# Not for the Law to Approve or Disapprove—A Comment on Professor Mnookin's Paper*

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In my comment on Professor Mnookin's paper I intend to discuss what ought and ought not to be the function of law in supervening parental wishes about medical care for their newborn child. I will reach conclusions and make recommendations similar to Professor Mnookin's, but I arrive at them by a somewhat different route. I am not qualified to and I will not discuss the political observations and assessments that he makes.

Law, in a democratic society, is meant not to confuse, but to clarify for each of us in ordinary language the extent to which the state intends to restrict our freedom to decide. As parents, we decide what medical care to give our newborn child; as doctors, we decide what care to provide or even to impose without regard to parental wishes. The words of a statute should provide the basis upon which ordinary citizens can know the extent to which they are free to decide. Legislatures ought not make their statutory answers obscure.

And although their statutes may be clearly written, legislatures must not operate on the assumption that only we as members of some professional elite are entitled to know that the laws do not really mean what they say—that they are not expected to be enforced. I cannot embrace as *prescription* Professor Mnookin's endorsement of the Thurman Arnold statement that laws "are enforced because we want to continue our conduct, and unrepealed because we want to preserve our morals."[1] I do not

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1. T. Arnold, The Symbols of Government 160 (1935). Unfortunately, this sentence and the two sentences introducing it may describe and possibly even explain the state of law. "No way has yet been discovered of preventing moral attitudes from persisting long after they are in direct conflict with human behavior. Most unenforced criminal laws survive in order to satisfy moral objections to established modes of conduct." *Id.* at 159-60.



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and cannot share with Mnookin the view that this ought to be the way in which legislatures should perceive the law.

On the other hand, the use of coercive force by the state to impose some belief contrary to that held by parents about medical care for their child, or contrary to that held by the doctors of their choice, must rest on a very substantial societal consensus. On this proposition concerning the actual use to which the power of the state should be put, Professor Mnookin and I are probably in agreement. What we disagree upon is whether the law on the books should, as I believe, reflect accurately that consensus and no more. There should be no place in these laws for conscious ambiguity about their meaning or their enforcement.

An examination of the problem must begin with identifying the relationship of parent and child in law and their relationship to the state. To be a *child*, particularly an infant child, is to be at risk and to be dependent and without the capacity or authority to decide what is "best" for oneself. To be an *adult* is to be a risk-taker, independent and with the capacity and authority to decide what is "best" for oneself. To be an *adult who is a parent* is to be presumed in law to have the capacity, authority and responsibility to determine and to do what is good for one's children. Indeed, the child has a right to parents who have and assume full responsibility for making life and death judgments on his or her behalf. The law must protect parental autonomy to make those decisions which they, as the child's representative, think are best for their child, for their other children, for their family. The law must safeguard that arena of privacy that we call the family. Legislatures and courts must stay the long arm of the law and of private, well-intentioned do-gooders from breaching family integrity, from tearing the delicate and complex fabric of human relationships that is the family. To make that observation is also to recognize that adults can exploit their children, that the family may become a cover for such exploitation, and that the state may have reason and justification for intervening when a societal consensus is reflected in law that what the parents are or are not doing is wrong.

We recognize however—here Professor Mnookin and I agree—how enormous is the confusion—philosophically, ethically and politically—about what is the right or what is the wrong decision for parents whose consent is sought for "life" sustaining or "life" supporting medical intervention for their newborn child. That there is no societal consensus is, we would agree, solid evidence for denying the state the authority to use its coercive power to impose someone's notion of the "only right" course upon an infant whose parents have chosen otherwise. Respect for the dignity of parents as human beings and for the integrity of family as a human institution dictates that there be a strong presumption against

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state intervention and in favor of honoring the enormously difficult decisions that parents must sometimes make about medical care for their children. As one such parent observed:

> My husband and I would have done anything to save that baby's life, to make her better. In the hours that followed we had hope that operations could be performed: we consoled each other with stories of remarkable children we had both known who were retarded or had birth defects.
>
> However our hopes were soon dashed. . . . Nothing could be done to fix her heart and lungs or her wrist or her inability to suck. "This is one of nature's lousy tricks," a young resident told us. But we were the parents. We were responsible. . . . We cared for her and faced our responsibilities. Luckier than some other Does, we had no choice but to wait. However, those other Does are not shirking their responsibilities. They are trying to figure out, sanely and rationally, what will be best for their babies. They do not need squads of government inspectors or lawyers or judges to tell them what to do. The squads and lawyers and judges will have no part in the raising of these Baby Does, and it is inappropriate for them to be a part of the agonizing decisions. In the rare cases where parents behave irresponsibly, there are trained, compassionate doctors to make those decisions. After the babies die, the issue is not closed. Our children will have to undergo amniocentesis and prenatal testing because there has been a "genetic failure" in our family. And they will know what to do, just as we did. They will not need a Big Brother to guide them.[2]

Hardly more need be said about what ought to be beyond the limits of law. To say this is not to maintain that parents will always make the "right" decision—the decision you or I would reach. It is to say that the absence of societal agreement about what is a right or wrong decision should reserve that decision to the parents. To so reserve it means to protect parental decisionmaking and the decision itself from automatic review by agents of the state, by legislatively mandated hospital committees, or by self-appointed private investigators. The birth of a baby Doe is, by itself, no justification for state intervention—no justification for intrusion on the privacy of the family. Thus, precisely because there is no objectively wrong or right answer, the burden must be on the state to establish *wrong*, not on the parents to establish that what is *right* for them is necessarily right for others. Thus the state, prior even to conducting an investigation that intrudes on a particular family, must know not only the definition of a wrong decision but also that there is probable cause for

2. Anonymous, *The Parents Doe*, THE NATION, Feb. 25, 1984, at 213.

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believing that a wrong decision has been made.

Apparently the newborn infant's right being discussed is not his or her right to extraordinary medical intervention to prevent death. Rather it is only a right *not to have* his or her parents but to have other adults called judges or members of hospital committees make the "life" or "death" decision. Since society cannot agree on guidelines for these parent substitutes, there is no justification for taking away from parents, who may or may not wish to seek outside counsel, the decision that is theirs to make for their child. There is nothing to suggest that the ethics of the mothers and the fathers are diminished by the birth of their child, or that other adults, who may themselves be parents, are better qualified to make the hard decisions just because the legislature designates them "judge" or "member" of a hospital review committee.

The requirement that the language of law be clear, precise and unambiguous about what it mandates and under what circumstances it may intrude on the private ordering of our lives is meant to serve two functions: one, to restrain the exercise of state power by declaring the extent, nature and limits of the state's authority to invade parent-child, doctor-patient and family relationships; and two, (at the same time and with the same language) to give fair warning to each of us as parents or as health care professionals of the limits the state has placed upon the decisions that we may make about medical interventions for newborn infants. I would not, as I think Professor Mnookin would, rely on Arizona's neglect and child abuse statutes to resolve the question we confront at this conference. On their face and without regard to what courts may have ruled, the language of those statutes does not satisfy the power-restraint and fair-warning standards essential to safeguarding family integrity, parental autonomy and the child's right to autonomous parents.

If there is to be state intervention, I would be inclined toward using language not unlike that in the new Arizona statute.[3] I would, however, oppose such a statute myself, because I do not believe there is a real consensus here or anywhere else about these matters. These deliberations attest to that. On the other hand, a presumption of consensus goes, at least conceptually, with the adoption of a position by the legislature. The appeal of the statute is that it declares in rather precise and specific language the extent to which discretion is to be taken from parents. It does not place the decision in a bio-ethics committee. It does not transfer parental discretion to some officially mandated committee to determine the

3. ARIZ. REV. STAT. ANN. § 36-2281 (Supp. 1975-84); *see* ARIZ. REV. STAT. ANN. § 13-3620 (Supp. 1984-85); ARIZ. REV. STAT. ANN. § 36-2281, -2284 (Supp. 1975-84).

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right answer on a case-by-case basis. I say this because the committees that have been discussed are left without guidelines for determining what is right or wrong. Of course, I think that this so because we cannot find guidelines about which we would agree. Thus I come back to saying that it is better to leave the discretion—the difficult decision—with parents than to turn it over to some other adults.

Sometime ago we—Anna Freud, Albert Solnit and I—suggested language that might be used in a statute authorizing the state to intervene when parents refuse medical care for their child.[4] That language does not quite meet our standards for power restraint and fair-warning. We proposed that state intervention would be justified (a) if medical experts agree that the refused treatment is non-experimental and appropriate for the child, that is, there is no conflict among the experts about the appropriateness of the medical recommendation *and* (b) if denial of the treatment will result in the death of the child *and*—this is the difficult part—(c) if the treatment can reasonably be expected to result in what society would want for every child, a chance for normal healthy growth or *a life worth living.* The problem lies in construing the meaning of the phrase "a life worth living". The cases on which we are focusing do not concern infants who expect normal healthy growth toward adulthood when, as adults, they can decide what is best for themselves without regard to parental control or without regard to some other adult making critical judgments on their behalf. But I would suggest that the *Doe* case to which Professor Mnookin and others have referred may well fit into the "life worth living" category, and that through case law meaning might in time be given to that phrase. Of course, there must be more than a common understanding about the meaning of "a life worth living". If society insists through law that these children receive medical treatment rejected by their parents, the state must be ready to provide the special financial, physical and psychological resources essential to making *real* for the child it "saves" *the value it prefers.*[5]

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4. *See* BEFORE THE BEST INTERESTS OF THE CHILD 91-109, 194 (1979).

5. For an interesting English decision on this issue see, *In re* B. (A Minor) [1981] 1 W.L.R. 1421, 1423-24 (C.A.) (Templeman, J.):

> [I]f this little girl does not have this operation she will die within a matter of days. If she has the operation there is a possibility that she will suffer heart trouble as a result and that she may die within two or three months. But if she has the operation and it is successful, she has Down's syndrome, she is mongoloid, and the present evidence is that her life expectancy is short, about 20 to 30 years.
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> The parents say that no one can tell what will be the life of a mongoloid child who survives during that 20 or 30 years, but one thing is certain. She will be very handicapped mentally and physically and no one can expect that she will have anything like a normal existence. They make that point not because of the difficulties which will be

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Thus, one of the limitations on the justification for intervention is that the state may intervene only if it is prepared to assure that the situation will be made better, not worse, for the child. If the parents will not or cannot assume responsibility for the new burdens—if you will, for the extraordinary demands on the limited amount of "bread" that they have for their family[6]—and if the state is unwilling to fully provide for the child's care, there is no justification for intervention. The state must be able and prepared to provide the child with a permanent family—not an institutional warehouse—that wishes to give the "saved" child the nurture, affection, stimulation and continuity of care that are essential to a life worth living.

I have no idea what the family situation was in the Indiana *Doe* case nor do I have any idea what the state was willing to provide in terms of care opportunities for that child in the event intervention was authorized, so I am unable to be as emphatic as Professor Mnookin about the appro-

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> occasioned to them but in the child's interest. *This is not a case in which the court is concerned with whether arrangements could or could not be made for the care of this child, if she lives, during the next 20 or 30 years; the local authority is confident that . . . good adoption arrangements could be made and that in so far as any mongol child can be provided with a happy life then such a happy life can be provided.*
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> . . . .
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> On behalf of the parents, Mr. Gray has submitted very movingly, if I may say so, that this is a case where nature had made its own arrangements to terminate a life which could not be fruitful and nature should not be interferred with. He has also submitted that in this kind of decision the views of responsible and caring parents, as these are, should be respected, and that their decision that it is better for the child to be allowed to die should be respected. Fortunately or unfortunately, in this particular case, the decision no longer lies with the parents or with the doctors, but lies with the court. It is a decision which of course must be made in the light of the evidence and views expressed by the parents and the doctors, but at the end of the day it devolves on this court in this particular instance to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die. . . . Faced with that choice I have no doubt that it is the duty of this court to decide that the child must live. The judge was much affected by the reasons given by the parents and came to the conclusion that their wishes ought to be respected. In my judgment he erred in that the duty of the court is to decide whether it is in the interests of the child that an operation should take place (emphasis supplied).

6. Recall Mr. Jonsen's discussion of the moral significance act of an of omission as dependent upon the priority of obligations in a given situation.

> [I]f a starving person comes to your door and you have bread in the house, it is an omission not to give him that food. Is this a sin? If the householder has a family in a time of famine, Aquinas argued that he has prior duties to his children. Therefore, not to give bread to the stranger at the door is not a morally culpable omission. The omission/commission distinction therefore must be understood in relationship to an understanding of what obligations exist in a given situation.

Jonsen, *Traditional Distinctions for Making Ethical Judgments*, 1984 ARIZ. ST. L.J. 661, 662.

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priateness of that decision.

Going back to some of Professor Mnookin's earlier remarks, I sense with him that there is something precious and disproportionate about the amount of time in thought and in discussion that is being devoted to this particular matter. There is, however, something very gratifying about the extent of interest here and everywhere in the country. It is that we, as a society, are sensitive and alert to the needs of those who are handicapped. We will not ignore them. We do not treat them or think of them as appropriate subjects for extermination, but regard them as fellow human beings who deserve our concern and whose dignity we respect. At the same time, the notion of disproportion that Professor Mnookin raises must be confronted if only to assure ourselves that our concern for the Baby Does and their parents does not become a device by which we, as members of society, blind ourselves to the needs of those who are unable to provide sufficient food or medical care for themselves because of the way in which limited resources are distributed. We ought not feel too good about our involvement and investment in the matter that brings us together. It must not give us permission to ignore the extent to which there *is* hunger in society, a need that cannot be covered over by White House pronouncements to the contrary. There *are* starving children. Conferences such as this must not be used as an excuse for not dealing with society's failure to provide every human being with what most of us believe is minimally essential to "a life worth living".

I have one more comment about Professor Mnookin's paper. I do not see, as he does, that the only option for law is to *approve* or *disapprove* the withholding or withdrawal of care in the kinds of cases with which we are concerned. I see another choice open to the legislature and to the courts—a choice obvious once said—it is that the law ought not to be *invoked* to approve or disapprove. It is that the law must sometimes acknowledge, indeed declare, that it does not know what the conventional wisdom is. It is that the state recognizes that a *right* answer for you may be a *wrong* answer for me and that the *wrong* answer for you may be the *right* answer for me. That is, there is no universally wrong or right decision, independent of the family in which it is made. It is not that the state or society is indifferent, but that it has high regard for family integrity and parental autonomy. The great risk—the great danger—is not in the few "mistakes" that will be made by allowing the freedom to decide to be widely dispersed—to be left with the many decision-making units we call family. The risk to avoid is the massive mistake for society and especially for individual families that may result from centralizing the decision-making process or from dehumanizing family relationships by concentrating such personal and complex decisions in impersonal courts or legisla-

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tively mandated hospital ethics committees. The law should rely on the more personal, flexible and highly decentralized system of family decision-making, and the law must be open about its reason for taking that position. It must acknowledge that no one has the right answer for everyone or almost everyone, that legislatures do not know enough and cannot learn enough to justify their authorizing the use of coercive force to impose one answer on all parents or to provide adequate guidelines for courts or hospital review committees to exercise parental discretion for children not their own. Legislatures must not "cop out" by writing or by leaving unrepealed laws that are in conflict with custom and practice and that they expect not to be enforced.

I will close with an observation made by C.S. Lewis:

> Of all tyrannies a tyranny sincerely exercised for the good of its victims may be the most oppressive. . . . [T]hose who torment us for our own good will torment us without end for they do so with the approval of their own conscience.[7]

That view guides me in my thoughts, and I hope yours, about the limits of law and its relation to each of us.

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7. Lewis, *The Humanitarian Theory of Punishment*, 6 RES JUDICATAE 224, 228 (1952).

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