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The Relevance of Benefit: Competing Notions of What Justice Requires¹

Gary Atkinson

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Prologue

One might have to think back as far as 1968 and the shootings of Martin Luther King and Robert Kennedy to find a death which so gained the attention and ire of the nation as that of a nameless male infant in Bloomington, Indiana. The child died April 15, 1982 as a result of a decision by parents and physician not to remove an obstruction in his esophagus blocking food from entering his stomach. Although the blockage could have been corrected by relatively simple surgery, the procedure was not performed because the infant was believed afflicted with Down's syndrome. The child lived six days without food or fluids, and died before an appeal could reach the United States Supreme Court, alleging that the refusal of treatment represented a denial of the infant's constitutional right of due process. The evidence indicated that the infant almost certainly did have Down's syndrome. But chromosome studies, the only means of being absolutely certain of the diagnosis, were not done.

Apparently in response to the controversy surrounding this infant's death, the Office for Civil Rights of the Department of Health and Human Services (HHS) issued May 18, 1982 a "Notice to Health Care Providers." The "Notice" warned that it was a violation of Section 504 of the Rehabilitation Act of 1973 to withhold food or medical treatment from a handicapped infant if "(1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated." The relevant part of Section 504 states that "no otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." The "Notice"

warned that failure to respect 504 could result in loss of federal funds for the offending institution.

On March 7, 1983 the Office of the Secretary of HHS issued an "Interim Final Rule" which came to be known as the "Baby Doe Rule" owing to its perceived connection with the Bloomington "Infant Doe" case. The purpose of the "Rule" was to add to regulations implementing Section 504: (1) the protections afforded handicapped infants were to be brought to the attention of health professionals and others who would be likely to know of the occurrence of possible violations; (2) speedier investigation of alleged violations was provided for, since the requirement of a 10-day waiting period in the 1973 Act would often preclude action in time to save the lives of infants being discriminatorily withheld from treatment; and (3) round-the-clock access to hospital records to assure compliance was required.

Since the stated ultimate purpose of the "Interim Final Rule" was to save the lives of handicapped infants, and since the Secretary believed that those who had knowledge of violation of Section 504 might lack opportunity to provide immediate notice to federal officials, the "Rule" required that a notice be posted in delivery, maternity, and pediatric wards giving the relevant information regarding Section 504 and declaring that "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law." The notice also was to list the number of what came to be called the "Baby Doe Hotline," a toll-free number open 24 hours a day where HHS could be reached by anyone "having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care."

The "Interim Final Rule" took effect March 22, 1983. It received wide attention and vehement criticism, particularly from the medical profession. Suit was brought in federal court to block implementation of the rule, and a stay was issued April 22. In response to the opposition from the medical profession, the Secretary issued, on July 5, 1983, a new set of "Proposed Rules." Instead of setting a date on which the rules were to be implemented, the document merely specified that comments on the proposal be submitted by September 8. The "Proposed Rules," contained the major points of the "Interim Final Rule," but added the requirement that state child protective agencies be involved to assure greater compliance with state laws prohibiting child abuse and neglect.

On Jan. 12, 1984, the Secretary of HHS issued its "Final Rule" to take effect Feb. 13. As a result of nearly 17,000 comments submitted in response to the "Proposed Rules," a few changes were made regarding the required notice and certain enforcement procedures. Also, greater attention was given to the possible usefulness of Infant Care Review Committees in developing appropriate standards and in making decisions about specific cases. But the fundamental principles embodied in the "Interim Final Rule" and the "Proposed Rules" remained unchanged.

This paper examines the HHS documents in order to explicate the Reagan administration's understanding of the requirements of justice for the defective newborn. Although the guidelines may, in fact, be the best means available for assuring that justice is done, it will be argued that the underlying ethical principles are inadequate in failing to take account of morally relevant considerations that are defensible in justice and sanctioned by the Church's official teachings.

What Justice Requires

This paper assumes, without argument, that newborns fall within the scope of justice and that the age of a born human being is by itself no more morally relevant than race, sex, IQ, or physical strength or beauty.² If this position be granted, then it may seem obvious that a serious injustice was done in Bloomington. This paper argues for that view. But let us begin by considering how one might, while admitting that infants fall within the scope of justice, offer one of two defenses for the way Infant Doe was treated.

First, one could appeal to what may be called an "absolute quality-of-life" standard, holding that there are certain lives so low in quality that the person would be better off dead, and that one might be doing him an actual injustice by allowing him to live (i.e., the assertion underlying "wrongful life" suits). Then one would have to claim that a person with Down's Syndrome meets whatever conditions there are for possessing such a "negative quality of life."

Set aside the objection that no confirming tests were undertaken to verify the diagnosis of Down's syndrome in the case of Baby Doe. Set aside, too, the point that Down's syndrome displays considerable variation in its expression from severe retardation to borderline normal, with the vast majority falling in the range of moderate retardation. There remain two general objections to such an approach.

There is one serious objection which can be brought against *any* absolute quality-of-life standard: there is, in fact, no consensus about what makes a life not worth living. The judgment that a given individual's life is not worth living is subjective and idiosyncratic in the extreme. It is a judgment that could be called "ideological" in expressing a particular conviction regarding the meaning of human existence. What one person finds tolerable another finds intolerable. Second, empirical studies of individuals actually afflicted with Down's syndrome show that they do not share the view that life with that condition is not worth living.

Thus, what appeals to an absolute quality-of-life standard comes to in this case is a position favoring the killing of a non-consenting human being by a second person using a quality-of-life standard the victim himself would be unlikely to share. If we examine what justice requires for a moment from a Kantian perspective and if we were to conduct the thought experiment of designing rules for a society in which we are to be born and live, we would certainly not adopt a rule permitting such killing. The

adoption of this rule will be seen to be even more unjustifiable when we reflect on the possibility that the person making such negative quality-of-life judgments for the helpless individual might be in the position of being required to care for him if he is not killed. For example, the parent who uses an absolute quality-of-life standard to judge his child's life not worth living is precisely the one who would incur the cost and other burdens of care if the child does not die. The possibilities for bias and gross abuse are manifest.

An alternative defense of the Bloomington case would be to admit this serious moral objection to the use of any absolute quality-of-life standard, at least when it is imposed on someone who has not already expressed his views. Still, one could maintain that the objection is considerably lessened when appeal is made to a "relative quality-of-life" standard. The point of such a standard is simply to make explicit what we all recognize: that physical and mental normalcy is preferable to physical impairment or mental retardation, that it is better to walk on two legs than to get around in a wheelchair, better to have the mental capacity to read a book than not to have it. The reason why from a Kantian perspective the use of such a standard is not unjust is that it is one to which, within rough limits, we all can agree.

What follows from the use of a relative quality-of-life standard is the conviction that we benefit a person more by restoring him to normal health and functioning than if we leave him in a more or less seriously impaired condition. This must be distinguished from the view that we do the person no good at all. That would be a judgment expressive of an absolute quality-of-life standard. It is one thing to say that a mentally defective individual has a low quality of life. It is quite another to suggest that the individual's quality of life is zero or negative. For instance, using a relative quality-of-life standard, we would have to say about Karen Ann Quinlan that her quality of life was low and that we were doing her relatively little good in keeping her alive. But, since Karen herself did not tell us, we could not say that we were doing her absolutely no good at all. The issue here is not the truth of these judgments but the justice of acting on them when their acceptance by the party most involved is in doubt.

One Step to Complete Defense

Now there remains one more step to complete the second defense of the non-treatment of the Bloomington Baby. This is the principle that the help we are required to render in justice normally depends on four features: (1) the significance of the good that can reasonably be expected; (2) the degree of harm caused by the rendering of aid for the person being thus "aided"; (3) the degree of burden that must be assumed by those providing aid; and (4) the nature of the relationships among the parties. For instance, justice may require us to stop and render aid to someone involved in a serious accident, but we would not be required in justice to help him change a flat tire. A surgeon may be required to operate on a patient, but not if there is

no anesthetic available. Although we may not have a duty in justice to save a stranger's life at the risk of our own, we might have one if the only cost of doing so is that of being late for an appointment. And we would blame a parent who refuses to pay the cost of educating his child, though we would not blame a stranger for refusing.

Use of relative quality-of-life standard also is sanctioned by authoritative Church teachings. Pope Pius XII's famous 1957 statement on the "Prolongation of Life" makes it clear that the Christian duty to preserve life depends on the context:

But normally one is held to use only ordinary means — according to circumstances of persons, places, times and culture — that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends.³

The idea of not being obliged to assume a "grave burden" in prolonging life receives expansion in the Sacred Congregation for the Doctrine of the Faith's 1980 "Declaration on Euthanasia." Instead of employing the phrase "ordinary means" to refer to obligatory therapies, the "Declaration" focuses on the distinction between "proportionate" and "disproportionate" means:

It will be possible to make a correct judgment as to the means by studying the type of treatment used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.

It is also permissible to make do with the normal means that medicine can offer. Therefore one cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or community.⁴

The language of "means that do not involve any grave burden for oneself or another" in the 1957 statement becomes "a medical procedure disproportionate to the results that can be expected" in the 1980 document. But three points seem clear in both statements: (1) that decisions regarding the obligatoriness of certain treatments are context-dependent; (2) that the burdens imposed on others of providing treatment may legitimately be taken into consideration; and (3) that the degree of expected benefit to the patient is another morally relevant consideration. The Church's official teaching is perfectly consistent with secular notions of justice in this regard.

Thus, on both secular theories of justice and historical Catholic principles, the obligation one has to preserve another's life is relative to a proportion between the benefits expected and the burdens imposed. And if

appeal to proportional benefit can indeed be justified, then a defense of letting Infant Doe die could be offered as follows. A rejection of an absolute quality of life standard prevents us from saying that we harm Infant Doe by letting him live. But we can say that we will do him less good by preserving his life than by preserving the life of a completely normal child. If we join with this the point that caring for a child with Down's syndrome can be particularly onerous both for parents and society, we can see how one might claim that the ratio of benefit to cost is too low to mandate treatment. Society clearly has no obligation to spend \$10,000,000 to restore a human being to normal functioning. Nor do we as a society have the responsibility to expend the effort necessary to raise a child with Down's syndrome.

It bears noting that this argument about what is required in justice is *not* necessarily utilitarian. It is not even necessarily consequentialist, if that term be taken to refer to the thesis that consequences alone matter. This argument does not maintain that allowing the child to die is justified because overall social utility will be thereby maximized. Nor is it argued that the benefit to society is too small to justify the expenditures. Rather, the claim is that the expected benefit to the child himself is too small relative to the cost to require treatment. If one rejects the propriety of this line of reasoning, it will be difficult if not impossible to escape the conclusion that justice does indeed require the spending of \$10,000,000 to save a life.

The major defect with the argument in this case is not its form or the moral relevance of the considerations it advances, but simply the plausibility of its principal premise, that the expected benefit to the child is too low, given the burden of care, to require treatment. Caring for a child with Down's syndrome is no doubt more difficult than for the average child, but how many physically and mentally normal children for a number of reasons impose a burden on their parents and society equal to or greater than that posed by children with Down's syndrome? And as for benefit, individuals with Down's syndrome seem to value their own lives as much as normal people value theirs.

If it be objected that such individuals are mentally too deficient to make correct judgments in this area, we might well ask how *that* assertion could be defended. And we might note the many seriously physically handicapped persons who find great value in their lives. A Christian will recognize the defective child as the object of God's enduring love. And even from a secular viewpoint, a spirit of tolerance, while recognizing the desirability of physical and mental normalcy, will not be quick to denigrate the goodness of persons' lives, especially when their possessors find them good. And finally, from a Kantian perspective, it simply does not appear credible that an individual who sets aside his own idiosyncratic values should choose for a society in which he was to be born and live, a policy that would allow infants with Down's syndrome to die at the wishes of their parents. An adult with a full formed set of idiosyncratic values might very well honestly say, "If I were an infant with Down's syndrome I would

not want to live," but justice cannot permit the imposition of such values on another person.

The "Baby Doe" Guidelines: What Justice Does Not Require

The language of all the HHS documents is the language of nondiscrimination. The "Proposed Rules" are filled with such references. For instance, there is mention of the need for "expeditious investigation and immediate enforcement action when necessary to protect a handicapped infant whose life is endangered by discrimination."⁵ The document declares that the "discriminatory failure of health care providers to feed a handicapped infant or to provide medical treatment essential to correct a life-threatening condition" is a violation of Section 504 of the Rehabilitation Act which "requires that health services be provided to the handicapped on a basis of equality with those not handicapped".

The key to the Reagan administration's position and an indication of where its weakness lies can be found in this paragraph:

Section 504 is in essence an equal treatment, nondiscrimination standard. Congress patterned Section 504 on Title VI of the Civil Rights Act, which prohibits discrimination based on race. Programs or activities receiving federal financial assistance may not deny a benefit or service solely on grounds of a person's handicap, just as they may not deny a benefit or service on grounds of a person's race.⁶

This analogy between the handicapped person and the person discriminated against on the basis of race is revealing. If we think racial discrimination wrong, it is because we assume either (1) that the service being denied members of the disfavored race would be at least roughly as beneficial to them as it is to the persons receiving the service or (2) that there exists an alternative service which would be as valuable. And we also think this discriminatory behavior wrong partly because it results from a spirit of hate or callous indifference towards the disfavored race rather than for some morally defensible reason. The contention that a service denied members of one race would not benefit them and cannot be substituted for by an alternative service would, if true, be an effective response to any charge of racial discrimination. Thus, if an analogy between racial discrimination and the withholding of care for handicapped infants is to be sustained, it will need to be shown (1) that there exists at least some beneficial service being denied handicapped infants and (2) that denial of the service has no morally defensible explanation.

The history of judicial interpretation of Section 504 shows an awareness of the first point. That section contained reference to an "otherwise qualified handicapped individual" without an explanation of the significance of the phrase "otherwise qualified." A 1979 Supreme Court decision clarified this language by declaring such a person to be one capable of benefitting, in spite of his handicap, from the program offered. The issue, then, as Section 504 is applied to the care of handicapped

infants, is which infants are "otherwise qualified," i.e., are capable of benefitting from the services being offered to others, but denied them.

The position of the Reagan administration on this point is clear. The "Final Rule" states:

In the context of receiving medical care, the ability to benefit for a handicapped person is the ability to benefit medically from the treatment or services. If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's present or anticipated physical or mental impairments, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that health care providers may not, solely on the basis of present or anticipated physical or mental impairments of an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.⁷

This does not mean, though, that handicapped infants must be given all treatments that would ordinarily be provided normal children:

These interpretative guidelines make clear that . . . futile treatments or treatments that will do no more than temporarily prolong the act of dying of a terminally ill infant are not required by section 504, and that, in determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.⁸

Although it would be permissible, for example, not to engage in surgery to prolong the life of an anencephalic infant who will die soon, whatever is done, treatment may not be withheld because of cost ("cost should not be a determinative factor in deciding upon treatment for seriously impaired newborns")⁹ or because of the burden of care imposed on the family ("excluding consideration of the negative effects of an impaired child's life on other persons").¹⁰

Now there is much that is right with the position of the Reagan administration. In spite of some self-serving statements from the medical profession, there does exist a significant bias against handicapped infants which renders them victims of unjust undertreatment. It is possible to disagree about the frequency of such occurrence. But how many of those who contend that the problem is minor would be content with the remark that political oppression in American society constitutes a minor problem because there are so few genuinely political prisoners in our jails? The very legitimacy of the American system rests upon its concern for justice *for all*. And although there are limits to what any human institution can be expected to accomplish, we cannot afford to take lightly any institutional injustice — injustice which is perpetrated *through* our institutions rather than *in spite* of them.

But there is a weakness, too, in the Administration's position, one suggested by the analogy drawn with racial injustice. We assume that

providing second-rate schools for blacks is wrong because we believe not only that they could benefit from better schools but also that not providing better schools results from racist attitudes. In other words, we oppose second-rate schools for blacks as unjust because we think that there is no morally defensible reason for not providing better ones.

The Reagan administration's position comes close to the suggestion that there is *no* morally defensible reason for withholding from the handicapped infant medically beneficial treatment which would ordinarily be given to the normal child. But it would seem that the assumption ought to be that whatever considerations are deemed legitimate within a general theory of justice are also defensible *mutatis mutandis* when dealing with the care of infants, defective or normal. Consider once again the four reasons cited above with possible applications to pediatric medicine: (1) no benefit at all can reasonably be expected from the proposed therapy (e.g., the infant will die soon whatever is done); (2) the benefit is too low to justify the harm done (e.g., a Tay-Sachs child requires cardiac surgery); (3) the cost of rendering aid is too heavy to require its imposition (e.g., the child needs a liver transplant in order to live); and (4) the relationship among the parties does not impose a given duty (e.g., an overworked surgeon refuses to perform an operation on an infant not his patient). These are legitimate considerations within a general theory of justice, and though they no doubt create special problems in the practice of pediatric medicine, this is no reason for thinking them inappropriate or unjust. Surely the burden of proof ought to be on those who admit the general moral relevance of these considerations but deny their acceptability in determining the ethically mandated care of the defective child.

It may be objected that no one is upset over decisions not to engage in cardiac surgery for a child with Tay-Sachs or not to seek a liver transplant for an anencephalic infant. What is bothersome because unjust, are decisions like the one in Bloomington, to withhold simple surgery for children with Down's syndrome. But if one examines the cases which actually generate the greatest moral uncertainty as opposed to controversy (egregiously wrongful acts are often highly controversial), one finds that such cases are not instances of withholding food and fluids from children with Down's syndrome. The cases which create the most moral uncertainty are precisely ones in which there exist general moral considerations favoring discontinuance of treatment, but for which the HHS guidelines would seem to mandate continued therapy.

A Case

To illustrate the point that the Reagan administration's requirements may conflict with general considerations of justice, consider the following true case, one which is unfortunately not atypical.

An infant (let us call him Robert) was admitted to a neonatal intensive care unit (NICU) shortly after birth. He weighed 960 grams at birth, with a heart rate, respiration, and blood pressure of zero and a body temperature

of 93 degrees. He was diagnosed as having perinatal asphyxia for an undetermined length of time. Robert has been at the NICU for more than three months. During that time he has experienced recurrent periods of slow heartbeat (bradycardia) and loss of spontaneous breathing (apnea). He has been placed on and taken off a respirator several times. Robert has a bulging fontanelle and was diagnosed as having had an intracranial hemorrhage. A CT-scan and an EEG have revealed some abnormalities. Robert neither sucks nor swallows. In the middle of the fourth month after birth, a neurological examination shows probability of "significant neurological involvement." The best the neurologist is willing to hazard for Robert is that he will be of low normal intelligence. The child has had seizures and was placed on phenobarbital until it was discontinued when the doses became toxic. Use of the respirator has damaged the child's lungs, and there is some fear that continued use of the tube through which he is fed will cause constriction of the trachea. Robert has contractures which make a neurological examination difficult. He has developed scurvy and rickets. The neurological examination suggested that the child might grow out of his apnea and bradycardia. The seizures appear likely to continue but may be partially controllable. None of the attending professionals believe Robert is dying, though his overall prognosis is "very poor." His mother seems willing to take Robert into her home, but she is young and unmarried and lives with her mother in a house with no running water, phone or electricity. A phone is available at the home of relatives, about one mile away. They have a car, but it is unreliable. The social worker on Robert's case doubts whether the mother will be able to provide the medical care that would become necessary in an emergency.

The HHS guidelines maintain it to be a violation of Section 504 for a recipient of federal funds

to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if:

- (1) the withholding is based on the fact that the infant is handicapped; and
- (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.¹¹

If Robert develops apnea while he is off the respirator, should we place him back on? Do we have a legal or moral duty to do so?

We may begin to answer these questions by examining them from the point of view of the Reagan administration. We would first need to know whether Robert counts as an "otherwise qualified handicapped infant." It would be most implausible to suggest that he does not. Robert is not dying, though the respirator is occasionally necessary to prolong his life. The fact that Robert only occasionally needs respiratory support indicates that his lungs are not irreversibly damaged. He may grow out of his periods of apnea and bradycardia. Is use of the respirator "medically contraindicated"? No. It is true that the respirator may have impaired Robert's lungs, but this is common and recovery is quite possible. The alternative to use of a respirator now is a quick death by asphyxiation. If we were to

decide not to resuscitate Robert should he once again develop apnea, would this be based on the fact that Robert is handicapped? It must be. Use of the respirator is standard practice in NICU's. Only his poor prognosis for mental normalcy and the difficulties his care is likely to encounter at home, not any terminal illness, explain why anyone would think twice about withholding treatment. Thus, it appears inescapable that, according to the Reagan administration guidelines, not returning Robert to the respirator would be a violation of Section 504.

Bu are we morally obliged to re-institute respirator therapy? A case can be made for a negative answer, one consistent with Church teaching. First of all, we need not and should not maintain that Robert's life is not worth living. We would simply say that we had already done enough for Robert, more than could be demanded by justice. The prospect for significant benefit to Robert is slim. The burdens already assumed by the provision of care are large, to say nothing of the suffering to which we have subjected Robert. The ratio of expected benefit (Robert's) to cost (both for Robert and others) is too small for treatment to be required in justice. To deny legitimacy of considering the proportion of burdens to expected benefits in the care of defective newborns would be (1) to assign them a special status possessed by no other human being and (2) at the same time to subject them to the danger of requiring painful therapies no matter how poor the prognosis.

Without suggesting that the Church's principles *require* the non-treatment of Robert, we may still insist that nothing in the Church's position requires treatment, either. As Pope Pius remarked, life and all temporal activities are subordinated to spiritual ends. We owe Robert, as we owe any helpless person, the type of care we would think obligatory in our own case. But since we have no duty to impose excessive burdens on ourselves or others to preserve our own life, there are limits to what can in justice be imposed on us for the care of others.

The Reagan administration has acted to remedy a serious injustice occurring in the care of the most helpless among us. Reasonable people may well disagree on the best way of seeing that justice be done. This paper has not been concerned to evaluate the workability of the guidelines, but to examine the defensibility of the underlying principles. It may very well be the case that in order to assure that injustices like the one in Bloomington not occur, the procedures to be implemented *must* exclude relative quality-of-life assessments or consideration of the burden of care for family and society. But even if this were true, it is a suggestion that needs argument and should not be assumed at the outset. Also, it is one thing to say that certain morally acceptable principles cannot be applied in a given context because of their unworkability or danger of abuse. It is quite another to maintain that those principles are themselves improper and that appeal to them displays a poor sense of justice. This paper has been concerned to show simply that considerations excluded by the HHS documents are defensible within a general theory of justice and are consistent with Church

teaching. The wisdom of their employment within the context of perinatal medicine has not been addressed here.

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