Organ Harvest from the Legally Incompetent: An Argument Against Compelled Altruism

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ORGAN HARVESTS FROM THE LEGALLY INCOMPETENT: AN ARGUMENT AGAINST COMPelled ALTRUISM

Abstract: Organ transplants may offer the best hope of long term survival for individuals afflicted with certain cancers or other debilitating diseases. The hope that a transplant may inspire in an organ recipient should not, however, be the determinative factor when the proposed source of the organ is incompetent. Competent adults are not compelled to act altruistically by undergoing a surgical invasion for the benefit of third parties. Children and mentally incompetent adults should likewise be protected from such compelled altruism. Case by case adjudication of petitions to harvest organs from incompetents are inevitably driven by a concern for the recipient and an unwarranted deference to parental authority, and not by concerns for the autonomy and well being of the incompetent donor. This Note argues that organ harvests from legal incompetents should be statutorily prohibited.

INTRODUCTION

It is axiomatic that advances in medical science which hold the promise of resolving questions of life and death tend to create ethical dilemmas of right and wrong. Organ transplants are one such advance. An organ transplant often offers the best hope of long term survival from certain cancers and other debilitating diseases. But that best hope cannot be realized unless a close, genetically matched organ can be quickly obtained. There are two sources of organs: those that are donated and those that are harvested. Organs are "donated" by competent adults who voluntarily and altruistically consent to give what is sometimes called, "the greatest gift." Organs are "harvested" from cadavers or living related children and mentally disabled adults—individuals who are unable to give a competent, valid con-
sent. It is this latter method of obtaining organs that poses the ethical dilemma: may the altruistic gift of an organ be compelled from a legal incompetent? Absent exigent circumstances, medical personnel must obtain parental or guardian consent before providing necessary medical treatment to children and mentally disabled adults. The requirement that parental consent be obtained is based on the principle that children and mentally disabled adults lack the maturity or ability to understand the consequences of accepting or foregoing treatment. Parental consent is considered sufficient to authorize necessary medical treatment on the grounds that parents are in the best position to determine and act on behalf of their children's best interests. For those same reasons, when medical treatment is unnecessary, but will improve the health of the child or mentally disabled adult, parental consent is again both necessary and sufficient.

The sufficiency of a parent or guardian's consent is less clear, however, when the treatment is medically unnecessary and the beneficiary of the treatment is a third party—such is the case when a

4 See Daniel B. Griffith, The Best Interest Standard: A Comparison of the State's Parens Patria Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients, 7 Issues L. & Med. 283, 308 (1991) (stating: "A person cannot make an informed decision if she lacks the capacity to reason and make judgments, her decision is not voluntary, and she lacks a clear understanding of the risks and benefits of alternatives as well as the nature and prognosis of the disease").

5 See id.

6 Physicians may treat children without parental consent if there is a risk to life or limb. See W. Page Keeton et al., Prosser and Keeton on the Law of Torts § 18, at 117 & n.37 (5th ed. 1984). Furthermore, the state's interest in protecting the public health and welfare may override the need for parental consent. See, e.g., Jacobsen v. Massachusetts, 197 U.S. 11, 30 (1905) (upholding constitutionality of compulsory vaccines).

7 See Little v. Little, 576 S.W.2d 493, 495 (Tex. App. 1979, writ denied); Griffith, supra note 4, at 308; cf. Bach v. Long Island Jewish Hosp., 267 N.Y.S.2d 289, 290–91 (N.Y. Sup. Ct. 1966) (holding that the consent of a minor emancipated by marriage was sufficient to authorize medically unnecessary treatment).

8 See Charles H. Baron, Live Organ and Tissue Transplants from Minor Donors in Massachusetts, 55 B.U. L. Rev. 159, 165 (1975). Although the parental right to direct a child's upbringing has been recognized as a fundamental right, the state may, under its parens patria power, burden that right or terminate parental rights altogether. See, e.g., In re Tabatha R. v. Ronda R., 587 N.W.2d 109, 115, 119 (Neb. 1998) (upholding an order removing a child from the care of the parents when one parent was incarcerated and the other was in an institution for the criminally insane). See also Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (overriding guardian's decisions regarding a minor's religious upbringing); Sherr v. Northport, 672 F. Supp. 81, 96 (E.D.N.Y. 1987) (overriding parents' objections to compulsory immunizations for their school-age child).


parent or guardian wishes to harvest an organ from a child or ward to save a sibling. In this context, the interests of the incompetent no longer drive the medical treatment. Rather, the incompetent's interests must be reconciled with or subsumed beneath the family and doctor's understandable desire to save the sibling. Yet, despite the absence of medical necessity or medical benefit, when confronted with petitions to harvest organs from incompetents, courts generally retreat behind presumptions of parental beneficence and give these procedures the blessing of judicial approval.

In contrast, competent adults are under no compulsion to submit to organ harvests for the benefit of third parties. Adults may decline to be tested for initial compatibility, and if compatible, may stop the process at any time. Both the common law doctrine of informed order declaring that the parents had the right to consent on the child donor's behalf; Curran, supra note 9, at 892; Jennifer K. Robbennolt et al., Advancing the Rights of Children and Adolescents to be Altruistic: Bone Marrow Donation by Minors, 9 J.L. & HEALTH 213, 216-17 (1994-95). See Joel D. Kallich & Jon F. Merz, The Transplant Imperative: Protecting Living Donors from the Pressure to Donate, 20 J. CORP. L. 139, 143 (1995) (stating that "[u]nlike medical care provided to improve the health of a patient, organ donation provides no therapeutic benefit to the organ donor"); Good Samaritan Hosp. v. Ohio Dept. of Health, 642 N.E.2d 1160, 1162 n.2 (Ohio Ct. App. 1994) (noting that "bone marrow is an organ"). This Note only specifically addresses bone marrow and kidney harvests, but the argument applies to other organ harvests as well.

12 See Curran, supra note 9, at 892.

13 See Little, 576 S.W.2d at 497 (citing John A. Robertson, Organ Donation by Incompetents and the Substituted Judgment Doctrine, 76 COLUM. L. REV. 48, 53 (1976)) (stating: "Judicial approval for intra-family transplants from incompetent donors has been granted in most cases.").

14 See generally McFall v. Shimp, 10 Pa. D. & C.3d 90 (1978) (refusing to compel a competent adult to undergo a bone marrow transplant for the benefit of his cousin).

15 See Roberta G. Simmons et al., Gift Of Life: The Social And Psychological Impact Of Organ Transplantation 289 (1977) [hereinafter Gift Of Life] (noting the case of a daughter who backed out the night before she was to donate a kidney to her mother). See generally Lanie Friedman Ross et al., Ethics of a Paired-Kidney-Exchange Program, 337 NEW ENG. J. MED. 1392, (1997), available at <http://www.nejm.org/content/1997/0336/0024/1752.asp>. Friedman Ross et al. advocate a kidney exchange program that addresses the problem of adult donors withdrawing their consent at the last minute. Under this model, an individual who is willing to donate a kidney but who is a poor tissue match for his or her ill recipient would be paired with a second mismatched pair and the kidneys would essentially be bartered between them: willing Donor A would provide a kidney to Recipient B, and willing Donor B would provide a kidney to Recipient A. The proponents warn, however, that the transplants would have to take place simultaneously to eliminate the possibility that Donor B might withdraw her consent after Donor A had already undergone surgery. See id.
consent and the rejection of a general duty to rescue support the competent adult's decision to assist or ignore the needs of third parties. Similarly, competent adults may prohibit post-mortem harvests of their organs by making those wishes known by an advance directive.

Society has long accepted and expected that in certain contexts the law will treat the legally competent differently from the legally incompetent. Contract and labor laws, for example, prevent the latter group from forming contracts or working in particular industries. These distinctions are justified, in part, by society's interest in protecting those who are unable to protect themselves because of age or mental infirmity. Nevertheless, when courts and legislatures rush to defend legally competent donors from compelled harvests but defer to third-party interests when faced with legally incompetent donors, the differences take on a disturbing texture.

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17 See, e.g., Head v. Colloton, 331 N.W.2d 870, 876 (Iowa 1983) (refusing to disclose identity of a potential bone marrow donor in a hospital donor registry to an individual suffering from leukemia); McFall, 10 Pa. D. & C.3d at 91; see also Greatest Gift, supra note 3, at 620 (arguing that even in the limited contexts in which states have found a duty to rescue, no legislature has gone so far as to require that the rescuer put him or herself at risk). But see Fordham E. Huffman, Comment, Coerced Donation of Body Tissue: Can We Live with McFall v. Shimp? 40 Ohio St. L.J. 409, 414-22 (1979) (articulating four criteria which, if satisfied, would permit a patient to obtain a court order requiring an unwilling donor to undergo an organ harvest under threat of civil and criminal penalties).

18 See Aaron Spitall, Mandated Choice for Organ Donation: Time to Give it a Try, 125 ANALS INTERNAL MED. 66 (1996), available at <http://www.acponline.org/journals/annals/>, under Past Issues (noting that a Gallup poll confirmed the general sense that the individual, not the family, should make the decision about post-mortem organ donations, and further, that the family should not be able to override advance directives); cf. Perry v. Saint Francis Hosp. & Med. Ctr., 886 F. Supp. 1551, 1561-62 (D. Kan. 1995) (finding that the use of deception to obtain a family's consent to extensive post-mortem donation was sufficiently outrageous to support a claim for intentional infliction of emotional distress).

19 See generally Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261 (1990) (O'Connor, J., concurring) (noting that it may be necessary for states to adopt special procedures in order to protect the liberty interests of incompetent patients); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) (holding that it is the manner in which the state preserves and upholds the rights, rather than the substance of those rights, that distinguishes an incompetent from a competent individual).


21 See Saikewicz, 370 N.E.2d at 428 (stating: "The 'best interests' of an incompetent person are not necessarily served by imposing on such persons results not mandated as to competent persons similarly situated. . . . To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons.").

22 See Strunk v. Strunk, 445 S.W.2d 145, 146 (Ky. 1969); McFall, 10 Pa. D. & C.3d at 91; Louise Harmon, Falling Off The Vine: Legal Fictions and the Doctrine of Substituted Judgment,
This Note will argue that organ harvests from children and mentally disabled adults should be categorically prohibited. Case-by-case adjudications of petitions to harvest organs from these individuals inevitably turn on a balance of the relative benefits and harms arising from organ transplants. The cost-benefit analysis is flawed for two reasons. First, courts refuse such a balance of benefits and harms when asked to compel competent adults to donate organs. Second, the information on which the cost-benefit analysis is based is both incomplete and incorrect. Moreover, using the most vulnerable members of society to shield us from the pain of a loved one's illness or imminent death is unfair. It forces the child or mentally disabled adult to take on life and death burdens for which they are wholly unprepared and exposes them to harms from which they are wholly unprotected. Only legislation which requires that individuals be fully competent to give an informed, meaningful consent before being candidates for live organ donations can alleviate the inherent dangers of adjudicating these issues case-by-case.

Part I of this Note provides an overview of organ transplantation and discusses the psychological effects and family dynamics that color the experience of donors and recipients. This foundation is necessary to critically examine the speculative psychological benefits courts rely on when they authorize organ harvests from children and the mentally disabled. Part II surveys the major case law in this area and notes a recent case which goes beyond the mere authorization to har-
vest an organ and actually discusses the recognition of a right to another's organ. Part II also examines the legal standards to which courts explicitly turn when deciding the cases. Finally, Part III analyzes the cost-benefit analysis underlying the court decisions that have authorized organ harvest petitions in light of the research presented in Part I. Part III then discusses why the judicial standards are unworkable and suggests legislative action as the way to ensure uniform and proper outcomes.

I. BACKGROUND

A. Procedures and Effects of Bone Marrow and Kidney Transplants

When faced with a child in need of an organ, parents and doctors often look to siblings because they tend to be more suitable donors than other family members or unrelated donors. Sometimes, desperate parents will even conceive additional children solely to provide the older sibling with a donor. As Part II will show, it is settled that a court has no authority to compel a competent adult to donate an organ. In contrast, courts adopt a posture deferential to the needs of


33 There is a 25% chance that a sibling will be a bone marrow match. See Ferrell v. Rosenbaum, 691 A.2d 641, 652 (D.C. 1997). Bone marrow transplants are used to treat aplastic anemia and some forms of leukemia and severe immunodeficiency diseases, although the therapy may offer no long-term advantages over conventional chemotherapy for patients with leukemia. See BMT Review, supra note 2, at 299. In 1984, approximately 450 bone marrow transplants were performed on children. See Deane L. Wolcott et al., Psychological Adjustment of Adult Bone Marrow Transplant Donors Whose Recipient Survives, 41 TRANSPLANTATION 484, 484 (1986) [hereinafter BMT Donors]. In 1997, the number was up to 2000. See Corinna Kaarela, After a Child Donates Bone Marrow to a Sibling, Self-Esteem Often Fares Worse Than That of Non-Donor Brothers and Sisters, UCSF PRESS RELEASE, Aug. 8, 1997, (visited Jan. 9, 2000) <http://www.ucsf.edu/pressrel/pr0897/0808bone.html>.


35 See McFall v. Shimp, 10 Pa. D. & C.3d 90, 91 (1978); see also Head v. Colutton, 331 N.W.2d 870, 872-73 (Iowa 1983) (refusing to disclose the identity of a matched donor who refused to donate bone marrow, despite the petitioner's grave medical condition); In re George, 630 S.W.2d 614, 622 (Mo. Ct. App. 1982) (refusing to open adoption records for an individual in need of a bone marrow transplant). But see Huffman, supra note 17, at 414-15 (suggesting a "construct" by which plaintiffs who satisfy certain criteria may obtain a court order and compel a reluctant donor to cooperate under threat of civil and criminal penalties).
third parties when the organ source is not legally competent, and they
generally find authority to permit such harvests. The emerging ra-
rationale among opinions authorizing harvests and commentators sup-
porting the practice is that organ harvests psychologically benefit the
volunteered donor. These opinions argue that permitting the har-
vest ensures the child or mentally disabled individual’s psychological
well-being by preventing the death of a sibling and by conferring on
him or her the benefits associated with altruistic acts.

Setting aside the question of whether speculative psychological
benefits constitute a sufficient justification for this sort of bodily intru-
sion, these rationales assume away several important questions which
this Note will attempt to answer: (1) Are different transplant proce-
dures sufficiently similar to warrant generalizing the experience of
one type of donor to another? (2) Is the child or mentally disabled
adult protected from psychological harm when his or her sibling sur-
vives? and (3) Can data regarding the experience of adults who vol-
unteer to donate an organ reliably predict the experience of the child
or mentally disabled adult who is volunteered?

1. Different Transplant Procedures Yield Different Results

There are two obvious differences between a bone marrow and a
kidney transplant: First, bone marrow regenerates while a kidney does
not; and second, whereas bone marrow is extracted through a thick
needle, making it seem analogous to the common experience of do-
nating blood, a kidney transplant requires major surgery. These do

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harvest from seven year-old twin); In re Doe. 981 N.Y.S.2d 932, 933 (N.Y. App. Div. 1984)
(per curiam) (regarding bone marrow harvest from mentally retarded adult); Little v.
Little, 576 S.W.2d 493, 497 (Tex. App. 1979, writ denied) (regarding kidney harvest from
young girl with Down’s Syndrome).

57 See Rachel M. Dufault, Bone Marrow Donations by Children: Rethinking the Legal Frame-
work in Light of Curran v. Bosze, 24 CONN. L. REV. 211, 230 (1991); Robbennolt, supra note
10, at 214.

58 See supra note 37, at 230; Robbennolt, supra note 10, at 214.

59 See generally Baron note 8; Robertson, supra note 14.

60 See infra notes 43–58 and accompanying text.

61 See infra notes 59–94 and accompanying text.

62 See infra notes 98–126 and accompanying text.

63 See supra note 2, at 300. After undergoing tissue typing, a bone marrow
harvest must be done under general anesthesia so the marrow can be extracted via multi-
ple punctures in the pelvis area with a rigid needle screwed through the bone. See id. It
takes approximately half an hour and upwards of 200 taps to extract one liter of bone mar-
row fluid from an adult; the procedure must be repeated at various intervals to extract
sufficient bone marrow fluid from a child. See Baron, supra note 8, at 163 n.20; Diane M.
not, however, constitute the only differences between the two types of transplants. The other perhaps more significant differences have less to do with the manner in which the organ is harvested and more to do with the underlying disease which has created the need for the organ in the first place. These differences, in turn, materially affect the experience of the donor.

The time frame in which a family must locate a suitable donor and the post-transplant prognosis for the organ recipient, are two such factors that differ dramatically depending on the nature of the disease and that can seriously and adversely affect the donor. In terms of the timing of the transplant, options short of a kidney transplant from a living related donor exist for most people in need of a kidney. Dialysis, for example, can sustain an individual with no functioning kidney for upwards of twenty-five years, depending on the nature and severity of the underlying disease. Organs from cadavers have become more available as awareness about the great need for organs and comfort with the idea of donating has grown.

Gianelli, Bearing a Donor? Ethical Concerns Raised Over Having Baby for Marrow Match, Am. Med. News 3, available in 1990 WL 3259464. Although the greatest physical risk is from the anesthesia, infection is also a concern. See Gianelli, supra; Celia Hall, Donor's Operation Carries Little Risk, Daily Telegraph, Apr. 19, 1997, at 3.

Renal transplants are significantly more involved. Donors tend to experience a great deal of pain and discomfort post-transplant and there is a 28.2% risk of complications, ranging from mild infections and lung problems to extreme cases in which the donor contracts the same illness which afflicted the recipient. See Gift of Life, supra note 16, at 166. Major complications include damage to the spleen or adrenal glands, major bleeding and pulmonary embolisms. See Kallich & Merz, supra note 11, at 147. In addition, both donors and recipients have a permanent scar running from mid-abdomen to mid-back. See Gift of Life, supra note 16, at 166.

44 See BMT Donors, supra note 33, at 484-85, 487.
45 See id.
46 See id.
48 See id.
49 Between 1990 and 1995 the number of cadaveric kidneys available in the United States rose from 9878 to 11,818, a small but not insignificant increase. See Laura G. Dooley & Robert S. Gaston, Stumbling Toward Equity: The Role of Government in Kidney Transplantation, 1998 U. Ill. L. Rev. 703, 721 n.98. But see Kallich & Merz, supra note 11, at 142-43 (noting that the low rate of increase in the number of available cadaveric kidneys can likely be traced to a decrease in the number of automobile fatalities and an increase in diseases such as HIV that preclude transplantation). Authors Kallich & Merz conclude that the pressures on living donors will increase as the supply of cadaveric organs becomes insufficient to meet the demand. See id.
ally related donors, such as spouses and friends, are also becoming more acceptable sources of kidneys.\(^{50}\) Until recently, doctors were reluctant to mine this particular source of organs because of compatibility concerns; however, developments in immunosuppressive pharmacology have reduced the need for the type of close genetic match that was formerly thought necessary.\(^{51}\) These options materially affect the experience of the donor by reducing the pressure a family may feel to come up with an immediate donor, and by easing the psychological pressure on the individual family member that he or she is the patient’s only hope.\(^{52}\)

A bone marrow transplant, on the other hand, may be the patient’s best hope for survival.\(^{53}\) Furthermore, the window of opportunity for performing a bone marrow transplant is generally quite

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\(^{51}\) See id. In particular, the introduction of the immunosuppressive Cyclosporine can be credited with widening the set of kidney donors. See id.; Kallich & Merz, supra note 11, at 140-41. But see Hart, 289 A.2d at 389 (listing the serious and permanent side-effects associated with immunosuppressives).

\(^{52}\) BMT Donors, supra note 33, at 484-85. This is not to suggest that these options are optimal. Dialysis is a demanding treatment and patients often find the treatment and its strict regimen of food, medication and exercise physically and emotionally draining. See generally Psychonephrology I: Psychological Factors in Hemodialysis and Transplantation (Norman B. Levy ed., 1981) [hereinafter Psychonephrology].

\(^{53}\) See BMT Review, supra note 2, at 299. The efficacy of the treatment depends on the underlying disease. See id. While a bone marrow transplant may be the optimal treatment for some individuals with aplastic anemia, leukemia patients may fare no better from a bone marrow transplant than from the regular course of chemotherapy. See id. Advances in medical science may eventually provide alternatives to current practices. For example, transplants between individuals who are not closely matched may become more feasible, umbilical cord blood may provide a source of bone marrow, and cloning whole organs may become possible. See, e.g., Andrew Skolnick, *Application Considered for Immunotoxin in Treatment of Graft-vs-Host Disease*, 265 JAMA 2041, 2042 (1991) (stating that new drug shows promise in reducing graft-versus-host disease (GVHD) for patients receiving bone marrow transplants from their parents); Richard Saltus, *Report Offers Vision of Versatile Fix-it Cell*, BOSTON GLOBE, Nov. 6, 1998, at A3 (reporting that scientists isolate human cells with the potential to develop into any kind of cell in the human body, and that “stem cells,” which are only present “in the first few days of embryonic life,” can reproduce in a petri dish). Autologous transplants, the removal (prior to chemotherapy) and subsequent reinfusion (after chemotherapy) of the patient’s own bone marrow are being used for certain types of cancers, but other types continue to require allogenic transplants, that is, bone marrow from a donor. See Dexter v. Kirschner, 984 F.2d 979, 981, 987 (9th Cir. 1992) (rejecting claim that under the Equal Protection Clause of the Fourteenth Amendment the state Medicaid system was required to fund both allogenic and autologous bone marrow transplants).
small. The urgency of the situation makes it more likely that a bone marrow donor, unlike a kidney donor, will feel that the life or death of the ill family member is in his or her hands. For children and mentally disabled adults, the urgency has the added effect of encouraging hasty court proceedings with little adversarial content. Moreover, a failed bone marrow transplant exacts a higher price than a failed kidney transplant because death from the complications associated with a bone marrow transplant tends to be more agonizing than death from the underlying disease. The fact that kidney and bone marrow transplants may yield vastly different results is a critical difference between the two types of transplants because, as discussed in the next section, the psychological well-being of the donor is often tightly bound to the ongoing health and well-being of the recipient.

2. The Potential for Psychological Harm from Donating an Organ

Courts that have authorized organ harvests have assumed a cause and effect relationship between a transplant and the prevention of psychological harm. In other words, courts assume that permitting the transplant will ensure the survival of the sibling, which in turn will

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54 See Baron, supra note 8, at 182 (noting that the urgency of the situation results in the adult donor being pressured to make an immediate decision while for the incompetent donor, the situation results in a rushed legal proceeding in which the donor's interests go unprotected). But cf. Doe, 481 N.Y.S.2d at 932-33 (granting petition to harvest bone marrow from severely retarded adult notwithstanding the fact that the life of the ill sibling, also an adult, was not in immediate jeopardy).

55 See id. at 184. In addition to concerns about conflicts of interest, doctors may be better equipped to be information resources than vigorous advocates for the interests of young or incompetent donors. See id.

56 See id. at 163 n.19; Deane L. Wolcott et al., Adaptation of Adult Bone Marrow Transplant Recipient Long-Term Survivors, 41 TRANSPANTATION 478, 484-85 (1986) [hereinafter BMT Recipients]; see also Newmark v. Williams, 588 A.2d 1108, 1117-18 (Del. 1990) (upholding parents' right to refuse aggressive cancer treatment for their young son). In Newmark, the court found that the treatment was "the most aggressive form of cancer therapy short of a bone marrow transplant." Id. at 1118. If the treatment itself did not kill the boy, it would offer him a forty-percent chance of survival, measured not in terms of cure, but in terms of living for two additional years, cancer free. See id. at 1119 n.12.

57 See generally id.; Hart, supra note 8; Doe, 481 N.Y.S.2d at 933; Little, 576 S.W.2d at 499; cf. Curran v. Bosze, 566 N.E.2d 1319, 1343-44 (Ill. 1990) (refusing to authorize a bone marrow transplant where the sibling relationship was too tenuous to support a finding of psychological benefit).
protect the child or mentally disabled donor from psychological harm, or alternatively, will provide the donor with a psychological benefit. Undoubtedly, some transplants do achieve their purposes with no measurable ill effects on the donor. Research indicates, however, that this best outcome may be far less common than people realize.

Transplant operations often create a unique link between the donor of an organ and its recipient. Sometimes, this link opens the door to greater closeness and a sense of mutual support. The link, however, also tends to bind the pair in such a way that the donor's psychological well-being and the quality of the donor-recipient relationship becomes dependent on the recipient's health and well-being. One team of researchers at the University of California, Los Angeles (UCLA) studied these various effects. In one study, the UCLA researchers found a high, direct correlation between a recipient's perception of his or her health, social functioning and overall well-being and the donor's perception of their relationship. They suggested that "physical or psychosocial deterioration in [bone marrow transplant] recipients may result in significant psychological distress in the donor."

Unfortunately, significant physical or psychosocial "deterioration" is common among bone marrow recipients because bone marrow transplants involve a high risk of severe, short-term illness and an of-

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60 See Hart, 289 A.2d at 389; Doe, 481 N.Y.S.2d at 933; Little, 576 S.W.2d at 499; cf. Curran, 566 N.E.2d at 1343-44.
61 See BMT Donors, supra note 33, at 487.
62 See id. at 485. Wolcott et al. noted that little attention has been paid to the long-term psychological adjustment of bone marrow donors because, overall, kidney donors seem to adjust quite well. In other words, researchers have wrongly assumed that the experience of one set of donors can accurately predict the experience of another set of donors. See id. at 484; BMT Recipients, supra note 57, at 478.
63 See BMT Donors, supra note 33, at 487. See generally Roberta Simmons, Psychological Reactions to Gift Giving, in PSYCHONEPHROLOGY, supra note 52, at 227.
64 See Marissa Ayala, supra note 34, at 78.
65 See BMT Donors, supra note 33, at 487; Simmons, supra note 63, at 234.
66 See generally BMT Donors, supra note 33; BMT Recipients, supra note 57; BMT Review, supra note 2.
67 See BMT Donors, supra note 33, at 487. In addition, the passage of time post-transplant did not diminish the correlation between the recipient's wellness and the donor-recipient relationship. See id. A sister who donated a kidney to her brother reported that he had been avoiding her for three months following the operation. "I was never so crushed. I would call him up and he would be as cold as ice. I was destroyed. To this day I don't mention the kidney in front of him... He has never come out and said 'Thank you.'" Simmons, supra note 63, at 234.
68 BMT Donors, supra note 33, at 487.
ten low rate of long-term survival. The statistics are grim: the one-year survival rate averages only fifty to sixty percent, and among those recipients who survive, approximately twenty-five percent experience significant health problems. For many recipients, significant health problems manifest in the form of Graft Versus Host Disease (GVHD), a disease caused by the transplant itself. Bone marrow produces white blood cells; white cells form the core of our immune system. An essential result of a bone marrow transplant, therefore, is that the immune system of the donor is transplanted into the recipient:

Just as a host’s immune system will [treat] a transplanted liver or heart as foreign tissue and react against it, a transplanted immune system will [treat the] host’s entire body as foreign tissue and react against it. ... Acute GVHD manifests itself in one of three ways: a skin rash that can progress to blistering and ulceration, liver damage that can progress to liver failure, and damage to the intestinal lining that can lead to massive gastrointestinal bleeding. Chronic GVHD, which ... can either follow an episode of acute GVHD or arise spontaneously, has symptoms that resemble those of autoimmune diseases like lupus and scleroderma, including severe rashes, thickening and scarring of the skin, and limitation of joint motion.

GVHD is the single greatest threat to a bone marrow recipient’s health following a transplant. In addition to the medical complications caused by GVHD, the drugs used to treat GVHD are strongly associated with a wide spectrum of psychiatric and physical syndromes, including renal failure, delirium, anorexia, chronic sleep

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69 See id.; see also R. v. Cambridge Health Auth., 2 All E.R. 129, 133-35 (C.A. 1995) (upholding the Health Authority’s refusal to fund a second bone marrow transplant where the treatment would only yield a 10% chance of survival if the treatment itself did not kill her); BMT Recipients, supra note 57, at 478, 480, 482.

70 See BMT Recipients, supra note 57, at 478. Statistics can, of course, mean different things to different people, numbers which give a donor pause might well give a recipient hope. But lest the reader lose sight, the question is not whether a recipient may benefit from the transplant but whether the benefits courts impute to organ donors are likely to be realized.

71 See Ronald Kline, New Marrow for Old, MIT ALUMNI TECH. REV., Nov. 1993, at 43.

72 See id.

73 Id.

74 See id.
disorders and gonadal dysfunction. Furthermore, even patients who suffer from no GVHD complications have shown neurological damage from the regular course of cancer treatment alone. Although researchers continue to search for a way to prevent GVHD, one researcher noted that while GVHD often kills its victims, those who survive the most severe bouts of the syndrome seem to have a greater chance of long-term survival.

To date, only one study has focused particularly on the experience of minors from whom bone marrow was harvested for the benefit of a sibling. Researchers at the University of California, San Francisco found that fully one-third of children whose siblings were bone marrow recipients suffered from signs of post traumatic stress syndrome, even if the transplant had taken place years earlier. The children were depressed, complained of recurrent nightmares, had overdeveloped fears of hospitals and needles and had a constant sense of dread that the experience might be repeated. This was true for both siblings who donated and siblings who did not donate. The sib-

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75 See BMT Review, supra note 2, at 305-06. Post-bone marrow transplant delirium led, in at least one reported case, to stupor and coma. See id.
76 See id. at 305. Severe cognitive impairment and altered interpersonal behavior were observed in a small percentage of patients at the UCLA clinic where the transplants and subsequent studies were performed. See id.
77 See generally Kline, supra note 71.
78 See Kaarela, supra note 33.
80 See Cohen, supra note 79, at 20; Kaarela, supra note 33.
81 See Cohen, supra note 79, at 20; Kaarela, supra note 33. It should not come as a surprise that all of the siblings showed signs of trauma, regardless of whether they were selected to donate. Proponents of organ harvests from minors might use this fact to argue that because the whole family unit is traumatized by the illness visited on one of its members, the situation for the young donor is not made worse by his participation in the organ harvest. The UCSF study did not, however, control for the accumulated effects of the non-donors being eliminated from the harvesting procedure. It is very possible, therefore, that the trauma non-donors experience is as much a result of the donor selection process as it is a result of the illness itself. For example, the non-donor's trauma might be a consequence of the child's fear and worry of possibly being chosen and the guilt that attends his feelings of relief for having escaped selection. Additionally, the child may experience conflicted feelings of jealousy regarding the attention and praise the donor sibling receives and confusion about how to understand all of these feelings in the face of his sister or brother's struggle to live. See, e.g., Roger Dobson, Your Sister Could Save Your Life. Luckily She Wants To, INDEF. (LONDON), May 14, 1996, at 6.

Furthermore, the study may support an argument that the emotional cost of extraordinary medical treatments on individual family members and the family unit as a whole may, in some cases, outweigh the remote chance of a cure for the ill child. See generally George Howe Colt & Eugene Richards, The American Family: Part Five; When a Child is Sick, LIFE, Aug. 1991, at 58 (reporting one family's experience with childhood leukemia.
lings who donated, however, were more withdrawn, anxious, depressed and had a lower sense of self-esteem, which the researchers attributed to a guilty fear that their tissue might not be "good enough." Other researchers have similarly warned that if the child turns out to be an incompatible donor or the transplant is unsuccessful, "[t]he . . . guilt which may follow in the wake of [that] failure could be transferred to the donor child with untoward effects, either in early bonding or later, as the child grows up under the shadow of having failed in an important task." Moreover, negative reactions to these procedures are not restricted to young donors. Despite the fact that a bone marrow harvest is less complicated surgically, the percentage of adult bone marrow and kidney donors reporting negative reactions to the donation experience was roughly the same. Nor are difficulties in the ongoing relationships between donors and recipients limited to those cases in which the recipient fared poorly or died. Contrary to the expectation that a good medical result for the recipient will lead to a good psychological result for the donor and the relationship, some donor-recipient pairs become estranged even when the recipient is a long-term disease-free survivor. This finding led the UCLA researchers to express concern that the approximately ten to twenty percent of the adult donors in one study who exhibited adverse psychological consequences was only the "tip of the iceberg," because those donor-recipient pairs who had become estranged declined to participate in the study at all. Lastly, they cautioned that donors as a class may show a "relatively high incidence of pathological grief reactions" if their recipients do not survive.

and noting that the healthy sibling was withdrawn, angry and resentful, the father developed heart problems as a result of the stress and the mother, who worked two and sometimes three jobs to support the family, came home each night ragged and worn out).

See Cohen, supra note 79, at 20.


See GIFT OF LIFE, supra note 16, at 154, 169; Kallich & Meiz, supra note 11, at 148 n.30.

See supra note 62 and accompanying text; see also BMT Donors, supra note 33, at 487.

See BMT Donors, supra note 33, at 487; see also GIFT OF LIFE, supra note 16, at 171-75. One author has noted that "The donor who demonstrates clear ambivalence prior to donation is likely to find the recipient reacting with hostility rather than gratitude for the gift. The reluctant gift may be accepted, but the donor loses more than the gift in the exchange." GIFT OF LIFE, supra note 16, at 175.

See BMT Donors, supra note 33, at 487.

See id. at 488.
Kidney transplants similarly bind the fate and well-being of donors and recipients. While short-term health and long-term survival for the kidney recipient are decidedly better than for the bone marrow recipient, kidney recipients have exhibited disturbing psychological effects as a result of the transplant, and this in turn affects the donor and the donor-recipient relationship. The psychological effects observed in kidney recipients include delusions that the transplant will lead to a full and complete recovery and a refusal to acknowledge the true risks involved. In addition, recipients may become depressed or suffer from the psychotic belief that they have taken on the qualities of the donor through the transplanted organ. More commonly, kidney recipients manifest a chronic fear and worry that they are living on stolen time. Finally, recipients of kidneys donated by relatives have reported that they suffer from guilt and a sense of having an unpayable debt hanging over their heads, an emotional residue that is uncommon for individuals who receive kidneys from cadavers.

For the kidney donor, the physical toll of the harvesting procedure is much greater than that exacted on the bone marrow donor from the bone marrow extraction procedure. A kidney harvest involves major surgery and results in the permanent loss of an organ as well as a scar running from mid-back to mid-abdomen. Moreover, because the rejection rate for even closely matched kidneys can run as high as twenty percent, kidney donors may experience not only a sympathetic or guilt reaction, but may feel that they underwent major surgery and gave up a kidney for nothing.

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89 See generally Psychonephrology, supra note 52.
90 See Pietro Castelnuovo-Tedesco, Transplantation: Psychological Implications of Changes in Body Image, in Psychonephrology, supra note 52, at 219, 222; Jorge Steinberg et al., Psychological Factors Affecting Acceptance or Rejection of Kidney Transplants, in Psychonephrology, supra note 52, at 185, 189.
91 See Castelnuovo-Tedesco, supra note 90, at 220-21. One researcher hypothesized that these psychological effects were peculiar to treatments which effectively extend rather than save a patient's life. See id. In other words, individuals who are treated by having diseased tissue or organ surgically removed are more likely to see their treatment as reclaiming their proper life span than are those whose treatment involves the receipt of another's tissue or organ. That no psychosis or delusions were reported among recipients of life-saving treatments is evidence for the researcher's hypothesis. See id.
92 See id.; Gift of Life, supra note 16, at 171-72.
93 See Gift of Life, supra note 16, at 166.
94 See id. at 169. In one study, the rejection rate for kidneys was 18% and a number of donors exhibited or reported having severe negative reactions to the news. See id. One brother who donated reported becoming hysterical when he found out that his kidney had been rejected, exclaiming: "What a waste for me and what a horrible thing for him." Id.
The physical and psychological differences between bone marrow and kidney transplants make it difficult to speak of organ transplants as an undistinguished class of procedures. Differences in the underlying diseases and in the transplant procedures lead to different stresses and different types of risks. Similarly, the methods by which individuals become donors vary to such a degree that to speak of organ donors as an undistinguished class of individuals is misleading. Just as the bone marrow donor may be more likely to experience psychological trauma than the kidney donor, the donor who is volunteered may be more likely to experience psychological or physical trauma than the donor who steps forward as a mature and competent volunteer.

B. *The Volunteer vs. the Volunteered*

Adults become live donors when they register with organ procurement organizations or agree to donate in response to a family member’s acute need. The context in which an adult donates and the factors leading to the decision to donate vary. In turn, context and motivating factors may determine the donor’s experience of the donation itself. The set of adult organ donors can therefore be broken down into three distinct groups: (1) the altruistic, anonymous adult donor; (2) the family member who decides to donate in response to internal pressures; and (3) the family member who decides to donate in response to external pressures. Because minors and mentally disabled adults cannot volunteer but must be volunteered by parents or guardians, they make up a fourth, closed class of compelled donors.

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95 See supra notes 43–58 and accompanying text.
96 See infra notes 99–126 and accompanying text.
97 See infra notes 99–126 and accompanying text.
98 See generally Mark F. Anderson, Encouraging Bone Marrow Transplants From Unrelated Donors: Some Proposed Solutions to a Pressing Social Problem, 54 U. PITT. L. REV. 477 (1993); Kallich & Merz, supra note 11.
99 See GIFT OF LIFE, supra note 16, at 165; Anderson, supra note 98, at 550 (noting that the donor who is “forced to undergo an operation that exposes her to a small but significant health risk as well as physical discomfort for several days ... will likely suffer serious psychological trauma...”).
Adults who decide to participate in organ procurement organizations do so voluntarily out of a sense of charity and social duty. These donors generally remain anonymous, as do the identities of the recipients. Much has been written about the satisfaction and heightened self-esteem these donors experience when they learn that their organ or tissue may have given someone a fighting chance to survive. It may be, however, that it is the anonymity and voluntariness peculiar to this type of organ donation that permits the donor to experience the euphoria of having done something utterly selfless and good.

Family members who decide to donate organs when illness strikes close to home fall into two primary groups: those who donate in response to a sense of moral obligation and those who donate in response to pressure from families or medical personnel. Generally,

102 See Anderson, supra note 98, at 529. Additionally, an individual’s willingness to donate at all may depend on the voluntariness of the donation process. Charitable organizations that attempt to coerce participation by pressuring volunteers or making them feel guilty, for example, are likely to see a reduction in their contributions. See Alan Radley & Marie Kennedy, Charitable Giving by Individuals: A Study of Attitudes and Practices, 48 Hum. Rel. 685 (1995) (noting that when people experience charitable solicitations as intrusive, refusing to give becomes “an exercise of one’s rights as a private citizen” rather than a “breach of a social norm”).

103 See Head, 331 N.W.2d at 872 (refusing to disclose identity of a potential bone marrow donor in a hospital donor registry to an individual suffering from leukemia). Although participants in bone marrow registries remain anonymous, if their bone marrow is used and the recipient survives the first year post-transplant, the donor and recipient’s identities may be disclosed with both parties’ consent. In some cases, a lasting relationship may develop between the formerly anonymous donor and the recipient of the tissue. The author of this Note had the opportunity to speak with one such donor about his experience. Mr. Nicholas Economou participated in a local bone marrow registry near his home in Virginia. His bone marrow ultimately went to a five year-old girl, Carly Scherer of Buffalo, New York, who was suffering from a rare form of leukemia. The transplant was performed in June 1995, Mr. Economou and Carly met in June 1996. Though separated by thousands of miles, the two families have since become very close. Carly will be declared cured in May 2000, an event in which both families will share. See Telephone Interviews with Nicholas Economou, November 1999-January 2000; see also Louise Continelli, Girl Earns Place Among Cancer Survivors, BUFFALO NEWS, Feb. 9, 2000, at 5B.

104 See Officer Is One in a Million, HERALD (GLASGOW), Sept. 17 1998, at 12 (recounting the experience of a Scottish police officer whose participation in the UK bone marrow registry led to him becoming a donor). One donor has noted: “What could be more worthwhile than offering somebody the chance of life—it really is an amazing feeling.” Id.

105 See id. Moreover, the fact that such stories receive this type of media attention and public commendation indicates that these acts of altruism are considered acts of heroism.

106 See GIFT OF LIFE, supra note 16, at 233–50; Simmons, supra note 63, at 230. Family members who donate also make up a third, middle group. This group arrives at the decision to donate after more deliberation than those who feel morally obligated. See GIFT OF LIFE, supra note 16, at 254–58. At the same time, for these donors family pressure plays an
when adults decide to donate in response to a sense of moral obligation—that is, on the basis of an internal motivation—they experience their participation as voluntary and generally feel good about their decision in both the short-term and the long-term. While the ill family member’s need for the organ triggers the donor’s feeling of moral obligation, the donation itself is driven by the need to satisfy the feeling of obligation. The donor’s participation does not, ultimately, depend on the outcome of the transplant nor the risks involved. A clear and developed sense of one’s moral obligation, therefore, seems to reduce the likelihood that a donor will be ambivalent about giving up the organ, and may in turn immunize him from the psychological after-effects noted above.

The second group of family members decide to donate in response to pressure from family or from medical personnel. This pressure can range from subtle situational pressures, to messages as blatant as: “if you don’t donate, s/he will die.” Whereas moral obligation can properly be called an internal motivation, these pressures are external and can be quite intense. More than half of the kidney

 identifiable, albeit a less coercive and corrosive, role. See id. at 257-58. For purposes of this analysis, the more extreme types of decision-making capture the key components of the more mediated decision-making process.

108 See id. at 238, 239-50.
109 See id.
110 See id. at 165.
111 See Kallich & Merz, supra note 11, at 144 (pressure from medical personnel); GIFT OF LIFE, supra note 16, at 154-65 (family pressure).
112 See GIFT OF LIFE, supra note 16, at 165 (noting that 12% of the case studies involved “blatant unwelcome types of family pressure”).
113 See generally, e.g., Lawse v. University of Iowa Hosps., 434 N.W.2d 895 (Iowa Ct. App. 1988). In one case, a living kidney donor brought an action against the hospital and doctors for wrongful removal of his kidney. See id. at 896. Thirteen years after he donated a kidney to his brother, the donor’s remaining kidney failed. See id. at 898. The donor claimed that because the hospital and staff had negligently failed to respond to his unwillingness to donate, his consent had been coerced. See id. The donor specifically alleged that the doctor and hospital had coerced him by giving him misinformation or insufficient information: (1) despite the fact that his brother was doing well on dialysis, he had been told that his brother would die without his kidney; (2) he was counseled that “there was basically no risk to him, it was like having an appendix removed” and (3) information about his tissue typing had been shared with other family members before he had been informed of the results—information that could not help but affect those members’ willingness to donate. At the same time, information about another brother’s refusal to donate was kept from him. See id. at 897. The court frankly discussed the coercive effect of family pressure and aired the concern that as a result, related donors may never be able to give a truly informed consent. See id. The case was dismissed, however, because the statute of limitations had run out. See id. at 898.
donors in one study group were subject to pressure that researchers felt had a "compulsory quality." Even when the pressure is not overt, the threat of family sanctions may be coercive to the point where family members feel that they truly have no choice. The face of death, however, only rarely changes existing and entrenched family dynamics. A hard but undeniable truth is that family members may not be loved or valued equally. Sibling rivalry, favoritism and other pre-illness conflicts affect the way families manage the stress of the illness, as well as the process by which donors may be selected. Moreover, these factors color the long term experience of the donor and may even affect the medical success of the transplant.

114 See GIFT OF LIFE, supra note 16, at 160-61. Fifty-four percent of the donors in the study group were subject to such "compulsory" pressures. See id. at 161.

115 See Kallich & Merz, supra note 11, at 144-46. One author has noted: "The social mores of the family [may] dictate that all members . . . offer to donate their organs . . . Violating this norm entails substantial and likely penalties that few would endure willingly, such as excommunication from the entire family unit." Id. at 146. One mother spoke about the pressure on her ten-year-old daughter to donate:

In a way, I suppose, she didn’t really have a choice. We simply told her the facts. We didn’t say, “Look if you don’t do it, Lewis will die,” because that would have been too much, but she knew as much. At the end of the day a parent isn’t going to say, “The choice is yours. If you decide not to, that’s fine, we’ll just prepare for our son’s funeral.” If she had had very strong views against being a donor, I don’t know what we would have done.

Dobson, supra note 81. In fact, the ten year-old daughter had hoped she would not turn out to be a match and spoke of her fear of hospitals and needles. See id. None of this, however, amounted to the daughter holding “strong views” in the mother’s eyes. See id.

116 See Baron, supra note 8, at 173; Fatter & Marshall, supra note 30, at 1248.

117 See BMT DONORS, supra note 33, at 487. “[O]ne mother remarked openly to [the transplant team] . . . ‘Isn’t it strange that it ends up our [son, the] black sheep . . . is the donor to our favorite [daughter].’” See id. This comment led to staff aptly to ask, “What will these parents do to this donor son psychologically if she dies?” See id.

118 See id.; see also Baron, supra note 8, at 173 (noting the danger that parents will be “particularly insensitive” to the harms a “disfavored donor” might suffer or “particularly impressed” with the benefits a “favored recipient” might receive).

119 See GIFT OF LIFE, supra note 16, at 445; see also Castelnuovo-Tedesco, supra note 90, at 222-23 (reporting the case of a boy who made a suicidal gesture, rejected the grafted kidney and died after discovering that the kidney had been donated by his “ne’er do well” father); Steinberg, supra note 90, at 189. Steinberg attempted to predict the acceptance or rejection of transplanted kidneys on psychological factors alone. See id. at 186-87. Of the twenty-six recipients in the study, only one was rated as “unlikely” to retain the transplanted kidney. See id. at 188-89. In that case, a forty-eight year-old aunt agreed to donate a kidney to her ill and estranged twenty-six-year-old niece. See id. The family urged the aunt to be the donor because of their belief that the operation would reunite the two women. See id. Notwithstanding her aunt’s willingness to donate, however, the niece maintained her distance. See id. This reaction angered the aunt, and prompted the aunt to tell her niece to “[t]ake my fucking kidney . . . [.] I don’t want to see you again.” See Steinberg,
Notwithstanding the internal and external pressures on family members to volunteer, adults may decide that for whatever reason, they are unwilling to step forward. Among the immediate family, studies have found that adult siblings of ill family members are the least willing to donate while parents and children are the most willing. Nor is it uncommon for an adult family member to publicly manifest a willingness to be a donor but, in the privacy of a medical consultation, indicate by actions or words that he or she does not actually wish to donate. In response, medical personnel have been known to manufacture medical excuses that provide unwilling donors a graceful way out and that protect them from further family pressure.

Minors and mentally disabled adults make up the final set of donors, but rather than volunteering to donate, these donors are volunteered by a parent or guardian. The question for medical personnel, then, turns not on the child or mentally disabled adult's willingness to donate, but on the parent or guardian's legal authority to consent to the donation on behalf of the child or ward. This is the way that judges and courts most commonly become involved in the process of obtaining organs from live donors.

supra note 90, at 189. As predicted, the aunt's kidney was rejected shortly after the transplant. See id.

120 See Simmons, supra note 63, at 228 (forty-three percent of family members declined to be tested for initial compatibility); see also Friedman Ross, supra note 16 (expressing the concern that an organ exchange program which effectively eliminates the "incompatible donor" excuse may be problematic for those donors who count on being able to express their show of support for the family member without being under any obligation to donate).

121 See Gift of Life, supra note 16, at 203-04. The percentages of family members who donated or volunteered to donate were: parents (86%); adult children (66%); sisters (48%) and brothers (46%). See id. at 203. Despite their relative unwillingness to donate, most related organs come from siblings. See id. at 204.

122 See Gift of Life, supra note 16, at 289; Fellner & Marshall, supra note 30, at 1246; Kallich & Merz, supra note 11, at 152.

123 See Gift of Life, supra note 16, at 212, 289; Fellner & Marshall, supra note 30, at 1246. But see Kallich & Merz, supra note 11, at 144-45 (noting that although most pressure can be traced to the family, transplant teams sometimes become so invested in the survival of a patient that they ignore a potential donor's worries or reluctance to donate).

124 See generally Hart, 289 A.2d 386; Little, 576 S.W.2d 493.

II. CASE LAW AND THE APPLICABLE LEGAL STANDARDS

Uncertainty about a parent or guardian's right to consent to medically unnecessary organ harvests from children and mentally disabled adults has led doctors and hospitals to require court orders to preempt any question of liability.\(^{126}\) State courts are the current forum for adjudicating such petitions.\(^{127}\) There are currently no statutes authorizing or compelling organ harvests from compatible incompetents.\(^{128}\) In their absence, courts have historically applied the "best interest" or "substituted judgment" standard.\(^{129}\) Regardless of which standard is applied, a cost-benefit analysis underlies most judicial reasoning, balancing the benevolent desire of the family to save the life of an ill family member against the known physical risks and theoretical psychological benefits that might accrue to the organ donor.\(^{130}\)

A. The Standards and Analyses Courts Apply to Incompetent Donors

The judicial standards to which courts turn when faced with a petition to harvest organs from legal incompetents have roots that pre-date the organ procurement dilemma by hundreds of years.\(^{131}\) The best interest standard, for example, can be traced back to the

\(^{126}\) See, e.g., Glantz, supra note 125, at 220–24; cf. Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941) (holding that a fifteen-year-old's consent was invalid to authorize a physician to perform a skin graft on him for the benefit of his cousin, but indicating, in dicta, that the parents' consent would likely have been sufficient). See generally Baron, supra note 8.

\(^{127}\) See generally, e.g., Curran v. Bosze, 566 N.E.2d 1319 (Ill. 1990); Little v. Little, 576 S.W.2d 493 (Tex. App. 1979, writ denied).

\(^{128}\) See Curran, supra note 9, at 892; Baron, supra note 8, at 177. Professor Baron noted in his 1975 article that at that time there was one state statute that permitted 14-year-olds to consent to donate organs, but that statute has since been repealed. See id. Currently, the only statutes governing organ harvests involve post-mortem harvests. See, e.g., David A. Jeffries, Note, The Body as Commodity: The Use of Markets to Cure the Organ Deficit, 5 IND. J. GLOBAL LEGAL STUD. 621, 631 (1998) (noting that all fifty states and the District of Columbia adopted the 1968 Uniform Anatomical Gift Act and its 1987 revisions, designed to encourage organ donation and provide guidelines for organ procurement efforts). At least two commentators, however, have advocated some form of legislation which would mandate either participation in donor registries or the actual donation. See generally Anderson, supra note 98 (mandatory participation in bone marrow registries with voluntary donation); Huffman, supra note 17 (compulsory donation under threat of civil and criminal penalties).


\(^{130}\) See Hart, 289 A.2d at 390–91; Doe, 481 N.Y.S.2d at 933.

\(^{131}\) See Dolgin, supra note 13, at 361.
dramatic social, philosophical and economic shifts of the 18th and 19th centuries, which in turn led to changes in the way that children were perceived and the way that childhood was understood. Where children were once treated as simply small adults, the view emerged that children should be safeguarded from many of the ills of adulthood and an increasingly industrialized society. The best interest standard developed as a way for the legal system to accommodate this emerging view and today it remains the governing principle for adjudicating civil cases involving minors. Courts generally invoke this standard under the *parens patria* power of the state—the state’s responsibility and authority to protect society’s most vulnerable members.

The substituted judgment doctrine, on the other hand, was originally applied in cases involving the property or estate of a now incompetent but formerly competent individual. In its present form, the standard requires that decisions be made not by substituting a court or guardian’s values, but rather in accordance with the values or wishes the individual expressed while still competent. Whereas

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152 See id. The evolution of a child-centered approach in custody disputes, for example, can be traced from the early view that fathers had an absolute right to custody, to the presumption that the mother was the proper custodian, to the recent, more flexible, best interest standard that permits a court of equity to consider the individual circumstances. See Griffith, supra note 4, at 292.

153 See Dolgin, supra note 13, at 360-61.

154 See id. at 361. See generally Curran, 566 N.E.2d at 1319 (holding that the best interest standard was the proper one for evaluating petitions to harvest organs from minors and mentally incompetent).

155 See Griffith, supra note 4, at 305, 331; see also Doe, 481 N.Y.S.2d at 932.

156 The substituted judgment doctrine can be traced back to the English case *Ex parte Whitbread*, 35 Eng. Rep. 878 (Ch. 1816) and the English law of lunacy. See Harmon, supra note 22, at 19. The chancellor in that case was faced with the niece of a lunatic (someone who had once been of sound mind and who might regain his sanity) who pleaded that she needed a greater apportionment of her uncle’s money. See id. at 20. Rather than try to gain some insight into this particular lunatic’s situation or his relationship with this particular relative, the chancellor instead relied on what the objective, “reasonable lunatic” would wish to do under the circumstances. See id. at 22. Because the *Whitbread* decision was about “remedy[ing] an inconvenience... that might result from the general rule of law” without disturbing accepted and established allocations of rights and property, Harmon contends that the substituted judgment doctrine constituted a legal fiction from its very inception. See id. at 7, 22-23; Lynn E. Lebit, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgments Doctrine*, 7 J.L. & HEALTH 107, 108 (1992-93). The doctrine has been recognized in American courts since 1844, but only since *Strunk v. Strunk* has it been extended to medical decisions involving individuals who were never of sound mind. See Harmon, supra note 22, at 32.

157 Cf. *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261, 356 (1990) (Stevens, J., dissenting). The expectation is that the substitute decisionmaker will have sufficient information or insight into the proclivities of the individual or situation to make a decision which closely approximates the decision the individual would make for himself if he were
the best interest standard might properly be described as paternalistic, the substituted judgement standard, in theory, protects the individual's right to make decisions for him or herself. The doctrine has since grown beyond its roots in property law to encompass non-therapeutic medical decisions made on behalf of incompetents. Furthermore, the doctrine has been applied to individuals who were never legally competent, a practice which exposes the values of the true decisionmaker: the court or guardian.

A survey of reported cases helps to establish the outer limits to which courts will go to find authorization for an organ harvest and to highlight the judicial reasoning that supports imposing a global prohibition on harvests from minors and mentally disabled adults.

1. Substituted Judgment Standard Applied

In 1969, the Kentucky Court of Appeals decided *Strunk v. Strunk*, the first reported organ transplant case. *Strunk* expanded the scope of the substituted judgment doctrine, holding that a mother's consent was sufficient to authorize the removal of one of her mentally retarded son's kidneys. The recipient, Tommy, was twenty-eight years old and suffering from a fatal kidney disease; the donor, Jerry, was twenty-seven years old, with a mental age of six. Each member of the family was tested for compatibility, but Jerry was the only potential match. In order to reach its holding that the substituted judgement

able. See id. Griffith argues that the usefulness of the standard diminishes as evidence of past preferences becomes less reliable and that where the evidence is unreliable, the standard constitutes a legal fiction. See Griffith, supra note 4, at 303.

138 See Griffith, supra note 4, at 318–23.

139 See generally *Strunk*, 445 S.W.2d 145; Robertson, supra note 14.

140 See *Strunk*, 445 S.W.2d at 146; Harmon, supra note 22, at 34–35 (criticizing *Strunk* for eliminating the protection the original standard provided to incompetent individuals). See generally Lebit, supra note 136.

141 Many cases go unreported. For a sample of Massachusetts slip opinions authorizing harvests, see Baron, supra note 8, at 161–62 nn.15–16.

142 445 S.W.2d 145. Although *Strunk* was the first reported transplant case, there were a substantial number of unreported cases dating back to 1957. See Baron, supra note 8, at 161–62 nn.15–16 (discussing twenty-two unreported cases out of the Massachusetts courts, including the first petition brought before any court; in every case, courts of equity were found to have the power to authorize organ transplants between minor siblings).

*Strunk* remains the most frequently cited organ transplant case and has sparked a great deal of debate. Most commentators and courts have concluded that the *Strunk* court arrived at the proper decision but applied an improper standard.

143 See *Strunk*, 445 S.W.2d at 149.

144 See id. at 145–46. Jerry was permanently institutionalized. See id. at 146.

145 See id.
standard was the correct standard to apply, the *Strunk* court analogized the transfer of an incompetent’s organ to the transfer of an incompetent’s real or personal property.\(^{146}\) *Strunk* is widely recognized as the first United States case to extend this doctrine beyond questions of property to medical decisions made on behalf of an incompetent when the incompetent’s own health was not threatened. *Strunk* also extended the doctrine to situations involving individuals who had no history of ever having been legally competent.\(^{147}\)

*Strunk* set the unfortunate precedent of invoking the substituted judgment doctrine while relying on a determination that the transplant was in the incompetent brother’s best interest, a determination that was framed in terms of a cost-benefit analysis.\(^{148}\) Finding that the benefit (saving his brother) outweighed the cost (losing his kidney), the court reasoned that the transplant was in Jerry’s best interest, and therefore, within the power of the court to authorize.\(^{149}\)

The *Strunk* dissent, however, noted that the extension of the substituted judgment doctrine to medically unnecessary procedures was not only without precedent, but inconsistent with existing state case law and contrary to the scope of existing state statutes.\(^{150}\) Additionally, although sympathetic to the terrible choices facing the family, the dissent voiced the concern that taking a body part from one who could not fully understand or consent brought to mind the types of human experiments conducted during World War II.\(^{151}\)

After *Strunk*, courts were divided regarding the proper scope and application of the substituted judgment doctrine.\(^{152}\) Some courts rejected *Strunk’s* reasoning; others embraced and extended it.\(^{153}\) In 1972, in *Hart v. Brown*, the Connecticut Superior Court followed in *Strunk’s* footsteps by holding that a court of equity had the power to authorize a kidney transplant from a seven year-old to her twin sis-

\(^{146}\) See id. at 148.

\(^{147}\) See id. at 148; Harmon, supra note 22, at 34–35.

\(^{148}\) See *Strunk*, 445 S.W.2d at 148.

\(^{149}\) See id. at 150 (Steinfeld, J., dissenting).

\(^{150}\) See id. at 149–50.

\(^{151}\) See id. at 149. The Strunk dissent stated: “[T]o hold that committees, guardians or courts have such awesome power [to remove a kidney from a mentally incompetent individual for transplant purposes] even in the persuasive case before us, could establish legal precedent, the dire result of which we cannot fathom. Regretfully I must say no.” Id. at 151.

\(^{152}\) See, e.g., Hart, 280 A.2d 386; *In re Richardson*, 284 So. 2d 185 (La. Ct. App. 1973); *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975).

\(^{153}\) See generally Hart, 289 A.2d 386; *Richardson*, 284 So. 2d 185; *Pescinski*, 226 N.W.2d 180.
Hart similarly relied on the substituted judgment doctrine for its equity powers, but engaged in a cost-benefit analysis to determine whether or not the transplant was in the child-donor's best interests. Transplants between identical twins enjoy the greatest long-term success, because the genetic similarities reduce the possibility that the organ will be rejected. A transplant from any other individual requires that the recipient be given immunosuppressive drugs to inhibit the body's natural defenses. Suppressing the immune system puts the recipient at risk of infection and other diseases, and the drugs themselves have well-documented short and long-term side effects. The Hart decision turned almost exclusively on the severity of potential complications the recipient twin might endure if a kidney other than her identical twin's were used. The court went so far as to characterize any outcome that would require resort to immunosuppressive drugs as "cruel and inhuman." As a "close, independent and objective investigation of [the parents'] motivation" indicated that the decision was morally sound in the eyes of the community, the court held that permitting the parents to substitute their consent for the consent of their minor child was the only just result.

2. The Best Interest of the Child Standard and the Interests of Third Parties

A few years after Strunk was decided, two courts explicitly rejected its extension of the substituted judgment doctrine to petitions involving organ harvests from individuals who have never been competent. Instead, the courts applied the best interest standard. Both the Lou-

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154 289 A.2d 386.
155 Id. at 389-90.
156 See id. at 388.
157 See id. at 389.
158 See id. (stating: "The side effects of the immunosuppressive drug ... are numerous and include the possibility of bone marrow toxicity, liver damage, and a syndrome called Cushing syndrome—a roundish face, a 'buffalo hump' on the back of the neck, and growth retardation. Some less common side effects are a demineralization of the bone mass which will result in the collapsing of bones of the spine; aseptic necrosis of the femoral head of the hip, making a person unable to walk; peptic ulcer disease with bleeding; hairiness; sexual immaturity; and cataracts of the eyes.").

159 See Hart, 289 A.2d at 389.
160 See id. at 391.
161 See id. at 389-90. The court recounted the testimony of the Hart family's clergyman and the guardian ad litem who all agreed that the transplant should go forward. See id.
162 See Richardson, 284 So. 2d at 187; Pescinski, 226 N.W.2d at 182.
isiana Court of Appeals, in In re Richardson, and the Wisconsin Supreme Court, in In re Pescinski, denied the guardians' petitions to authorize kidney harvests from incompetent siblings. These courts reasoned that when a transplant is for the sole benefit of a third party, it is, by definition, not in the best interest of the incompetent individual.

Pescinski and Richardson distinguished Strunk, noting that guardianship laws in neither state could support the procedural or substantive posture of that decision. Rather, the laws in both states empowered guardians merely to protect the estate of an incompetent, not to make independent decisions regarding the disposition or betterment of the estate. The Pescinski and Richardson courts reasoned that such unqualified protection of a property right could not be greater than the protection of a minor or incompetent's "right to be free from bodily intrusion." Richardson held that because the organ harvest was for the sole benefit of the older sibling, the transplant was not in the best interest of the retarded brother and therefore, the court denied the petition. The Pescinski court denied the petition on similar grounds: holding that absent the consent of the incompetent individual, neither the court nor the guardian had the authority to consent to an organ transplant that would benefit only a third party.

The Pescinski dissent sharply criticized the majority for its unwillingness to adopt the substituted judgment doctrine. The dissenting judge reasoned that where an individual is incompetent and unable to speak for himself, it is appropriate for a court of equity to substitute its own judgment and do for the incompetent what the court is certain the incompetent would do for himself if he were able.

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163 See Richardson, 284 So. 2d at 187; Pescinski, 226 N.W.2d at 182.
164 In Richardson, the potential donor was a seventeen year-old retarded boy who had a mental age of about three; the average life expectancy for his type of retardation was only twenty-five years. The recipient was his thirty-two year-old sister. See Richardson, 284 So. 2d at 186. In Pescinski, the potential donor was a thirty-nine year-old catatonic schizophrenic. The recipient was his thirty-eight year-old sister who had been on dialysis for five years. See Pescinski, 226 N.W.2d at 180–81.
165 See Richardson, 284 So. 2d at 187; see also Pescinski, 226 N.W.2d at 182.
166 See Richardson, 284 So. 2d at 187; see also Pescinski, 226 N.W.2d at 182.
167 See Richardson, 284 So. 2d at 187; see also Pescinski, 226 N.W.2d at 183 n.1 (Day, J., dissenting) (noting that the majority analogized permitting the kidney harvest to giving away the incompetent's property).
168 See Richardson, 284 So. 2d at 187.
169 See Pescinski, 226 N.W.2d at 181, 182.
170 See id. at 182 (Day, J., dissenting).
171 See id. at 184.
dissent's view, the substituted judgment standard weighs the harms and benefits that might accrue to both siblings from prohibiting or permitting the transplant. The dissent argued that in this case, prohibiting the transplant harmed the incompetent brother because it condemned him to be forever "a receiver, a taker, but never a giver." The Pescinski and Richardson majorities, on the other hand, refrained from balancing harms and benefits. Rather, once the courts found that no benefit would flow to the incompetent donors, the courts' analysis was complete.

Courts that adopted Strunk's explicit substituted judgment reasoning, however, still adhered to its underlying best interests analysis. In 1984, in In re Doe, the New York Supreme Court, Appellate Division, affirmed the trial court's order authorizing a bone marrow transplant from a forty-three year-old severely retarded adult to his thirty-six year-old leukemic brother. As the source of the court's power to authorize the transplant was grounded in its parens patria power, the court held that it could only authorize such a transplant if it found the transplant to be in the incompetent's best interests. In determining the best interests of the incompetent donor, the trial court did the same type of cost-benefit analysis that the Strunk court used and that the Pescinski dissent advocated, finding that the possible death of the leukemic brother outweighed the possible physiological and psychological harm from the harvest itself.

In 1990, in Curran v. Bosze, the Supreme Court of Illinois denied a petition to harvest bone marrow from minor twins, and in so doing, dealt directly with the differences between the substituted judgment and best interest standards. The father brought a petition on behalf of his twelve year-old son in order to compel the mother of his three year-old illegitimate twins to have them tested for compatibility. The

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172 See id. at 183.
173 See id. at 184. In holding that the court could only authorize action that would benefit the incompetent financially or physically, the dissent argued, the incompetent “is forever excluded from doing the decent thing, the charitable thing.” Id.
174 See Richardson, 284 So. 2d at 187; Pescinski, 226 N.W.2d at 181.
175 See Doe, 481 N.Y.S.2d at 933. The appellate decision is no more than a page long, with few facts and little analysis. The lower court's decision has been sealed, as are many such decisions. See, e.g., Baron, supra note 8, at nn.15 & 16.
176 See Doe, 481 N.Y.S.2d at 932-33.
177 See id. at 933.
178 See 566 N.E.2d 1319; see also Lebit, supra note 136, at 108.
179 See Curran, 566 N.E.2d at 1321. Both trial and appellate courts denied the father's request that the question of compelling compatibility testing be decided separately from the question of compelling the transplant itself. See id. at 1345. The legal strategy behind
facts showed that the twins’ parents had never been married, the twins’ paternity was established by a blood test shortly after birth and the siblings had met on only two occasions.\textsuperscript{180}

In its carefully drafted opinion, \textit{Curran} rejected the use of the substituted judgement doctrine in adjudicating petitions involving minors and other individuals who had never been legally competent.\textsuperscript{181} The court reasoned that it is a competent adult’s “philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death” to which he or she looks to make important decisions about submitting to or refusing medical treatment.\textsuperscript{182} Under \textit{Curran}, where because of age or infirmity an individual has not developed a personal value system, application of the substituted judgment doctrine “undermin[es] the foundation of self-determination and inviolability of the person upon which the right to refuse medical treatment stands” because the decisionmaker must substitute his or her own values for those of the incompetent.\textsuperscript{183} \textit{Curran} held that the best interest standard was the proper one to apply in these situations and outlined three factors that courts should consider when determining whether a transplant is in the best interests of the child or ward: (1) the parent must be informed of the risks and benefits of the harvesting procedure; (2) the primary caretaker must be prepared to provide the donor with the necessary emotional support and (3) the relationship between the donor and recipient must be close.\textsuperscript{184}

In determining the best interests of the young twins, \textit{Curran} heavily relied on testimony that the twins would suffer psychological harm,

\begin{footnotes}
\textsuperscript{180} See \textit{Curran}, 566 N.E.2d at 1320, 1321. The blood test took place in the context of a paternity suit filed by the mother against the father. See \textit{id.} at 1320.

\textsuperscript{181} See \textit{id.} at 1325–26; Lebit, supra note 136, at 108 (noting that “[t]he father argued that under the doctrine of substituted judgment, the children would agree to submit to the procedure if they were old enough to make an informed, rational decision.”).

\textsuperscript{182} See \textit{Curran}, 566 N.E.2d at 1323.

\textsuperscript{183} See \textit{id.} at 1324 (quoting \textit{In re Estate of Longeway}, 549 N.E.2d 292, 299 (Ill. 1989)).

\textsuperscript{184} See \textit{id.} at 1325–26, 1343.
\end{footnotes}
not from being compelled to donate bone marrow, but rather from undergoing the harvest without the support of their mother.\textsuperscript{185} The court also relied on psychiatric testimony tending to show that no benefit could be attributed to the twins absent a close relationship with their half-brother.\textsuperscript{186} Applying the best interests test, the \textit{Curran} court found that both parents were well-informed about the risks and benefits of the procedure, but questioned the mother’s ability to provide the necessary emotional support because of her objections to the transplant.\textsuperscript{187} Furthermore, the court found that the relationship between the half-siblings went no deeper than their paternal blood ties.\textsuperscript{188} Because two of the three factors were unsatisfied, the bone marrow transplant was not in the twins’ best interests, and therefore the court denied the father’s petition.\textsuperscript{189}

Whether courts follow \textit{Strunk’s} explicit application of the substituted judgment standard or its implicit search for the best interests of the child or ward, petitions to authorize organ harvests from incompetents have been decided on the basis of a cost-benefit analysis.\textsuperscript{190} Some courts frame the equation exclusively in terms of harm to the donor: will the possible loss of a sibling cause more psychological or physical harm to the donor than the operation itself?\textsuperscript{191} Other courts have framed the analysis in terms of the benefits that they and the parents hope the incompetent will realize from his or her participation in the transplant.\textsuperscript{192} Some courts seek to balance the relative

\textsuperscript{185} See id. at 1335.

\textsuperscript{186} See id. at 1343-44.

\textsuperscript{187} See \textit{Curran}, 566 N.E.2d at 1344.

\textsuperscript{188} See id. at 1344.

\textsuperscript{189} See id.

\textsuperscript{190} See Lebit, \textit{supra} note 136, at 113. Professor Baron has noted that “[I]n effect, [the parents] are given the authority to sacrifice the interests of the prospective donor if they reasonably conclude that the costs to him are outweighed by the potential benefits to the recipient.” Baron, \textit{supra} note 8, at 172.

\textsuperscript{191} See \textit{Strunk}, 445 S.W.2d at 146; \textit{Doe}, 481 N.Y.S.2d at 932. Both the \textit{Strunk} and \textit{Doe} courts concluded that the psychological harm the incompetents might experience from the death of their sibling outweighed the physical risks of the harvesting procedures. See \textit{Strunk}, 445 S.W.2d at 146; \textit{Doe}, 481 N.Y.S.2d at 932.

\textsuperscript{192} See \textit{Curran}, 566 N.E.2d at 1343-44. \textit{Curran} held, for example, that in order to authorize an organ harvest, a court must find that the donor will benefit psychologically from the transplant and furthermore, that donors can only be expected to realize the psychological benefit when the donor has an existing relationship with their sibling-recipient. See \textit{id.} \textit{Richardson}, on the other hand, held that a court must find a more tangible benefit to the donor before it can authorize the harvest. See 284 So. 2d at 187. The \textit{Richardson} court analogized an organ harvest to the transfer of property: if the transfer of the ‘property’ will not benefit the owner, then a guardian does not have the authority to give that ‘property’ away. See \textit{id.}.  


harm to which donors and recipients will be subjected, or alternatively, the relative benefits donors and recipients will realize.\textsuperscript{193}

The benefits/harms approach is peculiar to petitions involving minors and mentally disabled adults. Petitions to compel competent adults to undergo medically unnecessary surgical procedures have yielded results similar to the \textit{Richardson, Pescinski} and \textit{Curran} line of cases, but the analysis has been markedly different.\textsuperscript{194}

\section*{B. The Standards and Analyses Courts Apply to Competent Donors}

The detailed analyses courts use when deciding whether or not to permit an organ harvest from a minor or incompetent adult stand in striking contrast to the quick and sharply worded dismissal of a similar claim brought against a competent adult.\textsuperscript{195} For example, in 1978, in \textit{McFall v. Shimp}, the Pennsylvania District and County court held that a court of equity had no authority to compel a competent adult to submit to a bone marrow transplant.\textsuperscript{196} The plaintiff in \textit{McFall} suffered from a rare, and ultimately terminal, bone marrow disease. The defendant, his cousin, had undergone compatibility tests, and although he was a match, he declined to donate.\textsuperscript{197} The court, in an opinionated and brief decision, took both parties to task.\textsuperscript{198} Criticizing the plaintiff for advocating such a blatant violation of an individual’s right to bodily integrity, the court warned, “[f]or a society which respects the rights of one individual, to sink its teeth into the jugular vein . . . of one of its members and suck from it sustenance for another member, is revolting to our hard-wrought concepts of jurisprudence.”\textsuperscript{199} Notwith-

\textsuperscript{193} The \textit{Hart} court and the \textit{Pescinski} dissent are typical of this approach. See \textit{Hart}, 289 A.2d at 389–90; \textit{Pescinski}, 226 N.W.2d at 183 (Day, J., dissenting). The \textit{Hart} court weighed the harms that the immunosuppressive drugs would cause the ill twin if she were to receive a kidney from anyone but her twin. See 289 A.2d at 389–90. The court also noted that because the twins were close, the donor-twin would benefit psychologically from participating in the kidney transplant and, therefore, the \textit{Hart} court approved the harvest. See id. at 389. The \textit{Pescinski} dissent similarly advocated a balancing of the donor and recipient’s "relative need" for the organ. See 226 N.W.2d at 182–83 (Day, J., dissenting). The dissent argued that the petition should have been granted because the ill sibling would die without a kidney, whereas the mentally disabled brother would survive with only one kidney. See id.


\textsuperscript{195} See \textit{McFall}, 10 Pa. D. & C.3d at 91–92.

\textsuperscript{196} See \textit{id.} at 91.

\textsuperscript{197} See \textit{id.} at 90.

\textsuperscript{198} See \textit{id.} at 91–92.

\textsuperscript{199} \textit{Id.} at 92 (emphasis in original).
standing its desire to condemn the defendant's refusal on moral grounds, the court concluded that under the law, a competent adult could not be forced to submit to a medical procedure for the benefit of a third party.200

This unequivocal protection of a competent individual's right to bodily integrity despite the needs of a third party has been echoed in the provocative context of the rights of a fetus as against the rights of its mother.201 In 1994, the Appellate Court of Illinois held, in In re Baby Boy Doe, that no balancing test should be used to weigh a viable fetus's rights against the right of a competent woman to refuse a cesarean section even if honoring the woman's refusal might harm the fetus.202 The oxygen supply to a thirty-five week old fetus was slowly being cut off as a result of a placental malfunction.203 The obstetrician recommended that labor be induced or a cesarean performed in order to prevent retardation or death.204 The mother refused, in part on religious grounds, stating that her faith in God's healing powers compelled her to await natural childbirth.205 The court then made three specific findings: (1) the fetus would be viable outside the womb without any medical assistance; (2) the chances that the fetus would survive natural childbirth were close to zero; and (3) the odds of the mother dying from a cesarean section were about one in 10,000.206

The court analogized Baby Boy Doe to cases protecting an individual's right to refuse medical treatment including life sustaining treatment, the right to bodily integrity and the privilege of not being compelled to undergo medical procedures for the benefit of a third

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200 See McFall, 10 Pa. D. & C.3d at 91, 92.
201 See Baby Boy Doe, 623 N.E.2d at 330.
202 See id. The state argued that the fetus's own right to life should be weighed against the mother's right to consent to or decline medical treatment. See id. Three years later, in In re Brown, the Illinois Supreme Court reaffirmed and extended Baby Boy Doe, holding that the state's interest in preserving the life of a viable fetus was also insufficient to compel a pregnant woman to submit to medical treatment on behalf of that fetus. See 689 N.E.2d 397, 406 (Ill. App. Ct. 1997). At issue in Brown was a mother's refusal, on religious grounds, to accept a blood transfusion. See id. On appeal, the court held that the trial court had been wrong to appoint a guardian ad litem to represent the fetus and order that the blood transfusion be performed over the mother's objections. See id.; John J. Paris, Planning on a Miracle: The Case of Mother Versus Fetus, 111 CHRISTIAN CENTURY 244, available in 1994 WL 13156725 for a discussion of Baby Boy Doe and two additional, similar cases.
203 See Baby Boy Doe, 623 N.E.2d at 327.
204 See id.
205 See id.
206 See id. at 328.
Adopting the reasoning of other courts confronted with similar disputes, the court found that it was the "woman's decision, not the fetus's interest [that was] the only dispositive factor." Citing Curran and Pescinski, the court analogized the invasiveness of a cesarean section to a kidney or bone marrow harvest:

If a sibling cannot be forced to donate bone marrow to save a sibling's life, if an incompetent brother cannot be forced to donate a kidney to save the life of his dying sister, then surely a mother cannot be forced to undergo a cesarean section to benefit her viable fetus.

Lastly, the court painted a graphic picture of the way in which compelled medical treatment on a competent adult would need to be carried out, highlighting how alien such a practice is in our society. Therefore, the court not only determined that the woman's fundamental rights to autonomy and bodily integrity should be protected, but that the third party's interest (in this case, the fetus) should not even be factored into the analysis.

These recent cases indicate that a competent adult's right to decline a surgical procedure for the benefit of a third party continues to be entitled to fierce protection. On the other hand, as discussed in the next section, the notion that parents and guardians have the authority to compel a minor or incompetent to undergo a surgical procedure continues to be a matter of contention.

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208 See Baby Boy Doe, 623 N.E.2d at 332 (citing In re A.C., 573 A.2d 1235, 1237 (D.C. 1990) (en banc)).

209 Id. at 333-34 (citations omitted). In dicta, Baby Boy Doe distinguished between compelling a major bodily intrusion, such as a cesarean section or an organ harvest, for the sake of the fetus, and compelling a minor bodily intrusion, such as a blood transfusion. See id. at 334. Three years later, the same court confronted a similar dilemma and explicitly disagreed with Baby Boy Doe's characterization of a blood transfusion as a minor bodily invasion. See Brown, 689 N.E.2d at 405.

210 See Baby Boy Doe, 623 N.E.2d at 335 (quoting A.C., 573 A.2d at 1261 n.8). In Baby Boy Doe, the court stated: "Enforcement could be accomplished only through physical force or its equivalent. [The mother] would have to be fastened with restraints to the operating table, or perhaps ... rendered unconscious by forcibly injecting her with an anesthetic, and then subjected to unwanted major surgery. Such actions would surely give one pause in a civilized society, especially when [the mother] had done no wrong." Id. Three years later, a similar tone of disapproval attended the court's comment that the mother in Brown had been physically restrained and sedated in order to perform the blood transfusion over her objections. See Brown, 689 N.E.2d at 400.

211 See Baby Boy Doe, 623 N.E.2d at 326.
procedure for the benefit of a third party threatens to become a legal presumption.

C. Petitions to Harvest Organs Pave the Way for New Legal Dilemmas

Law students learn early on about the treacherous slippery slope and its use as a rhetorical weapon to justify a court’s refusal to recognize new rights and privileges. It is unusual, however, to find an opinion that starkly represents the actual slide down that slope.212 In 1997, in *Ferrell v. Rosenbaum*, the District of Columbia Court of Appeals recognized the right of a leukemic child to have a sibling conceived who might provide her with bone marrow.213 The mother brought suit against her daughter’s geneticist claiming that his failure to timely diagnose the child’s leukemia constituted medical malpractice.214 The mother claimed that by the time the diagnosis was made, she and the father were estranged, and, therefore, the geneticist’s negligence robbed the mother of the opportunity to conceive additional children who might serve as bone marrow donors.215

The court opined that it was the loss of the opportunity to survive (in the form of a potential sibling’s bone marrow), rather than the loss of survival itself, that constituted the alleged harm.216 The court’s analysis of the cause in fact turned on a series of hypotheticals: if the diagnosis had been timely made, and the parents had decided to conceive another child and they had been successful in conceiving a child who was not only a suitable match but who did not suffer from the same genetic defect, then the chances the child would recover from a bone marrow transplant were in the range of seventy-five to eighty percent.217 The court overturned the lower court’s grant of summary

213 See id. at 651.
214 See id. at 643. The undisputed evidence of medical malpractice was damning: the child was born with obvious and severe physical deformities including undersized and immature thumbs and a lack of external ear canals, both symptoms of a progressive and fatal form of leukemia called Fanconi anemia. See id. at 643–44. On the basis of these physical abnormalities, the geneticist ordered a series of diagnostic tests, including a chromosome test. See id. The tests confirmed the child’s condition, but in his deposition the geneticist admitted that he never reviewed the results, nor the results of additional tests taken over the next year. See id. at 649 n.15.
215 See id. at 644, 651. The parents separated when the child was two. The mother subsequently lost touch with the father. At the time of the hearing, the father was believed to be homeless somewhere in California. See id. at 644.
216 See id. at 651.
217 See *Ferrell*, 691 A.2d at 650–52. The mother argued that the odds of conceiving a baby that was a genetic match but who did not share the same genetic defect were 18.75%. 

judgment for the doctor/defendant, holding that a reasonable jury could find the doctor violated the standard of care, and furthermore, that the misdiagnosis was a substantial factor in the harm visited on the child because it precluded her from her best chance of obtaining a matched sibling donor.  

The dissent argued that whether the father would have been willing to conceive other children was speculative at best, particularly given that the parents had separated when the child was only two years old. The mother’s assertion that he would have been willing to conceive additional children or reconcile with the mother lacked any evidentiary support. Without that crucial link in the chain, the dissent concluded that the mother could not prove that the geneticist’s negligence was a substantial factor in the alleged harm. The majority responded that the father would only have needed to donate sperm; therefore, whether the parents reconciled was irrelevant. The court concluded that if a jury found a breach of the standard of care, “that breach was a proximate cause of [the child’s] injury.”

Malek’s alleged right has no precedent in case or statutory law, but does have practical and popular roots. Pediatric oncologists and cancer treatment centers have for many years known and approved families’ decisions to conceive children as bone marrow donors.
The practice came to popular attention in the early 1990s when the Ayala family publicly announced their decision to conceive a donor baby, despite their ages and the need to reverse the father's vasectomy. Their experience drew a great deal of attention and, while ethicists questioned the practice, the popular sentiment was overwhelmingly positive. Less well known, however, is the incidence of abortion for fetuses which fail to match or the incidence of adoption for babies conceived as donors. The Ferrell decision, therefore, rested on the presumption that parents not only have the authority to harvest bone marrow from a matching sibling, but can freely conceive, abort or put up for adoption children who serve as donors or who fail in their function as organ donor.

III. Analysis

Courts confronted with petitions to compel children and mentally disabled adults to undergo surgical invasions for the benefit of third parties analyze the petitions in terms of costs and benefits. Courts confronted with competent adults, on the other hand, have refused this approach on the grounds that it would violate the individual’s right to autonomy and bodily integrity. Differences between legally competent and incompetent individuals do not justify the dif-

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226 See CHILDREN OF CHOICE, supra note 34, at 213-14. Both parents were over forty. See id.; see also Marissa Ayala, supra note 34, at 78.
227 See, e.g., Marissa Ayala, supra note 34, at 79; Price of Life, supra note 224.
228 See Price of Life, supra note 224 (reporting the case of a couple who conceived a bone marrow match and then gave the child up for adoption); Gianelli, supra note 43 (reporting the case of a couple who wished to conceive, test and abort fetuses until they conceived a bone marrow match); see also CHILDREN OF CHOICE, supra note 94, at 213-14; but see Kearney & Caplan, supra note 83, at 269 (asserting that no such cases have actually been reported).
229 See Ferrell, 691 A.2d at 651.
230 The cost-benefit analysis has been criticized elsewhere as vague and standardless. See generally Lebit, supra note 136; Robertson, supra note 14.
231 See Greatest Gift, supra note 3, at 620-21 (noting that one state statute that indeed imposes a duty to rescue “does not in any way attempt to place the value of one life over the value of another,” but that a law compelling an individual to submit to a medical procedure on behalf of a third party would necessarily assume “that one individual’s right to be free from ‘danger of peril’ is somehow less important than another’s similar right”). Friedman argues that expanding the doctrine to compel Good Samaritanism “cannot legally or ethically be maintained.” See id. at 619. But see Huffman, supra note 17, at 414-15 (suggesting a “construct” by which plaintiffs who satisfy certain criteria may obtain a court order and compel a reluctant donor to cooperate under threat of civil and criminal liability).
ferent analyses. Moreover, the information on which the cost and benefit determinations have been based is incorrect, incomplete and hence, misleading.

A. Costs and Benefits: The Math Is All Wrong

Courts authorizing organ harvests from legal incompetents have relied on a number of mistaken and interrelated assumptions: (1) the surgical risks of an organ harvest constitute the only risks; (2) the transplant will ensure the survival of the ill sibling; (3) the survival of the sibling will ensure the integrity and well-being of the sibling relationship and family as a whole; and (4) the donor will benefit psychologically from his or her participation in the process. Unfortunately, research indicates that each element of this house-of-cards justification is subject to question. For starters, the physical risks of surgery are not the only risks to which donors are exposed. In fact, the psychological harm of compelling donation may be grave, the physical benefit to the recipient may be small and the relationship between donor-recipient pairs may be permanently damaged.

1. Information Deficits Regarding the Costs of Harvesting Organs

Because courts have ignored or been unaware of the psychological toll of being compelled to donate an organ, judicial assessments of the potential harm have been greatly underestimated. Courts applying a cost-benefit analysis to organ harvest petitions have generally measured the cost to donors in three ways: (1) the risk that death or serious injury will result from the harvest; (2) the temporary or per-

232 See In re Estate of Longeway, 549 N.E.2d 292, 297 (Ill. 1989) (stating: "No right is more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of [the individual's] own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." (internal quotations omitted)).

233 See infra notes 234-75 and accompanying text.


235 See supra notes 69-77, 89-94 and accompanying text (health prospects for transplant recipients); supra notes 85-88, 120 and accompanying text (estrangement of donor-recipient post-transplant); supra note 43 and accompanying text (harvesting procedures).

236 See supra notes 46-94 and accompanying text.

237 See Kallich & Merz, supra note 11, at 145 (noting that "considerable disagreement exists in the field of transplantation regarding the risks of donation . . .").
manent physical changes that the harvest will cause; and (3) the overall level of surgical complication or invasiveness of the procedure.\textsuperscript{238} By measuring the costs to the incompetent in physical terms, courts have implied that absent a physical harm, there can be no psychological harm.\textsuperscript{239} Research has shown this to be an incorrect implication.\textsuperscript{240}

As noted in Part I, to date, only one study has focused on the effects of organ harvests on minor sibling-donors—that is, on the psychological effects of being volunteered by one's parents to donate bone marrow to an ill sibling.\textsuperscript{241} That study revealed that the young donors were withdrawn, anxious, depressed, had lowered self-esteem and exhibited symptoms of post-traumatic stress disorder.\textsuperscript{242} Although the body of research into the psychological effects of organ harvests on adult sibling-donors is far from robust, it supplements the little evidence we have regarding incompetent donors. The latter studies reveal that even the most favorable circumstances attending an adult donor's participation do not necessarily insulate him or her from psychological harm.\textsuperscript{243} Donors are often plagued by the worry that the donor's bone marrow will immunologically attack the recipient's body or that the kidney will be rejected.\textsuperscript{244} Rather than mark the turning point for patients and families after a prolonged and debilitating illness, the transplant can mark the beginning of a grueling treatment process that leads to a death more agonizing than death from the underlying disease.\textsuperscript{245} The donor's guilt from having caused or contributed to that suffering can be great.\textsuperscript{246} These harms occur among adult sibling donors even when the decision to donate is voluntary, even when there is an established relationship between the donor and recipient and even when the ill family member becomes a long-term, "

\textsuperscript{238}See Hart v. Brown, 289 A.2d 386, 389 (Conn. Super. Ct. 1972) (noting that kidney donor would only be restricted from contact sports and the surgery would only last two and one-half hours); Doe, 481 N.Y.S.2d at 933 (noting that bone marrow harvest posed minimal medical risk). \textit{But see} Curran, 566 N.E.2d at 1344-45. Although Curran turned on the psychological effects on the young donors, the psychological harm that so concerned the court was limited to the mother's inability to provide the twins the necessary emotional support; the court was either unaware of or unconcerned about the potential psychological harm flowing from participation in the bone marrow harvest itself. \textit{See id.}

\textsuperscript{239} See Hart, 289 A.2d at 389; Doe, 481 N.Y.S.2d at 933.

\textsuperscript{240} See supra notes 38-90 and accompanying text.

\textsuperscript{241} See supra notes 73-77 and accompanying text.

\textsuperscript{242} See Kaarela, supra note 33.

\textsuperscript{243} See supra notes 79-83 and accompanying text.

\textsuperscript{244} See supra notes 58-69 and accompanying text.

\textsuperscript{245} See supra notes 58-69 and accompanying text.
disease-free survivor.\(^\text{247}\) Favorable circumstances, however, are often absent; pressure to donate can be coercive and family dynamics and agendas often subtly—or overtly—guide selection of the donor.\(^\text{248}\) As a consequence, the potential for psychological harm rises.\(^\text{249}\)

Perhaps more importantly, evidence that adult related donors suffer psychological harm should sound an alarm for those concerned about the welfare of children and mental incompetents precisely because of key differences between the two sets of people: adults have real world options and internal resources that are simply unavailable to the legal incompetent.\(^\text{250}\) Being an adult means making choices that are guided by and, in turn, contribute to the development of one’s internal moral compass.\(^\text{251}\) Furthermore, being an adult means that even if one feels compelled to act, ultimately one chooses to give in to the compulsion.\(^\text{252}\) Unlike children and mentally disabled adults, adult prospective donors have the maturity and legal standing to decline to be tested for compatibility or to bring the organ procurement process to a halt at any time.\(^\text{253}\) Ambivalent and fearful, yet psychiatrically stable, adults may even be provided with mock medical reasons to relieve them of further family pressure and excuse them from any familial obligation.\(^\text{254}\)

To the extent that courts adjudicating organ harvest petitions recognize the potential for psychological harm, they answer it by inviting experts to testify.\(^\text{255}\) Courts hope this testimony will reveal any unseemly intention guiding the parent or guardian’s selection of the

\(^{247}\) See supra notes 80–82 and accompanying text.

\(^{248}\) See supra notes 103–13 and accompanying text.

\(^{249}\) See BMT Donors, supra note 33, at 487 (noting researchers’ concerns that because estranged donors and recipients refused to participate in the study, the difficulties reported by the study participants were only the “tip of the iceberg”).

\(^{250}\) See supra notes 54–90 and accompanying text.

\(^{251}\) See supra notes 95–103 and accompanying text.

\(^{252}\) See supra notes 95–103 and accompanying text.

\(^{253}\) See, e.g., McFall v. Shimp, 10 Pa. D. & C.3d 90, 91–92 (1978) (refusing to compel a competent adult to undergo a bone marrow harvest for the benefit of his cousin); In re Pescinski, 226 N.W.2d 180, 183 (Wisc. 1975) (Day, J., dissenting) (noting the “impracticality” of obtaining an organ from another brother when, in fact, the brother had simply exercised his right to refuse to donate); cf. Friedman Ross, supra note 16. During the experimental phase of a living donor liver-transplantation program, parents of small children with liver disease underwent a psychiatric evaluation. When asked about their willingness to donate a portion of their livers the parents “were able to say no even when the lives of their children were at risk and no alternative therapies (such as dialysis) were available.” See id.

\(^{254}\) See supra notes 117–18 and accompanying text.

\(^{255}\) See, e.g., Hart, 289 A.2d at 389–90.
particular donor or that it will indicate whether the selected donor runs a particular risk of sustaining psychological harm.\textsuperscript{256} This evaluation process, however, offers little protection to the average child or mentally disabled adult for two reasons. First, it suggests that only the rare individual, either because of extraordinary circumstances or a predisposition to psychiatric problems, will suffer psychological harm.\textsuperscript{257} Second, it assumes that a certain level of fear and uncertainty is acceptable—an assumption courts will not make about competent adults.\textsuperscript{258} Moreover, in the rare circumstance that a child or mentally disabled adult does attempt to say "no" to the harvest, medical personnel and family members treat the incompetent as merely afraid, not unwilling.\textsuperscript{259} The ambivalent and fearful, yet psychiatrically stable, child or mentally retarded adult will not receive the graceful exit from the process that the competent adult is entitled to. Rather, he or she can expect a sympathetic hand to hold while being put under anesthesia and, perhaps, counseling post-harvest to help integrate the experience of having been compelled to undergo the surgery.\textsuperscript{260} However, neither the process by which children and mentally disabled adults become donors, nor a post-facto therapeutic Band-Aid can

\textsuperscript{256} See id. at 374; Little v. Little, 576 S.W.2d 493, 499 (Tex. App. 1979, writ denied).

\textsuperscript{257} See Curran, 566 N.E.2d at 1338, 1343 (predisposition to psychological harm measured in terms of the mother's inability, because of her objections to the bone marrow harvest, to provide emotional support during the frightening, unfamiliar hospital procedure). But see Little, 576 S.W.2d at 499. The Little court noted that the donor who had Down's Syndrome had a "high threshold for pain" but that her limited intelligence might make the experience "more burdensome" than it would be for an adult. These factors, however, did not, apparently, amount to any peculiar disposition for psychological harm nor unusual circumstance warranting the court's concern. See id. at 499.

\textsuperscript{258} See Curran, 566 N.E.2d at 1338.

\textsuperscript{259} See Curran, 566 N.E.2d at 1338, 1343; see also Baron, supra note 8, at 191.

\textsuperscript{260} See Curran, 566 N.E.2d at 1338, 1343 (noting that the consent and emotional support of the parent "is important to ease the fears associated with such an unfamiliar procedure"); see also Baron, supra note 8, at 191 (reporting a Maryland court that left open the question of whether the medical providers would be "required to offer the donor follow-up psychiatric care.").
remedy the fundamental wrong of placing these individuals in the role of family rescuer.261

That this complex array of psychological harms has gone largely unnoticed by courts confronted with petitions to harvest organs from legal incompetents is made all the more troubling by the fact that the benefits imputed to the incompetents are entirely psychological.262 Psychological benefits cannot accurately be measured if psychological harms have been omitted from the equation. And, as discussed below, one must question whether courts are correct to impute the psychological benefits of an altruistic adult donor to the incompetent who is compelled to donate an organ.263

2. Information Deficits Regarding the Benefits of Harvesting Organs

As noted above, courts underestimate the costs associated with donating organs by omitting the psychological costs. At the same time, courts inflate the benefits side of the equation by adding theoretical psychological benefits.264 That courts are willing to entertain speculation about psychological benefits is understandable: organ transplants provide no medical benefit to the donor, therefore any benefit would have to be psychological.265 Nevertheless, research does not support the optimism that attends the speculations.266

In every reported case in which an organ transplant has been permitted, courts have relied on the assumption that the compelled donor would realize one of two psychological benefits: the opportunity to maintain a relationship with the recipient-sibling and the psychological benefit of having acted altruistically.267 Taking these

261 See Curran, 566 N.E.2d at 1338, 1343. But see Little, 576 S.W.2d at 499.
262 See Hart, 289 A.2d at 387 (noting that transplant will lead to the family being "happy" rather than "distressed"); Doe, 481 N.Y.S.2d at 933 (noting that donor will benefit from advocacy and company of recipient); cf. Curran, 566 N.E.2d at 1344-45 (noting that donors lacked sufficient relationship with sibling-patient to expect them to benefit psychologically). Baron notes that it is the rare guardian ad litem who fights the petition to authorize an organ harvest. See Baron, supra note 8, at 184-85. More commonly, all parties come to the court having already agreed that the recipient's benefits outweigh the donor's harms. See id. This may explain the lack of judicial ink on the subject.
263 See infra notes 269-86 and accompanying text.
264 See Doe, 481 N.Y.S.2d at 933; Little, 576 S.W.2d at 499; infra notes 269-86 and accompanying text.
265 See supra notes 81-84, 114 and accompanying text.
266 See supra notes 59-80 and accompanying text.
267 See Hart, 289 A.2d at 387; Doe, 481 N.Y.S.2d at 933; cf. Curran, 566 N.E.2d at 1344 (denying petition to compel a bone marrow harvest where there was no established relationship between the half-siblings).
benefits in turn, the expectation that the sibling relationship will be unaffected or improved by the transplant may go unmet. The link between donors and recipients is such that the donor’s psychological well-being and a continued relationship with the recipient may depend on the recipient’s perception of his or her ongoing well-being and the long-term success of the transplant. Aggressive cancer treatments, however, often offer no more than a minimal chance of survival, yet carry a significant risk that the treatment will harm the patient or lead to a painful and protracted death. In addition, the treatment can exact a huge financial and emotional toll on the family. Therefore, because transplants rarely yield a return to perfect health, the link between donors and recipients created by the transplant can lead to a deterioration in the quality and strength of the ongoing relationship. Moreover, the benefits of an enhanced or ongoing relationship may not manifest even if the transplant is a medical success. If the donor was at all ambivalent about donating, the recipient may forever hold it against him despite the fact that he ultimately came through. The recipient’s feelings of debt or guilt from having needed so great a sacrifice from the donor can also create an unbridgeable gap between the two family members.

Alternatively, courts impute to volunteered children and mentally disabled adults the psychological benefits that may flow to competent adult volunteers. Courts and commentators use words like “donation,” “gift” and “altruism” to support this assignment of benefits. Neither the language nor the imputed benefits reflect the experience

268 See supra notes 81–84, 111–14 and accompanying text.
269 See supra notes 62–63 and accompanying text.
270 See generally Newmark v. Williams, 588 A.2d 1108, 1118 (Del. 1990). The Newmark court upheld the parent’s right to refuse an aggressive course of cancer treatment which doctors believed was the only hope for their three-year-old leukemic child. See id. at 1110. Doctors considered the treatment “the most aggressive form of cancer therapy short of a bone marrow transplant.” See id. at 1118. If the treatment itself did not kill the boy, it would offer him a forty-percent chance of survival, measured not in terms of cure, but in terms of living for two additional years, cancer free. See id. at 1118, 1119 n.12.
271 See id.
272 See supra notes 58–63 and accompanying text.
273 See supra notes 81–84, 111–14 and accompanying text.
274 See supra note 82.
275 See GIFT OF LIFE, supra note 16, at 171–72; supra note 90 and accompanying text.
276 See Curran, 566 N.E.2d at 1325, 1344–45; Baron, supra note 8, at 178.
277 See Curran, 566 N.E.2d at 1325, 1344–45; Baron, supra note 8, at 178; Robbenolt, supra note 10, at 228 (arguing that the best interests standard is flawed precisely because it “imposes self-seeking values upon children” and “fails to allow [them] to act altruistically.”).
of the legally incompetent individual compelled to undergo a surgical
invasion for the benefit of a third party. Commentators argue that
retaining the language of voluntariness reminds us that parents have
beneficent motives when they involve their children in the organ pro-
curement process. Compassion for parents, however, is an insuffi-
cient justification for employing euphemisms. While the term
"organ donor" is an efficient catchall phrase for the process by which
human organs are obtained for transplantation, in this context, verbal
efficiency masks meaningful differences between the affirmative act of
giving and the passive experience of having something taken away.

Concerns about coercive family pressure, physical and psycho-
logical harm, the proper respect for individual autonomy and inap-
propriately imputed psychological benefits are intensified for the
child conceived as an organ donor. Those who approve of, or who
are at least unwilling to criticize these practices argue that question-
able, selfish motives often underlie people's decisions to have a child
or terminate a pregnancy. If we are not going to police every deci-
sion, so the argument goes, then we cannot police any decision. But
this view glosses over a material difference between conceiving chil-
dren who may, as individuals, serve their parents' ends and conceiving

278 Cf. Curran, 566 N.E.2d at 1334 (psychiatrist testified that young "mentally and
physically healthy children do not understand abstract concepts such as death because
they just haven't had the opportunity to have cognitive development sufficient to manage
things like abstractions, hypotheses, and so on.") (internal quotes omitted).
279 See Kearney & Caplan, supra note 83, at 264.
280 See Dobson, supra note 81 ("Adults are not usually compelled to display altruism,
but children are regularly 'volunteered' by their parents.").
281 See id.; supra notes 78-84, 98-125 and accompanying text.
282 See Kearney & Caplan, supra note 83, at 274. "In the immediacy of the desire to save
the life of a family member, there may be an undue emphasis on the conceived child's
purpose in saving another life. This could arise from the parents themselves, their families,
or others in their community. . ."
283 Professor George Annas of Boston University Law School was quoted as saying:
"[W]e're going to have to depend upon the good sense of the medical community to
discourage this, and so far the medical community hasn't shown much sense. I hope we
don't get to . . . where we have to legislate this, but we will if it becomes a big thing." Price
of Life, supra note 224; see Kearney & Caplan, supra note 83, at 282. But see CHILDREN
OF CHOICE, supra note 34, at 211-17. Robertson argues that the only difference between con-
ceiving with the intention to "farm the uterus" for tissue and then aborting versus conceiv-
ing and then deciding to abort for any other personal reason is purely symbolic. See id., at
213-14. "Deliberate creation of fetuses to be aborted for tissue procurement is more ethi-
cally complex and defensible than its current widespread dismissal would suggest." Id., at
214.
284 See CHILDREN OF CHOICE, supra note 34, at 215; Price of Life, supra note 224 (quoting
the director of the Center for Biomedical Ethics at Case Western Reserve Medical School
in Cleveland that few decisions to have children can "stand up to rational scrutiny.").
children whose body parts may serve their parents' ends. In the former case, the children will inevitably grow into adults and, as adults, will have the autonomy to choose to fulfill or disappoint their parents' expectations. Children conceived as organ donors, on the other hand, are never given the opportunity to break from their parents' expectations by making their own choices. Parity for donation—the act of conceiving a child to produce an organ donor—reflects a dissected view of children that is incompatible with current understandings of the psychological development of identity and the social and legal concepts of individual autonomy. Prohibiting harvests from minors and mentally disabled adults is the only way to eliminate the incentive to conceive children to create matching donors.

When it overturned the lower court's decision granting summary judgment to the geneticist, Ferrell v. Rosenbaum recognized the legal viability of the mother's novel claim that medical negligence robbed her of the opportunity to conceive potential bone marrow donors for her daughter. In recognizing the claim, Ferrell took one giant step toward recognizing one individual's right to claim the organ of another. What happens then to the family who refuses to conceive another baby, or the family that refuses to volunteer its other children to be tested for compatibility? Might a court find that a parents' duty to care for an ill child extends to compelling the parents

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285 See Price of Life, supra note 224 (quoting a senior associate from one of the nation's leading bioethics think tanks, "[i]t's the classic nightmare of using people as tissue and organ banks, and . . . we have to respond to it as the classic nightmare. There's a revulsion that . . . kick[s] in.").


287 See Price of Life, supra note 224 (stating: "What is the purpose of any human being or child? . . . [I]t's not to be used as an object for another person").

288 See id.

289 See id.

290 See id.

291 See 691 A.2d 641, 651 (D.C. 1997) (vacating the superior court's grant of summary judgment on the grounds that the geneticist's negligence was a substantial factor in the child's injury).

292 See id.

293 See Kearney & Caplan, supra note 83, at 279 (expressing the concern that to the extent the state's interest in a woman's reproductive process is unsettled, the possibility exists that a woman could be legally compelled to conceive and carry a donor baby to term).

294 A 1990 news article reported that a couple consented to use their six-year-old daughter as a bone marrow donor for their leukemic son only after a court threatened to charge them with child abuse and remove the children from the home. See Andrea Boroff Eagan, Who Decides for Women?, AMERICAN HEALTH, Sept. 1990, at 42. Eagan contrasts this with the report of an Arkansas man who refused to donate bone marrow to his leukemic brother but was left in peace. See id.
to conceive other children as organ donors? 293 Ferrell, the Ayala story and similar news reports transform these extreme hypotheticals into realistic possibilities. 294

Adults experience psychic or psychological benefits when they act without any expectation of reward and when they do not bear the burden of the life or death of a loved one. 295 Altruistic behavior is made possible by advances through stages of cognitive development. 296 Children do not achieve the ability to act altruistically until sometime in early adolescence, and mentally disabled adults may never reach that stage. 297 Imputing the psychological benefits of altruistic behavior to individuals who, because of age, cognitive ability and circumstances cannot make altruistic choices, is myopic. 298 Whatever lesson the child may learn from being compelled to donate an organ or from being conceived to donate an organ, it surely will not be about the good of giving of oneself utterly and selflessly. 299

293 See Eagan, supra note 292; cf. Bone Marrow Dispute, WASH. POST, Jan. 20, 1990, at B5. A Virginia woman filed a claim against the father of her four month-old son to compel him to be tested for bone marrow compatibility as it was his “duty and obligation to undergo minimally intrusive tests and, if eligible, to donate bone marrow to his son.” See Eagan, supra note 292; cf. Bone Marrow Dispute, supra, at B5 (internal quotes omitted). USA Today followed the story and interviewed ethicists who logged their disapproval of compelling a parent to donate to their child. See Andrea Stone, Father Sued for Bone Marrow, USA TODAY, Jan. 19, 1990, at 3A. The news reports noted that the woman had repeatedly pleaded with the father to come forward and he had refused. A week after the story broke, however, the claim was dropped when the father underwent tests, claiming that he had been unaware that a sample of his blood had been sought. See id.

294 See Kearney & Caplan, supra note 83, at 279; Eagan, supra note 292.

295 Cf. Curran, 566 N.E.2d at 1335 (reporting psychiatrist’s testimony that whether a child feels guilty about not having donated will depend entirely on the parent taking responsibility for having made a difficult decision and not laying the burden on the child); see GIFT OF LIFE, supra note 16, at 444–45.

296 See Curran, 566 N.E.2d at 1334; see also supra notes 102–10 and accompanying text.

297 See Nathan Seppa, Teen’s Altruism Grows Like They Do In Sports, APA MONITOR, June 1996; cf. Curran, 566 N.E.2d at 1334 (noting a psychiatrist’s testimony that “mentally and physically healthy children do not understand abstract concepts such as death because they just haven’t had the opportunity to have cognitive development sufficient to manage things like abstractions, hypotheses, and so on.”).

298 See Curran, 566 N.E.2d at 1334; Seppa, supra note 297; supra notes 103–125 and accompanying text.

299 See Curran, 566 N.E.2d at 1334; Seppa, supra note 297; supra notes 103–125 and accompanying text.
B. No Judicial Standard or Adjudicative Proceeding Will Uniformly Lead to the Proper Result

Adjudicating petitions to harvest organs on a case-by-case basis tempts judges to stretch legal doctrine to the breaking point in order to reach what they hope is the least regrettable decision. The heartwrenching issues these petitions involve make this inevitable. Commentators have suggested various methods of correcting the inherent dangers of the current system, including adopting stricter, more clearly defined standards, changing the forum in which the petitions are heard and assigning experienced guardians ad litem to all donors. None of these proposals, however, goes to the heart of the problem; case-by-case adjudications are inherently flawed because they substitute the consent and judgment of a third-party decision-maker for the consent and judgment of the individual undergoing the surgical invasion. It is immaterial whether that third-party decision-maker is a judge or a board of impartial experts, whether the decision is made by a state court or an administrative board, or whether more advocates are added to the complicated mix of people already involved in these petition. The harm is done when substitute deci-

500 See Hart, 289 A.2d at 390. The Hart court expressed the dilemma: "[The] question before this court is whether it should abandon the [recipient] to a brief medically complicated life and eventual death or permit the ... parents to take some action based on reason and medical probability in order to keep both children alive." Id.; see also Baron, supra note 8, at 183.

501 See Hart, 289 A.2d at 390; Baron, supra note 8, at 183.

502 See, e.g., Baron, supra note 8, at 187 (suggesting that guardians ad litem be appointed for all donors, that all guardians be members of an established panel to ensure that the attorneys in that role have some expertise in the area and further, that proceedings take place in probate court because probate judges deal daily with "intrafamily conflict and tension"); Linda Delaney et al., Altruism by Proxy: Volunteering Children for Bone Marrow Donation; Opinions of Various Professionals, 312 British Med. J. 240 (1996) (suggesting that "a forum, independent of the parents and medical advisers" made up, perhaps, of independent medical social workers should be responsible for deciding the petitions); Griner, supra note 101, at 608-10 (advocating adoption of a rebuttable presumption against harvesting organs from minors which could only be overcome by clear and convincing evidence that the donor would benefit physically or financially); Lebit, supra note 136, at 127-29 (suggesting a "higher scrutiny best interests standard" which would require clear and convincing evidence that a compelled procedure is in the child or mentally disabled adult's best interests, the evidence to be provided in large part by the legal, medical and philosophical communities).

503 See Baron, supra note 8, at 187; Delaney, supra note 302; Griner, supra note 101, at 608-10; Lebit, supra note 136, at 127-29.

504 See Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 428 (Mass. 1977). In Saikewicz, the court stated:
sionmakers make the kind of intensely personal and medically unnecessary decision on behalf of an incompetent that few would suggest ought to be made on behalf of a competent individual.\footnote{505}

Criticizing those decisions that reached the wrong result does not get us very far, however. Rather, Curran, the decision that reached the right result after applying a closely tailored best interest analysis, best illuminates the dangers inherent in adjudicating these petitions case-by-case.\footnote{506} The Curran court denied the father’s petition to harvest bone marrow from his three year-old twins for the benefit of their half-brother.\footnote{507} The court articulated a three factor test to determine whether the organ harvest was in the best interests of the minor twins.\footnote{508} Curran’s test focused on the need for the parents’ informed consent to the procedure, their willingness to emotionally support the donor and the closeness of the relationship between the donor and the ill sibling.\footnote{509}

Applying its tailored analysis to the facts before it, the Curran court determined that the harvest was not in the twins’ best interests because the relationship between the twins and their terminally ill half brother was not close, and the custodial parent was unwilling to consent to the harvest and therefore, unable to emotionally support the twins.\footnote{510} The guidelines the Curran court injected into the for-

The significant decisions of life are more complex than statistical determinations. Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the unique perspective of the person called on to make the decision. To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.

\textit{Id.}; see also Baron, supra note 8, at 187; Delaney, supra note 302; Griner, supra note 101, at 608–10; Lebit, supra note 136, at 127–29.

\footnote{503} See Dolgin, supra note 13, at 399, 413–14. Dolgin further argues that substitute—or paternalistic decisions—may inflict harm rather than protect children from harm. See id. at 413. As an example, Dolgin discusses court decisions which require young, pregnant teenagers to petition judges for permission to undergo abortions. See \textit{id.} While adult women may seek abortions without having to justify, or even understand, the basis of their decision, such procedures demand that the teenager be able to articulate the reasons underlying her decision to seek an abortion in the intimidating setting of a judge’s chamber or courtroom. See \textit{id.} at 414. Dolgin’s argument is that this procedural requirement burdens, rather than protects, a teenager’s right to terminate a pregnancy. See \textit{id.}


\footnote{507} See \textit{id.} at 1344.

\footnote{508} See \textit{id.} at 1325–26, 1343–44.

\footnote{509} See \textit{id.}

\footnote{510} See \textit{id.} at 1343–44.
merly ad hoc standard, however, do not provide legal incompetents with any greater protection than they received from courts applying any other standard. This is so because: (1) *Curran’s* best interest standard relies on the same false assumption, rampant throughout these opinions, that psychological benefits will flow to siblings who have an established relationship and that the relationship will immunize the donors from psychological harm; and (2) the “new” standard very much defers to parental authority—in this case, the refusal of one parent to consent on behalf of the children. Looked at through this lens, *Curran* hardly lives up to the ground-breaking, controversial reputation it seems to have developed among commentators.

Both the straightforward cost-benefit analysis and *Curran’s* more tailored benefits-only analysis distort the original purpose of the best interest standard. Rather than safeguard children from cold, marketplace realities, the analysis permits courts to put the legally incompetent individual’s right to autonomy and bodily integrity on a scale. Whereas judicial proceedings offer legal incompetents only minimal protection against being compelled to “act” altruistically, the law and the medical community categorically protect competent adults from that same compulsion. Differences between the two groups do not justify such disparity of treatment. Ultimately, no judicial standard will lead consistently to the proper result because no standard can account for the fact that children and mentally incom-

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511 See Curran, 566 N.E.2d at 1335; supra notes 81–84, 114 and accompanying text.
513 See, e.g., Dufault, supra note 37, at 230; Robbennolt, supra note 10, at 216–17.
514 See Dolgin, supra note 13, at 361.
515 See Curran, 566 N.E. 2d at 1339–40; cf. Patricia Huna, Infants as Organ Transplant Donors: Should it Happen?, 6 Sum. Health Law. 24, 26 (1992). Huna adheres to the belief that the best interest standard removes third-party interests from the equation and goes on to argue that that is one of the failings of the test. See Huna, supra, at 26. Only those courts committed to denying the parents’ request, however, actually apply the test in this way. See generally In re Richardson, 284 So. 2d 185, 186 (La. Ct. App. 1973); In re Peschinski, 226 N.W.2d 180 (Wisc. 1975). Courts determined to permit the harvest routinely weigh the costs to the recipient against the benefit to the donor, and thereby, reinsert third-party interests back into the equation. See generally In re Doe 481 N.Y.S.2d 932, 933 (N.Y. App. Div. 1984); Little v. Little, 576 S.W.2d 493, 497 (Tex. Civ. App. 1979).
516 See, e.g., In re Baby Boy Doe, 623 N.E.2d 326, 330 (Ill. App. Ct. 1994); McFall v. Shimp, 10 Pa. D. & C.3d 90, 90 (1978). For two arguments that adults should be compelled to be tested or donate organs, see generally Anderson, supra note 98, and Huffman, supra note 17.
517 See Griner, supra note 101, at 608.
petent adults are not only unable to give a meaningful, fully informed, legally valid "yes," they are also unable to simply say "no."318

C. Organ Harvests from Children and Mentally Disabled Adults Should Be Prohibited

The presumption that parents and children are not adversaries with disparate interests is deeply rooted in this country's jurisprudence and legislation, and for good reason.319 The state has an interest in preserving and protecting family autonomy because the family unit is able to fulfill social functions that the state may be unable or less able to fulfill.320 Although parents have a fundamental right to control the environment in which a child grows, that right should not extend to invading one child's body in the hope that another child might benefit.321 Deference to a parent's desire and authority merely assumes away the problem of how to adequately protect the disparate interests of all family members when those interests collide.322

The roles that family members play within their small social units have undergone significant shifts in the past thirty years.323 No longer must people silently lose their individuality and autonomy as a neces-
sary consequence of their family membership. No longer are children viewed as simply miniature-sized adults, nor the mentally disabled viewed as defective human beings. Emerging technologies, shifting social demographics, and developments in the social and brain sciences are just some of the factors that have contributed to this evolution of family and society. As a society evolves, so must its body of law.

Sometimes, it is the common law that can best reflect and respond to baseline shifts in the social order; at other times legislative action is necessary to adequately articulate newly defined rights and duties and to provide guidance for how to protect and enforce these new rights and duties. Previously, children who were otherwise qualified could hold the same jobs as adults, and children as young as twelve could legally marry. Today, the age of consent in most states has risen from twelve to eighteen; child labor laws have been passed to keep children out of factories; and although children over fourteen may work, their employment is subject to strict statutory guidelines. These laws have restricted children’s participation in adult activities, notwithstanding the family’s social or economic needs which child labor or an early marriage might have satisfied.

The only solution to this dilemma is legislation which requires that an individual be legally competent to give an informed, valid

324 See id. at 357 (discussing Griswold and noting that the body of family case law was almost exclusively developed during the 1960s and 1970s).

325 See Deborah Hardin Ross, Sterilization of the Developmentally Disabled: Shedding Some Myth-Conceptions, 9 FLA. ST. U. L. REV. 599, 600 n.5 (1981) (noting that historically, the mentally retarded individual has been considered a “menace,” a “subhuman organism,” “diseased,” an object of “pity,” “dread” or “ridicule,” or an “eternal child”). Today, medication and appropriately tailored educational opportunities permit many mentally disabled adults to be high functioning and semi-independent. See, e.g., The Arc of the United States (The National Organization of and for People With Mental Retardation and Related Disabilities and Their Families), (visited February 1, 2000) <http://www.thearc.org/>.

326 See Dolgin, supra note 13, at 361.

327 See generally Dolgin, supra note 13.

328 See id. at 370–71. The case law is “contradictory and uncertain” in its response to the changing status of children and childhood. “Sometimes children ... are assumed to be best protected when their individuality is ... subsumed by parental authority. ... Sometimes children are recognized as complete human beings. ... Sometimes the law reinforces parental authority even against children burdened by the exercise of that authority.” See id.

329 See id. at 361 n.84.

330 See 29 C.F.R. § 570.2 (1998) (child labor regulations); Dolgin, supra note 13, at 406.

331 See 29 C.F.R. § 570.2 (1998) (child labor regulations); Dolgin, supra note 13, at 406.
consent before he or she may be a candidate for organ donation. Legislation which prohibits children and mentally disabled adults from being volunteered as donors would also eliminate the incentive parents currently have for conceiving children as donors. Furthermore, legislation would effectively halt the slide down the slippery slope threatened by the court’s recognition of the malpractice claim in Ferrell. Our legal system should no longer condone compelled organ harvests by resorting to idealized notions of the family and unrealizable expectations of altruistic behavior.

CONCLUSION

Children and mentally disabled adults are often volunteered to undergo surgical procedures so that third parties might benefit from their organs, while the legal system staunchly protects the competent adult’s right to opt out of the same procedures. These inequitable results are not justified. The notion that parents, guardians and judges adequately protect the child and mentally disabled adult’s best interests when they permit the harvests is not supported by research regarding the adverse psychological effects that flow from organ transplants. If the psychological benefits courts and commentators cite are at best speculative when an individual chooses to undergo a surgical invasion, they are impossible to predict when the surgical invasion is compelled. Legislation must be drafted that eliminates volunteered donors from the rolls of donor candidates, because, as long as children and mentally disabled family members are legal organ sources, parents, doctors and judges will be faced with the untenable task of harming one child in the hope that another will be saved.

We live in a remarkable age—neither birthplace nor genetics need be determinative of who we will be or how long we will live. But the same advanced technologies that have the potential to free us from living or dying according to a fixed blueprint also foster the view

332 See Harmon, supra note 22, at 7 (noting that one can avoid an undesirable result from the application of a general rule of law by changing the general rule of law rather than by fabricating a legal fiction).
334 For a thorough discussion of the constitutional objections to compelling children and mentally disabled adults to donate organs, which, to date, only the lower court in Curran has raised, see Greatest Gift, supra note 3, at 622–26.
335 See Dolgin, supra note 13, at 429; Robbeinolt, supra note 10, at 229, 330.
336 See McFall v. Shimp, 10 Pa. D. & C.3d 90, 92 (1978); In re Pescinski, 226 N.W.2d 180, 183 (Wis. 1975) (Day, J., dissenting); supra notes 115–17 and accompanying text.
337 See supra notes 56–90 and accompanying text.
that children and the mentally disabled are no more than the sum of their body parts. By holding out the elusive promise that death can be cheated and all disease checked, medical technology too often tempts parents and doctors to try to prolong life at all costs—even when it is a child or mentally disabled adult who ends up footing the bill.

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