Parental Autonomy and the Obligation Not to Harm One's Child Genetically

Ronald M. Green

Until recently, genetics counselors and medical geneticists considered themselves lucky if they could provide parents with predictive information about a small number of severe genetic disorders. Testing and counseling were indicated primarily for conditions of this sort. Out of respect for the autonomy of parental reproductive decision making, the prevailing ethic of genetic counseling stressed "nondirectiveness" and "value neutrality." As summarized by Arthur Caplan, the hallmarks of this stance include

> (1) a willingness to provide testing and counseling to all who voluntarily seek it, (2) the presentation of information concerning findings in a manner that is balanced and comprehensible to patients or clients, (3) the fair and balanced presentation of all options for action if a problem is discovered, (4) a willingness to answer all questions asked by those seeking services, and (5) an obligation to protect privacy and confidentiality at all times regardless of societal needs or benefits.[1]

The flood of new information being produced by the Human Genome Project poses many challenges to prevailing social policy and to the ethics of genetics professionals. Some of these challenges stem from the new prospects for harm to children that neglect of emerging genetic information may involve. For example, the increasing number of diagnosable genetic disorders, including some for which early detection may have therapeutic value, has raised the question whether pressure should be brought to bear on parents (or prospective parents) to undergo testing to prevent serious harms to their offspring or society.[2] This issue has already arisen in the United States in connection with the debate over programs of screening for maternal serum alpha-fetoprotein, or hypothyroidism,[3] and it may grow as therapies are developed that increase the value of early diagnosis or treatment of genetic disease.

A related problem derives from morally questionable uses of genetic information made possible by the dramatic expansion of knowledge concerning the genetic basis of many human phenotypes. As this knowledge increases, it will take us beyond the familiar realm of disease prevention to the possibility of selecting for a wide variety of traits. One does not have to engage in elaborate argumentation to understand the burdens associated with Tay-Sachs disease or Lesch-Nyhan syndrome. But as our knowledge grows of the genetic causes of many less serious conditions or even of what are now regarded as normal variations in the human population, new questions will arise as to whether parents should either receive or be allowed to act on such information. These questions have already appeared in connection with ongoing debates about whether genetics professionals should provide parents with information about genetic traits or conditions such as sex (where no sex-linked disease is involved) or nonsymptomatic carrier status.[4] Although many genetics professionals continue to adhere to the elements of nondirectiveness and believe that parents should be given whatever information they request, some commentators, fearful of raising again the specter of eugenics or authorizing unjustified parental interventions in a child's life, have argued for restrictions on parental access to information. In some cases, these restrictions are based on the view that genetic medicine should only address preventing serious disease conditions.[5]

Whatever the outcome of these debates, emerging knowledge of genetics has recently raised a new possibil-

Journal of Law, Medicine & Ethics, 25 (1997): 5–15.

ity: that parents may be in a position to use genetic information in ways that not only have nothing to do with the prevention or cure of disease but also actively involve the infliction of harm or suffering on their child. Whatever one's view of the appropriateness of providing nondisease-related genetic information, this extreme possibility raises new questions in its own right. Will society permit parents to access and use information about their child's genetic inheritance regardless of the harm that the resulting reproductive decisions inflict on the child? Will genetics professionals have to rethink their commitment to parental autonomy, perhaps by taking a more active counseling role to prevent harmful parental choices or by imposing new limits on the "menu" of genetic tests available?

Two challenging cases

Two cases that have provoked much comment illustrate the urgency of these questions about the limits of parental autonomy where harm to the child is involved. The first is hypothetical and has been mentioned in the genetics literature for some time.[6] It concerns a married couple, both of whom are "deaf of deaf." They inherited the condition of deafness from their parents and were raised in nonhearing households. Currently, not one of the more than 100 genes that can cause hereditary deafness has been identified, but some believe that a decade from now, many will have been sequenced.[7] At that time, this hypothetical couple visits a genetics counselor with an unusual request. The woman is pregnant and they want her fetus to be tested for the "deafness gene." The counselor believes she understands their concern, and, as a matter of course, asks if they plan to abort any fetus who will be deaf. The parents respond, "Of course not!" If the fetus has the gene for deafness, they say, they plan to carry it to term. It is a "normal" hearing child they want to abort. They explain their reasoning to the astonished counselor by saying that they feel more comfortable having a child "just like themselves."

The second case actually occurred and shows how fast we are moving from possibility to reality. It concerns achondroplasia, an inherited autosomal-dominant condition that causes diminished growth in the long bones of the legs, leading to dwarfism. Several years ago, the gene for achondroplasia was identified and cloned.[8] If two people with achondroplasia marry, each of whom is heterozygous, chances are that two of every four children they have will be also be heterozygous and will be short statured. These youngsters may need some surgical intervention early in life to prevent more serious bone problems. Although short stature can be a significant handicap, they can, with effort, lead relatively normal lives, marry, and have children.[9] On average, one child in four born to the couple will not inherit the achondroplasia gene and will be of average height. And one child in four will be homozygous for the gene. This condition is fatal: the child invariably dies in infancy after a tragic downward course.

A researcher who helped identify this gene understandably felt that he had made a significant contribution by allowing short-statured parents the option of aborting fetuses with the lethal double copy of the gene. You can imagine his surprise when he received a telephone call shortly after news of the discovery was published.[10] The call was from one member of a couple, each of whom was affected by achondroplasia. The caller asked whether it was possible to test for the presence and the absence of the gene. The couple wanted this information, they said, because they planned to abort not just all fetuses homozygous for the achondroplasia gene, but any unaffected ones as well. They were intent on only having short-statured children.

Limits to parental choice

These two cases illustrate the challenge that new genetic knowledge poses to the availability of genetic information and to the tradition of nondirective counseling. They raise the ethical question whether society or genetics professionals can tolerate the exercise of unlimited parental access to genetic information and autonomy in genetic decision making. In what follows, I argue that substantial parental access to genetic information, nondirective counseling, and parental autonomy in reproductive decision making should continue to characterize society's thinking and practice. Parents, I argue, not only have a right to autonomy in re productive decision making, but also they usually are the best protectors of their child's interests, including the child's interest in a healthy start in life. In the special case of parents who carry a genetic disease and who are at risk of passing the condition on to their offspring, we must also be especially careful not to burden their lives further by ill-considered moralistic judgments and intrusions. All these considerations reinforce the value of open access to genetic information and nondirective counseling.

I take this position, however, while simultaneously affirming parents' obligation not to inflict genetic harm knowingly or negligently on their children. I argue that, to the extent it is within our control, we should strive to give our children lives unimpaired by serious genetic (or congenital) disorders and we should take reasonable care to avoid doing so by inadvertence or neglect. This obligation has been affirmed in different formulations by others.[11] In the remarks ahead, I try to hold together these two tensely related claims: that we should strive to respect parental autonomy in genetic and reproductive decision making *and* that, as parents, we have an obligation not to inflict knowingly genetic harm on our children. The argument I am making is essentially a moral one, although I will occasionally refer to adjacent areas in the law to illustrate my points.

Positions denying that parents can genetically harm their children

Some individuals who have thought about this tension between seemingly conflicting rights and obligations have sought to resolve it by denying that parents can ever wrong their children by deliberately bringing them into being, even with otherwise avoidable genetic impairments. Those who hold this view confer virtually unlimited autonomy on parents in their reproductive decision making. I believe that this approach is mistaken: parents can wrong their children by knowingly or carelessly bringing them into being in certain circumstances of life. So I must first indicate why I believe this shortcut route to defending parental autonomy is unacceptable.

Some who stress virtually unlimited parental autonomy rely heavily on current U.S. abortion law, according to which a woman has the right to terminate a pregnancy for any reason during the first two trimesters. This right is founded ethically and legally on the woman's right to privacy in reproductive decision making. It follows from this right that parents may also choose *not* to terminate a pregnancy, even when the consequences of their choice for the child or for society are very unfortunate.[12]

It is easy to see that in a society where maternal and parental decision making is privileged in these ways, a woman cannot be compelled to continue or end a pregnancy for genetic reasons. This right creates the ability to terminate fetuses unaffected by genetic disease in order to give birth only to an affected child. Counselors to whom I have spoken frequently invoke the right of abortion when explaining their willingness to cooperate with parents who request assistance in selecting for a genetically impaired fetus and aborting unaffected fetuses, as in the cases of the deaf couple or those with achondroplasia.

Nevertheless, as we consider parents' rights in the area of genetic decision making, we should put this matter aside. A woman (or couple's) almost absolute right to terminate (or continue) a pregnancy does not imply a corresponding legal or ethical duty on the part of genetics professionals to provide assistance in determining which characteristics the child will have. Where discernible harms to others are created by parental reproductive decision making, genetics professionals have the right—and perhaps the duty—to refuse to offer their expertise in assistance.[13] In the future, genetics counselors or society, without compromising couples' right to terminate or continue a pregnancy, may decide to limit the menu of genetic traits or conditions about which couples should be allowed to demand information.

In addition, parental genetic decision making will increasingly take place without pregnancy or abortion being at issue. Counselors currently provide preconception testing to prospective parents for a variety of conditions. The technology of preimplantation genetic diagnosis is now available, allowing genetic selection of embryos before the beginning of a pregnancy. The genetic testing of gametes lies on the more distant horizon, but it, too, may some day help further remove genetic decision making from the context of abortion.[14]

So the issue of parents' rights in this area cannot be answered simply by pointing to a woman's nearly absolute right to abort or not abort. In a world of preconception genetic testing or preimplantation genetic diagnosis, questions about parents' right to access genetic services and the limits of parental autonomy will persist. The fact that these technologies require the cooperation and assistance of medical personnel takes them beyond the private sphere of parental decision making. Will society or genetics professionals permit parents the ultimate determination of their child's genetic constitution no matter what the parents request?

In approaching this question, I also want put aside a set of ethical and legal positions that would make unchecked parental autonomy much easier to defend. These positions are based on the view that children cannot be wronged by deliberately or negligently being brought into being with serious health problems. Among moral philosophers, this position has been developed by thinkers like Derek Parfit and David Heyd.[15] In the area of law, a roughly similar position has been worked out in a series of rulings that reject wrongful life as a basis for legal actions against negligent medical professionals.[16]

Although these philosophical and legal positions differ in some ways, a common thread of ethical reasoning runs between them. All share the moral view that no one is harmed by being brought into existence, no matter how dreadful the resulting circumstances of their life, when the alternative is never having been at all. Imagine, for example, that an obstetrician fails to inform a pregnant woman with rubella about the likely medical effects on her fetus. If the woman had been properly informed, she might have chosen to terminate the pregnancy. Instead the child is born with grave birth defects. According to some philosophers and legal theorists, the child itself cannot be said to have been harmed by the professional's failure to inform. To hold that a person is harmed by someone is to say that they have been made "worse off" by the other's conduct and would have been "better off" had the professional acted differently. But in this case, if the doctor had informed the mother, she would most likely have terminated the pregnancy and the child would never have been born.

Philosophers like Parfit and Heyd argue that we have moral duties only to identifiable, actual persons. There are no moral duties to persons who are merely possible but who, as a result of our reproductive decisions, are never conceived. No one has a right to be born. For the same reason, there are no moral obligations to help "someone" avoid coming into being even to avoid serious harms fol-

lowing birth. According to these philosophers, it is logically incoherent to say that a being who does not exist can somehow be made better off by avoiding its birth. They also argue that the child born with serious defects cannot complain because the alternative is for that child never to have been. On the side of law, theorists and jurists who have rejected the concept of wrongful life deny that we can ever value nonexistence over life. Although some theorists note that adult human beings who face intense suffering sometimes choose to end their lives,[17] opponents of the wrongful life position point to the conceptual and practical difficulties in trying to found a legal claim for damages on the comparison of a life with suffering versus absolute nonexistence.

These philosophical and legal views make it easy to defend virtually unlimited parental autonomy in reproductive decision making. Nevertheless, although I agree with the importance of parental reproductive autonomy, I believe these views are mistaken in holding that a child is not wronged if it is deliberately (or negligently) brought into being with a genetic condition that causes it significant suffering.

The appropriate benchmark

The error in these positions lies in trying to compare the condition of a child born with a disorder to the state of such a child had it never been born. This comparison inevitably forces us into the impossible task of trying to compare existence and nonexistence. But the condition of a child born with a reduced health status should not be compared with that child's own nonexistence. Rather, it should be compared with the *reasonably expected health status of others in the child's birth cohort*. This is the appropriate benchmark, I believe, because it is the one that most parents are likely to use in deciding whether to have a child in the first place, and it is also the benchmark that the child and those around it are likely to use in assessing the quality of its start in life.

To understand this point better, it helps to see that before conception (for most people) and even following conception during early pregnancy (for many others), lives are in a sense "fungible"; they are interchangeable generic units, rather than identifiable and unique. Parents intending to have a child do not imagine the identifiable child "Mary" whom they come to know in the years following her birth, but a "generic" child with qualities like those of most other children being born in its cohort. It is this imagined child whom they usually have in mind in choosing to have a child in the first place, and against whom they and others measure the actual condition of the real child when it is born. The real child is a source of joy, when, as is usually the case, he/she is experienced as even better than the child they had imagined. But sometimes, as well, the real child (however much it is loved) is experienced as a source of sadness (for its parents, itself, or others) because it is born with physical or mental problems that are viewed as rendering its life significantly more difficult than that of the imagined average child. Parents who are given the unintended child because of a professional's negligence have good reason to regard both themselves and the child as wronged, just as if a healthy living child of theirs had been injured by medical malpractice.

Similarly, when a child is born and grows, the child and others inevitably measure its life in terms of the other lives it might reasonably be thought to have lived in its family and time. Despite the claims of philosophers like Parfit and Heyd, it is by no means senseless for a person to think "If my mother had only waited a few months until after the rubella epidemic had passed to conceive me, 'I' would never been born with this deformity." Taken strictly, this statement is nonsense: the child who could have been conceived and born after a delay of some months is not the same child as the one who was conceived and born earlier. But if we think of ourselves before conception or birth as an imaginary fungible intended child of our parents, who could come into being with roughly the same physical and mental attributes as other children, this statement makes perfect sense. Because parents are properly regarded as proxy decision-makers for their child's health status, it is therefore reasonable for a child to feel wronged when poor decision making by parents (or by those who advise them) leads the child to be born with serious impairments or suffering relative to others in its birth cohort.

The moral idea of measuring a child's actual condition at birth with the expected health status of other children in the child's cohort has recently had resonance in some legal writings on the issue of wrongful life. Michael Kelly,[18] for example, argues that damages in wrongful life suits should be approached not in terms of standard tort conceptions (where the rightful position of which plaintiffs have been deprived is their condition before the wrong occurred), but in terms of the idea of damages that prevails in the area of misrepresentation law. Here the rightful position is the one the wronged party was led to expect would result if the misrepresented claims had proven true. For example, in misrepresentation law, investors might be awarded not simply the money they lost in a fraudulent investment scheme but also the monetary returns they would have received if the misrepresentation about the promised gains had been true. This way of awarding damages recognizes that losses created by misrepresentation include frustrated expectations and the costs of opportunities foregone.

Kelly's reasoning coheres well with the moral argument that, in our thinking about harms at birth, we should compare the status of the actual child born with that of the average child in its birth cohort. This is the child who most

parents strive to bring into being, and for whose loss they should be compensated when others act negligently. To the extent that parents are properly regarded as surrogate medical decision-makers for their not-yet-competent children, this is also the child whom many of us would reasonably feel we could have been had our parents (or the medical professionals they called on for help) not acted with sufficient attention to our well-being. (Even in those cases where parents' genes unavoidably cause disease, the options of donor insemination or egg donation today and gene therapy in the future permit us to think of ourselves as having been born other than we were.) As such, this reasonably expected health status is a benchmark for assessing both others' negligence *and* parents' carelessness in reproductive decision making.

In terms of moral reasoning, we can regard this benchmark of reasonably expected health status as one that rational persons would select in order to fashion a public rule of reproductive conduct most likely to protect the vital interests of real persons.[19] Hence, whether an identifiable person is made worse off by our reproductive decision is beside the point. What is important is the public rule of conduct meant to shape people's reproductive behavior in ways that reduce likely harm to born persons.

Complexities

Obviously, many specific details of this idea of comparing a child's health expectations at birth with the reasonably expected health status of others in its birth cohort must be worked out. One question has to do with the relative degree of harm to which anyone may allowably expose a child. Some may argue for morally condemning only the most grievous harms involving intense physical or mental suffering or disability on the child's part relative to others of its cohort,[20] or those states of existence of which it can be said that the suffering in a child's life clearly outweighs its benefits.[21] But these measures seem too extreme. Because no one is wronged by *not* being given the opportunity to be born (I believe Heyd and others are right about this[22]), and because we cannot predict just how much suffering any given child will tolerate, a more cautious standard should prevail. The standard I have in mind involves "significantly greater" suffering or disability than others in the child's birth cohort. Encouraging us to err on the side of caution, this tells us that we should try to avoid even moderate degrees of harm for those we bring into being. Such a standard, I believe, is reflected in current social attitudes about women's responsibilities to avoid smoking or consuming alcohol during pregnancy. In many people's minds, even the risk of small degrees of harm to one's child requires self-restraint in these respects.

This standard of "significantly greater" suffering or disability establishes a lower threshold for wrong than that created by those who believe we are obligated to avoid the birth of someone only in those cases where that life is not worth living or where death would clearly be a worthwhile choice even for a living person. As a practical measure, we can determine whether harm is significant by asking whether, as a generality, children (or, later, adults) with a specific condition would prefer to have lived their lives free of their specific congenital disorder or disability. It should be noted that this is a different question than the more extreme and, I believe, inappropriate one of asking whether they would prefer to be dead.

That congenital difficulties can also have the positive effect of strengthening an individual creates two difficulties for this standard: it makes it odd to think of putting such evaluative questions to people, who may understandably find it hard to separate the complex facts of their biography from their disability; and it questions the idea that congenital defects constitute a harm. As far as the first difficulty is concerned, although individuals with a disorder or handicap often do appreciate the personal growth that adversity can bring with it, they are also frequently able to recognize the evil and unchoiceworthiness of the adversity itself. As for the second difficulty, it is commonly recognized in law and ethics that the positive character benefits that can accompany an injury do not excuse it or remove the fact that a wrong has been done.

Another problem is the question of the cohort against which a child's birth condition should be measured. On the one hand, this group has to be larger than the family because children invariably assess their lives in relation to the peers with whom they interact and about whom they meaningfully think "I could have been one of them." On the other hand, the benchmark group cannot be some abstract, timeless, and ideal community, because that would create an unrealistic and impossible standard against which to measure people's actual reproductive decision making. The appropriate measure has to be relative to the era and social group in which we live. The expectations Americans have today for a child's health prospects at birth, for example, are far higher than those that existed two centuries ago, but it would be ridiculous to say that our forebears wronged their children by having them at all in those backward circumstances. Similarly, it would be cruel and pointless to say that citizens of India wrong their children by bringing them into being in a far less developed economy with less health care than, say, the United States. Considerations of justice also suggest that we should not ordinarily permit social inequities to become a basis for restrictions on parents' reproductive freedom. We must recognize, therefore, that the health status to which the results of parents' reproductive decision making is compared is established with regard to the available life situations to which we may reasonably and rightfully aspire.

Despite the obvious problems that some cases raise

and the need for further thinking in this area, I do not believe that these difficulties of measurement need bog us down. People know what the prospects are for most children born in a cohort. They are also able to identify the conditions that may reasonably lead the child and others to conclude that, in terms of its health, it had started life at a significant disadvantage.

This reasoning leads me to state with precision the moral norm I want to defend:

> In the absence of adequate justifying reasons, a child is morally wronged when he/she is knowingly, deliberately, or negligently brought into being with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up.

It is this reasonably expected health condition and the level of life prospects of others in the child's birth cohort, not the state of nonexistence, that is the appropriate benchmark for assessing harm in reproductive decision making. I am also now in a position to state the specific obligations of parents (and, by extension, those who assist them in effecting their reproductive choices) to their children. I contend that:

> Parents have a *prima facie* obligation not to bring a child into being deliberately or negligently with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up.

Two qualifications

Against this background, I now make two very important qualifications. First, this obligation not to deprive our children deliberately or negligently of a relatively healthy and normal start in life is a *prima facie* one. This means that it is not absolute but must always be weighed against our competing obligations and against rights possessed by other persons or ourselves, not least of all our rights as parents. We have seen that parents have a right to exercise procreative autonomy that ordinarily prohibits the government from preventing them from having children or forcing them to have an abortion. This right is reinforced by their right to the liberty of their religious beliefs if these beliefs oppose abortion. Conflict between parents' religious beliefs and the child's welfare are not unique to reproductive issues. In other areas of law, such as those dealing with education or health care, society's respect for parents' religious liberty often competes with what Joel Feinberg has termed the "child's right to an open future."[23] Thus, even where there is reason to believe that a child's prospect of a relatively healthy start in life is jeopardized by starting or continuing a pregnancy, there are also good moral and legal reasons for respecting the parents' decisions. This same consideration may ground parents' refusal to undertake prenatal diagnosis. In cases where parents have no principled reason for refusing to act on knowledge of possible genetic harms to their child, however, willful refusal to undertake available testing for serious disorders becomes morally less justifiable.

Parents' *prima facie* right of privacy and autonomy in reproductive decision making leads to a second very important qualification. Although parents have an obligation not to bring a child into being deliberately or negligently with a significantly reduced health status, this relative measurement of a child's start in life is always imperfect. No one can guarantee that a child will have all the abilities and opportunities open to others in its cohort, and it would be foolish to insist on strict equality in these matters. Further complicating things is that the quality of a child's life is very much a result of the quality of the parenting it receives. The burdens of some disorders or some forms of disability are more than offset by being raised in a loving home. A child born with a handicap into a loving family has reason to regard itself as lucky when compared with a physically more normal child whose parents give it less attention or love.

The point is that assessing a child's expectations requires a complex global judgment that takes into account all the reasonably foreseeable circumstances of the child's life, including the willingness and ability of the parents to compensate for other less than desirable features of the child's health at birth.[24] In most instances, this complex, global judgment will also best be made by parents, who, in the absence of clear evidence to the contrary, are closest to all facts involved in the decision and are reasonably presumed to want the best for their offspring. These presumptions might be overridden only when the parents' decision is likely to result in significant suffering and disability for their child without clear offsetting advantages, and when no other compelling *prima facie* rights support the parents' decision.

We are now in a position to understand the extent and limits of parental autonomy in genetic decision making where harm to the child is involved. In most instances, I believe, we should defer to parents' decisions about the genetic constitution of their progeny. We should do so, however, not because we believe with Parfit, Heyd, or others that parents cannot logically wrong children in this respect, nor even because we hold that birth in any condition is better than nonexistence. Rather, we must assume that parents have an obligation not to bring a child into being knowingly, deliberately, or negligently with a condition likely to cause it significantly greater disability or suffering

than others in its birth cohort. But in most cases, we will also defer to parents' thinking about these matters and recognize that *their* global judgment about the prospects facing their children is normally to be respected. This is perhaps especially true where parents with a disability are concerned, because they can be expected to approach these decisions with utmost seriousness about the stakes for their child. Only when clear evidence indicates that the parents are unconcerned about their child's well-being or that their judgment about their child's prospects is clearly wrong can we conclude that they may be acting in a morally irresponsible way.

Responding to genetic harm

When society determines that certain choices are irresponsible, it has a range of options. In some cases, a negative judgment may lead to nothing more than the public expression of blame: the conclusion that these people are irresponsible. Even this moderate response, of course, can have serious effects on people's lives and is warranted only when there is a solid and well grounded consensus that the parents' choices are unjustifiably harmful and can be influenced by public opinion. More flagrant cases of irresponsibility may lead us, whether we are acting as medical professionals, legislators, or government officials, to establish uniform standards of behavior for parents and professionals. For example, where we judge parents' likely use of genetic information to be morally unacceptable, we can establish rules saying that certain kinds of parental requests for assistance will not be respected. This thinking makes genetics professionals responsible for expressing our social judgment and could take the form of legally or professionally established limits to the menu of genetic information or services available to parents.

The existence of patterns of serious parental mischoice and misconduct in this area may prompt other recourses. We might reconsider the tradition of nondirective counseling and permit or require genetics professionals to play a more active role in informing parents about the inappropriateness of certain choices. This can extend to their playing a more active role in advising prenatal testing or even seeking to influence parents' specific decisions about starting or continuing a pregnancy. However, because nondirective counseling has such great value in promoting trust in the counseling professions and encouraging people to use counseling services, this option is far from desirable. It would be justified only if it promised real benefit and if other alternatives, such as improved public education, failed to prevent serious parental misconduct in reproductive decision making.

Finally, at the farthest extreme, we may go so far as to restrict parental reproductive autonomy by actively discouraging and even criminalizing some kinds of especially pernicious genetic or reproductive choices. Obviously, this is a last resort, because it involves not only the severest restrictions on procreative liberty, but is usually also very difficult to enforce. The debates surrounding the incarceration of crack-addicted pregnant women illustrate the complexities, difficulties, and, usually, the inadvisability of this extreme option.[25]

Case applications

The discussion so far has been abstract. I want to conclude by reviewing a series of cases of parental genetic choices against the framework of the parents' rights and obligations and the scope of professional responsibility that I have developed. The deafness case mentioned at the outset imposes great strain on the requirement that parents have an obligation not to bring a child into being deliberately with a significant degree of suffering or disability relative to others in its birth cohort. To be born deaf in a world made up mostly of hearing persons is to face a series of disabilities. Some members of the deaf community reject altogether the claim that deafness is a disability, and maintain that they are "normal but different."[26] However, quite apart from the aesthetic and social satisfactions denied to such a child, throughout life he/she faces an elevated level of serious risk: they are unable, for example, to hear the car horn or warning cry that could prevent injury or death.

On the other hand, real satisfactions are open to the deaf child that are denied to hearing persons. One is the warmth and camaraderie of the deaf community; another is the beauty and complexity of sign language.[27] These and other satisfactions, if they do not offset every hardship facing the deaf child, may mitigate the parents' wrong.

Then there are the rights of the parents themselves. These are not trivial. They are *prima facie* claims that must be placed on the balance. Those who have defended the right of deaf parents to select for a child like themselves have pointed to a growing sense of solidarity within the deaf community that has been sharpened by the perceived indifference or hostility of the hearing world. In this respect, the deaf share an experience with other embattled racial or ethnic minorities. In the effort to explain why a deaf couple may be uncomfortable with a hearing child, one deaf individual asked me to imagine the situation of a black couple who, through some odd genetic mutation, gives birth to a white baby. Will the couple be able fully to accept their child, or will they inevitably regard it as belonging to an alien world?

These hardships to the parents enter into our thinking as we determine how to respond to the parents' request. On balance, I believe the issues here are not compelling enough to lead us to say that we *must* establish legal or professional norms impeding such a choice on the parents' part. However, neither is it clear that the parents' rights

are strong enough to lead us to conclude that genetics professionals *must*, as a matter of professional responsibility, bow to the parents' wishes regardless of counselors' personal views. When no pressing moral reasons counsel otherwise, medical professionals have a right to decide to whom they will offer their services and for what reasons. All these considerations suggest that, in cases of this sort, individual freedom should prevail on both sides. Parents should be free to seek professionals willing to assist them in their requests. Genetics professionals, whether working alone or in clinical groups, should be free to make their own decisions or to set their own policies in responding to requests for information of this sort. Whichever policy they choose cannot be faulted as clearly wrong.

The case of the parents with achondroplasia raises issues that weigh for and against unrestricted parental autonomy and professional cooperation. On one side, the relative disability of a child with achondroplasia is arguably not as great as that of a deaf child. Apart from one or more childhood surgeries needed to forestall potential developmental problems, these children grow up normally. They live a normal life span reasonably free of pain. They can marry and have children (women with achondroplasia require a cesarean-section to deliver).[28] Their height is an inconvenience—even handicapped toilet facilities pose a problem for the short statured—and many people affected by achondroplasia also experience severe stigmatization. But none of these hardships necessarily prevents them from pursuing and achieving major life goals open to other persons.

On the other hand, there are possibly fewer pressing parental reasons for their deliberately creating a child with even this modest degree of disability. The argument about parents' desire for fellowship and solidarity with their children in the face of a hostile world is less compelling here. Thanks to the short-statured community's own efforts and society's response, there is considerably less overt discrimination today against little people.

These parents have other concerns. I have been told by some people affected by achondroplasia that they prefer to have a child like themselves because they fear disciplinary problems with a normally statured child who may tower over its parents by age seven or eight. The issue is not the parents' wish for control but their concern for the child's proper upbringing.

Finally, some little people share concern with many other disabled persons that they must resist confirming society's negative judgment of them and their condition. Believing that disability is often a social construct rather than an intrinsic state of being, they feel compelled to evidence in their reproductive decision making their belief that the proper response to disability is not the eugenic prevention of the birth of disabled people but the elimination of socially constructed barriers.[29] The additional fear is that if the numbers of those with disabilities diminish, they will lose political power and become more susceptible to stigmatization or state-imposed eugenic measures.[30] For those who reason this way, it is not only the parents' rights of procreative autonomy but also general moral considerations of justice that take precedence over obligations to the child.

These are valid concerns. They will play an increasing role in our thinking as science uncovers the genetic cause of more and more conditions associated with stigmatized or oppressed groups. Nevertheless, I believe that, for the present, we do not have to fear that individual reproductive choices by parents seeking not to have a child with a disability will further erode the status of the disabled in our society. It is by no means clear that a decision not to have a child with a disability requires a negative judgment in any way on the life or worth of those born with such a problem.[31] It is possible for us to hold that it is not wise or ethical deliberately to add to the normal risks of disability or suffering a child may face, while also insisting that a child actually born with problems deserves all the support we can give it. Furthermore, many serious congenital anomalies arise from new mutations or noninherited chromosomal abnormalities,[32] and many other serious disabilities occur later in life as a result of injury or disease, suggesting, as John Fletcher and Dorothy Wertz put it, that "disability will always be with us."[33] Even in a world of widespread prenatal testing, society will still have to develop better ways of meeting the needs of many people with disabling conditions.

In terms of parents' obligation to provide their child a relatively healthy start in life, therefore, the case of the child affected by achondroplasia is in some ways less and in some ways more difficult than that of the deaf parents. But again, on balance, it seems wise not to prohibit actively the exercise of parental autonomy, while leaving medical practitioners on an individual or clinic-by-clinic basis free to determine whether they will cooperate with parents' requests. Some may disagree with my conclusions in these two cases, believing that a more uniform consensus on support or prohibition is required. The framework for deliberation about these issues I offer may help us further discuss and narrow our disagreements. The relevant question is whether children born in these circumstances are so seriously harmed relative to others in their birth cohort that more strenuous social or professional intervention—including across-the-board limitation of parents' access to relevant genetic services—would be morally justified.

It may seem that I have woven the net of parental genetic responsibility so loosely that just about any parental choice can get through. But a third and final case suggests that this is not so. This case is drawn from the clinical experience of the Hungarian physician/genetics counselor

Andrew Czeizel.[34] It concerns a woman thirty-three years of age who visited Dr. Czeizel with a request for assistance. She already had two children who suffered from celiac disease, an inherited intestinal absorption problem that rendered them unable to digest carbohydrates properly, most of all gluten. The children would get severe diarrhea from grain-based food, such as flour, bread, pasta, and pastry. To avoid great abdominal discomfort (including diarrhea, steatorrhea, and flatulence), as well as general muscular debility and retarded physical growth, they had to follow a special strict diet. Even with this diet, the children still occasionally experienced serious problems. Although this condition improves somewhat after puberty, it becomes worse again between the ages of thirty-five and fifty-five.

Dr. Czeizel describes this case as "memorable" because the mother came to him wanting help in assuring the birth of a third child *with the disease*. She explained that the diet her two children had to follow was so complicated that providing the same diet for a third child would be simpler. She wished to extend her family, but she did not want to cook "ordinary" meals for the newcomer.

Because this disease is caused by a variety of genes and was not at that time susceptible to prenatal diagnosis, Dr. Czeizel was able to deny the woman's request purely on medical grounds. But here, I believe, we have a reasonably clear case illustrating the limits of parental autonomy in genetic decision making for one's child. As described, this woman's request for assistance appears not to be morally acceptable. To gratify her wishes for a child and to spare herself the inconvenience of adding an additional dietary regimen to her duties, she was willing to impose a life-long sentence of pain and disability on the child. It is possible, of course, that the mother does not see things this way: that her previous experience with her children led her to view this as a mild disorder fully compatible with a rich and fulfilling life. Such a viewpoint merits serious attention. But it cannot be accepted on the mother's word alone. It must be assessed in terms of its accuracy in view of the range of expressions of the disease.

Given the severity of this disorder in many cases, it is hard to avoid the conclusion that a child who has been forced to live with retarded growth, recurrent pain and embarrassment, and the need to avoid many of the foods of his/her peers has been harmed. Although pressing parental claims may override the child's suffering, none is present in this case. As a result, it seems that here, at a minimum, there is room for a departure from the traditional stance of value neutrality, with a counselor permitted to convey to the parent the moral inappropriateness of this request. If requests of this sort are common, there may also be room for development of a uniform standard of professional responsibility that would prohibit counselors, on the threat of censure, from acceding to such requests. This formal limitation of the menu of services would also prevent parents in cases like this from pitting one counselor against the other as a way of securing needed assistance.

Conclusion

The Human Genome Project and other developments in genetic science place us at the threshold of dramatic new choices. To date, virtually open access to genetic services and information and the ethic of nondirective counseling have served us well, encouraging parents to seek counseling for known serious disorders and freeing counselors from the charge of promoting a eugenics agenda.[35] Increasingly, however, and for good reasons, some students of this issue have called for limits on access to genetic services as well as reconsideration of value neutrality and the unquestioning priority this ethic places on parental autonomy. They have warned us that emerging genetic information is opening before us a range of parental choices, not all of which we will be comfortable permitting.

I suggest that some of these concerns have ethical substance. Parents' right to autonomous decision making about their children's genetic constitution is not the only consideration we must factor into our thinking in this area. Parental obligations are also involved here, not least of which is the obligation to avoid knowingly, deliberately, or negligently inflicting genetic harm on our children. I predict we will see this obligation invoked in instances of moral controversy.

Nonetheless, I have also maintained that we should always listen to and seek to understand parents' reasons for their requests for assistance. Even in many difficult and challenging cases of choice, we should give parents the benefit of making reproductive choices that affect their child's genetic constitution. Parents are best suited to understand and shape the lives of their offspring. Their freedom of decision in this area should have presumptive priority in our moral and legal thinking.[36] Only in extreme cases are we warranted as a society in denying them access to the professional services they need to realize their choices or in preventing them from exercising those choices. These extreme cases are characterized by the following two features: (1) the likelihood that, relative to others in the birth cohort, the child will experience significant pain, disability, or limitations in life options as a result of avoidable genetic factors; and (2) the parents' reasons for bringing the child into the world in this condition do not constitute reasonable or compelling grounds for respecting their choice. In the clearest of these cases, counseling professionals are justified in suspending strict value neutrality and communicating their own moral views to parents. They may also be justified, individually and collectively, in limiting access to their services.

References

1. A.L. Caplan, *If I Were a Rich Man, Could I Buy a Pancreas?* (Bloomington: Indiana University Press, 1992): at 131.

2. L.B. Andrews, "Legal Aspects of Genetic Information," *Yale Journal of Biology and Medicine*, 64 (1991): at 36–39.

3. G.J. Annas and S. Elias, "Maternal Serum AFP: Educating Physicians and the Public," *American Journal of Public Health*, 75 (1985): 1374–75; R. Steinbrook, "In California, Voluntary Mass Prenatal Screening," *Hastings Center Report*, 16, no. 5 (1986): 5–7; and L.B. Andrews et al., Institute of Medicine, *Assessing Genetic Risk: Implications for Health and Social Policy* (Washington, D.C.: National Academy Press, 1994): at 276–77.

4. C. Strong, "Tomorrow's Prenatal Testing: Should We Test for 'Minor' Diseases?," *Archives of Family Medicine*, 2 (1993): 1187–93; A. Clarke et al., "The Genetic Testing of Children: Report of the Working Party of the Clinical Genetics Society (UK)," *Journal of Medical Genetics*, 31 (1994): 785–97; D.C. Wertz, J.H. Fanos, and P.R. Reilly, "Genetic Testing for Children and Adolescents: Who Decides?," *JAMA*, 272 (1994): 875–81; D.E. Hoffmann and E. Wulfsberg, "Testing Children for Genetic Predispositions: Is It in Their Best Interest?," *Journal of Law, Medicine & Ethics*, 23 (1995): 331–44; and American Society of Human Genetics Board of Directors, American College of Medical Genetics Board of Directors, "ASHG/ACMG Report: Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents," *American Journal of Human Genetics*, 57 (1993): 1233–41.

5. See Strong, *supra* note 4; P. Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (New York: Simon & Schuster, 1996): 204–19; and J.R. Botkin, "Fetal Privacy and Confidentiality," *Hastings Center Report*, 25, no. 5 (1995): 32–39.

6. W.E. Nance, "Parables," in D.M. Bartels, B.S. LeRoy, and A.L. Caplan, eds., *Prescribing our Future: Ethical Challenges in Genetic Counseling* (New York: Aldine De Gruyter, 1993): 89–94.

7. See *id.* at 92; and P. Coucke et al., "Linkage of Autosomal Dominant Hearing Loss to the Short Arm of Chromosome 1 in Two Families," *N. Engl. J. Med.*, 331 (1994): 425–31.

8. R. Shiang et al., "Mutations in the Transmembrane Domain of FGFR3 Cause the Most Common Genetic Form of Dwarfism, Achondroplasia," *Cell*, 78 (1994): 335–42.

9. T.E. Kelly, *Clinical Genetics and Genetic Counseling* (Chicago: Book Medical Publishers, 2nd ed., 1986): at 292–93.

10. Radio interview with J.J. Wasmuth, National Public Radio, "All Things Considered" (Feb. 7, 1995).

11. S.B. Twiss, "Parental Responsibility for Genetic Health," *Hastings Center Report*, 4, no. 2 (1974): 9–11; S.B. Twiss, "Ethical Issues in Genetic Screening: Models of Genetic Responsibility," in D. Bergsma et al., eds., *Ethical, Social and Legal Dimensions of Screening for Human Genetic Disease* (New York: Stratton Intercontinental Medical Book, 1974): 225–61; L.M. Purdy, "Genetic Diseases: Can Having Children Be Immoral?," in J.J. Buckley, ed., *Genetics Now: Ethical Issues in Genetic Research* (Washington D.C.: University Press of America, 1978): 25–39; M. Shaw, "Conditional Prospective Rights of the Fetus," *Journal of Legal Medicine*, 5 (1984): 63–116; A. Czeizel, *The Right to be Born Healthy: Ethical Problems of Genetic Counseling in Hungary* (New York: Alan R. Liss, 1988); B. Steinbock and R. McClamrock, "When is Birth Unfair to the Child?," *Hastings Center Report*, 24, no. 6 (1994): 15–21; and C.B. Cohen, "'Give Me Children or I Shall Die!': New Reproductive Technologies and Harm to Children," *Hastings Center Report*, 26, no. 2 (1996): 19–27.

12. J.A. Robertson, *Children of Choice* (Princeton: Princeton University Press, 1994): ch. 2.

13. See Botkin, *supra* note 5, at 33. Jeffrey Botkin argues that some parental requests for genetic information about their embryo or fetus can inflict psychological harms on the future child or can limit the child's freedom. Although Dr. Botkin's position is similar in form to the one I offer here, my argument focuses on the need to avoid clear physical harms to the child. I do not agree that the putative psychological or other harms he lists justify limiting parental autonomy.

14. G. Levinson et al., "Recent Advances in Reproductive Genetic Technologies," *Bio/Technology*, 13 (1995): 968–73.

15. D. Parfit, *Reasons and Persons* (Oxford: Clarendon Press, 1984); and D. Heyd, *Genethics: Moral Issues in the Creation of People* (Berkeley: University of California Press, 1992). Related treatments of this issue include M.A. Warren, "Do Potential People Have Moral Rights?," *Canadian Journal of Philosophy*, 7 (1977): 275–89; R.I. Sikora and B. Barry, *Obligations to Future Generations* (Philadelphia: Temple University Press, 1978); G. Kavka, "The Paradox of Future Individuals," *Philosophy and Public Affairs*, 11 (1982): 93–112; J. Woodward, "The Non-identity Problem," *Ethics*, 96 (1986): 804–31; M. Hanser, "Harming Future People," *Philosophy and Public Affairs*, 19 (1990): 47–70; R. Faden, "Reproductive Genetic Testing and the Ethics of Parenting," *Fetal Diagnosis and Therapy*, 8, Supp. 1 (1993): 142–47; Steinbock and McClamrock, *supra* note 11; D. Brock, "The Non-identity Problem and Genetic Harms—The Case of Wrongful Handicaps," *Bioethics*, 9 (1995): 269–75; and J.C. Heller, *Human Genome Research & The Challenge of Contingent Future Persons* (Omaha: Creighton University Press, 1966).

16. N.S. Jecker, "The Ascription of Rights in Wrongful Life Suits," *Law and Philosophy*, 6 (1987): 149–65; P.G. Peters Jr., "Rethinking Wrongful Life: Bridging the Boundary Between Tort and Family Law," *Tulane Law Review*, 67 (1992): 397–454; and M.B. Kelly, "The Rightful Position in 'Wrongful Life' Actions," *Hasting Law Journal*, 42 (1991): 505–89.

17. See Kelly, *supra* note 16, at 537.

18. See *id.* at 525.

19. R.M. Green, B. Gert, and K.D. Clouser, "The Method of Public Morality versus the Method of Principalism," *Journal of Medicine and Philosophy*, 18 (1993): 479–91.

20. S. Callahan, "An Ethical Analysis of Responsible Parenthood," in A.M. Capron et al., eds., *Genetic Counseling: Facts, Values and Norms* (New York: Alan R. Liss, 1979): 217–38.

21. J.P. Kahn, "Genetic Harm: Bitten by the Body that Keeps You?," *Bioethics*, 5 (1991): 289–308.

22. See Heyd, *supra* note 15, at 44–45.

23. J. Feinberg, "The Child's Right to an Open Future," in W. Aiken and H. LaFollette, eds., *Children's Rights, Parental Authority, and State Power* (Totowa: Rowman and Littlefield, 1980): 124–53.

24. See Twiss, "Parental Responsibility for Genetic Health," *supra* note 11, at 9.

25. J.D. Arras, "Having Children in Fear and Trembling," *Milbank Quarterly*, 68 (1990): 53–82; W.R. Cohen, "Maternal-Fetal Conflict, I," in A. Goldworth et al., eds., *Ethics and Perinatology* (New York: Oxford University Press, 1995): 10–28; P.H. Jos, M.F. Marshall, and M. Perlmutter, "The Charleston Policy on Cocaine Use During Pregnancy: A Cautionary Tale," *Journal of Law, Medicine & Ethics*, 23 (1995): 120–28; and R. Macklin, "Maternal-Fetal Conflict, II," in Goldworth et al., eds., *id.* at 29–46.

26. I.K. Jordan, "Ethical Issues in the Genetic Study of Deafness," in R.J. Ruben, T.R. Van De Water, and K.P. Steel, eds., "Genetics of Hearing Impairment," *Annals of the New York Academy of Sciences*, 630 (1991): 236–39.

27. K.S. Arnos, J. Israel, and M. Cunningham, "Genetic Counseling of the Deaf: Medical and Cultural Considerations," in Ruben, Van De Water, and Steel, eds., *supra* note 26, at 212–22; J.B. Christiansen, "Sociological Implications of Hearing Loss," in Ruben, Van De Water, and Steel, eds., *supra* note 26, at 230–35; E. Dolnick, "Deafness as a Culture," *Atlantic Monthly*, 272 (1993): 37–53; and A. Solomon, "Defiantly Deaf," *New York Times Magazine*, Aug. 24, 1994, at 38–45, 62–68.

28. See Kelly, *supra* note 9.

29. L. Sawisch, "A Different Approach," in S. Ball, ed., *Strategies in Genetic Counseling: The Challenge of the Future* (New York: Human Sciences Press, vol. 1, 1988): 96–108; A. Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities," *American Journal of Law & Medicine*, XXVII (1991): 15–50; A. Asch, "The Human Genome and Disability Rights," *Disability Rag & Resource*, Jan./Feb. (1994): 12–15; and M. Saxton, "Commentary on 'Society's Diseases,'" *Hastings Center Report*, 26, no. 3 (1996): 22.

30. D.C. Wertz, "Ethical and Legal Implications of the New Genetics: Issues for Discussion," *Social Science and Medicine*, 35 (1992): 495–505.

31. See Kitcher, *supra* note 5, at 236–37.

32. A.G. Motulsky and J. Murray, "Will Prenatal Diagnosis with Selective Abortion Affect Society's Attitude Toward the Handicapped?," in K. Berg, ed., *Research Ethics* (New York: Alan R. Liss, 1983): 277–91.

33. D.C. Wertz and J.C. Fletcher, "A Critique of Some Feminist Challenges to Prenatal Diagnosis," *Journal of Women's Health*, 2 (1993): 173–88.

34. See *supra* note 11.

35. A.L. Caplan, "Neutrality is Not Morality: The Ethics of Genetic Counseling," in Bartels, LeRoy, and Caplan, eds., *supra* note 6, at 158.

36. See Robertson, *supra* note 12.