
The Moral Status of the Profoundly Disabled: Persons or Something Less?

Suppose a child is born who, throughout his life, will be profoundly retarded. . . . How shall we describe such human beings? Is it best to say that they are no longer persons? Or is it more revealing to describe them as severely disabled persons?¹

The Concepts of Personhood and Full Moral Status

Personhood in our culture carries important consequences. In the legal context, personhood ensures maximum legal protection for profoundly mentally disabled beings. The Fourteenth Amendment of the U.S. Constitution, for instance, protects all “persons” against deprivation of life, liberty, or property without due process of law and safeguards persons against invidious or arbitrary government discrimination. Beyond constitutional protection, public discourse often refers to basic or natural or intrinsic “rights” in the sense of certain inviolable moral entitlements or protections.² Some or all of those morally grounded benefits might also be confined to “persons,” although nonpersons with a diminished moral status may still receive significant protections. In the context of health-care ethics, a central theme is respect for persons, meaning adherence to certain protections and forms of solicitous treatment associated with human dignity.³ Implicit in that ethical entitlement to respect is a judgment that all persons have full moral status. In moral philosophy, the term *person* is often associated with beings that have special value or importance—that is, full moral status. Because of these important implications of personhood, it is critical to determine at the outset of this book whether profoundly disabled human beings qualify as persons—as beings entitled to full moral and legal status.⁴

Resolving whether profoundly disabled humans have full moral stature has considerable importance in the domain of surrogate decision making that occupies this book. As the introduction suggests, some states might seek to exclude entire subject matters of medical decision making affecting the profoundly disabled (such as sterilization or removal of life support) from the realm of surrogate control. If the profoundly disabled are persons and thus entitled to maximum legal status and protection, they may oppose such categorical exclusion and claim a right to have such disputed decisions made by surrogates on their behalf. For example, an incapacitated person who needs a sterilization operation to avoid harsh medical consequences or to maximize sexual freedom has a strong interest in having sterilization chosen for him or her. Access to a full range of surrogate medical choices therefore affects the well-being of profoundly disabled humans. Such personal-welfare interests underlie a possible constitutional right to surrogate choice (which I call a *right to constructive choice*). Discussion of a claim of entitlement to constructive choice occupies a central place in chapter 2.

The concept of personhood can come into play in various other ways when surrogates are accorded authority to make certain medical decisions on behalf of the profoundly mentally disabled. An example is end-of-life decision making. If profoundly disabled beings are not persons, then decisions to terminate life-sustaining medical intervention (and thereby precipitate death) are facilitated. This factor has already surfaced in the debates surrounding the medical handling of grievously disabled infants, with some commentators asserting that infants, as nonpersons, have no entitlement to the customary presumption that life should be preserved.⁵ If profoundly disabled infants have full moral status, then they get the same respect for their lives and well-being as children and adults.⁶

The possible implications of treating profoundly disabled humans as nonpersons also resound in the context of the medical handling of permanently unconscious human beings. The most extreme view is that a permanently unconscious human being, having no capacity to experience his or her environment or to have interactions with other beings, lacks a critical qualification for human existence and ought to be deemed dead.⁷ An alternative view is that a permanently unconscious being is alive but has been reduced to a nonperson who lacks customary human interests in con-

tinued life, such as experiencing an environment or relating to other beings. A decision to withdraw life support is then apparently consistent with the unconscious nonperson's own limited interests. If the permanently unconscious being is indeed a nonperson, a surrogate's effort to dictate the withdrawal of life support would be reinforced (given the diminished moral stature of a nonperson). Some commentators offer that account to explain why American law generally allows life support to be withdrawn from a patient in a permanently unconscious state even though the patient is not suffering and arguably has an interest in living because of the remote chance of a miraculous recovery.⁸ If the permanently unconscious patient is not a person, then the interests of surrounding family and caregivers—that is, “real” persons—may assume greater importance in resolving the patient's fate. An incapacitated patient's medical fate is not ordinarily decided by reference to the burdens on family associated with treatment or nontreatment. But the absence of personhood in the patient could allow family interests not only to come into play but to become prominent or even dominant.⁹ Moreover, if the permanently unconscious being is deemed a nonperson, perhaps it would be justifiable to harvest organs from the unconscious being or to conduct medical research on that being before ending life support.

Absence of personhood could also affect the role that third-party interests—particularly parents' and siblings' interests—play in determining the medical course for the profoundly disabled being in a variety of medical situations. Other examples (beyond the context of permanently unconscious patients) show how the diminished moral stature of a human being would help determine society's willingness (and perhaps moral entitlement) to subjugate that being's interests to the needs of other human beings.¹⁰ It is self-evident that a *person's* interests in bodily integrity, personal well-being, and self-determination preclude harvesting nonvital tissue (a kidney or bone marrow) without personal consent—even if another person's life or several persons' lives could be saved. In other words, a person's medical course is not shaped by a utilitarian calculus encompassing social interests.¹¹ But if a profoundly disabled being is a nonperson, shouldn't a surrogate be able to approve the performance of a nontherapeutic medical experiment to benefit future generations of people? Wouldn't a profoundly disabled being's status as a nonperson determine the prioritizing of access

to scarce medical resources or to other societal goods that facilitate people's opportunities to flourish?¹² And what about harvesting of nonvital tissue to benefit a real person?

An illustrative case arose with regard to anencephalic newborns—infants born without upper brains and fated to live short, insentient lives devoid of human interaction. Some commentators urged that an anencephalic baby's parents be allowed to consent to harvesting the baby's organs to benefit other children.¹³ The American Medical Association's Council on Ethical and Judicial Affairs initially endorsed such a practice,¹⁴ although the council later withdrew its approval. In this instance, the deathlike (that is, nonperson) status of the anencephalic being contributed to the commentators' willingness to allow an organ harvest—a willingness to exploit a living human's body for the benefit of others.

The moral stature of a profoundly disabled being is relevant to other issues in the context of surrogate decision making. An important question (to be explored in chapter 6) is the significance of the voice of the profoundly disabled patient—the expressions uttered by the nonrational patient, including those that either assent to or oppose a proposed medical intervention. These expressions cannot reflect the considered judgment of an autonomous person, but they might still reflect the will and feelings of a person. Establishing the profoundly disabled as persons with full moral status can help to determine the import to be attributed to their expressions.

Denying personhood (and full moral significance) to profoundly disabled humans would not mean depriving them of all moral status. At the very least, as sentient beings they would be entitled to be protected against needless suffering.¹⁵ And their human status would limit the nature and extent of exploitation of profoundly disabled humans to satisfy the needs of others. That is, there might have to be important interests of “real” persons at stake in order to justify any exploitation of human nonpersons. Still, treatment as nonpersons would substantially truncate the interests of profoundly disabled humans.¹⁶ Their lives might not be protected against nonpainful death. Their interests would be secondary in the allocation of societal resources. “Real” persons' interests would naturally enter into surrogate medical decision making and perhaps receive even heavier weighting than the nonperson's interests.

Treatment of the profoundly disabled as being nonpersons and having inferior moral status would also affect public attitudes and empathy. The

interests of humans somehow get more respect when acknowledged as being connected to persons.¹⁷ Lainie Friedman Ross comments that a severely retarded individual is deserving of respect but is “owed less [respect] than that owed to a fully actualized person.”¹⁸ Some philosophers would accord rights to mentally disabled persons to a degree “proportionate to the degree to which they approach being” full persons (meaning beings who are capable of acting as moral agents).¹⁹ This phenomenon of diminished respect flows in part from people’s tendency to identify with and respect most highly those beings who most resemble themselves. This is not to say that human beings don’t count morally unless they are perceived as persons but only that there is a tendency to respect their interests less—to attribute less weight to their interests than to those of others—if personhood is deemed lacking. That tendency might well affect surrogate medical decision makers who are acting on behalf of the profoundly disabled.²⁰

Criteria of Personhood

If the potential importance of personhood to shaping the rights of the profoundly disabled is acknowledged, then the issue becomes the criteria for personhood. A central task of moral philosophy is to identify a set of characteristics that distinguish “persons” from other living beings.²¹ That task is not necessarily confined to distinguishing human beings from nonhuman animals. Considerable controversy exists about whether all live human beings qualify as persons (with concomitant full moral status). A number of philosophers contend that personhood requires a level of intellectual function that would exclude some or all profoundly disabled beings. For those philosophers, neither mere existence as a human being nor sentience (capacity for pleasure and pain) suffices for personhood.

While many philosophers regard high intellectual function as the principal determinant of personhood (and as the element that gives humans special moral value), there is no consensus about the precise level of intellectual function that is necessary and sufficient to confer personhood. Some philosophers look to autonomy and rationality (capacity to reflect and act on reason) as the key determinant.²² Others demand greater intellectual capacity, such as a capability to make life plans and projects or a capability to communicate with others by language. Some go further and demand moral agency—the capacity to ponder and grasp moral principles—as a

prerequisite to personhood.²³ Along those lines, Tom Beauchamp reserves moral personhood to those who “understand moral reciprocity and communal expectation.”²⁴ At a less demanding level, some philosophers look to self-consciousness—awareness of personal identity over time—as the key element.²⁵ Self-consciousness is sometimes given a refined meaning—“reflective consciousness”—under which a person must not only be aware of self but also aware of having personal experiences. James Walters goes further, including in his definition of self-consciousness “the capacity to be aware of one’s distinctive self as a relatively autonomous being among other such selves.”²⁶

Any position viewing high intellectual capacity of the human mind as the key to personhood and concomitant full moral status would exclude some profoundly disabled beings. Some profoundly disabled people are so severely neurologically damaged that they cannot reason or communicate, although they can experience pleasure and pain.²⁷ Others have the capacity for rudimentary autonomy, yet their mental function is so limited that they cannot qualify as moral agents: “Ethical reasoning depends upon certain kinds of cognitive as well as emotional capacities, including complex intellectual skills required to universalize and empathize.”²⁸ Even a less demanding standard than moral agency—one that requires psychological continuity (a consciousness of personal identity over time)—would exclude at least some profoundly disabled beings from personhood.²⁹ This would especially be so under a definition of self-consciousness that requires “reflective consciousness” as opposed to mere sensory awareness of self and of an environment.³⁰ The status of a profoundly disabled being would also be uncertain under a view that treats capacity for human relationships as the key to personhood.³¹ The nature of the intellectual or emotional capacities deemed critical to human relationships would then determine the status of profoundly disabled beings.

Other philosophical conceptions of the criteria necessary for personhood are more expansive and would clearly encompass the profoundly disabled (even if they would exclude some other human beings). One example is a position that accords personhood to any conscious human being who is capable of interacting on any level with other humans.³² While permanently unconscious humans would then be excluded from personhood,³³ virtually all profoundly disabled humans would be included despite their

very limited cognitive capacity. Another expansive position acknowledges the personhood of any human being who is sentient and capable of experiencing pleasure or pain.³⁴ An even more expansive position—one that is often grounded in a religious perspective—upholds the intrinsic value of any live human being, even a permanently unconscious one.³⁵ Such a position would accord full moral status and concomitant rights to any live human being, no matter how profoundly disabled.

If a high level of mental function distinguishes the human species and makes human beings worthy and valuable, why should profoundly disabled persons be treated as persons with full moral stature? One approach is to deny that personhood is grounded in any particular criterion such as high intellectual function. Many philosophers insist that all human beings are persons and that all humans are equally worthy and valuable regardless of intellectual level. One basis for that position is religious faith. According to the book of Genesis, humans are unique in being created in the image of God. This supposedly gives all humans a divinelike status (although the divinelike qualities are usually cognitive elements such as reason, judgment, and moral concern).³⁶ Even though the godlike qualities involve intellectual capacity, the human species as a whole is deemed worthy because of its generally high intellectual capacity and because all species members are viewed as possessing a “radical” intellectual potential from conception.³⁷ From that perspective, nonactualization of human potential does not negate that original radical capacity. The reality, though, is that some human beings lack cognitive capacity or even the potential for developing such capacity from the moment of conception. Attributing high mental function (or potential function) to all species members therefore rings hollow.

Some secular philosophers also contend that all human beings, regardless of intellectual function, have full moral status. That premise is sometimes based on intuition or moral (nonreligious) faith.³⁸ For example, Lois Shepherd calls concern and respect toward helpless beings “an essential part of being human, of existing.”³⁹ Peter Byrne speaks of a “humanist perception” that all humans are morally equal.⁴⁰ Jean Elshtain posits a sort of secular golden rule of moral reciprocity. Each human must respect even the most debilitated humans because anyone could end up in such a debilitated condition.⁴¹

The Legal and Moral Status of the Profoundly Disabled

We have seen two theories of personhood—one grounded in intellectual function and the other in species membership. Which of those visions prevails? And why? For starters, I agree with Hilde Lindemann Nelson that personhood is largely a cultural construct that is reflected in social practice.⁴² American society recognizes as persons with full moral status all live human beings, even those who cannot articulate their feelings and emotions so that their personalities are the product of interpretation by the people around them. That social construct does not even require consciousness for full moral status, as attested by the treatment of permanently unconscious humans as persons.

Using social practice as a key mark of personhood would seem to present grave threats of abuse, as historically illustrated by slavery and the holocaust. My response is that social practice cannot be an exclusive determinant and must be subjected to critical scrutiny. As part of that scrutiny, the concept of intrinsic human dignity must serve as a limit or check when social practice excessively contracts the criteria of personhood. When social practice expands the definition of personhood (for example, by including some nonhuman animals), no moral violation generally takes place. Perhaps intrinsic human dignity would be offended by an overly expansive definition of personhood (for example, treating rocks as persons), but certainly the inclusion of profoundly disabled humans within the category of persons does not constitute an offense to human dignity. Nor does inclusion of all humans derogate the status of nonhumans.⁴³

American society has constructed a version of personhood that includes all live human beings as rights-bearing persons with full moral stature. Law currently treats even the most profoundly disabled human beings as persons. Constitutional protection of persons attaches at live human birth.⁴⁴ The U.S. Supreme Court adhered to that position when it refused to view a woman's exercise of procreative choice via an abortion as impinging on the interests of a person protected by the Fourteenth Amendment. That is, the Court did not treat an unborn fetus as a person with equal status to the mother. While the Court declared that government might generally preclude postviability abortion, the government's interest was deemed to be protection of a *potential* person rather than an actual person.

Courts and legislatures generally strive to safeguard the interests of born-alive humans without regard to level of intellectual function.⁴⁵ The traditional *parens patriae* authority is oriented toward protecting vulnerable people. Within that framework, a profoundly disabled human is no “less worthy of dignity and respect in the eyes of the law than a competent person.”⁴⁶ That approach is evident in the legal response to permanently unconscious beings at both ends of the trajectory of human existence— anencephalic newborns and adults who have deteriorated to a permanently vegetative state (PVS). (Both a patient in a permanently vegetative state and an anencephalic infant retain lower-brain function and thus are not dead under a whole-brain standard for declaring death.) The law consistently treats permanently unconscious beings as persons entitled to respect.⁴⁷ In a 1992 Florida case,⁴⁸ parents of an anencephalic infant sought judicial authorization to have vital organs removed from their newborn in order to donate those organs to other critically ill infants whose lives could be salvaged. The parents argued that their anencephalic newborn, permanently lacking neocortical function and totally unable to interact with his environment, was for all practical purposes dead and ought to be declared dead to permit some human gain to be extracted from an otherwise unmitigated tragedy. (Apparently, the organs would be less suitable for transplant if surgeons waited until the anencephalic infant became totally brain dead.) The court summarily rejected the parents’ plea for permission to transplant organs. The judge made clear that as long as the infant had even rudimentary, autonomic brain function, he would be regarded as a live person and protected against killing, by organ harvest or otherwise, even for the purpose of salvaging another human life or lives. A similar attitude solicitous of the well-being of an anencephalic infant prevailed in a federal district court in Virginia in 1993.⁴⁹ That court ruled that an anencephalic infant was protected by federal legislation prohibiting discrimination against the disabled. According to the court, a hospital’s withdrawal of a life-sustaining respirator from the anencephalic infant (counter to the mother’s wishes) would constitute unlawful discrimination against a disabled person.

A similar judicial attitude treats a PVS patient as a person entitled to protection against abusive treatment or invidious discrimination. All states deem a patient who is in a permanently vegetative state to be alive and entitled to continued life support unless a conscientious surrogate determines

by some acceptable criterion that life support should be withdrawn. In most jurisdictions, that criterion is either best interests of the patient (a judgment that the insensate patient would be better off dead than alive) or substituted judgment (a determination that the patient, if miraculously capable of decision, would opt for death rather than a permanently insentient limbo). A few states are more restrictive, precluding removal of life support unless the PVS patient had previously expressed such a wish. In *Cruzan v. Director, Missouri Department of Health*,⁵⁰ the parents of a Missouri woman who had been rendered permanently unconscious as a result of an automobile accident sought judicial authorization for withdrawal of life-sustaining medical intervention (a tube supplying artificial nutrition) from their daughter. The state insisted on clear and convincing evidence of the now incompetent patient's prior wishes as a precondition to withdrawal of life support. The parents asserted their insentient daughter's liberty-based right to have her medical fate determined by a conscientious guardian. The U.S. Supreme Court, in upholding Missouri's insistence on clear and convincing evidence, relied on the public interest in protecting vulnerable persons (including permanently unconscious patients) against possible exploitation. To the majority (in a five to four decision), Missouri at least had a rational reason for insisting on prior instructions from the patient. No member of the Court hesitated in accepting permanently unconscious patients as persons deserving of legislative and constitutional protection.⁵¹

What are the reasons for the established practice of treating profoundly disabled humans as rights-bearing persons with full moral status? There are a number of explanations—some emotional, some practical, and some theoretical. On an emotional plane, one consideration is a “sentimental regard that we tend to have for beings of our own kind.”⁵² Many people have an instinctive emotional affinity toward beings who at least look like they are fellow persons: “We find it revolting to even think about killing a newborn baby whose anatomical features are so like our own,”⁵³ even if the newborn possesses only primitive intellectual function. Jane English comments on species affinity: “Our psychological Constitution makes it the case that . . . our ethical theory . . . must prohibit certain treatment of persons who are significantly personlike.”⁵⁴ This emotional factor helps account for the practice of fully respecting profoundly disabled beings. (A similar emotional affinity may help account for the Supreme Court's construction of “viability” as the point at which states can protect a fetus from abortion;

a third-trimester fetus bears a strong physical resemblance to newborns and thereby strikes an emotional chord in observers.⁵⁵)

Another, perhaps less persuasive, reason to accord maximum moral status to the profoundly disabled is their role in enhancing the emotional lives of other persons.⁵⁶ People can form strong attachments to fellow humans—even those who operate at a dismal intellectual level. Mary Anne Warren calls this factor “transitivity of respect”—a notion that society ought to respect the fact that some persons love and attribute full stature to profoundly disabled beings.⁵⁷ In other words, society ought to accept the moral significance that some persons attribute to profoundly disabled beings. This rationale for legally protecting the profoundly disabled—as contributors to social relations—seems less persuasive for two reasons. Nonhuman animals serve a similar function, and no consensus yet supports personhood or comparable rights for even higher-functioning animals. And if the status of a profoundly disabled being is dependent on social contacts, some such beings might be excluded from protection because they had been abandoned by parents or other family. Unless health-care providers or others have bonded with the isolated being, full moral stature might be found lacking—a clearly undesirable result.

Other, more practical reasons exist for deeming profoundly disabled humans to be persons with full moral status regardless of their low level of intellectual function. Even philosophers who tend to associate personhood and full moral status with high intellectual function find “social considerations” or a general public interest in imputing full stature and rights to the profoundly disabled.⁵⁸ For example, an instrumental rationale is available. Societal solicitude toward helpless and vulnerable human beings (even nonpersons) may help cultivate sentiments of sympathy and caring within the general population.⁵⁹ Protection of the profoundly disabled can also be viewed as a symbolic reminder of the sanctity of human life. Reluctance to neglect or abandon any human being conveys a social message about the worth of all human life. The further claim is that there is symbolic importance in how society treats frail and vulnerable beings; by protecting the profoundly disabled, society seeks to promote an atmosphere where the infirm are well treated and secure. Exclusion of certain human “nonpersons” from full protection and respect would risk eroding respect for humans who qualify as persons but are still intellectually marginal.⁶⁰

Other social interests are promoted by according full stature and rights to profoundly disabled beings. If personhood and rights-bearing status were reserved to humans who have a particular level of intellectual function, hazards would exist regarding a possible arbitrary fixing of the relevant line and an arbitrary or abusive application of such a line. How much permanent brain dysfunction warrants exclusion from the human community? Even if a clear, coherent line were theoretically establishable, its administration might still be problematic. Here's an example. At one point, physicians at a Loma Linda, California, medical facility were willing to use anencephalic infants as potential organ donors.⁶¹ The definition of anencephaly seemed clear—including total absence of neocortical or upper-brain function. Yet the Loma Linda staff received numerous calls from outside physicians volunteering newborns who, while exhibiting serious deficits, retained significant intellectual function. Treatment of all human beings as rights-holding persons safeguards against the arbitrary exclusion of some helpless individuals. In short, good practical reasons exist to treat profoundly disabled humans as rights-bearing persons with full moral stature.

These “practical” considerations justify the legal system’s attribution of full rights-bearing status to all live humans. Is there also a theoretical basis for according full *moral* status to all human beings? As noted, some moral philosophers regard a high level of intellectual function (rationality, autonomy, or moral agency) as the key to personhood and full moral status. And many people’s intuition may be that richer experiential lives “count for more.”⁶²

This spectrum of intellectual thresholds for personhood seem somewhat arbitrary. (Each propounder of a requisite level of intellectual function has a rationale, but none of them seems convincing.) One of the common elements in this spectrum is that most of the suggested levels of intellectual function would exclude many if not most profoundly disabled individuals. That fact makes it worth asking whether any theoretical basis other than religious faith reinforces the practical reasons for including all humans as persons.

Alan Gewirth has articulated a theory that is capable of rationalizing full moral status for almost all profoundly disabled humans. Gewirth sees purposive or goal-oriented behavior as the characteristic that makes persons special and worthy.⁶³ However, Gewirth himself doesn’t clearly fix the level

of intellectual function necessary for being a purposive agent and in at least some writings seems to deny full moral stature to profoundly disabled humans.⁶⁴ Evelyn Pluhar adapts Gewirth's approach to full moral status in a way that clearly attributes full moral significance to almost all profoundly disabled humans.⁶⁵ Pluhar defines *purposive behavior* (which she agrees is the key to full moral status) as including all "conative" beings—those who are goal directed and have desires, even basic desires for survival, food, shelter, and companionship. For her, that level of purposive agency is possessed by any human with even very low-level intellectual abilities.⁶⁶

What makes purposive behavior and conscious desire the keys to full moral status? In a way, Gewirth and Pluhar do not look so much at characteristics that make beings particularly worthy of protection but, rather, try to assess moral harm. To some extent, Pluhar relies on intuition in saying that profoundly disabled but purposive people are morally significant. (I already noted the emotional factor that helps account for legal protection for profoundly disabled humans.) Perhaps the further point is that to Gewirth and Pluhar, frustration of purposive behavior (by death or inhumane treatment) just seems to be a significant enough harm to warrant empathy and concern. Some philosophers in defining moral harm tend to ask whether the being whose status is in issue is capable of valuing his or her own existence.⁶⁷ From their perspective, frustration of conscious humans' desire to live constitutes a moral wrong because it deprives them (without justification) of something that they value.⁶⁸ For Pluhar, there is no hierarchy of moral harm in killing a highly intelligent person as opposed to a mentally disabled person. "A bright, young human adult loses a complex network of relationships and has her life plan aborted. A significantly retarded human of the same age loses just as much from *his* perspective. Each loses *all that is precious*, all that matters to him or her."⁶⁹

All this appeals to me. I like John Keown's suggestion that a person is anyone "having the ability to achieve some purposeful or self-directed action or to achieve some goal of importance to him or her self."⁷⁰ For me, this formulation focuses on the "common nature" of human beings—their mental capacity. The fact that the profoundly disabled have impaired brain function and don't reach an intellectual level that is typical of humans doesn't negate their common humanity. While I readily understand a position that attributes full moral status to every member of the human species—even permanently unconscious ones—some cognitive function seems to

me like an integral part of a common human nature. In effect, the purposiveness position deprives permanently unconscious humans of moral status and confers full moral status on any conscious human being who is capable of purposive behavior, even toward basic or simplistic goals. Any profoundly disabled person who does not meet the suggested criterion for moral status (conative conduct) would still receive full legal protection for the practical reasons cited above. The current legal structure goes further and protects even permanently unconscious humans. As is developed in chapters 2 and 4, this does not mean that permanently unconscious beings must be kept alive. In most states, a surrogate may remove life-sustaining medical intervention from a permanently unconscious human. I will go further and argue that preservation of permanently unconscious persons violates intrinsic human dignity. First, let me explain what I mean by intrinsic human dignity.

The Role of Intrinsic Human Dignity

I argued earlier that all humans have full legal status and that virtually all humans (excluding primarily the permanently unconscious) have full moral status as persons. An important concomitant of personhood is entitlement to respect for dignity.⁷¹ For reasons already cited, profoundly disabled persons get that respect for dignity even though they lack the intellectual capacity that generally characterizes the human species.

Because human dignity plays an important role in resolving the issues that are addressed in this book, I need to better explain at the outset what I mean by human dignity. After all, human dignity means many things to many people, as the term *dignity* is used in varied senses. People can comport themselves with an air of dignity—that is, with a certain calm and composure. Another meaning of dignity has to do with enjoyment of a secure environment and protection of well-being. Some commentators see the provision of decent living conditions as a central requirement of respect for human dignity. Their object is to secure for all persons the material conditions in which the human spirit can operate and flourish.⁷² In that vein, the Universal Declaration of Human Rights treats economic security as being indispensable for human dignity and the development of person-ality. A similar concern about a humane and nurturing environment was certainly part of the legal attack that was launched in the United States in the 1970s against the poor conditions in which the mentally retarded were

living in public institutions.⁷³ The provision of decent living conditions may be a worthwhile goal for humanists, but only at an extreme level of deprivation is human dignity implicated.

More commonly, the concept of human dignity functions as an intrinsic value or an inherent stature that demands respect. That notion of dignity as an inherent stature underlies and informs many human rights. Respect for human dignity helps account for concepts such as freedom and justice and for rights such as bodily integrity, physical security, freedom of speech and conscience, freedom of association, privacy, and personal mobility.⁷⁴ As the introduction to the Council of Europe's Convention on Human Rights explains: "human dignity constitutes the essential value" that underlies various human rights protected by the Convention.⁷⁵ I am interested in exploring (at this point and in the rest of the book) the nature and degree of the respect that flows from the intrinsic dignity of human beings. What conduct toward human beings is so disrespectful of their moral stature that it violates intrinsic human dignity? What core of respect, what minimum norm of behavior, is morally owed to every human being? And how does that norm get applied to profoundly disabled persons?

Many commentators stress a strong link between dignity and autonomy, in part because they value human intellectual capacity for considered choice as a key human attribute.⁷⁶ For those commentators, upholding autonomy is a basic aspect of respecting human dignity. This veneration of autonomy extends to medical decision making for persons who are fully competent, competent to make *some* medical decisions, or formerly competent. An ethic that upholds autonomy dominates both medical mores and the legal framework governing medical interventions affecting task-competent persons. Traditional legal doctrine requiring informed consent for medical interventions underscores the importance that our culture attaches to self-determination. Personal choice in medical decision making is such an integral element of American culture that it has even been acknowledged to be part of fundamental liberty under the Fourteenth Amendment—among the "choices central to personal dignity and autonomy" that qualify for special constitutional protection.⁷⁷ Many courts have recognized that the upholding of a competent patient's medical choice is integral to human dignity.⁷⁸

Autonomous choice also plays an important role in determining the medical fate of formerly competent persons. Every state has recognized what I call "prospective autonomy"⁷⁹ via laws that compel adherence to

advance medical directives—personal instructions issued by competent persons to govern their postcompetence medical handling.⁸⁰ Even for previously competent persons who fail to articulate their medical choices in advance, law often seeks to honor self-determination in shaping the standards that are imposed on surrogate decision makers. Substituted judgment is a common legal approach that instructs a surrogate decision maker to implement the medical course that the now incompetent patient would have chosen; that projection of the patient's wishes is grounded on the patient's own values and preferences when available.⁸¹

Most persons do not articulate postcompetence medical preferences in advance. In the absence of prior expressions, many states direct a surrogate decision maker to adhere to the incompetent patient's best interests. In jurisdictions where "best interests" is supposed to govern postcompetence medical decisions, a strong self-determination current is still present. The previously competent patient's own values and preferences are deemed highly relevant to defining the now incompetent patient's best interests. When those values and preferences are undiscernible or indeterminate, the patient's best interests are determined by an examination of the factors that most competent people deem crucial to their postcompetence medical handling—principally, the avoidance of extreme pain and other intolerably demeaning conditions. Thus, even under an objective best-interests formula, surrogates are in a sense required to honor self-determination by applying factors (benefits and burdens) that most people would want considered. This is part of an effort to project what the now incompetent patient would have wanted by assuming (in the absence of contrary indications) that this formerly competent patient would want his or her well-being promoted and by defining well-being according to how most competent persons would define their own postcompetence well-being.

An ethic of human dignity focused on self-determination cannot readily be applied to persons who have never been competent. It is true that the prevailing medical and legal approach is to honor the maximum self-determination possible for mentally disabled persons. This means upholding their decisions when they can understand the nature and consequences of the particular medical decision in issue. However, profoundly disabled persons, as I have defined them, have never had sufficient cognitive function to understand the nature and consequences of serious medical issues. Nor have they adopted philosophical or religious values that might guide

medical decisions on their behalf. The central ethic in surrogate decision making for the never competent cannot therefore be autonomy. Conventional wisdom and many judicial opinions assert that ethical focus shifts to the never competent person's best interests—meaning personal well-being in the sense of physical and psychic integrity.

Chapter 4 addresses in detail the best-interests formula as it has been applied to serious medical decisions for profoundly disabled persons. It explains how law purports to apply a best-interests formula geared to the well-being of the never competent person as assessed by a reasonable person—a competent person who is making a considered choice while facing the circumstances that affect the never competent patient, and assuming the perspective (as far as possible) of the never competent patient. (This in essence is also the standard that is applied to a formerly competent patient who never indicated personal values or preferences to guide postcompetence decision making.)

This usage of a best-interests formula—with its focus on the well-being of the never competent person—is supported by a couple of theories that are consistent with human dignity. First, the common law traditionally regards government as having a *parens patriae* protective duty toward helpless persons. This is certainly a pervasive theme when formal guardians have been judicially appointed to make surrogate medical decisions for a never competent person or when a judge is charged with making the ultimate decision on behalf of a never competent patient.⁸² A strict best-interests formula is customarily articulated in those contexts. Second, a patient's best interests are commonly viewed as an appropriate and humane default standard for surrogate decision making where never competent persons cannot make binding personal choices.⁸³ That is, considered choice by a profoundly disabled person is impossible, but the courts assume that any human being, no matter how mentally disabled, would want to have their own interests protected and promoted. Respect for persons therefore includes protection of the well-being interests of never competent persons.

While both these perspectives seem to dictate a surrogate's strict adherence to a ward's personal interests, practice does not necessarily follow that narrow course. My own perspective (to be further explained in chapter 4) is that best interests is not the standard that always governs surrogate medical decisions on behalf of never competent persons. I suggest in chapters 4 and 5 that the term *best* interests of the incompetent person does not

really mean the maximum possible promotion of the patient's interests and that the interests of other persons may sometimes come into play.

Whatever the precise bounds of the best-interests legal standard, the point remains that one element of human dignity—respect for autonomy—has diminished importance in the context of serious medical decisions on behalf of profoundly disabled persons. Yet an absence of autonomy by no means relegates the profoundly disabled person to an undignified status.

A different aspect of human dignity occupies a central role in shaping the medical fate of profoundly disabled persons. I call this critical element *intrinsic human dignity*—meaning a core conception of basic respect to which every human being is entitled, regardless of cognitive capacity.⁸⁴ That notion of basic respect for every human being serves as an ultimate moral constraint on the surrogate treatment of profoundly disabled persons. That normative sense of human dignity, an inviolable core of respect, has been acknowledged in numerous legal contexts ranging from various international conventions on human rights to the constitutional jurisprudence of several countries.⁸⁵ For example, Canadian jurisprudence recognizes that “human dignity has an absolute core that may not be infringed.”⁸⁶

An integral part of human dignity is freedom from demeaning or degrading treatment. The full moral status of persons insulates them against unjust debasement and unwarranted contempt or humiliation, at least at extremes.⁸⁷ But not every offense to a person's dignity—not every frustration of will or subjection to embarrassment—is violative of intrinsic human dignity. My concept of intrinsic human dignity refers only to conduct that is so disrespectful and degrading of a person that it intolerably assaults core human dignity—that is, it violates an irreducible minimum of respect owed every human being.⁸⁸ Prison inmates are relegated to living conditions that are demeaning and undignified, but only when the conditions become so degrading as to be intolerably inhumane do they violate intrinsic human dignity. Bodily integrity is an important dignitary interest, but only when that interest is egregiously invaded—as with rape, torture, or other unjustified bodily encroachments—is core human dignity violated. As the European Council has explained, every unprovoked use of physical force against a person in custody may be degrading and deplorable, but only when police conduct causes intense physical or mental suffering or takes particularly repugnant forms does it become violative of the provi-

sion of the European Convention on Human Rights that protects intrinsic human dignity.⁸⁹

A similar conception of core matters entitled to special protection appears in the context of competent persons. While autonomy is certainly linked to dignity, not every constraint on personal choice violates intrinsic human dignity. Only when *fundamental* liberty interests (such as freedom of conscience or choices about marriage and procreation) are intolerably invaded or denied does core human dignity get violated.

How do we differentiate between run-of-the-mill infringements of dignity and impingements on inviolable, core human dignity? In each culture, the definition of core human dignity is fixed by the collective conscience of the community as informed by experience and critical reflection. There is an inevitable element of cultural variability. One culture's notion of a fundamental freedom—as with polygamy, abortion, driver's licenses for women, or euthanasia—may offend human dignity in another culture. Some cultures will deem dwarf throwing or participation in degrading peep shows or clean-shaven faces for men to be intolerably demeaning; others will not. At the same time, some universal norms of human dignity—for example, a ban on slavery—prevail across cultures. And each culture will have some elements of dignity that it considers inviolable.

A core conception of human dignity is relevant to several situations (addressed later in this book) in which profound mental disability necessitates surrogate control of serious medical decisions. As is shown in the next chapter, the concept of intrinsic human dignity can provide a basis for a claim that mentally incompetent persons are entitled to have a surrogate decision maker choose for them, at least as to medical decisions that can benefit the incompetent person. That is, it may be violative of human dignity to exclude certain categories of medical decisions (for example, contraception or end-of-life decisions) from surrogate authority. The notion of intrinsic human dignity thus promotes broad access to all kinds of surrogate medical decisions that may prevent profoundly disabled persons from reaching an intolerably demeaning or undignified condition.

Intrinsic human dignity is also relevant in defining the protective legal standard (commonly articulated as the “best-interests” standard) that binds surrogate decision makers when they make important medical decisions on behalf of profoundly disabled persons. In chapters 4 and 5, I argue that

the applicable legal standards permit some consideration of third-party interests, such as those of integral family members. At the same time, I assert that while surrogate decision makers may properly consider third-party interests in certain areas, such as tissue donation or participation in non-therapeutic research, intrinsic human dignity imposes significant protections against unconscionable exploitation of profoundly disabled persons. Finally, intrinsic human dignity informs how surrogate decision makers must treat the voice or expressions of the profoundly disabled (Chapter 6). In short, I contend in this book that the normative force of intrinsic, core human dignity informs in several respects the legal and moral framework for surrogate decision making on behalf of profoundly disabled persons. I now address how intrinsic human dignity relates to a profoundly disabled person's entitlement to a surrogate's determination about an appropriate medical course.