, pp. 114, 171.

<sup>25</sup> Theodore Friedman and Richard Roblin, "Gene Therapy for Human Genetic Disease?" *Science* 175 (1972) 949-55.

<sup>26</sup> Robert F. Murray, M.D., personal communication.

search purposes; it is morally proper to study the remains of an abortus for research into human genetics when that abortus has been obtained legally and without tying the research to the abortion. In genetic counselling centers in which elective abortion also occurs, physicians should be very cautious about the recruitment of their patients and abortuses into research programs. Above all, the physician doing the abortion and the principal investigator doing the research should never be the same person.

Only parents who are definitely at risk for genetically defective children should be admitted to amniocentesis. Not only the risks of the procedure justify this stricture, but more so the ethics of parenthood. Prevention of known and verifiable risk of serious genetic disease may be, in particular families, an acceptable protection of the family. I do not make this as a general principle for all families. Some families cannot survive the addition of one more defective child. In other families, as Daniel Callahan has argued, it is not *inevitable* that the severely handicapped person can expect little or no fulfilment in life.<sup>27</sup> The impressive testimonies of heroic families and their handicapped children, even after the appearance of amniocentesis, are legion.<sup>28</sup> The argument for elective abortion following amniocentesis should only be made related to specifically verified risks in the context of the needs of particular families. At this stage of the development of genetic medicine, *only* if parents are able to tell children, tested or untested, "We made the decision to enter testing because of specific and known risks, and *we* made the decision," will the parent-child bond not be weakened. The more personal and the less coerced a decision, the more opportunity for personally relating to children the reasons why. Nothing could weaken or dissolve the parent-child bond more effectively than children becoming afraid that their parents made such decisions for trivial reasons of personal convenience or because they were forced into it for external societal reasons. The arguments of J. V. Neel, a geneticist, tend, in my view, towards creating a climate of threat to parent-child relations:

... I suggest we see the advent and potential applications of prenatal diagnosis as one more of those steps whereby man, consciously or unconsciously, has grasped the reins of his own genetic destiny. . . .

Early abortion based on prenatal diagnosis can be viewed as the modern counterpart of infanticide based on congenital defect. All over the world, primi-

<sup>27</sup> Daniel Callahan, *Abortion: Law, Choice and Morality* (London: Macmillan, 1970) p. 497.

<sup>28</sup> One excellent discussion of an afflicted child and his family is found in Robin White, *Be Not Afraid* (New York: Dial, 1972).



tive man seems to have recognized the need for curbing his reproduction, and when the limited means at his disposal for so doing failed then practiced infanticide, especially directed towards the defective. I find it difficult to see in our recent and continuing reproductive performance, condemning so many infants to a miserable death and so many of the survivors to marginal diets incompatible with full physical and mental development, any greater respect for the quality of human existence than evinced by our primitive ancestors.<sup>29</sup>

There is nothing in the technique of amniocentesis which "grasps" any gene or inserts any remedial medicine into a child's genetic destiny. No research on the genetic products of the fetus can be done from the fluid withdrawn. The language here is at least inflated and gives the reader an impression that something "genetic" has changed. Nothing could be more destructive of the trust required in parent-child relations than for genetic testing to be understood as motivated by infanticide. The cause of infanticide could never justify prenatal diagnosis within the moral code which presently governs the relation of medicine to the family. The only warrants, at present, which justify abortion following prenatal diagnosis are a positive diagnosis and the undue hardship or misery which would come to a particular family. The portrait of the negotiations in a "condominium" between state, family, physicians, and supporting counsellors drawn by George Williams in an earlier discussion of abortion in this journal presupposes the absolute opposition of the religious communities to the kind of eugenic-abortion policy depicted by Neel.<sup>30</sup> Prenatal diagnosis exists, at this stage, to help particular families gain accurate information about particular at-risk pregnancies. Only in this context can parents exercise the care for the born and the unborn which their roles require. Where parents understand their roles in a religious context, as representative of the love of God to the born and the unborn, and the more personally responsible and accountable the parents are for their decisions, the more adequately they convey the effective meaning of God's love. The more pressure families feel from eugenically inspired groups or "lobbyists" for embryonic transfer or sex determination,<sup>31</sup> the less

<sup>29</sup> James V. Neel, "Ethical Issues Resulting from Pre-Natal Diagnosis," in Harris, *op. cit.*, p. 221.

<sup>30</sup> George H. Williams, "Religious Residues and Presuppositions in the American Debate on Abortion," *THEOLOGICAL STUDIES* 31 (1970) 71.

<sup>31</sup> The self-understanding of some physicians and lawyers who enter the public debate on crucial ethical matters sometimes resembles that of salesmen or lobbyists. The following quotation should suffice: "The lobbyists for reform in the laws of drug and alcohol addiction, abortion, and sexual behavior have achieved much public approval in their areas of concern; can biologists in experimental embryology expect so much more by doing any less?" (Robert G. Edwards and David J. Sharpe, "Social Values and Research in Human Embryology," *Nature* 231 [1971] 90).

personal and accountable they can be to their own children for the decisions they make while in genetic counselling.

One could argue, as does Neel, that it is more just and causes least suffering to the fetus to abort it, rather than allowing it to suffer pain and illness, or to endure injustices on the mentally retarded. This argument is vulnerable because of its inherent paternalism. Whenever a strong group argues on behalf of a weaker group that their removal would be better than their survival, we should not be duly impressed.

One could argue, as did H. J. Muller,<sup>32</sup> that it is unjust to society to allow more defective children to be born. This argument is especially vulnerable to the charge of intolerance. By and large the families of genetically defective children must bear the weight of their care and nurture. Consideration of the family's situation and values should be the fulcrum upon which the morality of the uses of genetic knowledge from amniocentesis turns. Daniel Callahan has expressed a view quite similar to mine in his reflection on the Baltimore case:

I am told . . . that we owe it to the fetus to abort it if it has Down's Syndrome. Yet when I read of the actualities of Down's Syndrome it becomes clear that most mongoloids are happy, that many have a minimally adequate intelligence level, that many can be trained for simple jobs, that they are capable of giving and responding to affection.

That does not sound like a life of suffering to me. Perhaps, though, it means a life of suffering for the parents. But, if so, then that is a very different matter; a riddance of the mongoloid serves the parents and not necessarily the child himself. That should be said clearly. . . . Even in the case of Tay-Sachs disease, far more severe than Down's Syndrome, the suffering of the child itself is apparently not great; the course of the disease brings a mercifully quick degeneration of cognitive and affective faculties; the greatest suffering is on the part of the parents. I, myself, would feel that the parents would have a moral right to turn to abortion in that case and for those reasons. But I would hope that no one would be fooled into thinking we were really acting for the sake of the child, nor that anyone would be fooled into thinking that we were doing anything other than taking the life of the fetus in order to preserve the welfare of the parents.<sup>33</sup>

As Neel himself shows in the same essay cited, as well as in another place,<sup>34</sup> it is highly unlikely that any significant reduction of deleterious genes in the gene pool will be effected through prenatal diagnosis and

<sup>32</sup> H. J. Muller, "Should We Weaken or Strengthen Our Genetic Heritage," in Hudson Hoagland and Ralph W. Burhoe, eds., *Evolution and Man's Progress* (New York: Columbia Univ. Press, 1962) p. 23.

<sup>33</sup> Daniel Callahan, "Who Should Be Born: Is Procreation a Right?" Symposium on Human Rights, *op. cit.*, Panel no. 1, pp. 7-8.

<sup>34</sup> Neel, *op. cit.*, pp. 222, 223; see also Neel, "Pre-Natal Diagnosis and Therapeutic Abortion," *Perspectives in Biology and Medicine* 11 (1967) 129-35.

selective abortion. There is no effective eugenic argument for its wide-scale use. There is an argument for amniocentesis to be used for the relief of certain distressed families. If it can be shown that parental care of the living, in decisions arrived at through accurate information, would be seriously diminished through the birth of a predictable and severely defective child, parents may responsibly elect abortion. In those cases where the existing parent-child or marital bond could be said to be in serious jeopardy, it does not become an ethically insoluble tragedy for the parents to elect abortion. The interest of preservation of the family bond and its resources may, in specific cases, be chosen above the interest of preserving until birth the life of a severely deformed infant for whom no treatment is available.

### *The Social Consequences of Genetic Intervention*

To argue as I have done opens one to the criticism that, if this direction is followed, there will be less tolerance in society for the weak, the imperfect, the unlovely, and the unacceptable. To suggest that we ought to act to reduce the suffering of parents seems to some to deny the good purposes to which pain can be turned. To others, my arguments reinforce the economic and social dominance of the middle and upper classes, since they tend to act upon genetic knowledge much more frequently than minority or lower-class groups. These consequences will be likely if the therapeutic goals of genetic medicine are displaced by eugenic goals. The treatment of the disease is the ultimate goal. Therapy will be a realizable goal in a society where the parent-child bond has not been undercut by well-intentioned scientists.

The avoidance of responsibility in treating genetic disease and acting upon its presence in the unborn undercuts one of the central social values, to reduce suffering in all of its forms. One does not have to hold the position that parents are required to agree to abortion of every defective fetus. I hold that genetic-counselling centers ought not to compel parents to agree to abortion prior to amniocentesis, for this position works against the voluntarism inherent in present practice. Finally, there should be extraordinary efforts to extend genetic medicine to those groups in society who have been discriminated against economically and medically. Unless the benefits of medicine are distributed equally among groups in society, the people will not perceive "benefits" as being in their interest. For practical purposes, medical policy towards genetic treatment should be directed towards those diseases which are catastrophic in their personal and physical consequences. We should beware of those who plan to engineer vast social changes through genetic engineering, such as raising the level of intelligence or reducing aggression in mankind.

### *New Steps in Genetic Medicine*

I chose to follow the progress of couples in amniocentesis because this procedure appears to occupy the center stage of the application of human genetics to practical problems at the present time. It is as if amniocentesis is a "forerunner" of solutions to future problems. I found that the "consumers" of genetic progress (parents) were conservative in their consideration of proposals for sex determination, implantation, and genetic surgery. Their base line for decision on genetic progress was related to serious genetic disease rather than to whole upgrading populations. They realized that they were the first generation of parents to benefit from information gained from prenatal diagnosis, and they were eager that its benefits be extended widely. Their views, on the whole, coincide with mine as to the ethical parameters of progress in genetic medicine. Theological tradition tends to support man's intervention into natural processes to improve his physical and social environment. This is not to say that an unlimited blessing is extended to technical progress. Theologians must beware of providing "cover" for medical progress or codes of behavior which are derived entirely apart from faith. Each proposal in genetics must be evaluated for the benefits and risks to human beings contained in it. Moreover, risks must be assumed by informed human beings who are agreed as to the terms of their experiment. To this theologian, human genetics at present does not violate anything inherently "human," for the most characteristic act of man is to attempt to change himself and his condition. The most authentic Western religious visions prompt interventions into our condition as long as we do not expect to seize eternity or ultimate security through any one or several of these man-made plans. We must not deceive ourselves: human genetics will create as many problems as it solves. Nevertheless, when one has unleashed the full force of ethical self-criticism upon amniocentesis and its effect on parent-child relations, he emerges with no compelling reasons to cry "stop it!" Indeed, one can imagine strictly therapeutic uses for the newest projections for human genetics, including implantation and sex selection. It is the task of the nonmedical professions aligned with physicians to call to them to adhere to their therapeutic calling and resist any attempt to hasten the "kingdom of God" through technical progress.

### *A New Stage of Life*

Others have discussed the development of new "stages of life" in the context of the development of modern culture.<sup>35</sup> It is plausible that the

<sup>35</sup> Especially Kenneth Keniston, *Young Radicals* (New York: Harcourt, Brace, and World, 1968), and Erik Erikson, *Childhood and Society* (New York: Norton, 1953).

demands of an advanced industrial society create a set of needs plus the means for the appearance of a new stage of life: prenatal. The "discovery" of childhood is a comparatively recent development in the history of the Western family, as Aries shows so convincingly.<sup>36</sup> When Mrs. C. says of her son, "We knew him longer," there is evidence for an intimate involvement of parents, particularly of the middle class, with their children from conception forward. Given the means to study and monitor the development of the fetus, and given the recognition of the complex demands in the environment the fetus will enter, it stands to reason that some adults in this period will surround the fetus with whatever supports or interventions they hope will better equip its development. Before this period in history, human beings reckoned that the first stage of life began at birth. Judged by our own actions and inventions, we are assisting in the birth pangs of a new stage of life prior to the birth of the child. One of the consequences of this development will be the assignment of developing human status to the fetus from conception. There is no way to avoid regarding the embryo as human, although the stages of development through which the fetus passes towards birth will carry decisive weight in defining its identity. The more the unknowns of human development prior to birth are exposed to light, possibly the more care can be extended to unborn children. But because care is never "pure" and is mingled with self-interest and ideology, the unprotected fetus is more than ever exposed to the wish fulfilments of adults. One of the primary tasks of ethical inquiry for the generation to come will be defining the limits and possibilities of intervention into the newest human stage of life. The primary task of theological inquiry, as put so well by Gustafson's recent writings, is to frame the ethical inquiry in pondering on two questions: "What do we value about the human?" and "What is the relation of the empirical and descriptive to the ethically normative in our concept of human?"<sup>37</sup> As the family is still a central agent of the experience of being human, no continuing search for the uniquely human can bypass an evaluation of how our changes of ourselves affect our experience of family.

<sup>36</sup> Philippe Aries, *Centuries of Childhood* (New York: Vintage, 1962).

<sup>37</sup> James M. Gustafson, "What Is the Normatively Human?" *American Ecclesiastical Review* 165 (1971) 192-207.