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The Bane of Surrogate Decision Making:
Defining the Best Interests of
Never-Competent Persons

Norman L. Cantor*

*Rutgers U. School of Law, Newark, ncantor@andromeda.rutgers.edu

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The Bane of Surrogate Decision Making: Defining the Best Interests of Never-Competent Persons

Norman L. Cantor

Abstract

The medical fate of never-competent persons cannot be resolved according to the approach governing previously competent persons – surrogate focus on self-determination via advance instructions or projections of what the now-incompetent person would want in the circumstances. For never-competent medical patients, the commonly stated approach to surrogate decision making is best interests of the incapacitated ward.

This article examines and questions the conventional wisdom regarding a “best interests of the patient” standard. When a parent is the surrogate decision maker, the medical course chosen need not be the best course, so long as it is a plausible medical option and is not so antithetical to the patient’s interests as to constitute neglect or abuse. And while third party interests are not officially part of a never-competent patient’s interests, third-party interests constitute a looming omnipresence that inevitably influences surrogate decision making at the margins. That is so especially where the never-competent patient’s own interests are murky or in equipoise, and the potential impact on third parties is extreme.

Never-competent persons, as possessors of full moral status, are also entitled to be treated with dignity. This normally means that a surrogate decision-maker will maximally preserve the life of a ward. Sometimes, though, respect for the intrinsic human dignity of a fatally stricken ward dictates that the ward be allowed to die. A permanently unconscious person offers an example, as does an infant with multiple deficits whose short life will be pervaded by intrusive medical interventions. In these rare instances, the deterioration or debilitation of a human being

is so extreme that further medical intervention would be inhumane. This is so for some never-competent persons, just as it is for some formerly competent persons.

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Anglo-American law has traditionally recognized a sovereign's authority to protect helpless populations. This state authority, known as the *parens patriae* power, is described as "the inherent equitable authority of the sovereign to protect those persons within the state who cannot protect themselves because of an innate legal disability."¹ Some persons' mental function is so limited that they cannot be accorded self-determination regarding important matters affecting their lives. These profoundly disabled² persons³ are so mentally impaired that they cannot make serious medical decisions for themselves. Someone (a surrogate) must decide on behalf of such incapacitated persons whether to initiate and maintain medical interventions. That surrogate is usually a family member, but it can sometimes be a judicially appointed guardian or even a court (as to particularly delicate medical issues like sterilization or organ donation). In all instances, the profoundly disabled person is vulnerable -- unable to assert independent judgment or to effectively protest against any ill-considered surrogate decisions.

Government's *parens patriae* authority is the vehicle for safeguarding a profoundly disabled person against abusive surrogate decisions. The watchword for *parens patriae* jurisdiction is the best interests of the disabled person. Because the rationale for governmental oversight is protection of the ward, it is natural that the concept of best interests of the ward should dominate surrogate decisionmaking for never-competent persons.⁴ That is, whenever government intervenes to scrutinize a surrogate's medical determination on behalf of a helpless person, or whenever a problematic medical issue is reserved for judicial resolution, that helpless person's interests are ostensibly the key factor. Not surprisingly, then, best interests of the

profoundly disabled patient has emerged as the common guideline for surrogate decisionmaking in disparate medico-legal areas including end-of-life decisions, abortion, sterilization, and organ donation.

Identification of best interests of the patient as the prevailing standard for surrogate decisionmaking leaves many questions unresolved. As examples, what are the components of the best interests formula -- i.e., what kinds of benefits and burdens can be considered by a conscientious surrogate? How are the interests and well being of a profoundly disabled and barely communicative person assessed and measured? To what extent does quality of life play a role in decisionmaking for the profoundly disabled? Whose perspective on quality of life governs -- that of the guardian, the ward, or some hypothetical reasonable person? What is the role of human dignity within a best interests of the patient formula? Is it permissible for a surrogate decisionmaker to consider the interests of other persons, such as surrounding family and caregivers? How about the interests of society in avoiding extraordinary expense or in allocating scarce medical resources in a sound fashion? Must a surrogate decisionmaker seek to advance the best interests of the ward, or is it sufficient to act in a manner generally consistent with the ward's interests? What standard of proof of best interests should the surrogate employ - preponderance of the evidence, clear and convincing evidence, or some other standard of inquiry? These questions will be addressed in this article, primarily in the setting of end-of-life decisionmaking and sterilization, as the jurisprudence under those two headings is relatively well developed.

The Focus on a Never-competent Patient's Well Being

Most jurisprudence relating to end-of-life medical decisions by surrogates focuses on

fulfillment of the self-determination interest of formerly competent patients. (I am referring here to the medical handling of the full range of mentally incapacitated patients, not just never-competent, profoundly disabled persons). The earliest decisions regarding end-of-life care -- Quinlan and some succeeding cases -- articulated a substituted judgment standard in order to preserve the now-incompetent patient's liberty interest in choosing whether to accept or refuse life-sustaining medical intervention.⁵ That early effort to honor self-determination of formerly competent persons has been reinforced by subsequent developments. Every jurisdiction that has spoken to end-of-life surrogate decisionmaking has upheld a formerly competent patient's prerogative to shape post-competence care either by advance medical directive or other prior expressions. In most jurisdictions, the formerly competent patient's values and preferences -- even if not explicitly directed toward end-of-life choices -- are also deemed relevant to surrogate decisionmaking. This is so under a substituted judgment formula, where a patient's religious values or philosophical preferences can be determinative of post-competence care.⁶ And it is often the case under a best interests of the patient formula, at least in the many jurisdictions where the formerly competent patient's wishes, values, and preferences are considered part of the now-incompetent patient's interests to be implemented by a surrogate. All this reliance on prior expressions and previously formed values seeks to honor the previously competent patient's autonomy or self-determination.

Even if the patient's previous values and expressed preferences don't furnish clearcut guidelines, the surrogate decisionmaker can still draw guidance from a projection of what most people would want done for themselves in the circumstances of the particular case. Again, this is so under both a substituted judgment standard and a best interests formula. Under the former, a

surrogate may assume that a now-incompetent person (who has not provided contrary indications) would want what a strong majority of people would want done in the circumstances.⁷ Under a best interests approach, the factors to be considered by a surrogate -- physical and mental suffering, chances of recovery, nature of patient interaction with his or her environment, regaining of function, indignity, etc. -- are drawn from what most people consider to be critical factors in shaping post-competence decisionmaking. The overall object of the surrogate becomes to replicate the now-incompetent patient's likely choices as determined by what most people would want done for themselves.⁸ Now-incompetent patients are assumed to want their interests furthered and to have those interests defined according to majority preferences -- absent personal indications to the contrary. I call this constructive preference, as opposed to actual preference, because the approach governs formerly competent persons who have not left clearcut indications of their own end-of-life medical choices. But the approach still seeks to honor self-determination by implementing the now-incompetent patient's likely, albeit putative, wishes.⁹

This article focuses on the profoundly disabled. Profoundly disabled persons, by definition, have never had the capacity for autonomy -- have never had the ability to issue instructions concerning end-of-life treatment (or other serious medical matters) or to form values and preferences that would guide surrogate decisionmakers. And it is a lot more logical to attribute majoritarian values to formerly competent persons, who have once had the perspective of a competent person, than to attribute them to profoundly disabled persons whose values are either non-existent or opaque. Neither actual preference nor constructive preference would therefore seem to provide a determinative guide for this never-competent population.¹⁰

Not surprisingly, then, the bulk of commentators and courts have rejected application of a

substituted judgment standard – a standard seeking to replicate the patient’s own likely decision – in the context of a never-competent person. According to one early commentator, it is “non-sensical” to ask what a person with the mental age of a small child would choose.¹¹ And an Illinois court was similarly disparaging of the substituted judgment standard in the context of three and one-half year old twins, one of whose parents was hoping to use the twins as bone marrow donors to rescue the twins’ dying half brother. In finding substituted judgment irrelevant to the children’s situation, the court remarked: “[I]t is not possible to discover the child’s likely treatment/ non-treatment preferences by examining the child’s philosophy, religion and moral views, life goals, values about the purpose of life and the way it should be lived * * *.”¹² Another court recently noted the “limited relevance” of substituted judgment because children [and never-competent persons] have “no articulable judgment to be substituted.”¹³

A few sources nonetheless insist on talking about substituted judgment even in the context of never-competent persons. Massachusetts, for example, has clung to substituted judgment for the profoundly disabled ever since that standard was applied in 1976 to Joseph Saikewicz a 62 year old, severely retarded man whose cancer treatment was in issue. And a few cases and a few commentators about decisionmaking for profoundly disabled newborns recommend that surrogates put themselves in the place of the newborns and impute a judgment to the infant as though it were a moral agent. According to this commentary, the surrogate should ask: “Would the infant wish to lead such a life if it had the capacity of choosing for himself or herself.”¹⁴ This transposition of a judgment to a profoundly disabled infant is grounded in a commendable motive -- reminding the surrogate and all involved individuals about the human stature and personhood of the infant. But most commentators understandably deride

the notion of attributing judgments or preferences to profoundly disabled persons as being muddled and non-sensical.¹⁵ The strong majority of courts have refused to apply a substituted judgment standard in the context of never-competent patients.

Even in the few judicial decisions nominally applying a substituted judgment standard to a never-competent patient, the standards of substituted judgment and best interests often meld and the court ends up relying on the patient's best interests. Because there is no basis for ascribing a personal choice – in the sense of personal preference among competing values and interests – to a profoundly disabled person, the courts purporting to apply a substituted judgment standard end up resolving the disabled patient's medical fate according to a projected weighing of the patient's future pleasure and pain. In other words, they end up applying a best interests of the patient standard. That was true in Strunk v. Strunk, the 1969 case involving a kidney donation from a profoundly disabled sibling and in the 1976 Saikewicz case¹⁶ involving a profoundly disabled, terminal cancer patient. In each instance, the court selected a medical course for the never-competent person that the court believed would best promote the disabled person's interests in avoiding suffering (from loss of a beloved sibling or from the rigors of a chemotherapy regimen) and in deriving satisfaction or pleasure from existence.

The commonly articulated standard for the never-competent person is the same standard that has guided *parens patriae* jurisdiction for centuries -- the best interests of the patient. The strong majority of courts addressing surrogate medical decisions on behalf of profoundly disabled persons -- whether in the context of cessation of life support, sterilization, or organ donation -- have prescribed a best interests test. Most protocols governing clinical practice also prescribe that best interests should determine the medical fate of now-incompetent persons who

have never provided definitive guidance on their own.¹⁷ As applied to the end-of-life setting, this means that life support should be maintained unless the patient would be better off dead than alive, i.e., unless the burdens of further existence would outweigh the benefits.¹⁸ As applied to other medical issues such as sterilization, the issue becomes whether the benefits of the contemplated medical intervention would outweigh the detriments, i.e., whether the net welfare of the profoundly disabled patient would be advanced by performance of the contemplated procedure.

The Problematic of Assessing Well Being

Application of a best interests standard to profoundly disabled, dying patients presents special challenges. The determination of whether the patient is better off dead than alive provides an illustration. One underlying assumption in the context of end-of-life medical decisions is that a person's suffering can be so severe and unremitting as to outweigh the benefits -- the pleasures and satisfaction -- of further existence. In such instances, best interests dictate cessation of life-sustaining medical intervention. That approach to end-of-life decisions seems valid as applied to never-competent as well as previously competent beings. The devastating impact of intense pain on the patient and on inter-personal relations would seem as great for profoundly disabled persons as for others. While avoidance of unremitting suffering is not a self-determined value for a profoundly disabled person, our understanding of human nature and the horror of extreme, unremitting suffering¹⁹ warrant injecting that value into standards governing medical decisions for the never-competent patient.

How much suffering, though, is so intolerable as to make non-existence the right choice? And how can a surrogate make that assessment for a profoundly disabled person? There are

special difficulties that handicap that task.

For starters, what perspective does a surrogate assume when assessing the best interests of a never-competent person in the context of serious medical issues. The common wisdom concerning best interests says that the judgment of “a reasonable person” must be determinative as to the net well being of an incapacitated person.²⁰ This makes sense, as a profoundly disabled being cannot be expected to make or have a considered judgment about best interests when completely unable to grasp the component elements like non-existence or net welfare. Only a mentally competent person can make a considered judgment about whether the burdens of continued existence outweigh the benefits or whether the burdens and detriments of sterilization outweigh the benefits. The question is “what a reasonable person with the characteristics of the incompetent would [do] under similar circumstances.”²¹ And it is not far-fetched to suppose that a never-competent patient, if miraculously competent, would want medical decisions to be based on the patient’s interests as assessed by a reasonable person.

At the same time that a conscientious surrogate must use the reasonable person perspective in fixing what level of suffering should be deemed intolerable, that surrogate must scrupulously adhere to the disabled person’s perspective in discerning the levels of suffering and gratification actually present (or foreseeable) in any individual case. The object is to discern the benefits and burdens from the point of view of the profoundly disabled patient rather than that of a competent person (such as the surrogate) who has experienced the benefits and developed the expectations of a fully abled existence. The question is whether the particular patient would be better off dead than alive in the circumstances facing the patient,²² not whether the surrogate (or even the average capacitated person) would want to live in those circumstances.

It is inherently difficult for a fully capacitated surrogate to assume the point of view of a person who has always been profoundly debilitated. The competent surrogate's frame of reference is vastly different from the never-competent patient. It may be hard "for the fully competent person to have the sympathetic insight . . . into what it is like" to experience the world with gravely diminished mental function.²³ A strong temptation exists to transpose or project the fully capacitated surrogate's feelings onto the incapacitated patient.²⁴ For example, it is common to ascribe hunger to a gravely debilitated, dying patient who is refusing nutrition when the reality is that the patient is not hungry.²⁵ And while there is no reason to think that a profoundly disabled person suffers from the mere status of being extremely cognitively disabled, the capacitated observer may attribute feelings of frustration or anxiety that the capacitated person thinks he or she would feel in comparable circumstances. One commentator laments a "grave danger of injecting our own values onto the child who has absolutely no basis for the fears and horrors we might have for ourselves in a similar state."²⁶ The hazard also exists that the competent surrogate will undervalue the simple benefits that the disabled patient derives from existence and project negative feelings (e.g., frustration flowing from incapacity or embarrassment from posing a burden upon others) to the disabled patient based on a competent person's assumptions or prejudices about a profoundly disabled existence.²⁷

A similar hazard is that the competent surrogate will inject personal values into the best interests determination. (This happens, for example, when parents who are Christian Scientists or Jehovah's Witnesses use their own religious beliefs in forgoing important medical intervention for small children or other profoundly disabled charges). Or a competent surrogate's personal perspective on quality of life can distort an assessment of a profoundly

disabled patient's well being and best interests. A distorted, stereotyped view of the impact of Down's Syndrome led one set of parents in 1982 to inappropriately withhold life-preserving surgery for their newborn infant.²⁸ All this is not to say that the requisite surrogate judgments are impossible, only that there are reasons for scrutiny of such judgments.

While the burdens of a profoundly disabled person's existence may in some instances outweigh the benefits so that cessation of life-sustaining medical intervention becomes consistent with that patient's best interests, a surrogate decisionmaker's determination of that status faces another major hurdle in assessing the experiential reality of a profoundly disabled person -- a person whose cognitive understanding and communicative ability are likely to be extremely limited. To determine the best interests of a profoundly disabled person, a surrogate must be sensitive to "noncognitive notions of well being" grounded in "emotional and relational well being."²⁹ Yet assessing the subjective reality behind the disabled person's sounds and gestures is an extremely daunting task.³⁰ At the extremes, this assessment or measurement barrier may be surmountable by an attentive surrogate. Susan Martyn exhorts "caring interpreters" to determine what the profoundly disabled patient "finds meaningful in life" and "how that person experiences life."³¹ The behavior and expressions of some persons may reflect such extreme and unmitigated suffering as to readily prompt a conclusion that non-existence is preferable to life. Or, by contrast, a profoundly disabled person's continued participation in, and response to, ostensibly enjoyable activity may make a life-affirming conclusion easy.³² Putting those extremes aside, discernment of the profoundly disabled patient's experiential reality may be dependent on interpretation of signals and expressions -- including enigmatic verbal expressions as well as non-verbal communication such as grimaces, moans, screams, smiles, and gestures -- that are

difficult to decipher. The difficulty of discerning the true feelings of the disabled person is, of course, compounded by the previously mentioned temptation of a fully capacitated surrogate to project certain feelings onto an incapacitated ward.

The problematic of assessing the best interests of profoundly disabled beings is illustrated in the context of infants or young children born with grave afflictions certain to shorten their lives.³³ In some instances, their abbreviated lives will be accompanied by extreme dysfunction, considerable pain and suffering, and fairly continuous and intrusive medical interventions. State law generally accepts the principle that the best interests of at least some afflicted children would be served by withholding or withdrawing life-sustaining medical intervention.³⁴ Yet parents and health care providers seeking to apply this principle must cope with various uncertainties -- uncertainty in measuring degree of pain, uncertainty in projecting precise level of mental dysfunction, uncertainty regarding duration of potential survival, and uncertainty in determining whether the suffering outweighs potential satisfactions from interactions with people and environment.³⁵ Take Baby Rena as an example.³⁶ She was an 18 month-old infant dying of AIDS. She had become ventilator dependent and was constantly sedated to relieve pain. She retained some awareness of her environment. Every time she was handled in any fashion her blood pressure shot up and tears streamed from her eyes. Was it in her best interests to have the ventilator withdrawn so that she would die? Was her suffering so extreme and unremitting that she would be better off dead than alive?³⁷ Baby Rena was already 18 months old and her condition and prognosis were well established. The difficulty of surrogate decisionmaking is compounded in the case of newborns whose prognoses are ultimately dismal, but whose precise levels of pain and cognitive dysfunction cannot yet be fixed.

Opposition has always existed to any parental prerogative to withhold or withdraw life support from an infant, even where that decision purports to be in the infant's best interests. Part of that opposition stems from fear of parental (or professional) prejudice or ignorance about life as a disabled person, as occurred in the 1982 Indiana case allowing the withholding of critical medical treatment from a Down's syndrome infant. There, the parents determined to withhold lifesaving treatment on the basis that Down's syndrome children "don't do very well" and cannot be happy.³⁸ In the wake of that 1982 incident, the federal government sought to curb all decisions allowing newborns to die. An initial federal attempt to attack such decisions as unlawful discrimination against disabled persons failed. The courts ruled that the federal regulations exceeded the scope of authority that Congress had conferred.³⁹ Congress responded in 1984 by adopting the Child Abuse Amendments to a statute dealing with federal grants to states for the operation of child protection programs. Those amendments conditioned the grant of federal funds upon state establishment of procedures to ensure that "medically indicated treatment" would always be provided to infants. Narrow statutory exclusions from required treatment applied only for comatose infants, infants unavoidably dying so that treatment would be futile, and situations where treatment would be "virtually futile" and "inhumane."⁴⁰ Federal interpretive guidelines indicated that the last-mentioned exclusion covered only treatment "highly unlikely to prevent death in the near future" and did not cover non-treatment "based on subjective opinions about future quality of life of a disabled person."⁴¹

The impact of these federal efforts upon neonatal care practices is unknown, but it may well be "quite small."⁴² The federal regulations themselves don't apply directly to health care providers; the only sanction for "non-compliance" would be withdrawal of federal funding for

certain state child abuse prevention programs (as opposed to any direct penalty upon a health care provider).⁴³ The federal impact is also likely small because of the compelling need to make some decisions not to treat newborns with certain severe deficits. Some congenital anomalies entail a foreshortened lifespan, as well as severe neurological impairment, physical incapacity, repeated bodily invasions, and suffering so acute that the affected infant is simply tortured by continued treatment. Infants with trisomy 13 or 18 provide examples.⁴⁴ Also, some children with Tay Sachs face the prospect of dying in very early childhood after inexorably declining via mental retardation, convulsions, blindness, and considerable pain.⁴⁵ These situations involving irremediable suffering and continuous bodily intrusions can make withholding of life support consistent with a child's best interests, even if precise measurement of suffering is not possible.

Extreme difficulties in assessing best interests are encountered as well in the context of profoundly disabled adults. Physicians and surrogates must sometimes determine the medical fates of adults whose grave mental disability leaves them aware but uncomprehending, permanently immobile, totally helpless, communicative only by grunts, cries, or smiles, and whose fatal affliction leaves them dependent on constant medical intervention.⁴⁶ British courts faced such a case in 1996.⁴⁷ R. was a 23 year-old so profoundly disabled that her cognitive function was at the level of a newborn child. She was unable to communicate verbally, but responded to stimuli with grimaces, cries, or smiles. She was incontinent. Because R. had recently lost the ability to chew, one medical issue became whether to install a gastrostomy tube. Her parents, who had devotedly cared for R. for 23 years, also wondered whether antibiotics should be used to fight recurrent infections that had begun to plague R. When physicians petitioned for judicial guidance, the court responded that the relevant decision-making standard

is best interests of the patient. That meant a determination of whether, judging from the perspective of R., her future life would be so afflicted as to be unbearable. Using that best interests standard, the British court ruled that a gastrostomy tube should be installed (i.e., R.'s current level of suffering did not outweigh the benefits of her existence), that cardiopulmonary respiration should not be instituted in the event of cardiac arrest (perhaps on the assumption that any cardiac arrest would mark a further decline in R.'s condition so that the burdens of CPR would exceed the benefit of life extension?), and that antibiotics could be withheld during some future infection episode if the parents and physician then agreed that such withholding would be in R.'s best interests (i.e., R.'s condition might deteriorate to the point when even a simple life-sustaining intervention would be contrary to her best interests). R.'s story helps show the delicacy of a best interests determination in the context of some profoundly disabled and gravely physically afflicted adults.

Another uncertainty complicates application of a best interests standard to a profoundly disabled, fatally stricken person who is facing prospective pain and suffering during a contemplated treatment process. It is commonly asserted that the disabled person's incomprehension of the reasons for instituting painful medical interventions (i.e., failure to understand the curative or restorative hope behind a contemplated medical intervention) will heighten the anxiety and distress to be experienced by that person. The National Conference of Catholic Bishops admonishes physicians that a demented patient may find treatment "more frightening and burdensome" than other patients.⁴⁸ The spectre of heightened suffering by an uncomprehending patient was part of the rationale of the Massachusetts court that concluded that 67 year-old Joseph Saikewicz should not receive chemotherapy for leukemia even though most

competent patients would opt for chemo in the circumstances. Joseph's incomprehension about the reasons for the needles to be used in administering chemotherapy would supposedly cause Joseph extreme distress and agitation and would necessitate his being restrained for extended periods of time. He might also be distressed by side affects whose origins he would not understand. (Commentators have wondered, though, whether Joseph Saikewicz's best interests would have been better served by a trial run of chemotherapy to see whether the feared consequences really ensued and, if so, whether sedatives succeeded in palliating his suffering.⁴⁹) Another Massachusetts court cited the heightened burdens that a profoundly disabled woman would experience if she were denied an abortion. According to the judicial finding: "Normal discomforts of pregnancy such as bladder pressure, an increasingly bulky body, and backache would be felt as unendurable by Jane because she would not fully understand their cause."⁵⁰ These projections of heightened suffering flowing from the incomprehension of profoundly disabled persons might be accurate, but they might also be the product of speculation fueled by a surrogate's projection of imagined feelings or by negative perceptions of the patient's worth. In short, while a best interests standard for surrogate medical decisionmaking makes theoretical sense, its application to profoundly disabled patients is complicated by difficulties of assessment and measurement of patients' feelings and emotions. And that problem of applying a best interests standard is compounded if the patient's intrinsic human dignity becomes part of a best interests calculus.

Quality of Life, Dignity, and Never-competent Persons

The 1983 President's Commission for the Study of Ethical Problems in Medicine listed "quality as well as the extent of the life sustained" as an element within a best interests of the

patient standard.⁵¹ Following that lead, a number of court opinions mention quality of life (or human dignity) as a relevant factor to be used by a surrogate in assessing an incapacitated patient's best interests when making end-of-life treatment determinations.⁵² A few state statutes explicitly mention dignity in the same context.⁵³ I submit that quality of life entails more than weighing benefits and burdens -- the delicate task of measuring and balancing feelings and emotions described in the last section -- in severely debilitated patients. It includes a determination of whether the patient's deterioration is so extreme that life has become intrinsically undignified.

The importance of quality of life and avoidance of extreme indignity is easily understandable with regard to formerly competent persons. Most competent people care mightily about quality of life within the dying process. That concern was a major force behind the death with dignity movement that has been active in the United States for more than 30 years. People commonly fear that grave debilitation -- particularly, severe dementia -- will entail embarrassment and/or frustration stemming from helplessness, dependence, and incapacity. Even if these distasteful feelings might not materialize, people care about the image and memories that they will leave behind, images in the minds of loved ones that may be soiled by the patient's extreme mental and physical deterioration during the dying process. These common preoccupations with indignity in the dying process are readily observable in the context of competent patients contemplating their prospective medical fates -- in decisions to reject life-sustaining medical interventions, in advance medical directives, and in attitudinal surveys showing "paramount importance [attached to] . . . functional independence and the maintenance of mental faculties."⁵⁴ Afflicted patients seeking access to assisted suicide are often motivated by

a desire to avoid helplessness and indignity, rather than avoidance of pain. Justice Souter in Glucksberg portrayed the petitioning dying patients as seeking “an end to their short remaining lives with a dignity that they believed would be denied them by powerful pain medication, as well as by their consciousness of dependency and helplessness as they approached death.”⁵⁵

Justice Stevens in Glucksberg accepted the notion that a person’s interests in dignity in the dying process and in shaping the legacy of memories that survives might well qualify as a fundamental aspect of liberty.⁵⁶

Some commentators question the relevance of the concept of indignity to the handling of profoundly disabled persons. One objection is that any indignity -- in the form of embarrassment or humiliation -- will not actually be experienced by a gravely incapacitated patient and that it cannot be demeaning or degrading to suffer debilitation, especially if others are providing loving, life-supporting care to a human being.⁵⁷ That objection seems short-sighted to me. Unsensed invasions of personal interests, including affronts to dignity, may be terribly offensive even if unsensed. What about the performance of unconsented medical experiments, or harvesting of non-vital tissue, or sexual molestation with regard to even insensate, dying patients? Wouldn’t those actions be deemed clearly violative of important dignity interests? What would we think about administration of medical care that violates a now-incompetent (and insensate) patient’s religious precepts? Joel Feinberg correctly notes that incapacitated beings can be victimized by “harms” to their interests (even if unsensed) as well as by “hurts” that are experienced. In short, a profoundly disabled person has important dignity interests whether or not the person actually senses invasions of those interests.

A stronger objection to use of the concept of indignity in the death and dying context is

that the concept's imprecision and subjectivity would engender arbitrariness and abuse by surrogates making end-of-life decisions for the profoundly disabled. This concern about exploitation of vulnerable persons led to the policy pursuant to which a few states barred terminal surrogate decisions absent clearcut prior expressions. Recall Judge Wachtler's admonition in a 1988 case involving continuation of life support for an elderly woman left barely conscious by a series of strokes: "No person or court should substitute its judgment as to what would be an acceptable quality of life for another."⁵⁸ Recall also the previously mentioned problem of perspective -- the concern that able-bodied surrogates might project distorted visions of intolerable quality of life (grounded on their own baseline notions of function necessary to a dignified existence) onto their incapacitated wards. Surrogates might be subject to the ignorance and prejudice that frequently characterize public attitudes toward gravely incapacitated persons. That certainly occurred in the previously mentioned 1982 Indiana case in which an Indiana couple determined to withhold lifesaving treatment from their Down's syndrome infant. Another fear is that judgments about intolerable quality of life would mask social worth assessments along the lines employed by the Nazis in their euthanasia program. A surrogate's quality of life judgment evokes in some people the fearful notion of a life not worth living, a notion that would supposedly jeopardize the well being of helpless persons and undermine respect for the sanctity of life.⁵⁹

The spectre of abuse of quality of life judgments seems easy enough to curb in the context of previously competent persons. First, some people provide living wills or other prior expressions that articulate their personal vision of an intolerable quality of life -- a level of deterioration which that person would deem intolerably undignified. Implementation of a

person's expressed value preferences may not always be easy -- given the frequent imprecision of advance directives -- but surrounding medical personnel can at least use the prior expressions in monitoring surrogate decisions to assure that a surrogate is acting consistently with the now-incompetent patient's expressed values. Second, even without advance expressions, we know a lot about how competent people regard an intolerable quality of life for themselves, at least in certain post-competence scenarios. For example, polls and surveys consistently show that at least 90% of people would not want to be given life-sustaining medical intervention if mired in a permanently unconscious state. Similarly, most people recoil at the prospect of lingering in a barely conscious state in which they no longer recognize or interact in a meaningful fashion with their loved ones or surrounding caregivers.⁶⁰ And gravely debilitated patients may begin to act in ways so antithetical to their previous values and character as to support a surrogate's judgment that the previously competent patient would deem the deteriorated status intolerably undignified.⁶¹ The point is that surrogate decisionmakers have some foundation -- grounded either in the now-incompetent patient's personal preferences and values or in consensus preferences that people have toward their own prospective end-of-life treatment -- for making some judgments about an intolerable quality of life with regard to previously competent persons. Understandings about common preferences toward indignity in the dying process enable medical personnel to monitor the behavior of surrogate decisionmakers. Health care providers can refuse to cooperate with surrogate decisions that deviate either from the patient's demonstrated values or from common attitudes about indignity. Part of professional responsibility is to show fidelity to the patient's vision of a humane and dignified dying process.

The harder issue is whether sufficient understandings exist about the concept of

intolerable indignity as applied to profoundly disabled persons -- never-competent beings.

Certainly, dignity cannot mean the same thing for a never-competent, profoundly disabled person as for a previously competent person.⁶² Take incontinence as an example. That condition might represent utter humiliation for a competent or previously competent person, yet not embarrass or particularly trouble a profoundly disabled person. The same goes for extreme dementia. While a previously acute person might experience frustration, anxiety, and embarrassment from a precipitous decline in mental faculties, the lifelong profoundly disabled person might have no similar feelings.⁶³ Meaningful emotional relationships can exist for a person without even near-normal intelligence so long as some ability to interact with others is present.

Every person's concept of personal dignity is shaped in part by his or her circumstances and experiences. The New York State Task Force on Life and the Law comments in this vein: "While some adults who were once fully capable might not want to live with severe mental handicaps, adults who are profoundly retarded have never known or aspired to a different kind of life."⁶⁴ A person who has always had extremely limited cognitive function thus may have modest expectations about quality of life. Existence as a locus of pleasure and pain may fulfill their interest in dignity. Indeed, the concept of a minimally acceptable quality of life is entirely beyond the ken of a profoundly disabled person. In the absence of notions of intolerable indignity formed by the affected individuals themselves, or people similarly situated, how can surrogate decisionmakers apply the concept of indignity to profoundly disabled persons?

My response is that intrinsic human dignity can be sufficiently defined to play a legitimate, if limited, role in end-of-life decisionmaking on behalf of the profoundly disabled. Respect for all persons includes upholding their intrinsic or basic human dignity. The critical

task is to give content to the notion of intrinsic human dignity, in the sense of a minimally acceptable quality of life, without jeopardizing the well being of helpless human beings. Bruce Jennings suggests that any “dying person has a right to a certain quality of living while dying.”⁶⁵ I concur in his notion that certain dying conditions can be so inhumane as to constitute “a moral trespass upon personhood.”⁶⁶ And I agree that pain, suffering, intrusive bodily invasions, protracted physical restraint, and mental deterioration to a point of non-recognition of the surrounding environment are relevant indices in assessing intolerable trespasses upon human integrity.

A recent case illustrates the relevance of extreme indignity to a determination of best interests.⁶⁷ Nicholas Truselo, a 3 month old child, had suffered extensive brain trauma from an adult’s shaking (shaken baby impact syndrome). According to the physicians’ assessment, Nicholas would never be able to walk, speak, see, or communicate. He would be dependent on constant medical intervention. In deciding that Nicholas’ best interests dictated removal of life support (a ventilator and nasogastric tube), the court relied heavily on the child’s dismal quality of life. Judge Ableman explained:

Nicholas will never stand, sit, eat, walk, speak, read, write, think, or exist without constant care for even the most basic of life’s functions. He will be confined to his bed and will suffer constant lung infections because of his virtually non-existent gag reflex. He will never be able to communicate joy, fear, happiness, or sadness, will never be able to form relationships with others, and will live with tubes, machines, and other specialized medical care. He will never react to his surrounding environment, will never give or receive love, and may be subjected to substantial pain and discomfort. The physicians have evaluated the child’s condition and have concluded that a future sustained by radical medical treatment, and entailing virtually no quality of life, is not a valued alternative, despite its effectiveness in extending life or delaying death.

While Judge Ableman mentioned pain, it seemed to be indignity and quality of life that prompted his best interests determination. The most obvious element of indignity was Nicholas’ total

inability to relate to his environment.

The understandable apprehension -- already mentioned -- is that human dignity is too imprecise a concept to be useful, especially in the setting of end-of-life decisionmaking for a vulnerable population like the lifelong profoundly disabled. The concept of human dignity is used in diverse ways and in a variety of contexts. Some jurists, for example, see human dignity as a concept helping to shape several aspects of fundamental liberty -- for example, protection against excessively harsh punishment or against intolerable invasion of physical and emotional privacy. Justices William Douglas, William Brennan, and Thurgood Marshall often invoked human dignity as a basis for recognizing civil and political rights for which they were advocating, including freedom of expression and freedom of conscience. Other social observers use the concept of human dignity to evoke a utopian notion of affirmative social obligations toward disadvantaged communities, including provision of sufficient resources to allow maximum development of individual capacities.⁶⁸ Another vision of human dignity precludes using a person solely as a means to advance the well being of others. These diverse perspectives on human dignity confirm the elusiveness of the concept. Yet that doesn't mean that the concept is inherently unmanageable any more than other important but elusive notions such as liberty, justice, fairness, and equality. (Indeed, concepts of liberty, fairness, and equality have considerable application in American jurisprudence.)

One mark of the imprecision of the concept of human dignity is the fact that, in the context of end-of-life decisionmaking for incapacitated persons, human dignity is sometimes used to support diametrically opposed approaches. Take, for example, the handling of a patient who has permanently deteriorated to a point of semi-consciousness, no longer aware of, or

interacting with, his or her environment and dependent on artificial nutrition and hydration (ANH) for subsistence. One perspective is that this formally vital individual is being denied basic human dignity by continuation of life support and prolongation of a degrading dying process. The contrary perspective is that respect for human dignity -- the intrinsic worth and equality of every human being -- demands that nurture in the form of ANH be continued for the helpless being. Given such disparate views of human dignity, and given the pluralistic nature of American society, how can intrinsic human dignity be meaningfully used in end-of-life surrogate decisionmaking?

One useful source of content for intrinsic human dignity is constitutional jurisprudence. While the federal Constitution does not explicitly mention human dignity, the concept of human dignity provides an important “background norm” and aid in the interpretation of various constitutional rights.⁶⁹ An example is found in the jurisprudence surrounding the 8th Amendment’s prohibition of cruel and unusual punishment. In 1958, Chief Justice Warren called human dignity the “foundation” of the 8th Amendment and insisted that the amendment’s meaning must be drawn from “the evolving standards of decency that mark the progress of a maturing society.”⁷⁰ (Warren then ruled that government imposition of statelessness as a punishment involves such psychic torture as to be constitutionally impermissible). In 1976, the Supreme Court employed the human dignity norm in finding that a correctional institution’s deliberate indifference to a prisoner’s serious medical needs is violative of the 8th Amendment.⁷¹ These cases illustrate the close connection between human dignity and evolving constitutional norms shaped by decent and humane social treatment -- a theme repeated beyond the 8th Amendment context.

The link between intrinsic human dignity and constitutional jurisprudence appears in the application of other parts of the Constitution. The Fourth Amendment's ban on unreasonable searches and seizures evinces a concern with dignity reflected by the Amendment's restriction of government access to personal space and information. That dignity concern emerges particularly sharply in cases involving bodily integrity. In rejecting some government efforts to penetrate the body in order to secure criminal evidence, the justices have expressed strong solicitude for personal control over the private space that is the human body.⁷² The Supreme Court "sees human dignity implicated in government appropriation of the body by touching, undressing, or penetrating the body."⁷³ This is not to say that all government invasions of the body are constitutionally prohibited; cases upholding government intrusions such as vaccination and collection of blood samples (from drivers involved in accidents) contradict that notion. Yet even the cases upholding such intrusions recognize a close tie between human dignity and bodily integrity and therefore demand strong governmental justification before allowing bodily invasions.

A classic case, Rochin v. California,⁷⁴ illustrates that the judicial distaste for bodily searches is grounded on a dignity-based revulsion toward forced bodily invasions. In Rochin, police forcibly pumped the stomach of a suspected narcotics dealer in order to preserve evidence. The Supreme Court threw out the evidence not because of police disregard for the niceties of the Fourth Amendment warrant requirement, but because the police conduct "shocked the conscience." The forced stomach pumping was too revolting to the justices' sense of dignity. The Court's solicitude for bodily integrity (and associated dignity) as an element of liberty also surfaced in cases in the 1990's. Cruzan in 1990 and Glucksberg in 1997 together established that

a competent person has a right to reject even life-sustaining medical intervention. Part of the basis for that liberty is traditional respect for bodily integrity and accompanying revulsion toward the spectacle of forcing an unwilling person to receive treatment. Justice O'Connor explicitly commented on the human degradation associated with forced treatment in her concurring opinion in Cruzan and several other courts have noted how forced medical treatment offends basic human dignity.⁷⁵ The intolerable degradation stems from several elements - - the overriding of the patient's will, the unwanted bodily invasion, and the distasteful restraints necessary to overcome a resisting patient's will.

Of course, acknowledgment of an important interest in bodily integrity as an aspect of human dignity does not help much in understanding the scope of a profoundly disabled person's intrinsic human dignity. In the first place, no person's right to preserve bodily integrity is absolute. The same constitutional jurisprudence that recognizes an important interest in bodily integrity also recognizes that various competing interests can sometimes prevail in a balancing process. For example, public health can justify compulsory vaccination, public safety can warrant blood alcohol tests, and well-founded needs of law enforcement can sometimes justify searches of bodily cavities or even surgical intrusions. In those instances, competing interests override the normal revulsion toward forced bodily intrusions. More importantly, the welfare interests of an incapacitated person often provide a legitimate basis for overriding that person's will even if this entails what would otherwise be deemed an undignified and repulsive bodily invasion. Forced medication of mentally incapacitated persons whose conduct endangers themselves or others provides one illustration.⁷⁶ Another example is the common medical practice of providing critical treatment for a small child or a mentally disabled adult -- where

such treatment strongly advances the interests of the patient -- despite the patient's objections and even resistance. In short, while a profoundly disabled person has a strong dignity-based interest in bodily integrity, preservation of that person's life or promotion of that person's well being will often provide a sufficient justification for a forced bodily invasion. Again, the problem often boils down to the measurement and weighing of the profoundly disabled person's various interests, i.e., determining whether the burdens of continued existence (including impact from the contemplated medical intervention) outweigh the benefits.

Another link between human dignity and the Constitution emerges in the jurisprudence interpreting the meaning of Fourteenth Amendment liberty. In elevating certain personal prerogatives to "fundamental" liberty status, the Court has stressed constitutional respect for intimate choices "central to dignity and autonomy."⁷⁷ This theme has surfaced in the reproductive rights context (with its link to control over the human body) and in the right to reject life-sustaining medical intervention (with another link to bodily integrity).⁷⁸ In short, establishing that any particular aspect of self-determination or personal status is integral to human dignity provides a strong impetus for ranking that element high within the jurisprudence of constitutional liberty.⁷⁹

All this testifies to a strong connection between human dignity and constitutional jurisprudence implementing certain constitutional provisions. Is that jurisprudence, in turn, translatable into norms that could shape or inform a concept of intrinsic human dignity applicable to profoundly disabled persons whose medical fates are being determined by surrogates? To some extent, the constitutional treatment of dignity merely reinforces norms that already prevail in the medical decisionmaking context as discussed earlier under the heading of

measuring the patient's well being. One norm established there -- that persistent and unremitting suffering saps human dignity and can serve as an important guide to surrogate decisionmaking pursuant to a best interests standard -- is amply reinforced in the constitutional jurisprudence. The Supreme Court has relied in several contexts on the notion that extreme suffering intolerably degrades persons. For example, the unnecessary infliction of pain associated with failure to meet prison inmates' serious medical needs was a key element in the Court's determination that such failure could violate the 8th Amendment.⁸⁰ Concern about unnecessary suffering also prompted the comments by five Justices in Glucksberg in 1997 that any state barriers to effective pain relief would impinge on a dying patient's fundamental liberty interests and might even prompt a reconsideration of the Court's position that state bans on assisted suicide were constitutional.⁸¹ Some commentators have suggested that the concurring Justices in Glucksberg were implicitly announcing a constitutional "right to be free of unnecessary pain and suffering at the end of life."⁸² All this judicial sensitivity to extreme suffering confirms that best interests doctrine -- in allowing the withdrawal of life support from persons suffering irremediably -- draws on and is fully consistent with intrinsic human dignity. (The problem, as noted earlier, comes more in applying the doctrine -- i.e., in assessing when suffering outweighs any pleasures and satisfactions in a profoundly disabled person's existence).

The incapacitated patient's dignity interest complicates the balancing process entailed in the best interests formula. If a profoundly disabled patient is stricken with life-threatening cancer and will have to be physically or chemically restrained during administration of chemotherapy, how much should the offense to dignity count in the surrogate's decision whether to initiate treatment? Presumably, not much if the forced restraint will be temporary or sporadic

and much more if the restraint will be prolonged. Presumably, the offense to dignity should count more if the patient will experience frustration and anxiety from struggle against the restraints. The percentage chance of significant remission and the potential duration of remission are relevant variables as well. We know that the degradation of a forced bodily invasion does not always violate intrinsic human dignity, but sometimes it does.

So far, I have suggested that dignity matters for a profoundly disabled person even when that person cannot appreciate any affront to dignity. At the same time, I concede that the dignity interest is ordinarily so hard to quantify and to factor into the best interests formula that it would seldom be determinative of a dying person's fate. Are there circumstances where a never-competent person's status is so intrinsically demeaning that the dignity interest alone -- separate from any interest in avoidance of suffering -- would justify removal of artificial life support? I think that permanent unconsciousness represents one such circumstance. Permanent insentience -- permanent inability to relate to a person's environment, to interact with fellow humans, or to experience any of the pleasures associated with human existence -- constitutes an intrinsically undignified status for a human being. This is so whether the permanent unconsciousness comes about at the beginning of life, as with an anencephalic infant, or at its conclusion, as when a formerly conscious person deteriorates to a permanently vegetative state. In both instances, a surrogate decision to maintain artificial life support ought not be permissible because of the affront to intrinsic human dignity.

Some support exists for this notion of permanent unconsciousness as intrinsically undignified. Certainly, numerous cases -- starting in 1976 with the Quinlan case in New Jersey -- uphold surrogate determinations to end life support for permanently unconscious persons.⁸³

Sometimes, the articulated judicial rationale is that allowing the permanently insensate patient to die promotes that patient's best interests. Is that surrogate prerogative to end the permanently unconscious person's existence consistent with the customary legal requirement that surrogate action be confined to a person's best interests? Superficially, the answer would appear to be no, for a permanently unconscious person's interests, albeit extremely limited, would still seem to be in continued life. There is always some infinitesimal chance that a misdiagnosis has occurred or that a miracle will happen and the person will regain consciousness. The insensate person is not in pain (so far as known).⁸⁴ Moreover, while we assume that the person lacking neo-cortical function is experiencing no positive feelings, we cannot know that. Withdrawal of life support does not seem to advance the tangible best interests of a permanently unconscious person. If not best interests, what accounts for a surrogate decisionmaker's legal prerogative to let the permanently unconscious person die?

As to formerly competent persons now mired in permanent unconsciousness, the justification for surrogate decisions to remove life support can be found in an effort to honor the patient's likely preferences. Numerous surveys, as well as examination of preferences expressed in advance medical directives, establish that the vast majority of competent persons would not want to be maintained in a permanently unconscious state. A decision to remove life support from a permanently unconscious, previously competent person therefore accomplishes what that person would very likely have wanted to be done in the circumstances. In effect, the surrogate is effectuating the previously competent patient's autonomy interest as best that can be done -- by making a substituted judgment about what the now-incompetent patient would want done if able to choose. In the absence of explicit instructions or other indicia of the now-incompetent

patient's actual wishes, the best way to honor self-determination is by constructing the patient's likely preferences based on knowledge of what most people would want in the circumstances.⁸⁵

An alternative explanation for removing life support from a permanently unconscious person might be that the interests of loved ones in avoiding the emotional and financial costs of a protracted death watch justify the decision to terminate care. Some commentators assert that the interests of others, such as surrounding family and care givers, account for judicial willingness to endorse removal of life support from permanently unconscious persons. No court articulates that rationale, though it would be consistent with my suggestion later that the interests of third parties influence surrogate "best interests" determinations at the margins. The margin here is permanent unconsciousness, a point where the patient's actual interests (including a tiny chance of regaining consciousness) are problematic at best. As to previously competent persons, this marginal consideration of loved ones' interests is also consistent with the patients' likely wishes. (Most people don't want their loved ones to be subjected to heavy burdens during a protracted death watch while the dying person is in a permanently unconscious state).

I have another explanation for the wide acceptance of surrogate decisions to remove life support from permanently unconscious persons, even from persons such as children or profoundly disabled beings who have never been competent. My view is that permanent unconsciousness is an intrinsically undignified state for any human being, so that being allowed to die is respectful of the unconscious patient's human dignity. Judges understand the intrinsic indignity of a permanently unconscious status and are therefore willing to uphold surrogate decisions to withdraw further treatment in that circumstance. Some cases involving permanent unconsciousness explicitly cite quality of life and human dignity while endorsing removal of life

support.⁸⁶ I would also suggest that surrogate respect for intrinsic human dignity is part of a never-competent patient's interests even if the patient can no longer experience the consequences of demeaning treatment. Indeed, respect for human dignity is what insulates the never-competent patient from regularly being subjected to bodily invasions such as tissue harvesting or hazardous medical experimentation that would benefit others.⁸⁷ In short, the legal handling of end-of-life decisions on behalf of permanently unconscious patients accords those patients full moral status (by implementing intrinsic human dignity) even though the surrogate is permitted to let the patient die.

If a permanently unconscious status is intrinsically undignified, is a surrogate obligated to opt for removal of life support from such an incapacitated ward? The answer under prevailing law and custom is clearly no. The Cruzan case, discussed earlier, upheld Missouri's insistence that Nancy Beth Cruzan's permanently unconscious life be preserved (absent clear evidence of her contrary wishes). And the Baby K case upheld a mother's determination to continue life support to her anencephalic infant. While numerous cases and statutes uphold a surrogate decision to remove life support from a PVS patient, none declare that a surrogate must follow that course. Estimates are that thousands of PVS patients are regularly maintained in the United States by continued medical intervention. All this confirms that current law does not regard a surrogate's conduct as abusive if the surrogate chooses to preserve a permanently unconscious patient's existence.

My own position diverges from the prevailing law. Because I regard permanent unconsciousness as intrinsically undignified, I would make removal of life support from a permanently unconscious person mandatory unless, in the case of a previously competent patient,

that patient had indicated a wish to be preserved in such a demeaning status. My exception for the expressed will of a previously competent person is debatable. Sometimes, when society outlaws an inherently inhumane practice such as slavery, it allows no exceptions for consent. On the other hand, we sometimes allow people to choose conditions that most other people would regard as intrinsically demeaning. Lois Shepherd points out that people can choose to be undignified -- for example, by groveling.⁸⁸ People can self-submit to horribly inhumane relationships. And people whose religion or philosophy values all human life, no matter how degrading, ought probably to be able to choose preservation in a permanently unconscious state. (This is so as long as their resources last; I am not suggesting that public funds must be devoted to preserving a permanently unconscious state). In the absence of such personal choices to accept what is generally regarded as an undignified status, I would require that a surrogate respect intrinsic human dignity by allowing a permanently unconscious person to die.

My suggested framework would make the controversial Wanglie case correctly decided. There, a husband as guardian successfully fought to maintain ANH for his permanently unconscious 86 year-old wife. (The wife's hospital had sought a court order to remove the husband as guardian on the basis that he was improperly insisting on "futile" care for his wife). The judge upheld the husband's guardianship because the husband purported to be implementing his wife's articulated religious beliefs that all life is sacred and ought to be preserved. Under my suggested framework, Ms. Wanglie's religiously based preference was properly upheld even though it involved submission to an intrinsically undignified status. If she never made such a choice or never embraced such values, then her husband should indeed have been removed as guardian and Ms. Wanglie should have been relieved from her intrinsically undignified state by

removal of life support.

Notice that the option to extend a permanently unconscious existence would not apply to a never-competent person, a lifelong profoundly disabled person. Denial of an option of choosing (more precisely, having a surrogate make a choice on the disabled patient's behalf) an intrinsically undignified existence does not seem to me to be a serious disadvantage or harm. The denial reflects a notion that no one ought to be subjected to an intrinsically undignified status without explicit consent. A choice of degradation can only be made volitionally (just as a choice of marital partner can only be made volitionally and is therefore excluded from surrogate control). Generally, the difficulty of defining intrinsic indignity for a never-competent person protects that person against premature termination of life support. The profoundly disabled person "benefits" from a tighter standard of indignity than that applied to a previously competent person. That is, a possibly degrading condition -- like extreme dementia or incontinence -- is more likely to be deemed intolerably undignified pursuant to the actual values of a previously competent patient or pursuant to constructive choice on behalf of a previously competent person than by notions of intrinsic indignity. In other words, any notion of intrinsic indignity covering a never-competent person would be narrow. So far, only a few conditions -- permanent unconsciousness, mental decline to a semi-conscious state where the person can no longer recognize and relate to others, and serious irremediable suffering -- might be classified by reference to contemporary norms as an intrinsically undignified status. And current law and practice have not yet reached a consensus even as to permanent unconsciousness.

Admittedly, my approach to intrinsic indignity -- making removal of a permanently unconscious patient's life support mandatory (absent contrary preferences by a previously

competent person) -- is contrary to prevailing practice. Perhaps it is unrealistic to expect society to label artificial preservation of life support as an inhumane, intrinsically demeaning practice -- at least in any circumstance other than extreme, unremitting suffering. Government is understandably hesitant to impose its views of intrinsic indignity when the consequence is to force the death of live beings (by removal of life support). This is especially so in a pluralistic society where cultural and religious attitudes toward permanently unconscious beings may vary. But perhaps it is only a matter of time. A societal consensus has been reached that a human being is dead when all brain function has ceased, even though nails and hair continue to grow and hormonal secretions take place and the heart and lungs could continue to function for months or years via artificial maintenance. A similar consensus may evolve that permanent unconsciousness (with no upper brain function), while not identical to death, constitutes an intrinsically undignified existence that ought not be artificially extended.⁸⁹

Must Medical Decisions Be in the “Best” Interests of a Profoundly Disabled Person?

The typical understanding is that a best interests judgment requires maximizing the helpless ward's interest or determining “the highest benefit [for the ward] among available options.”⁹⁰ I suggest that definition is not always accurate. Although “best interests” is the common watchword when government acts within its *parens patriae* authority to supervise the handling of helpless populations, a surrogate decision on behalf of a profoundly disabled person does not always have to be the best choice for the disabled person. Sometimes, a surrogate determination need only be reasonably consistent with the interests of the disabled person -- an appropriate choice within several acceptable options. And sometimes a surrogate's determination need meet an even less restrictive standard -- that the determination not be abusive

in the sense of subjecting the dependent person to serious risk of harm. The most obvious situation where a less restrictive standard than “best” interests applies is where a profoundly disabled person is being cared for at home, i.e., is being raised as part of a family unit by a parent or parents.

American custom and law give parents considerable dominion over their children. In part, this tradition is grounded on the assumption that parents will generally act benevolently toward their children.

The law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More importantly, historically it [the law] has recognized that natural bonds of affection lead parents to act in the best interests of their children.⁹¹

But neither law nor tradition compel parents to adhere to a child’s best interest. In myriad circumstances, parents are free to disadvantage or even harm a child without violating legal bounds.

One area in which parents are free to deviate from their children’s best interests relates to child custody itself. Numerous decisions confirm that natural parents are entitled to custody even where their children’s interests would be better served by remaining with foster parents or with aspiring adoptive parents.⁹² A similar parental prerogative to deviate from best interests (in a fashion short of serious neglect or abuse) applies to a multitude of child-rearing decisions. This principle covers formal and informal education, social interactions, allocation of household responsibilities, and distribution of rewards, benefits, and sanctions within the family. “Even though we often talk about doing what is best, it is clear that the courts and the American public do not really believe that such a high standard is necessary or even appropriate.”⁹³ Parental autonomy allows subordination of the best interests of a child to family well being, to sibling

well being, to religious dictates, or to philosophical preferences guiding parental dominion (again, short of serious neglect or abuse). The Supreme Court has acknowledged this societal deference to parental control:

[T]he best interests of the child is not the legal standard that governs parents' or guardians' exercise of their custody: so long as certain minimum requirements of child care are met, the interests of the child may be subordinated to the interests of other children or indeed even to the interests of the parents or guardians themselves.⁹⁴

Many rationales support the social policy of broad deference to parents in child rearing. As noted, there is an underlying assumption that parents will generally act in a benevolent fashion toward their offspring. At the same time, parental control of child rearing advances a social interest in pluralism -- an interest in cultivating a diverse range of cultural and ideological perspectives.⁹⁵ Parental control is also perceived as an efficient mechanism for raising children. The practical reality is that government would not have the resources to control child-rearing decisions even if it thought that it could do a better job than many parents. And there is considerable doubt whether government could or would do a sounder job of child rearing (or of close supervision of child rearing) even if it possessed the resources for such an undertaking.⁹⁶ In short, parental autonomy serves a useful social function in facilitating the upbringing and socialization of successive generations of citizens.

The federal Constitution also insulates parental decisionmaking in some measure from governmental interference. Parental autonomy in child rearing is recognized by the Supreme Court as a fundamental aspect of liberty under the Fourteenth Amendment. The Court's solicitude for the parental role dates back to its 1923 decision in Meyer v. Nebraska⁹⁷ striking down a state law prohibiting both the teaching of a subject in a foreign language and the teaching of a foreign language and acknowledging the important parental liberty interest in raising

children. Although Meyer was a product of an era of aggressive judicial intervention confining governmental management of economic and social affairs generally, its solicitude for parental autonomy has endured. Supreme Court opinions continue to acknowledge “a fundamental liberty interest of natural parents in the care, custody, and management of their children.”⁹⁸

The most recent confirmation of parents’ fundamental right “to make decisions concerning the care, custody, and control of their children” came in April 2000 in Troxel v Granville.⁹⁹ There, the Court considered a parent’s substantive due process challenge to a Washington statute permitting “any person” to petition for a visitation order (in the face of parental opposition to such visitation) and authorizing a judge to grant visitation if the court determines that visitation would serve the best interests of the child in issue. The Washington courts had struck down the statute as an impermissible interference with parental liberty both because it allowed any person to petition (not just an especially bonded or connected person) and because it supplanted parental judgment without any prerequisite finding of significant harm to the child flowing from the parental decision regarding visitation. By a 6 to 3 margin, the U.S. Supreme Court ruled that the Washington statute was unconstitutional, at least as it had been interpreted and applied in the case at hand. Justice O’Connor spoke for a four justice plurality in Troxel. She declined to decide whether the due process clause requires a threshold showing of substantial harm before a court can constitutionally interfere with a parental decision regarding visitation. She did find a constitutional defect in the statute’s failure to give any “special weight” to the parental determination about the advisability of visitation.¹⁰⁰ Justice O’Connor declared that the due process clause precludes state interference with childrearing simply because a judge believes that a better decision than the parent’s could have been made. In other words, the

Washington statute's deficiency was its failure to accord any deference to the parental judgment regarding visitation to children.¹⁰¹

Constitutional jurisprudence regarding parental decisionmaking is somewhat in disarray.¹⁰² In theory, parental autonomy, as a fundamental liberty, is insulated against government interference unless government meets a strict scrutiny standard of judicial review -- a standard requiring government to demonstrate a compelling interest in the particular interference and a showing that the government intervention is carefully tailored to accomplish its object. Yet in application of constitutional doctrine the Court has sustained a wide variety of state impingements upon parental autonomy aimed at promoting children's welfare or public health. A constant tension exists between judicial concern for parental liberty to control the family and judicial respect for various other interests including the state's *parens patriae* role as protector of children's welfare. Judicial respect for government's *parens patriae* role has contributed to the Supreme Court's upholding of compulsory education, compulsory inoculations, and prohibition of child labor, to cite a few interferences with parental control that have withstood constitutional challenge. In such instances, the Court seems to resolve the tension between parental autonomy and children's welfare with an ad hoc balancing approach rather than a careful application of strict scrutiny doctrine.

Another interest justifying interference with parental dominion is promotion of older children's self-determination. Some states have sought to promote the self-determination interests of adolescents and teenagers by creating a "mature minor" exception to the normal parental prerogative to control health decisions on behalf of children.¹⁰³ Some states have also encouraged physicians to provide certain sensitive treatments, such as for venereal disease and

substance abuse, without parental authorization.¹⁰⁴ And the Supreme Court has given mature minors a constitutional right to control their own fates regarding abortion.¹⁰⁵

The bottom line appears to be that government may interfere with parental dominion in order to advance a variety of significant interests, especially children's welfare. To answer the question posed but left unanswered by Justice O'Connor in Troxel, states are probably not constitutionally required to demonstrate particularized, substantial harm to children as a prerequisite to interference in parental control of child rearing. The state may make categorical interventions to protect children's well being, as in the case of child labor laws and as in the case of a ban on parental consent to non-therapeutic medical experimentation carrying more than minimal risk for never-competent patients.

What implications flow from this constitutional jurisprudence upon parental control of medical decisions regarding children obviously incapable of making their own medical decisions? In large part, states conform to the constitutional framework by recognizing a fundamental liberty interest in child rearing and leaving medical decisions in the hands of parents. Absent an emergency situation, medical personnel commit a battery (a tortious touching) by performing medical procedures without parental consent. This principle applies to a wide range of medical interventions from medication for small problems to surgical invasions for serious conditions-- subject to the forementioned exceptions for mature minors and for certain sensitive medical issues such as abortion.

Note that the parental prerogative to control medical decisions for minors (as recognized in state jurisprudence) does not ordinarily confine parents to choosing treatments in the best interests of the child, i.e., the objectively best medical course. As many commentators have

recognized, medical circumstances often yield a range of plausible approaches;¹⁰⁶ parents are certainly entitled to select from this range of reasonable medical responses. But the deference toward parental choice goes further than this in many jurisdictions. Some courts uphold parental choice among alternative approaches so long as the chosen course is “not totally rejected by responsible medical authority.”¹⁰⁷ This means, for example, that a parent of a profoundly disabled child can opt for a more dangerous, professionally disfavored course of medical intervention because it would be more palatable to the child (more sensitive to the child’s emotional well being).¹⁰⁸ Other jurisdictions express their deference to parental medical decisions by refusing to intervene unless a decision is “clearly contrary” to the child’s best interests.¹⁰⁹ Most jurisdictions make government interference with parental medical decisions contingent upon a showing of serious harm to the child,¹¹⁰ meaning harm serious enough to constitute child neglect or abuse. This approach recognizes “the paramount right of parents to decide questions affecting the welfare of their children until such right is forfeited by neglect.”¹¹¹

This state deference to parental decisionmaking leaves limited room for parents to interpose religious and cultural beliefs (and perhaps familial interests) into medical decisions on behalf of their children. For example, a Jehovah’s Witness parent opting for bloodless surgery (meaning no transfusion of blood products) may be selecting a medically disfavored course in order to save the child patient’s soul by obeying what the parent perceives as a divine injunction. States tolerate such an option so long as the choice does not seriously threaten the child’s life or well being to the point of constituting child neglect. Many states explicitly provide some sort of exemption from child abuse prosecution for parents opting for spiritual healing techniques.¹¹² Parents opting for circumcision of their infants provide another illustration of tolerable parental

choices influenced by religious or cultural values that deviate from a child's best medical interests.¹¹³ Again, so long as serious harm to the child is not threatened, parents are generally allowed flexibility in making medical choices for their offspring even if the choices deviate from the child's best interests.

In contrast to this deference to parental choice in a wide range of medical decisions, states commonly identify certain classes of "critical" medical decisions where a strict best interests standard is judicially applied. These critical determinations include abortion, sterilization, organ or tissue donation, and (in most instances) withholding or withdrawal of life support. These areas are singled out as problematic either because of the intrinsic danger (withdrawal of life support and electroconvulsive therapy), concern about obvious conflicts of loyalties (organ donations to siblings), a history of exploitation surrounding the medical procedure (sterilization), or the critical constitutional interest at stake (abortion). Parental choice is displaced in these areas (with the exception of end-of-life decisions in many jurisdictions) and the critical medical decision is assigned to the courts. Judges, in turn, are supposed to make an independent determination of the child-patient's best interests -- meaning selection of the best course for the child -- before authorizing one of these controversial medical interventions. Even when a critical medical issue is left to parents rather than a court -- as is the case with end-of-life decisionmaking in many jurisdictions -- the articulated standard is usually declared to be best interests of the patient.

Sterilization decisions on behalf of disabled persons provide an illustration of judicial application of a strict best interests standard. The shady history of eugenic sterilization, with senseless sterilization of thousands of Americans between 1907 and 1950, is well known. That

history explains the judicial rejections of non-voluntary sterilization that prevailed in the 1960's and 1970's. The judicial attitude subsequently changed in response to petitions by parents seeking authorization for sterilization not for eugenic reasons, but supposedly because the mentally disabled person's own interests would be served. And when judicial receptiveness to surrogate petitions for authorization of sterilization emerged after 1980, it was accompanied by strict procedural and substantive safeguards aimed at ensuring that sterilization would be authorized only when the disabled patient's interests so dictated.¹¹⁴ Under this post-1980 jurisprudence, sterilization could be authorized only after a judicial hearing at which the disabled person was represented by counsel and after expert medical input regarding the patient's welfare with and without sterilization. Courts articulated various areas of inquiry to guide the judicial determination, including probability of pregnancy and availability of alternative contraceptive means. Most critically, the presiding judge could only authorize sterilization upon finding clear and convincing evidence that sterilization would be in the disabled person's best interests.¹¹⁵ A few jurisdictions went even further and insisted upon a finding of "medical necessity" as a prerequisite to sterilization.¹¹⁶ Most courts have also articulated a strict best interests of the patient standard in determining whether to authorize organ and tissue donations from decisionally incapacitated patients. Even the few courts articulating a substituted judgment standard for purposes of authorizing an organ donation have ended up applying a best interests standard -- a standard requiring a determination that the donating patient will incur a net benefit despite the risks involved.

Another area where courts have tended to articulate a strict best interests standard to guide non-judicial surrogate decisionmakers is withdrawal of life-sustaining medical

intervention. While most jurisdictions allow private decisionmaking (usually by next of kin acting in conjunction with medical personnel) rather than insisting upon judicial determinations regarding end-of-life decisions, courts often impose a decisionmaking standard of clear and convincing evidence that cessation of life support is in the best interests of the patient.¹¹⁷ This is so as to previously competent persons who have not left indicia of their post-competence treatment preferences, and it is especially so for never-competent persons (who could not have issued prior instructions). A best interests standard fixes the requisite finding for the surrogate as clear and convincing evidence that the burdens of continued existence outweigh the benefits. A few sources see the clear and convincing standard as a constitutional requirement,¹¹⁸ but most see that standard merely as an understandable (but not constitutionally required) precaution to safeguard the lives and well being of vulnerable patients.¹¹⁹

While the clear and convincing evidence standard is a well-intentioned device, its necessity or advisability in all end-of-life situations is quite debatable. As I explained earlier, discerning and measuring the actual burdens and benefits being experienced by profoundly disabled persons is a daunting task. It is not clear that net suffering can be clearly and convincingly demonstrated in very many situations.¹²⁰ A natural response to this fact might be: “fine, if you can’t confidently say that a person’s suffering markedly outweighs his or her satisfactions, then keep that person alive.” Yet keep in mind a point made earlier -- that quality of life, in the sense either of avoidance of irremediable suffering or avoidance of an intolerably undignified status, is often the determinative factor shaping end-of-life treatment. Both of these elements arguably point toward some leeway in a bonded surrogate’s decision. Perhaps, as some commentators have suggested, surrogates with close bonds to their wards have an instinctive

sense of whether their loved ones are suffering irremediably or whether they have reached a point of such extreme deterioration and indignity that they are better off dead than alive. Perhaps it should be sufficient as a prerequisite to surrogate authorization of removal of life support for a surrogate to be able to reasonably say (subject to scrutiny by surrounding medical personnel and even an institutional ethics committee) that the dying patient has permanently declined to a point where continued medical intervention violates intrinsic human dignity. (Keep in mind the earlier point that the concept of intolerable indignity for a never-competent person is not the same as that for a formerly competent person. The concept of intrinsic indignity for a never-competent person is narrow, and must be cautiously applied).

Some relaxation of the strict requirement of clear and convincing evidence of net suffering seems to have occurred in many jurisdictions, at least with regard to the status of permanent unconscious persons. A surrogate is allowed to forgo life support for a permanently unconscious patient even though there can be no pretense that the burdens of the patient's continued existence clearly outweigh the benefits.¹²¹ The law accepts permanent unconsciousness as an area in which a surrogate is allowed to say that a person's deterioration is so extreme that the person would be better off dead than alive. (I have argued that offense to intrinsic human dignity explains that conclusion). Commentators like Nancy Rhoden have convincingly argued that there should be other gray areas in which a bonded surrogate's judgment ought to be upheld unless some challenger (family member, health care provider, or member of a protective agency) shows that the surrogate judgment is unreasonable.¹²² The point is that "clear and convincing evidence" that burdens exceed benefits may be an overly stringent standard as applied to gravely debilitated dying persons.

A similar point can be raised about the standard guiding sterilization decisions on behalf of profoundly disabled persons. Numerous cases dictate that the burden of proof on any surrogate seeking sterilization is a showing of clear and convincing evidence of best interests.¹²³ The widespread judicial invocation of a “clear and convincing evidence” requirement was based on the perception that sterilization entails a permanent impingement of a person’s fundamental liberty interest in procreation.¹²⁴ That perception is sound with regard to the range of mildly or moderately disabled people who may be capable of child rearing. But a profoundly disabled person -- the subject matter here -- is incapable of assuming the role of a parent and raising a child. Absent that child-rearing capacity, sterilization does not deprive a person of a fundamental interest in procreation.¹²⁵ For a profoundly disabled person, the decision regarding sterilization is like any serious medical decision. It involves a serious bodily invasion and carries certain risks, and a surrogate (a court under prevailing practice) must make a judgment whether the potential gains warrant those negative consequences. The potential gains for a profoundly disabled person may include freedom from an incomprehensible burden of gestation, labor, and childbirth, and sometimes freedom from intrusive personal monitoring interfering with sexual activity.¹²⁶ Arguably, a court (or other surrogate) ought to be able to decide by a preponderance of the evidence (rather than clear and convincing evidence) that pregnancy and birth carry greater detriments for the profoundly disabled person than tubal ligation. The preponderance of the evidence standard is employed by at least a few courts already.¹²⁷ Again, the idea is not to discard the best interests standard as a determinative guideline, but to employ a lesser requirement of proof than clear and convincing evidence in light of the unavoidable indeterminacy of some medical issues.

Can the Interests of Others be Included within a Patient's Best Interests?

The previous section showed that critical medical decisions affecting profoundly disabled persons -- including end-of-life decisions, sterilization, organ donation, and abortion -- are supposed to be made according to a best interests of the patient standard. (This was so even though a surrogate is not always confined to the very best choice). This section considers to what extent, if any, the interests of others, particularly a loving family, might enter into a calculus of the patient's interests.

Competing family interests arise and have obvious appeal to a surrogate decisionmaker in a variety of circumstances. For example, when the medical issue is maintenance of life-sustaining treatment for a profoundly disabled, dying patient, emotional trauma being experienced by surrounding loved ones is a potential consideration. The emotional stake of family could potentially influence the surrogate's decision in either direction -- toward premature termination of life support or toward unwarranted extension of life support. A desire to relieve extreme emotional, physical, and/or financial burdens on a family conducting an agonizing death watch might tempt a surrogate to withdraw life support earlier than would otherwise be the case. On the other hand, family guilt or grief or unwillingness to come to terms with the impending death can provide an incentive for prolonging the patient's dying process beyond a humane point.

Competing family interests are apparent in other medical contexts as well. When a surrogate contemplates an organ or tissue donation from a healthy, profoundly disabled person to a critically ill sibling, the life of that sibling and the welfare of the family as a whole loom as factors that might influence a decision to impose risks and burdens on the disabled donor. When a surrogate contemplates sterilization for a profoundly disabled person, potential family interests

also arise -- including the burden of monitoring the patient's behavior absent sterilization and even the possible burden of child rearing should the disabled patient ultimately become a parent. One question, then, is what role, if any, these understandable and pressing family interests can legitimately play in deciding the medical fate of a profoundly disabled patient.

Family interests are not the only possible distractions from focus on a mentally disabled person's best interests in the context of medical decisionmaking. When the issue is sterilization or abortion, for example, social interests are arguably implicated.

Public concerns about reproduction by mentally disabled persons impacted public policy in the United States for many years. A eugenic rationale was the impetus for the state statutes that in the first half of the twentieth century impelled sterilization of many thousands of institutionalized disabled persons. That is, the object was to protect and improve society by preventing reproduction on the part of those persons deemed likely to produce mentally disabled offspring. Recall Justice Holmes' famous 1927 comment that three generations of idiots were enough. As late as 1962, a court authorized sterilization of a retarded person on the basis that the welfare of society would be promoted by the avoidance of more retarded children.¹²⁸ In short, social welfare, not the welfare of the affected individual, accounted for the original utilization of non-voluntary sterilization.

The eugenic rationale for sterilization is now a thoroughly discredited relic. While Buck v. Bell has never been explicitly overruled, the widespread understanding among legal scholars is that sweeping laws targeting the mentally disabled for sterilization -- as employed during the first half of the twentieth century -- are surely unconstitutional.¹²⁹ Focus has shifted from laws mandating sterilization in order to improve the gene pool to individualized judicial determinations

of whether a sterilization procedure promotes the best interests of a disabled person. Petitions for judicial authorization of sterilization came to be brought by parents or other guardians asserting that sterilization would be in the best interests of their disabled wards. The earliest judicial appraisals of best interests tended to be skeptical about the motives for petitions and in the late 1960's and 1970's a number of state courts refused to authorize sterilization of retarded persons in response to petitions by parents.¹³⁰ Several factors influenced these decisions -- revulsion at the sorry history of eugenic sterilization, concern for protecting the emerging constitutional liberty interest in procreation, and fear that common prejudices about disabled persons would prompt abusive sterilization decisions.¹³¹

In the 1980's, the common judicial attitude shifted perceptibly. More and more state courts ruled that judges had *parens patriae* power (grounded in their intrinsic equity jurisdiction) to authorize sterilization so long as such a surgical procedure was found to be in the best interests of a profoundly disabled person.¹³² And while the courts didn't always grant a parental petition, they did recognize that certain factors sometimes make sterilization consistent with the disabled person's own interests. A disabled person might have a medical condition that would make pregnancy and/or childbirth either a hazardous or torturous process. Or pregnancy, labor, and delivery might have grave emotional consequences for a profoundly disabled woman having no grasp of the concept of pregnancy and its natural outcome. Or a profoundly disabled person may have an interest in sexual interactions free from the intrusive monitoring that would be necessary if effective contraception were not in place. Such factors might, depending on the circumstances, justify a sterilization procedure despite the attendant bodily invasion, pain, medical risks, and impact on future procreation. And the public has a pecuniary interest in all forms of contraceptive

decisions where either the medical procedure will be financed by public funds or where any offspring will become public charges. While a person's liberty interest in procreation is constitutionally protected, it is surely less robust where the potential parent is clearly incapable of raising a child. In order to safeguard against biased or exploitative sterilization decisions, the courts prescribed careful procedures for determining the potential patient's best interests, including a full hearing, legal representation for the disabled person, full medical investigation, and clear and convincing evidence that sterilization would indeed be in the patient's interests because less invasive contraceptive alternatives were absent.

These precedents demonstrate judicial recognition that a disabled person's own interests can sometimes dictate sterilization. They also state that the interests of third parties -- parents, institutional personnel, or society as a whole -- cannot properly enter into a best interests calculus. But they do not address whether there is a valid theoretical justification for injecting third party interests into surrogate medical decisionmaking on behalf of never-competent persons. I will briefly consider whether such a theoretical underpinning exists.

One claim for inclusion of third party interests is that justice or fairness requires it. John Hardwig is the principal advocate for that proposition.¹³³ Hardwig argues that where families have struggled and sacrificed for the incapacitated patient (and where a medical decision entails burdens upon the surrounding family), fairness and equity demand consideration of family interests along with those of the patient. For him, the surrogate decisionmaker should "harmonize and balance" family interests in order to avoid the "injustice" of an exclusively patient-centered ethic. Such consideration of family interests would have impact in many circumstances, including a situation where caring for an infant born with multiple deficits would impose considerable

emotional and economic costs on parents and siblings.¹³⁴

A similar argument (that considerations of fairness or justice warrant attention to third party interests) can be constructed when a surrogate is contemplating sterilization for a profoundly disabled person. For example, where the disabled person is living at home, absence of effective contraception may significantly increase the supervision or monitoring burden upon devoted caretakers already expending considerable efforts on behalf of the disabled person.¹³⁵ Or where a disabled person is incapable of child rearing, so that any child born to that person will end up being the responsibility either of the disabled person's parents or state social service agencies, there's room for a claim that fairness dictates attention to third party interests (including the well being of the helpless prospective child) in weighing the possibility of sterilization.

A justice rationale for injecting other parties' interests into determination of an innocent and helpless person's medical fate is questionable. Justice does not demand that a caretaker be free of all onerous burdens. The potential for "unfair" burden is implicit whenever a person assumes a relation entailing responsibility for another person. This is so for a guardian, a spouse, a parent, or even a teacher. In all these situations, the burdens of caretaking sometimes turn out to be disproportionate to the benefits. A once satisfying marital relationship may be rendered torturous as a result of an accident making one spouse totally dependent on the other. This may be unlucky for the person suddenly saddled by caretaking, but perhaps it's not unjust for a spouse or parent to be saddled with unexpected burdens. Justice cannot mean that burdens within a relationship must mesh perfectly with deserts. Persons entering into these fiduciary relationships understand at the outset that burdens may turn out to exceed any anticipated rewards. Also, the person whose serious medical fate is being determined is usually an innocent victim of some

serious affliction (as opposed to someone who is simply being self-indulgent).

Another concern about achieving justice under John Hardwig's approach is that it ostensibly would entail a difficult and unseemly calculus by any surrogate decisionmaker. Hardwig's fairness calculation involves a case by case assessment of the degree of burden and sacrifice previously or prospectively invested by the third party (family member) whose interests are to be considered.¹³⁶ For Hardwig, a parent who has previously been inattentive toward a child does not deserve much solicitude in determining whether the burdens of future care might be "unfair." Yet this kind of inquiry into relational history is arguably unseemly and not well suited to the surrogate or to medical personnel attending the incapacitated patient whose fate is being determined. There is also the problem of incommensurability. In the end-of-life decisionmaking context, for example, how much do physical and emotional tolls on surrounding family count when weighed against a period of debilitated, but tolerable existence for the dying patient? It is hard enough to determine the net interests of the patient without bringing third party burdens into the best interests formula.¹³⁷

An alternative rationale for consideration of third party interests is fulfillment of the putative wishes of the disabled patient. Both the President's Commission for the Study of Ethical Problems in Medicine and the New York Task Force on Life and the Law -- two of the most distinguished bodies that have analysed end-of-life decisionmaking -- have suggested that a best interests decisionmaking formula might accommodate third party interests on the theory that the now-incapacitated patient would want burdens on loved ones to come into play.¹³⁸ This approach certainly makes sense where the patient was previously competent and articulated his or her concern for loved ones when contemplating a future dying process. The patient's prior attitude

toward familial interests counts either under a substituted judgment approach (trying to replicate the patient's wishes) or because the patient's articulated values and preferences help to shape the content of that patient's best interests.¹³⁹ As to a previously competent patient, it might also make sense to consider family interests even if the patient has not previously expressed that wish, on the theory suggested by the New York State Task Force that most people have such strong solicitude for their immediate families that they would want such interests to be considered.¹⁴⁰ Some surveys of seriously ill people's preferences for their own end-of-life handling do show strong concern for the physical and emotional burdens to be posed for surrounding loved ones.¹⁴¹ Thus, there is some empirical support for the Task Force's rationale.

Whatever the appeal of using family interests as a decision-making factor with regard to previously competent patients, it's problematic to ascribe to lifelong profoundly disabled persons an altruistic wish to have the interests of loved ones considered in critical medical decisions. I have already rejected a substituted judgment formula in this decision-making context because profoundly disabled persons never had the capacity to form determinative wishes on complex issues of medical decisionmaking. That incapacity applies to the task of weighing third party interests against the patient's own well being. As Margaret Battin has noted,¹⁴² altruism that deserves respect is the product of deliberation about the positives and negatives of self-sacrifice. The attribution of a wish to show consideration for the interests of others is a convenient fiction in the context of never-competent persons.¹⁴³ There may be good reasons to consider third party interests along with the profoundly disabled patient's, but fulfillment of putative wishes is not one of them.

Third party interests may incidentally enter the picture of surrogate decisionmaking when they happen to coincide with an incapacitated patient's own interests. There are a few situations

where the interests of a profoundly disabled person can be materially advanced by an action that immediately benefits a surrounding family member. This is sometimes the claim, for example, where parents seek to harvest a non-vital organ from a profoundly disabled person; assertedly, the disabled person would be harmed by failure to donate the organ because that person would lose a devoted caretaker (the organ donee) or because the family would be so devastated by the loss of a family member that the disabled donor would suffer. Or a family might claim that sterilization is in the best interests of a disabled person because otherwise the family unit would be severely disrupted by the burden of supervising the disabled person's sexual behavior; family peace of mind then supposedly furnishes a benefit to the person slated for sterilization.¹⁴⁴ These claims warrant consideration by a surrogate decisionmaker, as there are indeed instances when the interests of the incapacitated patient and the affected family members coincide. But in the absence of such circumstances where the disabled person benefits derivatively from accommodation of loved ones' needs, attribution of altruistic wishes to the profoundly disabled patient or inclusion of third party interests within the patient's interests rings hollow.

What do the cases and commentators say about the relation between a mentally incapacitated patient's medical fate and third party interests? The issue has perhaps received the most attention in cases addressing surrogate decisionmaking on behalf of previously competent persons. In that context, some courts do suggest that the interests of a now-incapacitated patient's family are an appropriate part of the surrogate's decision-making calculus. This approach is most common in jurisdictions using a substituted judgment standard, i.e., the surrogate is supposed to follow the patient's actual or likely wishes. Some courts using a substituted judgment approach are willing to employ a premise that most competent people care considerably about the physical, emotional, and

financial well being of loved ones. As long as the now-incapacitated patient was previously intimately connected with family, they allow a surrogate to project that the patient would want burdens on the family to be a relevant factor in medical decisionmaking on the now-incompetent patient's behalf. One court commented: "An individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment would likely have on his family."¹⁴⁵

Where the ward is a never-competent person, there appears to be much less judicial willingness to permit third-party interests -- including burdens on family or caretakers -- to play a role in surrogate medical decisionmaking. This is especially so where the ward is institutionalized (therefore not part of an intact family unit) or is an infant who has never been part of a family unit. For example, in one case involving life support for a permanently unconscious child, and another involving dialysis for an institutionalized, mentally disabled person, the courts determined to ignore burdens on family or institutions as a relevant consideration.¹⁴⁶ In the latter instance, when the trial court mentioned the potential burden placed on the patient's family from a dialysis regimen as a relevant decision-making factor, the appellate court admonished that the interests of persons other than the patient must be ignored in fixing the patient's medical course.

Non-judicial commentary within the field of death and dying is more divided, particularly as to the moral relevance of third party interests in deciding the fate of a mentally incapacitated patient. Some commentators, like Yale Kamisar, insist that so long as an incapacitated patient has even the slightest interest in continued existence, burdens upon others have no appropriate role in a decision-making calculus.¹⁴⁷ Other commentators see the interests of third parties as an appropriate or even necessary factor in surrogate decisionmaking.¹⁴⁸

All ambivalence about the role of third party interests is absent from the judicial expressions in the post-1980 cases regarding sterilization in the best interests of a mentally incapacitated ward. This line of cases is acutely sensitive to the fact that earlier generations of mentally disabled persons had been exploited by non-voluntary eugenic sterilization. (Keep in mind also that sterilization decisions generally involve never-competent rather than formerly competent patients -- thus making it harder to attribute altruism or solicitude for the interests of others to an incapacitated person). The cases uniformly and unequivocally stress that any surrogate authorization of sterilization for an incapacitated person must be grounded on the ward's own interests. The following quotations are typical in their insistence upon exclusive focus on the ward's interests. "[T]he court considers only the best interests of the incompetent, not the interests or convenience of parents, guardians, or society."¹⁴⁹ "The fundamental right involved must be safeguarded to assure that sterilization is not a subterfuge for convenience and relief from the responsibility of supervision."¹⁵⁰ "[In considering the ward's best interests], the welfare of society or the convenience or peace of mind of the ward's parents or guardian plays no part."¹⁵¹ The post-1980 opinions not only disclaim any reliance on family or social interests in making best interests determinations, they constantly emphasize the importance of protecting the health and procreative interests of the disabled person for whom sterilization is being contemplated.

In sum, the current doctrinal framework of best interests leaves little room for surrogate consideration of third party interests in the settings of sterilization or end-of-life medical decisions on behalf of never-competent persons. The whole best interests formula is geared to protecting the interests of helpless persons themselves without consideration of the incommensurate interests of the helpless person's family or caretakers. Law is understandably reluctant to openly encourage

balancing of a helpless person's life or procreative capacity against the comfort, convenience, and well being of others. The main exception (in the context of end-of-life decisionmaking) is for previously competent persons who may have defined their personal interests as embracing the well being of others -- an exception that cannot apply to lifelong disabled persons.

From my perspective, all this judicial emphasis on patients' well being does not mean that third party interests are in fact irrelevant to surrogate decisionmaking on behalf of profoundly disabled persons. The reality is that third party interests constitute a "looming omnipresence" influencing surrogate decisionmaking in subtle and not so subtle ways.¹⁵² And at least at the margins -- meaning circumstances where the burdens on third parties are extreme and the net interests of an incapacitated ward are very much in doubt -- the impact of third party interests seems inevitable and legitimate.

A number of situations reflect the almost unavoidable impact of third party interests. One such situation is where a critically ill, incapacitated person is experiencing a difficult dying process causing emotional anguish to the surrounding family. This emotional burden upon the family might impel the family, acting as surrogate decisionmaker, in either of two directions -- unwarranted extension of artificial life support or premature termination of such support. An example of the former is a situation where a family is insisting that a gravely debilitated, dying patient be maintained on life support despite the health care providers' perception that the unconscious, or semi-conscious, or conscious and suffering patient is deriving no benefit from the continued care. The family may be motivated by grief, by guilt at being the agent of termination of a loved one's life, or by their religious conviction that all life is precious. Many health care providers will defer to the family's wishes not because the patient's best interests dictate continued medical intervention,

but because the providers are either solicitous of the family's discomfort or fearful of antagonizing the family. The surrounding family members are in a position to make a fuss and assert their interests while the patient is oblivious or at least helpless. Rather than create friction and controversy and possible bad publicity, the health care providers acquiesce in this derogation of the patient's interests.¹⁵³

Sometimes, the impetus stemming from consideration of family interests is in the opposite direction -- toward termination of life support. This is almost certainly the case when an infant is born with multiple, severe deficits. While the medical personnel may not yet be able to assess the precise long-term fate of the infant, they know already that the parents will be facing enormous hardship and stress and that the infant's eventual quality of life is problematic at best. A strong temptation then exists for the attending physician to take cognizance of the parental ordeal ahead and to influence the parents to consent to withholding of life-sustaining medical intervention -- not because of the infant's best interests but because of the family interests at stake.¹⁵⁴ That consideration of family interests was overt in the 1970's when physicians started writing about selective non-treatment of newborns.¹⁵⁵ Raymond Duff, a well known neonatologist of the time, operated on the premise that "families need to be spared the chronic sorrow of caring for infants with little or no possibility of meaningful lives." A similar attitude continues today among some physicians, albeit in more covert fashion.

A comparable phenomenon likely takes place where an adult patient has deteriorated to a point at which there is little chance of the patient's deriving benefit from continued medical intervention. When the patient has reached this gray area in which any benefit (other than biological existence) is dubious, there's a strong impetus for the surrogate decisionmaker and

attending medical personnel to bring the interests of the patient's loved ones into consideration.¹⁵⁶ This is one of the margins at which third party interests almost inevitably come into play.

The marginal influence of third party interests is perceptible in other medical contexts as well. The phenomenon seems to occur when the medical issue is organ or tissue donation from a mentally disabled person to a critically ill sibling or other close relative. While the cases articulate a strict best interests of the donor patient standard, in applying that standard the surrogate decisionmakers appear to be influenced by the critical need of the sick relative. That is, tissue donation will sometimes be authorized when the donee relative's survival will help the donor patient in some measure (as a caretaker) even though it is unclear whether donation will really further the donor's best interests. Also, when a mentally disabled person is living at home with siblings and parents, it is almost impossible for a surrogate decisionmaker to ignore those third party interests. This fact was acknowledged in a case where the medical issue was whether to authorize anti-psychotic medication for a mentally ill child living at home with his siblings.¹⁵⁷

The dollar cost of end-of-life treatment is another part of the "looming omnipresence" of third-party interests. Treatment and non-treatment decisions are unquestionably influenced by cost factors, at least where the costs are considerable and where the patient's status is so debilitated that it is unclear where the patient's best interests lie, i.e., whether the patient is better off dead than alive. While medical protocols and even state statutes may exclude cost as a relevant factor,¹⁵⁸ high cost is almost impossible to disregard. For example, if there is only a very slight chance that a medical intervention will be successful in extending life, and if the proposed intervention is extremely expensive, cost will likely impact on the medical decision.¹⁵⁹ Sometimes, the role of health care cost is explicitly recognized. For example, society makes allowance for parents who are

facing extraordinary financial hurdles with regard to their children's medical care. An explicit exemption under child neglect statutes is provided for parental failure to provide medical care that would be beyond the family's financial capability. Nor is the influence of economics reserved to the setting of incapacitated patients. Society limits the funding of some expensive medical procedures on the basis of cost-worthiness even where competent patients are involved.¹⁶⁰

As in the case of end-of-life surrogate decisionmaking, it is impossible to entirely exclude consideration of the prospective burdens on others when a surrogate is deciding whether to authorize a sterilization procedure. Those burdens act as a "looming omnipresence" over the surrogate's weighing of sterilization just as they do in the death and dying setting. For example, the burdens involved in supervision of a disabled patient (in order to prevent unprotected sexual activity) unavoidably play a role when sterilization is in issue. While the judicial opinions constantly stress that close supervision of the disabled person should be considered as a less drastic alternative to sterilization, and they admonish that convenience to caregivers should not be a factor, they really mean that reasonable supervision efforts should be considered. At some point, the burden of constant supervision becomes an unreasonable burden on caretakers, a fact that ultimately gets noted.¹⁶¹ (Of course, courts also recognize that constant supervision as an alternative to sterilization can be restrictive to the disabled person and counter to the maximal normalization that is an object of enlightened caretaking).¹⁶² And while it is unseemly for courts to mention the potential financial burden on the state in raising any offspring of a profoundly disabled person, that factor too looms over the sterilization determination.¹⁶³ Again, at the margins or extremes the interests of third parties do inevitably influence surrogate determinations of whether to authorize sterilization for a profoundly disabled ward.

The lesson here is that a best interests decision-making standard cannot be applied in a manner that entirely excludes third-party interests. The looming omnipresence of family emotional and financial interests inevitably materializes and influences decisionmaking in extreme cases -- especially where the pure best interests of the patient are difficult to determine and where the burdens upon others are considerable. This is not shocking. While I previously noted that justice does not mean that caretakers must be freed from onerous burdens, it may be fair to consider the sacrifices that caretakers make, at least at the margins where the interests of the disabled wards are indeterminate or in equipoise. Consideration of family interests at the margins recognizes that there is a limit to the duty of sacrifice that even a fiduciary such as a parent or guardian owes to his or her ward. Some kinds of parental or family sacrifices are unreasonable. A parent shouldn't have to bankrupt a family in order to extend a dying child's life. A parent shouldn't have to jeopardize the well being of a sibling (by diverting important resources away from that healthy person), even in order to extend another child's life.

Consider the case of the conjoined twins that was litigated recently in Great Britain.¹⁶⁴ Both twins would have died absent separation. Physicians demanded that the parents authorize a separation operation that might preserve the healthier twin but would precipitate the prompt death of the feebler twin. When the parents refused to accelerate one child's death (even for the purpose of rescuing the other child), the British courts intervened and ordered the operation. To me, it seems wrong to call the parents' conduct child neglect.¹⁶⁵ Yes, the parents were failing to save their salvageable child's life, but their conduct was inspired by unwillingness to precipitate their other child's prompt death. To me, this is an illustration of the rare case where consideration of a third party's interest (the feebler twin) warranted a parental choice not to pursue the pure best interests of

a dependent child (the stronger twin).

It is debatable whether consideration of family and other third party interests should be explicitly articulated as part of a best interests formula.¹⁶⁶ The current framework is deceptive in ostensibly excluding third party interests while actually tolerating them in certain circumstances. Yet, arguably, third party interests should be left as a looming omnipresence in the hope that they will be employed only at the margins where they almost unavoidably come into play. Open endorsement risks encouraging an extension of consideration of third-party interests to a broad range of circumstances where the incommensurate nature of other people's interests might undermine sound surrogate decisionmaking on behalf of an incapacitated patient.

VI. CONCLUSION

The medical fate of never-competent persons cannot be resolved according to the approach governing previously competent persons -- surrogate focus on self-determination or constructive autonomy. For never-competent medical patients, the commonly stated approach to surrogate decision making is best interests of the incapacitated ward. However, the literal best interests standard gets applied primarily when a governmental agent -- usually a court -- is the responsible decision-maker. When a parent is the surrogate decision maker, the medical course chosen need not be the *best* course, so long as it is a plausible medical option and is not so antithetical to the patient's interests as to constitute neglect or abuse. And while third party interests are not officially part of a never-competent patient's interests, third-party interests constitute a looming omnipresence that inevitably influences surrogate decision making at the margins. That is so especially where the never-competent patient's own interests are murky or in equipoise, and the potential impact on third parties is extreme.

Never-competent persons, as possessors of full moral status, are also entitled to be treated with dignity. This normally means that a surrogate decision-maker will maximally preserve the life of a ward. Sometimes, though, respect for the intrinsic human dignity of a fatally stricken ward dictates that the ward be allowed to die. A permanently unconscious person offers an example,¹ as does an infant with multiple deficits whose short life will be pervaded by intrusive medical interventions. In these rare instances, the deterioration or debilitation of a human being is so extreme that further medical intervention would be inhumane. This is so for some never-competent persons, just as it is for some formerly competent persons.

¹ See Ben A. Rich, Reflections on the Social Construction of Death, 24 J. Legal Med. 233, 239 (2003).

1. In re Grady, 426 A.2d 467, 479 (N.J. 1981). See also Douglas R. Rendleman, *Parens Patriae from Chancery to the Juvenile Court*, 23 South Carolina L. Rev. 205, 240 (1971).

2. I define profoundly disabled persons as people whose cognitive function places them at the bottom of the ranges applicable to the mentally retarded. Mental retardation is roughly defined as significantly subaverage intelligence (less than 70 I.Q.) coupled with substantial impairments in at least two areas of social behavior. Burton Blatt, *The Conquest of Mental Retardation* (1987) 68-69; James W. Ellis, *Decisions By and For People with Mental Retardation: Balancing Considerations of Autonomy and Protection*, 37 Vill. L. Rev. 1779, 1795 (1992). Most retarded persons, however, have enough cognitive capacity to make at least some medical decisions for themselves. The contemporary approach is to assess decision-making capacity according to the complexity of the particular issue at hand and to grant self-determination to any person, regardless of mental disability, who can understand the nature and consequences of that issue and is capable of exercising rational choice. Even under this approach seeking to maximize the self-determination opportunities of the mentally disabled, some persons are so mentally impaired that they can make virtually no medical decisions for themselves. I am referring to the small percentage of mentally disabled persons whose IQ is below 30, qualifying them as severely or profoundly retarded. See Thomas L. Whitman, Cynthia L. Miller, & Deirdre Mylod, *Mental Retardation*, in *Encyclopedia of Disability and Rehabilitation*. These persons are so severely cognitively disabled that any important decision affecting them must ultimately be made by some surrogate.

3. I use the term persons here advisedly. Some moral philosophers contend that human beings who are profoundly mentally disabled do not meet the minimum criteria for personhood.

However, law appropriately treats the profoundly disabled as persons and I will use that terminology throughout.

4. Alan Handler, Individual Worth, 17 Hofstra L. Rev. 493, 528 (1989); Michael Kindred, Guardianships and Limitations Upon Capacity, in *Mentally Retarded Citizens and the Law* (Kindred, ed.), 85 n.109. Surrogate decisionmaking is also necessary for previously competent persons who have lost the requisite capacity for medical choices. However, as will be explained infra, the legal framework is somewhat different for previously competent persons. The focus of this article is profoundly disabled, never-competent persons.

5. For a review of the earliest cases addressing surrogates' end of life determinations, see Norman L. Cantor, Twenty-five Years after Quinlan: A Review of the Jurisprudence of Death and Dying, 29 J. of Law, Medicine & Ethics 182, 183-84 (2001).

6. See *In re Boyd*, 403 A.2d 744, 750 (D.C. Ct. App. 1979)(implementing the formerly competent patient's deeply felt religious preferences is the "only way to pay full respect to the individuality and dignity" of that person); A.C., 573 A.2d 1235, 1247, 1249-50 (D.C. Ct. App. 1990).

7. A.C., 573 A.2d at 1249-50; *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417, 430 n.15 (Mass. 1976); *In re Bryant*, 542 A.2d 1216, 1220 (D.C. App. 1988).

8. For further explanation of how people's common preferences shape end-of-life decisionmaking, see Norman L. Cantor, Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions, 48 Rutgers L. Rev. 1193 (1996). See also John Arras, The Severely

Demented, Minimally Functional Patient: An Ethical Analysis, 36 J. Am. Geriat. Soc'y 938, 943 (1988).

9. To honor self-determination, "we should try our honest best to do what we think [the formerly competent patient] would have chosen." Deryck Beyleveld & Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (2001), 245.

10. This is not to say that the expressions of incapacitated persons are irrelevant to surrogate decisionmaking. The wishes and feelings of never-competent persons are still important for surrogate decisionmakers.

11. Allen Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 U.C.L.A. L. Rev. 386, 397 (1981).

12. *Curran v. Bosze*, 566 N.E.2d , 1326 (Ill. 199). See also *In re Pescinski*, 226 N.W.2d 180, 181-82 (Wis. 1975); *Matter of Susan S.*, 1996 WL 75343 (Del. Ch. 1996): "It is one thing to imagine what a person who was once of sound mind would have done in a given situation and quite another to imagine the same thing for someone who was never of sound mind."

13. *Truselo v. Carroll*, 2000 WL 33324536 (Del. Fam. Ct. 2000). See also *In re K.I.* 735 A.2d 448, 455-56 (D.C. 1999); *In re Christopher I.*, 131 Cal. Rptr. 2d 122, 133 (Calif. App. 2003).

14. Max Charlesworth, *Disabled Newborn Infants and the Quality of Life*, 9 J. Contemp. Health L. & Policy 129, 136 (1993); Max Charlesworth, *Bioethics in a Liberal Society* (1993), 51-52. See also *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984); *In re Barry*, 445 So.2d 365 (Fla. Ct. App. 1984); *Matter of Susan S.*, 1996 WL 75343 (Del. Ch. 1996)(using substituted judgment in a sterilization case).

15. James W. Walters, *What is a Person?* (1997), 60; Joel Feinberg, *Freedom and Fulfillment* (1992), 20.

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16. 370 N.E.2d 417 (Mass. 1976).
17. AMA Council on Ethical and Judicial Affairs, Section 2.20; Los Angeles County Medical Association, Guidelines 4-5; John M. Stanley et al, The Appleton Consensus: Suggested International Guidelines for Decisions to Forego Medical Treatment, 15 J. Medical Ethics 129, 133 (1989) (critical issue for surrogates is whether “continued treatment would lead to unacceptable burdens without sufficient compensating benefits”).
18. E.g., Conroy, 486 A.2d 1209, 1231 (N.J. 1986); Matter of L.W., 482 N.W.2d 60, 70 (Wis. 1992); In re C.A., 603 N.E.2d 1171, 1181 (Ill. App. 1992); K.I., 735 A.2d 448 (D.C. 1999).
19. Johanna Meehan, Plurality, Autonomy, and the Right to Take One’s Life, 47 Drake L. Rev. 87, 102-03 (1998)(relying on Elaine Scurry, *The Body in Pain* (1986)); Jamie Mayerfeld, *Suffering and Moral Responsibility* (1999), 24-27, 40-42.
20. President’s Commission for the Study of Ethical Problems in Medicine, *Deciding to Forgo Life-Sustaining Treatment* (1983), 136; Beauchamp & Childress, *Principles of Biomedical Ethics* (4th ed. 1994), 218; Dan W. Brock, *Ethical Issues in Exposing Children to Risks in Research*, in *Children as Research Subjects* (M. Grodin & L. Glantz eds. 1994), 85. K.I., 735 A.2d 448, 464 (D.C. 1999)(quoting Karen Rothenberg, 33 St. Louis U. L.J. 575 ; Wentzel, *supra* note , 447 A.2d at 1258.
21. Paul B. Solnick, Proxy Consent for Incompetent Non-Terminally Ill Adult Patients, 6 J. Legal Medicine 1, 15 (1985).
22. See Susan R. Martyn, Substituted Judgment, Best Interests, and the Need for Best Respect, 3 Cambridge Quarterly of Health Care Ethics 195, 200 (1994) (“The central inquiry is whether continued life currently has value to [the never-competent patient]”); [Mark R. Wicclair, *Ethics and the Elderly* (1993)] at 58-60;

23. R.S. Downie & K.C. Calman, *Healthy Respect: Ethics in Health Care* (2d ed. 1994), 75. See also Martha Minow, *Making All the Difference* (1990), 327-28.
24. Lois Sheperd ably describes the phenomenon of projecting the surrogate's own feelings in the course of imagining what life is like for a profoundly disabled person. Lois Sheperd, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, *Public Law and Legal Theory*, Working Paper # 77 (April 2003), 11, 16.
25. Dena S. Davis, *Old and Thin*, 15: , *Second Opinion* (Nov. 1990), 26, 29-30.
26. P. Riga, *Right to Die or Right to Live? Legal Aspects of Death and Dying* (1981) 155.
27. Nazi doctors perceived disabled lives as inherently stressful that ending those lives would be relieving the unfit from their own misery.
28. *Baby Doe v. Hancock County Board of Health*, 436 N.E.2d 791 (Ind. 1982)
29. Stephen G. Post, *Dementia in our Midst: The Moral Community*, 4 *Cambridge Q. Of Health Care Ethics* 142, 143-44 (1995).
30. Rebecca Dresser has written often and incisively about the difficulty of assessing the experiential reality of disabled persons supplying little or no verbal input. Dresser & John Robertson, *Quality of Life and Non-treatment Decisions for Incompetent Patients*, 17 *J. Law, Medicine & Health Care* 234, 241 (1989); R. Dresser, *Missing Persons: Legal Perspectives of Incompetent Patients*, 46 *Rutgers L. Rev.* 609 (1994); R. Dresser, *Relitigating Life and Death*, 51 *Ohio State L.J.* 425, 428 (1994). On the difficulty of discerning the true feelings of aware but non-communicative dying persons, see Michael H. Cohen, *Toward a Bioethics of Compassion*, 28 *Ind. L. Rev.* 667, 674-75 (1995).
31. Susan Martyn, *Substituted Judgment, Best Interests, and the Need for Best Respect*, 3 *Cambridge Q. of Health Care Ethics* 195, 199-201 (1994).

32. For an example, see *Matter of R.H.*, 622 N.E.2d 1071, 1077 (Mass. App. 1993) (regarding initiation of kidney dialysis for a mentally retarded patient).

33. See generally Robert Weir, *Selective Nontreatment of Handicapped Newborns*

34. *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991); *In re K.I.*, 735 A.2d 448, 460 (D.C. 1999); *In re C.A.* 603 N.E.2d 1171, 1181-82 (Ill. App. 1992); *Truselo v. Carroll*, 2000 WL 33324536 (Del. Fam. Ct. 2000); Tina Kelley, *Ruling Supports Parents' Rights to Decide on Child's Life Support*, N.Y. Times, 5/17/2003. But see *Infant C.*, 1995 WL 1058596 (Va. Cir. Ct. 1995) (a lower court disclaiming authority to authorize a DNR order for a neurologically devastated 1 year-old in the custody of the state department of social services); *Miller v. Hospital Corporation of America*, #14-98-00582 (Texas Civ. App. 2001), affirmed S.W.2d (Texas 2003); *Montalvo v. Borkovec*, 647 N.W.2d 413 (Wis. App. 2002).

35. On the disparate perspectives of competent adults and profoundly disabled infants, see John D. Arras, *Toward an Ethic of Ambiguity*, 14:2 *Hastings Center Rep.* (April 1984), 29-31.

36. Weiser, *Washington Post*, 7/14/91, p. A-1. See also Kathleen Knepper, *Withholding Medical Treatment from Infants: When Is It Neglect?* 33 *U. of Louisville J. or Family Law* 1, 21 (1994).

37. On the problematic of judging when a profoundly disabled person's existence is "too painful to be bearable," see Carl E. Schneider, *Hard Cases*, 28:2 *Hastings Center Rep.* (March 1998), 24 (recounting the story of Tracy Latimer, , killed by her father in order to end her suffering).

38. Peter G. Filene, *In the Arms of Others* (1999), 109-10. (Infant Doe's parents "necessarily projected their own values, feelings, and needs about whether extending his life would be worthwhile.")

39. *Bowen v. American Hospital Association*, 476 U.S. 610 (1986). See generally Tucker & Goldstein at pages 19:16 to 19:18.
40. *Id.* at 19:21, quoting from 42 U.S.C.A. Section 5106(g)(10).
41. *Id.* at 19:22, citing 45 C.F.R. Part 1340; Knepper, *supra* note at 18-19.
42. Carol A. Heimer, *Competing Institutions: Law, Medicine and Family in Neonatal Intensive Care*, 33 *Law & Society Review* 17, 57 (1999).
43. But see Montalvo, *supra* note , contending that the federal regulations are directly applicable to clinical practice.
44. Tracy K. Koogler, Benjamin S. Wilfond, & Lainie Friedman Ross, *Lethal Language, Lethal Decisions*, 33:2 *Hastings Center Report* (2003), 37, 38-39. See also *Truselo v. Carroll*, *supra* note ; Angie L. Guevara, Note, *In re K.I.: An Urgent Need for a Uniform System in the Treatment of the Critically Ill Infant*, 36 *U. San Francisco L. Rev.* 237, 247 (2001).
45. See *Curlender*, 165 *Cal. Rptr* 477, 479-81 (Cal. App. 1980), described in *Shepherd*, *supra* note at 43 n.102.
46. Betty Dew, *Do Those Who Cannot Speak Really Have a Voice?* 20 *Law, Med. & Healthcare* 316 (1992)(recounting the case of Joseph Finelli, a 57 year-old brain damaged patient).
47. *In re R.*, [1996] 3 *FCR* 473, 31 *BMLR* 127, 2 *FLR* 99.
48. National Conference of Catholic Bishops, *Nutrition and Hydration: Moral and Pastoral Reflections*, 15 *J. Contemporary Health Law & Policy* 455, 469 (1999).
49. Teresa Harvey Paredes, *The Killing Words? How the New Quality of Life Ethic Affects People with Severe Disabilities*, 46 *S.M.U. L. Rev.* 805, 829 (1992).
50. *Matter of Jane A.*, 629 *N.E.2d* 1337, 1340 (Mass. App. 1994). John Storar was a profoundly disabled adult who found cancer therapy (involving blood transfusions) to be disagreeable and

distressing in part because of non-comprehension of their purpose. Nonetheless, a New York court ruled that sedation would sufficiently mitigate John's apprehensions to make continued chemotherapy be in John's best interests. In re Storar,

51. President's Commission for the Study of Ethical Problems in Medicine, *Deciding to Forgo Life-Sustaining Treatment* (1983), 135. See also Guevara, *supra* note at 247-48 citing studies showing physicians' use of quality of life factors in neonatal care.

52. See *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987); *In re Grant*, 747 P.2d 445, 451 (Wash. 1987); *Newmark v. Williams*, *supra*; *Care and Protection of Beth*, 587 N.E.2d 1377 (Mass. 1992); *Foody v. Manchester Hospital*, 482 A.2d 713, 718-19 (Conn. Super. 1984); *In re Torres*, 357 N.W.2d 332 (Minn.); *AMB*, 640 N.W.2d 262 (Mich. App. 2001); *Myers*, 610 N.E.2d 663 (Ohio Common Pleas 1993); *Truselo*, *supra* note .

53. Md Code Annot., Health §5-601(e); N.Y. Surrogate Court Procedures Act §1750-b(2).

54. *Singer et al* 281 at 165.

55. *Glucksberg v. Washington*, 117 S. Ct. at 2289.

56. 117 S.Ct. at .

57. John Finnis, *Euthanasia, Morality, and Law*, 31 *Loyola L.A. L. Rev.* 1123, 1143 (1998).

Leon Kass also contends that human life is inherently dignified no matter how debilitated or full of suffering that life may be. Kass, *Life, Liberty and the Defense of Dignity* (2002), 248. Kass asserts that dignity in dying means showing endurance and courage in the face of fear and pain that is often part of the dying process. *Id* at 248, 253. That whole concept of persevering in the face of death matters little for profoundly disabled persons who do not grasp that they are mortally ill.

58. Westchester Medical Center (N.Y. 1988).
59. Carl E. Schneider, Rights Discourse and Neonatal Euthanasia, 76 Calif. L. Rev. 151, 175 (1988); Lois Shepherd, Dignity and Autonomy after Washington v. Glucksberg, 7 Cornell J. L. & Pub. Policy 431, 448 (1998); Matter of Finn, 625 N.Y.S.2d 809, 813 (Sup.Ct. 1995).
60. Many commentators regard deterioration to a point where the previously competent patient lacks capacity to interact with loved ones as a key guide to surrogates contemplating cessation of life support because of the incapacitated patient's quality of life. See Rebecca Dresser, Relitigating Life and Death, 51 Ohio State L.J. 425, 430 (1990); Emanuel Lancet at 108; Gostin 17 Law, Med. & Health Care , 296-97; John Arras, The Severely Demented, Minimally Functional Patient, 36 J. Am. Geriatric Society 938 (1988); Dan W. Brock, Justice and the Severely Demented Elderly, 13 J. Med. & Philosophy 73 (1988).
61. In re Spring, 399 N.E.2d 493, 496, 499-500 (Mass. App. 1979).
62. See Judith C. Ahronheim, Jonathan D. Moreno, & Connie Zuckerman, Ethics in Clinical Practice (2d ed. 2000), p. 43; Downie & Huff , supra note at 74
63. Deborah K. McKnight & Maureen Bellis, Foregoing Life-Sustaining Treatment for Adult, Developmentally Disabled Public Wards, 18 Am. J. Law & Medicine 203, 213 (1992).
64. New York State Task Force on Life and the Law at 113.
65. Bruce Jennings, The Liberal Neutrality of Living and Dying: Bioethics, Constitutional Law, and Political Theory in the American Right-to-Die Debate, 16 J. Contemporary Health Law and Policy 97, 119 (1999).
66. Id at 126.
67. Truselo v. Carroll, 2000 WL 33324536 (De. Fam. Ct. 2000).
68. Some advocates for the developmentally disabled see human dignity as demanding provision

of sufficient resources to allow each handicapped person to achieve maximum possible independence and “normalization.” E.g., R.C. Allen, *Legal Rights of the Disabled and Disadvantaged* (1970); Deryck Beyleveld & Roger Brownsword, *Human Dignity, Human Rights, and Human Genetics*, 61 *Modern L. Rev.* 661, 663 (1998).

69. Gerald L. Neumann, *Human Dignity in U.S. Constitutional Law*, in *Zur Autonomie des Individuums* (Simon & Weiss, eds. 2000) at 249, 270-71; Barbara Bennett Woodhouse, *The Dark Side of Family Privacy*, 67 *Geo. Wash. L. Rev.* 1247, 1261 (2000)(describing human dignity as an essential ingredient in the penumbras of several constitutional provisions). Charles Tremper, *Respect for the Human Dignity of Minors: What the Constitution Requires*, 39 *Syr. L. Rev.* 1293, 1305-07 (1988). Some commentators call human dignity “a pervasive underlying value” within the Constitution. *Id.* at 1298-99. Jordan Paust, *Dignity as a Constitutional Right*, 27 *Howard L.J.* 145, 176-80 (1984).

70. *Trop v. Dulles*, 356 U.S. 86, 100-01 (1958). Justice Blackmun, in an early opinion written before his term on the Supreme Court, relied on concepts of human dignity and decency in declaring unconstitutional the whipping of prisoners. *Jackson v. Bishop*, 404 F.2d 571 (8th Cir. 1968).

71. *Estelle v. Gamble*, 429 U.S. 97, 102, 105-06 (1976). Of course, the subjectivity of the human dignity concept is perhaps underlined by an ongoing dispute among Supreme Court justices about the relation between human dignity and the death penalty. While there was judicial consensus that respect for the humanity of criminals requires individualized consideration of an offender’s character and record before imposition of capital punishment, there was bitter dispute about whether capital punishment is an inherent violation of human

dignity. Compare *Woodson v. North Carolina*, 428 U.S. 280 (1976) with *Furman v. Georgia*, 408 U.S. 238, 270 (1972).

72. *Winston v. Lee*, 470 U.S. 753 (1985); *Rochin v. California*, 342 U.S. 165 (1952).

73. *Neuman*, *supra* note at 265.

74. *Rochin v. California*, 342 U.S. 165 (1952).

75. *A.C.*, 573 A.2d 1235, 1244 (D.C. App. 1990); *Louisiana v. Perry*, 610 So.2d 746 (La. 1992).

76. *Washington v. Harper*, 110 S. Ct. 1028 (1990).

77. *Thornburg v. American College of Obstetricians*, 476 U.S. 747, 772 (1986); *Planned Parenthood of Southeast Pennsylvania v. Casey*, 505 U.S. 833, 851 (1992).

78. Justice Stevens' opinion in *Washington v. Glucksberg*, 117 S. Ct. 2258, 2306 (1997)

stressed a dying patient's liberty interest not just in controlling bodily invasions, but "in dignity, and in determining the character of the memories that will survive long after her death." But see *Shepherd*, *supra* note , rejecting the concept of dignity in shaping liberty to control the time and manner of dying.

79. I suggest that the notion of basic human dignity helps explain why certain liberties that had not historically enjoyed widespread public acceptance or even government tolerance nonetheless were accorded the status of fundamental liberties by the Supreme Court. This is so with regard to inter-racial marriage and abortion. In both instances, the Court classified the liberty interests as fundamental according to "the traditions and collective conscience of the people" despite common legislative antipathy toward the conduct in issue.

80. *Estelle v. Gamble*, 429 U.S. 97, 104-05 (1976). Felicia Cohn, *The Ethics of End-of-Life Care for Prison Inmates*, 27 J. L. Med. & Ethics 252, 254-55 (1999).

81. *Washington v. Glucksberg*, (concurring justices) Note especially Justice

Stevens' assertion that avoidance of pain and agony in the dying process is at the heart of fundamental liberty under the Fourteenth Amendment.

82. David A. Pratt, Too Many Physicians: Physician-Assisted Suicide after Glucksberg/Quill, 9 Alb. L.J. Sci. & Tech. 161, 223 (1999); Susan Adler Channick, The Myth of Autonomy at the End of Life: Questioning the Paradigm of Rights, 44 Vill. L. Rev. 577, 602, 606 (1999); David J. Garrow, The Right to Die: Death with Dignity in America, 68 Miss. L.J. 407, 417-19 (1998); Alan Meisel, Legal Issues in Decision Making for Incompetent Patients, in Advance Directives and Surrogate Decisions Making in Health Care (H. Sass R. Veatch, R. Kamura, eds. 1998).
83. E.g., Matter of Lawrance, 579 N.E.2d 32 (Ind. 1991); Guardianship of L.W., 482 N.W.2d 60 (Wis. 1992); Care and Protection of Beth, 587 N.E.2d 1377 (Mass. 1992); In re Moorhouse, 593 A.2d 1256 (N.J. App. Div. 1991).
84. "Pain cannot be experienced by brains that no longer retain the neural apparatus for suffering." AMA Council on Ethical and Judicial Affairs, Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support, 263 JAMA 426, 428 (1990).
85. See Norman L. Cantor, Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions, 48 Rutgers L. Rev. 1193, 1241-63 (1996).
86. See In re Myers, 610 N.E.2d 663 (Ohio Common Pleas 1993); In re Christopher I., 131 Cal. Rptr. 2d 122, 134 (Cal. App. 2003); Brophy
87. Ironically, some commentators would use human dignity as a rationale for the contrary result – as a justification for allowing the exploitation of never-competent persons' tissue. I will address that rationale infra at pp.
88. Lois Shepherd, Dignity and Autonomy after Washington v. Gluckberg: An Essay about Abortion, Death, and Crime, 7 Cornell J. Law and Public Policy 431, 454 (1998).

89. See Kristi E. Schrode, Comment, *Life in Limbo: Revising Policies for Permanently Unconscious Patients*, 32 *Houston L. Rev.* 1609 (1995); Rosamond Rhodes, *Futility and the Goals of Medicine*, 9 *J. Clinical Ethics* 194, 200 (1998)(asserting that no consensus yet exists about whether the goals of medicine include preservation of mere biological existence).
90. Beauchamp & Childress, *supra* note at 173.
91. *Parham v. J.R.*, 442 U.S. 584, 602 (1979), quoted in Rachel M. Dufault, *Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 *Conn. L. Rev.* 211, 235 n.120 (1991).
92. E.g., *Peterson v. Rogers*, 445 S.E.2d 901 (N.C. 1994); *In re Doe*, 638 N.E.2d 181 (Ill. 1994); *In re Baby Girl Clausen*, 502 N.W.2d 649 (Mich. 1993), *aff'd* 509 U.S. 1301 (1993); see Gregory A. Kelson, *In the Best Interests of the Child: What Have We Learned from Baby Jessica and Baby Richard?* 33 *J. Marshall L. Rev.* 353, 372 (2000).
93. Robert Veatch, *Ethical Dimensions of Advance Directives and Surrogate Decision Making*, *supra* note at 74.
94. *Reno v. Flores*, 113 S.Ct. 1439, 1448 (1993). See generally F. Schoeman, *Parental Discretion and Children's Rights*, 10 *J. Phil. & Med.* 48 (1985); Lainie Friedman Ross, *Children, Families, and Health Care Decision-Making* (1998), 10-12, 30, 42.
95. "A diverse array of conflicting claims about the good is both possible and desirable in a humane political order." Christopher C. Kutz, *Just Disagreement: Indeterminacy and Rationality in the Rule of Law*, 103 *Yale L.J.* 997, 1024 (1994). See also Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for their Children: Is Deference Justified?* 73 *Temple L. Rev.* 1, 6 (2000).
96. Robert A. Burt, *Developing Constitutional Rights Of, In, and For Children*, 39 *L. &*

Contemp. Prob. 118, 121 (1975).

97. 262 U.S. 390 (1923).

98. Santosky v. Kramer, 455 U.S. 745, 753 (1982), quoted approvingly in Troxel v. Granville, 120 S.Ct. 2054 (2000).

99. 120 S.Ct. 2054, 2060-61 (2000).

100. Id. at 2062.

101. Justice O'Connor noted that -- in contrast to Washington state -- some states in regulating visitation orders uphold parental decisions unless a petitioner rebuts a presumption that the parental decision is reasonable. Ibid.

102. For a lucid and convincing description of the doctrinal disarray surrounding parental decisionmaking, see David D. Meyer, The Paradox of Family Privacy, 53 Vand. L. Rev. 527, 528-29, 545-46 (2000).

103. E.g., E.G., 549 N.E.2d , 326-27 ; But see Novak v. Cobb County Hospital Authority, 849 F. Supp. 1559 (D.Ga. 1994).

104. These statutes recognize that parental interests sometimes diverge from their children's interests and that public health interests may override child-rearing interests when maintenance of parental control would discourage children's resort to important medical treatment.

105. Planned Parenthood v. Danforth, 428 U.S. 52, 74 (1976);

106. E.g., New York State Task Force on Life and the Law, When Others Must Choose (1992), 107; Alexander M. Capron, Where is the Sure Interpreter? 22:4 Hastings Center Report (July 1992), 26-27.

107. Matter of Hofbauer, 419 N.Y.S.2d 936 (N.Y. 1979); Jane Doe, 418 S.E.2d 3 (Ga. 1992); In re Hudson, 126 P.2d 765, 771 (Wash. 1992).

108. *Matter of Mathews*, 650 N.Y.S.2d 373, 377-78 (App. Div. 1996).
109. *Soleveich* See generally Carol A. Heimer, *Competing Institutions: Law, Medicine and Family in Neonatal Intensive Care*, 33 *Law & Society Review* 17, 51-52 (1999); Tracy Koogler, Benjamin Wilford, & Lainie Friedman Ross, *Lethal Language, Lethal Decisions*, 33:2 *Hastings Center Report* (2003), 37, 39-40.
110. *Custody of a Minor*, 393 N.E.2d 836, 841 (Mass. 1979); *Matter of Hudson*, 126 P.2d 765, 771 (Wash. 1942); *Matter of Cabrera*, 552 A.2d 1114, 1118 (Pa. Super. 1989); Laura M. Plastine, *In God We Trust: When Parents Refuse Medical Treatment for their Children Based Upon Their Sincere Religious Beliefs*, 3 *Const. L.J.* 123, 139-45 (1993); Knepper, *supra* note at 3, 7-8.
111. *In re Hudson*, *supra* note at 778.
112. Jennifer Hartsell, *Mother, May I . . . Live? Parental Refusal of Life-sustaining Medical Treatment for Children Based on Religious Objections*, 66 *Tenn. L. Rev.* 499, 509 (1999). The exemption does not cover instances when serious harm to the child is threatened or ensues. *Id.* at .
113. See Rebecca Dresser, *Standards for Family Decisions: Replacing Best Interests with Harm Prevention*, 3:2 *American J. of Bioethics* 54 (Spring 2003)
114. E.g., *Matter of Hayes*, 608 P.2d 635 (Wash. 1980); *Matter of C.D.M.*, 627 P.2d 607 (Alas. 1981); *Matter of Shirley Hilstrom*, 363 N.W.2d 871 (Minn. App. 1985).
115. E.g., *Motes v. Hall County Department of Family and Children's Services*, 306 S.E.2d 260, 262 (Ga. 1983); *In re W.*, 637 P.2d 366 (Colorado 1981). See generally, Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 *Duke L.J.* 806 (1986); Eric M. Jaegers, Note, *Modern Judicial Treatment of Procreative Rights of Developmentally Disabled Persons: Equal Rights to Procreation and Sterilization*, 31 *U.*

Louisville J. Fam. L. 947 (1992).

116. *In re Debra B.*, 495 A.2d 781 (Me. 1985); *Matter of A.W.*, 637 P.2d 366 (Colo. 1981); *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244 (Md. App. 1982).

117. *Conroy* ; *Rasmussen*; *Beth Israel Medical Center*, 519 N.Y.S.2d Grant

118. *Bopp & Marzden, Cruzan: Facing the Inevitable*, 19 *Law, Med. & Health Care* 37, 43 (1991); *Motes v. Hall City Department of Family Services*, 306 S.E.2d 260 (Ga. 19); *Knight v. Beverly Health Bay Manor Center*, 820 So.2d 92, 100 (Ala. 2001).

119. John Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 *Ga. L. Rev.* 1139, 1164-65 (1991); Michele Yuen, *Comment, Letting Daddy Die: Adopting New Standards for Surrogate Decisionmaking*, 39 *U.C.L.A. Law Review* 581, 631 (1992); Daniel B. Griffith, *The Best Interests Standard: A Comparison of the State's Parens Patriae Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients*, 7 *Issue in Law & Medicine* 283, 315-16 (1991).

120. Nancy Rhoden, *Litigating Life and Death*, 102 *Harv. L. Rev.* 375, 379, 393, 419-20 (1988); Neal F. Splaine, *Note*, 27 *Suffolk U. L. Rev.* 905, 939 (1993);

121. *Dresser*, *supra* note , 3 *AJOB* at 55; But see a number of jurisdictions that ban removal of life support absent proof that the patient, while competent, clearly indicated that he or she would not want treatment in the circumstances at hand.

122. Nancy Rhoden, *supra* note , 102 *Harv. L. Rev.* at 379, 393, 419-20; Ardath Hamann *Family Surrogate Laws: A Necessary Supplement to Living Wills*, 38 *Villanova Law Review* 103, 159 (1993); Arras, *supra* note, 36 *J. Am. Geriatric Society* at 943. See also Drabick, 245 *Cal. Rptr.* 840, 844 n.7 (Cal. App. 1988).

123. E.g., *In re Debra B.*, 495 A.2d 781 (Me. 1985); *In re V.S.D.*, 660 N.E.2d 1064 (Ind. App.

1996).

124. Note, however, that a decision regarding sterilization involves choice between 2 fundamental liberty interests -- a right to procreate and a right to refrain from procreation.

125. Scott, *supra* note , 1986 Duke L.J. at 831-32.

126. “[I]f the woman truly can never parent, it probably is in her interests not to give birth to a child who will have to be removed.” Field & Sanchez at 106.

127. *In re Wirsing* 573 N.W.2d 51, 55 (Mich. 1998).

128. *In re Simpson*, 180 N.E.2d 206 (Ohio Prob. Ct. 1962), noted in Donald Gianella, *Eugenic Sterilization and the Law*, in *Eugenic Sterilization* (Robitscher, ed. 1973), 64-65.

129. See, e.g., Roberta M. Berry, *From Involuntary Sterilization to Genetic Enhancement: The Unsettled Legacy of Buck v. Bell*, 12 Notre Dame J. L. Ethics & Pub. Policy 401, 428-30 (1998); Paul A. Lombardo, *Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. Contemp. Health L. & Policy 1, 19 (1996).

130. *Frazier v. Levi* (Tex. 1969); *M.K.R.*, 515 S.W.2d 467 (Mo. 1974); *Hudson v. Hudson*, 373 So.2d 310 (Ala. 1979); *Annot.*, 74 A.L.R.3d , 1214. But see *Sallmaier*, 378 N.Y.S.2d , 991 (N.Y. 1976); *Wyatt*, 368 F.Supp. , 1384 (1974)

131. *Price & Burt*, ; *Sherlock & Sherlock*, *Sterilizing the Retarded*, 60 N.C. L. Rev. 943 (1982). Instances of abusive decisionmaking had in fact surfaced in this period. See *Stump v. Sparkman*, 435 U.S. 349 (1978); *Downs v. Sawtelle*, 574 F.2d 1 (1st Cir. 1978).

132. *Matter of Hayes*, 601 P.2d 635 (Wash. 1980); *Grady*, 426 A.2d , 481 (N.J. 1981); *P.S. v. W.S.*, 452 N.E.2d 969, 976 (Ind. 1982); *Matter of Romero*, 790 P.2d 819 (Colo. 1990); *Moe*, 432 N.E.2d 712, 718 (Mass. 1982) *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244 (Md. App. 1982); *AW.*, 637 P.2d 366, 376 (Colo. 1981). Plus *Larson* at 430-31 & *Scott* at 822-

23. A few cases suggest that a showing of medical necessity -- a standard even more demanding than plain best interests -- is a prerequisite to a surrogate's consent to sterilization for a disabled person. See note , supra.

133. John Hardwig, *The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions*, 4 J. Clin. Ethics 20 (1993); Hardwig, *The Problem of Proxies with Interests of Their Own*, 1992 Utah L. Rev. 803 (1992). Another commentator expressing some sympathy with the justice rationale is Dan Brock. See Dan W. Brock, *What is the Moral Authority of Family Members to Act as Surrogates of Incompetent Patients?* 74:4 Milbank Q. (1996), 599 [1996 WL 10469296].

134. George P. Smith, *Death Be Not Proud: Medical, Ethical and Legal Dilemmas in Resource Allocation*, 3 J. Contemp. Health L. & Policy 47, 59 (1987).

135. See William A. Kraiss, Note, *The Incompetent Developmentally Disabled Person's Right of Self-Determination: Right-to-Die, Sterilization, and Institutionalization*, 15 Am. J. L. & Med. 333, 357 (1989)(suggesting a legitimate parental interest in a daughter's sterilization); *Michigan Protection and Advocacy Service v. Kirkendall*, 863 F.Supp. 482, (E.D. Mich. 1994).

136. Hardwig, note supra, 1992 Utah L. Rev. at 814-15.

137. Of course, the problem of commensurability is always present in the absence of very explicit prior instructions from the now-incapacitated patient. If the average patient wants the economic or emotional burden on surrounding family to be considered, questions still arise about in which debilitated circumstances the patient wants these extrinsic factors (economic and emotional burdens) to come into play and about how much weight these factors warrant. And if a now-incompetent patient previously specified that the interests of family should be part of the surrogate's calculus, then the incommensurability problem is unavoidable. See Md. Code

Annot., Health §5-605(c)(2)

138. President's Commission for the Study of Ethical Problems in Medicine, *Making Health Care Decisions* (1983), at 180. See also Brock, *supra* note [74 *Milbank Q.*].

139. See Md. Code Annot., Health §5-605(c)(2)

140. N.Y. State Task Force on Life and the Law, *When Others Must Decide* (1992), 109. The Task Force suggests that it would be necessary to make a strong showing that the average person would want the interests of third parties to be considered in the circumstances at hand. And the Task Force gives a caveat that the boundary of consideration for others would be harm to the patient. This is somewhat puzzling. If third party interests advance a termination of life support prior to the point when such a decision would otherwise have been made, that seems like a form of harm. Perhaps the Task Force meant harm in the sense of suffering experienced by the patient.

141. Peter A. Singer, Douglas K. Martin, & Merrijoy Kelner, *Quality End-of-Life Care: Patients' Perspectives*, 281 *JAMA* 163, 166 (1999).

142. Margaret Battin, *The Least Worst Death* (1994), .

143. Martha Field objects to ascribing consideration of others to newborns, seeing it as "projecting upon the baby a personality that allows society to do what it wants for reasons other than the child's own interests." Martha Field, *Killing the Handicapped -- Before and After Birth*, 16 *Harv. Women's L.J.* 79, 89 (1993). See also Schneider, *supra* note , 76 at 165, 172.

144. For such an argument, see Scott, *supra* note , 1986 *Duke L.J.* at 845.

145. *Guardianship of Roe*, 421 N.E.2d 40, 58 (Mass. 1981)(anti-psychotic medication). She also *In re Ingram*, 689 P.2d 1363, 1370 (Wash. 1984) (cancer treatment); *In re Torres*, 357

N.W.2d , 339 (Minn.) (permanently unconscious patient).

146. See R.H., 622 N.E.2d 1071, 1078 (Mass. App. 1993); *Care and Protection of Beth*, 587

N.E.2d 1377, 1383 (Mass. 1992); See also A.C., 573 A.2d 1235 (D.C. Ct App

1990)(emphasizing that a surrogate must focus on the patient's interests rather than those of others). But see *Guardianship of Jane Doe*, 583 N.E.2d 1263, 1268 (Mass. 1992).

147. Kamisar, *When is There a Constitutional "Right to Die"?* 25 Ga. L. Rev. 1203, 1236-37

(1991). See also Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 Calif. L. Rev.

151, 175 (1988); Shannon Jordan, *Decision Making for Incompetent Persons* (1985), 72-73.

148. Baruch Brody, *Life and Death Decision Making* (1988), 31.

149. *Matter of Terwilliger*, 450 A.2d 1376 (Pa. 1982).

150. *Matter of Shirley Hilstrom*, 363 N.W.2d 871, 876 (Minn. App.1985).

151. *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244, 1253-54 (Md. App. 1982).

152. Robert Veatch observes that third party interests "unavoidably influence treatment

decisions" on behalf of incapacitated persons. Robert M. Veatch, *The Patient - Physician*

Relation, Part 2 (1991), 229. See also *Guardianship of Roe*, 421 N.E.2d 40, 55 (Mass. 1981)

where the court considering whether to compel anti-psychotic medication noted the impossibility of ignoring the interests of siblings living with the ward.

153. The legitimacy of third-party interests surfaces even when the medical fate of a fully competent person is in issue. Consider, for example, a seriously ill Jehovah's Witness and parent who is refusing a critical blood transfusion on religious grounds. Courts addressing whether to override the patient's objection to treatment often cite the interests of "innocent third parties" as a potential compelling justification for judicial intervention. E.g., *Public Health Trust v. Wons*, 541 So.2d 96 (Fla. 1989); *Fosmire v. Nicoleau*, 551 N.Y.S.2d 876, 551 N.E.2d 77 (N.Y. 1990).

The cases end up finding either that the dependent child's interests are satisfied by continued availability of the second parent or that the patient's fundamental liberty interest outweighs the concerns about an "abandoned" child. The point here is that the third party interests -- there, the dependent children of a competent medical patient -- are deemed legitimate and important. Of course, injecting third party interests when the competent patient has assumed a fiduciary relationship to the third party is not the same as injecting third party interests into medical decisionmaking for a never-competent person (who cannot have a fiduciary role).

154. Robert N. Wennberg, *Terminal Choices: Euthanasia, Suicide, and the Right to Die* (1989), 200.

155. See Duff & Hollingshead, As quoted in Martha Minow, *Making All the Difference: Inclusion, Exclusion, and American Law* (1990), 319 n. 27. See also Capron re Baby Doe.

156. James Childress, *Dying Patients: Who's in Control?* 17 J. Law, Medicine & Health Care 227, 229 (1989).

157. *Guardianship of Roe*, 421 N.E.2d 40, 55 (Mass. 1981).

158. See, e.g., Los Angeles County Medical Assoc. Guidelines, at 4-5; N.Y. Surrogates Court Procedures Act §1750-b(2).

159. Veatch, *supra* note , at 229. Ruth Fader urges that costs of care be acknowledged as part of a best interests formula. Ruth Fader, 53 Md. L. Rev. , 1213

160. Candace Cummins Gauthier, *Philosophical Foundations of Respect for Autonomy*, 3 Kennedy Inst. of Ethics J. 21, 35 (1993).

161. Angela D. at 417.

162. C.W., 640 A.2d at 436.

163. See *North Carolina Ass'n for Retarded Children*, 420 F. Supp. at 455-56.

164. In re A (Conjoined Twins) [2000] HRLR 721 (Eng. C.A.); Rachel Donnelly, Twin 'Critical But Stable' as Sister Dies, *The Irish Times*, 11/8/00.
165. See also Daniel Sulmasy, _____ America (2000).
166. Compare Robertson, *supra* note _____, 25 Ga. L. Rev. at 1250-51 and Fader, *supra* note _____ (both favoring articulation of third-party interests) with Minow, 53 Md. at 1180-81 (opposing).