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Medical Care for the Child at Risk: On State Supervention of Parental Autonomy

Joseph Goldstein

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.¹

Introduction

To be a child is to be at risk, dependent, and without capacity or authority to decide what is “best” for oneself.

To be an adult is to be a risktaker, independent, and with capacity and authority to decide and to do 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.

The law is designed to assure for each child an opportunity to meet and master the developmental crises on the way to adulthood—to that critical age when he or she is presumed by the state to be qualified to determine what is “best” for oneself.² As Jeremy Bentham observed not so long ago in 1840:

The feebleness of infancy demands a continual protection. Everything must be done for an imperfect being, which as yet does nothing for itself. The complete development of its physical powers takes many years; that of its intellectual faculties is still

¹ Copyright © 1977 by Joseph Goldstein. This essay will be part of a forthcoming volume, Who Speaks for the Helpless?, now being prepared by the Behavior Control Research Group of the Hastings Center, Institute of Society, Ethics and the Life Sciences under a grant from the National Science Foundation. I wish to acknowledge the provocative assistance of my colleagues on the Proxy Consent Committee of the Hastings Institute and the research and editorial assistance of Benjamin Lopata and Jeff Thaler, students at the Yale Law School. I am also indebted to Lon Babby, Robert Burt, Owen Fiss, Sonja Goldstein, Neil Peck, Donn Pickett, and Albert J. Solnit for their criticism.

² Walton Haley Hamilton Professor of Law, Science, and Social Policy, Yale University and Professor, Yale University Child Study Center.

2. See Goldstein, On Being Adult and Being An Adult in Secular Law, 105 DAEDALUS, Fall 1976, at 69, 71-72.
slower. At a certain age, it has already strength and passions, without experience enough to regulate them. Too sensitive to present impulses, too negligent of the future, such a being must be kept under an authority more immediate than that of the laws . . . .

That "more immediate" authority is parental authority. Thus, society's law, in accord with nature's law, seeks to assure for each child permanent membership in a family with at least one and preferably two caretaking adults. The law, reflecting Bentham's view, has a strong presumption in favor of parental authority free of coercive intrusion by agents of the state. Indeed, it is a function of law to protect

3. 1 J. BENTHAM, THEORY OF LEGISLATION 248 (Boston 1840). Similarly, Freud observed: The biological factor is the long period of time during which the young of the human species is in a condition of helplessness and dependence. Its intra-uterine existence seems to be short in comparison with that of most animals, and it is sent into the world in a less finished state . . . . Moreover, the dangers of the external world have a greater importance for it, so that the value of the object which can alone protect it against them and take the place of its former intra-uterine life is enormously enhanced. This biological factor, then, establishes the earliest situations of danger and creates the need to be loved which will accompany the child through the rest of its life.

S. FREUD, INHIBITIONS, SYMPTOMS, AND ANXIETIES 139-40 (1926) (emphasis added).


5. The extent to which parental authority is protected by the Constitution is not of primary concern in this essay. Yet it should not go unrecognized that the Supreme Court has established that the Fourteenth Amendment protects, as a liberty interest, the very nature of family life. See Cleveland Bd. of Educ. v. LaFleur, 414 U.S. 632, 639-40 (1974) (mandatory maternity leave for teachers denial of due process); United States v. Orito, 413 U.S. 139, 142 (1973) (constitutional right of privacy includes right of marriage, procreation, motherhood, child rearing, and education); Roe v. Wade, 410 U.S. 113, 152-53 (1972) (right of privacy, founded in Fourteenth Amendment's concept of liberty, extends to child rearing and education); Wisconsin v. Yoder, 406 U.S. 205, 230-35 (1972) (parental right to direct religious education of child); Stanley v. Illinois, 405 U.S. 645, 651 (1972) (presumption that unwed father unfit to keep his children violates due process and equal protection); Griswold v. Connecticut, 381 U.S. 479, 485-86 (1965) (constitutional protection for marital privacy); Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1923) ("liberty" of parents to direct education of their children); Meyer v. Nebraska, 262 U.S. 390, 400-03 (1923) ("liberty" of parents to raise children). Under these cases, that interest extends from the very decision to conceive children and initiate a family to the right to direct a child's upbringing.

The traditional protection of the family relationship from state intrusion is also acknowledged in tort law by a general rule of reciprocal immunity for both parents and their minor children from liability for personal torts committed by them on one another, as well as a specific parental exemption for disciplinary efforts which otherwise would be perceived as intentional torts on these minor children. W. PROSSER, HANDBOOK OF THE LAW OF TORTS § 27, at 136-38 (4th ed. 1971) (citing cases both upholding immunity and rejecting immunity); see also J. GOLDSTEIN & J. KATZ, THE FAMILY AND THE LAW 399-408 (1965); W. PROSSER, J. WADE & V. SCHWARTZ, CASES AND MATERIALS ON TORTS 140-42, 639-51 (6th ed. 1976). Such immunity is further reinforced by penal statutes like the following from New York:

The use of physical force upon another person which would otherwise constitute an offense is justifiable and not criminal under any of the following circumstances:

1. A parent, guardian or other person entrusted with the care and supervision of a minor or an incompetent person, and a teacher or other person entrusted with the
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family privacy as a means of safeguarding parental autonomy in child rearing.\textsuperscript{6} At the same time the law attempts to safeguard each child's entitlement to autonomous parents who care and who feel responsible and who can be held accountable for continually meeting the child's ever-changing physical and psychological needs.

Like all authority, however, parental authority may be abused. Family privacy may become a cover for exploiting the inherent inequality between adult and child.\textsuperscript{7} Thus children who, by definition, are both physically and psychologically at risk may sometimes be placed at further risk by the adult "caretakers" who are presumed to be essential to their well-being.

This essay explores the role for law in protecting children from parental exploitation and parents and children within a family from state exploitation in the provision or denial of medical care. The goal is to determine the extent to which the law should supervene, not only the right and obligation of parents to decide what medical attention should or should not be provided for their children, but also the reciprocal right of children to have their parents assume responsibility for making such decisions.\textsuperscript{8} This quest incorporates two questions about empowering the state to breach its commitment to family privacy and to parental autonomy: (1) What circumstances, if any, should constitute \textit{probable cause} for the state to intrude on family privacy by investigating parental decisions about a child's health and medical care and supervision of a minor for a special purpose, may use physical force, but not deadly physical force, upon such minor or incompetent person when and to the extent that he reasonably believes it necessary to maintain discipline or to promote the welfare of such minor or incompetent person.

N.Y. \textit{Penal Law} § 35.10 (McKinney 1967). A similar provision is contained in the Model Penal Code § 3.07(1).

6. This notion is not unlike what Chafee said of the First Amendment: "[I]t and other parts of the law erect a fence inside which men can talk. The law-makers, legislators and officials stay on the outside of that fence." \textsc{Z. Chafee, The Blessings of Liberty} 108 (1950). Together, privacy and autonomy give content to another concept, "family integrity," which was explicitly recognized by the Court in \textit{Stanley v. Illinois}, 405 U.S. 645, 651 (1972), and which is to be found in Justice Harlan's dissent in \textit{Poe v. Ullman}, 367 U.S. 507, 551-52 (1961) ("The home derives its pre-eminence as the seat of family life. And the integrity of that life is something so fundamental that it has been found to draw to its protection the principles of more than one explicitly granted Constitutional right.") See also \textit{Griswold v. Connecticut}, 381 U.S. 479, 500 (1965) (Harlan, J., concurring) (relying upon his dissent in \textit{Poe}).


care needs? and (2) What must such an investigation find in order to justify the abridgement of parental autonomy by substituting the state's judgment for that of the parents? Although both of these questions are important, this essay focuses on the second question, for it presents the ultimate dilemma of when should the state itself become the "parent"?

This question of primary focus arises in two quite distinct forms. The first, on which this essay does not dwell, takes the form of generally applicable societal judgments that no parents shall have a choice, for example, with regard to having their children vaccinated against smallpox. Such legislative infringements of parental autonomy are without regard to any specific individual parent's wishes. They are perceived as a "reasonable and proper exercise of police power" in furtherance of compelling state interests, for example, to safeguard society generally from a smallpox epidemic.\(^9\)

The second form of intrusion and the one on which this essay does dwell, is less precisely defined. It concerns case-by-case determinations that turn on whether the state should supervise or supervene individual parental judgments concerning health care for their children. The authority for state intervention is found in often vague and imprecise neglect, abuse, and delinquency statutes, as well as in administrative and judicial decisions that some children under certain circumstances are entitled to obtain or to reject medical care without regard to or against their parents' wishes.\(^10\) In an effort to tease out some tentative guides for fixing limits to intrusions on parental autonomy and family privacy, a series of cases will be examined that involve (a) a choice between life and death for "normally" formed and "malformed" newborn infants; (b) a choice between life and death for a teenager; (c) non-life-threatening choices for young children and teenagers; and (d) two interrelated life-threatening and non-life-threatening choices concerning a transplant from a well child to a dying sibling.

I. Presumptions of Parental Autonomy and Family Privacy

The cases are analyzed in terms of the strong presumptions in our legal system in favor of parental autonomy and family privacy and against coercive state intervention. The law presumes the capacity

\(^9\) See Jacobson v. Massachusetts, 197 U.S. 11 (1905) (upholding state compulsory vaccination law). Such laws may remain in force even though, with the passage of time, they may, as in the case of vaccination against smallpox, no longer be medically sound.

\(^10\) The neglect laws are collected in S. Katz, M. McGrath & R. Howe, Child Neglect Laws In America (1976) [hereinafter cited as Child Neglect Laws].
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and recognizes the authority of adults to parent their children in accord with their own individual beliefs, preferences, and life styles. It does not establish rules for child rearing to accord with some particular religious or scientific ideal. It requires only that parents meet minimal standards of child care negatively set in neglect, abuse, and abandonment statutes and affirmatively set in provisions such as those obligating parents to send their children to school, to keep them out of the labor market, and to have them vaccinated against smallpox. In accord with fundamental notions of liberty, the law thus presumes that parents, as adults, are qualified to decide how to meet the needs of their children until these children themselves become adults presumed competent to decide what is in their own and their children's interests.\footnote{1}

The right to family privacy and parental autonomy, as well as the reciprocal liberty interest of parent and child in the familial bond between them, need no greater justification than that they comport with each state's fundamental constitutional commitment to individual freedom and human dignity.\footnote{2} But the right of parents to raise their children as they think best, free of coercive intervention, comports as well with each child's biological and psychological need for unthreatened and unbroken continuity of care by his parents.\footnote{3} No other animal is for so long a time after birth in so helpless a state that its survival depends upon continuous nurture by an adult. Although breaking or weakening the ties to the responsible and responsive adults may have different consequences for children of different ages, there is little doubt that such breaches in the familial bond will be detrimental to a child's well-being.\footnote{4} But "so long as a family is intact, 11. See Goldstein, supra note 2, at 72.

12. See Mnookin, Child-Custody Adjudication: Judicial Functions in the Face of Indeterminacy, 39 LAW & CONTEMP. PROB. 226, 266-67 (1975). The Supreme Court has recognized at least two separate parent-child interests that are protected by the Fourteenth Amendment. One is the entitlement of natural parents and their children to each other, an interest which rests on the fact of biological reproduction and arises when the child is born. The other protected interest is in the "familial bonds" which develop over time between parents, whether biological or not, and the children in their long-term care. Stanley v. Illinois, 405 U.S. 645, 651-52 (1972). For a discussion of the impact of a commitment to human dignity on other legal issues, see Goldstein, For Harold Lasswell: Some Reflections on Human Dignity, Entrapment, Informed Consent, and the Plea Bargain, 84 YALE L.J. 683 (1975).


The breaking of bonds by adolescents should not be confused with their forcible breaking by the state: With adolescents, the superficial observation of their behavior may convey the idea
the young child feels parental authority is lodged in a unified body which is a safe and reliable guide for later identification." Court or agency intervention without regard to or over the objection of parents can only serve to undermine the familial bond which is vital to a child’s sense of becoming and being an adult in his own right.

Beyond these supplemental biological and psychological justifications for insulating parent-child relationships and safeguarding each child’s entitlement to a permanent place in a family of his own, there is a further justification for a policy of minimum state intervention. It is, as Bentham recognized, that that law does not have the capacity to supervise the delicately complex interpersonal bonds between parent and child. As parens patriae the state is too crude an instrument to become an adequate substitute for parents. The legal system has neither the resources nor the sensitivity to respond to a growing child’s ever-changing needs and demands. It does not have the capacity to deal on an individual basis with the consequences of its decisions or to act with the deliberate speed required by a child’s sense of time and essential to his well being. Even if the law were not so incapacitated, there is no basis for assuming that the judgments of its decisionmakers about a particular child’s needs would be any better than (or indeed as good as) the judgments of his parents. Only magical thinking will permit the denial of these self-evident, but often ignored, truths about the limits of law.

To recognize how vulnerable the developmental processes are between infancy and adulthood and how essential parents are for continually safeguarding children from never-ending risks is also to recognize that parents may fail. They may place their children at unwarranted risk rather than promote their survival to adulthood. That danger justifies a policy of minimum state intervention rather than one of no state intervention.

Yet recognition that parents may disserve their children’s interests still does not mean that the state necessarily can or will do better. Nor does it justify acceptance of the vague and subjective language of

that what they desire is discontinuation of parental relationships rather than their preservation and stability. Nevertheless, this impression is misleading in this simple form. It is true that their revolt against any parental authority is normal developmentally since it is the adolescent’s way toward establishing his own independent adult identity. But for a successful outcome it is important that the breaks and disruptions of attachment should come exclusively from his side and not be imposed on him by any form of abandonment or rejection on the psychological parents’ part.

BEYOND THE BEST INTERESTS, supra note 4, at 34.

15. From a discussion with Anna Freud (notes on file with Yale Law Journal).

16. See BEYOND THE BEST INTERESTS, supra note 4, at 31-34, 49-52.
neglect and abuse statutes which give the state unguided discretion to supervise parental decisions with regard to health care for their children. If legislatures are to give full recognition to a child's entitlement to a permanent family and the entitlement of parents, no matter how poor, to raise their children as they think best, they must acknowledge the need for a realistic reappraisal of abuse and neglect statutes—statutes which generally, vaguely and overbroadly, provide that a child who is being denied proper care may be found “neglected.” Legislation must be made to see that the requisite of parental consent to medical care for children becomes meaningless if refusal to consent automatically triggers state inquiry or a finding of neglect. State statutes then must be revised to hold in check, not release, the rescue fantasies of those it empowers to intrude, and thus to safeguard families from state-sponsored interruptions of ongoing family relationships by well-intentioned people who “know” what is “best” and who wish to impose their personal health-care preferences on others.

It is in this value-laden setting that an examination of cases is made to determine how and to what extent the state should seek to supervise or supervene parents in their decisions to secure or deny medical care for their children.

II. Life-or-Death Decisions

State supervision of parental judgment would be justified to provide any proven, nonexperimental, medical procedure when its denial would mean death for a child who would otherwise have an opportunity for either a life worth living or a life of relatively normal healthy growth toward adulthood—to majority when a person is 17. For the precise wording of the state statutes, see Child Neglect Laws, supra note 10; Goldstein, Why Foster Care—For Whom for How Long?, 30 The Psychoanalytic Study of the Child 647 (1976).

18. While a life of relatively normal healthy growth is assumed to be a life worth living, it is not assumed that all lives worth living from a societal-consensus point of view could be characterized as relatively normal or healthy. For example, a quadraplegic child, in need of a blood transfusion for reasons unrelated to that condition might, for society, be a “life worth living” though not a life of normal healthy growth.

For an example of a decision about whether a life was worth living, see D. Kearns, Lyndon Johnson and the American Dream 89-90 (1976):

During the summer Sam Johnson suffered another major heart attack. He was put in the hospital and kept in an oxygen tent for months. When Lyndon returned to Texas on his father's sixtieth birthday, Sam pleaded with his son to take him out of the hospital and back to his home where he could be with friends and family. At first Lyndon resisted. The doctors said that Sam needed an oxygen tent, and none was available in Stonewall. But Sam Johnson would not listen to logical objections. "Lyndon," his son recalled him saying, "I'm going back to that little house in the hills where the people know when you're sick and care when you die. You have to help me."

Finally, Johnson agreed. "I realized," Johnson said later, "how dangerous it was
freed of parental control and presumed competent to decide for himself. The state would overcome the presumption of parental autonomy in health-care matters only if it could establish: (a) that the medical profession is in agreement about what nonexperimental medical treatment is right for the child; (b) that the expected outcome of that treatment is what society agrees to be right for any child, a chance for normal healthy growth toward adulthood or a life worth living; and (c) that the expected outcome of denial of that treatment would mean death for the child.

These criteria for intervention were met by Judge Murphy, for the Superior Court of the District of Columbia, in *In re Pogue.* He authorized blood transfusions for an otherwise healthy newborn infant who would have died had his parents’ decision to reject the treatment been honored. At the same time Judge Murphy, recognizing the distinction between being an adult and being a child with regard to medical care choices, declined to order blood transfusions for the infant’s mother who, in the face of death, refused to consent to such intervention. Over the objection of the “adult” parents’ wishes and without regard, of course, to the infant’s “wishes,” Judge Murphy, as a substitute parent, decided to protect the child’s right as a person to reach the age of majority when he will become entitled to make such
to let my father go home. But I also believed that a man had a right to live and to die in his own way, in his own time. God knows that hospital depressed me something terrible and I was only visiting. No matter how sweet the nurses and the doctors are, they’re not your family. They don’t really know anything about you, they don’t know anything about all the things that are going on in your head . . . . Yes, I understood why my daddy wanted to leave and I respected his wish. I brought him his clothes, I helped him dress, and I carried him home.”

In his own room in the Johnson City house, Sam briefly seemed to improve. Then only two weeks later, on October 23, 1937, he died.

19. *In re Pogue,* Wash. Post, Nov. 14, 1974, § C, at 1, col. 1 (No. M-18-74, Super. Ct., D.C., Nov. 11, 1974). Judge Murphy relied upon a similar case in which a court refused to order a blood transfusion for an adult. *In re Osborne,* 294 A.2d 373 (D.C. Ct. App. 1972) (84-year-old Jehovah’s Witness). In a case that did not involve religious beliefs, a Pennsylvania common pleas court refused to order surgery for a 60-year-old woman. The court based its decision upon the woman’s right to privacy. *In re Yetter,* 62 Pa. D. & C.2d 619 (C.P. 1973). But in *In re President of Georgetown College,* 331 F.2d 1000 (D.C. Cir.), *cert. denied,* 377 U.S. 978 (1964), the court ordered a blood transfusion for a 25-year-old Jehovah’s Witness who was the mother of 7-month-old child. Judge Skelly Wright explained that he had ordered the transfusion because she had ordered the transfusion because the woman wanted to live. *Id.* at 1009. In State ex *rel.* Swann v. Pack, 527 S.W.2d 99 (Tenn. 1975), *cert. denied,* 96 S. Ct. 1429 (1976), the court, after holding that the Holiness Church of God in Jesus Name “is a constitutionally protected religious group,” *id.* at 107, held that the state could prohibit, as a nuisance, the handling of poisonous snakes. The court observed: “Yes, the state has a right to protect a person from himself and to demand that he protect his own life.” *Id.* at 118. Even here, however, the court’s order was influenced by its recognition of the parental right to control the religious upbringing of children. Because of that recognition the court did not restrict its order to prohibiting snake handling in the presence of children. Instead, snake handling was prohibited altogether.
life-or-death decisions for himself. The judge implicitly found the infant's parents temporarily incompetent to care for the child, while simultaneously acknowledging the adult status of the mother by declining to use her refusal of blood as a basis for declaring her a danger to herself and thus incompetent, as if a child, to decide for herself.20

The scientific "fact" that death, for both the infant and the mother, was inevitable without transfusion—the nonexperimental medical procedure—was not in dispute. Nor was there any societal doubt about the desirability—the "rightness"—of the predicted outcome of the transfusion—an opportunity for normal, healthy growth, a life worth living. The issue was whether the judge and doctors, as adults with an unqualified value preference for life, could use the power of the state to impose their "adult" judgment on adults in law whose own "adult" judgment gave greater weight to another preference. On behalf of the adult the answer was "No"; on behalf of the child the answer was "Yes."21 Thus coercive intervention by the state was justified where the parents' decision would have deprived a child of proven medical treatment and consequently of an opportunity for healthy growth and development to adulthood.

There would be no justification, however, for coercive intrusion by the state in those life-or-death situations (a) in which there is no proven medical procedure, or (b) in which parents are confronted with conflicting medical advice about which, if any, treatment procedure to follow, or (c) in which, even if the medical experts agree about treatment, there is less than a high probability that the nonexperimental treatment will enable the child to pursue either a life worth living or a life of relatively normal healthy growth toward adulthood. These standards are anchored in such common law notions as that of plain duty given expression in Justice Field's jury charge regarding criminal liability for acts of omission:

[T]he duty omitted must be a plain duty, by which I mean that it must be one that does not admit of any discussion as to its obligatory force; one upon which different minds must agree, or will generally agree. Where doubt exists as to what conduct should be pursued in a particular case, and intelligent men differ as to the


proper action to be had, the law does not impute guilt to anyone, if, from omission to adopt one course instead of another, fatal consequences follow to others.\textsuperscript{22}

Outside of a narrow central core of agreement, “a life worth living” and “a life of relatively normal healthy growth” are highly personal terms about which there is no societal consensus. There can thus be no societal consensus about the “rightness” of always deciding for “life,” or of always preferring the predicted result of the recommended treatment over the predicted result of refusing such treatment. It is precisely in those cases in which reasonable and responsible persons can and do disagree about whether the “life” after treatment would be “worth living” or “normal,” and thus about what is “right,” that parents must remain free of coercive state intervention in deciding whether to consent to or reject the medical program proffered for their child.

The high-probability-of-a-life-worth-living or of relatively-normal-healthy-growth standard is, it must be remembered, designed not to facilitate but to inhibit state intervention. This broad standard is meant to reenforce a policy of minimum state intervention. In its breadth and in its evidentiary demands it saddles the state with the burden of overcoming the presumption of parental autonomy. Intervention would thus be limited to those individual life-or-death cases in which the state could establish that the medical profession agreed upon the rejected medical treatment and that the treatment would provide the dying child with an opportunity for what societal consensus held to be either a life worth living or a life of relatively normal healthy growth. The state, of course, would remain without authority to challenge parental decisions to provide medical treatment in order to save their dying child even if the state could establish that there was a societal consensus that the expected outcome of such treatment was not a “life worth living.”

Absent medical agreement about what treatment is indicated, or absent a societal consensus about the rightness of the predicted result of treatment, there would be no justification for disqualifying parents from (or for qualifying agents of the state for) making the difficult choice—for giving their personal meaning to “right” or to “worth living” or to “normal healthy growth.” No one has a greater right or responsibility and no one can be presumed to be in a better position, and thus better equipped, than a child’s parents to decide what course

\textsuperscript{22} United States v. Knowles, 26 F. Cas. 800, 801 (N.D. Cal. 1864) (No. 15,540).
to pursue if the medical experts cannot agree or, assuming their agree-
ment, if there is no general agreement in society that the outcome of
treatment is clearly preferred to the outcome of no treatment. Put
somewhat more starkly, how can parents in such situations give the
wrong answer since there is no way of knowing the right answer? In
these circumstances the law’s guarantee of freedom of belief becomes
meaningful and the right to act on that belief as an autonomous parent
becomes operative within the privacy of one’s family.23 Precisely be-
cause there is no objectively wrong or right answer, the burden must
be on the state to establish wrong, not on the parent to establish that
what is right for them is necessarily right for others. Indeed it is in
just such cases that the Constitution, which separates church and, to a
different degree, science from state, dictates abstention from imposing
one group’s orthodoxy about health care or truth about the meaning
of life or, for that matter, death upon another.24

Ultimately, then, it must be left to the parents to decide, for ex-
ample, whether their congenitally malformed newborn with an ascer-

23. Although the case of Karen Ann Quinlan involved a 22-year-old woman, Chief
Justice Hughes’s opinion contains an apt description of the conflicting interests:
The claimed interests of the State in this case are essentially the preservation and
sanctity of human life and defense of the right of the physician to administer medical
treatment according to his best judgment. In this case the doctors say that removing
Karen from the respirator will conflict with their professional judgment. The plain-
tiff answers that Karen’s present treatment serves only a maintenance function; that
the respirator cannot cure or improve her condition but at best can only prolong
her inevitable slow deterioration and death; and that the interests of the patient, as
seen by her surrogate, the guardian [Karen’s father], must be evaluated by the court
as predominant, even in the face of an opinion contra by the present attending
physicians. Plaintiff’s distinction is significant. The nature of Karen’s care and the
realistic chances of her recovery are quite unlike those of the patients discussed in
many of the cases where treatments were ordered. In many of those cases the
medical procedure required (usually a transfusion) constituted a minimal bodily
invasion and the chances of recovery and return to functioning life were very good.
We think that the State’s interest contra weakens and the individual’s right to
privacy grows as the degree of bodily invasion increases and the prognosis dims.
Ultimately there comes a point at which the individual’s rights overcome the State
interest.

Because of her comatose condition, however, Karen could not exercise her right to
decline treatment. “The only practical way to prevent destruction of the right,” the
Chief Justice explained,
is to permit the guardian and family of Karen to render their best judgment . . .
as to whether she would exercise it in these circumstances. If their conclusion is in
the affirmative this decision should be accepted by a society the overwhelming
majority of whose members would, we think, in similar circumstances, exercise such
a choice in the same way for themselves or for those closest to them. It is for this
reason that we determine that Karen’s right of privacy may be asserted in her behalf,
in this respect, by her guardian and family under the particular circumstances
presented by this record.

Id. at 41-42, 335 A.2d at 654.
24. For an initial attempt to develop this argument, see Goldstein, supra note 2, at 70.
tainable neurologic deficiency and highly predictable mental retardation, should be provided with treatment which may avoid death, but which offers no chance of cure—no opportunity, in terms of societal consensus, for a life worth living or a life of relatively normal healthy growth. Dr. Raymond Duff has argued persuasively:

Families know their values, priorities and resources better than anyone else. Presumably they, with the doctor, can make the better choices as a private affair. Certainly, they, more than anyone else, must live with the consequences. Most of these families know they cannot place that child for adoption because no one else wants the child. If they cannot cope adequately with the child and their other responsibilities and survive as a family, they may feel that the death option is a forced choice. . . . But that is not necessarily bad, and who knows of a better way.25

For the law to adopt the Duff position would not mean abandonment of its commitment to defend human life. Special procedures could be established within hospitals to protect infants and their parents from possible misdiagnoses, though not from “erroneous” moral judgment. The function of such a procedure would be to verify the medical prognosis, not the ethical base, on which the parental decision relied.26 If the prognosis proved to be incorrect and if the

25. Kelsey, Shall These Children Live? A Conversation With Dr. Raymond S. Duff, 72 REFLECTION, Jan. 1975, at 4, 7 (Yale Divinity School Magazine). For other expressions of Dr. Duff’s views, see Duff & Campbell, Moral and Ethical Dilemmas in the Special-Care Nursery, 289 NEW ENGLAND J. MED. 885 (1973); Duff & Campbell, On Deciding the Care of Severely Handicapped or Dying Persons: With Particular Reference to Infants, 57 PEDIATRICS 487 (1976).

26. In In re Quinlan the court proposed the establishment of a review procedure by a hospital committee which it mislabels an “Ethics Committee”:

[U]pon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital “Ethics Committee” or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor, on the part of any participant, whether guardian, physician, hospital or others.

70 N.J. at 54, 355 A.2d at 671 (emphasis added). Contrary to its own reasoning, which recognized that the ethical question concerning continuance or discontinuance of the life-support system must be left to the parents or guardian to resolve, the court concluded that the attending doctors must not only provide their medical prognosis but also determine the ethical question, that the life-support system “should be discontinued,” before such action may be taken. Yet, consistent with its reasoning, and despite the label, the court restricted the hospital to a review of the medical, not the ethical, decision. The “Ethics Committee” would, as it should, only determine if the doctors were correct in their prediction that “there is no reasonable possibility of Karen’s ever emerging from her
parents refused to accept the revised finding, the state would be em-
powered, as it was in the blood transfusion case, to order the recom-
mended treatment. If the tragic prognosis is warranted, then the law,
as Duff argues, should treat the decision as a “private affair”—whether
it be for medical means to sustain life or for humane shelter and care
not necessarily designed to avoid death.

If parental autonomy is not accorded the recognition argued for in
this essay, and if society insists through law that such children, indeed
any children, receive medical treatment rejected by their parents, the
state should provide the special financial, physical, and psychological
resources essential to making real for the child it “saves” the value it
prefers. The state should become fully responsible for making “un-
wanted” children “wanted” ones.27 Minimally and ideally the state
should fully finance their special-care requirements; in the event their
parents do not wish to remain responsible for them, the state should
find adopting parents who with unbroken continuity could meet not
only the child’s physical needs but also his psychological requirements
for affectionate relationships and emotional and intellectual stimula-
tion.28

Except for meeting the child’s physical needs the task, however large
the allocation of financial resources, may well be beyond the limits of
law. The law is too crude an instrument to nurture, as only parents
can, the delicate physical, psychological, and social tissues of a child’s
life. Even if it could force, and it may not, unwilling adults to adopt
children, the law does not have the capacity to make an “unwanted”
child a “wanted” one. If the past and present provide a basis for
prediction, an institutional setting (not adoption or long-term foster
care with the same family) is the more likely but hardly satisfactory
prospect for the after “care” of such children until their majority or

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27. For a discussion of the concept of a “wanted” child, see BEYOND THE BEST IN-
TERESTS, supra note 4, at 5-7. The Model Child Placement Statute proposed by the
authors states: “A wanted child is one who receives affection and nourishment on a
continuing basis from at least one adult and who feels that he or she is and continues
to be valued by those who take care of him or her.” Id. at 98.

28. Parents are traditionally free, though not necessarily encouraged, to give up their
children for adoption. It is interesting that the Uniform Adoption Act of 1953 provided
in optional § 17 that adoptive parents could petition to annul if “within two years
after the adoption a child develops any serious and permanent physical or mental
malady or incapacity as a result of conditions existing prior to the adoption and of
which the adopting parents had no knowledge or notice.” The Revised Uniform Adop-
tion Act (1969) has no such provision. For the text of the 1953 Act, see 9 UNIFORM LAWS
ANNOTATED 5-10 (1973).
death. Insitutional arrangements have not provided the affectionate and other psychological ties such children—no matter how limited their potential for healthy growth and development—demand and deserve. As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than either assume full responsibility for the treatment, care, and nurture of such children or honor the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life.

The case of Karen, a teenage patient suffering from an irreversible kidney malfunction, provides another life-or-death example in which the standard of an opportunity for a life worth living or a life of relatively normal healthy growth toward adulthood would preclude state supervision of parental judgments. Karen's case poses the question whether state intervention should be authorized to review the choice of an adolescent who, with her parents' permission and concurrence, decides to choose death over "life." Following an unsuccessful kidney transplant, Karen and her parents refused to consent to the continuation of "intolerable" life-support devices. The decision to proceed as if family privacy and parental autonomy were, or at least should be, protected was described in an article by her doctors:

[F]ollowing the transplant's failure, thrice-weekly hemodialysis was performed. Karen tolerated dialysis poorly, routinely having chills, nausea, vomiting, severe headaches and weakness. . . .

. . . .

[A]fter it was clear that the kidney would never function, Karen and her parents expressed the wish to stop medical treatment and let "nature take its course." . . . [S]taff members con-

29. For a description of the conditions in one institution, New York's Willowbrook State School for the Mentally Retarded, see Judge Judd's opinion in New York State Ass'n for Retarded Children, Inc. v. Rockefeller, 357 F. Supp. 752, 755-57 (E.D.N.Y. 1973). Referring to the "inhumane" conditions at the school, Judge Judd mentioned the "loss of an eye, the breaking of teeth, the loss of part of an ear bitten off by another resident, and frequent bruises and scalp wounds" as typical complaints. Id. at 756.

For an effort to reverse the course of the past, see Consent Judgment in the Willowbrook Case, No. 72 Civ. 356/357 (E.D.N.Y. Apr. 30, 1975). Similarly, see Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972), which has been described as "dealing with a remote, rural state institution in Alabama housing some five thousand retarded children in conditions of unrelieved horror." Burt, Developing Constitutional Rights Of, In, and For Children, 39 LAW & CONTEMP. PROB. 118, 138 (1975).


31. From a conversation with Judge James H. Lincoln, Judge of the Probate Court, Juvenile Division, Wayne County, Michigan.
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veyed to the family that such wishes were unheard of and unacceptable, and that a decision to stop treatment could never be an alternative. The family did decide to continue dialysis, medication, and diet therapy. Karen's renal incapacity returned to pre-transplant levels and she returned to her socially isolated life, with diet restriction, chronic discomfort, and fatigue.

On May 10, Karen was hospitalized following ten days of high fever. Three days later the transplant was removed. Its pathology resembled that of the original kidneys, and the possibility of a similar reaction forming in subsequent transplants was established.

On May 21, the arteriovenous shunt placed in Karen's arm for hemodialysis was found to be infected, and part of the vein wall was excised and the shunt revised. During this portion of the hospitalization, Karen and the parents grudgingly went along with the medical recommendations, but they continued to ponder the possibility of stopping treatment. . . . On May 24, the shunt clotted closed. Karen, with her parents' agreement, refused shunt revision and any further dialysis.

Karen died on June 2, with both parents at her bedside. . . . Shortly [before] her death she thanked the staff for what she knew had been a hard time for them and she told her parents she hoped they would be happy. We later learned that before her death she had written a will and picked a burial spot near her home and near her favorite horseback riding trail. In the final days she supported her parents as they faltered in their decision; she told her father, "Daddy, I will be happy there (in the ground) if there is no machine and they don't work on me any more."32

For Karen and her parents no medical treatment offered the possibility of resuming a relatively normal life or a life worth living. The recommendation of the nursing and medical staff to continue the life-support system was not a scientific, but a moral judgment. The rightness of forcing the consequences of their choice upon Karen rather than honoring her and her parents' decision could not be established. There was then no basis for exercising the power of the state to supervene the judgment of Karen's parents. Had Karen been an adult, on the law's chronological scale, there is no question, or there ought not to be, that out of respect for her dignity as a human being, the doctors would have had to abide by her request to end the treatment. As a New York court once declared, "[I]t is the individual who is the subject of a medical decision who has the final say and . . . this must necessarily be so in a system of government which gives the

greatest possible protection to the individual in the furtherance of his own desires."

For the doctors to have proceeded with dialysis against the wishes of teenage Karen and her parents would have constituted an assault in tort and in crime. Together as a family they must be entitled in law to be free, as they were, of the coercive force of the state or of the medical authorities. The law of torts and crime is designed, or ought to be, to protect family integrity by providing such safeguards against the supervention of parental judgment by the medical staff or other "agents" of the state.

Had the situation been different, had Karen's parents insisted, over her objection, on continuing the life-support system, would the state have been justified in supervening their judgment? Or had Karen insisted, over her parents' objection, on continuing the life-support system would the state have been justified in supervening their judgment? The answer to both questions should be "No," albeit an uneasy "No," particularly to the second question. It is, after all, the function and responsibility of parents to evaluate and make judgments about the wishes and requests of their children. It is, after all, the meaning of parental autonomy to make such decisions. Further, neither court nor hearing agency is likely to be as competent as, for example, were Karen's parents to determine her capacity for choice and whether to abide by it. The law should avoid giving the discretion for such subjective judgments to its agents.

But the uneasiness about the "No" answers remains. It stems from a

Likewise, Chief Justice Hughes, for the New Jersey Supreme Court, in In re Quinlan, 70 N.J. 10, 38-42 355 A.2d 647, 662-64 (1976), upheld Miss Quinlan's constitutional right as an adult to her privacy, free from state intrusion, in making such life-or-death choices. The court, because of her incompetence, further acknowledged her father's authority, as guardian, to exercise that right on her behalf. It observed:

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval . . . and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death.

. . . [N]o external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case, could be made by a competent patient terminally ill, riddled by cancer and suffering great pain; such a patient would not be resuscitated or put on a respirator.

* * *

[N]o external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case, could be made by a competent patient terminally ill, riddled by cancer and suffering great pain; such a patient would not be resuscitated or put on a respirator.

Id. at 39, 355 A.2d at 668.

34. See, e.g., Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941) (consent of parent necessary before surgical procedure to graft skin from 15-year-old to his cousin); N.Y. PENAL LAW § 120 (McKinney 1975) (assault if physical injury caused); cf. F. HARPER & F. JAMES, THE LAW OF TORTS 634-35 (1956) (extent of damages recoverable by parent against third person for tortious injury to child).
fear that a few parents might not follow a child’s express wish to undergo treatment which might seem intolerable to them, though not to the child. It also stems from a growing concern that for some matters, particularly with regard to health care, the general statutory age of adulthood, of emancipation, has been set too high. The question then, and one addressed in the next section, is not whether Karen specifically but whether all persons aged 16(?) in such circumstances as Karen found herself ought to have the controlling voice in law rather than their parents or guardians—whether it be for life or not to avoid death. But until legislatures or courts find a formula for determining under what circumstances and at what age below majority children may become their own risk takers for certain health care decisions, ultimate responsibility must remain with parents or, if they be disqualified, with adult guardians, who may (as Karen’s parents did) or may not decide to support their child’s choice.

III. Emancipation of Children for Health Care Purposes

The law, both case and statutory, has begun to emancipate some minors to determine for themselves what health care course to pursue. For example, 16-year-olds have been granted the right to enter or leave mental institutions over the objection of parents who, in the past, had the authority to arrange for their admission or release as voluntary patients. For another example, pregnant minors have been given adult status for purposes of determining whether to obtain an abortion. In the case of "mentally ill" 16-year-olds, these modifications of parental autonomy silently rest on a not totally unwarranted suspicion that mental institutions provide little, if any, medical treatment, and more openly upon a fear of parental abuse, not unlike the exploitation of the system by members of a family wishing to put a difficult spouse, parent, or sibling out of sight. The reasons which seem to underlie renewed challenges to the commitment of adults for mental health care without their consent prompt and seem to justify a limited emancipation of children in this area. As for pregnancy, the justifica-


tion for emancipation appears to stem from a recognition that those who insist on parental consent are concerned less with the child's well-being than with strengthening their general opposition to abortion, which they cloak in the magical notion that law can improve family communications by compelling a young woman in trouble to consult with her parents when such family trust does not exist.\textsuperscript{38}

There may, then, be situations which justify abiding by the health-care choices of children without regard to the wishes of their parents—situations that justify emancipating children and thus relieving their parents of the right, as well as the responsibility, to determine whether to consider or to accept the treatment preferences of their children. Unlike the life-or-death problems already addressed, the issue here is whether and when children, not the state, should be given the otherwise parental right to determine for themselves what medical course to pursue. The question, which could only arise in situations in which the state would not be authorized, under the standards proposed, to supervene parental autonomy, is: Under what specific circumstances should the law presume children to be as competent as are adults, to be their own risk takers for all or some health-care purposes?

Any answers to this question which favor qualifying minors, as adults, for certain health-care decisions should provide standards for establishing emancipation status which are as impersonal and as non-judgmental as is the chronological-age standard for establishing adult status.\textsuperscript{39} Whatever the rationale for the emancipation, access to such status for all children in a designated category should be open and automatic. The right to partial emancipation should not rest on satisfying, on a case-by-case basis, some body of wise persons that the particular child is "mature enough" to choose or that the particular child's choice is "right."\textsuperscript{40} To introduce such a subjective process for decision would be not to emancipate the child but rather to transfer

\textsuperscript{38} For the view of Planned Parenthood of New York City, see N.Y. Times, May 11, 1976, at 32, col. 2.

\textsuperscript{39} For a discussion of this point, see Goldstein, supra note 2, at 71-72; and Katz, Schroeder & Sidman, Emancipating Our Children—Coming of Legal Age in America, 7 Fam. L.Q. 211 (1973).

\textsuperscript{40} Emancipation from 1900 to the early 1960s was almost exclusively judicial and conformed closely to the dominant societal attitudes during that period. . . . The approach to judicial emancipation was on a case by case basis, and the doctrine was often manipulated by the courts to conform with a judge's own values rather than with the best interests of the child. Katz, Schroeder & Sidman, supra note 39, at 213. For a position which fails to recognize that one of the functions of parents is to make judgments about their children's competence to choose and that courts are incompetent to make such judgments, see Note, State Intrusion into Family Affairs: Justifications and Limitations, 26 Stan. L. Rev. 1383 (1974).
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to the state the parental control and responsibility for determining when to consult and abide by the child's choice. To require relatively objective criteria for establishing emancipation statutes is not to take a simplistic view of children but rather to recognize how varied and complex all children are and how inadequate courts are for assessing a child's capacity for decision. The law then must limit the state to determining by some relatively objective standard who is entitled to decide, not what specific decision is to be preferred in a particular case nor whether a specific child has the "wisdom" to make a choice. To resolve the question of emancipation by authorizing a court or hearing agency to decide each case on the basis of which choice is "right" or which child in a given category is "mature enough" is to deny to both—parent as well as child—autonomy to decide and family privacy in which to decide. The question thus becomes: Under what specific circumstances should persons who are children in law and generally responsible to and the responsibility of their parents be presumed qualified and authorized to make medical treatment choices free of parental control?

The requisites of an acceptable answer would be satisfied by a law in furtherance of the strong societal commitment to safeguard "life" which provided, for example, that children of any age (or above 12?) are emancipated who in a life-or-death situation wish, against their parents' decision, to pursue treatment. Although such a provision is not being proposed it would meet the criteria set forth above only if emancipation carried with it the right of the child to change his mind—to agree with his parents—and to refuse or to withdraw consent for the proffered treatment. That right would have to be recognized, not for purposes of symmetry, but because to do otherwise would constitute a cruel hoax on child and parent. Far better to acknowledge from the outset in such situations that the child is not being emancipated for health-care purposes, that the state knows what is right and that its judgment is being imposed on both parent and child without regard to their wishes. Legislatures or courts could more easily satisfy the requisites of an acceptable answer by avoiding the express wishes of the minor as a standard of emancipation and by establishing, as some have done, such "impersonal," "objective" criteria as a chronological age fixed below that for an adult (e.g., 16) coupled with a specific medical diagnosis or prognosis (e.g., pregnancy, irreversible kidney malfunction, or mental illness). Pregnancy alone, without regard to a child's age, would be a sufficiently objective standard for emancipation to determine whether or not to obtain an abortion.

This brief consideration is not meant to provide a definitive answer
to this difficult question but rather to illustrate how age and diagnoses could and should be used as statutory criteria for the partial emancipation of children from parental authority in some health care decisions, whether or not they involve life-or-death choices. It is to non-life-or-death choices that this essay now turns.

IV. Non-Life-or-Death Decisions

When death is not a likely consequence of exercising a medical care choice there is no justification for governmental intrusion on family privacy; nor is there justification for overcoming the presumption of either parental autonomy or the autonomy of emancipated children. Where the question involves not a life-or-death choice but a preference for one style of life over another, the law must restrain courts and medicine men from coercively imposing their “kindness”—their preferred life styles—in the form of medical care upon nonconsenting parents and their children. The law, in adopting such a position, cannot presume that parents do not make “mistakes.” Nor can it challenge the scientific “facts,” prognoses, or diagnoses upon which experts base their recommendations. Rather the law must recognize that it cannot find in medicine (or for that matter in any science) the ethical, political, or social values for evaluating health-care choices. Courts must avoid confusing a doctor’s personal preference for a certain style of living with the scientific bases upon which the recommendation rests.41

The presumption of parental capacity to decide is meant to hold in check judges or doctors who may be tempted to use the power of the state to impose their personal preferences, their “adult parental” judgments upon parents whose own adult judgment may give greater weight to another preference.

In implementing this basic commitment to parental autonomy and to family privacy, the law does not take a simplistic view of parents, of the parent-child relationship, or of the family. Rather, it acknowledges not only how complicated man is, but also how limited is its own capacity for making more than gross distinctions about man’s needs, natures, and routes of development. The law recognizes and respects the diverse range of man’s religious, cultural, scientific, and ethical beliefs and the overlapping and ever-changing modes of their expression within and between generations at all stages of the life cycle. Thus a prime function of law is to prevent one person’s truth (here about health, normalcy, the good life) from becoming another person’s tyranny. It is in terms of that function that parental decisions in non-

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life-or-death situations to reject medical-care recommendations for their children will be analyzed.

The case of In re Sampson\(^{42}\) illustrates how vaguely worded neglect statutes may be invoked in the name of health care to violate a family's privacy, to undermine parental autonomy, and to foster a community's, if not a judge's, prejudice against the physically deformed. Under the Family Court Act of New York,\(^ {43}\) Judge Hugh Elwyn declared Kevin Sampson, aged 15, "a neglected child."\(^ {44}\) He made this finding in order to establish his authority to veto a decision by Kevin's mother not to permit blood transfusions for Kevin during surgery. He ordered her to force Kevin to undergo a series of operations which had been recommended by the Commissioner of Health and by duly qualified surgeons to correct a facial condition called neurofibromatosis. Judge Elwyn observed that Kevin had "a massive deformity of the right side of his face and neck. The outward manifestation of the disease is a large fold or flap of an overgrowth of facial tissue which causes the whole cheek, the corner of his mouth and right ear to drop down giving him an appearance which can only be described as grotesque and repulsive."\(^ {45}\) He went on to psychologize and predict:

[The massive deformity of the entire right side of his face and neck is patently so gross and so disfiguring that it must inevitably exert a most negative effect upon his personality development, his opportunity for education and later employment and upon every phase of his relationship with his peers and others.\(^ {46}\)]

Judge Elwyn made this assertion with apodictic certainty even though he acknowledged that "the staff psychiatrist of the County Mental Health Center reports that 'there is no evidence of any thinking disorder' and that 'in spite of marked facial disfigurement he failed to show any outstanding personality aberration.'"\(^ {47}\) Nevertheless, the judge added, "this finding hardly justifies a conclusion that he has been or will continue to be wholly unaffected by his misfortune."\(^ {48}\) He also noted that Kevin had been exempted from school, not because he was intellectually incapable, but, it may be assumed, because he

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\(^{44}\) Id. at 676, 317 N.Y.S.2d at 658.

\(^{45}\) Id. at 659, 317 N.Y.S.2d at 643.

\(^{46}\) Id. at 660, 317 N.Y.S.2d at 644.

\(^{47}\) Id., 317 N.Y.S.2d at 644.

\(^{48}\) Id., 317 N.Y.S.2d at 644. According to Judge Elwyn, a psychologist had found Kevin to be extremely dependent. The staff psychiatrist reported that Kevin demonstrated "'inferiority feeling and low self concept.'" Id., 317 N.Y.S.2d at 644.
appeared to his classmates and teachers as he did to Judge Elwyn himself, "grotesque and repulsive." But the judge's speculations on behalf of the state as *parens patriae* did not lead him to consider that under the protective cloak of family privacy, a loving, caring, accepting, autonomous parent had somehow been able to nurture in Kevin a "healthy personality." Kevin, after all, had developed in spite of state-enforced prejudice and discrimination against the physically different in school, health agency, and court.

The testimony of the doctors who recommended surgery justified not a finding of neglect but rather a reaffirmation of parental autonomy. The doctors admitted that "the disease poses no immediate threat to [Kevin's] life nor has it as yet seriously affected his general health" and that surgery was very risky and offered no cure.\(^4\) Further, the doctors found in the central nervous system no brain or spinal cord involvement and that delay until Kevin was 21, would decrease, not increase, the risk. The court replied with blind arrogance:

> [T]o postpone the surgery merely to allow the boy to become of age so that he may make the decision himself as suggested by the surgeon and urged by both counsel for the mother and the Law Guardian . . . totally ignores the developmental and psychological factors stemming from his deformity which the Court deems to be of the utmost importance in any consideration of the boy's future welfare and begs the whole question.\(^5\)

And without regard to the relationship of Kevin's well-being to the integrity and support of his family, the court added: "'Neither by statute nor decision is the child's consent necessary or material, and we should not permit his refusal to agree, his failure to cooperate, to ruin his life and any chance for a normal, happy existence.'"\(^5\)

The judge, who by an act of conjury had qualified himself as prophet, psychological expert, risk taker, and all-knowing parent, described but ignored a powerful reason for concluding that state authority should not suprervene parental judgments about the rightness

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49. *Id.* at 661, 317 N.Y.S.2d at 644.
50. *Id.* at 672, 317 N.Y.S.2d at 655.
51. *Id.* at 673, 317 N.Y.S.2d at 656 (quoting *In re Seiferth*, 309 N.Y. 80, 87, 127 N.E.2d 820, 824 (1955) (Fuld, J., dissenting)). For a contrary view of the importance of a child's preference regarding surgery, see *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972). Ricky Green was a 15-year-old boy who, as the result of polio, had a 94 degree curvature of the spine. Doctors proposed a spinal fusion to straighten the spine, but Ricky's mother refused her consent for blood transfusions during the operation. Saying that the "ultimate question" concerned Ricky's wishes, the Pennsylvania Supreme Court remanded the case for a determination of Ricky's wishes. *Id.* at 350, 292 A.2d at 392. After talking with Ricky, the court found that he did not want the operation; his wishes were honored. *Green Appeal*, 452 Pa. 373, 307 A.2d 279 (1973).
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for their child of a recommended medical treatment when death is not in issue. Judge Elwyn wrote:

It is conceded that "there are important considerations both ways" and that the views expressed by the dissenting Judges in Seiferth have not been universally accepted. Moreover, it must also be humbly acknowledged that under the circumstances of this case "one cannot be certain of being right." Nevertheless, a decision must be made, and so, after much deliberation, I am persuaded that if this court is to meet its responsibilities to this boy it can neither shift the responsibility for the ultimate decision onto his shoulders nor can it permit his mother's religious beliefs to stand in the way of attaining through corrective surgery whatever chance he may have for a normal, happy existence, which, to paraphrase Judge Fuld [author of the dissent in Seiferth], is difficult of attainment under the most propitious circumstances, but will unquestionably be impossible if the disfigurement is not corrected.52

Were his humility real, the judge would not have allowed himself to believe that he, rather than Kevin's mother, was best qualified to determine the meanings of "a normal and happy existence" for her son. In Kevin's eyes either might be proven "wrong" retrospectively. But nothing, not even magic, can qualify a judge to make that prediction with equal or greater accuracy than the parent. Nor is any judge prepared, as are parents, personally to assume day-to-day responsibility for giving the Kevins the care they may require as a consequence of such a personal value choice about life style.

Laws of neglect must be revised to restore parental autonomy and safeguard family privacy not only because judges cannot be substitute parents and courts cannot be substitute families but also because the power of the state must not be employed to reinforce prejudice and discrimination against those who are cosmetically or otherwise different. When Judge Elwyn referred to Judge Fuld's dissent, it was to a case in which the court refused to find Martin Seiferth, aged 14, a neglected child even though his father would not compel Martin to undergo the surgery recommended for the repair of a cleft palate and harelip.53 Martin's father, despite his own beliefs, would have consented to the surgery had Martin been willing. Their decisions were based not upon "religious" beliefs, but upon a belief that "forces in the universe" would allow Martin to cure himself. Despite evidence far less equivocal than that in Kevin's case, the majority of the court refused to be trapped by rescue fantasies of the health department and

52. 65 Misc. 2d at 674, 317 N.Y.S.2d at 657.
its doctors or by strong prejudices which the court was being asked to reenforce in an effort to "save" the child from himself and his parents. The court refused to order surgery, not because it thought it lacked authority, but because it thought Martin's reluctance to have the surgery foretold an unwillingness to participate in the therapy following the operations. Thus it was unwilling, unlike Judges Elwyn and Fuld, to substitute its or a state agency's value preferences about life style and about who and what is beautiful or natural for those of the responsible parents.

If Martin Seiferth, as an adult, chose to undergo the recommended surgery, it would not invalidate the argument that the court should not even have had discretion to do other than to protect him and his parents from state intrusion. In fact, Martin Seiferth chose not to have the surgery. "After attending one of the vocational high schools in the city, where he learned the trade of upholsterer and was elected president of the Student Council, he set up in business on his own and is, despite his disfigurement, active and successful."54 The county health department that originated the case reacted as if experience offered no lessons about the need for minimum state intervention on parental autonomy and family privacy:

"[He] had graduated . . . at the head of [his high school] class. It was his intention then to become an interior decorator. . . . [T]he Health Department [is] still of the opinion that the operation should have been performed in order to give this young man a fuller opportunity for the development of his talents."55

The law must be designed to protect its citizens from just such official blindness to the forceful imposition of personal wishes or beliefs on those who share neither the wish nor the belief about the value of medical care or "fuller opportunities" for their children.

V. Interrelated Decisions Not Involving Life or Death for One Child and Involving Life or Death for Another Child

Should the state have authority to invade the privacy of a family in order to review the deliberations of parents who have to decide whether to let one of their children die or whether to attempt to supply a lifesaving organ for transplant by consenting to "unnecessary" surgery on one of their healthy children?

The answer ought to be "No." But that was not the answer of a

55. Letter from Mr. Elmer R. Weil, county attorney of Eric County, to Joseph Goldstein (Apr. 28, 1964), quoted in id. at 993-94.
State Supervention of Parental Autonomy

Connecticut court in *Hart v. Brown.* In that case doctors advised Mr. and Mrs. Hart that the only real prospect of saving their eight-year-old daughter Kathleen's life from a deadly kidney malfunction was to transplant a kidney from Margaret, her healthy twin sister. The doctors recommended and the Hart parents consented to the “unnecessary” surgery on Margaret to provide Kathleen with an opportunity to pursue a relatively normal life. But the hospital administration and the doctors refused to accept parental consent without a court review. They acted out of a concern for their livelihood, not for the lives or well-being of Margaret or of Kathleen. Understandably, they feared becoming liable for money damages because the law might not accept parental consent as a defense to assault and malpractice, were such suits brought.

The Harts were thus forced to turn to the state to establish either their authority to decide or the rightness of their decision. They initiated a declaratory judgment action. There followed hearings and proceedings before Judge Robert Testo which intruded massively on the privacy of the family and set a dangerous precedent for state interference with parental autonomy. There was no *probable cause* to suspect that the parents might be exploiting either of their children, only that the doctors and administrators in refusing to accept the parental choice might be risking the well-being of both children and the family. The court upheld the parental choice, though not their autonomy to decide.

Although Judge Testo's decision avoided tragic consequences for the Harts, he did set a precedent for unwarranted and undesirable intervention by the state. He held:

To prohibit the natural parents and the guardians ad litem of the minor children the right to give their consent under these circumstances, *where there is supervision by this court* and other persons in examining their judgment, would be most unjust, inequitable and injudicious. Therefore, natural parents of a minor should have the right to give their consent to an isograft kidney transplantation procedure *when their motivation and reasoning are favorably reviewed by a community representation which includes a court of equity.*

57. Interestingly, the doctors were willing to rely on parental consent, without court review, to remove both of Kathleen's kidneys and thus leave her with "no potential kidney function" and with the "prospect of survival . . . because of her age, at best questionable." Id. at 372, 289 A.2d at 388. Cf. *In re Nemser,* 51 Misc. 2d 616, 621-25, 273 N.Y.S.2d 824, 629-32 (1966) (petition for appointment of guardian to amputate foot of 80-year-old woman; judge's complaint about resort to court).
58. 29 Conn. Supp. at 378, 289 A.2d at 391 (emphasis added). For another view of
Had the Hart parents refused to consent to Margaret’s surgery and the transplant of her kidney to Kathleen, equally unwarranted proceedings might have been brought to establish their neglect in order to obtain court authority to impose the doctors’ recommendation. Doctors can, because of their special training, make diagnoses and prognoses; doctors can indicate the probable consequences for a Margaret or a Kathleen of pursuing one course or another. But absent a societal consensus, nothing in their training, or for that matter in the training of judges, qualifies them to impose upon others their preferred value choices about what the good or better is for such children or for their families. The critical fallacy is to assume as Judge Testo does in his declaratory judgment—as the legislature does in its laws of neglect and abuse—that the training and offices of doctors, legislators, and judges endow them not just with the authority but also with the capacity to determine what risks to take for someone else’s child, in circumstances where there is no right or wrong answer or set of answers.

That some will object to and be uneasy about the substantial limits this essay proposes be placed upon the power of the state to supervene parental decisions about health care for their children cannot be denied. But it is the absence of a substantial societal consensus about the legitimacy of state intrusion on parental autonomy, on the entitlement of children to autonomous parents, and on family privacy in situations beyond the proposed limits which is the best evidence for holding in check the use of state power to impose highly personal values on those who do not share them. Further, the limits set by the standard of normal healthy growth toward adulthood or a life worth living, by the life-or-death choice and by the requirement of proven medical procedures has a built-in flexibility which can respond both to new findings in medicine and to new and changing consensuses in society.

the issues presented by such cases, see Lewis, Kidney Donation by a 7-Year-Old Identical Twin Child: Psychological, Legal, and Ethical Considerations, 13 J. Child Psych. 221-43 (1974). But see In re Richardson, 284 So. 2d 185 (La. App.), cert. denied, 284 So. 2d 338 (La. 1973) (affirming lower court’s refusal to approve of kidney transplant from mentally retarded 17-year-old to his 32-year-old sister); see also Howard v. Fulton-DeKalb Hosp., Auth., Civ. No. 3-90430 (Super. Ct., Fulton County, Ga., Nov. 29, 1973) (finding invalid mother’s consent to transplant from her 15-year-old, moderately retarded daughter, since mother would be recipient of kidney). The court in Howard, however, authorized the transplant under a doctrine of “substituted judgment.” The case, along with others that pose similar issues, is discussed in Nolan, Anatomical Transplants Between Family Members—The Problems Facing Court and Counsel, [1975] Fam. L. Rep. (BNA) 4035.