

THE *ElderLaw* JOURNAL

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FOREWORD

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TRIBUTE

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Wayne R. LaFave

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ESSAY

The Right to Live

Leigh B. Middleditch, Jr.

Joel H. Trotter



PRODUCED BY STUDENTS OF THE COLLEGE OF LAW
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Jack Liu, Photographer

EUGENE F. SCOLES

FOREWORD: ACCELERATION OF DEATH OF THE TERMINALLY ILL WITH PHYSICIAN ASSISTANCE

Eugene F. Scoles

I am highly gratified to be honored by this issue of *The Elder Law Journal*. The appreciation and respect of one's peers and those involved in the development of law is one of life's greatest rewards. That most of my peers are also friends is even more rewarding, not withstanding the occasional practical joke or bit of humor that relieves academic life.¹

The Elder Law Journal plays an important role in the development of law in an area of increasing concern to the legal profession and to society. Matters within the scope of elder law have an ever-growing relevance as well to the practice of many other professionals such as care managers, health care providers, social workers, gerontologists, and financial and insurance advisors.

The issues treated in the *Journal* demonstrate the complexity of this sphere of the law. The articles in this issue serve as an illustration. Professor Harris explores a subtle but strikingly persistent phenomenon that is highly significant in political and legislative activity. Messrs. Middleditch and Trotter address an important conflict that is,

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1. Earlier references to some such whimsical relief may be found in 63 OR. L. REV. 533-56 (1984); 1989 U. ILL. L. REV. 829-44. As a former colleague once observed, "It's nice to hear these things while you are alive."

in part, an outgrowth of the cost and limited availability of health care services in this country. The piece by Professor Pickering Francis, as well as those by law students Zieger, Herrington, and Hedges, reflect the overwhelming impact of the often overweening governmental involvement in highly personal decisions and needs.

All of these pieces reflect the need for exploration, discussion, and understanding of the complex interwoven fabric of law, economics, social policy, and ethics in what has come to be called elder law. Most of the attorneys now concerned with this area of the law have been previously involved with matters of individual and family protection involving family law, the planning and administration of intergenerational property transactions, or poverty law. These areas have always involved matters of personal autonomy and competence requiring consideration of the influence of all family members, resources, and events. Where personal ambitions, affections, and financial concerns are complicated by health care factors, such as insurance and Medicare, in an aging population, elder law has emerged as a near specialty to address the resulting complexity.

In this constant tension among individuals, their family and associates, and our governmental and social infrastructure, the relative force of the policies furthering the personal autonomy of competent individuals, group protection, as well as social and economic responsibility, fluctuate with the changing circumstances. Assuring and protecting fully informed decisions by competent persons is most important. Consequently, adequate representation and advice for all the participants is critical and is often limited. The particular need for ombudsman assistance and protection increases with the expanding elderly segment of our nonaffluent citizenry if they are to avoid substantial loss of effective personal autonomy.

Health care matters demand particular attention because the necessity for care increases with age and often overwhelms family resources. Social and governmental attempts to meet individual needs necessarily involve legal guidelines for providers. Existing guidelines for near-death decisions are unclear as the nature and extent of governmental or legislative interest is still evolving. One instance involves pain management for the seriously or terminally ill, a situation in which reasonably careful providers following directions of their patients need protection from the risk of criminal or civil liability or professional discipline. Recently, health care issues have focussed on

whether appropriate care in extreme cases includes medical assistance in hastening death at the request of a competent patient.

Physician assistance in hastening death at the request of competent terminally ill patients is a complicated issue and one on which many different views currently are held. The following is submitted as an appropriate resolution of the governmental interest in this most personal matter.²

Many of our early, historically developed concepts simply are not compatible with the present state of health care. For example, many people inappropriately refer to physician-assisted death of the terminally ill as "assisted suicide." The term "suicide" traditionally connoted self-inflicted death that prematurely terminated a life that held the promise of meaning, value, and enjoyment, a life during which the person's present problems might be overcome. Common comments following a suicide were, "He was so young," or "What a waste," all reflecting the premature termination of life that was potentially valuable to the individual and to society. Accelerating the death of a terminally ill person is quite different from the historical concept of suicide. Modern technology frequently extends our physical bodily existence beyond any prospect of value or enjoyment. A terminally ill person who hastens death just has not committed "suicide" in the traditional sense. Rather, we are talking about brief shortening of the last days of life when the quality of living is gone and there is no potential for its improvement. This distinction is tacitly reflected in the absence of prosecutions of doctors who quietly help a terminally ill patient briefly hasten death.

There are many things we ought not frame as legal issues, and perhaps this is one of them. However, our "overlawed" society has thrust this matter into the legal realm and upon our courts. The issue demands careful analysis that goes beyond the value-laden generalizations and emotions that cloud our thinking.

There are competent people who are in such extreme discomfort from terminal illness that they seriously want to accelerate their death. There are competent doctors who believe their patients' wishes and

2. The remainder of this piece is reprinted from *Early Concepts of Life and Death Are Not Compatible with the Present State of Health Care*, REGISTER-GUARD (Eugene, Or.), May 18, 1997, at B1. This piece, which appeared on the editorial opinion pages of the *Register-Guard*, was written before the more recent U.S. Supreme Court cases and the legislative referral referendum on the Death with Dignity Act of 1994, OR. REV. STAT. §§ 127.800-897 (1996).

directions should be honored and that those patients should not be forced to suffer a horrible, lingering, but certain death. Thus narrowed, the question as restated is whether those patients and those doctors should be free of restraint by the rest of us to do what they competently and conscientiously decide is best to do. Should the closing of life in these circumstances be regarded as a private matter between physician and patient? Protection of the *autonomy* of the individual in private matters is highly valued and one of the strongest policies in our law. In the provision of medical care, the law protects that autonomy by assuring that the patient is *competent* and that patient decisions are *informed*. At the core of the debate over physician-assisted death of the terminally ill are these two basic legal principles: *autonomy of competent persons* and *informed consent* to medical procedures.

Generally, in our society, we legally recognize personal autonomy by permitting people to do what they want as long as it does not unduly interfere with others. Broadly stated, this right to do in private anything that does not adversely affect or endanger others is the starting point for measuring governmental regulation of our activities. We protect vulnerable persons by establishing standards to assure the competence and understanding necessary for a valid decision. Health care providers, along with the lawyers who advise them, are greatly experienced experts in assuring competence and informed consent. There seems no reason why reliance on that expertise is not as appropriate in the matter of accelerating death as it is in open heart surgery.

The law has long recognized the right of the individual to reject medical treatment for prolonging life when others are not endangered. More recently, the law has recognized the right of a competent person or the person's authorized agent to withdraw life support such as respirators or tubal feeding and hydration. Some suggest significant difference exists between the affirmative act of withdrawing life support with knowledge of the certain result of death and the act of administering a drug with knowledge of the same certain result of death. However, both involve an affirmative act taken in the best interests and consistent with directions of the patient with knowledge that death is certain to follow.

The alternative to physician-assisted death can be a prolonged, painful death, traumatic to all concerned, which in many instances would not have occurred had not prior "semiheroic" medical intervention failed. In this situation, some physicians offer hospice care

and extensive palliative or pain management therapy. Commonly prescribed pain relief medication seems to be medically acceptable even if the medication not only kills the pain but also kills the patient by causing heart or respiratory failure. Hospice care is also well accepted, a practice in which death can result from starvation or dehydration. To suggest that a doctor “doesn’t intend death,” and is therefore not morally responsible when death is a known consequence of heavy sedation or pain-relieving medication, appears to be a semantic screen to accommodate the existing practice of physician-assisted death without admitting it. It appears that many patients seek and obtain medications from their family physicians that permit the patients to die in their sleep.

What are the interests of the state, of our government, in precluding competent, informed, terminally ill patients from obtaining the assistance of physicians in briefly shortening their unbearable lives? When is the life of an individual worth more to the state than it is to the person living it? The protection of the public is the usual reason for limiting the otherwise autonomous acts of individuals. What is the danger to the public from the private, consensual acts of physician and patient when each is competent, fully informed, and free from coercion?

In bluntly realistic economic terms, the extension of a non-productive life that burdens the health care system with fruitless efforts weighs in favor of a public interest in supporting assisted death of the terminally ill. However, this economic burden argument in an era of limited resources and managed health care underlies the “slippery slope” argument. This danger is avoided by appropriate safeguards assuring patient autonomy and informed decisions.

Economic considerations are also sometimes an expressed concern in family relationships and surrogate decisions for fear of coerced decisions. However, standards assuring patient autonomy seem an adequate safeguard. Further, the intimate concerns of a competent patient may well include economic factors supporting accelerating death, particularly for those who would prefer that their property go to support and protect their loved ones rather than to the health care industry for expensive but futile ministrations.

There is another stark truth that is seldom articulated. People can and do kill themselves. For one who is fully physically able, there are many ways to self-destruct. Anyone who is reasonably mobile can terminate his life. However, because of limited mobility, the termi-

nally ill person may lose that opportunity and have to rely on others for assistance. Such a person naturally turns to a physician who has the knowledge necessary for a dignified, clean, and quiet death. Should the state discriminate against these persons to preclude them from exercising their choice as physically able people can and do?

Physician assistance in accelerating death at the insistence of a terminally ill patient raises ethical and moral concerns which may control the attitudes of most people regarding it. But, the state's governmental interests need to be separated from our private preferences. Laws can regulate only conduct and not the moral attitude of individuals. Further, in our system of government, we assiduously avoid imposing the moral, or concomitant religious, views of the majority upon others by governmental action. Thus, personal preferences are not a reason to restrict the choices of patients so long as their actions do not endanger or unduly interfere with others.

On the other hand, professional ethical standards concern fair conduct toward others and are appropriately the subject of governmental regulation of specialized professions serving the public. The medical profession's ethical standards govern the conduct of physicians to insure that physicians further their patients' well-being. Traditionally, medical ethics have required physicians to try to cure patients and overcome disease, not to aid in dying. Modern medicine often extends patients' physical life far beyond hope of cure and results only in the artificial extension of physical life. In this new situation, in which cure or recovery of the patient is not a prospect, the well-being and comfort of the patient has become more and more a focus of medical treatment rather than the traditional sole object of curing the patient. Pain management, palliative care, and hospice reflect this trend. This change of direction has led many doctors and others to believe that the patient's well-being and quality of life is the primary object of the medical profession. In the case of the competent terminally ill patient this latter view may include assisting the patient to achieve a reasonable end to a futile life. Whether the patient's well-being ethically extends to hastening death centers on the dubious difference between withdrawal of life support or ministration of pain and body numbing drugs while the body dies of disease, on the one hand, and on the other, ministrations of life-terminating drugs to the terminally ill patient certain to die within a short time. In this narrow area of disagreement within the medical profession, the direction of the competent patient should control. The only governmental interest

would seem to be the concern for patient autonomy and informed consent, just as in other areas of health care.

In assessing the interwoven issues and concerns incident to competent and fully informed terminally ill patients seeking the assistance of their physicians, several elements stand out. This really is a new social issue in a new health care setting and is unlike the historically familiar suicides of the past. It needs to be addressed as a new issue. Many patients feel that a quiet, dignified end of life is preferable to an expensive, lingering, and painful degradation to ultimate physical death. Many physicians believe that their professional obligation to treat their patients during life includes accommodating the patients' wishes for ending life with dignity. There is evidence that physicians frequently quietly accede to patient wishes to help them slip out of life in a private, dignified manner. For purposes of assessing the role of government, there is little difference between this matter and other serious health care decisions. The governmental interest is not to prohibit but to assure that the patient and the physician are protected when they competently choose an alternative after being fully informed in the circumstances. Legislation which provides standards assuring patient autonomy and fully informed decisions is essentially the only appropriate legislative intrusion in this most private and personal aspect of an individual's life.

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ON SCOLES

Wayne R. LaFave

It is indeed fitting and proper that this issue of *The Elder Law Journal* should be dedicated to my former colleague Eugene F. Scoles, for he is without question an elder. I do not mean to suggest by this that Gene, affectionately known as “Skippy” by his legion of friends, is a presbyter, a caprifoliaceous tree, or the udder of a cow (to mention but a few of the various meanings of “elder” put forward by the lexicographers). I am thus tempted to more precisely describe Scoles by use of the appellation “geezer,” except that such a politically incorrect term, commonly used when making sport of the chronologically challenged,¹ would surely raise the hackles of the editors of this upstanding journal.

Not only that, but to use only the g-word to characterize Gene would not do justice to the man, as he is that and much, much more.

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1. Just type the word “geezer” into your Internet browser, and you will see what I mean. Three examples will suffice here:

- (1) GEEZER (speaking to friend): I just got a brand new hearing aid.
FRIEND: What kind is it? GEEZER: About 4:30.
- (2) GEEZER (speaking to his doctor): Are these pills for impotency safe? DR.: Just one problem: swallow them real fast or you’ll get a stiff neck.
- (3) On a lark the geezer’s friends dispatched a “lady of the evening” to his chambers. She boldly entered and declared, “I’m here to give you super sex”; the geezer thought a moment and replied, “I’ll have soup.”

I hasten to add that none of these stories has anything to do with Scoles. He purports that all his equipment is intact, and that he doesn’t like soup!

On the basis of my association with Gene during the many years we were colleagues on the Illinois law faculty, another word I would use to describe Scoles is *persistent*. He simply doesn't know the meaning of failure.² Just one example, if I may. Back in the '60s, Gene and I and several other members of the meager band which then made up the law faculty were rather frequent luncheon companions. Several days a week, we would together make the rounds of Champaign-Urbana's finest eating establishments (and, because that list is quickly exhausted, many that were not so fine). It only took a few of these engagements before I became convinced, as later turned out to be the case, that each session would conclude in exactly the same way. The waitress would come by to ask if anyone would like dessert, Gene would ask the waitress if the establishment was serving Nesselrode pie, the waitress would answer in the negative, and we would then pay the bill and depart. My bafflement about that ceremony continues to the present day. I mean, just what is Nesselrode pie? And why did Gene always ask if they had it? And, for that matter, had he received an affirmative response would he have ordered a piece? Or, did he think that the query and his air of disappointment at the negative answer would somehow justify the modesty of his tip?

Another word I would use to describe Eugene Scoles is *practical*, provided of course that the word is immediately followed by another, to wit: jokester. Gene has a great sense of humor, and could not resist the temptation to put something over on his Illinois colleagues whenever the opportunity presented itself. I was the victim on many occasions, and only now am able to even the score ever so slightly. But as an example, I would prefer to mention a trick played on someone else, the inestimable John Cribbet, who after the events set out below accepted the deanship at the College of Law so that he could hand Scoles his walking papers.³ The Cribbets were having a party at their lovely, well-appointed home in Champaign. They had a striking sunken bath in their beautiful main floor *salle de bains*, and it was their custom to fill the tub and float some flowers in it for the gala parties which were a frequent occurrence at the Cribbet manse. They had done so again for a soiree to which all the law faculty, their spouses,

2. I was tempted to conclude this sentence with the phrase "or, for that matter, untold thousands of other words," but resurrection of that hoary chestnut, no matter how apt in this instance, is beneath me.

3. As he ultimately did. Scoles' story is that he left to assume a deanship, but who in their right mind would do something like that voluntarily?

and numerous campus and community dignitaries were invited. Shortly after the arrival of the Scoles at the party, a school of goldfish were discovered swimming in the aforementioned tub by a startled dowager who had stepped into the chamber to powder her nose. I'm not sure whether Gene ever confessed to this prank, but no confession was necessary, as his colleagues to a man (yes, back then they were only men) knew to a certainty the source of the ichthyoid intruders, especially when Scoles tried to cover his tracks with a decidedly piscine alibi. (I must add that this event occurred about a year prior to my arrival at Illinois, but I am confident of the accuracy of the aforementioned account in light of the frequency with which I have heard the story from a great variety of reliable sources.)⁴

Still another word that can properly be used to describe Gene Scoles is *Waltonian*, by which I mean Izaak rather than Sam, for I doubt whether Gene has ever set foot in a Wal-Mart. But his love for the out-of-doors is unparalleled; indeed, Gene never misses a chance to spend time in the wide open spaces, not just communing with nature but interacting with it in a more aggressive fashion. For one thing, Gene enjoys hunting, especially with bow and arrow, and he has bagged a great many deer over the years while at the same time reducing the bovine population only slightly. But Scoles even more so fancies himself a piscatorialist, and with good reason, for on many occasions he has "laid aside business, and gone a-fishing."⁵ Indeed, he seems to have patterned himself after the central character in Walton's *The Compleat Angler*, who, we are told, "is not simply a champion and expositor of the art of angling but a man of tranquil, contented temper, pious and sententious, with a relish for the pleasures of friendship, verse and song, good food, and drink."⁶

Gene Scoles' skills with the fly-rod are themselves legendary. One incident, related to me by Scoles confidant and bon vivant Richard Surles, deserves to be reported here, for it aptly illustrates just how dedicated a fisherman he really is. Gene was off in the wilderness, alone but for his trusty rod and flies, casting again and again into the stream in an effort to attract the fish he just knew were there. Zing, splash; zing, splash; zing, splash; zing, splash, but then just zi—. Scoles had apparently moved his arm inward ever so slightly, just

4. The stories have been essentially identical, although sometimes the fish have been represented as being capacious carp worthy of an emperor's moat.

5. IZAAK WALTON, *THE COMPLEAT ANGLER* 20 (The Ecco Press 1995) (1653).

6. 12 *ENCYCLOPEDIA BRITANNICA* 482 (15th ed. 1997).

enough so that this time he did not cast by his head, but instead whipped the hook into his right ear with tremendous force. The hook was embedded in his ear to such an extent that he could not remove it (the hook that is, not the ear). After a bloodcurdling scream so intense that birds for miles around took wing, Gene becalmed himself and contemplated his course of action. He then drove into town, but passed right by the medical clinic and traveled on to the general store where, line in hand, he hoisted himself by the ear onto the scales and registered his catch with the impressed storekeeper. He was a shoo-in for the "Catch of the Season" award, and the trophy still graces his mantel today.

So, the picture of Scoles which has emerged thus far is that of a persistent, practical (jokester), Waltonian geezer. This is an accurate albeit admittedly incomplete portrait, for I am reasonably confident that the aforementioned attributes do not entirely account for the decision of the editors of this august journal to dedicate an issue of the periodical to him.⁷ Although many other adjectives that could fairly be applied to Gene readily come to mind,⁸ there is but one other that I, as designated panegyrist, shall mention in this encomium: *scholarly*. Over the course of more than four decades in the professorate,⁹ Scoles has attained preeminence in two challenging fields: conflict of laws; and trusts and estates. His many writings and other work in these two areas are of the finest quality, and are justifiably highly regarded by the professors, students, lawyers, and judges who have occasion to use the products of his labors.¹⁰

7. No one, I am sure, would confuse *The Elder Law Journal* with *Field and Stream*.

8. Don't bother looking down here, as I am not going to mention them, even in a footnote. I have no intention of testing the limits of Scoles' sclerodermatousness.

9. Scoles received the J.D., LL.M., and J.S.D. degrees from Iowa, Harvard, and Columbia law schools, respectively. He began his law teaching career in 1946 at Northeastern, moved on to the University of Florida in 1948, and then came to Illinois in 1956, where he remained until he assumed the deanship at the Oregon law school in 1968. He served as dean until 1974 and then remained on the Oregon faculty until his return to Illinois in 1982, where a year later he was named the Max L. Rowe Professor of Law. Scoles "retired" in 1989, and that word needs to be in quotes, as he thereafter taught part-time at Oregon and other schools and has continued his other professional activities.

10. For one thing, Scoles' work is very frequently relied upon by appellate courts. I know this to be so, as I did a "Scoles" search in a computerized legal database, taxing that service to such a degree in uncovering hundreds upon hundreds of cases that smoke began pouring out of my computer.

the way from President of the American Association of Law Schools to grand poo-bah of the Champaign County chapter of the Izaak Walton League. But I wish to give particular mention to one other accomplishment of Eugene Scoles, for it exemplifies perhaps better than anything else the bringing to bear upon a series of difficult issues his vast knowledge in *both* the conflicts and estates fields. I refer to his service as U.S. Delegate to The Hague Conference on Private International Law Special Commission on Decedents' Estates. Gene attended meetings at the Hague in November 1986, March-April 1987, September-October 1987, and finally the three-week plenary session in October 1988 at which the thirty-three participating nations approved without dissent the Convention on the Law Applicable to Succession to the Estates of Deceased Persons. The Convention serves to provide practical and predictable rules for determining the applicable law to avoid the costly confusion and delay incident to settling estates of decedents who die leaving assets in different countries. Scoles played a major role in this urgently needed reform; two drafting committees were involved in this endeavor, and Gene served as chairman of the Federal Clauses Committee and sat on the General Drafting Committee.

Well done, Gene Scoles. These are extraordinary accomplishments, and especially so for a fisherman, for if we are to believe Izaak Walton, there is

No life, my honest scholar, no life so happy and so pleasant as the life of a well-governed angler, for when the lawyer is swallowed up with business, and the statesman is preventing or contriving plots, then we sit on cowslip banks, hear the birds sing, and possess ourselves in as much quietness as these silent silver streams, which we now see glide so quietly by us.¹⁵

I am thus delighted to join the editors of *The Elder Law Journal* in saluting Eugene F. Scoles for his many years of outstanding achievements.

And one final thing: I was just kidding about the "Skippy" nickname.

15. WALTON, *supra* note 5, at 114.

Gene's accomplishments in the area of conflict of laws are many indeed, starting with a dazzling array of articles which have graced the pages of law reviews all across the country. This is particularly impressive when one takes account of the fact that conflicts is the most perplexing of all the legal labyrinths, and, indeed, as Walton said of angling, is a subject that "can never be fully learnt."¹¹ He (Scoles, not Walton) wrote the fourth edition of *Goodrich on Conflict of Laws*, published in 1964, which later became the Scoles and Hay *Conflict of Laws Hornbook*, a joint effort by Gene and his Illinois colleague Peter Hay,¹² and it has since been published in two editions. And then there is Scoles' *Cases and Materials on Conflict of Laws*, which he coauthored with Russell Weintraub. It was Justice Frankfurter, I believe,¹³ who once observed that "the most constructive way of resolving conflicts is to avoid them."¹⁴ Scoles obviously subscribes to this axiom, for he has long endeavored to prevent conflict of laws problems from arising by ensuring the uniformity of legislation in various fields. He was a commissioner on Uniform State Laws for nearly fifteen years, and, as will be mentioned more particularly below, played a critical role in the development of several uniform laws in the trusts and estates field.

Speaking of which, it may be said that in this latter area as well Scoles has been a prolific and influential scholar. In the law reviews and in other fora, Gene has produced commentary on a variety of problems having to do with estate planning, the administration of estates, and other aspects of the geezer-postgeezzer transition. He is the coauthor with Ed Halbach of *Problems and Materials on Decedents' Estates and Trusts*, now in its fifth edition if I haven't lost count, and also *Problems and Materials on Future Interests*. Especially noteworthy is Gene's work with the Commissioners on Uniform State Laws; he served as Reporter-Draftsman for the Uniform Probate Code (and has since served on the Joint Editorial Board for that Code), for the Uniform Succession Without Administration Act, and (I am wearing myself out merely listing them) the Uniform Custodial Trust Act.

Along the way, Scoles has been engaged in a great variety of other activities and has occupied an interesting array of positions, all

11. WALTON, *supra* note 5, at 21.

12. To the best of my knowledge, they had an excellent working relationship, though I have heard it rumored that one of them viewed the other as cunctatious. Because that is only a rumor, I shall not pass it on here.

13. Which means I have looked it up.

14. See *Western Pac. R.R. Corp. v. Western Pac. R.R. Co.*, 345 U.S. 247, 270 (1953).

ELDERLY IMMIGRANTS: WHAT SHOULD THEY EXPECT OF THE SOCIAL SAFETY NET?

Leslie Pickering Francis

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) terminated federal benefits to many immigrants. The Balanced Budget Act of 1997 (BBA) only partially restored these benefits to select immigrants who lawfully resided in the United States before August 22, 1996. Professor Francis discusses how these statutory provisions particularly devastate elderly immigrants.

Professor Francis questions the morality of the congressional policy to end immigrants' dependence on public welfare benefits by analyzing whether Congress's justifications, which rely on principles of self-sufficiency, nondependency, and nonencouragement, really apply to elderly immigrants. The author finds that the statutes' termination of federal benefits is immoral when applied to elderly immigrants first because it is unlikely to motivate the typical elderly immigrant to become self-sufficient. She then argues that PRWORA denies the legitimate expectations of elderly immigrants, their relatives, and their communities; PRWORA is unfeasible; it discriminates; and it is uncompassionate and unfair to elderly immigrants, their relatives, and their communities. The author argues that the BBA does not cure PRWORA's defects because it denies and does not accommodate the unforeseeable disasters that strike elderly immigrants. Professor Francis concludes that Congress

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Professor Francis specializes in Health Law, Bioethics, and Legal Ethics. She is the author of a number of articles on issues in philosophy of law, health care, and professional ethics. She is currently a member of the American Law Institute, of the American Bar Association's Commission on the Legal Problems of the Elderly, of the Executive Committee of the Pacific Division of the American Philosophical Association, and of the Utah State Bar's Ethics Advisory Opinion Committee. She also chairs the American Philosophical Association's Committee for the Defense of the Professional Rights of Philosophers.

should restore federal benefits to elderly immigrants, at least to the point of providing a safety net.

In 1996, many elderly legal immigrants in the United States nearly lost their entire social safety net. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA)¹ would have ended federal means-tested benefits for most legal immigrants.² For the elderly, particularly the incompetent or ill, the most crucial losses would have been Supplemental Security Income (SSI) and Medicaid eligibility, including payment of nursing home charges. The Balanced Budget Act of 1997 (BBA)³ restored the most important of these losses to immigrants already in the United States before August 22, 1996.⁴ However, the BBA did not restore all losses, even for those immigrants in the United States before the cutoff date.⁵ Immigrants who arrive in the United States after August 22, 1996, remain subject to the PRWORA restrictions.⁶ Moreover, the period between the enactment of PRWORA and the enactment of the BBA was a time of frightening uncertainty for legal immigrants and a reminder of the fragility of their hold on social safety-net benefits.

This article begins by outlining the situation of elderly legal immigrants as it would have been had PRWORA continued to hold sway. It then outlines the current situation of partially restored benefits for these immigrants. I then examine and criticize arguments that were given in Congress for PRWORA's reduction of benefits. Next, I turn to the decision in the BBA to restore benefits to legal immigrants who arrived in the United States before PRWORA, but not to those who arrived afterwards. The principal reason offered for the distinction is that later arrivals are now on notice that they will be ineligible for federal means-tested benefits and that they therefore come to the United States with no legitimate expectations of safety-net support. I argue that this distinction cannot be justified and that safety-net benefits should be restored for all legal immigrants, including those arriving in the United States after August 22, 1996.

1. Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105 [hereinafter PRWORA].

2. These provisions were enacted in PRWORA's Title IV, which was entitled "Restricting Welfare and Public Benefits for Aliens." *Id.* § 400, 110 Stat. at 2260.

3. Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat. 251 (1997) [hereinafter BBA].

4. *See id.* § 5301, 111 Stat. at 597.

5. *See id.*

6. *See id.*

I. PRWORA and the Loss of Benefits for Legal Immigrants

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 was a far-reaching reform of the welfare system in the United States. The Act's overall goal was to move long-term welfare recipients into the work force and to transform welfare into a system of temporary support for those in crisis. Whatever judgment might be made about this overall approach, it is not a strategy that easily applies either to the very old (who have effectively left the work force) or to those who lack the cognitive or the physical capacities to work at any given time. Yet Congress decided in PRWORA to exclude legal immigrants from federal means-tested benefits apparently without attention to these concerns.⁷

The specifics of PRWORA were set out in some highly technical concepts. The first is that of a "qualified immigrant," an immigrant who has been admitted to the United States legally, for permanent residence, who has been granted asylum, who has been granted refugee status, or who has been permitted to stay in the United States under certain other limited bases.⁸ "Qualified" immigrants are those who without PRWORA would have had benefits eligibility; it is important to emphasize that PRWORA's limitation of benefits applied to immigrants whose presence in the United States was both legal and for the long term. Nonetheless, PRWORA excluded nearly all of the qualified from benefits eligibility. There were a few, limited exceptions to the reach of PRWORA exclusion. First, legal immigrants would remain eligible if they had worked at least forty qualifying quarters, quarters in which they earned at least a minimum amount and did not receive any federal means-tested benefit.⁹ The theory here may have been that ten years of paying taxes should vest eligibility for benefits paid from tax dollars. Legal immigrants could gain this eligibility vicariously through quarters worked by a spouse or a

7. Another consideration behind PRWORA was saving money, and the exclusion of legal immigrants was expected to yield a significant proportion of the overall savings. Much of the savings would have come from elderly immigrants: estimates were that 67% of the 500,000 who stood to lose SSI were over 65 years old, 41% were over 75 years old, and 39,000 were nursing home residents. See Memorandum from F. William McCalpin, Chair, Commission on Legal Problems of the Elderly, American Bar Association & Roger A. Clay, Jr., Chair, Commission on Homelessness & Poverty, American Bar Association, to the Commission on Mental and Physical Disability Law, et al. 2 (May 27, 1997) (on file with author).

8. See PRWORA § 431(b), 110 Stat. at 2274.

9. PRWORA § 402(a)(2)(B), 110 Stat. at 2262. The minimum amount for a qualifying quarter in 1997 was \$670. *Id.*

parent,¹⁰ but there are significant gaps in this vicarious eligibility. Divorced spouses could no longer claim quarters vicariously, even for those quarters accumulated before the time of the divorce.¹¹ Children could only lay vicarious claim to quarters worked by a parent before the child's eighteenth birthday;¹² thus disabled children who might never be able to work but who arrived in the United States over the age of eight were effectively precluded from vicarious eligibility, even if their parents worked every quarter after the date of their arrival.

PRWORA's second exception to denial of benefits eligibility for qualified immigrants applies to legal immigrants on active military duty¹³ or honorably discharged from the military.¹⁴ These immigrants would remain eligible for benefits as would spouses and unmarried dependent children who could vicariously benefit from the military status exception.¹⁵ Finally, refugees to whom the government granted asylum or withheld deportation would also remain eligible for benefits for five more years.¹⁶

PRWORA exclusions would have been particularly devastating for elderly immigrants for several reasons. Although immigrants could attribute their sponsors' income to the income eligibility determination, PRWORA did not provide that immigrants could attribute their children's quarters to their forty-quarter requirement. Therefore, immigrants entering the United States past retirement age, such as parents joining their children, would be unable to obtain eligibility from their children's work or military service. In addition, elderly immigrant spouses would lose their benefits upon divorce if they originally had become eligible for the benefits vicariously, whether or not they had desired the divorce. Imagine the difficult choice faced by an elderly person with a permanently demented spouse, who would like to divorce and remarry but recognizes that the cost will be the demented spouse's loss of safety-net benefits.

To be sure, PRWORA left one infallible way for legal immigrants to remain eligible for federal benefits: become citizens. This way too, however, poses particular difficulties for the elderly. Becoming a citi-

10. *See id.* § 435(1), 110 Stat. at 2275.

11. *See id.* § 435(2), 110 Stat. at 2275.

12. *See id.* § 435(1), 110 Stat. at 2275.

13. *See id.* § 402(a)(2)(C)(ii), 110 Stat. at 2263.

14. *See id.* § 402(a)(2)(C)(i), 110 Stat. at 2263.

15. *See id.* § 402(b)(2)(C)(iii), 110 Stat. at 2265.

16. *See id.* § 402(b)(2)(A), 110 Stat. at 2264.

zen, in addition to meeting residency and character requirements,¹⁷ requires passing a citizenship test in English and swearing an oath.¹⁸ In 1994, Congress amended the Immigration and Naturalization Act¹⁹ to permit persons with disabilities to apply for a waiver of the English and citizenship requirements.²⁰ In July of 1997, the INS promulgated regulations implementing the disability waiver.²¹ Only persons with disabilities may apply for the waivers; elderly persons whose ability to learn English or civics is complicated by Alzheimer's disease would be a perfect example. Being elderly itself, however, is not a disability; and to the extent that elderly noncitizens, for whatever non-disability-based reasons, face barriers to learning English, they will not be eligible for waivers. In addition, designated locations for the test may be difficult to reach for people who lack transportation or who have limited mobility. Distant locations may also seem remote and frightening for elderly persons who are not used to moving around American cities on their own; this remoteness may be compounded by the requirement at some centers that people coming for the test enter the testing center alone and without any support persons. Although at least some INS centers have demonstrated willingness to make accommodations for disabled persons with respect to the citizenship test, absolutely no waivers are allowed for the requirement that the applicant for citizenship be able to swear a meaningful oath.²² The result is that elderly persons who are too demented to understand and swear the citizenship oath are foreclosed from obtaining eligibility through the citizenship process.²³

The list of benefits that would have been lost under PRWORA is significant. PRWORA would have denied nonqualified immigrants, such as students lawfully in the United States but not on a permanent

17. See 8 U.S.C. § 1423(a)(1), (2) (1994).

18. See 8 C.F.R. § 301.1(b) (1997).

19. 8 U.S.C. § 1423(b).

20. See Immigration and Nationality Technical Corrections Act of 1994, 8 U.S.C. §§ 1101, 1423(b)(1) (as amended by Pub. L. No. 103-416, tit. I, § 108(a), 108 Stat. 4306, 4309-10).

21. 8 C.F.R. § 3.12.1(b)(3).

22. See 8 C.F.R. § 301.1. See Note, *The Functionality of Citizenship*, 110 HARV. L. REV. 1814 (1997), for a defense of the oath requirement as necessary to "meaningful" citizenship.

23. For stories describing the oath requirement's impact on persons with disabilities such as cerebral palsy or Alzheimer's disease, see Yvette Cabrera, *Disabled Immigrants Gain Citizenship Chance*, L.A. DAILY NEWS, July 4, 1997, at N1; Miguel Perez, *Citizenship Hurdle Absurd for Many Elderly, Disabled*, THE RECORD, Mar. 23, 1997, Review & Outlook, at 4.

basis, nearly all benefits. Nonqualified immigrants would be ineligible for *any* federal public benefits, including:

(A) any grant, contract, loan, professional license, or commercial license provided by an agency of the United States or by appropriate funds of the United States; and (B) and retirement, welfare, health, disability, public or assisted housing, postsecondary education, food assistance, unemployment benefit, or any other similar benefit for which payments or assistance are provided to an individual, household, or family eligibility unit by an agency of the United States or by appropriated funds of the United States.²⁴

The only benefits for which nonqualified immigrants would have remained eligible were immunizations—medical care that benefits others—and emergency medical and disaster relief.²⁵

Qualified immigrants did not face a much better situation with respect to benefits lost. Qualified immigrants would have been categorically ineligible for “specified federal programs,” such as food stamps and SSI.²⁶ The federal government provides SSI to aged and disabled persons who are indigent but ineligible for Social Security benefits. PRWORA left to the states’ discretion qualified immigrants’ eligibility for “designated federal programs,” including Medicaid, Title XX block grant programs, and Temporary Assistance for Needy Families (TANF).²⁷ However, PRWORA still placed significant limits on states’ determination of eligibility for federal benefits. Qualified immigrants remained categorically ineligible for any “means-tested federal public benefits” for five years after arriving in the United States.²⁸ Thereafter, the income of their sponsors and their spouse was to be “deemed” income of the immigrant for the purpose of eligibility determinations for means-tested benefits.²⁹ Interim INS regulations enforcing this provision provide for contractual enforcement of sponsorship support obligations by the federal government.³⁰

This structure of benefit loss, like the structure of exclusions, would have hit the elderly particularly hard. Medicaid is a major

24. PRWORA § 401(c)(1)(A), (B), 110 Stat. at 2262.

25. *See id.*

26. *See* PRWORA § 402(a)(3), 110 Stat. at 2264.

27. *See id.* § 402(b)(3), 110 Stat. at 2265.

28. *Id.* § 403(a), 110 Stat. at 2265.

29. *See id.* § 421(a), 110 Stat. at 2270.

30. The interim rules also require that the sponsor demonstrate income above 125% of the federal poverty guidelines for family size, that the sponsor’s family size include the sponsored immigrant(s), and that family members whose income is counted toward the 125% be contractually obligated for support. *See* Affidavits of Support on Behalf of Immigrants, 62 Fed. Reg. 54,346 (1997) (to be codified at 8 C.F.R. pt. 213a).

payor of nursing home care.³¹ After PRWORA, some nursing homes refused admission to elderly noncitizens whether or not they risked losing benefits eligibility.³² Elderly immigrants who do not meet the requirement of forty credited quarters are not eligible for Medicare, moreover, and may need to turn to Medicaid for access to health care more generally. Although PRWORA allowed states the option to open Medicaid eligibility to qualified immigrants residing in the country for at least five years,³³ it limited the program funds in a fixed federal block grant.³⁴ After Congress enacted PRWORA, states gave mixed signals about their willingness to open Medicaid programs to qualified immigrants. SSI and food stamps are also programs that are particularly important to the support of elderly immigrants living in poverty who have not met the Social Security requirement of forty qualifying quarters.³⁵ It is important to note as well that many elderly immigrants who fail to meet the forty-quarter requirement were in the work force, but in job sectors where the requirement that employers report income and pay FICA was unevenly enforced: job areas such as domestic work, child care, or agricultural labor.

One of the most significant problems for the states was the sheer ability to assume the expenses of extending Medicaid benefits without additional federal dollars.³⁶ The numbers of qualified immigrants, especially elderly qualified immigrants, are heavily concentrated in some districts, particularly in California, New York, and Florida. Dade County, Florida, alone would have faced a burden of 54,000 newly ineligible immigrants who had been receiving benefits³⁷—ten

31. Approximately one-half of the Medicaid budget is spent on nursing home care for indigent elderly people. See Valentine M. Villa et al., *Economic Diversity and an Aging Population: The Impact of Public Policy and Economic Trends*, GENERATIONS, Summer 1997, at 13, 15.

32. See *Legal Immigrants Denied NH Admission*, BROWN U LONG-TERM CARE QUALITY ADVISOR, July 14, 1997, at 5.

33. See PRWORA § 403(a), 110 Stat. at 2265.

34. See *id.* §§ 401-403, 110 Stat. at 2261-67.

35. Although immigrants who have lived in the United States for a long time are not more likely to use public benefits than citizens, elderly immigrants are more likely to depend on Medicaid and food stamps than elderly citizens (99% of whom receive Medicare). See Nancy San Martin, *Immigrants Arrive Poor, Then Thrive, Study Shows*, SUN-SENTINEL (Fort Lauderdale, Fla.), Apr. 9, 1997, at 1A.

36. For a description of the anticipated squeeze in Hawaii, a state with a significant immigrant population and the longest life expectancy in the nation, see Lucy Joikel, *Sink or Swim: Hawaii's Multibillion Dollar HealthCare Industry Faces a Sea of Change*, HAW. BUS., Sept. 1996, at 10.

37. See Jim Oliphant, *Unlikely Team Rises to Aid of Immigrants*, BROWARD DAILY BUS. REV., May 30, 1997, at A6.

percent of the estimated national total of one-half million.³⁸ New York City estimated a new burden of 110,000 newly ineligible immigrants—twenty percent of the estimated national total.³⁹

PRWORA, therefore, caused legal immigrants great concern about their uncertain futures in the United States. Appeals from many directions led Congress to pass the Balanced Budget Act of 1997, which amended PRWORA only a month before its eligibility limitations were to begin effect.

II. The Balanced Budget Act of 1997 and the Partial Restoration of Benefits to Legal Immigrants

The BBA partially repaired the safety net of benefits to some qualified legal immigrants. Immigrants who either received SSI or resided lawfully in the country before PRWORA's original enactment (August 22, 1996) remained eligible for SSI.⁴⁰ In addition, immigrants who received SSI were derivatively eligible for Medicaid, but not derivatively eligible for food stamps.⁴¹ The benefits restored by the BBA, even if incomplete, were important to immigrants lawfully residing in the country before PRWORA's enactment.

The BBA did not change PRWORA's impact on immigrants arriving in this country after PRWORA's enactment.⁴² Thus, immigrants arriving after PRWORA's enactment remain ineligible for SSI or food stamps. Their eligibility for designated federal programs such as Medicaid and TANF under the state block grants program depends upon the states in which they live.⁴³ They are ineligible for all means-tested federal public benefits for five years; thereafter, their sponsors' and spouses' incomes are deemed to be theirs.⁴⁴ These deeming provisions will be enforced contractually by the federal government; the government will seek restitution from the sponsor for any means-tested federal benefit received by a sponsored immigrant.⁴⁵

38. See *Test Waivers for Citizenship Won't Stop Lawsuit*, Disability Advocates Say, IMMIGR. ADVISOR, May 1997, available in LEXIS, News Library, ASAP II file.

39. See *id.*

40. See BBA §§ 5301(a)-(b), 111 Stat. at 597-98.

41. See *id.* § 5305(b), 111 Stat. at 597-98.

42. See *id.* § 5301, 111 Stat. at 597.

43. See PRWORA § 402, 110 Stat. at 2262.

44. See *id.* §§ 403(a), 421(a), 110 Stat. at 2265, 2270.

45. See *id.* § 421(c), 110 Stat. at 2270.

Perhaps the only cause for optimism for immigrants arriving after August 22, 1996, may be that the Department of Health and Human Services (DHHS) has announced a narrow construction of the statutory term "federal means-tested public benefit." The DHHS has construed "federal means-tested public benefit" to include only mandatory, means-tested programs, i.e., Medicaid and TANF.⁴⁶ Although PRWORA explicitly excludes certain programs such as school lunches,⁴⁷ the DHHS interpreted PRWORA also to exclude discretionary spending programs, such as child care assistance.⁴⁸

The BBA thus creates a radical dichotomy between the treatment of immigrants who arrived in the United States before PRWORA's enactment and the treatment of immigrants who arrived after PRWORA's enactment. In the remainder of this article I argue, first, that the congressional rationale for the PRWORA restrictions cannot be defended morally and, second, that the reasons offered for limiting the BBA restorations to immigrants present in the United States before PRWORA cannot be sustained.

III. Arguments Offered in Support of the Restrictions: An Ethical Critique

As support for the PRWORA restrictions, Congress put forth the principle of self-sufficiency as what it took to be the basic philosophy of American immigration policy.⁴⁹ It understood two more specific policy objectives as corollaries to the basic principle of self-sufficiency. The first corollary might be called the principle of nondependency: immigrants should not depend on public welfare benefits to meet their needs. Instead, they should rely on their own efforts, the resources of their families and sponsors, and the assistance of private charitable agencies.⁵⁰ The second corollary might be called the nonencouragement principle: the availability of public benefits should not serve as an incentive for immigrants to come to the United

46. See Personal Responsibility and Work Opportunity Reconciliation Act of 1996; Interpretation of "Federal Means-Tested Public Benefit," 62 Fed. Reg. 42,256 (1997).

47. See PRWORA § 422(b)(3), 110 Stat. at 2271.

48. See Interpretation of "Federal Means-Tested Public Benefit," 62 Fed. Reg. at 45,257.

49. See PRWORA § 400(1), 110 Stat. at 2260.

50. See *id.* § 400(2)(A), 110 Stat. at 2260.

States.⁵¹ Congress asserted, however, that in its judgment current immigration policy was not assuring self-reliance and that immigrants were increasingly depending on public benefits for support.⁵² Congress therefore concluded—no doubt in anticipation of potential equal protection challenges—that compelling federal interests supported the PRWORA restrictions.⁵³

In this discussion, my principal focus will be the ethical rather than the empirical claims asserted in PRWORA's statement of congressional policy, but the fact that there are serious reasons to question the empirical claims should not go unremarked. Although elderly immigrants are somewhat more likely to depend on public benefits than elderly nonimmigrants, long-term immigrants are not more likely to depend on them overall.⁵⁴ The explanation for the modest difference in rates among the elderly may be that elderly immigrants are somewhat less likely than nonimmigrants to be eligible for other elements of the social safety net, Social Security and Medicare in particular. Congress offered no data in support of the claim that immigrants are drawn to the United States by generous public benefits. In any event, were this the concern, it could be addressed more directly by immigration policies such as emphasizing skills or sponsorship.

The ethical argument I develop here makes use of variations on a typical example of those who stand to lose benefits under PRWORA. As initially described, my case is a sympathetic one for those who oppose the termination of benefits. I will consider less sympathetic variations, as the argument progresses, in order to consider the factors that make a moral difference. I will call my exemplar Mrs. I. She is a woman because the majority of nursing home residents who depend on Medicaid are women. Mrs. I is an elderly noncitizen who came to the United States with her husband over forty years ago. She has not obtained the forty quarters needed to qualify for Social Security or Medicare or to be exempt from the PRWORA limits. Her husband died before working a full forty quarters. She supported herself for many years by working as a domestic. Although she paid income taxes, neither she nor her employer paid FICA on her earnings. When Mrs. I became too ill to work, she lived with an adult daughter for

51. See *id.* § 400(2)(A), (B), 110 Stat. at 2260.

52. See *id.* § 400(3), (4), 110 Stat. at 2260.

53. See *id.* § 400(5), (6), 110 Stat. at 2260.

54. See San Martin, *supra* note 35, at A1.

several years. Now in the advanced stages of Alzheimer's disease, Mrs. I lives in a nursing home; her only sources of support are SSI and Medicaid. Her Alzheimer's disease is too advanced for her to be able to take a meaningful oath and meet the requirements for citizenship. Because there are morally significant differences between the situations of those already here who would have lost their benefits under PRWORA and the situations of later comers who will be ineligible for benefits under the BBA, I begin with a critique of the PRWORA restrictions.

A. PRWORA and Legitimate Expectations

In its original form, PRWORA would have resulted in the termination of Mrs. I's SSI income and food stamps. PRWORA would also have ended her Medicaid and other means-tested federal benefits if her home state did not choose to include her in these programs. Congress's articulated principles in PRWORA, however, do not justify cutting these benefits for incompetent elder immigrants like Mrs. I. Consider first the nonencouragement principle. Mrs. I's decision to come to the United States was made many years ago; she is now incompetent and too ill to engage in any decision making about her status. Incentives are a thing of the past for her; they do not operate now.

If Mrs. I were competent, by contrast, the nonencouragement principle might seem relevant. Incentives might operate, depending on her physical condition: the knowledge that she was at risk of losing her benefits might lead her to reconsider whether she should stay in the United States or attempt to return to her country of origin. The incentives, however, are unlikely to encourage her to become self-sufficient in the United States. Because she is not a recent arrival, and because all of her family and her connections are in the United States, it is far more likely that the incentive created for the competent elderly would have been the incentive to become citizens. Indeed, the rush of citizenship applications in the wake of PRWORA indicates that this was exactly the impact of PRWORA on those able to take advantage of the citizenship option.⁵⁵ These cases suggest that the real target of nonencouragement under PRWORA was people who had not yet arrived in the United States, the group still targeted for the loss of benefits under the BBA. The situation of this group is addressed below.

55. See Cabrera, *supra* note 23.

The principle of nondependency poses a somewhat more complicated question with respect to incompetent patients such as Mrs. I. Mrs. I's situation is what it is; planning for nondependency is not an option for her. Her options may be very limited. Certainly, she cannot be expected to become self-sufficient if she has advanced Alzheimer's disease. She may no longer have family or sponsors with resources to help out; indeed, she may have outlived these possible sources of support. Her only source for replacement of the loss of SSI and Medicaid funds, as well as other federal benefits, would be private charity. If she is significantly demented, however, she will be unable to make these arrangements on her own. The upshot of PRWORA in these cases, then, would be to rely on the hope that families, communities, or private charities would step in and take up support for the Mrs. Is of our world who can no longer rely on the federal government. This shift would impose a major new burden on private charities, one that they may not have the resources to meet and certainly would not have a legal obligation to meet. Thus, Mrs. I would have no assurance that her Medicaid bills would continue to be paid. Nursing homes, in the wake of PRWORA, raised concerns about where patients like Mrs. I were to go.

Suppose, on the other hand, that Mrs. I were competent, or that her sponsor, spouse, or family were available. A proponent of the principle of nondependency might argue that it would be justifiable to require Mrs. I to figure out how to provide for herself or to rely on her available sources of support. As to Mrs. I herself, there are several reasons why it would be wrong to interpret the principle of nondependency to require her to provide for herself. The first reason is that to do so would be a radical change in the long-standing rules that applied to her. I have argued elsewhere that legitimate expectations of a benefit are independent moral reasons for providing that benefit.⁵⁶ That is, the fact that someone has come to count on a benefit, such as Medicaid or Medicare, legitimately is a special, moral reason for providing that benefit. Expectations are legitimate when they are reasonable, when they have been encouraged by existing rules or policies, and when they are long-standing. Their importance is heightened when they also relate to means for respecting the basic needs and integrity of persons, and when they are supported by other

56. See Leslie Pickering Francis, *Consumer Expectations and Access to Health Care*, 140 U. PA. L. REV. 1881 (1992).

moral claims, such as claims of justice. Mrs. I's expectations of the availability of SSI and Medicaid are particularly powerful examples of legitimate expectations. They were reasonable and encouraged in light of the long-standing federal commitment to these programs. The unevenness of federal enforcement policy with respect to FICA, and Mrs. I's own acceptance of her employer's failure to pay, occurred when SSI and Medicaid were last resort forms of support for elderly immigrants who failed to qualify for Social Security or Medicare. Finally, their legitimacy is enhanced by their importance to Mrs. I and by claims of justice. The availability of SSI and Medicaid are crucial to Mrs. I's ability to pay for basic and unpredictable necessities of life. Mrs. I cannot anticipate whether she will suffer catastrophic health needs or whether she will become disabled and unable to work. In this unpredictability, the case for the legitimacy of Mrs. I's expectations of SSI and Medicaid are arguably even stronger than the legitimacy of her expectations of food stamps: although food is a basic necessity of life, food needs are relatively stable and predictable. On at least those views of justice that hold that there is a social responsibility to provide for basic health needs of those who cannot provide them for themselves, it would be unjust to deny Mrs. I basic health care for which she is unable to pay. Mrs. I's legitimate expectations of the safety net that had been in place for many years for people such as herself are thus one reason why it would be wrong to apply the principle of nondependency to her situation.

A second reason why it would be wrong to apply the principle of nondependency to require Mrs. I to provide for her own needs is that even in the best case scenario it is unlikely that she will be able to do so. Applying the principle of nondependency to Mrs. I herself would require her to go back to work. The likely range of jobs available to a woman of her age and skills is limited—perhaps domestic, child care worker, or server at a fast food establishment. From these jobs, she might be able to earn enough to pay for her basic living expenses, but it is much more questionable whether she would be able to find a job that would provide her with health insurance or the possibility of retirement benefits. At best, Mrs. I can be expected to use work to make up the loss of benefits such as food stamps or subsidized housing. If Mrs. I has health needs—and, of course, if she becomes disabled—the goal of requiring her to be self-sufficient will simply be unmet. Once again, Mrs. I will be dependent on private charity to make up the gap.

A third reason why it would be wrong to apply the principle of nondependency to Mrs. I is that it would treat her very differently from the elderly who are citizens. Requiring that elderly immigrants go back to work to support themselves imposes a lifetime burden on them that is not imposed on citizens. This burden is especially unfair to those who were already elderly or disabled and in the United States at the time of the rules change, and thus unable to take the new rules into account in planning how to live without safety-net benefits. Consider the tragic example related by Representative Hinojosa of Texas, in arguing for restoration of the benefits taken away by PRWORA for those already in the United States:

Mr. Rosendo Tijerina is a legal immigrant who has worked in Texas for eleven years. Last November he was involved in a serious auto accident. His legs and pelvis were crushed and his heart was injured as well. He is now totally disabled.

Yet under the welfare reform law, Mr. Tijerina is not eligible for supplemental security income. He has worked hard, paid his taxes, integrated himself and his family into his community and has been a contributor to our country's economy. He deserves better treatment than this.⁵⁷

Imposing this burden on people such as my hypothetical Mrs. I or the all-too-real Mr. Tijerina also places significant strains on community bonds. The practical effect of imposing a self-sufficiency requirement on people like Mrs. I would be to require them to work, quite literally until they can work no longer—perhaps even into their eighties or later. The failure to extend a safety net to those of an advanced age shows a quite remarkable lack of compassion. Finally, the incentive that is likely to be created by the PRWORA cutoff for competent people in the situation of Mrs. I is to become citizens. Thus PRWORA is unlikely to accomplish the goal underlying the nondependency principle in any event.

Until this point, I have considered applying the principle of nondependency to require Mrs. I to pay for her own needs. What about interpreting nondependency to require Mrs. I's relatives or sponsor to come to her aid? This interpretation is found in a limited form in PRWORA's deeming requirement, which would attribute the income of Mrs. I's spouse or sponsor to her in the determination of her income eligibility for Medicaid.⁵⁸ Defenders of the deeming re-

57. 143 CONG. REC. H4379 (daily ed. June 25, 1997) (statement of Rep. Hinojosa).

58. See PRWORA § 421, 110 Stat. at 2270.

quirement might argue that it is fair to require her spouse and sponsor to come to her aid. Defenders of the cutoff more generally might argue that it is fair to require noncitizens to turn to their families, friends, and communities if they cannot provide for their own needs. The arguments offered against relying on Mrs. I to provide for her own needs also apply to requiring Mrs. I to turn to such sources for whatever support they have available.

First of all, even for spouses and for sponsors, the deeming requirements represent a major change in the rules of the game. The sponsorship of Mrs. I may have occurred many, many years ago, and the connection between Mrs. I and her sponsor may be attenuated or nonexistent. Like Mrs. I, her spouse may have legitimately expected that a safety net would be there for her and that, despite her need for nursing home care, he would be able to maintain independent living. Although children, other relatives, and close community members are not legally obligated to Mrs. I through the deeming requirements of PRWORA, they may have the need to come to her aid thrust upon them by her sudden loss of benefits. The result may be unanticipated, significant disruptions in their own lives. The expectations of a safety net for Mrs. I, on the part of her sponsor, spouse, or relatives, arguably meet the criteria for legitimate expectations: they may well have been long-standing and encouraged by policy, they may cut deeply into both Mrs. I's and her family's abilities to lead minimally decent lives, and they are supported by claims of justice.

Moreover, both those subject to the deeming requirements and others close to Mrs. I may be unable to do much to contribute to her support. They may quickly become impoverished themselves, facing the same restrictions as Mrs. I if they are noncitizens. If Mrs. I's family takes her in, one or more adult members may no longer be able to work. The costs of her home health care alone may derail even the most modest educational plans for children in the family.

Finally, significant issues of fairness are raised for her family or sponsors by Mrs. I's need to turn to them for support. Mrs. I's children, for example, may be the only persons for her to turn to when she loses her SSI and Medicaid benefits. They will be faced with the choice of continuing to pay for her nursing home care, if they can; taking her in; or leaving her destitute and incompetent, with nowhere to go. This burden is not imposed on any other Americans, citizen or noncitizen. Even those who favor distinguishing citizens from noncitizens should note that this burden may fall on citizens: Mrs. I's chil-

dren may have been born in the United States or have become naturalized, even though she has not. Thus the result of the application of the principle of nondependency to Mrs. I under PRWORA is the disappointment of legitimate expectations and the imposition of potentially devastating and unfair burdens on her spouse, other relatives, or local communities.

PRWORA, to be sure, applied both to immigrants who had been in the United States for a very long time and to those newly arriving after the date of its enactment. Much of the concern voiced over PRWORA rested on the application of its changes to those who were already in the United States, perhaps for a lengthy period of time. As I have argued, applying both the nonencouragement and the nondependency principle to immigrants of long-standing duration is particularly problematic.⁵⁹ The BBA, however, amended PRWORA to apply its restrictions only to those arriving after August 22, 1996.⁶⁰ Contractual enforcement of the deeming requirements applies only after the effective date of the interim deeming rule, December 19, 1997.⁶¹ Sponsors of this approach argued that it is both reasonable and fair to treat immigrants differently once they are warned of the new restrictions. Arguing in support of the BBA changes, Senator Lautenberg contended:

The conference report also restores a basic level of fairness for people who have come into this country legally, who have obeyed the law, paid their taxes, and then fate delivers them a disability whether through accident or just sickness. Last year the Congress pulled the rug out from under these people and eliminated their disability benefits; for some, the only provision that they have that enables them to get along. But today we are restoring that basic safety net. It is the right thing to do.⁶²

But would restoring benefits to qualified immigrants arriving after August 22, 1996, also have been the right thing to do?

59. See *supra* Part III.A.

60. See BBA § 5301, 111 Stat. at 597.

61. 62 Fed. Reg. 54,346 (1997) (to be codified at 8 C.F.R. pt. 213a).

62. 143 CONG. REC. S8319 (daily ed. July 30, 1997) (statement of Sen. Lautenberg).

B. The Balanced Budget Amendment and Fair Treatment of Newly Arrived Immigrants

Senator Wellstone called August 22, 1996, "an arbitrary date on the calendar."⁶³ So it is, except for the fact that after that date immigrants considering coming to the United States were on notice that Congress had acted to end the social safety net for immigrants. Proponents of the continued imposition of restrictions on after-arrivers argue that it is supported by the principle of nonencouragement—because we do not want to encourage immigration by the potentially dependent—and by the principle of nondependency—because it is fair to expect later arrivals to know that they will need to count on their own resources or their sponsor's for support. For example, Daniel Stein, the Executive Director of the Federation for American Immigration Reform, argued on *Talk of the Nation*:

To the extent that you are taking welfare benefits away from American citizens, Americans aren't getting quality public education and other services. The broader policy question is clear: should we have an immigration program that allows people to bring elderly parents who are essentially past their working years and have them retire and be supported at taxpayer expense?⁶⁴

The efforts to put new arrivals on notice of the new requirements are intensified by the interim rule concerning affidavits of support. Immigrants arriving to join family members or to take up employment in a family enterprise must demonstrate that they are not likely to become a public charge.⁶⁵ To do this, the new immigrant must supply a sponsor, and the sponsor must file a support affidavit contractually obligating him to the federal government.⁶⁶ In addition, the sponsor must prove a household income exceeding 125% of the federal poverty line.⁶⁷ Notably, the affidavit also obligates the sponsor's spouse and any household members whom the household income calculation includes.⁶⁸ A sponsor may pledge assets rather than income, but the assets must sufficiently support the immigrant at 125% of the poverty line for at least five years (the minimum period of ineligibility for federal means-tested public benefits for qualified immigrants even

63. 143 CONG. REC. S6780 (daily ed. June 27, 1997) (statement of Sen. Wellstone).

64. *Talk of the Nation* (National Public Radio broadcast, Mar. 19, 1997).

65. See Affidavits of Support on Behalf of Immigrants, 62 Fed. Reg. 54,346 (1997) (to be codified at 8 C.F.R. pt. 213a).

66. See *id.*

67. See *id.* at 54,347.

68. See *id.*

if states choose to extend benefits afterwards).⁶⁹ Sponsors must also agree to notify both the state and the federal government of any changes of address.⁷⁰ Such sponsorship obligations cease only if the immigrant becomes naturalized, can be credited with forty quarters of work, or ceases to be a permanent resident of the United States. The sponsorship also ends when the immigrant or the sponsor dies.⁷¹

A crucial starting point for assessing the justifiability of continuing to exclude after-arrivers from benefits is whether the notice given by PRWORA makes a moral difference. In one way, it does. The announcement that they cannot count on a safety net should be clear to immigrants arriving after that date, as well as their sponsors and perhaps their families (although there is no guarantee of family knowledge unless families are involved in sponsorship). An immigrant's expectations of a safety net, then, would be neither reasonable nor encouraged. Indeed, this change is the very point of the nonencouragement principle as part of American immigration policy. Thus if encouragement and reasonableness are necessary for the legitimacy of expectations, after-arrivers would no longer have legitimate expectations of a safety net and this argument for providing them with a net would no longer hold. It does not follow, however, that other moral reasons for the safety net would also collapse, or even that expectations in any form would be irrelevant to the issue of the restoration of benefits. I shall argue that the other moral reasons given for the restoration of benefits to immigrants in the country before August 22, 1996, also apply to after-arrivers, at least to the extent of guaranteeing them safety-net protections for health needs and disabilities.

A major concern about excluding those already here from benefits was that the incentives sought to be created by PRWORA—nonencouragement and nondependency—were in fact unlikely to be created. There are similar questions about whether the new limits can be expected to discourage those who might have need of a safety net from coming to the United States. To be sure, after-arrivers have a new decision to make and new information with which to make it. Immigrants who know before arrival that they will have safety-net needs would rationally be discouraged by the PRWORA restrictions. These situations represent the intended goals of the new restrictions.

69. See *id.* at 54,349.

70. See *id.*

71. See *id.*

For example, Daniel Stein, Executive Director of the Federation for American Immigration Reform, articulated this goal on Talk of the Nation: "The system should not allow immigrants to bring elderly parents here over the age of fifty-five as a general rule."⁷² Another unarticulated and perhaps unrecognized but discouraged group will be parents of disabled children over the age of eight, who will never be able to achieve the forty quarters required for vesting through their parents and who may not be able to work or attain citizenship on their own. Questions about the fairness of these goals will be raised shortly, but to the extent that these groups will be discouraged by the restrictions, the nonencouragement principle might be thought to be achieving its goal.

Nonetheless, the new restrictions sweep far beyond nonencouragement of those with known needs. Those immigrants who come to the United States intending and able to work are not the targets of PRWORA nonencouragement. Yet they may well become those in need of safety-net benefits if unexpected disease or disability strikes. The PRWORA incentives will not discourage them from coming to the United States unless they are so risk-averse that they would prefer keeping whatever safety nets are available in their countries of origin to coming to the United States without a safety net. Once here, they will not be able to prevent the need for benefits: disability or disease may strike without warning or control. PRWORA incentives may discourage immigration by the elderly and by parents of children with disabilities, but they will not prevent populations of newly arrived immigrants who suffer catastrophes after arrival.

Another central concern raised about the PRWORA exclusions was their unfairness. The exclusions that continue in the BBA are also unfair for the same reasons. A way to begin to see the unfairness of the continued exclusions in the BBA is to consider the situation of people who bring their parents over, sponsor them, and believe they have the resources to care for them, but then suffer catastrophic medical events themselves. Suppose, for example, that Mrs. I's children arrived in the United States a number of years ago and have become reasonably prosperous citizens. (Indeed, they may even have been born in the United States during a time of Mrs. I's former residency.) Suppose also that it has become increasingly difficult for Mrs. I to care for herself at home in her country of origin and that most of her rela-

72. *Talk of the Nation*, *supra* note 64.

tives and friends there have died. She faces the prospect of a lonely old age with whatever safety net exists in her country of origin or the prospect of an old age cared for by her daughter but without any chance of receiving safety-net benefits. The only difference between the situation of Mrs. I and her daughter and the situation of countless other Americans and their aged parents is that Mrs. I has neither attained citizenship nor met the PRWORA exemption requirements. Mrs. I had the bad luck to have catastrophe strike too soon, while others did not. To have bad timing affect the lives of both Mrs. I and her family in such devastating ways, while it does not affect the lives of others similarly situated, is deeply unfair.

Similarly unpredictable, moreover, is whether the catastrophes of disease or disability occur before or after arrival in the United States. To be sure, those who know that they are already in need of support before arrival know that the United States will not extend safety-net benefits to them. They will be discouraged from coming. But the consequences will be that families of the already disabled will be discouraged from reuniting, while families of those who do not yet know their needs will not be discouraged. Once again, whether families suffer in this way is an arbitrary matter of timing and thus arguably unfair.

In these situations, the goal of ordinary support for Mrs. I is attainable from her family or sponsors. Such ordinary support, I would argue, is the appropriate scope of the principle of nondependency. Providing for Mrs. I's ordinary living expenses is something that her relatives or community can plan in a controllable way. What may well be beyond their reach, however, is catastrophe. Suppose Mrs. I's daughter becomes seriously ill herself and is unable to care for Mrs. I, or Mrs. I has expensive medical needs, or Mrs. I becomes demented (before she can herself qualify for citizenship) and so difficult that home care is impossible. The burdens any of these accidents might impose on Mrs. I's family are unpredictable and far beyond the ordinary expenses of care. Imposing obligations of support up to 125% of the poverty line on sponsoring communities or families is thus arguably fair, whereas categorical exclusions from SSI or Medicaid are not.

Such unforeseen disasters, moreover, are possibilities for the general immigrant population, including immigrants arriving ready to work, as indeed they are for any American citizen. Celia Munoz, Deputy Vice President for Policy, National Council of La Raza, framed the argument this way:

[Immigrants are] not superhuman Some of them have accidents. Some of them have illnesses. I think the fundamental question is, are we as taxpayers gonna support our immigrant neighbors who are also taxpayers, or are—we have we chosen to treat them in a much, much different fashion. And the sad truth of it is that we are treating them in a very unfair fashion.⁷³

Similarly, Representative Hinojosa's example of a legal immigrant disabled in an accident just before reaching the forty quarters required for exemption⁷⁴ could be any working American.

The issue raised by such unforeseen disasters is whether it is fair to conceive of the principle of nondependency for immigrants as covering all contingencies, no matter how unpredictable or catastrophic. An arguably fairer alternative would be to understand nondependency as responsibility for the ordinary necessities of life over a working life span to the extent that the ability to work remains. On this alternative, those aspects of the safety net that cover unpredictable and catastrophic needs should remain available, particularly SSI and Medicaid. Sponsorship obligations could similarly be construed to encompass maintenance up to 125% of the poverty level, but not to include a contractual obligation to reimburse the federal government for receipt of means-tested benefits that cover any catastrophic events, such as unexpected disability or health expenses. This alternative is arguably fairer because it extends a safety net to those contingencies people cannot control, plan for, or save for. As it now stands, however, luck determines the difference between an immigrant who becomes eligible for benefits by obtaining citizenship or working forty quarters and an immigrant who remains eligible for benefits because of a disability.

There is an argument to be made from expectations here, too. Immigrants who come to the United States ready and able to work legitimately expect to be able to provide for themselves. They have no reason to believe that the contingencies that give rise to dependency will occur to them—that they will have a severely disabled child, that they will be hit by a truck, or that they will suffer from breast cancer. They do not expect to bear catastrophic costs, because they have a reasonable expectation that life will go on without catastrophe. These are not, to be sure, expectations that the U.S. government has encouraged by long-standing policy. But they are expectations that a

73. *Id.*

74. See *supra* note 57 and accompanying text.

decent community would arguably encourage, at least to the extent the community is able. Decent communities cannot prevent catastrophes, but they can provide a safety net to cushion the effects of catastrophe. Immigrants newly arrived in the United States now face exclusion from this safety net.

IV. Conclusion

PRWORA threatened to exclude over one-half million legal immigrants in the United States, and all newly arriving immigrants, from the social safety net of SSI, food stamps, Medicaid, and other means-tested federal benefits. The BBA restored some of these benefits (but not food stamps) to immigrants in the country before August 22, 1996. Immigrants arriving after this date remain subject to PRWORA restrictions. These policies were justified by Congress in terms of the principles of nonencouragement and nondependency. I have argued, to the contrary, that there are good moral reasons for not understanding nonencouragement and nondependency to justify the exclusions. Legitimate expectations are an important reason for objecting to the reach of the PRWORA cuts. Fairness and ineffectiveness are two other reasons that tell against PRWORA. Although legitimate expectations do not provide an argument in quite the same way against the exclusion of after-arrivers from benefits, fairness and ineffectiveness do. The rules to be enforced under the BBA will neither prevent catastrophes from happening to people who are new to the United States nor provide them with the means to help themselves. On the other hand, it is fair—if less than compassionate—to expect immigrants or their sponsors to bear the controllable and expected costs of basic life maintenance, perhaps up to 125% of federal poverty guidelines. Congress should act to restore safety-net benefits at least to this extent. Perhaps the next step would be to reconsider whether a more compassionate society would insist on sponsorship requirements in the first place.

SEMANTICS AND POLICY IN PHYSICIAN- ASSISTED DEATH: PIERCING THE VERBAL VEIL

Leslie Joan Harris

During the last twenty years, courts and legislatures have developed principles that allow individuals and their surrogates to refuse medical care, even when refusal will lead to death. This article traces these developments, from early cases concerning withdrawal of respirators and decisions not to treat fatal illnesses through withdrawal or refusal of artificial nutrition and hydration to the current debate over physician-assisted death. Throughout these developments, those who believed that the law should allow refusal of care have characterized the issue as a matter of personal autonomy, while their opponents have called refusal of care "suicide" and denial of care "homicide." This article traces the rhetorical battle from the early cases through the most recent Supreme Court decisions on physician-assisted death, showing that the rhetoric predicts outcomes but does not explain them. The rhetoric reveals one important set of issues that are at stake in these decisions—who should choose among the varying definitions of respect for human life and the role that law should place in this debate. However, the language obscures other important issues that should be figured heavily in deciding whether to allow refusal of treatment, as well as physician-assisted death. These issues include how power should be distributed between doctors and their patients and how much of society's resources should be allocated to health care.

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Students in my Elder Law class over the years have taught me much about these issues, and I thank them. Thanks also to Gene Scoles, Caroline Forell, Garrett Epps, Margie Paris, and Carol Pratt for reading and commenting on prior drafts. Thanks also to Professor Charles Rowland of the Australian National University, who provided me with up-to-date information about the Rights of the Terminally Ill Act of the Northern Territory of Australia, and to Shannon Richard for research assistance. I am very pleased and honored to contribute to this issue of *The Elder Law Journal* honoring Gene Scoles, for he has been a generous friend and mentor to me, as to so many others.

In *Vacco v. Quill*¹ and *Washington v. Glucksberg*,² the Supreme Court reversed decisions from the Second³ and Ninth⁴ Circuits which held that the Constitution requires that terminally ill people be allowed to seek the assistance of physicians in ending their lives. In *Vacco* and *Glucksberg*, the Court found that legislation in the area of physician-assisted death does not violate equal protection or due process, leaving the continuing debate over physician-assisted death to the various state legislatures.⁵ Legislation to allow physician-assisted death has been introduced in more than fifteen states,⁶ though only Oregon has enacted this type of legislation.⁷ The Oregon statute survived an effort to repeal it by popular initiative in November 1997.⁸

1. 117 S. Ct. 2293 (1997).

2. 117 S. Ct. 2258 (1997).

3. *Quill v. Vacco*, 80 F.3d 716 (2d Cir. 1996).

4. *Compassion in Dying v. Washington*, 79 F.3d 790 (9th Cir. 1996) (en banc).

5. See *Glucksberg*, 117 S. Ct. at 2267 (Rehnquist, C.J.); *Vacco*, 117 S. Ct. at 2296 (Rehnquist, C.J.).

Litigation based on state constitutions is another potential arena for this struggle. For example, the trial court in *McIver v. Krischer*, No. CL-96-1504-AF, 1997 WL 225878 (Fla. Cir. Ct. Jan. 31, 1997), held that a terminally ill, competent, and not suicidal person has a constitutional right under the Florida Constitution to make the decision to terminate his own suffering, and to seek and obtain his physician's assistance to do so under the circumstances of this case. On July 17, 1997, the Florida Supreme Court reversed. *Krischer v. McIver*, 697 So. 2d 97 (Fla. 1997), available at <<http://www.law.stetson.edu/mciver.htm>>. The state supreme court opinion is at <<http://www.law.stetson.edu/elderlaw/krischer.htm>>.

6. For a review of this proposed legislation, see Daniel Callahan & Margot White, *The Legalization of Physician-Assisted Suicide: Creating a Regulatory Potemkin Village*, 30 U. RICHMOND L. REV. 1, 18-58 (1996). See also William J. Tarnow, *Recognizing a Fundamental Liberty Interest Protecting the Right to Die: An Analysis of Statutes Which Criminalize or Legalize Physician-Assisted Suicide*, 4 ELDER L.J. 407, 433-46 (1996).

7. See Oregon Death with Dignity Act, Oregon Ballot Measure 16, enacted by popular initiative in 1994, reprinted in Tarnow, *supra* note 6, at app.

8. The state legislature referred the Death with Dignity Act back to the voters recommending that they repeal it. H.R. 2954, 69th Leg. (Or. 1997). The electorate rejected this request and upheld the act by a margin of nearly 60%-40%. *Suicide Law Stands*, PORTLAND OREGONIAN, Nov. 4, 1997, § A, at 1.

The Oregon Death with Dignity Act was successfully challenged in the federal district court on the basis that it denied them from protection against incompetent doctors and their own mental incapacity. *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995). However, the Ninth Circuit reversed because the challengers lacked standing. *Lee v. Oregon*, 107 F.3d 1382 (9th Cir.), cert. denied, 118 S. Ct. 328 (1997). Although there has been discussion about the opponents of the act refileing with the plaintiff who does have standing, this had not occurred as of early November 1997.

In *Compassion in Dying v. Washington*, the Ninth Circuit, sitting en banc, sharply criticized the district court opinion in *Lee*. 79 F.3d at 838 n.139. On appeal, the Supreme Court commented, "*Lee*, of course, is not before us, any more than it was before the Court of Appeals below, and we offer no opinion as to the validity

This article puts physician-assisted death into historical and rhetorical context as public debate enters this new phase. The first part of this article will survey major legal developments over the last twenty years regarding medical decisions that are intended or likely to shorten life, including withholding and refusing treatment as well as physician-assisted death. Within this very short time, Western societies have had to confront these issues seriously, and the law has developed with amazing speed.

The second part of this article will discuss the rhetoric of the debate. At each major decision point, up to and including the decisions in *Vacco* and *Glucksberg* and the competing legislative proposals in Oregon, essentially the same arguments have been made in favor of and in opposition to changing the law, using very similar rhetoric. Those who favor the legalization of actions that shorten life characterize the issue as one of personal autonomy and speak of individual rights to make personal decisions regarding health care. Opponents speak of social interests in protecting the value of human life and call the proposed actions euthanasia or suicide. At each stage, as the then-current issue is settled, the language changes to reflect the outcome. Legally authorized actions that effectively hasten death are not called "suicide," but rather "refusal of health care." And the pejorative terms "euthanasia" and "suicide" are invoked by opponents at the next stage of legal development.⁹

While this rhetoric emphasizes some of the important moral and ethical issues that are at stake as we decide how to manage health care at the end of life, this language also conceals some other very important issues. The last part of this article will discuss some of these issues—the extent to which disputes over the meaning of a good life

of the *Lee* courts' reasoning. In *Vacco v. Quill*, however, . . . we hold that New York's assisted-suicide ban does not violate the Equal Protection Clause." *Glucksberg*, 117 S. Ct. at 2262 n.7.

The constitutional challenge in *Lee* is quite different from those in *Glucksberg* and *Quill*. The Supreme Court's holding in those cases—that the Constitution does not require states to allow physician-assisted suicide—does not mean that legislation allowing and regulating physician-assisted suicide is unconstitutional.

9. When discussing a death caused intentionally by a doctor, either by lethal injection or by prescribing or providing lethal medication, this article uses the term "physician-assisted death," which is intended to be morally neutral. This term is broad enough to include deaths that occur when a doctor withholds treatment, but for the sake of clarity, I will call such actions withholding life support or treatment. When discussing the views of others—courts, legislatures, and commentators—I will use their own terminology where precision is important.

and a good death should be resolved by law, the status of doctors in society, and how health care resources should be allocated.

I. Historical Perspective

Although serious discussion about legalizing euthanasia occurred over sixty years ago, the major events in the development of the "right to die" have occurred in the last twenty years.¹⁰ This section traces that history and considers what social forces have shaped the "right to die" debate.

A. Early Arguments for Euthanasia

In 1938 the Euthanasia Society of America was formed with the goal of legalizing euthanasia so that dying people would have the choice of avoiding prolonged agony, but this Society made no serious legal headway.¹¹ Philosophical, religious, and medical writers discussed the topic throughout the 1930s, 1940s, and 1950s.¹² Many of these early euthanasia advocates closely linked the practice with then-current eugenic arguments that openly called for policies to eliminate "socially undesirable" people.¹³ After World War II, as word of the Nazi atrocities spread, euthanasia ceased to be widely discussed.¹⁴ In this social context, even the common-law right to refuse medical treatment required justification.¹⁵

Glanville Williams's book *The Sanctity of Life and the Criminal Law*, published in 1957, reopened serious discussion of the topic.¹⁶ The focus of his concern was the cancer victim, in pain and begging for death.¹⁷ He proposed that euthanasia be allowed at the voluntary

10. See Jim Persels, *Forcing the Issue of Physician-Assisted Suicide: Impact of the Kevorkian Case on the Euthanasia Debate*, 14 J. LEGAL MED. 93, 101-04 (1993) (discussing bills legalizing euthanasia in Ohio and Nebraska).

11. See *id.* at 101.

12. See Yale Kamisar, *Some Non-Religious Views Against Proposed 'Mercy-Killing' Legislation*, 42 MINN. L. REV. 969, 970-71 (1958).

13. See *id.* at 1017-19.

14. See Persels, *supra* note 10, at 101.

15. See Donald L. Beschle, *The Role of Courts in the Debate on Assisted Suicide: A Communitarian Approach*, 9 NOTRE DAME J.L. ETHICS & PUB. POL'Y 367, 367 (1995) (citing cases from the 1960s).

16. GLANVILLE WILLIAMS, *THE SANCTITY OF LIFE AND THE CRIMINAL LAW* 311 (Alfred A. Knopf, Inc., 2d ed. 1966) (1957).

17. See *id.*

request of a competent, terminally ill person.¹⁸ Williams argued that his proposal furthered two goals—the merciful prevention of suffering and respecting the choice of the individual about how to live life.¹⁹

However, when courts took the first steps toward recognition of a strong common-law and constitutionally protected individual interest in avoiding unwanted medical treatment, they did not address claims from competent adults. Instead, these first cases involved incompetent persons—those who were in a persistent vegetative state or severely brain injured or retarded. From the perspective of protecting individual autonomy, these cases are far more difficult than Williams's paradigm case, for they involve incompetent people who can make no request and who, in some cases, do not appear, in the usual sense, to be suffering. A significant reason for this apparent anomaly is developments in medical technology that Williams's proposal could not take into account.

As Lewis Thomas reminds us, in the 1940s, not long before Williams wrote, people routinely died of infectious diseases such as pneumonia, meningitis, septicemia, and tuberculosis, as well as cancer and heart disease.²⁰ Antibiotics to fight infection, and technology which allows people to remain alive but in a persistent vegetative state or to have a substantial chance of surviving cancer or kidney failure, developed in the next decades. As these methods for maintaining life became widely available, questions arose about whether they should always be used.

B. Recognizing Brain Death as Death

A 1967 law review article raised the issue of whether a doctor is guilty of "cold-blooded murder" if the doctor turns off the respirator of a comatose patient with no sign of brain activity.²¹ Although the author argued that this action does not amount to murder, his argument assumed that such a person was still alive.²² In 1968 a team of Harvard Medical School doctors addressed this problem by proposing

18. See *id. passim*; see also Glanville Williams, *Euthanasia and Abortion*, 38 U. COLO. L. REV. 178 (1966); Glanville Williams, "Mercy-Killing" Legislation—A Rejoinder, 43 MINN. L. REV. 1 (1958).

19. See WILLIAMS, *supra* note 16, at 1-2.

20. See Lewis Thomas, *Dying as Failure*, 447 AM. ACAD. POL. & SOC. SCI. ANNALS 1, 2 (1980).

21. See George P. Fletcher, *Prolonging Life*, 42 WASH. L. REV. 999 (1967); see also Persels, *supra* note 10, at 111.

22. See, e.g., Fletcher, *supra* note 21, at 1001.

that "death" be redefined to include brain death as well as heart-lung death.²³ By the early 1980s, the proposed redefinition of death was widely accepted in the United States.²⁴ Although some scholars have proposed that the legal definition of "death" be further expanded to apply to anyone who has lost all conscious functions,²⁵ this proposal has not been seriously considered by most involved in this debate.²⁶ Instead, the law has developed to allow substantial diversity of practice in treating terminally ill people, as the next sections will describe.

C. Development of the Right to Refuse Lifesaving Medical Treatment

Through the 1960s and early 1970s, a number of courts required *competent* patients to accept treatment against their wishes, at least where the proffered treatment had a good chance of success.²⁷ The three most important early cases recognizing a constitutional right to refuse medical care, even if the result would be death, did not involve legally competent, terminally ill patients. Instead, each of the three dealt with a major complicating factor—the person was either legally incompetent, not terminally ill, or both legally incompetent and not terminally ill. In all three cases, the courts held that medical care

23. See Ad Hoc Comm. of the Harvard Med. Sch. to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 JAMA 337, 337 (1968). According to George Annas, the reason for the proposed change was that heart transplantation had become feasible and doctors needed to take a beating heart from one body to put it in another. See George J. Annas, *The "Right to Die" in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875, 878 (1996). Robert D. Truog offers criticism of the idea of "brain death" and calls for directly addressing the criteria for making organs available for transplantation. See Robert D. Truog, *Is It Time to Abandon Brain Death?*, 27 HASTINGS CENTER REP. 29 (1997).

24. See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIOR RESEARCH, *DEFINING DEATH* (1981); UNIF. DETERMINATION OF DEATH ACT (1980).

25. See, e.g., Raymond J. Devettere, *Neocortical Death and Human Death*, 18 LAW, MED. & HEALTH CARE 96 (1990).

26. See *id.*

27. See, e.g., *In re President & Directors of Georgetown College, Inc.*, 331 F.2d 1000 (D.C. Cir. 1964); *United States v. George*, 239 F. Supp. 752 (D. Conn. 1965); *Commissioner of Correction v. Myers*, 399 N.E.2d 452 (Mass. 1979); *John F. Kennedy Mem'l Hosp. v. Heston*, 279 A.2d 670 (N.J. 1971); *Raleigh Fitkin-Paul Morgan Mem'l Hosp. v. Anderson*, 201 A.2d 537 (N.J. 1964). All of these cases except *Myers* concern Jehovah's Witnesses who rejected blood transfusions. *Myers* was a prisoner who required hemodialysis and who refused, according to the trial judge's findings, to protest his placement in a medium security rather than a minimum security prison. The court ordered his treatment, though it would require putting him in restraints, to further the state's interests in protecting life and in orderly prison administration. Compare *Thor v. Superior Court*, 855 P.2d 375 (Cal. 1993) (en banc), see *infra* note 45.

could be rejected, establishing methods of analysis and principles for decision making that most courts have followed.

The first and still most famous case, *In re Quinlan*,²⁸ decided in 1976, raised both difficulties. Karen Ann Quinlan was in a persistent vegetative state, and her breathing was supported only by a respirator.²⁹ She was, therefore, incompetent, and she was not, in the ordinary sense of the word, terminally ill, for she could live indefinitely with life support. Nevertheless, the New Jersey court held that her respirator could be terminated.³⁰ The court reasoned that in general individuals have a constitutionally protected right to refuse medical care³¹ and that people do not lose the right because they are incompetent.³² Therefore, the court concluded that means should be created to allow others to decide whether to exercise the right for incompetent people, and it upheld the appointment of Quinlan's father as her guardian, allowing him to exercise her right to terminate life support.³³

A year later in *Superintendent of Belchertown v. Saikewicz*,³⁴ the Massachusetts Supreme Judicial Court decided whether a mentally retarded sixty-seven-year-old man with the mental age of two years and eight months would receive chemotherapy for his leukemia.³⁵ Here, the court had to deal with decision making for a never-competent person. Relying on *Quinlan*, the court concluded that Saikewicz had a right to refuse treatment and that he did not lose it just because he was not and never had been competent.³⁶ This court used a best interests test to reach the conclusion against ordering treatment.³⁷ Even though competent adults would probably have accepted the chemotherapy, the court refused to order it for Saikewicz because the chemotherapy would not cure the disease and would cause significant bad side effects that he could not understand.³⁸ *Saikewicz* is famous for listing the four state interests most commonly posed as limitations on the individual's right to determine medical care: preservation of life,

28. 355 A.2d 647 (N.J. 1976).

29. *See id.* at 654.

30. *See id.* at 671.

31. *See id.* at 663.

32. *See id.* at 664.

33. *See id.*

34. 370 N.E.2d 417 (Mass. 1977).

35. *See id.*

36. *See id.*

37. *See id.* at 427.

38. *See id.* at 430.

protection of the interests of innocent third parties, prevention of suicide, and maintaining the ethical integrity of the medical profession.³⁹ The *Saikewicz* decision, like most cases that followed it, recognized the state's interest in preserving life but held that that interest was not strong enough to prevail over the individual interest at stake, and it concluded that the acts contemplated could not properly be termed "suicide."⁴⁰

In the third early case, *Satz v. Perlmutter*,⁴¹ decided in 1978, a competent man, able to communicate but paralyzed by amyotrophic lateral sclerosis (Lou Gehrig's disease) sought to have his respirator removed.⁴² The state based its objection on its interest in preserving life, for Perlmutter, like Quinlan, could have lived for an indefinite time with the respirator.⁴³ Like the *Quinlan* and *Saikewicz* courts, the Florida court held that the Constitution protects individual choice to refuse treatment and that this right to choose is stronger than the state interest in preserving life.⁴⁴

Most other courts followed these strong early precedents, consistently refusing to order lifesaving medical treatment over the objection of a competent individual or an incompetent person's surrogate decision maker.⁴⁵ However, although the New York Court of Appeals recognized the right of competent people to refuse lifesaving medical

39. See *id.* at 425.

40. See *id.*

41. 362 So. 2d 160 (Fla. Dist. Ct. App.), *aff'd*, 379 So. 2d 359 (Fla. Dist. Ct. App. 1978).

42. See *id.*

43. See *id.* at 162.

44. See *id.*

45. For an extensive listing, see *Cruzan v. Harmon*, 760 S.W.2d 408, 412 n.4 (Mo. 1988) (en banc). Some of the most dramatic cases have arisen in California. In 1983, a California doctor treating a patient in a persistent vegetative state terminated a respirator, artificial nutrition, and hydration at the request of the family and was prosecuted for murder. In the first appellate opinion addressing the criminal liability of a doctor who withdraws life support, the court in *Barber v. Superior Court*, 195 Cal. Rptr. 434, 484 (Cal. Ct. App. 1983), rebuffed the prosecution, finding that people have the right to refuse medical treatment. In 1984, in *Bartling v. Superior Court*, 209 Cal. Rptr. 220 (Cal. Ct. App. 1984), the court applied this principle to allow a competent man with cancer to have a ventilator removed, even though he was not terminally ill. The court extended the principle even further in *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986), ruling that a woman with severe cerebral palsy, who was a quadriplegic, completely bedridden, almost entirely immobile, and in continuous pain had the right to refuse artificial nutrition and hydration, even though her life expectancy was 15 to 20 years. Most recently, in *Thor v. Superior Court*, 855 P.2d 375 (Cal. 1993) (en banc), the California Supreme Court held that a prisoner who was quadriplegic because of injuries suffered in prison had the right to refuse medication and artificial nutrition.

treatment,⁴⁶ the court did not allow withdrawal of life support for an incompetent person unless it was proven by clear and convincing evidence that the person would not have wished treatment under the circumstances.⁴⁷ Similarly, the Missouri Supreme Court in *Cruzan v. Harmon*⁴⁸ refused to allow third parties to withdraw life support from a person in a persistent vegetative state in the absence of clear and convincing evidence that the patient would have wanted life support to be withdrawn.⁴⁹ The Missouri court's opinion in *Cruzan* is the only reported appellate opinion after *Quinlan* to further imply that the state's interest in preserving life might justify requiring even a competent person to accept unwanted medical treatment.⁵⁰

At the same time that courts were developing common-law and constitutional doctrines that permit patients or their surrogates to refuse lifesaving medical care, state legislatures were enacting statutes to allow "health care advance directives"—living wills and durable powers of attorney for health care. The term "living will" was coined in 1969 to describe a document, executed in much the same form as a will, that expresses the signer's wish not to have life support if he or she is terminally ill and incompetent.⁵¹ California enacted the first statute allowing living wills in 1976, the year in which *Quinlan* was decided.⁵² A health care power of attorney is broader than a living will, designating a trusted person to make health care decisions of all kinds, not just those related to withdrawal of lifesaving care, in the event of the signer's incompetence.⁵³ The federal Patient Self-Determination Act of 1989 gave impetus to this trend by requiring health care facilities and agencies to disseminate information about the availability of advance directives.⁵⁴ Today only one state does not have a

46. See *Westchester County Med. Ctr. ex rel. O'Connor v. Hall*, 531 N.E.2d 607, 611 (N.Y. 1988); *In re Storar*, 420 N.E.2d 64, 71 (N.Y. 1981).

47. See *In re Storar*, 420 N.E.2d at 71.

48. 760 S.W.2d 408 (Mo. 1988) (en banc).

49. See *id.* at 424.

50. However, Justice Stevens, concurring in *Glucksberg* and *Vacco*, suggested that in some situations it might be constitutional to force unwanted medical care on a competent adult. See *Washington v. Glucksberg*, 117 S. Ct. 2302, 2310 (1997); *Vacco v. Quill*, 117 S. Ct. 2293, 2293 (1997).

51. See Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L.J. 539 (1969). For an overview of types of living will statutes, see Gregory Gelfand, *Living Will Statutes: The First Decade*, 1987 WIS. L. REV. 737.

52. See California Natural Death Act, 1976 Cal. Stat. c.1439, § 1 (codified as amended at CAL. HEALTH & SAFETY CODE §§ 7185-7195 (West 1990 & Supp. 1997)).

53. See CAL. HEALTH & SAFETY CODE § 7193.

54. 42 U.S.C. §§ 1395cc(f), 1395mm(c)(8), 1396a(w) (1994).

statute or case law recognizing the legal efficacy of living wills,⁵⁵ and at least thirty-eight states have statutes that allow durable powers of attorney for health care.⁵⁶

Parallel with the development of law surrounding termination of medical care for adults, questions about the treatment of severely disabled newborn babies were also becoming highly visible.⁵⁷ A famous article published in the *New England Journal of Medicine* in 1973 openly acknowledged that doctors sometimes allowed parents to decide not to authorize treatment for such babies, with the knowledge that the child's death would be highly likely.⁵⁸ The issue was brought dramatically to public attention in the early 1980s when lawsuits were filed challenging decisions to deny critical surgery to Siamese twins born in Illinois and to a child with Down's syndrome in Bloomington, Indiana.⁵⁹ In both cases the courts ultimately ruled in favor of the doctors and parents, but the public furor continued.⁶⁰ In 1983, in what was known as the Baby Jane Doe case, an activist lawyer sued parents in New York, seeking to override the parents' refusal to consent to surgery for a child born with spina bifida.⁶¹ The trial judge appointed a guardian for the child to consent to the surgery, but on the parents' appeal, the decision was reversed because the plaintiff lacked stand-

55. See JUDITH AREEN ET AL., LAW SCIENCE AND MEDICINE 1181 n.1 (2d ed. 1996) (45 states and the District of Columbia have enacted statutes which allow living wills. Michigan is the only state that has not recognized living wills by statute or case law.).

56. See *id.* (33 states and the District of Columbia have durable power of attorney for health care statutes. All the states without such statutes have general durable power of attorney statutes that could be interpreted to authorize powers of attorney dealing with health care. Some of these statutes—Arizona, Colorado, Indiana, Maryland, and Virginia—have judicial decisions or attorney general opinions supporting this interpretation.).

57. See Raymond Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (1973).

58. See *id.*

59. See ANGELA R. HOLDER, LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE 88-89 (1985) and sources cited within.

60. See *id.*

61. Spina bifida is the common name for a medical condition, meningocele, in which the spinal column fails to close properly during fetal development, often accompanied by hydrocephaly, the accumulation of cerebro-spinal fluid in the cranium. Mild cases of spina bifida can be surgically corrected so that the child has only relatively minor permanent disabilities. In more severe cases, even with surgery, the child may have major disabilities. If the spinal lesion is not closed soon after birth, though, the child is seriously at risk for meningitis, which can cause death. See Anthony Gallo, *Spina Bifida: The State of the Art of Medical Management*, 14 HASTINGS CENTER REP. 10, 10-11 (1984).

ing to bring the suit and had failed to comply with procedures for intervention in child neglect cases.⁶²

Beginning in 1982, the federal Department of Health and Human Services began to intervene and, by various routes, attempted to limit the practice of denying medical care to disabled newborns. The Department issued a notice declaring that denying medical care to severely disabled newborns constituted forbidden discrimination against the disabled under section 504 of the Rehabilitation Act.⁶³ It also promulgated a regulation requiring hospitals to display posters declaring that discriminatory failure to feed and care for handicapped infants was against the law and listing a hot line where people could anonymously report suspected cases.⁶⁴ Ultimately, the courts held that Congress did not intend section 504 to apply to decisions about medical care for disabled newborns.⁶⁵

In the interim, in 1984 Congress amended the Child Abuse Prevention and Treatment Act to require states to establish programs and procedures to prevent "medical neglect" of handicapped infants as a condition to receiving federal child welfare funds.⁶⁶ "Medical neglect" is defined so that parents could decide to withhold treatment only: (1) if the "infant is chronically and irreversibly comatose"; (2) if treating "would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant"; or (3) if the treatment would be "virtually futile in terms of the survival of the infant and the treatment itself would be inhumane."⁶⁷

62. See *Weber v. Stony Brook Hosp.*, 456 N.E.2d 1186 (N.Y.), *cert. denied*, 464 U.S. 1026 (1983).

63. See *Discriminating Against the Handicapped by Withholding Treatment or Nourishment: Notice of Health Care Providers*, 47 Fed. Reg. 26,027 (1982).

64. See *Nondiscrimination on the Basis of Handicap*, 48 Fed. Reg. 9630 (1983).

65. See *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984). *University Hospital* arose out of the Department of Health and Human Services' efforts to investigate the Baby Jane Doe case. The agency sought to obtain the baby's hospital records under section 504 of the Rehabilitation Act after the hospital and parents refused to release them. See also *Bowen v. American Hosp. Ass'n*, 476 U.S. 610 (1986).

66. Amendments to Child Abuse Prevention and Treatment Act, Pub. L. No. 98-457, tit. 1, § 106, 98 Stat. 1749, 1751 (1984) (codified as amended at 42 U.S.C. § 5106 (1994)).

67. 45 C.F.R. § 1340.15(b)(2) (1997). For a detailed interpretation of the terms in this section, see U.S. COMM'N ON CIVIL RIGHTS, *MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES* 82-90 (1989). The U.S. Commission on Civil Rights reported in 1989 that these requirements are not vigorously enforced by state child welfare agencies, which are the principal agencies responsible for enforcement. These agencies, according to the Commission, largely defer to the

By the early 1980s, the law in most states allowed termination of respirators, antibiotics, dialysis, chemotherapy, and other medical care used to treat life-endangering conditions, at least under some circumstances. The next major issue was whether providing artificial nutrition and hydration was also medical treatment that could be withdrawn under similar circumstances, or whether this kind of care was qualitatively different, the equivalent of providing food, drink, and warmth, which must be given to all people as a matter of fundamental decency.

D. Withdrawal of Nutrition and Hydration

Cases involving the termination of tube-feeding were highly controversial because of the uncertainty about whether this treatment is "medical" or "comfort" care and because patients typically were not terminally ill.⁶⁸ Patients often could be expected to live, sometimes for many years, if provided with nutrition and hydration. Further, although many of the cases involved people in a persistent vegetative state who had irreversibly lost all higher brain function,⁶⁹ some involved people who were conscious and, sometimes, competent.⁷⁰ In theory, the claim of a competent patient to refuse tube-feeding is easier to handle than that of someone in a persistent vegetative state because the former makes the decision for him or herself whereas someone else must make the decision for the latter. In reality, though, the cases involving competent people were more wrenching because of social ambivalence about whether withdrawal of artificial nutrition and hydration constituted withdrawal of treatment or simply leaving someone to starve.

judgment of hospitals, rather than investigating them. *See id.* at 18-25. In the end the Commission, which took the position that denial of medical care to newborns with disabilities is unlawful discrimination, concluded "that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984." *Id.* at 149.

68. For an early article raising the question of whether it would be medically ethical to withhold or withdraw artificial nutrition and hydration, see Carson Strong, *Can Fluids or Electrolytes Be 'Extraordinary' Treatment?*, 7 J. MED. ETHICS 83 (1981).

69. *See, e.g., Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc); *In re Jobes*, 529 A.2d 434 (N.J. 1987).

70. *See, e.g., Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986) (involving a competent, largely immobile woman with cerebral palsy); *In re Conroy*, 486 A.2d 1209 (N.J. 1985) (concerning a woman terminally ill and marginally cognitive).

Numerous articles debated whether artificial nutrition and hydration should be regarded as substantially different from other kinds of care. Leading ethicists such as Daniel Callahan argued passionately that it should. He wrote:

An important function of moral culture is to instill in its members deep feelings about the morality of various actions; and one of the most important in all cultures, save the most debased, is that the needy and the helpless must be fed If the practice of ceasing to feed some dying patients would remain . . . rare . . . , the matter need be of little public interest. But the enthusiasm that has greeted the opening up of the subject, the widespread frustration felt by many of those in charge of long-term or chronic care facilities in the face of the biological tenacity of their more vegetative charges, and the pressures to reduce or contain costs, are all reasons to guess that the practice may not remain rare and contained.⁷¹

For constitutional purposes, the Supreme Court's 1990 decision in *Cruzan v. Director, Missouri Department of Health*⁷² resolved the matter contrary to Callahan's view. *Cruzan* concerned whether artificial nutrition and hydration could be withdrawn from Nancy Cruzan, who, like Karen Ann Quinlan, was in a persistent vegetative state following an accident.⁷³ The Court treated nutrition and hydration as medical care, and it assumed without deciding that a competent adult has a right to refuse lifesaving treatment.⁷⁴ The specific issue before the Court was the constitutionality of a state rule allowing denial of life support to an incompetent person only upon proof by clear and convincing evidence that this would be the person's own wish.⁷⁵ The Court held that such a rule was not unconstitutional, concluding that the Constitution supported both the state's interest in preserving life and the state's interest in insuring that the choice of the patient is honored.⁷⁶

Even though the Supreme Court in *Cruzan* did not require states to develop legal mechanisms for allowing decisions to withdraw life

71. Daniel Callahan, *Public Policy and the Cessation of Nutrition*, in *BY NO EXTRAORDINARY MEANS* 61 (Joanne Lynn ed., 1986); see also Daniel Callahan, *On Feeding the Dying*, 13 *HASTINGS CENTER REP.* 22 (1983); Ronald A. Carson, *The Symbolic Significance of Giving to Eat and Drink*, in *BY NO EXTRAORDINARY MEANS*, *supra*, at 84; Alan J. Weisbard & Mark Siegler, *On Killing Patients with Kindness: An Appeal for Caution*, in *BY NO EXTRAORDINARY MEANS*, *supra*, at 108.

72. 497 U.S. 261 (1990).

73. See *id.* at 266.

74. See *id.*

75. See *id.* at 269.

76. See *id.* at 286-87.

support from incompetent people, state courts and legislatures, as well as Congress, have gone far toward developing such means. As described above, all but one of the states by statute or case law clearly allow living wills today, and most also allow durable powers of attorney for health care.⁷⁷

As this discussion shows, in most states, patients are allowed to reject life-preserving medical care whether or not they are terminally ill or suffering, and surrogates can make such a decision for incompetent patients. Within the medical profession, the mainstream view is that little difference exists between tube-feeding and other life-sustaining measures; therefore, doctors may ethically withdraw nutrition and hydration from certain dying, hopelessly ill, or permanently unconscious patients.⁷⁸ The next two important "right to die" issues that have come to the fore in the 1990s are whether doctors can withhold "futile" treatments regardless of patient wishes and whether doctors can assist patients in dying.

E. Withholding "Futile" Treatments

In 1991 doctors in Minnesota caring for Helga Wanglie, a patient in a persistent vegetative state, recommended that her life support be terminated.⁷⁹ Her husband, who had been appointed guardian, refused and insisted that everything possible be done for her.⁸⁰ The doctors went to court, seeking to terminate the husband's appointment as guardian on the grounds that he was not acting in her best interest.⁸¹ They argued that it was wrong to provide "futile" treatment to someone in a persistent vegetative state, the first time that such a legal claim had been advanced.⁸² The doctors lost.⁸³ Since then, several other conflicts between doctors and families have been

77. An issue, not developed in this article, is how important *constitutional* developments, as compared to common law and statutory, have been in the law regarding care at the end of life. Yet the first decisions recognizing an individual's right to refuse treatment, such as *Quinlan*, were, as noted above, constitutionally founded. We cannot know whether legislatures and courts would have moved as rapidly as they did without this constitutional foundation.

78. See Sidney H. Wanzel et al., *The Physician's Responsibility Toward Hopelessly Ill Patients: A Second Look*, 320 NEW ENG. J. MED. 844 (1989).

79. See *Helga Wanglie, Woman in Right-to-Life Battle*, CHI. TRIB., July 6, 1991, at 13.

80. See *id.*

81. See *id.*

82. See *Helga Wanglie's Life*, STAR-TRIB., May 26, 1991, at 18A.

83. See *In re Wanglie*, No. PX91-288 (Prob. Ct., Hennepin County, Minn., June 28, 1991); *Judge Denies Request to Cut Life Support*, CHI. TRIB., July 2, 1991, at 3. Some people have even proposed that "death" be legally defined as termination of

reported in the newspapers, and one, involving the treatment of an anencephalic baby, went to the U.S. Court of Appeals for the Fourth Circuit.⁸⁴ Courts have consistently upheld families' decisions to continue treatment despite doctors' claims that the treatments are futile.

Medical futility clearly raises the conflict between the autonomy of the physician and of the patient. From a medical perspective, the positions of families and doctors in the medical futility cases are completely reversed from *Quinlan*, but from a legal perspective, the doctors' position in the medical futility cases is consistent with their position in *Quinlan*. The essential point established in *Quinlan* was patient control over treatment, even in the face of medical resistance. Proponents of the futility doctrine assert that in some cases doctors should be able to determine treatment without consulting with the patient or patient's surrogate at all.⁸⁵ This posture alone explains why the doctors have not yet prevailed in litigation.⁸⁶

F. Physician-Assisted Dying

Physician-assisted death is, of course, nothing new. For years some doctors have given patients doses of painkillers that they know will shorten the patient's life.⁸⁷ The express motive in such cases, though, is to alleviate suffering, not to help a patient die.⁸⁸ In contrast,

[s]ome physicians, believing it to be the last act in a continuum of care provided for the hopelessly ill patient, do assist patients who request it, either by prescribing sleeping pills with knowledge of their intended use or by discussing the required doses and methods of administration with the patient. The frequency with which

conscious functions. See, e.g., Devettere, *supra* note 25. This radical proposal eliminates the option of providing treatment to anyone without conscious functions.

84. See *In re Baby K*, 832 F. Supp. 1022, 1025 (E.D. Va.), *aff'd*, 16 F.3d 590 (4th Cir. 1994). Some of the cases are discussed in Bethany Spielman, *Collective Decisions About Medical Futility*, 22 J.L., MED. & ETHICS 152 (1994).

85. See, e.g., J. Randall Curtis et al., *Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders*, 273 JAMA 124 (1995).

86. The term "medical futility" is controversial for other reasons as well. Several authors have noted a lack of consensus on the definition of medical futility and on its use in clinical practice. See *id.*; see also Jeffrey W. Swanson & S. Van McCrary, *Doing All They Can: Physicians Who Deny Medical Futility*, 22 J.L. MED. & ETHICS 318 (1994). Also, some suspect that changes in how insurers reimburse doctors and hospitals may motivate doctors to restrict access to expensive life-support systems, especially when its utility is dubious. When insurers pay doctors for their actual costs, doctors are motivated to provide more care. Current prospective-payment and managed-care systems give doctors an incentive to limit care costs. Robert M. Taylor & John D. Lantos, *The Politics of Medical Futility*, 11 ISSUES L. & MED. 3 (1995).

87. See Wanzer et al., *supra* note 78, at 847.

88. See *id.*

such actions are undertaken is unknown, but they are certainly not rare.⁸⁹

In 1991 Dr. Timothy Quill wrote about knowingly providing such help to his long-term patient Diane, who had leukemia. His article in the *New England Journal of Medicine* described Diane's request and his decision to prescribe barbiturates for her and to make sure that she knew how to use them.⁹⁰

The conduct of Dr. Jack Kevorkian, the most notorious example of a doctor-assisted death, contrasts dramatically with that of Quill.⁹¹ Indeed, legal commentators have debated whether Kevorkian is acting as a physician and whether the people he has helped are his patients.⁹² Yet, despite the differences between Kevorkian and Quill, neither doctor has been criminally convicted for his actions, though prosecutors have brought charges against each of them.⁹³

Both Kevorkian and Quill challenged the constitutionality of statutes that, as applied, made it a crime for doctors to comply with the request of a competent, terminally ill patient for help in dying.⁹⁴ While the Michigan Supreme Court rejected Kevorkian's due process challenge,⁹⁵ Quill's equal protection attack on the New York statute was successful in *Quill v. Vacco*⁹⁶ in the Second Circuit, although the Supreme Court reversed that holding.⁹⁷

Proponents of a constitutional right to physician assistance in dying rely heavily on the refusal of treatment cases, arguing that this kind of assistance should be legally considered a form of health care and that individuals should be able to request this assistance just as they request or reject other kinds of treatments. For example, in *Quill v. Vacco*, the Second Circuit accepted the following argument:

New York does not treat similarly circumstanced persons alike: those in the final stages of terminal illness who are on life-support

89. *Id.* at 878.

90. See Timothy E. Quill, *A Case of Individualized Decision Making*, 324 *NEW ENG. J. MED.* 691, 693 (1991).

91. For a detailed description of Kevorkian's career through 1993, see Persels, *supra* note 10, at 95-100.

92. See Annas, *supra* note 23, at 891-92.

93. The grand jury in Rochester refused to indict Quill. See B.D. Cohen, *On Death and Dying—MD Who Aided in Suicide Aims to Humanize Debate*, *NEWSDAY*, Aug. 11, 1991, at 3. Michigan courts dismissed indictments against Kevorkian, and juries refused to convict Kevorkian. See *People v. Kevorkian*, 527 N.W.2d 714 (Mich. 1994).

94. See *Kevorkian*, 527 N.W.2d at 714; Cohen, *supra* note 93.

95. See *Kevorkian*, 527 N.W.2d at 714.

96. 80 F.3d 716 (2d Cir. 1996).

97. *Vacco v. Quill*, 117 S. Ct. 2293 (1997).

systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated, except for the previous attachment of life-sustaining equipment, are not allowed to hasten death by self-administering prescribed drugs.⁹⁸

Similarly, the statutes permitting and regulating physician-assisted suicide that were enacted in Oregon are structurally similar to statutes dealing with the withdrawal of medical treatment that authorize living wills and durable powers of attorney for health care.⁹⁹

In contrast, those judges who find criminalization of physician-assisted dying constitutionally permissible sharply differentiate the practice from refusal of medical care.¹⁰⁰ The central point of the Supreme Court's majority opinions in *Washington v. Glucksberg*¹⁰¹ and *Vacco v. Quill*¹⁰² is acceptance of this distinction.¹⁰³

As the next section will discuss, a central part of the development of the law concerning the "right to die" over the last twenty years has been this value-laden battle over analogy and naming.

II. Language and the Law and Ethics of Dying

Common language, as well as the language of ethics and the law, uses terms that express moral and political judgments about the acceptability of refusing lifesaving medical care. The most fundamental distinction is expressed by use of the term "suicide," which connotes the needless, irrational, perhaps insane, taking of one's life, outside the bounds of accepted, much less protected, behavior.¹⁰⁴ Those who

98. 80 F.3d at 729; see also *Compassion in Dying v. Washington*, 79 F.3d 790, 815 (9th Cir. 1996) (en banc) (recognizing that a liberty in the refusal of life-sustaining food and water necessarily implicates a liberty interest in hastening one's own death).

99. Compare the Oregon statutes on advance directives, OR. REV. STAT. §§ 127.505-.658, to the Oregon Death with Dignity Act, Oregon Ballot Measure 16, enacted by popular initiative in 1994, reprinted in Tarnow, *supra* note 6, at app.

100. See *Compassion in Dying*, 79 F.3d at 839 (Beezer, J., dissenting); *id.* at 857 (Kleinfeld, J., dissenting); *Kevorkian*, 527 N.W.2d at 727-33.

101. 117 S. Ct. 2258 (1997). Not all of the Justices hold this view absolutely, though. See *infra* notes 139-60 and accompanying text.

102. 117 S. Ct. 2293 (1997).

103. See *Vacco*, 117 S. Ct. at 2296; *Glucksberg*, 117 S. Ct. at 2267.

104. If a person is called suicidal, the ordinary response is taking him or her into protective custody, to be observed and perhaps medicated. Although we believe in principle that a competent person can commit suicide, people who want to commit suicide are, for practical purposes, often presumed incompetent, which means that we are under no obligation to respect their wishes to die. In litigation over Oregon legislation allowing physician-assisted suicide, the challengers successfully argued at the trial level that the statute's provisions were inadequate to

believe that taking one's life in certain circumstances can be morally valid and should be legally protected reject the "suicide" label, giving the act some other name that evokes notions of personal autonomy.

For example, in *Cruzan*, Justice Scalia, who sided with the majority which held that the Constitution permits states to allow termination of life support only upon clear and convincing evidence of the person's wishes, said that there is no historically recognized right to "suicide."¹⁰⁵ Justice Brennan, who dissented, spoke of the long-recognized right to "avoid unwanted medical treatment."¹⁰⁶

Similarly, those who oppose physician-assisted dying call taking medication to end one's life or submitting to a lethal injection "suicide" and call writing the prescription or giving the injection "criminal homicide." On the other hand, proponents of legalization have coined new terms that connote individual choice, such as "right to die with assistance"¹⁰⁷ and "death with dignity."¹⁰⁸

This section describes the rhetoric used in the bioethical and legal debates surrounding "right to die" issues throughout the second half of this century, showing that at each stage advocates on each side used the same language.¹⁰⁹ The shifts in the meaning of terms, as law and social practice changed, indicate that the terms themselves are conclusory and not analytical.¹¹⁰ Nevertheless, the rhetoric is very influential, for it suggests what some of the issues are and evokes highly

ensure that those who sought such assistance were competent. See *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995), *rev'd*, 107 F.3d 1382 (9th Cir.), *cert. denied*, 118 S. Ct. 328 (1997).

105. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 293 (1990) (Scalia, J., concurring).

106. *Id.* at 301 (Brennan, J., dissenting).

107. Note, *Physician-Assisted Suicide and the Right to Die with Assistance*, 105 HARV. L. REV. 2021, 2023 (1992).

108. This is the term used in the Oregon measure legalizing physician-assisted dying. Oregon Death with Dignity Act, Oregon Ballot Measure 16, enacted by popular initiative in 1994, reprinted in Tarnow, *supra* note 6, at app.; see also Eugenie A. Gifford, *Artes Moriendi: Active Euthanasia and the Art of Dying*, 40 U.C.L.A. L. REV. 1545, 1546 (1993).

109. The distinction is not at stake in the debate around the futility of medical treatment. For further discussion of this issue, see *supra* text accompanying notes 79-86.

110. This discussion gives examples of language used in the debates over the last 20 years, but does not exhaustively survey case law and commentary. For other discussions of how terminology shapes ethical and legal concepts, see Leslie Bender, *A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia*, 59 TENN. L. REV. 519, 527-34 (1992) (naming alternatives and their implications), and Callahan & White, *supra* note 6, at 20 (criticizing the variety of language used and calling language used by proponents of physician-assisted suicide "Orwellian doublespeak").

emotional responses to those issues, while obscuring other important issues. This section discusses three sets of distinguishing terms: (1) "ordinary" and "extraordinary" care; (2) various words that connote the distinction between "killing" and "letting die"; and (3) terms that focus on the intended outcome of the actions. Following this discussion, the last section examines the Supreme Court's opinions in *Vacco v. Quill*¹¹¹ and *Washington v. Glucksberg*¹¹² through the lens of this rhetoric.

A. Ordinary Versus Extraordinary Care

For a time, particularly in the late seventies and early eighties, some medical and ethical discussions attempted to distinguish medical care which could properly be withheld or rejected from that which should be offered and accepted. For purposes of medical practice, "extraordinary" care could permissibly be withheld, whereas refusal of "ordinary" care was considered suicide.¹¹³ The distinction originated in the Catholic tradition.¹¹⁴ However, legal and ethical discussions have largely abandoned this terminology.

B. "Killing" Versus "Letting Die"—Passive and Active Euthanasia, Acts, Omissions, and Causation

A variety of terms in ethical and legal discussions have been used to draw a line between "killing" and "letting die" and between "committing suicide" and "escaping from suffering."

1. ACTIVE VERSUS PASSIVE EUTHANASIA

The ethical terms with the oldest and most elaborate lineage are "passive" and "active" euthanasia. The distinction is typically made in this way: "[P]assive euthanasia involves allowing a patient to die by removing her from artificial life support systems such as respirators and feeding tubes or simply discontinuing medical treatments neces-

111. 117 S. Ct. 2293 (1997).

112. 117 S. Ct. 2258 (1997).

113. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 126-27 (2d ed. 1983). For another statement of the difference, distinguishing the medical definition and the Catholic ethical definition, see Rev. Edward J. Bayer, *Perspectives from Catholic Theology*, in *BY NO EXTRAORDINARY MEANS*, *supra* note 71, at 89, 90-91.

114. See Joanne Lynn & James F. Childress, *Must Patients Always Be Given Food and Water?*, in *BY NO EXTRAORDINARY MEANS*, *supra* note 71, at 47, 53-54.

sary to sustain life. Active euthanasia, by contrast, involves positive steps to end the life of a patient, typically by lethal injection."¹¹⁵

When Glanville Williams proposed in the late 1950s to allow doctors to end the lives of terminally ill, competent, suffering patients at their request, he used these terms.¹¹⁶ In 1975, near the time of the *Quinlan* decision, when the moral and legal acceptability of withdrawing respirators and other sorts of life support was still disputed, a famous ethical debate over the topic was carried out in terms of "active" versus "passive" euthanasia. James Rachels argued that the distinction is not morally sustainable, asking "what is the point of drawing out the suffering" of a person who will die anyway?¹¹⁷ In reply, Tom Beauchamp argued that the distinction is morally significant and should be maintained because of the slippery slope problem, that "active" killing may lead to programs to exterminate people regarded as socially undesirable.¹¹⁸ Because the term "euthanasia" has become associated with this slippery slope,¹¹⁹ those who support actions that allow patients to die have largely quit using the term, while opponents continue to use the term for exactly the same reason.¹²⁰

2. ACTS VERSUS OMISSIONS AND LEGAL CAUSATION

On the legal side, early proponents of allowing withdrawal of life support confronted the legal distinction between acts and omissions. In most American jurisdictions, criminal liability for "omissions" is more limited than for acts, because a person is not legally liable for failure to act unless that person has a legal duty to act, and the sources of legal duty are limited.¹²¹ Writing in 1967, George Fletcher argued that a doctor who turned off the ventilator of a person

115. Gifford, *supra* note 108, at 1546 n.3, 1550-51; see also, e.g., Tom L. Beauchamp, *The Justification of Physician-Assisted Deaths*, 29 IND. L. REV. 1173 (1996) (discussing the differences between suicide and intention to relieve suffering, between various types of euthanasia, between euthanasia and physician-assisted suicide, and between killing and letting die).

116. See *supra* notes 16-19 and accompanying text.

117. James Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78, 78-79 (1975).

118. See Tom L. Beauchamp, *A Reply to Rachels on Active and Passive Euthanasia*, in ETHICAL ISSUES IN DEATH AND DYING 246, 249-53 (Tom L. Beauchamp & Seymour Perlin eds., 1978).

119. See *infra* text accompanying notes 157-60 for a discussion of the slippery slope argument.

120. See, e.g., Yale Kamisar, *When Is There a Constitutional "Right to Die"? When Is There No Constitutional "Right to Live"?*, 25 GEO. L. REV. 1203 (1991).

121. See WAYNE R. LAFAYE & AUSTIN W. SCOTT, JR., CRIMINAL LAW § 3.3 (2d ed. 1986).

with no brain activity¹²² should be treated as having “omitted” to care for the patient rather than having affirmatively “acted” to kill the patient and that the doctor “permitted death to occur” rather than “caused death.”¹²³ In *Barber v. Superior Court*, a 1983 criminal prosecution of a doctor for turning off the respirator of a patient in a persistent vegetative state, the court reversed the conviction, accepting the argument that the doctor had omitted to act when he had no duty to do so.¹²⁴

In other cases courts relied on principles of legal causation to preclude criminal liability for withdrawing life support. For example, in 1985, in *In re Conroy*,¹²⁵ one of the most important and famous cases concerning withdrawal of feeding tubes, the New Jersey court relied in part on a causation argument, saying that refusal of treatment is not suicide because the person’s underlying medical condition was not self-inflicted and the person dies from nature “taking its course.”¹²⁶

3. CRITICISMS OF THE DISTINCTIONS AS ARTIFICIAL

Although the distinction between “killing” and “letting die” seems clear with regard to the newest issue, physician-aided death, both supporters and opponents of the practice have denied that the distinction is morally significant. For example, Yale Kamisar, who opposed withdrawal of treatment as well as physician-assisted death,¹²⁷ wrote:

[M]any who support the “right to die” say they are strongly opposed to active euthanasia. I must say I do not find the arguments made by proponents of this distinction convincing. Least persuasive of all, I think, are the arguments that lifting the ban against active euthanasia would be “to embrace the assumption

122. At this time, “brain death” was not well established legally. See *supra* text accompanying notes 21-23.

123. See Fletcher, *supra* note 21, at 1007.

124. 195 Cal. Rptr. 484 (1983). *Barber* is discussed in *supra* note 45. See also Satz v. Perlmutter, 362 So. 2d 160 (Fla. Dist. Ct. App.), *aff’d*, 379 So. 2d 359 (Fla. Dist. Ct. App. 1978) (finding competent man wanting to withdraw respirator is not committing suicide, for he wants to live, but not with assistance, and if he dies, it will be from natural causes and not from his act).

125. 486 A.2d 1209 (1985).

126. *Id.*

127. When Kamisar was a young associate professor, he wrote a response to Glanville Williams’s proposal to allow active euthanasia at the request of competent, terminally ill, patients, laying out arguments that he and others have continued to make for the last 40 years. Kamisar, *supra* note 12, at 969. He denied that the distinction between active and passive euthanasia was morally significant and argued that neither practice was ethically acceptable, a position he has maintained to this day.

that one human being has the power of life over another" (the withholding or withdrawal of life-sustaining treatment embraces the same assumption) and that maintaining the prohibition against active euthanasia "prevents the grave potential for abuse inherent in any law that sanctions the taking of human life" (passive euthanasia, at the very least, presents the same potential for abuse).

Indeed I venture to say that a law that sanctions the "taking of human life" indirectly or negatively rather than directly or positively contains much more potential for abuse. Because of the repugnance surrounding active euthanasia—because it is what might be called "straightforward" or "out in the open" euthanasia—I think it may be forcefully argued that it is *less likely* to be abused than other less readily identifiable forms of euthanasia.¹²⁸

Similarly, Tom Beauchamp, who originally championed the distinction between "killing" and "letting die," has more recently argued that the distinction is difficult to make and creates moral and conceptual confusion.¹²⁹ He argues that the right to autonomy which justifies allowing patients to refuse treatment seems in principle to extend to a patient's request for physician-assisted death.¹³⁰

C. Intent to Die Versus Intent to Relieve or Escape Suffering

Although some definitions of "suicide" include all voluntary acts that result in the ending of one's life,¹³¹ the actor's intent has commonly been used to limit the scope of the term. In *Satz v. Perlmutter*,¹³² a 1978 Florida case involving the request of a competent man with amyotrophic lateral sclerosis (Lou Gehrig's disease) to turn off his respirator, the court denied that Abe Perlmutter wanted to commit suicide.¹³³ The court said that Perlmutter wanted to live, but not with

128. Kamisar, *supra* note 120, at 1216-17.

129. See Beauchamp, *supra* note 115, at 1178.

130. Beauchamp now concludes that nothing about "killing" or "letting die" entails judgment about the wrongness or rightness of either type of action or about the acceptability of the intentions of an actor who performs the actions. Instead, rightness and wrongness depend on the justification of the action. See *id.* at 1181-92; see also Gifford, *supra* note 108, at 1555-58.

131. See, e.g., George P. Smith, *All's Well that Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?*, 22 U.C. DAVIS L. REV. 275, 279 (1989) (quoting Richard B. Brandt, *The Rationality of Suicide*, in SUICIDE: THE PHILOSOPHICAL ISSUES 117, 118 (M. Battin & D. Mayo eds., 1980) ("Suicide may be defined 'as doing something which results in one's death, either from the intention of ending one's life or the intention to bring about some other state of affairs (such as relief from pain) which one thinks it certain or highly probable can be achieved only by means of death or will produce death.'")).

132. 362 So. 2d 160 (Fla. Dist. Ct. App.), *aff'd*, 379 So. 2d 359 (Fla. Dist. Ct. App. 1978).

133. *Id.* at 163.

assistance.¹³⁴ A Florida trial court recently made a similar distinction in *McIver v. Krischer*,¹³⁵ stating that a man who made a request for physician-assisted death "is not suicidal, but merely wishes to end what is to be a painful and protracted dying period."¹³⁶

The cases involving withdrawal of tube-feeding evoked some of the most spirited discussion about what kind of intention counted as "suicidal" and, by implication, homicidal, because the patients involved were not at immediate risk of dying from their underlying disease or condition, but rather perished most directly from lack of nutrition and hydration.¹³⁷ Yet most courts, like the court in *In re Conroy*, which involved termination of tube-feeding, said that patients who decline treatment are not suicidal, in part because they do not have the specific intent to die.¹³⁸

As this discussion shows, at each of the major steps in the development of the legal "right to die"—withdrawing or withholding life-saving treatments such as respirators, and withdrawing artificial nutrition and hydration—the ethical and legal debate has used remarkably similar terminology. Opponents of legalization call actions "euthanasia," "killing," and "suicide." Proponents accept that such categories exist but deny that the action currently under scrutiny fits

134. *Id.* at 162-63.

135. No. CL-96-1504-AF, 1997 WL 225878 (Fla. Cir. Ct. Jan. 31, 1997).

136. *Id.* at *9. The court said:

Mr. Hall testified that he wishes to live, but has decided to end his suffering at the point where he will no longer feel the comfort and assurance of knowing that his agony will be followed by a period of acceptably renewed health. Contemplating his future suffering, he wants to die at the time and place of his choosing by administering a substance which will induce immediate loss of consciousness and certain death shortly thereafter. Yet, he is afraid that any attempt to take his own life at that time will be unsuccessful, and will worsen his condition. Therefore, Mr. Hall has sought consultation and assistance of a physician to provide him with a prescription for a drug that Mr. Hall would self-administer to precipitate his instant death when he reaches the point where he is convinced that his only alternative is to experience a prolonged period of useless suffering.

Id. at *2. This decision was reversed by the Florida Supreme Court on July 17, 1997. *Krischer v. McIver*, 697 So. 2d 97 (Fla. 1997).

137. For a detailed and complex survey of the arguments, see Philip G. Peters, *The State's Interest in the Preservation of Life: From Quinlan to Cruzan*, 50 OHIO ST. L.J. 892 (1989).

138. See *In re Conroy*, 486 A.2d 1209, 1224 (N.J. 1985); see also *Vacco v. Quill*, 117 S. Ct. 2293 (1997) ("[A] patient who commits suicide with a doctor's aid necessarily has the specific intent to end his or her own life, while a patient who refuses to discontinue treatment might not.").

into the category, relying on the distinction between acts and omission and the principles of causation and intention.

Those who seek to extend the legal right to die avoid these terms because they connote illicit choices. This pattern of debate continues, as illustrated in the Supreme Court's recent decisions about physician-assisted death.

D. The Rhetorical Battle in *Vacco* and *Glucksberg*

All nine Justices in *Vacco* and *Glucksberg* agreed that the New York and Washington statutes criminalizing assisted suicide did not violate the Fourteenth Amendment, at least as challenged in the two cases.¹³⁹ However, these decisions produced six opinions, in which the Justices expressed differing views about the proper method for analyzing the due process challenge to the statutes, an issue not at stake in this article.¹⁴⁰ The Justices also examined whether the statutes might be unconstitutional in other circumstances not before the Court. The Justices expressed their differences over the latter issue in the rhetoric described above.

Justice Rehnquist's lead opinions, in which Justices Scalia, Thomas, and Kennedy joined, signaled strong rejection of the challenges to the statutes by the immediate and consistent characterization of physician-assisted death as "suicide."¹⁴¹ This usage is particularly significant in *Washington v. Glucksberg*, where the majority opinion begins with a lengthy discussion of the pedigree of legal disapproval of suicide.¹⁴² Following this discussion, the opinion moves to a shorter review of the history of criminalizing assisted suicide.¹⁴³ Even as the opinion discusses the current debate over physician-assisted death, it always speaks in terms of "assisted suicide," refusing to use alternative terminology.¹⁴⁴ Indeed, the opinion raises rhetoric to a constitutional level, saying that one of the two essential features of substantive due process analysis is "a 'careful description' of the asserted fundamental liberty interests"¹⁴⁵ and implicitly criticizing the challengers of

139. See *Vacco v. Quill*, 117 S. Ct. 2293 (1997); *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

140. On this issue compare particularly Justice Rehnquist's opinion in *Glucksberg*, 117 S. Ct. at 2261, to that of Justice Souter, 117 S. Ct. at 2275 (Souter, J., concurring in the judgment).

141. See *Vacco*, 117 S. Ct. at 2296; *Glucksberg*, 117 S. Ct. at 2251.

142. See *Glucksberg*, 117 S. Ct. at 2263-64.

143. See *id.* at 2264-67.

144. See *id. passim*.

145. *Id.* at 2268.

the statute for not using one term consistently to describe the right they assert.¹⁴⁶

Having laid this rhetorical background, the opinion comes easily to the conclusion that the statute is constitutional:

We now inquire whether this asserted right has any place in our Nation's traditions. Here, as discussed above . . . we are confronted with a consistent and almost universal tradition that has long rejected the asserted right, and continues explicitly to reject it today, even for terminally ill, mentally competent adults. To hold for respondents, we would have to reverse centuries of legal doctrine and practice, and strike down the considered policy choice of almost every State. . . .¹⁴⁷

. . . .
The history of the law's treatment of assisted suicide in this country has been and continues to be one of the rejection of nearly all efforts to permit it. That being the case, our decisions lead us to conclude that the asserted "right" to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause.¹⁴⁸

The opinion then concludes that the state has legitimate interests that are rationally related to banning physician-assisted death.¹⁴⁹

In *Vacco v. Quill*,¹⁵⁰ the Court considered whether criminalizing physician-assisted death but allowing withdrawal of life support violates equal protection.¹⁵¹ The majority opinion invoked several of these rhetorical devices in support of the distinction between physician-assisted death and a patient's withdrawal of life support. The opinion said:

The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication.

Furthermore, a physician who withdraws, or honors a patient's refusal to begin, life-sustaining medical treatment purposefully intends, or may so intend, only to respect his patient's

146. "Turning to the claim at issue here, the Court of Appeals stated that '[p]roperly analyzed, the first issue to be resolved is whether there is a liberty interest in determining the time and manner of one's death,' or, in other words, '[i]s there a right to die?' Similarly, respondents assert a 'liberty to choose how to die' and a right to 'control of one's final days,' and 'the liberty to shape death.' As noted above, we have a tradition of carefully formulating the interest at stake in substantive-due-process cases." *Id.* at 2268-69.

147. *Id.* at 2269.

148. *Id.* at 2271.

149. *See id.* at 2275.

150. 117 S. Ct. 2293 (1997).

151. *See id.* at 2298-2302.

wishes and "to cease doing useless and futile or degrading things to the patient when [the patient] no longer stands to benefit from them. . . . A doctor who assists a suicide, however 'must, necessarily and indubitably, intend primarily that the patient be made dead.' Similarly, a patient who commits suicide with a doctor's aid necessarily has the specific intent to end his or her own life, while a patient who refuses or discontinues treatment might not."¹⁵²

In contrast, all of the opinions of the Justices who concurred in *Vacco* and *Glucksberg* do not necessarily label physician-assisted death as "suicide," nor do they necessarily accept these rhetorical distinctions. Justice O'Connor stated:

I join the Court's opinions because I agree that there is no generalized right to "commit suicide." But respondents urge us to address the narrower question whether a mentally competent person who is experiencing great suffering has a constitutionally cognizable interest in controlling the circumstances of his or her imminent death. I see no need to reach that question in the context of the facial challenges to the New York and Washington laws at issue here.¹⁵³

Justice Breyer wrote:

I also agree with the Court that the critical question in both of the cases before us is whether "the 'liberty' specially protected by the Due Process Clause includes a right" of the sort that the respondents assert. I do not agree, however, with the Court's formulation of that claimed "liberty" interest. The Court describes it as a "right to commit suicide with another's assistance." But I would not reject the respondents' claim without considering a different formulation, for which our legal tradition may provide greater support. That formulation would use words roughly like a "right to die with dignity." But irrespective of the exact words used, at its core would lie personal control over the manner of death, professional medical assistance, and the avoidance of unnecessary and severe physical suffering—combined.¹⁵⁴

Justice Stevens described the right in this way:

[Nancy Cruzan's right to refuse treatment] embraces, not merely a person's right to refuse a particular kind of unwanted treatment, but also her interest in dignity, and in determining the character of the memories that will survive long after her death. . . . The *Cruzan* case demonstrated that some state intrusions on the right to decide how death will be encountered are also intolerable. The now deceased plaintiffs in this action may in fact have had a liberty interest even stronger than Nancy Cruzan's because, not only were they terminally ill, they were suffering constant and

152. *Id.* at 2298-99 (citations omitted).

153. *Glucksberg*, 117 S. Ct. at 2311 (O'Connor, J., concurring in both *Washington v. Glucksberg* and *Vacco v. Quill* combined).

154. *Id.* (Breyer, J., concurring in the judgments).

severe pain. Avoiding intolerable pain and the indignity of living one's final days incapacitated and in agony is certainly "[a]t the heart of [the] liberty . . . to define one's own concept of existence, of meaning, or the universe, and of the mystery of human life."¹⁵⁵

While I agree with the Court that *Cruzan* does not decide the issue presented by these cases, *Cruzan* did give recognition, not just to vague, unbridled notions of autonomy, but to the more specific interest in making decisions about how to confront an imminent death. Although there is no absolute right to physician-assisted suicide, *Cruzan* makes it clear that some individuals who no longer have the option of deciding whether to live or to die because they are already on the threshold of death have a constitutionally protected interest that may outweigh the State's interest in preserving life at all costs. The liberty interest at stake in a case like this differs from, and is stronger than, both the common law right to refuse medical treatment and the unbridled interest in deciding whether to live or die. It is an interest in deciding how, rather than whether, a critical threshold shall be crossed.¹⁵⁶

The Justices who concurred in the judgments in these cases did so because they found that, at least as presented, the state's interests in protecting individuals who are incompetent, far from death, or acting involuntarily justified legislation prohibiting physician-assisted death.¹⁵⁷ However, as the quotation above suggests, Justice Stevens indicated that he might find specific individuals to have constitutionally protected interests that would outweigh the state interests. Justices O'Connor, Ginsburg, and Breyer indicated that they would probably find the states' interests strong enough to justify a generally applicable ban on physician-assisted death, provided that the state does not prohibit palliative care for the dying.¹⁵⁸ In the most complex opinion, Justice Souter, concurring in the judgment in *Glucksberg*, did not so easily accept that an absolute ban on physician-assisted death was needed to protect individuals who are not terminally ill or who have not given consent for such a procedure.¹⁵⁹ He wrote:

The case for the slippery slope is fairly made out here, not because recognizing one due process right would leave a court with no principled basis to avoid recognizing another, but because there is a plausible case that the right claimed would not be readily containable by reference to facts about the mind that are matters of

155. *Id.* at 2307 (Stevens, J., concurring) (quoting *Planned Parenthood of South-eastern Pa. v. Casey*, 505 U.S. 833, 851 (1992)).

156. *Id.* (Stevens, J., concurring).

157. *See, e.g., id.* at 2302.

158. *See id.* at 2303 (O'Connor, J.); *id.* at 2310 (Ginsburg, J., concurring in the judgments "substantially for the reasons stated by Justice O'Connor"); *id.* at 2310 (Breyer, J., concurring in the judgment).

159. *See id.* at 2275.

difficult judgment, or by gatekeepers who are subject to temptation, noble or not.

Respondents propose an answer to all this, the answer of state regulation with teeth. . . . But at least at this moment there are reasons for caution in predicting the effectiveness of the teeth proposed.¹⁶⁰

The “slippery slope” or “wedge” concern has been raised throughout the development of the legal “right to die.” The concern is that even if a particular action can be justified as a legitimate choice, acceptance of that action will inevitably lead to policies allowing disabled, old, or ill people to be killed without their consent. To a degree the slippery slope argument has proven to be true; over the last twenty or so years, law and policy have redefined death to include brain death and now allow the withdrawal of lifesaving care, including artificial nutrition and hydration. As society decides whether to allow some form of doctor-assisted death, a major issue is whether this practice creates a substantial risk that the law will further evolve to allow “active involuntary euthanasia” of socially disadvantaged people. The next section considers this issue and other conflicts that are at stake in legal struggles over the “right to die.”

III. The Values at Stake

The language used in the “right to die” debate over the last twenty years reveals one major issue: what it means to value and respect human life, and whether a single understanding of this value will be socially imposed or whether a range of views will be tolerated. The first part of this section discusses this issue. The second part discusses two other issues which are also at stake, though these issues are not so apparent from the rhetoric: the position and authority of doctors in society and the allocation of health care resources.

A. The Disputed Meaning of “Respect for Human Life” and the Role of Law in Resolving the Dispute

The most basic issue suggested by the competing labels of “suicide” or “refusal of health care” is what is meant by the obligation to respect human life. On one side are those who believe that this obligation requires preservation of a person’s biological life at all costs. In contrast, support for withdrawal of medical care and for physician-

160. *Id.* at 2291.

assisted death is often based on a judgment that in some circumstances, maintaining biological life is not meaningful and can even be harmful.¹⁶¹

Ordinary people often express the latter view,¹⁶² and the cases about withdrawal of various forms of life support discussed above are full of statements from people indicating that they do not want to live on machines.¹⁶³ Physician-assisted death is also supported by claims for release from the pain and indignity often associated with intensive medical care,¹⁶⁴ and commentators have identified this as a central value advanced by allowing physician-assisted death.¹⁶⁵ Sometimes these arguments are met with the assertion that the proper response is better management of physical pain.¹⁶⁶ However, this argument is not truly responsive, though, for it assumes that the only pain which counts is physical and ignores divergent views about how to live and die peacefully and with dignity.¹⁶⁷

161. See, e.g., Larry Gostin, *Life and Death Choices After Cruzan*, 19 LAW MED. & HEALTH CARE 9, 10 (1991) ("The state interest in preserving the life of a person in [a persistent vegetative state] is purely theoretical. The state's authority to preserve 'life' has become a magical concept, often driven by blind ideology rather than by any thoughtful appreciation of the unique characteristics of human life. When an individual has no meaningful interaction with her environment, no recognition of familiar persons or objects, nor any human feelings or experience of any kind, the state's interest in life is a mere abstraction.").

162. See, e.g., Beauchamp, *supra* note 115, at 1193-94; Board of Trustees of the Am. Med. Ass'n, *Euthanasia Physician-Assisted Suicide: Lessons in the Dutch Experience*, 10 ISSUES L. & MED. 81, 82 (1994) [hereinafter *Lessons in the Dutch Experience*] (acknowledging widespread fear that high technology may maintain life long after life is meaningful).

163. See, e.g., *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 300 (Cal. Ct. App. 1986); *Bartling v. Superior Court*, 209 Cal. Rptr. 220, 221-22 (Cal. Ct. App. 1984); *Satz v. Perlmutter*, 362 So. 2d 160, 161 (Fla. Dist. Ct. App.), *aff'd*, 379 So. 2d 359 (Fla. Dist. Ct. App. 1978); *In re Farrell*, 529 A.2d 404, 408-09 (N.J. 1987); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 608-09 (N.Y. 1988); *In re Eichner*, 420 N.E.2d 64, 68 (N.Y. 1981). Commentators commonly make this argument as well. See, e.g., Gostin, *supra* note 161, at 10.

164. The 1994 Oregon Voter's Pamphlet in support of the ballot measure allowing physician-assisted suicide contains several personal stories of persons in pain who sought help in dying from family members. See OFFICIAL 1994 GENERAL ELECTION VOTERS' PAMPHLET—STATEWIDE MEASURES 125-27.

165. See, e.g., Beauchamp, *supra* note 115, at 1193-94; Bender, *supra* note 110, at 532.

166. See, e.g., OFFICIAL 1994 GENERAL ELECTION VOTERS' PAMPHLET—STATEWIDE MEASURES 127 (providing arguments in opposition from C. Everett Koop, former U.S. Surgeon General); NEW YORK STATE TASK FORCE ON LIFE & THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT (1994).

167. One of the most articulate proponents of the "right to die" is Dax Cowart, a man who was severely burned in an accident, kept alive, and treated over his objections over a 15-month period. He survived, though he is blind and disfigured

Those who believe that respect for life allows rejection of life support under some circumstances have generally not advocated that law forbid the provision of life support to terminally ill people or those on respirators.¹⁶⁸ Instead, they have argued that the law should be neutral, allowing individuals to choose whether to accept life support.

Where persons being treated are competent, the argument that their choices should be respected makes sense. However, if the person is incompetent, it is really quite difficult to speak meaningfully of the person's choices.¹⁶⁹ When courts allow termination of medical treatment in such cases, they allow some other person, ordinarily a family member, to make the decision; advance directives, particularly durable powers of attorney for health care, do the same, although the evidence of the patient's prior intent is more direct. The effect of these legal devices is to allow diverse interpretations about the meaning of

and has no fingers, and he eventually married and became an attorney. Despite this and in the face of arguments that at the time of his injuries he could not foresee what his life would be like, he has always maintained that his requests to die should have been honored. See Interview with Dax Cowart Ten Months After the Accident, reprinted in JUDITH AREEN ET AL., *LAW SCIENCE AND MEDICINE* 1112-17 (1st ed. 1984); Letter from Dax Cowart (Sept. 19, 1983), reprinted in *id.* at 1117 n.1; *Burn Victim Backs Right to Die*, REGISTER-GUARD (Eugene, Or.), Nov. 24, 1996, at 11D.

Compare the view of Justice Breyer, that only avoidance of severe physical pain would give rise to a constitutionally protected interest in physician-assisted death:

I do not believe, however, that this Court need or now should decide whether or not such a right is "fundamental." That is because, in my view, avoidance of severe physical pain (connected with death) would have to comprise an essential part of any successful claim [to a constitutionally-protected right to physician-assisted death]. . . [T]he laws of New York and of Washington do not prohibit doctors from providing patients with drugs sufficient to control pain despite the risk that those drugs themselves will kill. And under these circumstances the laws of New York and Washington would overcome any remaining significant interests and would be justified, regardless.

Washington v. Glucksberg, 117 S. Ct. 2302, 2311 (1997) (Breyer, J., concurring) (citations omitted). Contrast *id.* at 2304-10 (Stevens, J., concurring in the judgment) (recognizing other forms of pain and indignity as giving rise to constitutionally protected interest).

168. See Devettere, *supra* note 25 (proposing that neocortical death is consistent with our concepts of death but it should not become public policy because of a lack of understanding by the public and society).

169. Others note this anomaly. See, e.g., Louis M. Seidman, *Confusion at the Border: Cruzan, "The Right to Die," and the Public/Private Distinction*, 1991 SUP. CT. REV. 47, 55-59.

"respecting human life," an outcome that is quite consistent with broader themes of pluralism in American law.¹⁷⁰

The contrary view, that "respecting human life" requires preservation of biological life under most or all circumstances, is often religiously based, though it need not be.¹⁷¹ Those who hold this view have opposed all of the steps toward legalizing the "right to die" discussed in this article—termination of respirators and other life support, termination of artificial nutrition and hydration, and physician-assisted death.¹⁷² Sometimes the opponents accept in theory the autonomy-based claim for rejecting treatment, but they argue that the theory is too dangerous to implement because the risk of error in diagnosing a person's condition or in ascertaining that person's competence is too great.¹⁷³ The opponents' principal argument is the slippery slope argument, which supports absolute rejection of a "right to die." The New York State Task Force on Life and the Law used this rationale to argue against legalization of assisted suicide and euthanasia, saying:

Limiting suicide to the terminally ill would be inconsistent with the notion that suicide is a compassionate choice for patients who are in pain or suffering. As long as the policies hinge on notions of pain or suffering, they are uncontainable; neither pain nor suffering can be gauged objectively, nor are they subject to the kind of judgments needed to fashion coherent public policy. Euthanasia to cover those who are incapable of consenting would also be a

170. Examples are innumerable. See, e.g., *Roe v. Wade*, 410 U.S. 113 (1973) (abortion), *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (child rearing). Speaking about the *Cruzan* case, Seidman argues that holdings allowing the withdrawal of life support of incompetent people on autonomy grounds really mean "that the state is entitled to use Ms. Cruzan and her predicament as a means of advancing overall social welfare by alleviating the fear of others that they might someday lose their autonomy." Seidman, *supra* note 169, at 61.

171. See, e.g., Kamisar, *supra* note 12, at 969. A variation of this position holds that people with life-endangering conditions may not have a moral obligation to accept treatment, but they are obliged to accept their fate and remain alive until death comes "naturally." See Peters, *supra* note 137, at 957-67.

172. Much of the major litigation over right to die issues has been conducted by the National Legal Center for the Medically Dependent and Disabled, which always opposes measures to end life. For a review of the Center's activities, see Daniel Avila, *Saying No to Life: Reflections on Death and Justice*, 9 ISSUES L. & MED. 227 (1993). This journal, published by the Center, has printed many articles on right to die issues, especially ones advocating against extension of legal authorization to end life.

173. See, e.g., *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995), *rev'd*, 107 F.3d 1382 (9th Cir.), *cert. denied*, 118 S. Ct. 328 (1997) (challenging the Oregon statute allowing physician-assisted suicide).

likely, if not inevitable, extension of any policy permitting the practice for those who can consent.¹⁷⁴

Other warnings are even more grim, predicting that to allow withdrawal of life support or physician-assisted suicide will gradually lead to Nazi-like atrocities.¹⁷⁵ The idea that some treatments are "futile" and therefore should not even be offered, regardless of patient or family wishes, has been criticized on the same ground.¹⁷⁶

If the slippery slope argument is understood to mean that, with experience, we will come increasingly to accept as legitimate the wishes of very ill individuals to cease living, regardless of how their lives are ended, then the prediction has proven to be accurate. But this is *not* what people always mean by "slippery slope." Sometimes the argument is that law which protects a diversity of perspectives and individual choice against governmental control will evolve into a governmental policy to eliminate the poor, disabled, and sick without their consent and without considering their probable wishes or best interests. However, it is important to remember that Nazi practices originated through racist and eugenicist government policies, not policies to protect individual autonomy. Although such a development is not impossible, current law is very far removed in principle from policies that allow the systematic killing of socially disadvantaged people, and little evidence indicates that such consequences are likely.¹⁷⁷

To date, arguments which favor allowing individuals and their surrogates to refuse life support have prevailed over the concerns about errors and slippery slopes in part because autonomy claims are generally so highly regarded in our society and because so many people believe that a life supported only by means of sophisticated medical technology can be worse than death. We do not know whether this course will continue so that physician-assisted death eventually

174. NEW YORK STATE TASK FORCE ON LIFE & THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT at xv (1994); see also *Washington v. Glucksberg*, 117 S. Ct. 2258, 2273 (1997).

Many others make the same argument. Examples include Kamisar, *supra* note 12, at 1014-41 (responding to Glanville Williams's proposal to allow euthanasia when voluntarily requested by a competent terminally ill person, making explicit comparisons to Nazi atrocities); Beauchamp, *supra* note 115 (noting that the distinction between letting die and killing is morally significant and should be maintained because of the slippery slope problem); and Weisbard & Siegler, *supra* note 71, at 111.

175. See, e.g., sources cited *supra* note 174.

176. See, e.g., Swanson & McCrary, *supra* note 86, at 318.

177. Beauchamp, *supra* note 115, at 1198.

becomes accepted as well. To the extent that the legal debate over physician-assisted death is about whether an existing practice should be legitimated,¹⁷⁸ we might predict that the law will develop to allow the practice, for legal prohibition of all assisted death can be understood as enshrining the vitalist perspective and not allowing for diversity of views. But more than ideological difference is at stake in the debate over physician-assisted death, as the next section discusses.

B. The Role of Law in Determining the Status of Doctors and the Allocation of Health Care Resources

The debate over legalizing physician-assisted death is significantly influenced by the experience in the Netherlands, where the practice has been legal in some circumstances for more than twenty years.¹⁷⁹ Opponents of legalization regularly point to the Dutch experience to support the slippery slope argument.¹⁸⁰ However, other even more revealing lessons about the role of doctors in society can be drawn from the comparison.

178. See *supra* text accompanying notes 161-77. In addition to the arguments discussed in the text, one argument for legalization of physician-assisted suicide is the generic one that if law and practice part radically, the legal system loses its legitimacy. Bender, *supra* note 110, at 533.

179. In footnote 16 of *Glucksberg*, the Supreme Court discusses efforts in other countries to legalize physician-assisted death, citing a Canadian Supreme Court decision finding no constitutionally protected right, a failed legislative effort in New Zealand, and a negative report from the British House of Lords. See *Washington v. Glucksberg*, 117 S. Ct. 2258, 2266 n.16 (1997). The footnote acknowledges that the Colombian Constitutional Court has ruled that people have a right to "voluntary euthanasia" and discusses the experience in Australia. Under the Northern Territory of Australia Rights of the Terminally Ill Act of 1995, physician-assisted death is also lawful under some circumstances. However, the national Commonwealth Parliament enacted a law to overturn the Northern Territory Act. The Commonwealth Parliament has authority to override the laws of Australian territories, but not states. According to a retired law professor at the Australian National University, two people complied with the requirements of the act and were allowed to die with physician assistance under its terms, and two more complied with the requirements but were not assisted to die before the national repeal became effective. Letter from Professor Charles Rowland, Australian National University to the author (Apr. 18, 1997) (on file with the author). The *Glucksberg* footnote cites a *New York Times* article which says that three people were assisted to die under the provisions of the Northern Territory Act.

Professor Rowland reported that the Australian Parliament's close vote to repeal the Northern Territory law was affected by a "very effective and efficient low profile lobbying effort by people centred on the Roman Catholic Church." *Id.* He adds that a large majority of the public favors physician-assisted death and predicts that legislation to authorize physician-assisted death will be proposed in one or more Australian states. See *id.*

180. See, e.g., *Lessons in the Dutch Experience*, *supra* note 162.

1. THE DISPUTED INTERPRETATIONS OF DUTCH PRACTICE

Beginning in the 1970s, Dutch courts developed the criminal law affirmative defense of "necessity" or "choice of evils" to allow physicians to assist in the death of patients under certain circumstances.¹⁸¹ The necessity defense generally provides that a person who breaks a criminal law as a necessary means of preventing a greater evil is not guilty.¹⁸² This principle has been specifically applied in the Netherlands to physician-assisted death, and doctors who follow established guidelines will not be criminally prosecuted for performing "euthanasia." The Dutch use the term "euthanasia" as providing means to a patient to end life and performing the final act itself.¹⁸³ These guidelines require that:

1. The request for euthanasia must come only from the patient and must be entirely free and voluntary.
2. The patient's request must be well considered, durable and persistent.
3. The patient must be experiencing intolerable (not necessarily physical) suffering, with no prospect of improvement.
4. Euthanasia must be a last resort. Other alternatives to alleviate the patient's situation must have been considered and found wanting.
5. Euthanasia must be performed by a physician.
6. The physician must consult with an independent physician colleague who has experience in this field.¹⁸⁴

In 1990 an official Dutch nationwide study, known as the Remmelink study, examined "medical decisions concerning the end of

181. For more details, see John Keown, *The Law and Practice of Euthanasia in the Netherlands*, 108 L.Q. REV. 51 (1992). Some authorities speak of the Dutch doctrine being based on *force majeure*. See, e.g., Johannes J.M. van Delden et al., *The Remmelink Study Two Years Later*, 23 HASTINGS CENTER REP. 24, 25 (1993). The applicable principle is recognized in American and English law as "necessity" or "choice of evils." See LAFAVE & SCOTT, *supra* note 121, § 5.4; see also Barney Sniderman & Marja Verhoef, *Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases*, 34 ALB. L. REV. 374 (1996). Thanks to Mary Clayton, Associate Law Librarian at the University of Oregon, for these references.

Some writing in the United States about the Dutch law is unnecessarily mystifying. Anglo-American criminal law also develops specific criteria for affirmative defenses that exonerate people from what would otherwise be criminal homicide, based on the general principles of necessity and duress. One of the best known is self-defense. See LAFAVE & SCOTT, *supra* note 121, § 5.7.

182. See LAFAVE & SCOTT, *supra* note 121, § 5.4.

183. In 1990, the Dutch Minister of Justice agreed to a uniform procedure for handling cases. The doctor does not issue a declaration of natural death but informs local medical examiner, who reports to the prosecutor, who decides whether to prosecute. See Delden et al., *supra* note 181, at 30.

184. Keown, *supra* note 181, at 56 (quoting Mrs. Borst-Eilers, Vice-President of the Health Council, which provides scientific advice to the Dutch government on health issues).

life.”¹⁸⁵ These decisions included: decisions simply not to treat patients; decisions to give very high dosages of opiates to patients to alleviate pain with the knowledge that these dosages may hasten death; and, decisions to end a patient’s life intentionally at the patient’s request by lethal injection or by prescribing medication.¹⁸⁶ The report of the study published in the British medical journal, *The Lancet*, says that of all deaths that occurred in 1990 in the Netherlands, 17.5% resulted from doctors administering opiates to alleviate pain in such high dosages that the patient’s life might be shortened, and in another 17.5%, the doctor did not provide treatment that might have saved the patient’s life.¹⁸⁷ Doctors caused patients’ deaths, at the patient’s request, by intentionally administering lethal drugs in 1.8% of all deaths and by prescribing lethal drugs for patients in 0.3% of the deaths.¹⁸⁸ The report also found that physicians administered drugs with the intention of ending the patient’s life without an explicit and persistent request from the patient in 0.8% of the cases.¹⁸⁹ The *Lancet* report discusses the last category of cases, saying:

In more than half of these cases the decision has been discussed with the patient or the patient had in a previous phase of his or her illness expressed a wish for euthanasia should suffering become unbearable. In other cases, possibly with a few exceptions, the patients were near to death and clearly suffering grievously, yet verbal contact had become impossible. The decision to hasten death was then nearly always taken after consultation with the family, nurses, or one or more colleagues. In most cases the amount of time by which, according to the physician, life had been shortened was a few hours or days only.¹⁹⁰

The majority in *Glucksberg*, citing a secondary report based on the *Lancet* report, describes the results in more alarming terms:

The Dutch government’s own study revealed that in 1990, there were 2,300 cases of voluntary euthanasia (defined as “the deliberate termination of another’s life at his request”), 400 cases of assisted suicide, and more than 1,000 cases of euthanasia without an explicit request. In addition to these latter 1,000 cases, the study found an additional 4,941 cases where physicians administered lethal morphine overdoses without the patients’ explicit consent.¹⁹¹

185. Delden et al., *supra* note 181, at 30.

186. See Paul J. van der Maas et al., *Euthanasia and Other Medical Decisions Concerning the End of Life*, 338 LANCET 669 (1991).

187. See *id.* at 670, tbl.I.

188. See *id.*

189. See *id.*

190. *Id.* at 672.

191. *Washington v. Glucksberg*, 117 S. Ct. 2258, 2274 (1997).

The American opponents of physician-assisted death, including the *Glucksberg* majority, conclude that the Rummelink study supports the slippery slope argument.¹⁹² They say that the study shows that the Dutch guidelines to protect patients have not been consistently respected and that physician-assisted death cannot be controlled if legalized.¹⁹³ On the other hand, the researchers who conducted the Dutch study point out:

Requests for euthanasia and, to a lesser extent, for assistance in suicide by patients with a fatal disease are not rare in the Netherlands. Many patients want an assurance that their doctor will assist them to die should suffering become unbearable. We found that about two-thirds of these requests never end up as a serious and persistent request at a later stage of the disease, and of the serious and persistent requests about two-thirds do not result in euthanasia or assisted suicide since physicians can often offer alternatives. Many physicians who had practised euthanasia mentioned that they would be most reluctant to do so again, thus refuting the "slippery slope" argument. Only in the face of unbearable suffering and with no alternatives would they be prepared to take such action.¹⁹⁴

Interpretation of the Rummelink study is likely to have a substantial impact on the acceptance or rejection of physician-assisted death in the United States. Uncertainty about this interpretation ultimately led Justice Souter to conclude that the Constitution does not require states to allow this practice, for, he said, legislatures are far better suited than courts to resolve the uncertainty.¹⁹⁵

The Rummelink study does indicate that doctors in the Netherlands have not strictly adhered to the official guidelines governing physician-assisted death, for the study shows that in some cases physicians intentionally end patients' lives without explicit and persistent requests.¹⁹⁶ Yet, despite the knowledge that sometimes doctors do not adhere strictly to the guidelines, public support for physician-assisted death remains very high in the Netherlands.¹⁹⁷ Thus, for Americans to

192. See, e.g., *id.*

193. See, e.g., Callahan & White, *supra* note 6, at 1; John Keown, *Euthanasia in the Netherlands: Sliding Down the Slippery Slope?*, 9 NOTRE DAME J.L., ETHICS & PUB. POL'Y 407 (1995); *Lessons in the Dutch Experience*, *supra* note 162, at 89.

194. van der Maas et al., *supra* note 186, at 673.

195. See *Glucksberg*, 117 S. Ct. at 2292-93.

196. See Delden et al., *supra* note 181, at 24.

197. See Joseph P. Shapiro, *Euthanasia's Home*, U.S. NEWS & WORLD REP., Jan. 13, 1997, at 26. American opponents of physician-assisted suicide argue that the Dutch practice cannot be transferred to the United States, in part because substantial social consensus exists on many ethical issues in the Netherlands. Also, legal problems are resolved by consensus rather than by litigation to a much greater

understand the significance of the Rummelink study, we will need to know more than how many people died and in what ways; we will also need to learn more about the cultural and legal context of the Dutch rules and how these compare to American culture and law.

2. THE RELATIVE AUTONOMY OF DOCTORS AND PATIENTS

The Rummelink study raises more questions besides the extent to which Dutch doctors strictly adhere to guidelines for physician-assisted suicide. One question, which actually may be more important, is the extent to which doctors exercise professional discretion about ending patients' lives.

The study shows that doctors continue to exercise substantial judgment to grant or deny euthanasia and physician-assisted suicide.¹⁹⁸ Indeed, the researchers who conducted the Rummelink study concluded that "doctors themselves are responsible moral agents, not simply instruments of the patient's will."¹⁹⁹ Some opponents of legalizing physician-assisted suicide cite the Dutch experience to show that legalization would enhance doctors' power vis-à-vis patients.²⁰⁰ For example, Daniel Callahan and Margot White have argued:

The fact that the vast majority of physicians are ethical and well-intentioned is beside the point. The adherence to any publicly approved guidelines or safeguards for containing the practice of [physician-assisted suicide] and euthanasia within certain limits, however flawed such guidelines may be, depends almost exclusively on the good will and professional judgment of the individual physician who acts in private. Thus, it is not the patient's request for euthanasia that determines the outcome, but rather the physician's judgment that such a request is appropriate and that the patient is not suffering from impaired thinking in wanting to die. In other words, that the patient's request is warranted because, in the physician's judgment, the patient's life is not worth living.²⁰¹

On the other hand, the American Medical Association's (AMA) opposition to legalized physician-assisted death is based substantially on the fear that legalization would *deprive* doctors of authority and

degree than in the United States. *See id.* These cultural differences could just mean, though, that Americans will follow other paths, such as litigation, to resolutions of these issues.

198. *See* Delden et al., *supra* note 181, at 26.

199. *Id.*

200. *See* Callahan & White, *supra* note 6, at 28.

201. *Id.* at 64-65.

discretion.²⁰² The AMA's Council on Ethical and Judicial Affairs, after affirming that patients should have a right to refuse life-sustaining treatment, rejects physician-assisted death. The Council's report says:

Although a patient's choice of suicide also represents an expression of self-determination, there is a fundamental difference between refusing life-sustaining treatment and demanding a life-ending treatment. *The right of self-determination is a right to accept or refuse offered interventions, but not to decide what should be offered.* The right to refuse life-sustaining treatment does not automatically entail a right to insist that others take action to bring on death.

... Physicians serve patients not because patients exercise self-determination but because patients are in need. Therefore, a patient may not insist on treatments that are inconsistent with sound medical practices. Rather, physicians provide treatments that are designed to make patients well, or as well as possible. The physician's role is to affirm life, not to hasten its demise.²⁰³

These statements show that the power and professional autonomy of doctors is clearly at stake, but whether legalization would enhance or diminish doctors' authority is unclear. Other arguments for legitimating the practice of physician-assisted death cast light on the question.

Proponents of legalization repeatedly point out that some doctors may be deterred by fear of prosecution from granting requests for such assistance.²⁰⁴ They also argue that to the extent that physician-assisted suicide occurs, the practice is unregulated by law or by conventional medical norms.²⁰⁵ The premise of both of these arguments is that if physician-assisted death is not lawful but is actually practiced, as is the case today, its availability in general and in particular

202. See Council on Ethical & Judicial Affairs of the Am. Med. Ass'n, *Physician-Assisted Suicide*, 10 ISSUES L. & MED. 91, 93 (1994).

203. *Id.* (emphasis added); see also *Lessons in the Dutch Experience*, *supra* note 162, at 82.

204. See, e.g., Beauchamp, *supra* note 135, at 1199; Bender, *supra* note 110, at 532; see also OFFICIAL 1994 OREGON GENERAL ELECTION VOTERS' PAMPHLET—STATE-WIDE MEASURES 125-27 (containing arguments for and against Measure 16 which outline current law that requires people to act secretly to help loved ones or leaves dying people to die violently and alone).

205. See OFFICIAL 1994 OREGON GENERAL ELECTION VOTERS' PAMPHLET—STATE-WIDE MEASURES 125-27 (containing arguments for and against Measure 16 that outline procedural and substantive safeguards that will protect against abuse and stating that current law requires people to act secretly to help loved ones, without guidelines, safeguards, or reporting requirements); see also Wanzer et al., *supra* note 78, at 848 ("Physicians who act in secret become isolated and cannot consult colleagues or ethics committees for confirmation that the patient has made a rational decision. . . . The impulse to maintain secrecy gives the lie to the moral intuition that assistance with suicide is ethical.").

cases is entirely within the control of individual doctors. Whether any particular patient or family can obtain such help depends on their ability to find a willing doctor. This suggests that legalization would, at least in some senses, limit the control of individual doctors by bringing the practice into the open.²⁰⁶ On the other hand, Callahan and White are probably right that there would be little effective public scrutiny of how doctors, patients, and families actually made decisions with regard to physician-assisted suicide, just as there is little scrutiny today of how decisions to withdraw life support are made.²⁰⁷

The real issue is the extent to which we as a society trust doctors with this power over life and death, but this issue is certainly not unique to this aspect of medical practice.²⁰⁸

3. HEALTH INSURANCE, HEALTH CARE COSTS, AND CARE AT THE END OF LIFE

The cost of medical care and how medical care is allocated are also factors in the physician-assisted suicide debate. Opponents of legalization point again to the experience in the Netherlands, which has universal health insurance.²⁰⁹ Opponents maintain that universal health insurance protects against people ending their lives because they lack access to medical care.²¹⁰ They compare this situation to that in the United States, where many people do not have adequate health insurance, arguing that people in the United States may request physician-assisted death to avoid burdening their families with substantial

206. Citizen votes on proposals to allow physician-assisted suicide in Washington, California, and Oregon also suggest a public demand for control over the practice. All three measures were decided by a close margin, with those in Washington and California being defeated, and the one in Oregon passing. Polls conducted in Washington and California after defeat of the measures found public support for the concept but concern that the legislation actually proposed in those states contained too few safeguards and gave doctors too much authority. See Alexander M. Capron, *Sledding in Oregon*, 25 HASTINGS CENTER REP. 34 (1995); Peter Steinfelds, *Help for the Helping Hands in Death*, N.Y. TIMES, Feb. 14, 1993, § 4, at 1.

207. See generally Callahan & White, *supra* note 6 (analyzing proposed legislation to legalize physician-assisted death).

208. See Bender, *supra* note 110, at 533 ("As a society we readily give physicians a great deal of responsibility to exercise their best judgments and skills in caring for patients. If we are willing to presume they are responsible enough under most situations to deal with matters of life and death, why would they suddenly be less responsible in helping to implement patients' decisions at life's end?").

209. See Shapiro, *supra* note 197, at 24; see also *Lessons in the Dutch Experience*, *supra* note 162, at 87.

210. See Shapiro, *supra* note 197.

medical bills.²¹¹ This, they suggest, would mean that death was not voluntarily chosen.

The assumption implicit in this argument is that having to choose between extending one's life with expensive medical care or avoiding a burden to one's family is unacceptable. Yet avoiding costs that will burden surviving family members has surely been a motivation for choosing death throughout history and is today a reason for some decisions to refuse treatment at the end of life.

A subsidiary issue is whether family members, for the sake of avoiding expense, may pressure a relative near death to end his or her life, a problem which can also arise with decisions to refuse treatment. This problem is very complex, for implicit in it are questions about the extent to which family members legitimately try to affect each others' choices and for what reasons—questions beyond the scope of this article.²¹²

From a broader perspective, the relationship between legal and social attitudes toward physician-assisted death and access to health care is less clear. The U.S. medical system emphasizes high-tech, expensive care, often used for very ill people as they near the end of life. This emphasis on expensive medical technology has disadvantages, though. The high cost of expensive, high-tech care contributes to the American insurance problem, because bringing more people into the insured pool would create still more claims for access to expensive care.

Perhaps society as a whole would be better off if we all had access to basic health care but not necessarily to the expensive care needed to extend temporarily the lives of very ill or injured people. If as a society we more readily accepted death—by withdrawal of life support or with physician assistance—for the sake of avoiding high-cost end-of-life treatment, as well as avoiding the pain and indignity of living with such treatment, perhaps emphasis in the health care system would shift some toward ensuring broader access to basic care, such as prenatal care and substance abuse treatments. Empirically, these arguments are speculative, but it is still critical that we consider

211. *See id.*

212. Another place in which such issues arise is determining when influence over a testator becomes "undue." *See* EUGENE F. SCOLES & EDWARD C. HALBACH, JR., PROBLEMS AND MATERIALS ON DECEDENTS' ESTATES AND TRUSTS 652-64 (5th ed. 1993).

how our attitudes about death and care at the end of life affect the structure of our health care system.

IV. Conclusion

In declining to find that due process or equal protection requires states to allow physician-assisted dying, the Supreme Court in *Vacco* and *Glucksberg* clearly indicated that states should be allowed to continue debating this issue and that change should come, if it comes, through the legislative process. The Ninth Circuit's reversal of the holding in *Lee v. Oregon*,²¹³ a decision which the Supreme Court declined to review, leaves the Oregon statute allowing physician-assisted suicide standing. Oregon is left free to experiment with physician-assisted suicide, as are other states.

As we as a society deal with this issue, we will debate the issues raised by the rhetoric of "suicide" and "right to choose health care." But we must also consider how legalizing physician-assisted death would affect the balance of authority between doctors and patients and the allocation of health care resources, as among people and among kinds of care. These issues probably have a greater effect on the welfare of all of us, including socially disadvantaged people, than philosophical understandings about whether respect for human life allows physician-assisted death.

213. 891 F. Supp. 1429 (D. Or. 1995), *rev'd*, 107 F.3d 1382 (9th Cir.), *cert. denied*, 118 S. Ct. 328 (1997).

THE ANABOLIC STEROIDS ACT: BAD MEDICINE FOR THE ELDERLY

Jeffrey Hedges

The rampant abuse of anabolic steroids, and their harmful side effects, prompted Congress to classify steroids as a controlled substance. The Anabolic Steroids Control Act makes it a criminal offense for a physician to distribute steroids to a patient unless in the treatment of a disease or other recognized medical condition. While this legislation controls steroid abuse among athletes and minors, it also prevents the use of steroids in treating some legitimate conditions. The inability to prescribe steroid treatments has had a direct impact on the elderly.

Research suggests that the benefits associated with steroids, muscle growth and increased strength, help combat many of the illnesses and ailments associated with aging. However, further research in this area is useless if the treatments cannot be administered. In this note, Mr. Jeffrey Hedges explores the purpose and the effect of the Anabolic Steroids Control Act. He argues that although the legislation intended to prevent the abuse of steroids for nonmedical purposes, the expansive nature of the Act creates an unnecessary barrier to treating the degenerative effects of aging. Mr. Hedges suggests that the current legislation be amended to allow physicians to use their professional judgment in administering steroid treatment to the elderly. Only then might the revitalizing effects of a legitimate steroid treatment be fully explored and realized.

I. Introduction

Attorneys practicing in the area of elder law understand that an older client's needs extend far beyond legal dilemmas.¹ To effectively meet the needs of elder clients, attorneys must

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1. See Amelia E. Pohl, Note, *Introduction: What Is Elder Law Anyway?*, 19 NOVA L. REV. 459, 461 (1995). This article examines the practice area of elder law with special focus on the National Academy of Elder Law Attorneys (NAELA) and the National Academy of Elder Law Foundation (NAELF). NAELA was created to exchange information concerning the administration of benefit programs in differ-

move beyond conventional legal work and be capable and willing to offer practical assistance. Peter J. Strauss, author of several elder law publications,² states that often the attorney may be the right person to provide information about home care, nursing homes, special geriatric health problems, and adult day care.³ Specializing in elder law results in contact with insurance agents, geriatric care or case managers, and social service agency personnel. Because the practice of elder law leads to an accumulation of information and contacts, attorneys are rapidly becoming the "first-stop" in addressing issues outside of the legal context.

Part of the new role attorneys play in elder law includes scrutinizing legal issues and policies affecting clients. When circumstances create obstacles which hinder the quality of life for the elderly, it may be the responsibility of attorneys to seek change. On October 27, 1990, Congress passed the Crime Control Act of 1990.⁴ The legislation produced an anticrime package that included new banking and money laundering offenses, expanded the rights of crime victims, broadened the protection of child witnesses, enlarged correctional alternatives to prison, and expanded substance abuse prevention and treatment.⁵ The Anabolic Steroids Control Act of 1990⁶ was a product of the same legislation. In an effort to curb the misuse of steroids, Congress enacted laws regulating their possession and distribution.⁷ An unfortunate consequence, however, has been the restriction of steroid research and the legitimate use of steroids in the therapeutic treatment of the elderly.⁸

Health care costs continue to rise along with a push for legislation to increase the availability of medicine to all people. Reevaluating current laws which strangle beneficial treatments may be one method by which treatments for the elderly can become more efficient

ent states. *Id.* at 460-61. NAELF was created in an effort to require certification by way of examination for attorneys specializing in elder law. *Id.* at 462.

2. See, e.g., PETER J. STRAUSS ET AL., *AGING AND THE LAW* (1990).

3. See *id.* at 4.

4. Pub. L. No. 101-647, 104 Stat. 4789.

5. See Bennett L. Gershman, *The New Omnibus Crime Bill*, 18 WESTCHESTER B.J. 53 (1991).

6. Pub. L. No. 101-647, §§ 1901-1907, 104 Stat. 4851 (1990).

7. *Id.*

8. Although the legislation permits distribution to a patient only for the treatment of a disease, it qualifies that limitation for medical conditions recognized by the Secretary of Health and Human Services. 21 U.S.C. § 333(c) (1994); see also 137 CONG. REC. E450 (daily ed. Feb. 7, 1991) (statement of Rep. Hughes); H.R. REP. NO. 101-681, pt. 3, at 70-71 (1990), reprinted in 1990 U.S.C.C.A.N. 6472, 6474-75.

and affordable. This note offers an analysis of the current steroid legislation as it relates to the elderly and suggests that many persons who suffer from the deteriorating effects of age could benefit from the treatment of anabolic steroids. Such treatment will not occur, however, without a change in the legislation allowing physicians to use their professional judgment in administering steroid treatments to the elderly. The proposed modification would not take place at the expense of the congressional objectives in designing the current steroids legislation. The integrity of the Anabolic Steroids Control Act need not be sacrificed in order to allow legitimate treatment of the elderly.

II. Background

A. The Legislation

Pharmaceutical regulations originally dealt with drug safety and labeling.⁹ However, in 1962, federal pharmaceutical law began requiring drug manufacturers to demonstrate the effectiveness of the drugs they marketed.¹⁰ Many steroid manufacturers claimed that treatment of osteoporosis and growth hormone deficiency were valid medical uses of steroids.¹¹ The Food and Drug Administration (FDA) did not agree and rejected these claims.¹² In 1988, Congress passed the Anti-Drug Abuse Act¹³ which provided criminal penalties for anabolic steroid trafficking.¹⁴ A further step was taken in 1990, when Congress enacted the Anabolic Steroids Control Act.¹⁵ The Act places anabolic

9. See WILLIAM N. TAYLOR, *MACHO MEDICINE: A HISTORY OF THE ANABOLIC STEROID EPIDEMIC* 41 (1991).

10. See *Legislation to Amend the Controlled Substance Act (Anabolic Steroids): Hearings on H.R. 3216 Before the Subcomm. on Crime of the House of Representatives Comm. on the Judiciary*, 100th Cong. 73-74 (1988) [hereinafter *Hearings on the Controlled Substance Act*] (statement of Gloria Troendle, Deputy Director, Division of Metabolic and Endocrine Drug Products, Food and Drug Administration).

11. See *id.* This claim is still made not only by the drug manufacturers, but also by health care providers. See William C. Scott et al., *Medical and Nonmedical Uses of Anabolic-Androgenic Steroids*, 264 JAMA 2923, 2923 (1990).

12. See *Hearings on the Controlled Substance Act*, *supra* note 10, at 73.

13. Pub. L. No. 100-690, § 2401, 102 Stat. 4181, 4230 (codified as amended at 21 U.S.C. § 801 (1994)).

14. See *id.* The 1988 Act provided that an individual convicted of violation of the Food, Drug, and Cosmetic Act would be subject to forfeiture of specific property and imprisonment of up to three years or a fine or both if that individual distributed steroids without prescription. See Jeffrey A. Black, Comment, *The Anabolic Steroids Control Act of 1990: A Need for Change*, 97 DICK. L. REV. 131, 136 n.31 (1992).

15. H.R. 4658, 101st Cong. (1990).

steroids on Schedule III of the Controlled Substance Act (CSA).¹⁶ Schedule III drugs typically include those which may lead to moderate or low physical dependence or high psychological dependence.

16. See 21 U.S.C. § 812 (1994), which establishes the criteria for placement upon a Schedule and provides in relevant part:

(a) Establishment

There are established five schedules of controlled substances, to be known as schedules, I, II, III, IV, and V. Such schedules shall initially consist of the substances listed in this section. The schedules established by this section shall be updated and republished on a semiannual basis during the two-year period beginning one year after the date of enactment of this title and shall be updated and republished on an annual basis thereafter.

(b) Placement on schedules; findings required

Except where control is required by United States obligations under an international treaty, convention, or protocol, in effect on the effective date of this part, and except in the case of an immediate precursor, a drug or other substance may not be placed in any schedule unless the findings required for such schedule are made with respect to such drug or other substance. The findings required for each of the schedules are as follows:

(1) Schedule I

(A) The drug or other substance has a high potential for abuse.

(B) The drug or other substance has no currently accepted medical use in treatment in the United States.

(C) There is a lack of accepted safety for use of the drug or other substance under medical supervision.

(2) Schedule II

(A) The drug or other substance has a high potential for abuse.

(B) The drug or other substance has a currently accepted medical use in treatment in the United States or a currently accepted medical use with severe restrictions.

(C) Abuse of the drug or other substance may lead to severe psychological or physical dependence.

(3) Schedule III

(A) The drug or other substance has a potential for abuse less than the drugs or other substances in schedules I and II.

(B) The drug or other substance has a currently accepted medical use in treatment in the United States.

(C) Abuse of the drug or other substance may lead to moderate or low physical dependence or high psychological dependence.

(4) Schedule IV

(A) The drug or other substance has a low potential for abuse relative to the drugs or other substances in schedule III.

(B) The drug or other substance has a currently accepted medical use in treatment in the United States.

(C) Abuse of the drug or other substance may lead to limited physical dependence relative to the drugs or other substances in schedule III.

The Act also includes an official list of drugs to be considered "steroids" for the purpose of the Act.¹⁷

The classification of anabolic steroids as controlled substances has created criminal penalties similar to those for narcotic violations.¹⁸ Notably, the Act criminalizes a physician's distribution of steroids for any use in humans other than the treatment of a disease or other recognized medical conditions.¹⁹ In addition, although the FDA approved steroid use for nondisease conditions,²⁰ Congress gave the Secretary of Health and Human Services the power to exempt steroids from prohibition only if: (1) the substance is accepted for a rare dis-

(5) Schedule V

(A) The drug or other substance has a low potential for abuse relative to the drugs or other substances in schedule IV.

(B) The drug or other substance has a currently accepted medical use in treatment in the United States.

(C) Abuse of the drug or other substance may lead to limited physical dependence or psychological dependence relative to the drugs or other substances in Schedule IV.

17. See 21 U.S.C. § 802. The list includes 28 items. In 1991, two doctors voiced concern over a similar list in New York's steroid legislation. See Richard D. Amelar et al., *The Prescription and Proscription of Chorionic Gonadotropin*, 265 JAMA 1529, 1529 (1991). The doctors stated that by error other "useful" and "important" medication was included in the list to which the rules apply. See *id.* Unfortunately, drugs which were not anabolic steroids had found their way onto the list at the cost of great inconvenience, apprehension, and additional expense, but had not benefited anyone. See *id.*

18. See Anti-Drug Abuse Act of 1988, Pub. L. No. 100-690, 102 Stat. 4181. This Act was repealed in November of 1990, effective February 1991, by the Anabolic Steroids Control Act of 1990, Pub. L. No. 101-647 § 1905, 104 Stat. 4853.

19. See 21 U.S.C. § 333(e). The statute provides:

(e)(1) Except as provided in paragraph (2), any person who distributes or possesses with the intent to distribute any anabolic steroid for any use in humans other than the treatment of disease pursuant to the order of a physician shall be imprisoned for not more than 3 years or fined under title 18, United States Code, or both.

(2) Any person who distributes or possesses with the intent to distribute to an individual under 18 years of age, any anabolic steroid for any use in humans other than the treatment of disease pursuant to the order of a physician shall be imprisoned for not more than six years or fined under title 18, United States Code, or both.

20. See GOODMAN & GILMAN'S PHARMACOLOGICAL BASIS OF THERAPEUTICS 1451-54 (Alfred Goodman Gilman et al. eds., 1985) [hereinafter GOODMAN & GILMAN]. The approved conditions include "allergies, stunted growth in childhood, and maintaining muscle mass for geriatric patients who, although not suffering from a specific disease treatable by anabolic steroids, are in a state of debilitation." Black, *supra* note 14, at 140.

ease or condition, and (2) the substance has no significant potential for abuse.²¹

B. The Enhancers

Anabolic steroid use once existed only among elite athletes competing at the world-class level.²² It is now estimated that 5% to 75% of professional athletes and 2% to 20% of college athletes use steroids.²³ Other experts estimate that half of the 9000 athletes who competed in the 1988 Olympics used steroids at some time during their training.²⁴ Perhaps more alarming are reports indicating that as many as two million nonathletes have experimented with these drugs.²⁵ The widespread use of performance-enhancing drugs in sports has resulted in state and federal legislation restricting the distribution and use of anabolic steroids.²⁶

Despite the potential for abuse of steroids, these drugs can have beneficial effects. Most experts agree that steroids enhance the synthesis of proteins in the body, which ultimately leads to muscle growth.²⁷ As a result, these drugs remain useful in a variety of medical applications.²⁸

21. See 137 CONG. REC. E450 (daily ed. Feb. 7, 1991) (statement of Rep. Hughes).

22. See JAMES E. WRIGHT & VIRGINIA S. COWART, *ANABOLIC STEROIDS: ALTERED STATES 2* (Kendal Glandish ed., 1990).

23. See *Abuse of Steroids in Amateur and Professional Athletics: Hearings on H.R. 4658 Before the Subcomm. on Crime of the House Comm. on the Judiciary*, 101st Cong. 73 (1990) [hereinafter *Hearings on Steroid Abuse*] (statement by Robert E. Larsen, M.D., Team Physician, University of Minnesota Football Team).

24. See VIRGINIA ALVIN & ROBERT SILVERSTEIN, *STERIODS: BIG MUSCLES, BIG PROBLEMS* 65 (1992).

25. See *Hearings on Steroid Abuse*, *supra* note 23, at 67 (statement of Robert E. Larsen, M.D.).

26. See, e.g., Amelar et al., *supra* note 17, at 1529; 21 U.S.C. § 812(c) (1994).

27. See Herbert A. Haupt & George D. Rovere, *Anabolic Steroids: A Review of the Literature*, 12 AM. J. SPORTS MED. 469, 481 (1984).

28. Current medical applications include treatment of: "certain types of anemias, hereditary angio-edema, certain gynecologic conditions, and protein anabolism." William C. Scott et al., *supra* note 11. "They also may have a role or be useful in conjunction with: constitutional delay of growth, an adjunct to growth hormone therapy, and osteoporosis." *Id.* Steroids may also be used in the treatment of skeletal disorders due to the stimulation of protein in bone. WRIGHT & COWART, *supra* note 22, at 35. Surgeons prescribe steroids before an operation to improve the condition of certain patients or after surgery to promote wound healing. Other indications have been for fibrocystic breast disease, female breast cancer, and endometriosis. Due to the rehabilitating effects of the drug, doctors have prescribed steroids for the treatment of malnutrition and other conditions associated with advanced age. See *id.*

1. STEROIDS: WHAT THEY ARE AND HOW THEY WORK

Steroids are chemical compounds that affect metabolism—the process of changing food into energy.²⁹ Human sex hormones like testosterone, progesterone, and estrogen are also steroids.³⁰ Testosterone promotes constructive metabolism and tissue repair—often called the “anabolic effect”—and also induces secondary male sex characteristics—often called the “androgenic effect.”³¹ Anabolic-androgenic steroids were pioneered in the 1950s to separate the masculinizing (androgenic) and skeletal muscle-building (anabolic) effects.³² These steroids are synthetic derivatives of testosterone.³³ Currently, no steroid has been created which has a purely anabolic effect.³⁴ Anabolic steroids are often confused with corticosteroids which are “used to treat infections, arthritis (inflammation of the joints), asthma, and certain cancers.”³⁵ Corticosteroids, unlike anabolic steroids, do not build or enhance muscle tissue growth.³⁶

The anabolic process of steroids within the body is very similar to that of naturally occurring testosterone.³⁷ Testosterone is released into the bloodstream, where it attaches to cells throughout the body.³⁸ Once distributed throughout the body, testosterone promotes the formation of new deoxyribonucleic acid (DNA), which then results in protein production.³⁹ The protein, once outside the cell, forms new tissue or muscle.⁴⁰ Anabolic steroids cause these effects to occur much more rapidly than what occurs naturally.⁴¹ In addition, steroids help block the breakdown of existing muscle when they are exposed to strain, thereby preventing normal muscle fatigue.⁴² These beneficial

29. See SARAH STEVENS, STEROIDS 6 (1991).

30. See *id.* at 7.

31. See Herbert A. Haupt, *Anabolic Steroids and Growth Hormone*, 21 AM. J. SPORTS MED. 468 (1993).

32. See Scott et al., *supra* note 11.

33. See *id.*

34. See *id.*

35. SCOTT E. LUKAS, THE DRUG LIBRARY: STEROIDS 8 (1994).

36. See *id.*

37. See *id.* at 35.

38. See *id.*

39. See *id.*

40. See *id.* at 35-37.

41. See *id.*

42. See *id.*

effects, however, can only be sustained through continued steroid use.⁴³

Inaccurate reports alleging that steroids were ineffective⁴⁴ and dangerous largely shaped society's opinion of steroid treatment.⁴⁵ Current research proves that increases in skeletal muscle mass result from steroid treatment.⁴⁶ Historic claims that the risks of steroid use outweigh any benefits are now being challenged.⁴⁷ Although scientists have documented numerous side effects of steroid use, these side effects are misleading as they usually occur at far greater dosages than those prescribed for medical conditions.⁴⁸ Those abusing the drugs often "stack" the dosages by taking many types of anabolic steroids concurrently.⁴⁹ Adding to the misinformation is the fact that reports documenting side effects typically refer to long-term usage.⁵⁰ These factors all combine to give a false impression of steroids and their legitimate medical applications.

2. HUMAN GROWTH HORMONE

Human growth hormone (hGH) is not an anabolic steroid, but is commonly used like anabolic steroids to stimulate muscle development.⁵¹ Like steroids, hGH is a naturally occurring hormone found in all individuals.⁵² Originally hGH was difficult and expensive to obtain because it had to be extracted from the pituitary glands of cadav-

43. See George Fan, Note, *Anabolic Steroid and Human Growth Hormone Abuse: Creating an Effective and Equitable Ergogenic Drug Policy*, 1994 U. CHI. LEGAL F. 439, 446.

44. See Scott et al., *supra* note 11.

45. As with most drugs, certain side effects accompany steroid treatment. See GARY I. WADLER & BRIAN HAINLINE, *DRUGS AND THE ATHLETE* 65-66 (1989). The inaccuracies of the mentioned reports concern the side effects associated with abusers of the drug. See *id.* at 66-67.

46. See Scott et al., *supra* note 11, at 2.

47. See Fan, *supra* note 43, at 444.

48. See Council on Scientific Affairs, *Drug Abuse in Athletes: Anabolic Steroids and Human Growth Hormone*, 259 JAMA 1703, 1704 (1988). The *Underground Steroid Handbook* is written, edited, and revised by athletes who themselves use steroids. See Fan, *supra* note 43, at 444. The authors of the handbook state that most medical claims about steroid side effects are untrue. *Id.* at 470 n.40.

49. See Scott et al., *supra* note 11, at 2924.

50. See, e.g., *id.*; Norma M. Reddig, Note, *Anabolic Steroids: The Price of Pumping Up!*, 37 WAYNE L. REV. 1647, 1649 (1991); John Burge, Note, *Legalize and Regulate: A Prescription for Reforming Anabolic Steroid Legislation*, 15 LOY. L.A. ENT. L.J. 33, 36 (1994).

51. See ROBERT VOY, *DRUGS, SPORTS, AND POLITICS* 62 (1991).

52. See *id.* at 57.

ers.⁵³ With the advent of synthetic replication, the supply of hGH is no longer limited.⁵⁴

hGH increases nitrogen retention and may increase the rate at which amino acids are transported and transformed into proteins,⁵⁵ the building blocks of muscle.⁵⁶ hGH also promotes quicker muscle growth by stimulating the conversion of fat into energy.⁵⁷ This process allows resources which are typically used for energy to be converted to muscle tissue.⁵⁸ Because it is an anabolic hormone, hGH also promotes protein accretion.⁵⁹ This helps conserve body protein in those patients with caloric restrictions.⁶⁰

The reported side effects associated with hGH treatment most commonly include acromegaly and gigantism.⁶¹ Acromegaly is a condition marked by the progressive enlargement of the hands, feet, and face due to excessive production of growth hormone.⁶² In contrast, individuals with gigantism usually suffer an overgrowth of the entire body.⁶³ However, because growth zones in adult bones have sealed, the effects of gigantism are restricted to adolescents.⁶⁴ The prevalence of acromegaly and gigantism is disputed, and many scientists and health care providers advocate that such risks can be eliminated with supervision and moderation.⁶⁵ Other health care professionals believe the advantages of hGH outweigh the risks.⁶⁶ Dr. Louis Underwood, Professor of Pediatrics at the University of North Carolina, testified before the House that hGH, "unlike anabolic steroids, [did not] en-

53. See Kaup R. Shetty & Edmund H. Duthie, *Anterior Pituitary Function and Growth Hormone Use in the Elderly*, 24 *ENDOCRINE ASPECTS OF AGING* 213, 220 (1995).

54. See *id.*

55. See Haupt, *supra* note 31, at 471.

56. See THE BANTAM MEDICAL DICTIONARY 355 (rev. ed. 1990) [hereinafter BANTAM].

57. See Haupt, *supra* note 31, at 471.

58. See *id.*

59. See Shetty & Duthie, *supra* note 53, at 225.

60. See *id.*

61. See Haupt, *supra* note 31, at 472.

62. See BANTAM, *supra* note 56, at 5.

63. See *id.* at 181-82.

64. See Haupt, *supra* note 31, at 472.

65. See Geoffrey Cowley, *Attention: Aging Men*, *NEWSWEEK*, Sept. 16, 1996, at 68, 74. Dr. Stanley Slater, director of hormone research at the National Institute on Aging, states that many of the side effects can be limited or eliminated by lowering a person's dosage. See *id.*

66. See *Anabolic Steroids Control Act of 1990: Hearings on H.R. 4658 Before the Subcomm. on Crime of the Comm. on the Judiciary*, 101st Cong. 81 (1990) [hereinafter *Hearings on Steroids*] (statement of Dr. Louis Underwood, Professor of Pediatrics at the University of North Carolina).

hance strength or athletic performance and did not cause aggressive behavior, psychological dependency, or withdrawal-related mood changes."⁶⁷ Dr. Underwood has treated approximately 200 children with hGH "in the hopes of obtaining normal growth and achieving normal adult stature."⁶⁸ Because the supply of hGH is no longer limited,⁶⁹ and there are minimal adverse risks associated with its intake,⁷⁰ this hormone is being tested in various clinical conditions that are unrelated to growth retardation.⁷¹

Unlike anabolic steroids, hGH is not scheduled by the federal government under the Controlled Substances Act.⁷² Congress chose to leave hGH off the list, in part, because there was no consensus within the scientific community that the drug posed a great risk of being abused in a manner like steroids.⁷³ Nor are the side effects associated with steroid use seen in users of hGH.⁷⁴

III. Analysis

As with most policy decisions, the development of antisteroid legislation required balancing any benefits that steroids offer against the perceived dangers.⁷⁵ This "give and take" approach was used in designing the Anabolic Steroids Control Act.⁷⁶ Fueled largely by the potential for steroid abuse and possible side effects, Congress chose to

67. *Hearings on Steroid Abuse*, *supra* note 23, at 85-88.

68. *Id.* at 85.

69. See Shetty & Duthie, *supra* note 53, at 220.

70. See *Hearings on Steroid Abuse*, *supra* note 23, at 87.

71. See Shetty & Duthie, *supra* note 53, at 220.

72. 21 U.S.C. § 812 (1994).

73. At the time of the congressional hearings concerning steroid legislation, Ronald G. Chesemore, Associate Commissioner for Regulatory Affairs for the FDA, testified that the scientific community had not reached a consensus regarding the abuse potential of hGH. See *Hearings on Steroid Abuse*, *supra* note 23, at 47 (statement of Ronald G. Chesemore, Associate Commissioner for Regulatory Affairs for the Food and Drug Administration). This was due in part to the strict controls placed upon the distribution of hGH by the manufacturers. The FDA also found that illegal distribution of hGH was much less prevalent than the illicit distribution of steroids. *Id.*

74. See *Hearings on Steroid Abuse*, *supra* note 23, at 84.

75. Clearly, anabolic steroids present serious problems, especially with adolescents. See W.E. Buckley, *Estimated Prevalence of Anabolic Steroid Use Among Male High School Seniors*, 260 JAMA 3441, 3445 (1988). One survey suggests that as many as 6.6% of male 12th graders have experimented with the drug. See *id.*

76. See 137 CONG. REC. E450-02 (1991). See generally *Anabolic Steroids Control Act of 1990: Hearings on H.R. 4658 Before the Subcomm. on Crime of the House Comm. on the Judiciary*, 101st Cong. 90 (1990).

stringently regulate distribution at the cost of limiting viable treatments and research.⁷⁷

A. Treatment Denied

Unfortunately, in the legislative trade-off, treatments using steroids to combat many of the illnesses and conditions associated with old age were negotiated into the banned category.⁷⁸ In order for physicians to prescribe steroids, they must be addressing a known disease approved for such treatment by the Secretary of Health and Human Services.⁷⁹ Even then the Secretary of Health and Human Services has the power to regulate such treatments.⁸⁰ Although many illnesses facing the elderly are within the legal confines of steroid treatment, perhaps the most significant benefit associated with the drug is not legally permitted, that being increased muscle growth and strength.⁸¹ Ironically, this was the very reason steroids were designed.⁸² When Congress limited steroids for body-building purposes, its focus was on deterring uses for fashionable results.⁸³ In so doing, Congress necessarily created a barrier for the drug's revitalizing and rejuvenating effects to be utilized in the treatment of the elderly.

77. See 137 CONG. REC. E450-02 (1991).

78. See the definition of "anabolic steroids" in 21 U.S.C. § 802 (1994).

79. See 21 U.S.C. § 333(e)(1).

80. See *supra* note 21 and accompanying text.

81. The prescription of steroids for other than the treatment of disease is a violation of the Act. Therefore, physicians who prescribed steroids for "body building" purposes would violate the very heart of the Act. See 21 U.S.C. § 333(e)(1).

82. It is claimed that in the 19th century, a European physiologist began testing the results of injecting testosterone from roosters. See John Pine, *Myth Surrounding Steroids Began in 19th Century Europe*, REUTERS N. AM. SERV., Sept. 28, 1988. The first clinical use of testosterone occurred in 1938 when doctors treated underweight patients in order to stimulate weight gain. See Morris B. Mellion, *Anabolic Steroids in Athletes*, AM. FAM. PHYSICIAN, July 1984, at 114. In the 1954 Vienna World Powerlifting Championship, Dr. John Ziegler administered steroids to the U.S. weight lifters. See Roy Bergman & Robert E. Leach, *The Use and Abuse of Anabolic Steroids in Olympic Caliber Athletes*, CLINICAL ORTHOPEDICS & RELATED RES., Sept. 1985, at 170. Impressed with the results, Dr. Ziegler began studies which resulted in the development of Dianabol, an anabolic steroid with fewer masculinizing properties than testosterone. See *id.*

83. See 136 CONG. REC. S16615-03 (1990). Congress seemed particularly worried about the growing number of adolescents who were discovering that steroids enhanced their muscle size and strength. See also W.E. Buckley et al., *Estimated Prevalence of Anabolic Steroid Use Among Male High School Seniors*, 260 JAMA 3441 (1988). Congress heard reports that athletes were the most common users of anabolic steroids. See Mimi D. Johnson et al., *Anabolic Steroid Use by Male Adolescents*, 83 PEDIATRICS 921, 922 (1989).

1. STEROID REPLACEMENT

As people age, and their bodies undergo the slow process of deterioration, bone density⁸⁴ and lean body mass will steadily decrease.⁸⁵ For instance, a typical man will lose between 12 and 20 pounds of muscle as well as 15% of his bone mass between the ages of 40 and 70.⁸⁶ Although most people experience only normal degeneration as they age, some suffer from unusually severe muscle strength and bone density loss.⁸⁷ These losses can require hospitalization and high medical costs. The administration of replacement hormones is ideally suited for people in this condition.⁸⁸ The beneficial effects of testosterone for this purpose are no longer disputed.⁸⁹ A team of physicians recently tested the effects of testosterone and concluded that the administration of androgens would have beneficial effects in patients with chronic and wasting disorders.⁹⁰ Recently, physicians have begun to seriously study the possibility of replacement hormone treatment for the general increase in body strength and overall sense of well-being in the elderly.⁹¹

Enthusiasts believe that hormones may be the ultimate antidote for aging in both sexes.⁹² These drugs include testosterone, dehydroepiandrosterone (DHEA), melatonin, and hGH.⁹³ Dr. William Regelson of the Medical College of Virginia believes that aging can be delayed.⁹⁴ He claims that by restoring hormones "it is possible to slow

84. See Joel R. Pittman & Natalie Kujdych, *Osteoporosis: New Perspectives*, 140 *DRUG TOPICS*, Aug. 19, 1996, at 108, available in 1996 WL 11132318.

85. See Shetty & Duthie, *supra* note 53, at 220; see also Cowley, *supra* note 65, at 70.

86. See Cowley, *supra* note 65, at 70.

87. See *id.*

88. See *id.* at 71.

89. See Shalender Bhasin et al., *The Effects of Supraphysiologic Doses of Testosterone on Muscle Size and Strength in Normal Men*, 335 *NEW ENG. J. MED.* 1, 1 (1996). Forty-three normal men were placed in one of four groups: placebo with no exercise, placebo with exercise, testosterone with no exercise, testosterone with exercise. The intake of energy and protein and the exercise stimulus were standardized. The four groups were similar with respect to age and weight, height, and body-mass index before treatment. The only side effect noted was mild acne. The group receiving testosterone combined with exercise had the greatest increase in muscle size, however, the group receiving testosterone without exercise had significant gains which superseded the gains made by men exercising without testosterone. See *id.* at 3-4.

90. See *id.* at 6.

91. See Cowley, *supra* note 65, at 70.

92. See *id.*

93. See *id.*

94. See *id.* at 70.

and even reverse the aging process."⁹⁵ Other professionals agree. Dr. Norm Mazer of TheraTech, a company that researches testosterone therapy, stated, "We give eyeglasses to people as they age to maintain visual acuity. Why not give them testosterone to retain muscle strength and prevent osteoporosis?"⁹⁶

One of the few diseases that characterize the elderly is osteoporosis.⁹⁷ The disease decreases bone mass or density, resulting in weakened bones which are more susceptible to fracture.⁹⁸ Although there is no cure, early treatment may slow the loss of bone.⁹⁹ Current costs of treating osteoporosis and related injury in the United States exceed \$10 billion.¹⁰⁰ That number is expected to double in the next 25 to 30 years.¹⁰¹ In women, the single most significant bone loss event is estrogen deprivation at menopause.¹⁰² Long-term estrogen replacement therapy is the only reliable means of preventing this loss.¹⁰³ Although there is no equivalent term such as "male menopause," middle age does bring on changes in men¹⁰⁴ that affect the density of bone mass.¹⁰⁵ Like treatment in women, hormone replacement in men appears to support promising results.¹⁰⁶ Testosterone is now being suggested as a potentially beneficial therapy for older men with low serum testosterone levels.¹⁰⁷ Preliminary studies indicate that therapy might benefit bone, muscle, and psychosexual functions, without significant risk of adverse effects.¹⁰⁸

95. *Id.*

96. Cowley, *supra* note 65, at 71.

97. See Pittman & Kujdych, *supra* note 84.

98. See *id.*

99. See *id.* The disease is considered a major health risk concerning Americans, 80% of whom are women. One and a half million bone fractures annually are related to osteoporosis. One-third of all women, along with one-sixth of all men over 90 years of age, will suffer at least one fracture. See *id.*

100. See *id.*

101. See *id.*

102. See *id.*

103. See *id.*

104. See *id.* The process begins in a man's 40s or 50s and affects strength, sexuality, and the general sense of contentment. See *id.* It is occasionally referred to as "andropause" or "viropause." See *id.*

105. See *id.*; see also Joyce S. Tenover, *Androgen Administration to Aging Men*, 23 CLINICAL ANDROLOGY 877, 879 (1994) (stating that after age 60, hip fracture rates double for each additional decade).

106. See Tenover, *supra* note 105, at 884. Treatment with testosterone has resulted in an increase in calcium retention and a decline in urinary calcium excretion. Androgen therapy also has resulted in an increase in body weight, an increase in lean body mass, and a tendency for a decrease in body fat. See *id.*

107. See *id.* at 887.

108. See *id.*

2. EFFECTS OF GROWTH HORMONE ON BODY COMPOSITION

Gerontologists studying physiologic and metabolic alterations during aging believe that hormonal deficiency often advances age-associated changes.¹⁰⁹ As the body ages from age 30 to age 75 years, the size of the liver, kidney, brain, and pancreas decreases by approximately 30%.¹¹⁰ After age 50, growth hormone secretion gradually declines.¹¹¹ In some individuals it becomes undetectable.¹¹² This deficiency manifests into functional losses, which restrict an elderly individual's ability to undertake activities, withstand trauma, resist infection, process foods, and excrete medications.¹¹³ The associated loss in muscle mass reduces strength, mobility, the ability to breathe and cough, and, ultimately, the capabilities necessary for an independent life.¹¹⁴

The beneficial effects of hGH have been documented in GH-deficient children and young adults.¹¹⁵ Similar studies¹¹⁶ on the elderly conclude that the desirable hormonal effects of expanding lean body mass can be achieved while the undesirable side effects avoided.¹¹⁷ One recent study, lasting 21 months and involving 45 independent men aged 61 to 81, resulted in significant changes to the participants' lean body mass.¹¹⁸ The average subject gained 6% in lean body mass; 4% in skin thickness; 8% in liver volume; 23% in spleen volume; and 11% volume in 10 tested muscle areas.¹¹⁹ It should be noted that side effects of hGH are reportedly infrequent in these short-term and long-term studies.¹²⁰ Researchers indicate that any complications can be prevented without sacrificing the beneficial effects on body composition.¹²¹

109. Shetty & Duthie, *supra* note 53, at 213.

110. *See id.* at 221.

111. *See id.*

112. *See id.*

113. *See id.*

114. *See id.* Those studying these effects have concluded that these age-related changes are undesirable for at least three reasons. First, there is a direct relation between work capacity and lean body mass. Second, geriatric atrophy of lean body mass organs is associated with diminished functional capacities in muscle strength. Third, increased adiposity predisposes negative changes in blood pressure, glucose clearance, and the plasma lipoprotein profile. *See id.*

115. *See id.* at 223.

116. *See id.*

117. *See id.* at 224.

118. *See id.* at 223.

119. *See id.*

120. *See id.* at 227.

121. *See id.*

B. Challenging the Antisteroid Legislation

The limitations imposed upon steroid treatment are the result of scheduling under the Anabolic Steroids Control Act of 1990.¹²² While the Act combats most of the steroid activity which concerned Congress, it also includes limitations on viable treatments for elderly patients. Congress could not have intended this particular limitation when developing this law.

1. LEGISLATIVE PURPOSE

In the 1980s, the federal government began suspecting that drug manufacturers were producing anabolic steroids far in excess of the legitimate medical demand.¹²³ Federal administrators targeted steroid abuse. By May 1986, personnel from the Department of Justice, the FDA, and the Federal Bureau of Investigation had joined their efforts to establish a steroid trafficking task force.¹²⁴ Federal prosecutors began actively charging distributors under the Federal Food, Drug, and Cosmetic Act.¹²⁵ As criminal prosecution began to increase for illegal distribution,¹²⁶ Congress initiated hearings to investigate the depth of steroid abuse.¹²⁷ These hearings resulted in the promulgation of the Controlled Substances Act¹²⁸ and eventually the Anabolic Steroids Control Act of 1990.¹²⁹

Legislative history reveals that Congress did not intend to restrict the distribution of anabolic steroids to the elderly even for muscle enhancing purposes.¹³⁰ Legislators believed that a number of suspected health risks were associated with the misuse of anabolic

122. Anabolic Steroids Control Act of 1990, Pub. L. No. 101-647, § 1901, 104 Stat. 4851, 4851 (1991) (codified as amended at 21 U.S.C. § 801 (1994)).

123. See Burge, *supra* note 50, at 42.

124. See WRIGHT & COWART, *supra* note 22, at 117.

125. See *Hearings on Steroids*, *supra* note 66, at 39-40.

126. See Paul J. Golstein, *Anabolic Steroids: An Ethnographic Approach*, in ANABOLIC STEROID ABUSE 74, 83 (National Inst. on Drug Abuse Research Monograph No. 102, 1990). By 1988, more than 60 trafficking prosecutions had been successful, and another 120 persons were facing charges. See *id.*

127. See *Hearings on Steroid Abuse*, *supra* note 23, at 73; *Legislation to Amend the Controlled Substances Act: Hearings on H.R. 3216 Before the Subcomm. on Crime of the House of Representatives Comm. on the Judiciary*, 100th Cong. 77 (1988).

128. See The Anti-Drug Abuse Act of 1988, Pub. L. No. 100-690, 102 Stat. 4181.

129. Anabolic Steroids Control Act of 1990, Pub. L. No. 101-647, § 1901, 104 Stat. 4851 (codified as amended at 21 U.S.C. § 801 (1994)).

130. Cf. Burge, *supra* note 50, at 41-42 (explaining that the Controlled Substance Act, which controls substance abuse, was implemented to regulate only those drugs which have a psychological effect or are psychologically addictive. Because steroids are taken to enhance appearance or performance, placing them on the scheduling list does not serve the congressional intent for creating the Act).

steroids and therefore greater control over distribution was necessary.¹³¹ Congress was particularly concerned with steroid use among minors.¹³² Senator Biden addressed Congress by stating that "steroid abuse is nearly as widespread as the use of crack cocaine among male high school students."¹³³ This concern was heightened by statistics showing that 6.6% of twelfth grade male students used anabolic steroids.¹³⁴ Congressman Beryl Anthony commented that "this is not merely a debate over whether or not an athlete has the right to use steroids to improve his performance. Sports heroes as role models have a profound influence on the social direction of our youth."¹³⁵

The concern over adolescent steroid abuse was so strong that legislators included in the proposal penalties directed at coaches and trainers who encourage steroid use among athletes.¹³⁶ Testimony included statements by coaches who said, "[I]t is the responsibility of coaches to instill proper training habits . . . without sacrificing [the athlete's] future."¹³⁷ This proposal failed to become law in 1990. However, due to the influential nature of a coach's position, Representative Hughes reintroduced similar legislation in the 1991 Act.¹³⁸ He stated that by making it criminal for coaches to encourage athletes to use steroids, "it would help put an end to such exploitation. [Coaches] must not be allowed to use their positions of trust and authority by sacrificing the athlete's health and values in a craven attempt to achieve a competitive edge."¹³⁹ Congress's concern for adolescent steroid abuse was reinforced by testimony concerning the teenage psyche.¹⁴⁰ One commentator explained that student athletes fail to be convinced that steroid dangers are real.¹⁴¹ These athletes

131. See 137 CONG. REC. E450-02 (1991).

132. See, e.g., 136 CONG. REC. S16615 (1990) (comments from Senator Biden).

133. *Id.*

134. See Buckley et al., *supra* note 83, at 3445.

135. 134 CONG. REC. E3138-01 (daily ed. Sept. 28, 1988).

136. See H.R. 4658, 101st Cong. § 2(a) (1990). Penalties for these actions include up to two years imprisonment and fines under Title 18. See *id.* If the individual being induced is under 18, imprisonment may go up to five years and fines may be imposed. See *id.*

137. *Hearings on Steroid Abuse*, *supra* note 23, at 44 (statement by Chet Parlavecchio, football coach at Bloomfield High School, N.J.).

138. See generally H.R. 867, 102d Cong. (1991).

139. 137 CONG. REC. E450, (daily ed. Feb. 7, 1991).

140. See *Hearings on Steroid Abuse*, *supra* note 23, at 49 (statement by Richard Sandlin, former assistant coach for strength and fitness at the University of Alabama).

141. See *id.*

often believe anything improving physical strength and appearance could never be bad.¹⁴²

It was not only the prevalent abuse by children which captured the attention of Congress, but also the profile of steroid users in general. A representative from the Department of Justice informed Congress that many steroid users were very goal oriented and did not take steroids "to get high or to escape from reality."¹⁴³ Unlike those who abuse other drugs for their mind altering effect, the motives behind steroid use were thought to be more calculated; the user actually compares the associated risks to the chance of achieving a target goal.¹⁴⁴ Thus, Congress felt that legislation must discourage abusers who were willing to sacrifice their health to achieve short-term success.¹⁴⁵ The goal was to reduce the availability of anabolic steroids for nonmedical purposes, stem the abuse of steroids, deter users, and punish those who promote steroid abuse by selling and inducing others to use them.¹⁴⁶ These combined factors, equating to a high potential for abuse, prompted Congress to place steroids on the controlled substance list. The negative aspects of steroid abuse overshadowed the medical testimony concerning viable steroid treatments. Congress believed that because steroids were prescribed legally for "certain limited medical uses,"¹⁴⁷ it was in the best interest of the public to criminalize distribution except in these limited uses.¹⁴⁸ It appears from the legislative history that Congress was zealously confronting what it perceived to be the abuse of anabolic steroids for *non-medical purposes*.

2. CRIMINAL TREATMENT

The Secretary of Health and Human Services is charged with the duty of approving steroids for specific medical treatments.¹⁴⁹ Cur-

142. *See id.*

143. *Hearings on Steroids, supra* note 66, at 19 (prepared statement of Leslie Southwick, Deputy Assistant Attorney General, Civil Division, U.S. Department of Justice).

144. *See Reddig, supra* note 50, at 1656.

145. *See id.*

146. *See generally* H.R. 4658, 101st Cong. (1990).

147. *Hearings on Steroids, supra* note 66, at 38 (prepared statement of Ronald G. Chesemore, Associate Commissioner for Regulatory Affairs, Food and Drug Administration).

148. *See* 137 CONG. REC. E450 (daily ed. Feb. 7, 1991) (statement of Rep. Hughes); *see also* H.R. REP. NO. 101-681, pt. 3, at 94-95 (1990), *reprinted in* 1990 U.S.C.A.N. 6472, 6498-99.

149. *See* 21 U.S.C. § 802(41)(B)(i) (1994).

rently, treatment with "any drug or hormonal substance, chemically and pharmacologically related to testosterone (other than estrogens, progestins, and corticosteroids) that promotes muscle growth"¹⁵⁰ is legally forbidden unless in the treatment of a disease or other recognized medical condition. Therefore, pursuing hormone treatment in the elderly for other than federally approved diseases places the prescribing doctor at risk for violating the Anabolic Steroids Control Act, despite the fact that there are very beneficial treatments for the restoration of muscle and strength in the elderly.¹⁵¹ Although the intent of the legislation is served, the sweeping stroke with which it is applied dismisses many favorable applications for the elderly.

The FDA has approved steroid treatment for maintaining muscle mass for geriatric patients who, although not suffering from a specified disease treatable by anabolic steroids, are in a state of debilitation.¹⁵² However, only the Secretary of Health and Human Services may exempt steroid treatment from the Act's prohibition.¹⁵³ In doing so, the Secretary must determine that the steroid treatment does not belong under Schedule III of the Act. Currently, the treatment approved by the FDA will fail under Schedule III standards.¹⁵⁴ This unfortunate result not only limits significant treatment to the elderly, it also subjects physicians to criminal liability for advancing steroid treatment for nondisease conditions approved by the Secretary.

For these reasons,¹⁵⁵ the American Medical Association vehemently opposed the scheduling of anabolic steroids during congressional debates,¹⁵⁶ stating:

The medical facts do not support scheduling anabolic steroids under the CSA. Anabolic steroids have an accepted use in the treatment of several medical conditions, including certain ane-

150. *Id.* § 802(41)(A). This definition also includes a list of 28 drugs and substances which are to be considered anabolic steroids for the purpose of this Act. *See id.*

151. *See* Cowley, *supra* note 65, at 71.

152. *See* Black, *supra* note 14, at 140.

153. *See* 21 U.S.C. § 802(41)(B)(i).

154. These standards include: (1) whether the substance is accepted for a rare disease or condition and (2) whether the substance has any significant potential for abuse. 137 CONG. REC. E450-02 (1991).

155. The AMA also felt that scheduling anabolic steroids would not result in a reduction of widespread use because a majority of users acquire the drugs from illegitimate means. *See* Virginia S. Cowart, *Support Lags for Research on Steroid Effects*, 262 JAMA 2500, 2501 (1989).

156. *See Steroids in Amateur and Professional Sports—The Medical and Social Costs of Steroid Abuse: Hearings Before the Senate Comm. on the Judiciary*, 101st Cong. 78 (1989); Scott et al., *supra* note 11, at 2926.

mias, hereditary angioedema, and breast cancer. Moreover, anabolic steroids can be used safely under medical supervision. . . . [A]nabolic steroids should not be scheduled under *any* other schedule of the CSA since abuse of the drugs does *not* lead to physical or psychological dependence as is required for scheduling under the Act.

In addition, scheduling of anabolic steroids would not adequately address the problem of abuse of these drugs because it would not affect the major illicit sources of the drug—shipments from foreign countries and from veterinary supply houses. Scheduling would curtail only the relatively small amount of abuse that results from diversion of licit sources.¹⁵⁷

While the AMA recognizes and supports legislation which addresses the problem of misprescribing steroids, it continues to oppose the barrier created by scheduling steroids under the Controlled Substance Act.¹⁵⁸

If a physician decides to administer steroids for maintaining muscle mass and increasing strength and overall well-being, that physician will likely bear the burden of producing some evidence that his prescription falls within the proper medical standards of reasonable care.¹⁵⁹ Although most cases involving distribution of prescription drugs have required the government to prove the physician's practice was outside the bounds of his "professional medical practice,"¹⁶⁰ federal violations have only recently been prosecuted, and the proper procedure is largely uncertain. What is certain, however, is that when physicians prescribe steroids for other than approved illnesses,¹⁶¹ they open themselves up to a presumption of illegality based upon the reading of the Anabolic Steroids Control Act.¹⁶² The underlying purpose of the Act was to discourage the illegitimate distribution and consumption of anabolic steroids by those seeking to exploit the muscle-building components.¹⁶³ Congress's concern for the safety and well-being of citizens resulted in the unfortunate plight now facing

157. *Steroids in Amateur and Professional Sports—The Medical and Social Costs of Steroid Abuse: Hearings Before the Senate Comm. on the Judiciary*, 101st Cong. 78 (1989).

158. See Scott et al., *supra* note 11.

159. See *United States v. Hooker*, 541 F.2d 300, 305 (1st Cir. 1976).

160. *Id.*

161. See *supra* note 150 (Secretary of Health and Human Services).

162. See *supra* notes 150-55 and accompanying text (Secretary of Health and Human Services and statute).

163. See 137 CONG. REC. E450 (daily ed. Feb. 7, 1991) (statement of Rep. Hughes); see also H.R. REP. NO. 101-681, pt. 3, at 94 (1990), *reprinted in* 1990 U.S.C.A.N. 6472, 6473 (Anabolic Steroids Control Act passed as Title III of the Crime Control Act of 1990 to address criminal actions which endanger the physical safety or health of citizens).

doctors who treat the elderly. This limitation upon medically supervised steroid treatment is even more unreasonable when facts show that less than 20% of all anabolic steroids are distributed through medical professionals.¹⁶⁴ In effect, Congress has attempted to remedy rampant steroid use by targeting those who should remain unencumbered. In writing this law, Congress ignored the very professionals who were capable of providing expert advice and guidance on an issue completely beyond the scope of congressional aptitude. Congress disregarded not only the American Medical Association's recommendation to leave anabolic steroids off the scheduling list,¹⁶⁵ it also failed to recognize the objections of other governmental posts. Both the FDA and the National Institute on Drug Abuse evaluated anabolic steroids and did not recommend any administrative action to control steroids under the Controlled Substance Act.¹⁶⁶ Despite the opposition advanced by medical professionals¹⁶⁷ and regulatory agencies, Congress enacted legislation restricting steroids from many legitimate medical applications.

The federal government is not alone in the fight to regulate steroid abuse.¹⁶⁸ Many states now have rules and penalties similar to the Anabolic Steroids Control Act.¹⁶⁹ State legislators appear to have targeted the same concerns as Congress in promulgating laws against steroid abuse.¹⁷⁰ In some instances, states specifically warned practitioners that prescribing steroids to increase muscle size and strength in a person of good health is not a valid medical purpose,¹⁷¹ while others required posting notices designed to educate the public on the dangers of using steroids.¹⁷² A remarkable difference between the legislation at the federal level and that developed by states is that many

164. See Cowart, *supra* note 156, at 2501.

165. See *supra* note 158 and accompanying text (AMA's opposition).

166. See *Hearings on the Controlled Substance Act*, *supra* note 10, at 74 (testimony of Dr. Gloria Troendle, Deputy Director, Division of Metabolic and Endocrine Drug Products, Food and Drug Administration).

167. See *supra* notes 155-56 and accompanying text (AMA's opposition).

168. See Reddig, *supra* note 50, at 1663.

169. See, e.g., ARIZ. REV. STAT. ANN. §§ 32-1996, -2551, -2531, 36-2544 (West 1992 & Supp. 1996); CAL. CIV. CODE § 1812.97(a) (West Supp. 1997); N.M. STAT. ANN. § 30-31-41 (Supp. 1996); TEX. EDUC. CODE ANN. § 38.008 (West Supp. 1991); 1990 Mich. Legis. Serv. 31 (to be codified at MICH. COMP. LAWS ANN. § 333.26301-26306).

170. See sources cited *supra* note 169.

171. See sources cited *supra* note 169.

172. These posting notices contain statements of the penalties for unlawful use, delivery, and possession, while others include warnings explaining the physical dangers. See CAL. CIV. CODE § 1812.97(a) (West Supp. 1997).

states yield to a physician's legitimate medical determinations.¹⁷³ Specifically, some states do not require that all steroid prescriptions be for the treatment of some recognized disease or condition, as does the federal act.¹⁷⁴ In recognizing and anticipating steroid applications for nondisease treatment, these states defer to medical professionals.¹⁷⁵ This approach helps ensure the safety and care of countless patients every year. These states refused to replace a physician's medical expertise with their own meager knowledge of complicated scientific health issues. In doing so, they developed rules which maximize deterrence of steroid abuse in athletes while providing protection for those patients who may benefit from a doctor's care. These laws stand in sharp contrast to the Anabolic Steroids Control Act, which does not allow for such good faith determinations.¹⁷⁶ The Act specifically limits those treatments which are accepted and provides severe penalties for those in violation.¹⁷⁷ By respecting the federal law, physicians may not prescribe steroids to advance the physical strength and condition of the elderly. By subverting a doctor's determination concerning the best interests of a patient, elders are penalized as well—not for violating the law, but by submitting to it.

3. JUDICIAL IMPACT

Congress's focus on deterring athletes, especially young athletes, from abusing steroids influenced those charged to prosecute physicians in violation of the Act. United States Attorney Terree A. Bowers summed up the intentions of the Justice Department in enforcing the Anabolic Steroids Control Act against physicians:

The distribution of dangerous drugs to athletes seeking to increase their performance through artificial means simply will not be tolerated. As seen by this prosecution, the federal government is committed in its effort to identify and prosecute any physician using his or her medical practice as a conduit to distribute steroids and other drugs illegally.¹⁷⁸

This statement supports the conclusion that Congress intended to prevent the legal prescriptions of steroids for athletic purposes. How-

173. See Black, *supra* note 14, at 143.

174. See *supra* notes 150-51 and accompanying text (Secretary of Health and Human Services and two requirements).

175. See *Perzik v. Superior Court*, 4 Cal. Rptr. 2d 1 (1991); *Laura N. Buckner v. Allergan Pharm., Inc.*, 400 So. 2d 820 (1987).

176. See Black, *supra* note 14, at 143.

177. See *id.*

178. *Burge*, *supra* note 50, at 58-59 (quoting news release from United States Attorney's Office, Central District of California).

ever, there is no guarantee that doctors will enjoy immunity from prosecution if they prescribe steroids in other ways which may promote a person's strength. The puzzling question for the Department of Justice is whether to prosecute physicians who knowingly prescribe steroids for viable, yet unapproved, treatments.¹⁷⁹ If the purpose of the Act was to prevent steroid consumption primarily by athletes, that purpose would not be served by policing the medical community for infractions involving the elderly. The question then becomes one for the judiciary to interpret. The Eighth Circuit of the U.S. Court of Appeals showed hesitation in dealing with similar prosecutions against physicians for improper actions.¹⁸⁰ The court suggested that medical decisions properly belong to those in the medical profession.¹⁸¹ The court was concerned that the best interests of the patient would not be served if health care professionals' decisions were reviewed by persons unskilled in that field.¹⁸² "Questions regarding medical treatment, the nature, amount, and manner of administration of medication, the cultures and other tests essential to proper diagnosis, and kindred matters, are not suitable for determination by juristic science. Appropriate deference to qualified medical judgment is required with respect to the substantive issues involved."¹⁸³ It seems that a physician's right to prescribe anabolic steroids for the treatment of advanced age is precisely what the court meant by "substantive issues"¹⁸⁴ better left to qualified medical judgment. Unfortunately, physicians who rely on such deference may find other courts to be less sympathetic.

Although there have been few criminal prosecutions of physicians under the Anabolic Steroids Control Act, a number of doctors have been charged for violating the Controlled Substance Act.¹⁸⁵ Steroids are scheduled under the CSA,¹⁸⁶ therefore, the Act is relevant to a discussion of criminal prosecution of those physicians who violate

179. Specifically, when doctors such as Norm Mazer or William Regelson treat elderly patients with steroids in an attempt to increase muscle strength, may the government prosecute under the Anabolic Steroids Control Act? See Cowley, *supra* note 65, at 71.

180. See *Everett, M.D. v. Franciscan Sisters Healthcare, Inc.*, 882 F.2d 1383 (8th Cir. 1989).

181. See *id.* at 1386.

182. See *id.*

183. *Id.*

184. *Id.*

185. 21 U.S.C. § 841(a) (1994).

186. See *id.* § 812(c).

prescription guidelines. One of the debated issues is whether prescribing doctors must satisfy the burden of proving a legitimate medical reason for their prescription.¹⁸⁷ Case law on this issue is inconsistent.¹⁸⁸ The CSA provides, "Except as authorized by this subchapter, it shall be unlawful for any person knowingly or intentionally . . . to manufacture, distribute, or dispense, or possess with intent to manufacture, distribute, or dispense, a controlled substance"¹⁸⁹ However, "[p]ersons registered by the Attorney General . . . to manufacture, distribute, or dispense controlled substances are authorized to possess, manufacture, distribute, or dispense such substances . . . to the extent authorized by their registration."¹⁹⁰ As one court noted,¹⁹¹ a strict reading of the CSA permits physicians registered with the Attorney General to prescribe drugs with impunity. However, courts have refused to interpret the CSA so mechanically.¹⁹² The Seventh Circuit found it incumbent upon the defendant to prove that his actions were within legitimate professional standards of practice.¹⁹³ Fortunately, not all federal courts share this view. The Fifth Circuit has routinely held that the government must prove the lack of a legitimate medical reason in order to convict a registered physician of dispensing drugs in violation of 21 U.S.C. § 841(a).¹⁹⁴ The Fifth Circuit opined: "Without behavior beyond professional practice, there is no crime."¹⁹⁵ The court recognized the practical limitations of requiring physicians to

187. See *United States v. Outler*, 659 F.2d 1306, 1309 (5th Cir. 1981).

188. Case law has not resolved this issue. For instance, in *United States v. King*, 587 F.2d 956 (9th Cir. 1978), the court held that the prosecution had the burden of proof at trial. See *id.* at 964-65. However, in other cases, courts have indicated an unwillingness to find a doctor's prescription of anabolic steroids legitimate or medically reasonable without some probative evidence. See generally *United States v. Roy*, 574 F.2d 386 (7th Cir. 1978); *Perzik v. Superior Court*, 4 Cal. Rptr. 2d 1 (Cal. Ct. App. 1991); *State Med. Bd. of Ohio v. Murray*, 613 N.E.2d 636 (Ohio 1993).

189. 21 U.S.C. § 841(a)(1).

190. *Id.* § 822(b).

191. See *Outler*, 659 F.2d at 1309.

192. See *United States v. Moore*, 423 U.S. 122 (1975) (holding that a physician may be charged with the criminal violation of § 841(a) of the CSA whenever he prescribes a controlled substance without legitimate medical reasons. The Court held that implicit within the CSA is the a requirement that the physician behave beyond professional practice.).

193. See *United States v. Roy*, 574 F.2d 386 (7th Cir. 1978).

194. See *United States v. Rosen*, 582 F.2d 1032 (5th Cir. 1978); *United States v. Rogers*, 609 F.2d 834 (5th Cir. 1980); *United States v. Guerrero*, 650 F.2d 728 (5th Cir. 1981) (reversing district court decision on evidentiary grounds).

195. *Outler*, 659 F.2d at 1309.

defend themselves against every charged CSA infraction.¹⁹⁶ The court stated:

[T]he doctor always would have the burden at trial of proving the prescription was based on a legitimate medical need. The effect of this scheme would be a presumption that every physician who prescribes a drug does so without a legitimate medical reason. We do not believe Congress intended this result.¹⁹⁷

Although the First Circuit has held that a defendant claiming a medical exemption under 21 U.S.C. § 822(b)¹⁹⁸ bears the evidentiary burden with respect to its applicability,¹⁹⁹ the court has also agreed with the Fifth Circuit that the government has the task of proving that a practitioner's prescriptions were not issued for a legitimate medical purpose in the usual course of professional practice.²⁰⁰ These holdings leave a gray area of uncertainty for physicians wishing to prescribe anabolic steroids for conditions of advanced age. Any burden placed on physicians with respect to proving the viability of a chosen treatment will effectively discourage doctors from employing that option. With the passage of the Anabolic Steroids Control Act and the enthusiasm with which the Department of Justice has pledged to ensure its enforcement,²⁰¹ doctors would be taking a great risk in signing their name to any steroid prescription. This threat of prosecution has virtually eliminated all research and development as well as application of steroid treatments for aging conditions.²⁰²

Beyond the fear of criminal prosecution, physicians must also consider the financial cost of being charged with violating the Anabolic Steroids Control Act.²⁰³ In 1986, John D. Perzik, M.D., was in-

196. *See id.*

197. *Id.* at 1309 n.3.

198. 21 U.S.C. § 885(a)(1) (1994) provides: "It shall not be necessary for the United States to negative any exemption or exception set forth in this subchapter in any complaint, information, indictment, or other pleading or in any trial, hearing, or other proceeding under this subchapter, and the burden of going forward with the evidence with respect to any such exemption or exception shall be upon the person claiming its benefit."

199. *See United States v. Hooker*, 541 F.2d 300, 305 (1st Cir. 1976).

200. *See id.*; *see also United States v. Black*, 512 F.2d 864, 871 n.15 (9th Cir. 1975) (holding by the Ninth Circuit that the government bears the burden of showing a prescription falls outside the scope of professional conduct).

201. *See supra* note 179 and accompanying text.

202. Approved tests continue on a limited basis; however, the development of synthetic hGH has resulted in numerous tests being conducted on its hormonal benefits as applied to the elderly. *See supra* notes 61-71 and accompanying text.

203. *See generally Perzik v. St. Paul Fire & Marine Ins. Co.*, 279 Cal. Rptr. 498 (1991).

dicted in federal court for illegally dispensing steroids.²⁰⁴ In his effort to defend the action, Perzik consulted with his insurance company²⁰⁵ in an attempt to convince them to pay the costs of his legal counsel.²⁰⁶ His insurance company refused to pay.²⁰⁷ Perzik realized that his insurance company was likely to balk at paying any malpractice charges as well.²⁰⁸ Therefore, he filed a declaratory relief action seeking a determination that his insurance company had the duty to defend him as well as indemnify him for any and all damages arising from the federal investigation and criminal action.²⁰⁹ The court held for the insurance company on both issues stating, "It is clear to us that the federal criminal investigation and prosecution at issue here do not constitute covered 'professional liability claims,' no matter how broadly that phrase may be interpreted. Professional liability, in common parlance, refers to malpractice liability; it is quite distinct from criminal liability."²¹⁰ The distressing result of this case adds one more reason to the growing list of justifications for a physician to refuse to administer steroids to the elderly. In the face of possible criminal prosecution, and with the prospect of losing defense insurance and indemnification, it very well may be a fool who administers steroids for anything that is not a recognized medical condition under the Act.

IV. Recommendation

In restricting the possession and distribution of steroids, Congress has necessarily limited beneficial treatments available to the eld-

204. See *id.* at 499.

205. See *id.* The policy had an effective date of May 1, 1985. It stated in pertinent part:

This agreement provides protection against professional liability claims which might be brought against you in your practice as a physician or surgeon Your professional liability protection covers you for damages resulting from: 1. Your providing or withholding of professional services We'll defend any suit brought against you for damages covered under this agreement. We'll do this even if the suit is groundless or fraudulent. We have the right to investigate, negotiate and settle any suit or claim if we think that's appropriate. We'll pay all costs of defending a suit, including interest on that part of any judgment that doesn't exceed the limit of your coverage.

Id. at 500.

206. See *id.* at 500.

207. See *id.*

208. See *id.*

209. See *id.*

210. *Id.*

erly. This begs the question: Has Congress infringed upon the rights of physicians to administer medicine in ways which maximize the benefits of drug therapy? Certainly Congress has an interest in protecting society from the unwanted effects of prescription drugs. However, limitations placed upon the type of illnesses which are approved for treatment creates unnecessary obstacles while failing to meet the stated objectives.

By targeting the prescription of anabolic steroids and the treatments approved for their use, Congress has missed the mark. Deterrence and criminal enforcement could be achieved without restricting medically approved treatments. One commentator suggests removing steroids from Schedule III classification but requiring a mandatory "paper trail."²¹¹ Currently, every manufacturer, distributor, or physician who dispenses or conducts research with controlled substances must register with the Attorney General.²¹² This allows the Attorney General to set production quotas for scheduled drugs.²¹³ By removing anabolic steroids from the limitations of Schedule III but requiring a paper trail or record of sales and special duplicate order forms for anabolic steroid distribution, the objectives of Congress can still be met without undue burden on treatments for the elderly. This action would remove the automatic presumption of misprescription on the physician and return the burden of proving illegitimate conduct to the prosecutor.

The best solution may be to eliminate the criminal penalties levied against physicians who prescribe anabolic steroids for uses not recognized by the Secretary of Health and Human Services.²¹⁴ The law should allow physicians to determine when and if steroid treatments can be beneficial to their patients. The unreasonable limitation currently in place eliminates a doctor's professional judgment regarding new discoveries and treatments. Preventing the illegal distribution of steroids by physicians who knowingly violate the law is not

211. See Reddig, *supra* note 50, at 1671 (citing 21 U.S.C. § 823 (1988) and *Anabolic Steroids Control Act of 1990: Hearings on H.R. 4658 Before the Subcomm. on Crime of the House Comm. on the Judiciary*, 101st Cong. (1990) (statement of Rep. Levine explaining that pharmacists and manufacturers are required to keep records of certain sales and special duplicate order forms are issued by the Attorney General through the DEA)).

212. See *id.* (citing 21 U.S.C. § 822(a)(1)-(2) (1990)).

213. See *id.* (citing 12 U.S.C. § 826(a) (1990)).

214. The Anabolic Steroids Control Act makes it a criminal offense for a physician to knowingly distribute steroids for any use other than the treatment of a disease or other recognized medical condition. 21 U.S.C. § 333(e)(1) (1996).

the reason the Anabolic Steroids Control Act was advanced. Congress was aware that illegal steroids were purchased almost entirely on the black market,²¹⁵ and it targeted this problem effectively. Unfortunately, Congress also targeted the persons best qualified to make sound medical decisions about steroid treatment.

The law recognizes that physicians have a duty to use that degree of care, skill, and diligence which is used by ordinarily careful physicians in similar circumstances.²¹⁶ Courts and legislators have long recognized that medical decisions are better left to those trained and educated in that field. By enacting provisions which regulate steroid therapy and prevent the many beneficial uses available for the elderly, Congress has subverted an established principle. Patients must forgo an opportunity for better health and overall well-being because doctors will not prescribe strength-giving hormones. The most important characteristic of the doctor-patient relationship is the absolute trust patients have in their physicians—knowing that they will do everything possible to restore them to good health. Because the concepts of “good faith”²¹⁷ and “legitimate medical purpose”²¹⁸ are inherent limitations restricting the physician’s authority to prescribe medication, the need to criminally prosecute doctors for invalid use of steroids is not necessary.

V. Conclusion

There is a good reason for doctors to be reluctant in treating elderly patients with steroids. Many physicians are not convinced that the benefit of treatment outweighs the risks.²¹⁹ This is exactly the type of analysis patients expect from their doctors. We anticipate that physicians will inform themselves of the qualities and characteristics of potential treatments and of the products which they prescribe for

215. See 135 CONG. REC. S1807-02 (daily ed. Feb. 28, 1989). United Pharmaceuticals of Mexico used to distribute information through the U.S. mail directing people to a location in Mexico where steroids could be purchased. See *id.*

216. See *Zavalas v. Department of Corrections*, 861 P.2d 1026, 1028 (Or. Ct. App. 1992).

217. *Perzik v. Superior Court*, 4 Cal. Rptr. 2d 1, 3 (Cal. App. Ct. 1991).

218. *Id.*

219. See Leonard H. Calabrese et al., *The Effects of Anabolic Steroids and Strength Training on the Human Immune Response*, 21 MED. SCI. SPORTS EXERCISE 386, 386-92 (1989); Committee on Sports Med., *Anabolic Steroids and the Adolescent Athlete*, 83 PEDIATRICS 127, 127 (1989); J.W.M. Lenders et al., *Deleterious Effects of Anabolic Steroids on Serum Lipoproteins, Blood Pressure, and Liver Function in Amateur Body Builders*, 9 INT’L J. SPORTS MED., Feb. 1988, at 19-23.

medical care. We have grown to expect that doctors will exercise this kind of independent judgment, taking into account their knowledge of the patient as well as the proposed medical device or treatment. The patient places primary reliance upon that judgment, and courts generally recognize it as a professional duty.²²⁰ When reluctance to prescribe steroids for an age-related condition is based on medical perception, our reliance on good faith determinations is rewarded. However, when the reluctance is advanced by fear of government inquest, our trust in good faith judgments is eroded.

Most have difficulty contemplating their own approaching reality—that with longevity comes old age. Anabolic steroids and human growth hormone may not be the fountain of youth, but they do hold many promises for the growing population of senior citizens. Many illnesses requiring managed care possibly could be eliminated with hormone treatments. This would not only trigger a social benefit but a financial benefit as well. Congress has created a barrier for the revitalizing effects of steroids for the elderly. By simply allowing physicians to use their professional judgment in administering steroid treatments, congressional concerns about steroid abuse would still be addressed without infringing upon the rights of the elderly to receive proper care.

220. See, e.g., *Buckner v. Allergan Pharm., Inc.*, 400 So. 2d 820, 823 (Fla. Dist. Ct. App. 1981).

**STRENGTHENING THE OLDER AMERICANS
ACT'S LONG-TERM CARE PROTECTION
PROVISIONS: A CALL FOR
FURTHER IMPROVEMENT OF
IMPORTANT STATE OMBUDSMAN PROGRAMS**

Elizabeth B. Herrington

The problem of nursing home abuse is pervasive throughout the country. Nationwide, nursing home residents, as well as family and friends of residents, complain regularly about inadequate care. The federal government has recognized this severe problem and has attempted to address it legislatively through the use of ombudsmen. This legislation arose from the belief that an objective third party was necessary to monitor nursing home residents' care. Theoretically, the ombudsmen receive, investigate, and try to resolve problems or complaints affecting residents in long-term care facilities. Across the country, the role of the nursing home ombudsman varies substantially and reflects the policies established by the state program. Unfortunately, due to such problems as poor staffing and limited authority and autonomy, ombudsmen are not nearly as effective as they should be.

In this note, Ms. Elizabeth Herrington proposes several changes to the current ombudsman program. She emphasizes that the federal government needs to establish a uniform documentation system to see the actual effects of the ombudsman program. In addition, Ms. Herrington asserts that because ombudsman program funding is from the federal government, additional statutes should be implemented to en-

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sure residents in one state receive similar benefits as in another. She proposes that ombudsman programs should use in-house or outside legal counsel as their primary counsel for advice, representation, and consultation. Ms. Herrington also argues that by giving ombudsmen more authority and training and making other necessary improvements, the program will be an effective way to curb elder abuse in nursing homes nationwide.

I. Introduction

Patrick Shane Williams, a young male nurse, was found in the room of a screaming, half-naked eighty-four-year-old Alzheimer's sufferer.¹ An investigation by the nursing home ensued when Williams could offer no plausible explanation for the resident's agitated condition.²

Confronted with incriminating evidence, Williams confessed his wrongdoing to receive a plea bargain from the state.³ During his employment as a night nurse, he had raped again and again victims ranging from 61 to 102 years old.⁴ For three years at the Meadow Manor nursing home in Taylorville, Illinois, Williams had raped several women, all of whom were confused or demented.⁵ Although several complaints had been made about him, no one listened to the victimized women's pleas for help.⁶ Until this final incident, Williams maintained the women were delusional and no further investigation had occurred.⁷

Many complaints in nursing homes do not reach the outrageous abuse level of the Williams case, nor do the majority involve sexual abuse. According to recent data, however, the problem is extensive; the state-legislated Illinois Department on Aging Elder Abuse Pro-

1. See Jennifer Foote, *Sex Abuse Easy to Hide, Difficult to Prosecute*, PLAIN DEALER (Cleveland, Ohio), May 15, 1995, at 4E.

2. See *id.*

3. See *id.*

4. See *id.*

5. See *id.*

6. See *id.*

7. See Doug Finke, *Area Nursing Home Fined for Not Having Equipment*, THE STATE JOURNAL-REG. (Springfield, Ill.), June 28, 1995, at 11. The nursing home involved is the subject of several civil lawsuits filed by relatives of nursing home patients allegedly raped by Williams. Williams was sentenced February 22, 1995, to 10 years in prison after pleading guilty to aggravated criminal sexual abuse and attempted aggravated assault against the 84-year-old woman involved in the case. *Id.*

gram assisted nearly 5000 elder abuse victims in fiscal year 1995.⁸ The majority of these reports involved financial exploitation, which is highly associated with emotional abuse.⁹

Many experts believe these complaint rates are not indicative of the truly high incidence of resident negligence and abuse.¹⁰ The types of possible abuse also vary greatly among facilities. Once in the homes, many residents have no one to monitor their care closely. Choosing the wrong nursing home, therefore, may possibly consign a resident to physical and emotional hardships, including premature dependency or even premature death.¹¹ An attorney or family member may be called upon not only to counsel an elderly person on long-term needs, but also to assist that person in choosing providers.¹²

The federal government has recognized this severe problem and has attempted to address it legislatively.¹³ Such growing awareness of the need for protection in nursing homes led to the belief that a neutral third party must keep an objective eye on patients' care.¹⁴ As a result of these findings, the Long-Term Care Ombudsman Program was created by the federal government in the early 1970s.¹⁵ In a 1975 statement, former Commissioner on Aging, Arthur S. Flemming, warned that all the new nursing home regulations would be of little help "unless our communities are organized in such a manner that

8. See 1996 ILL. DEP'T ON AGING ANN. REP. 3.

9. See *id.*

10. See MARIA R. PIPPIDIS & KAREN F. STEIN, NATIONAL AGING RESOURCE CTR. ON ELDER ABUSE, ELDER ABUSE AND NEGLECT: A SYNTHESIS OF ELDER ABUSE RESEARCH 1 (1990) [hereinafter ELDER ABUSE]; Susan J. Hemp, Note, *The Right to a Remedy: When Should an Abused Nursing Home Resident Sue?*, 2 ELDER L.J. 195, 197 (1995).

11. See *Nursing Homes. When a Loved One Needs Care. In Search of the Right Home (Nursing Homes: Part I)*, CONSUMER REP., Aug. 1995, at 518, 518 [hereinafter *Nursing Homes*].

12. See JOAN M. KRAUSKOPF ET AL., ELDERLAW: ADVOCACY FOR THE AGING § 12.58 (West 2d ed. 1993).

13. See INSTITUTE OF MED., REAL PEOPLE, REAL PROBLEMS: AN EVALUATION OF THE LONG-TERM CARE OMBUDSMAN PROGRAMS OF THE OLDER AMERICANS ACT 44 (1995).

14. See *id.* at 41.

15. See *id.* at 2. Although current ombuds practitioners are both male and female, the majority of nursing home ombuds practitioners are female. When referring to the ombuds position, however, this note will use the term "ombudsman" to encompass both females and males serving in this capacity. This is due to the fact that historically, those who served in the ombuds office were male and were titled "ombudsmen." See Shirley A. Wiegand, *A Just and Lasting Peace: Supplanting Mediation with the Ombuds Model*, 12 OHIO ST. J. ON DISP. RESOL. 95 (1996). This does not implicate that males are more frequently utilized or have been found better qualified for such work.

new laws and new regulations are utilized to deal with the individual complaints of older persons who are living in nursing homes."¹⁶

In 1993, the Institute of Medicine began an evaluation of the long-term care ombudsman programs and made various recommendations.¹⁷ Many problems, however, still persist with the manner in which the program's objectives are currently implemented, and the federal government has not yet made needed changes. Although federally mandated, the funding and staffing of ombudsman program offices are regulated by the states, as are duties and powers delegated to the individual offices.¹⁸ As a result, states still vary in the role and responsibilities they place upon the ombudsmen.¹⁹ Many elder law advocates agree that although ombudsman programs in nursing facilities may have the potential to be a real force in modern quality assurance, their role to date has been ambiguous and interpreted differently by the majority of states.²⁰ Numerous barriers today still impede their maximum effectiveness.²¹

In August 1995, Consumer Reports performed an undercover investigation of fifty-three nursing homes and twenty-seven assisted living and board-and-care facilities across the country.²² Among other deficiencies, the findings of this investigation showed that the quality of care at thousands of this nation's nursing homes is "poor or questionable at best" and that government agencies set up to assist the public, such as area agencies on aging and state and local departments

16. 1993 ILL. DEP'T ON AGING LONG-TERM CARE OMBUDSMAN PROGRAM ANN. REP. 1.

17. See INSTITUTE OF MED., *supra* note 13, at 2. This study was conducted by an Institute of Medicine appointed 16-member expert committee comprising individuals recognized for their long-term care expertise and other relevant backgrounds. The committee engaged in many fact-finding activities to develop its evaluation. See *id.*

18. See *id.* at 99-100. States and localities vary in the manner in which they comply with both the actual law and spirit of these programs. In Illinois, of the ombudsmen surveyed in preparation for this note, few conducted training of their visiting volunteers identically. Almost every area varied somewhat in the manner in which they carried out their programs and recruited their volunteers, although many indicated they required 14 1/2 hours of initial training for area ombudsmen.

19. See *id.* at 87.

20. See generally GEORGE D. POZGAR, LONG-TERM CARE AND THE LAW, A LEGAL GUIDE FOR HEALTH CARE PROFESSIONALS (1992).

21. See INSTITUTE OF MED., *supra* note 13, at 147.

22. See *Nursing Homes*, *supra* note 11, at 518. The article was based on a year-long investigation into the long-term care system, during which a senior editor, posing as a daughter whose mother needed care, visited the nursing homes and assisted-living facilities, requested assistance from government and other referral agencies, and analyzed thousands of inspection reports from the Health Care Financing Administration. See *id.*

of elder affairs, provide "little or no useful, concrete information about specific facilities."²³ Over twenty years after the inception of the long-term care ombudsman programs, a question remains as to whether the programs constitute a real solution to the nursing home dilemmas across the country and, if so, how such programs may reach their maximum effect. In regard to ombudsman programs, Flemming's warning has proven to be justified.

This note proposes that the currently operated ombudsman programs are not effective and, therefore, must be examined and altered in order to rectify the problems existing in nursing homes today. The examination involves an in-depth look at the background of the programs, the function of ombudsmen, and their roles in nursing facilities. The author reviews the program at the national level and more specifically at the Illinois state level. The author analyzes the effectiveness of the current ombudsman programs as a remedy to nursing home complaints and the barriers to the program's ultimate success. Finally, this note proposes changes in the role of the ombudsman, improvement in the structure of the program, access to legal remedies, and more funding to support the program.

II. Background

A. The Need for Monitoring Nursing Homes

1. THE GRAYING AMERICAN POPULATION

The need for nursing home care has risen, causing a corresponding increase in the numbers of facilities established in this country.²⁴ In the United States today, 12.6% of the population is at least sixty-five

23. *Id.* at 518-19.

24. See Gerard Mantese et al., *Issues Relating to the Care of the Elderly in Nursing Homes*, 73 MICH. B.J. 176, 176 (1994).

A nursing home is one type of institutional living arrangement in which residents—usually older persons who cannot care for themselves—pay a fee to live in a facility which provides shelter, food, medical care, and assistance in daily functions, as needed. Many different living options may meet part or all of this definition, including home health care programs, adult day care centers, elderly housing, retirement villages, nursing homes, and hospices. . . . Another term often used is long-term care, which refers to prolonged health care and domestic services provided to people who are unable to do many things for themselves.

Id. The term "nursing home" encompasses this type of service as well and will be used throughout this note to refer generally to these various care options.

years old, and 1.3% is eighty-five and older.²⁵ According to the Population Reference Bureau, by the year 2020, the number of those at least sixty-five is expected to reach 52 million people, or 17.7% of the U.S. population.²⁶ By the year 2025, estimates predict an American population with approximately half as many teenagers as people over sixty-five.²⁷ By 2030, the number of eighty-five year olds may reach 2.2% of the population.²⁸

In 1980 approximately 1.2 million nursing home residents lived in the United States.²⁹ In 1990, there were approximately 1.5 million people³⁰ living in thousands of nursing homes in the United States. There is a 50% likelihood that a person will, at some time, be placed in a nursing home.³¹ Furthermore, the total number of nursing home residents is predicted to grow from an estimated 3.4 million in 1992³² to 4.8 million by 2050.³³

Two distinct groups of elderly residents have been recognized as needing nursing home care.³⁴ One group is made up of persons recovering in a skilled nursing facility after an illness, broken bone, or similar condition.³⁵ These people reside in the facility a relatively short time and are soon discharged, or their condition may worsen immediately and they die. The other group of residents more likely suffers from many chronic illnesses and may reside in the homes for

25. See Theresamarie Mantese & Gerard Mantese, *Nursing Homes and the Care of the Elderly*, 51 J. Mo. B. 155, 155 (1995).

26. See Bruce C. Vladek et al., *The Changing Face of Long-Term Care*, HEALTH CARE FIN. REV., Summer 1993, at 6.

27. See Gerard Mantese et al., *supra* note 24, at 176.

28. See POPULATION REFERENCE BUREAU, POPULATION REFERENCE HANDBOOK (1994).

29. See Mantese et al., *supra* note 24, at 176.

30. See CHAIRMAN OF THE SUBCOMM. ON HEALTH & LONG-TERM CARE, HOUSE SELECT COMM. ON AGING, 102D CONG., 1ST SESS., PROTECTING AMERICA'S ABUSED ELDERLY: THE NEED FOR CONGRESSIONAL ACTION 1 (Comm. Print 1991) [hereinafter PROTECTING].

31. See Mantese et al., *supra* note 24, at 176.

32. See PROTECTING, *supra* note 30, at 148.

33. See Mantese et al., *supra* note 24, at 176. Therefore, the use of nursing homes is expected to grow by 76% in the next 30 years. See *id.*; PROTECTING, *supra* note 30, at 176. Such changing character of the nursing home population and the fact there are relatively very few caregiver families that exist today has been well recognized among elder scholars. See Jan Ellen Rein, *Preserving Dignity and Self-Determination of the Elderly in the Face of Competing Interests and Grim Alternatives: A Proposal for Statutory Refocus and Reform*, 60 GEO. WASH. L. REV. 1818, 1820 (1992). Professor Rein notes that as projected, nearly one-fourth of all Americans will be age 65 or older, and one-fourth of those Americans will be placed in a nursing home at some time. *Id.*

34. See KRAUSKOPF ET AL., *supra* note 12, § 12.2.

35. See *id.*

an extended period of time, often years.³⁶ The average long-term resident stays in a facility more than two years.³⁷

Clearly, the changing character of society requires preparation for the pressure that will be placed on our care resources. To ensure that humane care for the needs of our aging population is provided, nursing homes will need more monitoring.

2. ILLINOIS NURSING HOME DEMOGRAPHICS

Each state has its own system of nursing facilities available for its aging population. In 1994, more than 100,000 individuals resided in Illinois nursing homes.³⁸ Thirty-eight percent of these residents are over eighty-five years old, 29% are between the ages of seventy-five and eighty-four, and 13% are between sixty and seventy-four years of age.³⁹

In 1994, Illinois had 1220 licensed long-term care facilities.⁴⁰ Of these, over two-thirds were privately owned by individuals or corporations.⁴¹ The remaining one-third was owned by religious, charitable, or fraternal groups.⁴² A small fraction of facilities was owned either by the state, federal, or local county governments.⁴³ Like many other states and their respective health departments, all of these Illinois facilities receive an annual licensure inspection by the Illinois Department of Public Health to monitor the quality of the care rendered.

3. THE PROBLEM OF ABUSE NATIONWIDE

The special needs of the dependent elderly in nursing facilities heightens the concern about the quality of their care. Although federal and state regulatory responses to abuse grew and ultimately

36. *See id.*

37. *See id.*

38. *See* 1994 ILL. DEP'T OF PUB. HEALTH LONG-TERM CARE FACILITY STATEWIDE SUMMARY PROFILE (Sept. 1995). When this note was written, these were the most recent compilations of Illinois statistics available. As of December 31, 1994, there were 103,108 residents in Illinois nursing homes. *See id.*

39. *See id.*

40. *See id.* This figure grew from 1119 in 1993, exemplifying the trend Illinois is showing in nursing care growth. *See* 1993 ILL. DEP'T ON AGING LONG-TERM CARE OMBUDSMAN PROGRAM ANN. REP. 8 (1994).

41. *See* ALTERNATIVES FOR THE OLDER ADULT, INC., YOUR GUIDE TO SELECTING A NURSING HOME 4 (1995).

42. *See id.*

43. *See id.* The exact figures cited by Alternatives for the Older Adult are as follows: 67% privately owned by individuals or corporations, 28% not for profit owned by religious, charitable, or fraternal groups, 5% public operated by the state, federal, or local county governments. *See id.*

peaked in the 1970s,⁴⁴ the problem still runs rampant in nursing homes nationwide.⁴⁵ Abuse may encompass a wide range of actions by nursing home staff, but has been specifically defined by one study as "the infliction of physical pain, injury or physical coercion."⁴⁶

"Elderly persons may suffer a series of losses [including] health, mobility, independence, faculties, and personal dignity."⁴⁷ Many nursing home residents require assisted feeding, bathing, and constant attention.⁴⁸ "Almost half . . . have senile dementia or chronic organic brain syndrome."⁴⁹ Nearly half of people over eighty-five have Alzheimer's disease.⁵⁰ Often residents suffer from "heart conditions, . . . visual impairments (including cataracts), urinary problems, . . . cancer or they might have had a stroke."⁵¹ Residents' various health problems may require constant care such as assistance with dressing, bathing, or getting in or out of bed or a chair.⁵²

According to the General Accounting Office (GAO), while these residents are becoming increasingly dependent, they are ironically given less care.⁵³ Nationwide, nursing home residents, as well as their family and friends, complain regularly about the inadequate care many residents receive in their nursing homes.⁵⁴ More than 197,820 total complaints were received in fifty states in 1993,⁵⁵ and nursing facility investigations have regularly found appalling conditions.⁵⁶ Federal review committees have recognized that high quality care still eludes many nursing homes today.⁵⁷

44. See Hemp, *supra* note 10, at 197.

45. See *id.* (citing COMMITTEE ON NURSING HOME REGULATION, INSTITUTE OF MED., IMPROVING THE QUALITY OF CARE IN NURSING HOMES 3 (1986)).

46. See ELDER ABUSE, *supra* note 10, at 2.

47. Mantese & Mantese, *supra* note 25, at 177.

48. See *id.* "Approximately 91% of all nursing home residents require assistance with bathing, and over half have bowel or urinary incontinence." *Id.*

49. *Id.*

50. See *id.* Alzheimer's is "described as an organic mental disorder caused by a progressive degeneration of brain cells." *Id.*

51. *Id.*

52. See PROTECTING, *supra* note 30, at 2.

53. See GENERAL ACCOUNTING OFFICE, MEDICAID AND NURSING HOME CARE: COST INCREASES AND THE NEED FOR SERVICES ARE CREATING PROBLEMS FOR THE STATES AND THE ELDERLY 26-27 (1983).

54. See INSTITUTE OF MED., *supra* note 13, at 77.

55. See *id.*

56. See *Nursing Homes*, *supra* note 11; *Today* (NBC television broadcast, Aug. 23, 1995). Interviewee Trudy Lieberman of Consumer Reports stated that through a survey of fifty nursing homes in eight states around the country she found "a great deal of neglect and poor care given to the residents of nursing homes." *Id.*

57. See GENERAL ACCOUNTING OFFICE, MEDICARE AND MEDICAID: STRONGER ENFORCEMENT OF NURSING HOME REQUIREMENTS NEEDED 3 (1987) [hereinafter MEDI-

The House Subcommittees on Health and Long-Term Care have provided statistics regarding the abuse of institutionalized elderly.⁵⁸ Approximately 35% of nursing home residents may be denied necessary medical and nursing care, 20% may not be provided a safe, clean environment at the facility, and 15% may be subjected to physical or sexual abuse.⁵⁹ The majority of negligence claims, however, come from injuries that occur when residents fall or wander away from staff members.⁶⁰

In a 1990 survey of 577 nurses and nurses' aides in long-term care facilities, four out of five respondents had seen at least one incident of psychological abuse of a resident in the preceding year, with the most prevalent form being yelling, swearing, or insulting a patient in anger.⁶¹ Half of the respondents observed swearing at or insulting patients.⁶² One-fifth of survey respondents reported physical abuse by using unnecessary physical restraints.⁶³ One in six said they saw nursing home staff push, pinch, or grab a resident in some manner.⁶⁴

Surprisingly, 10% of the respondents from the nursing homes reported that they themselves had committed one or more physically abusive acts.⁶⁵ Almost 40% of these same respondents reported that they had committed at least one psychologically abusive act within

CARE AND MEDICAID] (finding that approximately one-third of nursing homes failed to meet health or safety requirements in three consecutive inspections).

58. See PROTECTING, *supra* note 30, at 5-6.

59. See *id.* In this congressional survey:

9 of 10 require assistance bathing;

7 of 10 require assistance dressing;

1 of 2 require assistance going to the bathroom;

1 of 3 require assistance eating;

4 of 10 have trouble or cannot control their bowels or bladders.

Id. at 2.

60. See Marshall B. Kapp, *Malpractice Liability in Long-Term Care: A Changing Environment*, 24 CREIGHTON L. REV. 1235, 1242 (1991).

61. See Karl Pillemer & David W. Moore, *Abuse of Patients in Nursing Homes: Findings from a Survey of Staff*, 29 GERONTOLOGIST 314, 317 (1989). Pillemer and Moore conducted a phone survey of 577 respondents, "61% of which were nursing aides, 20% were licensed practical nurses, and 19% were registered nurses." *Id.* at 315.

62. See *id.* at 317. The majority of these had reported seeing abuse indicated that it had occurred more than once. Of the 577 respondents, "23% had witnessed other staff isolating a patient beyond what was needed to control him or her." Fifteen percent reported threats to residents, and thirteen percent reported witnessing denial of food or privileges to residents. See *id.*

63. See *id.*

64. See *id.*

65. See *id.*

the preceding year.⁶⁶ The study results suggest that maltreatment of elderly in nursing homes may occur as a common part of institutional life rather than merely in isolated, well-publicized incidents.

A variety of staff characteristics contribute to the level of abuse that occurs. Studies have shown that lower quality care tends to be provided by staff who are younger, less well educated, have fewer years of experience working in nursing homes, and are nursing aides rather than nurses.⁶⁷ None of these variables, however, relate to any particular form of abuse.⁶⁸

Instead of psychological or physical abuse by a staff member, sometimes a resident's relative is the offender.⁶⁹ Relatives have been found stealing from the resident's bank account, as well as denying the elderly relative an opportunity to object to being placed in the home against his or her will.⁷⁰ Because abuse may come from the only source of human contact available to an elderly victim, the abuse is especially egregious and unfair. The elderly may be at the mercy of these people they trust and are not able to actively seek out alternate help.⁷¹ There clearly needs to be a remedy available for abuses of the vulnerable elderly, a remedy within the homes themselves.

66. See *id.* This study also asked the facility staff members what characteristics are most prevalent among the physically and psychologically abusive staff people they observed. The characteristics included: (1) reporting frequent thoughts of quitting; (2) believing that "patients are like children"; (3) reporting high burn out; (4) reporting high conflict with patients; (5) complaining of stress in their personal lives. Characteristics found not to be explanative of abusive behaviors included: size and patient cost of the facility; age, experience, and education of the staff person; and the type of staff. See *id.* at 318.

67. See T.M. Baltz & J.G. Turner, *Development and Analysis of a Nursing Home Aid Screening Device*, 17 GERONTOLOGIST 66, 67 (1977).

68. See Pillemer & Moore, *supra* note 61, at 318.

69. See ELDER ABUSE, *supra* note 10, at 15.

70. Telephone Interview with Annette Scherer, Illinois Substate Ombudsman from Peoria, Ill. (Jan. 16, 1995).

71. Note the House Subcommittee on Health and Long-Term Care determined only one out of every eight cases of elder abuse is reported. This is even much lower than the estimate that one out of every three cases of child abuse is reported. A House Subcommittee's 1990 report reflects a decrease in reporting from the 1981 House Report, which estimated that one out of every five cases of elder abuse is reported. CHAIRMAN OF HOUSE SUBCOMM. ON HEALTH AND LONG-TERM CARE OF THE SELECT COMM. ON AGING, 1ST CONG., 2D SESS., REPORT ON ELDER ABUSE: A DECADE OF SHAME AND INACTION 1-28 (Comm. Print 1990).

B. The United States' Ombudsman Model Remedy

1. ORIGIN OF THE OMBUDSMAN MECHANISM

The term "ombudsman" is derived from an 1809 concept of the Swedish Parliament and originally designated a person who would listen to complaints about the government and attempt to resolve the disputes in an impartial manner.⁷² Throughout its various public agencies and private organizations, "the United States has more ombudspersons than anywhere else in the world."⁷³ Some ombudspersons are also used for dispute resolution settings other than traditional government functions.⁷⁴

Interestingly, the ombudsman dispute resolution mechanism has undergone substantial changes since implemented, and the current American ombudsman model bears little similarity to the classic Swedish model.⁷⁵ However, regardless of the changes to the original ombudsman model, the United States has clearly embraced the ombuds idea in the past twenty-five years, including its usage in nursing facilities.⁷⁶

72. See Wiegand, *supra* note 15, at 98. Although the ombudsman office originated in Sweden in the 18th century, "[t]he name 'ombudsman' derived from practices of medieval Germanic tribes." Under the decentralized, informal governments of these tribes, one of the punishments available for wrongdoers was to pay a fine. The lawbreaker's family was expected to pay such fine to the victim's family. A neutral third person collected the fine and delivered it to the victim's family to avoid further conflict. "Imagine a Viking with horned helmet marching up to the door of a medieval Nordic hut. The man of the house answers the call and then shouts back to his family: 'It's the man about the fine: the Ombudsman.'" *Id.* (citing Stanley V. Anderson, OMBUDSMAN PAPERS: AMERICAN EXPERIENCE AND PROPOSALS 2 (1969)). "Om" means "about"; "bud" originates from "offering" or "bribe"; one who visits regarding an offering is an ombudsman. The word has since come to mean any type of agent. *Id.*

73. *Id.* at 102 (footnote omitted). Numbers of ombudsmen throughout these organizations are difficult to estimate exactly. As of 1987, some examples of their implementation frequency included three dozen newspapers and nearly 4000 hospitals. Also, a great many businesses have client or consumer complaint offices which employ ombudsmen. Mary P. Rowe, *The Corporate Ombudsman: An Overview and Analysis*, 3 NEGOTIATION J. 127, 139 (1987).

74. See John M. Eckert et al., *Training and Orientation of Certified Ombudsperson Volunteers for Long-Term Care Facilities*, EDUC. GERONTOLOGY 743, 744 (1993). Mr. Eckert, an Illinois substate ombudsman from Evanston, Illinois, noted in his article that some of the newer roles for ombudspersons include helping mental patients, hospital psychiatric patients, and vocational rehabilitation clients. See *id.*

75. See Wiegand, *supra* note 15, at 96. According to Professor Wiegand, it is fair to say that few, if any, of the American ombuds offices exactly fit the classical model of the Swedish ombudsman. See *id.* at 103.

76. See *id.* at 103-10 for a history of the implementation of ombuds offices into federal and state governments over the past 25 years.

2. THE FEDERAL NURSING HOME OMBUDSMAN DEVELOPMENT

Responding to increasing concerns about the quality of nursing facilities, the care provided in them, and the government's ability to regulate these facilities, former President Richard Nixon proposed an eight-point initiative in 1971 to improve conditions in the nation's nursing facilities.⁷⁷ One point called for using state ombudsman investigative units to improve quality of care by focusing exclusively on the resident, in order to compensate for the limitations of regulations and other quality assurance strategies.⁷⁸ Then, in 1972, the Department of Health, Education, and Welfare (DHEW) gave five contracts for states to implement nursing facility ombudsman programs.⁷⁹ In 1973, due to a DHEW reorganization, the federal Administration on Aging (AOA) received administrative responsibility for the five experimental ombudsman programs.⁸⁰ Under the guidance of the AOA, the five programs were placed "within the infrastructure of the 'aging network' of state and area agencies on aging."⁸¹ "This network, through the [Older Americans Act (OAA)]⁸² . . . is authorized to foster the development . . . of supportive services for individuals 60 years of age or older."⁸³

"The 1978 amendments to the OAA provided the ombudsman program with federal enabling legislation by requiring each state to establish an ombudsman program."⁸⁴ This federal "mandate instructed ombudsman programs to investigate complaints; train and supervise volunteers; monitor the development of federal, state and local laws, regulations, and policies and provide public agencies with information about problems faced by [nursing facility] . . . residents."⁸⁵ The federal government, however, provided limited oversight and gave the states great flexibility to administer this mandate as they de-

77. See INSTITUTE OF MED., *supra* note 13, at 43.

78. See *id.*

79. See *id.* These demonstration programs were in Michigan, Pennsylvania, South Carolina, Wisconsin, and Idaho.

80. See *id.* Assignment of such programs "was consistent with AOA's statutory responsibilities for advocacy and coordination on behalf of the elderly at the federal level." *Id.*

81. *Id.*

82. Older Americans Act of 1965, Pub. L. No. 89-73, 79 Stat. 218 (codified as amended in scattered sections of 42 U.S.C.).

83. INSTITUTE OF MED., *supra* note 13, at 43.

84. *Id.* at 44.

85. *Id.*

sired.⁸⁶ Therefore, the state programs have taken on diverse roles, assumed different tasks, and developed differently.⁸⁷

In 1981, the program grew when Congress added oversight of "board and care" facilities to the ombudsmen's required responsibilities.⁸⁸ At that time, the ombudsman program's name changed from "Nursing Home Ombudsman" to "Long-Term Care Ombudsman" but federal funding was not increased with the expansion.⁸⁹

The idea of the volunteer ombudsman gained acceptance within communities nationwide. A 1986 Institute of Medicine report⁹⁰ documented an investigation which found resident abuses occurring nationwide, many of which violated rights of privacy, informed consent, and access to legal advocacy services. After issuance of this report, Congress passed landmark federal nursing home reform legislation in 1987.⁹¹ The Omnibus Budget Reconciliation Act,⁹² known as OBRA '87, contained two major legislative changes which attempted to unify states' compliance and their ability to reach and serve residents.⁹³ First, the Nursing Home Quality Reform Act mandated that nursing facility residents have "direct and immediate access to ombudspersons when protection and advocacy services become necessary."⁹⁴ Second, "the 1987 reauthorization of the OAA charged states to guarantee ombudsmen access to facilities and patient records," as well as provide more legal services for the program's use.⁹⁵ With this legislation, "[s]tate ombudsmen were also given the official authority to designate local programs to carry out ombudsman functions."⁹⁶ "Duly

86. *See id.*

87. All 50 states currently create ombudsman programs for their nursing facilities by statute, although these programs vary greatly in many aspects. *See id.* at 45-46.

88. *See id.*

89. *See id.* at 44-45.

90. INSTITUTE OF MED., IMPROVING THE QUALITY OF CARE IN NURSING HOMES (1986).

91. *See* INSTITUTE OF MED., *supra* note 13, at 45.

92. 42 U.S.C. § 3058 (1994).

93. *See* INSTITUTE OF MED., *supra* note 13, at 45.

94. *Id.* Note that the Institute of Medicine, under contract with the Administration on Aging, produced a comprehensive study of nursing home regulations and policies, with recommendations for reform. *See id.* at v. Many of the Institute of Medicine study's proposals were adopted by Congress in OBRA '87, which was "widely hailed as the most significant federal legislation affecting nursing homes since the creation of the Medicare and Medicaid programs in 1965." Joel M. Hamme, *Federal Nursing Home Reform: An Overview*, in THE LONG TERM CARE HANDBOOK: LEGAL, OPERATIONAL & FINANCIAL GUIDEPOSTS 9, 9 (1991).

95. INSTITUTE OF MED., *supra* note 13, at 45.

96. *Id.*

authorized employees and volunteers of these programs were then considered 'representatives' of the state ombudsman with all the ombudsman's rights and privileges accorded to them."⁹⁷

OBRA '87 legislation also codified specific high quality standards and emphasized meeting nursing home residents' needs.⁹⁸ Among other remedial provisions, OBRA established resident care standards, created a federal resident's "bill of rights" to be monitored by ombudsmen and residents themselves, and required a sharp reduction in the use of restraints on residents.⁹⁹

Congress then adopted regulations to enact OBRA '87 in 1991.¹⁰⁰ OAA amendments made in 1992, however, are the most recent regulations pertaining to ombudsmen duties.¹⁰¹ They highlight the role of local ombudsman programs and the state ombudsman's role as an advocate and agent for systemwide change in the treatment of elders in nursing facilities nationwide. Importantly, the majority of nursing facilities are Medicare and Medicaid participants and therefore must comply with the Nursing Home Reform Act and with OBRA's implementing regulations in order to receive compensation for residents backed by these two federal funds.¹⁰²

The ombudsman programs today operate in all fifty states, the District of Columbia, and Puerto Rico.¹⁰³ Some individual state statutes supplement and enhance the federal mandate of OBRA.¹⁰⁴ There are approximately 12,000 trained and state-licensed volunteers nationwide serving as long-term care ombudsmen under state run programs funded by the federal government and administered by the federal AOA.¹⁰⁵ The AOA reports that more than 218,000 complaints were

97. *Id.*

98. See Steven M. Levin et al., *Protecting the Rights of Nursing Home Residents Through Litigation*, 84 ILL. B.J. 36, 36-37 (1996).

99. See *id.*

100. See *id.* These codified standards then changed expectations from a goal of minimum maintenance of residents to the "highest practicable physical, mental, and psychosocial well-being" of individual nursing home residents. *Id.* (citing 42 C.F.R. § 483.25 of OBRA regulations).

101. See Older Americans Act Amendments of 1992, Pub. L. No. 102-375, 106 Stat. 1195.

102. See 42 U.S.C. §§ 1395(i)(3)(a)-(h), 1396(r)(a)-(h) (Supp. 1994).

103. See INSTITUTE OF MED., *supra* note 13, at 45.

104. See, e.g., CAL. WELF. & INST. CODE § 9700 (West 1995); FLA. STAT. ANN. § 415.106 (West 1997); MASS. ANN. GEN. LAWS ch. 19A, §§ 27-35 (Law. Coop. 1988).

105. See Robert W. Stock, *On Patrol to Help Those Who Cannot Help Themselves*, N.Y. TIMES, Oct. 24, 1996, at C4.

made by nursing home residents and their families to ombudsman programs in 1995, twice the figure reported in 1987.¹⁰⁶

III. Analysis

A. Implementation of Nursing Home Ombudsman Programs

1. THE INTENDED ROLE OF THE NURSING HOME OMBUDSMAN

A nursing home ombudsman, in theory, trouble-shoots or mediates unresolved problems between residents or their families and a nursing facility.¹⁰⁷ Researchers have concluded, however, that there is no exact job description accurately reflecting the duties of the ombudsman in the nursing home.¹⁰⁸ According to many definitions, good ombudsmen are objective mediators and problem solvers, but their goals may vary.¹⁰⁹ The role of nursing home ombudsmen combines this neutrality with the objective of advocacy and representation of residents' interests over those of other parties involved.¹¹⁰ Abuse of their duty of neutrality can cause them to forfeit the trust and respect of the constituencies they serve. Theoretically, the ombudsmen receive, investigate, and try to resolve problems or complaints affecting residents in long-term care facilities. Ombudsmen, however, can neither make, set, nor change laws, nor can they independently enforce particular recommendations.¹¹¹

The OAA does not specifically define the ombudsmen's role within a nursing facility.¹¹² Various theories have been posited concerning the functions of the ombudsmen once they reach the homes. Interviews with ombudsmen suggest that the positions may be inherently tension filled.¹¹³ For example, at times the "ombudsmen must often be highly critical of facilities and agencies under their review; on the other hand, they must be able to work cooperatively with these parties to ensure the resident is well-served."¹¹⁴ Ombudsmen also

106. See *id.*

107. See *id.*

108. See Wiegand, *supra* note 15, at 99.

109. See *id.*

110. See INSTITUTE OF MED., *supra* note 13, at 45.

111. See Jeffrey S. Kahana, *Reevaluating the Nursing Home Ombudsman's Role with a View Toward Expanding the Concept of Dispute Resolution*, 1994 J. DISP. RESOL. 217, 217 (1994).

112. See INSTITUTE OF MED., *supra* note 13, at 62.

113. Telephone Interview with Kathleen Allison, Illinois Substate Ombudsman from Bloomington, Ill. (Jan. 30, 1996).

114. INSTITUTE OF MED., *supra* note 13, at 45.

must interact with an extensive array of program administrators and policy makers regarding laws, regulations, and policy and program instructions.¹¹⁵

The OAA requires an ombudsman to identify, investigate, and resolve individual complaints relating to the residents of nursing homes.¹¹⁶ Research reveals, however, at least three different roles which ombudsmen may play within the nursing home: friend, advocate, and mediator.¹¹⁷

a. Therapeutic Role: Residents' Helpers First, ombudsmen may play a therapeutic or developmental role in the homes.¹¹⁸ Such a role may include education of residents and families of residents, or merely serving as a helper to the resident.¹¹⁹ The ombudsman who falls into this category is seen as providing emotional support to individual residents, thereby facilitating residents' adjustment in the nursing home. In this role, volunteer ombudsmen are often available to facilitate discussions about the merits of different nursing homes in their area to help concerned families make informed decisions about nursing home placement for a loved one.¹²⁰

b. Advocate Role: Active Legal Service Provider The ombudsman may act also as an active advocate on behalf of residents. Those states most closely adhering to the "legal advocate" philosophy emphasize the 1987 and 1992 amendments to the OAA which add the requirement that adequate legal counsel be available to the ombudsman program.¹²¹

115. See *id.* at 66.

116. See 42 U.S.C. § 3058(a)(3)(A) (1994).

117. See Kahana, *supra* note 111, at 228.

118. See Abraham Monk & Lenard W. Kaye, *The Ombudsman Volunteer in the Nursing Home: Differential Role Perceptions of Patient Representatives for the Institutionalized Aged*, 22 GERONTOLOGIST 194, 195 (1984).

119. Telephone Interview with Kathleen Allison, Illinois Substate Ombudsman from Bloomington, Ill. (June 27, 1997). Although residents and their families sometimes do become an ombudsman's friend, their role primarily remains more as a "helper" to residents rather than a friend. See *id.*

120. See generally *Nursing Homes*, *supra* note 11. Some ombudsmen appear more willing to implicate wrongdoing by certain nursing facilities than others. According to the report, Sister Gloria Maher, an ombudsman in New Orleans, stated, "I don't tell much about the bad [nursing homes]." *Id.* This suggests that in this role ombudsmen may sometimes not be as effective as in their other roles.

121. The states are required by the OAA amendments to provide the following:

The Vermont Long-Term Care Ombudsman Program is representative of this theory.¹²² Their program is part of Vermont Legal Aid and has continuous direct legal support, more so than some other states.¹²³ The Florida Program also relies on a full-time in-house counsel who actually specializes in long-term care issues.¹²⁴ Illinois, in contrast, does not directly utilize this model and does not have continuous direct legal support for complaints.¹²⁵

Although in need of legal services, most programs do not contain this component.¹²⁶ The legal needs of the ombudsman are usually of two types: complaint investigation coupled with daily advocacy, and program issues.¹²⁷ Legal issues often pervade a nursing home resident's life with respect to quality of benefits such as Medicare or Social Security.¹²⁸ A resident's benefits can be easily reduced by the facility administering them.

Although the state offices of the long-term care ombudsman do not seem to be litigation-prone organizations, they sometimes defend the rights of those living in a nursing home. For example, in 1994, nursing home residents assisted by the District of Columbia Office of the Long-Term Care Ombudsman filed a class action suit against the District for its failure to fully implement the Nursing Home Reform Law of 1987.¹²⁹ The previous year, another Washington D.C. ombudsman filed suit in order to gain the right to inspect a District

(1)(A) *adequate legal counsel is available*, and is able, without conflict of interest, to— (i) provide advice and consultation needed to protect the health, safety, welfare, and rights of residents; and (ii) assist the Ombudsman and representative of the Office in the performance of the official duties of the Ombudsman and representatives; and (B) legal representation is provided to any representative of the Office against whom suit or other legal action is brought or threatened to be brought in connection with the performance of the official duties of the Ombudsman or such a representative; and (2) the Office pursues administrative, legal, and other appropriate remedies on behalf of resident.

42 U.S.C. § 3058g(g) (1994) (emphasis added).

122. See Lori Owen & Michael R. Schuster, *Legal Support to Long-Term Care Ombudsman Programs: Seven Years Later*, 28 CLEARINGHOUSE REV. 617, 619 (1994).

123. See *id.*

124. See *id.* at 618.

125. See *id.* at 620.

126. See *id.* at 619. Many state ombudsman programs are housed within state agencies and therefore rely on the Office of the Attorney General for both legal advice and representation rather than actually containing legal services within their program. See *id.*

127. See *id.* at 617.

128. See *id.* at 617-18.

129. See *Newman v. Kelly*, 848 F. Supp. 228, 228 (D.C. Cir. 1994).

facility's records.¹³⁰ In that case, both pro bono counsel and Legal Counsel for the Elderly represented the ombudsmen.¹³¹

Ombudsmen surveys indicate that three legal support possibilities are available: the state attorney general's office, ombudsman program in-house counsel and private attorneys, or legal services program.¹³² Most state ombudsman programs depend on individual state Offices of the Attorney General for "formal advice, consultation, and legal representation."¹³³ Those states, like Illinois, have programs housed within a state agency.¹³⁴ Some also rely on the legal services department in their state for legal support.¹³⁵

The ombudsman advocate can use information-gathering powers on behalf of the residents to help bring political or legal action.¹³⁶ Federal law requires state nursing home ombudsmen to keep records of abuse and other problems in nursing homes, but often the categories of abuse are not specified in detail.¹³⁷ Therefore, this reporting requirement tells the federal government very little about problems in the homes. Some ombudsmen, however, are employed by their respective state departments, and therefore are not permitted to lobby their legislatures for program changes as actively as they might wish.¹³⁸

In January 1994, a survey was sent to state ombudsmen from the National Long-Term Care Ombudsman Resource Center.¹³⁹ The results showed that on average states relied mostly on informal counsel, as developed through relationships with agencies.¹⁴⁰ In response, several state ombudsmen suggested that funds should be made available to hire in-house counsel for the state program.¹⁴¹

130. See Owen & Schuster, *supra* note 122, at 618 n.5 (citing *Rye v. Kelly*, No. 93-12791 (D.C. Super. Ct. filed Nov. 8, 1993)).

131. See *id.*

132. See *id.*

133. *Id.* at 619.

134. See *id.* at 620.

135. See *id.* at 619. Note that some surveyed Illinois substate ombudsmen, including Esther Hays Wander of Carterville, Illinois, indicated that law school legal clinics such as that at Southern Illinois University were supportive of their local needs.

136. See Kahana, *supra* note 112, at 229.

137. See *id.* at 225-26.

138. Telephone Interview with Kathleen Allison, *supra* note 119.

139. See Owen & Schuster, *supra* note 122, at 616 n.7 (citing a survey sent to state ombudsmen in January 1994 by the National Long-Term Care Ombudsman Resource Center (NLTCORC)).

140. See *id.*

141. See *id.*

c. Mediation Role: Conduit for Resident Legal Help The ombudsman also might play a mediation role, that of a catalyst to ensure that legal service is made available to persons who would not ordinarily have access.¹⁴² Although the catalyst philosophy is advocate oriented, it perceives litigation by ombudsmen as “an ineffective method of resolving residents’ complaints.”¹⁴³ Proponents of this advocacy concept argue that the licensing agency or legal services programs should pursue legal remedies on behalf of residents.¹⁴⁴ Catalyst theorists argue that these legal agencies should perform their legal mandates.¹⁴⁵ Instead of the ombudsmen being involved in litigation, ombudsmen act as conduits of information for legal professionals under this theory.

Catalyst theorists’ experience and knowledge lead them to believe that involvement in litigation can strain the relationship ombudsmen have with facilities and other agencies, thereby making communication, consumer advocacy, and negotiation more difficult.¹⁴⁶ Legal services attorneys, rather than the actual ombudsmen, provide the legal representation. Some ombudsmen, as in Georgia, act as the resident’s representative.¹⁴⁷ This mediator role of the nursing facility ombudsman facilitates a method of dispute resolution that may be efficient, cost effective, and permits individually tailored solutions to be developed by the ombudsman that can be matched to the particular needs of the nursing home resident.¹⁴⁸

Regardless of which of the three ombudsman models is chosen by an individual state program, the pertinent OAA amendment requires “adequate” and “available” legal services.¹⁴⁹ These words indicate that some form of counsel must devote the time and resources to address an ombudsman’s particular needs within the state.¹⁵⁰ Research reveals, however, that ombudsman programs need more resources to retain counsel and legal services.¹⁵¹

Actual availability of adequate legal counsel is contingent on numerous factors. Often, too, such legal counsel must overcome con-

142. See Monk & Kaye, *supra* note 118, at 197.

143. Owen & Schuster, *supra* note 122, at 620.

144. See *id.*

145. See *id.*

146. See *id.*

147. See *id.*

148. See Kahana, *supra* note 111, at 222.

149. See Owen & Schuster, *supra* note 122, at 620.

150. See *id.*

151. See INSTITUTE OF MED., *supra* note 13, at 150.

flicts of interests and standing issues.¹⁵² If the ombudsman is not an attorney, which most are not, he or she needs the ready help of competent counsel that is sufficiently experienced in long-term care issues to zealously advocate on behalf of the programs. This requires more adequate and available funding and proper ombudsman training so they may anticipate the need for legal services.

Across the country, the role of the nursing home ombudsman varies substantially and reflects the policies established by the state program. Variability in organizational placement, program operation, funding, and utilization of human resources has given rise to at least fifty-two distinctive approaches to implementing the program.¹⁵³ Often the functions vary for an individual ombudsman as circumstances may dictate. When able to switch roles easily, the ombudsmen may be particularly well-suited to handle a wide range of disputes and may have greater ease in processing options they choose to pursue on residents' behalf.¹⁵⁴ Conflicts of interests to which ombudsmen respond may vary according to the types of disputes, the individuals or groups involved, the state requirements of a particular ombudsman program, and the experience of the particular ombudsman.¹⁵⁵

To fulfill their responsibilities, ombudsmen also must have thorough and up-to-date knowledge concerning various topics for the roles they perform. The ombudsmen must at least vaguely know the laws and regulations governing nursing facilities before they can make an assessment of whether a violation needing intervention has occurred. The AOA, since 1988, has supported a resource center that provides information for the ombudsman program.¹⁵⁶

The 1992 congressional amendments mandated that the AOA establish procedures for the training of ombudsmen, both paid and volunteer.¹⁵⁷ The AOA, however, has failed to do so.¹⁵⁸ Therefore, the states have made up their own guidelines for training new ombudsmen.¹⁵⁹ Depending on the particular state, different roles are

152. See Owen & Schuster, *supra* note 123, at 620.

153. See INSTITUTE OF MED., *supra* note 13, at 45.

154. See Kahana, *supra* note 111, at 229.

155. See *id.*

156. See INSTITUTE OF MED., *supra* note 13, at 71. The center is sponsored jointly by the National Citizen's Coalition for Nursing Home Reform and the National Association of State Units on Aging. See *id.* at 88.

157. See *id.*

158. See *id.*

159. See *id.* at 90.

more encouraged than others.¹⁶⁰ Where there are fewer visits per home due to fewer ombudsmen in a certain area, the ombudsmen likely focus more on advocacy rather than adopting a more therapeutic role. The Illinois program has developed its own specific arrangement.

2. THE DESIGN OF THE ILLINOIS LONG-TERM CARE OMBUDSMAN PROGRAM

Pursuant to statute, the Illinois Nursing Home Ombudsman Program¹⁶¹ was established through the federal Older Americans Act in 1971. The state promulgates administrative rules establishing responsibilities of the Illinois ombudsmen.¹⁶² In Illinois, the therapeutic or catalyst view of the ombudsman's role appears to be the current view of the program.¹⁶³

The Illinois Long-Term Care Ombudsman Program is organized in a pyramid structure.¹⁶⁴ This structure determines the level of influence the ombudsmen have—the most influential at the top of the triangle being the two paid state ombudsmen with offices at the Illinois Department on Aging in Springfield.¹⁶⁵ Illinois is divided into thirteen planning and service areas (PSAs) based on census data of persons over the age of sixty.¹⁶⁶ The two state ombudsmen oversee the operation of the ombudsman programs and assist residents and families in over 1000 nursing homes within Illinois counties.¹⁶⁷

Seventeen substate ombudsmen operate under the guidance of the two state ombudsmen. The number of substate ombudsmen per PSA varies depending upon the number of licensed beds for the eld-

160. See Kahana, *supra* note 111, at 232.

161. 20 ILL. COMP. STAT. 105/4.04 (West 1996).

162. Telephone Interview with Neyna Johnson, Co-Director of Illinois State Ombudsman Program (Oct. 31, 1995).

163. See *id.*

164. See *id.*

165. See *id.* The two state ombudsmen directors, Neyna Johnson and Beverly Rowley, oversee the 18 substate ombudsmen that are dispersed throughout the state, each covering a number of counties. 1993 ILL. DEP'T ON AGING LONG-TERM CARE OMBUDSMAN PROGRAM ANN. REP. 20. Illinois is divided into 13 planning and service areas (PSAs). See *id.* at 19. In these areas, the substate ombudsmen oversee and train volunteer ombudsmen that visit the homes. The number of visits per nursing home depends greatly on the number of volunteers the program attracts and can afford to train. See Telephone Interview with Kathleen Allison, *supra* note 119.

166. See Eckert et al., *supra* note 74, at 745.

167. See 1993 ILL. DEP'T ON AGING LONG-TERM CARE OMBUDSMAN PROGRAM ANN. REP. 8 tbl.1.

erly and the needs of each area.¹⁶⁸ Finally, at the base of this organizational structure are the volunteer ombudsmen who visit the homes on a regular basis and are the "eyes and ears" of the program. Ombudsmen visitors have an ongoing presence but do not have investigative power.¹⁶⁹ The substate ombudsmen recruit and oversee volunteer ombudsmen though the number of volunteers per PSA varies greatly.¹⁷⁰ Although volunteer ombudsmen appear to have little authority, they serve to gain the trust of residents through their repeated appearances at the homes.¹⁷¹

Pursuant to Illinois law, the Department of Aging rules dictate the responsibility of ombudsmen to investigate and resolve complaints "made by or on behalf of residents of long term [sic] care facilities relating to actions, inaction or decisions of providers, or their representatives, of long term [sic] care facilities, of public agencies, or of social services agencies, which may adversely affect the health, safety, welfare, or rights of such residents."¹⁷² When the need arises, the representatives are to report complaints to the relevant regulatory state agency. In the last four years, Illinois ombudsmen have fielded a 53% increase in abuse and neglect complaints.¹⁷³ The 1996 Illinois Department on Aging Annual Report states that between October 1994 and September 1995, the Illinois Ombudsman Program responded to 4124 complaints made by or on behalf of licensed long-term care facility residents.¹⁷⁴

According to a 1993 report on Illinois' program, the reported number of days between the beginning of an investigation of a nursing facility complaint and the resolution may vary, taking as little as one day to complete or lasting as long as 474 days.¹⁷⁵ An average resolution time is sixty days.¹⁷⁶ Of that total time, ombudsmen may spend from fifteen minutes to seventy hours investigating and resolving the complaint, with the average being five hours.¹⁷⁷

168. See Telephone Interview with Kathleen Allison, *supra* note 119.

169. See Telephone Interview with Neyna Johnson, Director of Illinois State Ombudsman Program (Mar. 7, 1996).

170. See *id.*

171. See *id.*

172. 20 ILL. COMP. STAT. 105/4.04 (3)(c) (West 1996).

173. See Levin et al., *supra* note 98, at 38 (citing ILL. DEP'T ON AGING, REPORT OF THE ILLINOIS LONG-TERM CARE OMBUDSMAN PROGRAM (unpublished excerpt)).

174. See 1996 ILL. DEP'T ON AGING ANN. REP. 4-5.

175. See 1993 ILL. DEP'T ON AGING LONG-TERM CARE OMBUDSMAN PROGRAM ANN. REP. 15.

176. See *id.*

177. See *id.*

No set ratio exists between the number of ombudsmen and the number of homes per PSA.¹⁷⁸ According to Illinois Substate Ombudsman Nancy Whitty, the ratios vary depending on how many volunteers the area can afford to train.¹⁷⁹ In the area she covers, for example, 6251 residents are served by fifteen volunteers.¹⁸⁰ Each volunteer in her area spends approximately twenty-five hours per month visiting.¹⁸¹ Volunteer presence can thus be calculated as roughly one hour per month in each home. According to a 1995 Illinois Long-Term Care Ombudsman Output Measures Report, some PSAs do not have any volunteers at all.¹⁸² In those PSAs that do utilize volunteers, funding must be available to recruit, train, and supervise both volunteer and paid ombudsmen to enable them to fit a specific role for their individual programs.¹⁸³

B. Training for Ombudsman Programs

Because ombudsmen, especially the volunteers, often are exposed to such a large number of possible abuses and situations needing their assistance, they require some training before monitoring the facilities.¹⁸⁴ First, volunteers must be recruited to spend their unpaid time working in the program.¹⁸⁵ Newspapers often run advertisements requesting interested persons to call and receive information concerning the ombudsman program.¹⁸⁶ No specific qualifications, educational levels, or past experience requirements are federally mandated for the volunteer positions.¹⁸⁷

178. See *id.* at 7-9.

179. See Telephone Interview with Nancy Whitty, Illinois Substate Ombudsman from Rock Island, Ill. (Jan. 30, 1996).

180. See *id.*

181. See *id.*

182. See OFFICE OF THE STATE LONG-TERM CARE OMBUDSMAN, LONG-TERM CARE OMBUDSMAN PROGRAM OUTPUT MEASURES: MANAGEMENT ADVISORY REPORT FFY 1995 [hereinafter OUTPUT MEASURES].

183. See, e.g., Bonnie Greenberg, *Volunteer Ombudsmen Needed at Nursing Homes: Residents' Rights Week Underscores Need for Advocates*, PEORIA J. STAR, Sept. 28, 1995, at 3.

184. See *id.*

185. See *Ombudsmen Being Sought for Elderly in Cattaraugus*, BUFFALO NEWS, June 5, 1995, available in 1995 WL 5480128.

186. See *id.*; see also *Ombudsman Serves as Advocate for County's Elderly*, INTELLIGENCER J. (Lancaster, Pa.), Sept. 15, 1995, at D1.

187. Cf. INSTITUTE OF MED., *supra* note 13, at 16 (Only the use of "well-trained" individuals is mentioned).

The training requirements now vary from state to state, both in length of time and the goals of preparation.¹⁸⁸ In Illinois, most employees of the ombudsman program are required to take approximately ten hours of basic training, while all but the ombudsmen visitors are required to attend an extra four hours of case investigation training.¹⁸⁹ Some states require longer training. New York requires thirty-six hours,¹⁹⁰ and Kentucky requires twenty-four hours of training, including negotiation and problem-solving skills.¹⁹¹

Under OAA provisions, ombudsmen are required to ensure that the residents have regular and timely access to the ombudsman services and that residents receive timely responses to complaints.¹⁹² Therefore, services provided by the ombudsmen should presumably be able to meet the needs of the residents. States, however, have no guidance from either Congress or the AOA as to how to interpret these rather vague requirements.¹⁹³ For example, the federal mandate does not specify whether it includes weekly visit requirements, state-wide complaint hot lines, or bilingual ombudsmen in areas having a large non-English-speaking resident population.¹⁹⁴

Further, the activities which are mandated by federal law such as "program emphasis, training and qualifications of volunteers, scope of and procedures for complaint resolution and education" are phrased broadly to enable states to fashion their own programs.¹⁹⁵ Among all the states, the result is a wide variation in ombudsman

188. See INSTITUTE OF MED., *supra* note 13, at 71-73.

189. See ILLINOIS DEP'T ON AGING, ILLINOIS DEPARTMENT ON AGING AND THE SUB-STATE OMBUDSMAN PROGRAM IN YOUR AREA LONG-TERM CARE OMBUDSMAN PROGRAM (1993) (pamphlet sent to interested people). Note, however, that in responding to a survey sent to substate ombudsmen in anticipation of this note, some indicated that their volunteer training varied somewhat from the 14 1/2 hour training requirement. Some ombudsmen, as in PSA 05, indicated that their volunteers received additional hours of in-service training after receiving the 14 1/2 hours pre-service training.

190. See *Ombudsmen Being Sought for Elderly in Cattaraugus*, *supra* note 185.

191. See Al Allen, *Nursing Home Ombudsmen Are Needed to Monitor Care*, THE COURIER J. (Louisville, Ky.), June 25, 1995, at 4H.

192. See INSTITUTE OF MED., *supra* note 13, at 80.

193. See *id.* at 53.

194. See *id.*

195. *Hearings Before the Subcomm. on Human Resources of the House Comm. on Educ. & Labor*, 98th Cong. 148 (1984) (prepared statement of the Association of Schools of Public Health).

training and roles in the process of redressing nursing home residents' complaints.¹⁹⁶

C. Funding of Ombudsman Programs

An estimated 865 paid staff nationwide are currently part of the ombudsman program.¹⁹⁷ The state and substate ombudsmen constitute the majority of the staff.¹⁹⁸ In 1982, the number of volunteers in the ombudsman programs was approximately 3306.¹⁹⁹ Since then, this number has more than doubled nationwide.²⁰⁰

Funding to pay salaries and volunteer training is gathered from multiple sources at the federal, state, and local levels. Most federal funding comes from the Titles III and VII of the OAA.²⁰¹ In 1993, federal dollars accounted for approximately 61% of the total program funding of nearly \$38 million.²⁰² States are required to match at least 15% of their Title III funds, but are not required to match any Title VII funds.²⁰³

Federal funds are not distributed equally among the states.²⁰⁴ The federal government allocates money according to the number of elderly people estimated to reside in each state.²⁰⁵ State laws then allocate money based on numerous factors such as the number of lower-income elderly in local areas and areas with overall greater social or economic need for the funding.²⁰⁶

Although not required, states will often provide some of their own funding to buoy the Title III money.²⁰⁷ In 1993, the states' overall contribution to the program reached 21% of its total funding.²⁰⁸ Five states, including Illinois, provided no state funds for the program. Illinois operates only through federal grants given to the Illinois Department on Aging through the AOA.²⁰⁹

196. See *id.* at 124-25 (statement of Mary Jane Lyman, Executive Director, Waxter Center for Senior Citizens, accompanied by Joyce Leanse, Associate Director, National Council on the Aging).

197. See INSTITUTE OF MED., *supra* note 13, at 53.

198. See *id.* at 46.

199. See *id.* at 57.

200. See *id.*

201. See *id.* at 189.

202. See *id.* at 58.

203. See *id.*

204. See INSTITUTE OF MED., *supra* note 13, at 190-91.

205. See *id.* at 192.

206. See *id.* at 58.

207. See *id.* at 192.

208. See *id.* at 190-91.

209. See Telephone Interview with Kathleen Allison, *supra* note 119.

Other sources of funding for the programs are local governments, the United Way, and various other charitable groups.²¹⁰ Funding, however, remains a large problem for state programs and many ombudsmen see it as a primary impediment to complete effectiveness of the program today.²¹¹

D. Overall Effectiveness of the Ombudsman Program

Through numerous studies, actual effectiveness of the ombudsman program has long been debated.²¹² The federal program is currently designed, in theory, to actively protect vulnerable elderly.²¹³ This is largely due to the stricter federal provisions implemented in 1987,²¹⁴ but the effectiveness is still questioned by some legal scholars.²¹⁵

In the summer of 1995, Consumer Reports magazine released its report rebutting the industry claim that nursing home conditions have improved since the federal rules were passed in 1987.²¹⁶ In that report, ombudsmen were not portrayed as dynamic problem solvers and therapeutic, but instead merely contacts in areas concerning the quality of nursing care.²¹⁷ The article also reported that ombudsmen often hesitate to state anything negative about nursing facilities and may often even be misleading to consumers searching for a quality nursing home.²¹⁸

In 1994, an in-depth analysis of two empirical studies assessing effectiveness of ombudsman programs was conducted.²¹⁹ One of the studies used in the analysis was performed from 1979-80 and was based on reports of resolved grievances from the perspectives of nurs-

210. *See id.*

211. *See* INSTITUTE OF MED., *supra* note 13, at 150.

212. *See* Kahana, *supra* note 111, at 229.

213. *See* INSTITUTE OF MED., *supra* note 13, at 53.

214. *See id.* at 45.

215. *See* Kahana, *supra* note 111, at 223.

216. *See* *Nursing Homes*, *supra* note 11, at 518.

217. *See id.*

218. *See id.* The article reported that sometimes using ombudsmen as a guide to quality homes can be misleading. As an example the author wrote that an ombudsman in Maryland had given him misleading information. The ombudsman supposedly reported that a facility gets "good surveys" and they (the ombudsmen) "don't get complaints from there." When checking this report, there were 12 substantiated complaints over the past three years and a state inspection report with 25 pages of deficiency citations.

219. *See* Kahana, *supra* note 111, at 230.

ing home residents, staff, and the ombudsmen.²²⁰ The other study, completed in 1991, reviewed the quality of care in homes implementing the ombudsman programs.²²¹

The 1979-80 study was divided on the success of ombudsmen in resolving disputes.²²² Among the residents polled for the study, 43.5% reported satisfactory resolution, 39.1% reported lack of resolution, and 17.4% were unsure of how they felt.²²³ Residents were most satisfied with the supportive or therapeutic aspect of the ombudsmen presence in the homes rather than any type of dispute resolution.²²⁴ These statistical results show that the ombudsmen's roles in the nursing facilities may be associated more with comfort and friendship to residents rather than actual effectiveness in changing practices by nursing homes.

In contrast to the 1979 study, the 1991 study focused more on quality of care in nursing homes where ombudsmen were present as opposed to those where ombudsmen were not present.²²⁵ This statewide survey of Missouri nursing homes demonstrated that quality of care is generally better in facilities with ombudsman programs in place.²²⁶

The Institute of Medicine, a private nonprofit think tank that works under congressional charter, also conducted an extensive 1994 study on the effectiveness of ombudsmen.²²⁷ Instead of a single-state analysis, as had been conducted in the 1979 and 1991 studies, the Institute sought to evaluate ombudsman programs nationwide.²²⁸ The study claimed that accurately evaluating the effectiveness of programs was quite difficult because of a significant lack of uniform data across the states.²²⁹

The study extensively evaluated the programs on their ability to make communities and residents aware of their existence, their skill

220. See *id.*; Abraham Monk & Lenard W. Kaye, *Assessing the Efficacy of Ombudsman Services for the Aged in Long-Term Care Institutions*, 5 EVALUATION & PROGRAM PLAN. 363, 364 (1982).

221. See Ralph L. Cherry, *Agents of Nursing Home Quality of Care: Ombudsmen and Staff Ratios Revisited*, 31 GERONTOLOGIST 302, 303-08 (1991); Kahana, *supra* note 111, at 230.

222. See Monk & Kaye, *supra* note 220, at 369.

223. See *id.* at 366.

224. See *id.* at 366-67.

225. See Cherry, *supra* note 221, at 302.

226. See *id.* at 303, 308.

227. INSTITUTE OF MED., *supra* note 13, at 129.

228. See *id.* at 129, 140.

229. See *id.* at 129-30.

for investigating and resolving complaints, their ability to convince nursing home providers of the program's usefulness, and their managerial skills concerning volunteer resources.²³⁰ Using these four criteria, the Institute's findings showed that the programs attained several goals in selected areas and in selected locations.²³¹

The study, however, also concluded the programs exhibit a great lack of uniformity across various states.²³² The study further explained that the federal government needs to implement an objective method of compliance review to help justify the massive funding needed for the programs.²³³ Finally, the study suggested there was mismanagement of volunteer services.²³⁴ The study concluded that the findings failed to provide unequivocal evidence of overall program effectiveness but recommended that programs continue to be implemented by federal provisions.²³⁵

E. Further Barriers to Maximum Effectiveness of Nursing Home Ombudsmen

1. THE NATIONAL LEVEL

Although on the whole, studies do indicate ombudsman programs can make a difference in residents' lives, the 1994 Institute of Medicine study suggested that nationwide, ombudsman programs continue to suffer from problems such as poor staffing, poor use of volunteers, and limited authority, accountability, and autonomy.²³⁶ Currently states are not required to meet minimum staff, volunteer, or other standards, and the federal government has not monitored state efforts.²³⁷ States and localities vary on the extent to which they comply with the law and spirit of operating statewide ombudsman programs.²³⁸ In short, there are numerous barriers that block the ultimate success of the state ombudsman programs.

The lack of necessary funding is probably the greatest of these barriers.²³⁹ Lack of funding results in lack of control at the local

230. *See id.*

231. *See id.* at 130.

232. *See id.*

233. *See id.* at 155.

234. *See id.* at 146, 148.

235. *See id.* at 152-53.

236. *See id.* at 154.

237. *See id.*

238. *See id.* at 5.

239. *See id.* at 150.

levels.²⁴⁰ Without any control over the income to the program or the program's budget, the local ombudsmen struggle to plan programs to train staff and volunteers.²⁴¹ Some surveyed Illinois substate ombudsmen also complained of insufficient legal services to pursue complaints.²⁴² This may be due in part to funding deficiencies.

Second, the manner of staffing the program with volunteers impedes the program's progress.²⁴³ Often due to minimal funding, the program lacks volunteers that are skilled and well trained for their roles.²⁴⁴ Many areas are in need of bilingual ombudsmen, as well as staff with health care backgrounds or experience in nursing.²⁴⁵ Often programs find it difficult to maintain volunteer involvement over significant periods of time, making funding for training sometimes wasteful.²⁴⁶

Finally, the lack of uniformity among state programs in their expectations of ombudsmen, and the lack of a federal system for monitoring progress, greatly impedes the effectiveness of the ombudsmen and their ability to improve services.²⁴⁷ For example, many local ombudsmen are uncertain of their relationship with other local programs that deal with aspects of nursing home care.²⁴⁸ No uniform structural support or legislation has ever determined what the relationship should be between various programs within the facilities.²⁴⁹ Furthermore, there are no sanctions available to impose if another state program refuses to work with the ombudsman program.²⁵⁰

Additionally, because of the various ways states have chosen to comply with the federal mandate in establishing ombudsman programs,²⁵¹ it is difficult to discover whether progress is being made throughout the programs at the same rate.²⁵² This means some local programs are more successful, and residents enjoy greater protection merely because the state either receives more funding, is better organ-

240. *See id.*

241. *See id.*

242. *See id.*

243. *See id.*

244. *See id.*

245. *See id.*

246. *See id.*

247. *See id.*

248. *See id.*

249. *See id.*

250. *See id.*

251. *See id.* at 129-31.

252. *See id.* at 129.

ized, or both.²⁵³ Hard federal data concerning the success of the program is essentially absent because of the lack of a national standard.²⁵⁴

Concurrent with the identification of barriers to the success of the ombudsman program is the necessary task of considering the ombudsman's role in the nursing home once the current barriers are overcome. The federal government needs to establish a stronger national standard with more funding and more assured legal assistance.

2. SPECIFIC ILLINOIS BARRIERS

In Illinois, there has not been a uniform assessment of the program as a whole. Although the Office of the State Long-Term Care Ombudsman now tallies annual output measures, there are limitations on the fourteen criteria areas measured in the state program.²⁵⁵ The most recent Output Report conceded in its findings that it is nearly impossible to collect information to measure all ombudsman activities, although the report has been expanded to collect additional types of data in the past few years.²⁵⁶

In some areas of the state, it does appear too few ombudsmen are involved in the program for it to reach its maximum effectiveness.²⁵⁷ Ideally, one volunteer should be assigned to a nursing home and visit it once a week so residents can depend on their habitual presence. Of the ten substate ombudsmen responding to a survey, most also agreed that the program needs more volunteer visitors in the nursing facilities.²⁵⁸ Often the number of nursing homes exceeds the number of visitors so greatly that the homes are visited only once a month in certain districts and only once a year in others.²⁵⁹ Volunteer efforts are not without their costs, however, and this poses substantial problems for some states like Illinois.

If the Illinois program is to be more successful, residents need the constant attention of ombudsmen in order to build their trust in

253. *See id.*

254. *See id.*

255. *See* OUTPUT MEASURES, *supra* note 182.

256. *See id.*

257. *See id.*

258. This survey was sent to the 17 substate ombudsman to aid in preparation for this note [hereinafter *Survey*]. It confirmed the research indicating that the programs have divergent organization schemes and number of volunteers even within the state of Illinois.

259. Telephone Interview with Kathleen Allison, *supra* note 119. For receipt of federal dollars, the mandate requires that homes be visited once yearly. Ms. Allison commented that although she desires to have the homes visited weekly in her area, often resources only allow visitors once every three months.

the ombudsmen and overcome their fear of being asked to leave the nursing home or their fear of retaliation by caregivers.²⁶⁰ According to the Illinois Department on Aging, many others besides residents utilize ombudsmen services to register and resolve complaints they have concerning resident care.²⁶¹ Pursuant to the 1995 Output Measures for Long Term Care Ombudsman Report, the ratio of investigating ombudsmen per number of beds in each PSA varied drastically, from one ombudsman per 1112 beds to one ombudsman per 8800 beds.²⁶²

Of the complaints received in Illinois in 1993 from residents or their family members, the most frequently reported were those concerning resident care.²⁶³ In acting on these complaints, the Illinois ombudsmen may either empower a resident to act on the complaint or serve as an advocate on his or her behalf.²⁶⁴ Illinois substate ombudsmen cite barriers to resolving complaints in the state of Illinois when they are pursuing action on complaints.²⁶⁵ Lack of available funding to enable ombudsmen to investigate claims is a primary problem, but lack of legal services is equally problematic.²⁶⁶

Finally, responding to a recent survey sent to Illinois substate ombudsmen, the Illinois ombudsmen indicated that the program suffers a disability by being under the control of the Illinois Department on Aging.²⁶⁷ Some ombudsmen indicated that state ombudsmen are usually restricted from taking a stand on legislative and policy issues or lobbying for more funding because of their status as state employees.²⁶⁸ If the ombudsman program were changed to become an independent agency under Illinois law, as are the programs in Oregon and Michigan,²⁶⁹ some substate ombudsmen believe they would be able to participate in active legislative advocacy more easily.²⁷⁰ These

260. See Greenberg, *supra* note 183, at 2.

261. See ILL. DEP'T ON AGING, *supra* note 8, at 10-11.

262. OUTPUT MEASURES, *supra* note 182.

263. See 1996 ILL. DEP'T ON AGING ANN. REP. 10-11. In fiscal year 1992, many of the complaints were received from residents' family members (28%), while 18% were made by nursing home staff, 21% were made by residents themselves, but only 15% were witnessed and reported by ombudsmen. See *id.*

264. See *id.* at 13.

265. See Survey, *supra* note 258.

266. See INSTITUTE OF MED., *supra* note 13, at 94; Survey, *supra* note 258.

267. See Survey, *supra* note 258.

268. See *id.* Substate ombudsmen Robyn O'Neill of Suburban Cook County and Margaret Niederer of Springfield both observed in their survey responses that the dependent status of the program impedes its ultimate effectiveness for change.

269. See OR. REV. STAT. § 441.100 (1996); Mantese et al., *supra* note 24, at 179.

270. Telephone Interview with Kathleen Allison, *supra* note 113.

frequently cited barriers reflect only three of the numerous problems impeding the ultimate effectiveness of many other states' ombudsman programs.

IV. Recommendations/Direction for the Program

In a 1992 GAO report, both the ombudsmen and the experts responding to report surveys stated that increasing residents' access to ombudsmen through regular facility visitations must occur if the program is to more fully develop.²⁷¹ The 1994 Institute of Medicine's evaluation clearly found that major improvements need to be made to the already-existing program.²⁷² Since that study, however, there has been no direct action taken to improve and better coordinate efforts of state ombudsman programs. The ombudsman program does have significant opponents, especially facility operators who do not like interference with the manner in which their nursing facilities are managed.²⁷³ Also the Republican-led Congress may possibly continue to tout antiregulatory measures and attempt to loosen its reins on the long-term care industry.²⁷⁴

Patients' rights groups believe this is a dangerous time for the roughly two million Americans in nursing homes and other long-term care institutions.²⁷⁵ Proponents of the ombudsmen think that the effect of the current program, even if fulfilling the helper function, is making a difference for the elderly residents.²⁷⁶ Two basic choices are available: (1) cut the program back and save taxpayers' dollars from being allocated to a program only successful in theory; or (2) reform the program as it exists. Clearly, as the 1994 Institute of Medicine study opined, the latter is the wise option.²⁷⁷ Because of the great degree of harm that may befall residents if the "watchful eyes" of ombudsmen are not present, solutions to fix the problems in the ombudsman program are necessary to give the program the teeth it currently lacks.

271. See GENERAL ACCOUNTING OFFICE, *THE OLDER AMERICANS ACT ACCESS TO AND UTILIZATION OF THE OMBUDSMAN PROGRAM* 19-20 (1992).

272. See INSTITUTE OF MED., *supra* note 13, at 161.

273. See Cherry, *supra* note 221, at 308.

274. See Elizabeth Mehren & Robert A. Rosenblatt, *Budget Ax Puts Seniors on Edge*, DETROIT NEWS, Aug. 27, 1995, at B1.

275. See *id.*

276. See Kahana, *supra* note 111, at 230.

277. See INSTITUTE OF MED., *supra* note 13, at 153-61.

A. Establish a Uniform, Reliable Documentation System

Before significant changes may be made to remove barriers to the program's success as suggested by the Institute of Medicine,²⁷⁸ the federal government needs to establish a uniform documentation system to see the actual effects of the ombudsman program. An accurate study of the program's effects is difficult because the ombudsman programs are set up differently in many of the states, and collection of data in a meaningful pre- and post-program implementation comparison study is nearly impossible.

Many ombudsmen cringe over paperwork, but documentation is critical to see forward progress in the programs. Activities are currently underway by the AOA to implement a revised reporting system for complaints.²⁷⁹ Without hard data showing the progress the program is making, the argument to maintain the program as it exists is weak.

Reliable documentation has an additional benefit. Legal practitioners may be asked to assist older persons or their families in the tough decision whether the elderly person should enter a nursing home and which is the correct one.²⁸⁰ The search for a facility should begin well before a client's need arises to ensure the likelihood an appropriate facility will be available. Long-term care ombudsmen may assist practitioners in these decisions, and elder law practitioners should be familiar with the way their local programs operate. Additionally, state survey reports should be available from their area long-term care ombudsmen, the state health departments, and the nursing homes themselves.²⁸¹ Indeed, ombudsmen can be an invaluable asset in many respects to nursing home care.

B. Federally Defined Requirements for Local Programs

Currently, every state is free to set up its ombudsman program according to its own guidelines.²⁸² Because individual states have varied numbers of volunteers at their nursing facilities and various methods of training their staff, different types of services to residents

278. *See id.*

279. *See id.* at 151. This revised system is entitled the National Ombudsman Reporting System. *See id.*

280. *See* KRAUSKOPF ET AL., *supra* note 12, at 449.

281. Written resources also may be available to aid elder law attorneys in the search for an appropriate client home. *See, e.g.,* U.S. DEP'T OF HEALTH & HUMAN SERVS., PUB. NO. HCFA-02174, GUIDE TO CHOOSING A NURSING HOME (1991).

282. *See* INSTITUTE OF MED., *supra* note 13, at 45.

are rendered.²⁸³ OBRA is a federal statute, and federal dollars support the programs. Although some states enhance this funding with state funds, a few do not.²⁸⁴ Because the program money is from the federal government, additional statutes should be implemented to ensure residents in one state receive similar benefits as in another.

Currently, clarity is lacking in how the program should be administered and in meaningful compliance review from the AOA.²⁸⁵ According to the Institute of Medicine, "at a minimum, the AOA ought to provide a checklist for the performance standards or indicators of good practice against which each state may be assessed."²⁸⁶

The AOA also should develop and distribute a policy statement detailing sanctions the AOA is authorized to use to enforce state compliance with statutory mandates of the long-term care ombudsman program. The statement should describe the sanctions and explain exactly which conditions require or justify invocation of sanctions.

The states need guidance if the ombudsman program is to become a cohesive, nationwide success. The Institute of Medicine suggested two key features and functions that are relevant to whether a state ombudsman program operates as a cohesive unit: methods by which local host agencies and individual ombudsmen are designated, trained, assisted, and monitored; and methods by which the state unit on aging carries out its responsibilities to the ombudsman program.²⁸⁷

Currently the AOA is not actively involved with the control over state programs.²⁸⁸ Instead, the AOA should work to obtain a more interactive stance in order to ensure greater success and compliance with the mandates of OAA. The AOA has provided no guidance on the infrastructure of the state programs, nor active monitoring of the states' allocation of federally provided funds.²⁸⁹

Also, state programs like that of Illinois may benefit from independence from the Illinois Department on Aging. This greater freedom to lobby for changes before the state legislature would enable the ombudsmen to more actively advocate for the rights of the individu-

283. See *id.* at 44.

284. See *id.* at 190.

285. See *id.* at 90.

286. *Id.* at 89 (citation omitted).

287. See *id.*

288. See *id.* at 88. "During the last half of the 1980s, AOA provided little oversight and technical assistance to the states on the implementation of the ombudsman program, and most of the effort took the form of monitoring by regional offices." *Id.*

289. See *id.*

als they serve in their respective areas. Among these lobbied-for changes would most likely be additional funding for their programs.

C. Ensure Adequate Legal Service

Not all states view the role of the ombudsman similarly within the context of the legal system. Very few state ombudsmen view legal remedies, especially litigation, as the basis of their advocacy efforts or program needs. Nevertheless, the ombudsmen need adequate legal services, which they often do not have. A 1994 National Ombudsman Resource Center survey indicated that less than half of the twenty-seven state ombudsmen responding to the survey thought their legal support was "very good" or "excellent."²⁹⁰ One-third responded that legal service was so inadequate that it did not meet their needs.²⁹¹

Congress has implemented statutes requiring that state agencies ensure that adequate legal services be available.²⁹² Ombudsman programs should use as their primary counsel for advice, consultation, and representation in-house or outside legal counsel who are experienced in dealing with long-term care, health care decision making, and other related substantive legal issues. In many jurisdictions, such legal counsel can be obtained through a legal services program, a public interest organization such as a protection and advocacy agency, or a private law firm specializing in elder law. The most important criteria for the legal counsel should be its availability on a regular or daily basis and its ability to handle a wide range of long-term care and issues related to the nursing home context. Furthermore, to enhance the ombudsman program's legal strength, states should pass laws permitting both residents and the Office of the Long-Term Care Ombudsman a more easily accessible private right of action to enforce long-term care and license laws.

If legal services and uniformity across programs are enhanced, the merits of the program will be more readily apparent both to the public and to legislators. Current ombudsmen complain of lack of flexibility and control due to funding constraints. The only way to ensure the program will not be cut from the federal budget is to enhance the program as it already exists, both through stricter federal statutes and more provisions for legal support. Only then may the program be recognized as a dynamic solution to the current abuses

290. See *id.* at 94.

291. See *id.*

292. See *id.* at 93.

and potential atrocities in nursing homes and a remedy worth expanding to include more staff and volunteers to reach more residents and community members. Until unification among the state programs and hard data proving the dramatic difference it makes for residents is collected, funding cannot be expected to grow. And without adequate funding, the program will only remain a worthy cause without actual documented positive results.

V. Conclusion

The ombudsman programs may be in jeopardy. In 1995, congressional Republicans sought to cut, among other nursing facility restrictions, federal funding for the ombudsman programs.²⁹³ Republican proposals would have shifted responsibility for quality nursing homes to the states, letting states, rather than the federal government, set and enforce standards.²⁹⁴ If the Republicans had succeeded, states also would decide whether or not to keep nursing home ombudsmen. The possibility existed, under the Republican proposal, that nursing facilities would be without their watchdog ombudsmen. Fortunately, the Republican proposal has not, to date, been successful.

More recently, the Department of Health and Human Services (HHS), the department that regulates nursing homes caring for patients under Medicare and Medicaid,²⁹⁵ has proposed cutting back on inspections of nursing homes due to its statistics showing that more than two-thirds of nursing homes are not complying with current federal standards.²⁹⁶ The HHS's rationale in cutting back such inspections is that this would allow inspectors to concentrate on homes with more serious problems.²⁹⁷ Such proposed changes would allow the scope of facility reviews to be greatly narrowed and would "reduce the number of residents who must be interviewed."²⁹⁸ The changes

293. See Mehren & Rosenblatt, *supra* note 274, at B1; *Less Nursing-Home Oversight*, DES MOINES REG., Oct. 18, 1995, at 10.

294. See *Less Nursing-Home Oversight*, *supra* note 293.

295. The Medicare and Medicaid Programs authorized by titles XXIII and XIX of the Social Security Act, 42 U.S.C. §§ 1395, 1396 (Supp. 1994), are administered by the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (HHS). See MEDICARE AND MEDICAID, *supra* note 57, at 8. The vast majority of nursing facilities now participate in these two programs. See *id.* at 10.

296. See *Government Seeks to Limit Scope of Inspections at Nursing Homes*, ST. LOUIS POST-DISPATCH, Dec. 17, 1996, at 14A.

297. See *id.*

298. *Id.*

would also reduce the number of medical records and other such documentation examined at each facility.²⁹⁹ Some nursing facility resident advocates see this proposal as authorizing, in effect, “drive-by surveys” of homes.³⁰⁰

The current status of the program should not continue. The ombudsman must possess more power and convince nursing home operators that negligent conduct will no longer be tolerated. More training of many additional ombudsmen, improved and uniform structure of the programs through regulations at the federal level, and more legal capabilities are requisite starting points. Studies have shown that nursing home residents need protection from abuse and neglect. Every facility should have protective ombudsmen visiting regularly to reduce the current abuses and avoid the potential atrocities in nursing homes.

Keeping in mind the at-risk, vulnerable status of the elderly in facilities today and the fact that numbers will continue to grow in the next three decades, the correct decision is to continue the ombudsman programs and make the necessary improvements.

299. *See id.*

300. *See id.* (quoting Ellen Reap of Delaware, president of the national organization of state officials who inspect hospitals and nursing homes). Mark Miller, a nursing home ombudsman in Virginia, called the proposed changes to nursing facility surveying “most definitely” contrary to the interests of nursing home residents. *See* Robert Pear, *Nursing Home Checkups May Be Cut*, PORTLAND OREGONIAN, Dec. 17, 1996, at A7.

**THE STATE GIVETH AND THE STATE TAKETH
AWAY: IN PURSUIT OF A PRACTICAL
APPROACH TO MEDICAID ESTATE
RECOVERY**

Jon M. Zieger

In the wake of skyrocketing Medicaid costs, numerous states have instituted estate recovery programs to infuse additional capital into the failing Medicaid system. However, as the "baby boom" generation begins to gray, questions as to the intrinsic economic fairness and administrative efficacy of such programs emerge. After acknowledging the need to lessen the financial strain created by Medicaid, Mr. Zieger traces the disparate approaches to Medicaid recovery embraced by state governments, as well as finds the common denominator between such seemingly diverse programs. Mr. Zieger also explores the potential impact such programs may have on the elderly, including the impoverished elder who is unable to secure legal advice and the financially secure individual who opts to utilize estate planning as a means of sheltering assets. Moreover, Mr. Zieger points out the way that case law leaves unresolved the amount of assets the surviving family of the Medicaid recipient ultimately may receive from the decedent's estate. Finally, Mr. Zieger concludes by balancing the needs of the genuinely poor with the state's concern for fiscal stability. In balancing these competing needs, Mr. Zieger advocates limiting recovery to estates of a certain size, furnishing adequate notice so that potential Medicaid recipients may make informed decisions as to whether to accept or decline such assistance, and limiting the scope of the Medicaid recipient's estate by embracing the definition of estate as promulgated under state probate codes.

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Mr. Zieger would like to thank his wife, Meka Zieger, for her thoughtful comments and patient support in preparing this note.

I. Introduction

As the cost of providing medical assistance to Medicaid¹ recipients has continued to increase dramatically in the decades since that program's inception,² states have sought various methods of reducing Medicaid expenditures. Estate recovery programs, designed to recoup Medicaid assistance from a recipient's estate, represent one method states have implemented to reduce Medicaid costs. Under these programs, the cost of medical assistance provided to a recipient becomes a debt of the recipient's estate or the estate of the recipient's surviving spouse.³ As part of its effort to recover these expended funds, a state will enact statutory guidelines and empower an agency to track the estates of former Medicaid recipients and their spouses. In certain cases, the agency may place liens upon the property of the recipient while he or she is still alive and may recover on such a lien.⁴ The ability to do so, however, is limited and varies substantially from state to state.⁵ Under certain conditions, the agency will collect the amount expended on the recipient's behalf, either upon the liquidation of the recipient's assets during the recipient's life or as a creditor from the recipient's estate.⁶ The issues for consideration are thus twofold. First, to what extent should the assets of Medicaid debtors be protected recovery, and second, what recipient safeguards should accompany this type of recovery? Concomitantly, the degree of protection to be afforded to the state as creditor also should be determined.

This note supports the concept of estate recovery programs as a useful and just method of controlling Medicaid costs but proposes an adjustment to the balance of such programs to achieve maximum re-

1. Although states have various names for their medical assistance programs for the poor and disabled, this note will use the term "Medicaid" to refer to these programs, both in the aggregate and for individual state programs.

2. From 1980 to 1996 (estimated) the total outlay of Medicaid funds has increased from \$24 billion to \$159 billion. See HEALTH CARE FIN. ADMIN., HCFA STATISTICS: EXPENDITURES, PROGRAM OUTLAYS/TRENDS tbl.26 (Aug. 5, 1997) <<http://www.hcfa.gov/stats/hstats96/blustat2.htm>>. In Florida, the state with the highest proportion of elderly citizens, Medicaid expenditures are expected to reach between three and four billion dollars by the year 2000. See Burton D. Dunlop et al., *Medicaid Estate Planning and Implementation of OBRA '93 Provisions in Florida: A Policy Context*, 19 NOVA L. REV. 533, 536 (1995); see also *The Perfect Sunset*, ECONOMIST, Jan. 27, 1996, at 14 (noting that by the year 2010, Florida's expenditures are expected to grow as high as \$9 billion from the current level of \$1.6 billion).

3. See, e.g., 305 ILL. COMP. STAT. 5/5-13 (West 1995).

4. See *id.*

5. See *infra* notes 82-105 and accompanying text.

6. See *infra* notes 54-118 and accompanying text.

coveries while maintaining the smallest possible impact on the recipient or the recipient's family. This note will examine the need for recovery and the policies behind estate recovery programs, namely defraying current costs and reducing future expenditures by encouraging elders to plan alternative methods of funding long-term care. Additionally, it will consider the effectiveness of current programs at achieving these goals. It will also briefly contemplate various planning strategies for avoiding estate recovery and certain challenges that have been brought to the programs. Finally, in light of the unprecedented political change that potentially faces Medicaid, this note will present and argue for provisions of a model estate recovery plan which the states—if left unrestricted by the federal government—should adopt to regulate this difficult area.

Obviously, this note is written against a background of political tumult, the likes of which Medicaid has not seen in its thirty-two-year history. Even the most sagacious political observer cannot predict the final outcome for Medicaid or estate recovery. The elder law advisor will certainly consider what follows accordingly.

II. History of Medicaid and the Recovery Problem

A. Medicaid

The federal medical assistance, or Medicaid, program was established by Title XIX of the Social Security Act of 1965.⁷ It is a joint federal-state program, operated primarily by the states, that makes medical assistance available to certain eligible persons.⁸ Medicaid is more comprehensive than Medicare and many private insurance plans. It can cover prescription drugs, in-home care, and other services that are not covered by Medicare.⁹ Perhaps most importantly for the elderly, it often covers long-term care that Medicare will not.¹⁰ Nationally, reports indicate that Medicaid pays the cost of sixty per-

7. Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286.

8. As with most other elements of Medicaid, eligibility requirements differ from state to state, but federal law requires that certain groups be eligible for Medicaid under a state program in order for the state to receive federal funding. For a discussion of federal eligibility requirements, see *infra* notes 20-41 and accompanying text.

9. See 42 C.F.R. § 440.225 (1996).

10. See *id.* §§ 440.1-270; see also 42 U.S.C. § 1395(x) (1994) (setting forth the various restrictions on Medicare coverage of long-term care).

cent of all nursing home bed days.¹¹ This statistic demonstrates the tremendous need that exists for long-term care coverage of some kind, as well as the substantial economic challenges that confront states.

Medicaid is presently administered at both the federal and state levels. On the federal level, the Department of Health and Human Services oversees Medicaid through the Health Care Financing Administration (HCFA), the body empowered to oversee both Medicare and Medicaid.¹² The program currently provides medical services for approximately thirty-six million people in total,¹³ approximately 4.4 million of whom are elderly persons.¹⁴ States accepting federal Medicaid funds are required to designate a single state agency to administer or supervise the state Medicaid plan.¹⁵ This role typically will be fulfilled by the state's department of social services or similar agency with oversight responsibility for the state's other welfare programs.¹⁶ The day-to-day operation of Medicaid is generally maintained at the local level by city or county agencies.¹⁷ Recovery may, however, be carried on by a separate state agency with oversight responsibilities for various state reimbursement programs.¹⁸ As a condition of receiving federal funding, the operation of individual state programs must conform to certain broad federal restrictions.¹⁹

Setting guidelines for Medicaid eligibility is largely a state task, with certain important federal limits. Under federal guidelines various groups of persons are considered "categorically" eligible for Medi-

11. See Keren Brown Wilson & Connie J. Baldwin, *Are Nursing Homes Dinosaurs? The Nursing Home Revisited*, GENERATIONS, Winter 1995-1996, at 69. Long-term care (both institutional and community services) accounts for over 30% of total Medicaid expenditures. See KAISER COMM'N ON THE FUTURE OF MEDICAID, MEDICAID UPDATE: EXPENDITURES AND BENEFICIARIES IN 1993, at 8 (1994) [hereinafter KAISER COMM'N, EXPENDITURES AND BENEFICIARIES].

12. See Medicare and Medicaid Programs, Quarterly Listing of Program Issuances and Coverage Decisions—Third Quarter 1994, 60 Fed. Reg. 132 (1995).

13. See HEALTH CARE FIN. ADMIN., HCFA STATISTICS, MEDICAID RECIPIENTS AND VENDOR PAYMENTS BY AGE tbl.6 (Aug. 5, 1997) <<http://www.hcfa.gov/medicaid/mnatstat.htm>>; see also 141 CONG. REC. S6785 (1995) (statement of Bruce C. Vladeck, Administrator, Health Care Financing Administration).

14. See HEALTH CARE FIN. ADMIN., *supra* note 13, at tbl.6.

15. See 42 U.S.C. § 1396a(a)(5).

16. See 42 C.F.R. § 431.10(c) (1996).

17. See Barbara J. Collins, *Medicaid*, in ELDER LAW INSTITUTE: 1995, at 55, 58 (PLI Tax Law & Estate Planning Course Handbook Series No. D4-5256, 1995).

18. For example, in Illinois the Technical Recovery Unit of the Bureau of Collections controls Medicaid estate recovery. Telephone Interview with Karl Schultz, State of Illinois Bureau of Collections, Technical Recovery Unit (Apr. 10, 1996) [hereinafter Schultz Interview].

19. See 42 U.S.C. § 1396a(a) (1994).

caid benefits.²⁰ As a condition of receiving federal funding, states must make Medicaid available to these individuals.²¹ Beyond these categories of individuals, states may provide Medicaid coverage to individuals who do not otherwise qualify for SSI and who are unable to meet their medical expenses.²² Within certain limits, states may also use more liberal methods for ascertaining what resources are available to an applicant in eligibility determinations for this optional category.²³

Although eligibility requirements vary among states,²⁴ the standards used typically create the possibility that a substantial estate may remain at the recipient's death. In fact, certain assets are exempt from consideration in determining resource eligibility of aged persons under the federally established SSI standards that generally serve as the baseline for categorical Medicaid eligibility. The principal place of residence, or "homestead,"²⁵ of an institutionalized applicant, including land attached to it, is exempt from consideration if a spouse or dependent relative continues to reside there.²⁶ Household goods and effects are also exempt, with no limitation on value for married

20. See §§ 1396a(a)(10)(A)(i)(I)-(VII). These categories include aged, blind, and disabled individuals receiving assistance under the Supplemental Security Insurance (SSI) program per 42 C.F.R. § 435.4, as well as qualified Medicare beneficiaries. See 42 U.S.C. § 1396d(p)(1). Qualified Medicare beneficiaries are those individuals who are eligible to receive Medicare Part A, but whose income falls below the federal poverty limit and whose assets do not exceed twice the SSI resource availability limit. See *id.*

21. See § 1396a(a)(10).

22. See § 1396a(10)(A)(ii). The rate of enrollment growth for elderly admitted to Medicaid through these other (noncash assistance) categories is increasing significantly faster than that of cash assistance (e.g., SSI enrollees, a group which has remained relatively stable for several years. See KAISER COMM'N, EXPENDITURES AND BENEFICIARIES, *supra* note 11, at 2.

23. See § 1396a(a)(10)(C).

24. More specifically, eligibility requirements for recipients of SSI differ between states that have elected to base eligibility on the requirements in existence for receipt of Medicaid prior to the enactment of SSI and those that have chosen to use the SSI standards for determining eligibility. See Roger A. McEowen, *Estate Planning for Farm and Ranch Families Facing Long-Term Health Care*, 73 NEB. L. REV. 104, 108 (1994). States in the former category may follow stricter eligibility guidelines. See *id.* For a list of "section 209(b)" states which opted not to adopt SSI eligibility as the eligibility determinant for Medicaid in the state, see *id.* at 108 n.21.

25. Pursuant to federal regulations, the state must define the phrase "individual's home" or "homestead" in the state recovery plan. See 42 C.F.R. § 433.36.

26. See 42 U.S.C. § 1382b(a)(1); 20 C.F.R. §§ 416.1210(a), 416.1212(c) (1997); see also *Correll v. Division of Soc. Serv.*, 418 S.E.2d 232 (N.C. 1992) (finding that under North Carolina law an individual need not own the home to exclude the value of land attached thereto which the applicant did own).

couples and up to \$2,000 for single individuals.²⁷ Additionally, one automobile is exempt from consideration and, if it is deemed necessary for certain essential daily activities, there will be no limitation on its value. If the automobile is not deemed necessary for such essential activities, only \$4,500 of its value will be exempt.²⁸ Certain burial funds²⁹ and insurance policies with small cash value are exempt.³⁰ Furthermore, capital assets which are considered necessary to the applicant's income and rental property or business property offering lodging or day care which has less than \$6,000 equity and which produces rental income equal to at least six percent of equity will be exempt.³¹ After excluding these resources, an applicant will, at a minimum, be eligible when his remaining income is sufficiently low to qualify for SSI.³² Additionally, many states provide eligibility for elders requiring nursing home care, even though they normally would not be eligible for Medicaid benefits, if the elderly person's income is insufficient to meet the costs of necessary care. These fall within the group of so-called medically needy recipients.³³ Thus, one may become eligible for Medicaid under a variety of measures and still have substantial assets, if not income.³⁴ In spite of these many exemptions, the bulk of most Medicaid recipients' estates is found in the value of the primary residence.³⁵

The elderly become eligible for Medicaid benefits most often as a result of their need for long-term or custodial care.³⁶ Moreover, the longer an individual lives past age sixty-five, the more likely recourse to Medicaid becomes.³⁷ With the cost of nursing home and other

27. See 20 C.F.R. §§ 416.1210(b), 416.1216(b).

28. See 42 U.S.C. § 1382b(a)(2)(A); 20 C.F.R. §§ 416.1218(b)(1)-(b)(2).

29. See 20 C.F.R. §§ 416.1210(1), 416.1231.

30. See *id.* §§ 416.1210(h), 416.1230(a).

31. See *id.* §§ 416.1210(d), 416.1222(a); see also *id.* § 416.1224 (exempting certain property with less than \$6000 equity which is used to produce certain agricultural products for the applicant's consumption).

32. See generally *id.* § 416.1100.

33. 42 C.F.R. § 435.4 (1996).

34. See *infra* note 234.

35. See Gary Mazart, *Protecting the Home in Government Benefits Planning*, 164 N.J. LAW 34 (1994).

36. Although many elderly recipients have been historically poor, the great increase in the percentage of recipients receiving Medicaid over age 85, suggests that long-term care is the basis of the need. See *infra* note 37.

37. According to HCFA data, 9% of the population between ages 65 and 74 receives Medicaid. That number rises to 13.5% for those ages 75 to 84, and to 32.5% for the age group 85 and above. See HEALTH CARE FIN. ADMIN., MEDICAID RECIPIENTS AS A PERCENTAGE OF POPULATION BY AGE tbl.6 (Aug. 5, 1997) <<http://www.hcfa.gov/medicaid/mnatstat.htm>>.

types of long-term custodial care averaging upwards of \$38,000 per year³⁸ a cost typically not covered by Medicaid,³⁹ many elders will exhaust their savings quickly and will become sufficiently impoverished to qualify for Medicaid.⁴⁰ When the recipient dies, the remaining estate will contain exempt assets plus whatever insurance or similar proceeds accrue as a result of the recipient's death. Medicaid recipients often will leave very small estates, however, the exemption of various assets in eligibility determination based on category rather than value⁴¹ creates the potential that substantial assets may remain.

B. The Need for Recovery

The need for policies which improve the fiscal integrity of Medicaid is becoming increasingly undeniable. Current demographic trends suggest that only significant reforms will allow Medicaid to continue to provide adequate health care to the indigent. Most significant among those demographic trends is the rapid growth of the elderly population: the so-called graying of America.⁴²

Approximately one of every eight Americans is elderly (sixty-five or older);⁴³ by the year 2030, however, one in five will be elderly.⁴⁴ More importantly, the so-called oldest-old, that portion of the population eighty-five years of age or older, are the most rapidly growing segment of American society.⁴⁵ By 1994, the oldest-old comprised approximately one percent of the population, up two hundred seventy-four percent from 1960.⁴⁶ This rate of growth was more than six times the total rate of population growth and nearly three times the growth of those aged sixty-five and older.⁴⁷ The expenditures per capita for these oldest-old recipients are substantially higher than for any other

38. See Robin Toner, *Critics Say Republican Budget Will Create Shortage of Nursing Home Beds for Elderly*, N.Y. TIMES, Nov. 12, 1995, § 1, at 30.

39. See 42 U.S.C. § 1395x (setting forth various limits on Medicare coverage for long-term care).

40. See Toner, *supra* note 38 (noting that half of all elders receiving long-term care will exhaust their resources in six months or less).

41. See *supra* notes 24-35 and accompanying text.

42. See Allan J. Mayer et al., *The Graying of America*, NEWSWEEK, Feb. 28, 1977, at 50.

43. See FRANK B. HOBBS, U.S. BUREAU OF THE CENSUS, THE ELDERLY POPULATION (Aug. 5, 1997) <<http://www.census.gov/www/pop-profile/elderpop.htm>>.

44. See *id.*

45. See *id.*

46. See *id.*

47. See *id.*

age group among Medicaid recipients.⁴⁸ Approximately twelve times more money is paid to vendors per recipient aged eighty-five and older than for those ages six to fourteen (the least expensive age group for Medicaid), and approximately one and one-half times as much as those aged seventy-five to eighty-four (the next most costly age cohort behind the oldest-old).⁴⁹ Included in the growing elderly population will also be a substantially larger proportion of African Americans, Hispanics, and Native Americans,⁵⁰ who tend to be poorer than their Caucasian counterparts.⁵¹

Thus, the general trend of increasing incomes for the elderly⁵² may be somewhat offset by the increasing proportion of historically poorer elders. These trends are sufficient to warrant a careful reappraisal of Medicaid's current practices and of their long-term feasibility. Alone, these facts do not imply that estate recovery should be an important part of any such reevaluation. However, combining the evidence of an aging population with the fact that most elderly households maintain the vast majority of their net worth in a principal residence⁵³ mandates that estate recovery become an essential tool to recoup Medicaid dollars. If the current exemption of the principal residence in eligibility determination is to continue, estate recovery will play a cardinal role in reaching the locus of many elders' wealth.

C. Estate Recovery Programs

Because estate recovery programs are largely creatures of state law and vary from state to state, a single definition of an estate recovery program is implausible. However, certain common elements can

48. See HEALTH CARE FIN. ADMIN., MEDICAID RECIPIENTS AND VENDOR PAYMENTS BY AGE tbl.6 (Aug. 7, 1997) <<http://www.hcfa.gov/medicaid/mnatstat.htm>>.

49. See *id.* Specifically, those aged 85 and above were responsible for \$12,387 per vendor in 1994, while those aged 6 to 14 were responsible for \$1,043 per vendor, and those aged 75 to 84, \$8,453 per vendor. *Id.*

50. See HOBBS, *supra* note 43.

51. See generally U.S. DEPT. OF COMMERCE, CURRENT POPULATION REPORTS, CONSUMER INCOME, SERIES P60-188, INCOME, POVERTY, AND VALUATION OF NONCASH BENEFITS: 1993 (1995) (discussing racial composition of poverty-stricken elderly).

52. See *infra* note 129 and accompanying text.

53. The median net worth (assets minus liabilities) of older households was approximately \$86,324 in 1993. See U.S. CENSUS BUREAU, ASSET OWNERSHIP OF HOUSEHOLDS: 1993 tbl.D (Aug. 5, 1997) (median net worth by age of householder and monthly household income quintile, 1993 and 1991) <<http://www.census.gov/hhes/www/wealth.htm>>. This figure suggests that, in the aggregate, elderly homeowners have the great bulk of their wealth tied up in the principal residence. See *id.*

be adduced. These elements characterize estate recovery programs as they currently exist in most states. Because certain classes of assets are exempted when determining eligibility for Medicaid, a deceased Medicaid recipient may have been sufficiently needy to qualify for Medicaid and yet still leave a substantial estate.⁵⁴ An estate recovery program focuses on recovering the amount expended on the recipient's behalf from these exempt assets after the recipient's death. The broad parameters of estate recovery programs are provided by federal law and thus can be conveniently examined.

The federal Medicaid estate recovery statute⁵⁵ and its corresponding regulations⁵⁶ currently circumscribe states' ability to seek recovery from a recipient's estate. Although these federal rules are not mandatory, conformity with them is a condition of receiving federal funding,⁵⁷ and such funding, in turn, is essential to state Medicaid programs. Thus, federal guidelines now exist as the outer limit of recovery within which states are free to set their own boundaries. However, since passage of the Omnibus Budget Reconciliation Act of 1993 (OBRA '93),⁵⁸ federal limits now provide a much smaller impediment to a state's efforts at maximum recovery.

The Omnibus Budget Reconciliation Act of 1993⁵⁹ made sweeping changes both to Medicaid laws and to estate recovery programs. Three major changes have substantially impacted state programs. The largest change permits the federal government to condition states' receipt of federal funds upon the establishment of recovery programs.⁶⁰ Prior to such legislation, most states sought recovery only from responsible third parties⁶¹ or, in some cases, from the estates of recipients who died with no surviving spouse or children. These laws were relatively ineffective at generating revenue. For example, in 1987, under a typically weak recovery regime, Florida collected an average of only seventeen dollars per Medicaid-funded nursing home resi-

54. See *supra* notes 24-41 and accompanying text.

55. 42 U.S.C. § 1396p (1994).

56. 42 C.F.R. § 433.36 (1996).

57. See 42 U.S.C. § 1396a(a)(18).

58. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66, § 13612, 107 Stat. 312, 627 (1993).

59. *Id.*

60. See 42 U.S.C. § 1396p(b)(1); see also § 1396a(a)(18) (making compliance with the recovery and adjustment provisions of § 1396p a condition for federal support of state plans).

61. See Dunlop et al., *supra* note 2, at 540.

dent.⁶² The second change allows states to begin seeking recovery from recipients aged fifty-five as opposed to sixty-five years of age.⁶³ Third, the Act also expanded the definition of "estate" from the common-law probate estate to a broader concept which includes other forms of property normally not part of the probate estate.⁶⁴ For instance, a state may decide to include life estate or joint tenancy holdings of the recipient in its estate recovery program.⁶⁵ These changes increase the likelihood that states will obtain recovery from a decedent's estate.

Under OBRA '93, each state is required to enact at least a basic estate recovery procedure in order to receive federal financial support for its Medicaid program.⁶⁶ However, a few states have had estate recovery programs in place for many years.⁶⁷ The success these programs enjoyed did much to persuade Congress to change federal policy on the subject.⁶⁸ In the wake of OBRA '93, many states have now enacted such programs,⁶⁹ even if sometimes reluctantly.⁷⁰ Thus, estate

62. See *id.* at 562. Additional support for the ineffectiveness of earlier recovery procedures is seen by the fact that the amount recovered by Medicaid through adjustments (including prior-period claims adjustments, third-party liability, and other collections) has increased significantly to \$1.4 billion in 1996. See HEALTH CARE FIN. ADMIN., *supra* note 2.

63. See *id.* But see Renee R. Neeld, *Medicaid Planning: 1993 OBRA Asset Transfer Restrictions and Estate Recovery*, 37 RES. GSTAS 329, 331 (1994) (suggesting that the change from 65 to 55 may have been a scrivener's error). Additionally, current HCFA regulations state that, inter alia, adjustments and recoveries may only be obtained "[f]rom the estate of any individual who was 65 years of age or older when he or she received Medicaid." See 42 C.F.R. § 433.36(h)(1)(i) (1996) (emphasis added). Nevertheless, the statute remains unchanged at "55." 42 U.S.C. § 1396p(b)(1)(B).

64. See 42 U.S.C. § 1396p(b)(4)(B).

65. See *id.*

66. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66, § 13612(a)-(c), 107 Stat. 312, 627-28 (1993) (codified as amended at 42 U.S.C. § 1396p(b)(1)).

67. See Dunlop et al., *supra* note 2, at 556-57.

68. See SPECIAL SENATE COMM. ON AGING, DEVELOPMENTS ON AGING: 1993, 1 S. REP. NO. 103-403, at 186-90 (1993).

69. See, e.g., ALASKA STAT. § 47.07.055 (Michie 1994); ARK. CODE ANN. § 20-76-436 (Michie 1994); CAL. WELF. & INST. CODE § 14009.5 (West 1994 & Supp. 1997); COLO. REV. STAT. § 26-4-403.3 (1994); DEL. CODE ANN. tit. 25, § 5003 (1994); FLA. STAT. ANN. § 409.910 (West 1995); IDAHO CODE § 56-218A (Supp. 1996); 305 ILL. COMP. STAT. 5/5-13 (1996); IND. CODE § 12-15-9-1-5 (West 1995 & Supp. 1996); IOWA CODE § 249A.5 (1995 & Supp. 1997); KAN. STAT. ANN. § 39-709 (1994); LA. REV. STAT. ANN. § 153 (West 1996); ME. REV. STAT. ANN. tit. 22, § 14(2-I) (West Supp. 1996); MD. ANN. CODE art. 88A, § 77 (1996); MASS. ANN. LAWS ch. 118E, § 31 (Law. Co-op. 1995 & Supp. 1997); MINN. STAT. ANN. § 256B.15 (West 1995 & Supp. 1997); MISS. CODE ANN. § 43-13-317 (1995 & Supp. 1996); MO. REV. STAT. § 473.398 (1995 & Supp. 1997); N.H. REV. STAT. ANN. § 126-A:51 (1995); N.J. REV. STAT. § 30:4D-7.2 (1995); N.M. STAT. ANN. §§ 27-2A-1 to -9 (Michie 1995); N.Y. SOC. SERV. LAW § 369

recovery has become a crucial consideration for Medicaid recipients and their advisors nationwide.

State recovery statutes endeavor to track closely the format of the federal statute on the subject.⁷¹ The Illinois estate recovery statute is one example.⁷² It provides that amounts expended under the state's Medicaid program for either: (1) a person of any age who is an inpatient in a nursing facility or other medical institution or (2) a person age fifty-five or older, "shall be a claim against the person's estate or against the estate of the person's surviving spouse."⁷³ The state is not permitted to recover the amount of the claim until after the death of the recipient's surviving spouse.⁷⁴ If the recipient's spouse is no longer living, then recovery may still only be obtained if there is no surviving child under age twenty-one, blind, or permanently and totally disabled. These safeguards for a recipient's dependents apply only if Medicaid expenditures were correctly made on the recipient's behalf.⁷⁵ If, however, the recipient was not properly entitled to the assistance, the agency may recover the expenditures at any time.⁷⁶

(McKinney 1995 & Supp. 1997); N.C. GEN. STAT. § 108A-70.5 (1996); OHIO REV. CODE ANN. § 5111.11 (Anderson 1996); 62 PA. CONS. STAT. ANN. § 1412 (West 1996); S.C. CODE ANN. § 43-7-460 (Law. Co-op. Supp. 1997); UTAH CODE ANN. § 26-19-13 (1995 & Supp. 1997); VA. CODE ANN. § 32.1-326.1 (Michie Supp. 1996); WIS. STAT. § 49-496 (1997).

70. See, e.g., 1995 S.C. Acts 71 (stating that "the General Assembly reluctantly complied with the federal mandate" to seek recovery).

71. See 42 U.S.C. § 1396p (1994); 42 C.F.R. § 433.36 (1996).

72. 305 ILL. COMP. STAT. 5/5-13 (West 1995) provides:

To the extent permitted under the federal Social Security Act, the amount expended under this Article (1) for a person of any age who is an inpatient in a nursing facility, an intermediate care facility for the mentally retarded, or other medical institution, or (2) for a person aged 55 or more, shall be a claim against the person's estate or a claim against the estate of the person's surviving spouse, but no recovery may be had thereon until after the death of the surviving spouse, if any, and then only at such time when there is no surviving child who is under age 21, or blind, or permanently and totally disabled. This Section, however, shall not bar recovery at the death of the person of amounts of medical assistance paid to or in his behalf to which he was not entitled; provided that such recovery shall not be enforced against any real estate while it is occupied as a homestead by the surviving spouse or other dependent, if no claims by other creditors have been filed against the estate, or if such claims have been filed, they remain dormant for failure of prosecution or failure of the claimant to compel administration of the estate for the purpose of payment.

73. *Id.*

74. See *id.*

75. See *id.*

76. See 305 ILL. COMP. STAT. 5/11-14.5 (West 1995).

A new definition of "estate" has substantially expanded states' ability to seek recovery of expended funds. Until OBRA '93, the term "estate" remained undefined in federal and state statutes or was defined only as the probate estate under certain state statutes.⁷⁷ Where the term was left undefined, courts generally interpreted "estate" as the common-law probate estate.⁷⁸ Under OBRA '93, states may opt to expand the definition of "estate" to include any other real or personal property and other assets in which the individual had any legal title or interest at the time of death (to the extent of such interest), including such assets conveyed to a survivor, heir, or assign of the deceased individual through joint tenancy, tenancy in common, survivorship, life estate, living trust, or other arrangement.⁷⁹ The federal mandate extends only to recovery from probate estates, and states need not take advantage of the full scope of this broad definition.⁸⁰ Several states have, however, written or amended their recovery statutes to make recovery available from much of the property authorized by the federal statute.⁸¹

1. MEDICAID LIENS

Under certain circumstances, a lien may be placed upon an institutionalized Medicaid recipient's property while the recipient is still living. Provisions for liens were first enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982⁸² (TEFRA '82), in response to rapidly increasing Medicaid expenditures and in an attempt to enhance the effectiveness of existing recovery programs.⁸³ Previously, such liens had been prohibited.⁸⁴ It is important to recognize the difference between liens and recovery under the statutory guidelines, because they are both governed by different restrictions and have different ramifications for the recipient. The lien is merely a security interest in a future recovery placed on the recipient's property while

77. See, e.g., 305 ILL. COMP. STAT. 5/5-13 (West 1995) (referencing the Illinois Probate Act of 1975 for a definition of "estate").

78. See, e.g., *Citizens Action League v. Kizer*, 887 F.2d 1003 (9th Cir. 1989).

79. 42 U.S.C. § 1396p(b)(4)(B) (1994).

80. See *id.*

81. See, e.g., IDAHO CODE § 56-218A (Supp. 1995); 305 ILL. COMP. STAT. 5/5-13 (1995); IOWA CODE § 249A.5 (1994); ME. REV. STAT. ANN. tit. 22, § 14(2-I)(F)(2) (West Supp. 1996); N.Y. SOC. SERV. LAW § 369 (McKinney 1995).

82. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, 96 Stat. 324 (1983).

83. See Medicaid Program; Liens, Adjustments, and Recoveries, 47 Fed. Reg. 43644 (1982).

84. See 42 U.S.C. § 1396p(b) (1988) (amended in 1993).

that person is still alive, whereas the estate recovery claim is "a bill presented to the heirs,"⁸⁵ requiring present payment. Although no recovery may be obtained while a Medicaid recipient is living, federal law allows the agency responsible for estate recovery to impose a lien upon the recipient's principal residence if certain conditions are met.⁸⁶ Two circumstances exist under which liens may be imposed on the property of a living recipient. First, a lien may be imposed on the property of a living recipient for benefits incorrectly paid, following a court judgment establishing the incorrectness of payment.⁸⁷ Second, a lien may be imposed on the real property of a recipient who is an inpatient in a medical institution or long-term care facility from which the recipient is not reasonably expected to return home.⁸⁸ The latter circumstance will suffice to justify imposition of a lien only on real property of the recipient.⁸⁹

Liens on the real property of long-term care and nursing facility patients are subject to further limitations. The first condition is that the recipient must be institutionalized in a nursing home or other long-term care facility that requires him to spend all but a minimal amount of his income for medical costs, and it must appear that the recipient cannot reasonably be expected to return home.⁹⁰ An additional condition, limiting both liens and recovery, is that there must be no surviving relative whose existence prevents application of a lien.⁹¹ This group includes a surviving spouse,⁹² a child under age twenty-one, or a child who is blind or permanently and totally disabled.⁹³ Moreover, if the lien is predicated upon a determination that the recipient is institutionalized and cannot reasonably be expected to return home, there must be no sibling who has lived with the recipient for at least one year immediately prior to admission to a medical institution.⁹⁴ There must also be no adult "caretaker" child.⁹⁵

85. Patricia Tobin, *Medicaid Basics and a Review of Amendments to Medicaid Law Under OBRA '93*, in *PLANNING FOR AGING OR INCAPACITY 1994: LEGAL AND FINANCIAL ISSUES* 203, 213 (PLI Tax Law & Estate Planning Course Handbook Series No. D4-5249, 1994).

86. See 42 U.S.C. § 1396p(a)(1) (1994); 42 C.F.R. § 433.36 (1996).

87. See 42 U.S.C. § 1396p(a)(1); 42 C.F.R. § 433.36(g)(1).

88. See 42 U.S.C. § 1396p(1)(B)(i).

89. See § 1396p(1)(B).

90. See §§ 1396p(a)(1)(B)(i)-(ii).

91. See § 1396p(b)(2).

92. See *id.*

93. See *id.*

94. See § 1396p(b)(2)(B)(i).

Before a lien founded upon permanent institutionalization may be imposed, a medical determination must be made that the recipient cannot reasonably be expected to return home.⁹⁶ This requires that the recipient receive notice of the determination and that a hearing comporting with traditional notions of substantive due process be made available to the recipient.⁹⁷ Furthermore, the notice must explain what is meant by the term lien and indicate that imposing a lien does not mean that the individual will lose ownership of the home.⁹⁸ The hearing is conducted according to state procedures established as part of the state Medicaid plan pursuant to federal regulation.⁹⁹ The burden of proof rests with the state to show that the recipient will not likely be discharged from the institution.¹⁰⁰

Additional restrictions safeguard the interests of the recipient by minimizing the impact of lien impositions. For example, no lien may be foreclosed to effect recovery, nor may a state recover any Medicaid expenditures from the estate except upon disposition of the property by the recipient (through either sale or transfer)¹⁰¹ or until after the recipient dies.¹⁰² Upon the occurrence of any of those events, however, the state is required by federal statute to seek recovery.¹⁰³ Moreover, it should be noted that if the recipient returns home, any lien placed under this provision is dissolved.¹⁰⁴ Thus, it is unlikely that the recipient will be detrimentally affected by the placement of a lien on his or her property.¹⁰⁵

2. ESTATE RECOVERY

The state may recover (in circumstances where no lien was imposed on the recipient's property during his or her lifetime or where property subject to a lien is sold) from the recipient's estate under

95. A "caretaker" child is one who resides in the recipient's home and who has taken care of the recipient for at least two years prior to admission to an institution, if such care permitted the individual to avoid institutionalization during that time. See § 1396p(b)(2)(B)(ii); see also 42 C.F.R. § 433.36 (1996) (requiring the state plan to specify the criteria by which a son or daughter can establish that he or she has been providing the care required to satisfy this provision).

96. See 42 U.S.C. § 1396p(a)(1)(B)(ii).

97. See *id.*

98. See 42 C.F.R. § 433.36(d).

99. See *id.*

100. See *id.* § 433.36(q)(2)(ii).

101. See 42 U.S.C. § 1396p(b)(1).

102. See § 1396p(a)(1).

103. See § 1396p(b)(1).

104. See § 1396p(a)(3).

105. But see *infra* notes 245-48 and accompanying text.

certain conditions. The state may also obtain "recovery" or "adjustment" for expenditures made on behalf of an individual who was age fifty-five or older for assistance consisting of "nursing facility services, home and community-based services, and related hospital and prescription drug services"¹⁰⁶ or any other services provided under the state plan for which the state chooses to seek recovery.¹⁰⁷ The recovery will be sought from property subject to a lien during the recipient's lifetime if that property is sold and was properly subject to a lien under the statute.¹⁰⁸ Otherwise, recovery will be sought from the estate¹⁰⁹ after the death of any dependent relatives, including a spouse, blind or disabled child, sibling who was resident in the home for at least one year, or caretaker child, as specified in the statute.¹¹⁰ If no such relatives remain, recovery may be sought immediately upon the recipient's death.¹¹¹

Finally, Congress tempered the relatively harsh impact of OBRA '93 by requiring states to establish hardship waiver procedures.¹¹² Congress now directs state agencies to establish these hardship guidelines in accordance with regulations promulgated by the Department of Health and Human Services.¹¹³ Under these provisions, the state waives application of its estate recovery procedures where recovery would work an "undue hardship" on the individual.¹¹⁴ Congress also intended for HCFA to provide special consideration for cases in which the estate is the sole income-producing asset of survivors, where the asset is a homestead of minimal value, or where other "compelling circumstances" exist.¹¹⁵ This part of OBRA '93 applies only to benefits paid after October 1, 1993.¹¹⁶ However, although the Department of Health and Human Services has given a conclusory statement of what

106. 42 U.S.C. § 1396p(b)(1)(B)-(i).

107. *See* § 1396p(b)(1)(B)(ii).

108. *See* § 1396p(b)(1)(A).

109. *See id.*

110. *See* § 1396p(b)(2)(A)-(B).

111. *See* § 1396p(b)(2).

112. *See* § 1396p(b)(3).

113. *See* § 1396p(d)(5).

114. *See id.*

115. *See* H.R. REP. NO. 103-11, at 209 (1993), *reprinted in* 1993 U.S.C.C.A.N. 378, 536.

116. *See* Omnibus Reconciliation Act of 1993, Pub. L. No. 103-66, §§ 13611(e), 13612(d), 107 Stat. 312, 628-29.

constitutes hardship,¹¹⁷ it has thus far failed to provide any further regulations to guide state agencies. Furthermore, the determination of hardship in a particular case is left to the discretion of the state agency¹¹⁸ and, therefore, cannot be counted on by individual recipients to avoid recovery.

D. Policy Behind Estate Recovery

Congress had numerous objectives in mind when it included estate recovery as a mandatory part of state Medicaid programs. Reducing overall costs by recouping a portion of expenditures and preventing capable individuals from using Medicaid as artificially inexpensive long-term care insurance became primary goals.¹¹⁹ However, in light of the relatively small impact of estate recovery in reducing overall costs,¹²⁰ the programs may prove most successful as incentives for the purchase of long-term care insurance and consequent disuse of the Medicaid system.

The foremost consideration behind estate recovery is the reduction of the overall cost of Medicaid to states by recouping some portion of Medicaid expenditures. It is difficult to ascertain the effectiveness of estate recovery at achieving this end, because some states may not yet have fully implemented recovery programs. For instance, in Missouri, a state with a comprehensive estate recovery program,¹²¹ \$1,316,925 was recovered during fiscal year 1993,¹²² and \$8,832,006 between 1981 and 1993.¹²³ The former figure represents less than one percent of all Medicaid expenditures in that state during the same year.¹²⁴ In Illinois recovery has been somewhat more effective, generating approximately \$10,669,740 in recoveries in fiscal year 1995 and placing liens upon property valued at \$1,371,991.¹²⁵ Moreover,

117. See HEALTH CARE FIN. ADMIN., STATE MEDICAID MANUAL, PART 3, at SM3 3810(c), available in HEALTH CARE FIN. ADMIN., LAWS, REGULATIONS, MANUALS (May 1997) (CD-ROM).

118. See Schultz Interview, *supra* note 18.

119. See SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 186-90.

120. See *infra* notes 122-28 and accompanying text.

121. See MO. REV. STAT. § 473.398 (1994).

122. See John J. Sastry, *Missouri's Estate Recovery Program*, 50 J. MO. B. 95, 95 (1994).

123. See *id.* at 95 n.1.

124. See KAISER COMM'N ON THE FUTURE OF MEDICAID, HEALTH NEEDS AND MEDICAID FINANCING: STATE FACTS 118 (1995). Missouri's total outlay for Medicaid in 1993 was \$2,252,000,000. See *id.*

125. Schultz Interview, *supra* note 18. It should be noted that a small portion of this total is attributable to recoveries of cash grant assistance rather than Medicaid.

the first two months of 1996 represent a substantial increase over 1995 recoveries, with \$10,014,599 recovered through the end of February 1996.¹²⁶ This increase appears to be the result of the changes in the law precipitated by OBRA '93, which only recently has been fully effectuated.¹²⁷ Additionally, although comparatively small, these figures must be examined in context. In spite of the disregard of certain large assets in determining eligibility,¹²⁸ most individuals will leave estates of negligible size, and often, no estate at all. Thus, the recovered dollars come primarily from middle-class elderly recipients who have become impoverished by long-term care expenditures and who have the bulk of their accumulated wealth invested in their primary residence. Nevertheless, Congress did possess a legitimate basis to believe that estate recovery would become a more effective solution in the future as the wealth of the elderly grows. As one would expect, net worths of older households have been steadily increasing, and as of 1993, this number had risen to \$86,324.¹²⁹ As the population's wealth increases along with the aging of the "baby boom" generation, the success of recovery programs will likely increase, and their importance in controlling Medicaid expenditures will grow.

The long-term care insurance industry was one of the major proponents of OBRA '93's estate recovery mandate.¹³⁰ This group argued that the threat of having a Medicaid recipient's estate consumed by Medicaid debts would provide a strong incentive for elders and their families to purchase long-term care insurance before the need for long-term care arises.¹³¹ Accordingly, Congress contemplated studies which suggested that elders were employing various planning strategies to artificially achieve Medicaid eligibility.¹³² Most frequently, elders converted cash reserves into exempt assets like burial funds or used savings to make home repairs, though occasionally they made

126. See *id.* Medicaid assistance liens have, however, been down somewhat according to the department, totaling \$415,006 through the end of February 1996.

127. See Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66, § 13612, 107 Stat. 312, 627 (1993); see *supra* notes 58-65 and accompanying text.

128. See *supra* notes 24-35 and accompanying text.

129. See U.S. CENSUS BUREAU, ASSET OWNERSHIP OF HOUSEHOLDS: 1993 tbl.D (Aug. 5, 1997) (median net worth by age of householder and monthly household income quintile, 1993 and 1991) <<http://www.census.gov/hhes/www/wealth.htm>>.

130. See Ira Stewart Wiesner, *OBRA '93 and Medicaid: Asset Transfers, Trust Availability, and Estate Recovery Statutory Analysis in Context*, 47 SOC. SEC. REP. SERVICE 757, 761 (1995).

131. See *id.*

132. See SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 186-88.

outright transfers.¹³³ Thus, the changes brought about by OBRA '93 were aimed both at reducing manipulation and at giving the state a second chance at the sheltered wealth after the recipient's death. For chronically poor Medicaid recipients, long-term care insurance is not a viable option because of its expense. Nevertheless, estate recovery may prove unsettling to members of the middle class who can foresee their potential dependence on Medicaid. As a result, many will seek out long-term care insurance long before the need for it arises and when the product is still financially within reach. At this juncture, there is insufficient evidence to establish any causal relationship between OBRA '93 or estate recovery and increasing long-term care insurance purchases.

III. Analysis

A. Paradigm Estate Recovery Statutes in Practice

A brief consideration of how estate recovery programs operate in practice may assist the elder law attorney in advising and planning for clients in this area. In most states, when the recipient originally applies for Medicaid, a tracking designation is assigned so that the state may record all expenditures made on the recipient's behalf.¹³⁴ Upon the death of a Medicaid recipient, the state agency empowered to carry out estate recovery typically will be notified of the recipient's death.¹³⁵ Notice may be accomplished by one of several possible avenues. Often the public assistance case worker will inform the agency responsible for recovery of the death, if that case worker is aware of it.¹³⁶ Alternatively, states may employ some type of death match report or may use clippings of applications for letters testamentary.¹³⁷ In Illinois, for example, the department responsible for collections maintains a staff throughout the state that regularly searches courthouse records for death certificates and applications for letters testamentary and then compares names of decedents with a list of Medicaid recipients bound for recovery.¹³⁸ Additionally, some state agencies require that the executor of an estate notify the state of the

133. See *id.* at 188.

134. See Sastry, *supra* note 122, at 97.

135. See *id.*

136. See Schultz Interview, *supra* note 18.

137. See Sastry, *supra* note 122, at 98.

138. See Schultz Interview, *supra* note 18.

recipient's death and the consequent opening of an estate.¹³⁹ Thus, by one of the aforementioned methods, the state agency is very likely to be notified of the recipient's death. In a few states, the agency is required to provide notice of the existence of the recovery claim to all heirs and devisees whose identity can be reasonably determined.¹⁴⁰ At that point, if the necessary conditions are met, the agency will present a claim to the estate of the recipient equal to the amount of assistance expended or the value of the recipient's estate, whichever is less, or by filing a claim in the court of competent jurisdiction for assets not included in the probate estate.¹⁴¹ The agency generally must do so within the time prescribed for claims against decedents' estates under state law.¹⁴² Such a claim generally takes precedence over all unsecured claims, except funeral and burial expenses and administrative costs, such as probate fees, taxes, and other death-related expenses.¹⁴³ This order is determined by state law,¹⁴⁴ however, and may vary. If there is a surviving spouse or a disabled or blind child, the agency will simply await the time when no such relative survives and then seek recovery from the original recipients' assets to the extent that they remain.¹⁴⁵ It is important to note that "the federal statute only contemplates that the deceased recipient's assets will be traced, not that other persons can become liable to pay over their own personal assets."¹⁴⁶

B. Effect of Estate Recovery Programs on Recipient's Surviving Family

The extent to which states are permitted to collect the Medicaid debts of a deceased recipient from the estate of that recipient's relatives remains largely unclear. Generally, the relatives of a recipient will be subject to recovery only to the extent that they have received assets of the recipient.¹⁴⁷ In these cases, the burden is on the agency seeking recovery to substantiate its entitlement to recoupment of ben-

139. *See id.*

140. *See, e.g.*, MINN. STAT. § 256B.15(1a)(c) (1995).

141. *See, e.g.*, ME. REV. STAT. ANN. tit. 22, §§ 14(2-1)(B)(1)-(2) (West 1994).

142. *See, e.g.*, MONT. CODE ANN. § 53-2-611(1) (1993).

143. *See, e.g.*, CONN. GEN. STAT. ANN. § 17b-95 (West 1997); MASS. GEN. LAWS ch. 198, § 1 (1994); N.J. REV. STAT. § 30:4D-7.2(d) (1994).

144. *See sources cited supra* note 143.

145. *See supra* notes 71-76 and accompanying text.

146. *See Demille v. Belshe*, No. C-94-0726-VRW, 1994 WL 519457, at *7 (N.D. Cal. Sept. 16, 1994).

147. *See id.*

efits from parties to whom the recipient transferred property.¹⁴⁸ Some courts have held that the Medicaid statute governing estate recovery and its corresponding regulations "restrict only the [state's] ability to seek reimbursement from the estate of the Medicaid recipient and provide no limitation on the [state's] ability to seek reimbursement from the estate of a spouse" for debts of the original recipient.¹⁴⁹ Conversely, in *In re Estate of Burstein*¹⁵⁰ the court found that the dominant purpose of the federal limits on estate recovery¹⁵¹ is to protect a spouse or permanently disabled child from loss of support during a recipient's lifetime and to allow the recipient to provide for them after death. The latter holding comports most closely with the understanding of the HCFA¹⁵² and seems appropriate in light of the strong safeguards for the interests of vulnerable family members that are included in the federal recovery legislation.¹⁵³

A somewhat more difficult question arises when state "responsible relative" statutes come into play.¹⁵⁴ Such statutes exist in most states, though they are seldom enforced.¹⁵⁵ These statutes make certain family members responsible for the necessary debts of their relatives.¹⁵⁶ When medical assistance is furnished, an implied contract with the responsible relative is considered to have been created.¹⁵⁷ Thus, for example, a parent might be responsible for the housing or medical needs of his or her child, even though the child does not reside with the parent. Similarly, a spouse with financial means might

148. See *In re Estate of Rhodes*, 561 N.Y.S.2d 344, 346 (N.Y. 1990).

149. *Nass v. Perales*, No. 85 CIV. 4485, 1986 WL 68487, at *2 (E.D.N.Y. Sept. 3, 1986).

150. 611 N.Y.S.2d 739 (N.Y. 1994).

151. See 42 U.S.C. § 1396p (1994).

152. See, e.g., 47 Fed. Reg. 43644-45 (1990) (considering the reduced likelihood of surviving children or spouses becoming charges of the state when estate recovery is limited to cases where no spouse or child under 21, blind, or permanently disabled, survives).

153. See 42 U.S.C. § 1396p(b)(2).

154. For a discussion of responsible relative statutes and the Health Care Financing Administration's position towards them, see generally George F. Indest III, *Legal Aspects of HCFA's Decision to Allow Recovery from Children for Medicaid Benefits Delivered to Their Parents Through State Financial Responsibility Statutes: A Case of Bad Rule Making Through Failure to Comply with the Administrative Procedure Act*, 15 S.U. L. REV. 225 (1988).

155. For a discussion of family responsibility laws, see generally Usha Narayanan, Note, *The Government's Role in Fostering the Relationship Between Adult Children and Their Elder Parents: From Filial Responsibility Laws to . . . What?, A Cross-Cultural Perspective*, 4 ELDER L.J. 369 (1996).

156. See, e.g., N.Y. SOC. SERV. LAW § 101(1) (McKinney 1992).

157. See *In re Estate of Craig*, 624 N.E.2d 1003, 1005 (N.Y. 1993) (interpreting N.Y. SOC. SERV. LAW §§ 363(3), 369(2)).

be held legally responsible for the medical expenses of an impoverished spouse even though the two no longer live together. Nevertheless, because federal statutes governing Medicaid estate recovery demonstrate a clear intent to prevent the impoverishment of Medicaid recipients and their relatives, state courts have held that federal Medicaid law does limit the state's ability to recover expenditures from a responsible relative.¹⁵⁸

In *In re Estate of Craig*,¹⁵⁹ the court held that recovery of correctly paid Medicaid expenditures could not be obtained from the estate of a surviving spouse.¹⁶⁰ In that case, the wife did not have sufficient means to pay the medical expenses of her husband (\$4,737.79) when those expenses were paid by Medicaid.¹⁶¹ At her death, the remainder of a reverse mortgage created an estate of approximately \$27,000.¹⁶² The court held that a responsible relative's duty accrued at the time of the Medicaid payments, if that relative had sufficient means.¹⁶³ If, however, the means to pay for the recipient's care did not come until after payment by Medicaid or, as here, until after the death of the potentially responsible relative, that avenue of recovery was foreclosed to the state.¹⁶⁴ Thus, it is only contemporaneous sufficient means that matter for the establishment of responsible relative liability. Moreover, the court found that the surviving spouse cannot be deemed a responsible relative with financial means simply because that spouse owns a home.¹⁶⁵ However, limitations to this general principle do exist:

An exception to this prohibition is allowed after the death of persons over 65 years of age when the asset may be liquidated to recoup the person's Medicaid payments. But the exception is qualified, and does not allow the state to reach even farther back for recoupment as to a predeceased spouse's Medicaid payments The exception is a one shot, not a double barreled opportunity.¹⁶⁶

158. See, e.g., *In re Estate of Harris*, 387 N.Y.S.2d 796 (N.Y. Sur. Ct. 1976).

159. 624 N.E.2d 1003.

160. See *id.* at 1006.

161. See *id.* at 1004.

162. See *id.*

163. See *id.* at 1005.

164. But see *In re Estate of Hooey*, discussed *infra* notes 182-94 and accompanying text.

165. See *In re Estate of Craig*, 624 N.E.2d at 1004.

166. *Id.* at 1005.

The state may not seek recovery from a recipient's estate while a surviving spouse is still living, even if the spouse no longer resides with the recipient.¹⁶⁷

Recovery from a recipient's estate while children of the recipient are living is also an area over which courts have differed. Some courts have held that if a minor, blind or disabled child of the recipient was not a beneficiary of the recipient's estate, the agency may still seek recovery.¹⁶⁸ Others have held that the plain meaning of the statutory language must control, and that if any family member mentioned in the statute survives, regardless of that individual's dependency on the recipient, recovery will not be allowed.¹⁶⁹ The factual question of whether a particular child is "totally disabled" as mandated by most state recovery statutes has sometimes proven troublesome as well.¹⁷⁰

C. Challenges to Estate Recovery

Even before OBRA '93 mandated widespread passage of estate recovery programs, recipients of Medicaid challenged their validity. Such challenges to recovery of correctly paid benefits by the recipient or his or her heirs have emphasized the scope of the recipient's "estate" subject to recovery.¹⁷¹ This avenue of attack has, however, been largely foreclosed by the changes brought about by OBRA '93.¹⁷² Similarly, estate recovery programs that limit aid to recipients sixty-five years of age or older have been hailed as antithetical to the Equal Protection Clause of the Fourteenth Amendment.¹⁷³ Such challenges, however, have consistently failed and courts have continued to uphold the distinction made by states as rationally related to legitimate state interests.¹⁷⁴

167. See *In re Estate of Rundell*, 344 N.Y.S.2d 6, 8 (N.Y. App. Div. 1973).

168. See, e.g., *In re Estate of Samuelson*, 493 N.Y.S.2d 784, 787 (N.Y. App. Div. 1985).

169. See, e.g., *In re Estate of Burstein*, 611 N.Y.S.2d 739, 740 (N.Y. Sur. Ct. 1994).

170. See, e.g., *In re Estate of Peck*, 416 N.W.2d 158 (Minn. Ct. App. 1987).

171. See, e.g., *Citizen's Action League v. Kizer*, 887 F.2d 1003, 1006-07 (9th Cir. 1989) (holding that real property passing by joint-tenancy is not part of the probate estate and therefore is exempt from California's estate recovery provisions).

172. See *supra* notes 64-65 and accompanying text.

173. See, e.g., *In re Estate of Turner*, 391 N.W.2d 767, 768-70 (Minn. 1986) (noting that relaxed eligibility standards for persons over 65 make recovery from such individuals alone a rational distinction); *In re Estate of Davis*, 442 N.E.2d 1227, 1230 (N.Y. 1982) (reasoning that the legislature may have believed that individuals below age 65 stood a better chance of regaining health and returning to self-sufficiency).

174. See sources cited *supra* note 173.

In *Demille v. Belshe*,¹⁷⁵ the federal District Court for the Northern District of California issued a permanent injunction against the application of California's estate recovery statute because California's recovery procedure was held to violate due process.¹⁷⁶ In that case, the heirs of recipients were denied access to a hearing until after liens were placed upon their real property.¹⁷⁷ California law provided that a lien was to be placed on the decedent recipient's interest in the real property of a surviving spouse, in the amount of the department's entitlement, with the lien "due and payable" only upon the death of the surviving spouse or the sale, transfer, or exchange of the real property.¹⁷⁸ The court held that the risk of erroneous deprivation was too high to allow such a lien to be attached prior to a hearing.¹⁷⁹ California's legislature recently repealed that part of the state's recovery procedure.¹⁸⁰ More generally, *Demille v. Belshe* stands for the proposition that the U.S. Constitution requires states to provide Medicaid recipients or their affected heirs with an opportunity for a hearing before applying any type of lien to real property.¹⁸¹

In *In re Estate of Hooley*,¹⁸² the Supreme Court of North Dakota considered the timing of the state's ability to recoup Medicaid benefits from a recipient.¹⁸³ In that case, the State Department of Human Services sought recovery for properly made expenditures from the estate of a recipient.¹⁸⁴ The beneficiaries of the estate countered that the claim against the estate was not filed in a timely manner under the state law.¹⁸⁵ This contention rested on the beneficiaries' belief that the state's claim for recovery arose only at the time of death.¹⁸⁶ If that were the case, state law would have allowed the creditor—here the state—only three months to bring its claim.¹⁸⁷ If, however, the claim

175. *Demille v. Belshe*, No. C-94-0726-VRW, 1995 WL 23636, at *1 (N.D. Cal. Jan. 12, 1995).

176. *See id.* at *2.

177. *See id.*

178. *See id.* at *3.

179. *See id.* at *2.

180. *See* CAL. WELF. & INST. CODE § 14009.5(c) (West Supp. 1997) (as amended by 1995 Cal. Stat. 548, § 2 (1995)).

181. *See generally* *Demille v. Belshe*, No. C-94-0726-VRW, 1995 WL 23636, at *2 (N.D. Cal. Jan. 12, 1995) (conferring the right to a hearing to those with an ownership interest in the affected property).

182. 521 N.W.2d 85 (N.D. 1994).

183. *See id.* at 86.

184. *See id.*

185. *See id.*

186. *See id.*

187. *See id.*

arose during the life of the beneficiary, a three-year window existed in which claims could be brought.¹⁸⁸ The court held that the state's claim arose at the time the benefits were received, not at the point of death.¹⁸⁹ The court noted, *inter alia*, that four circumstances must exist before the state agency may recover assistance funds under North Dakota's statutory guidelines,¹⁹⁰ which are illustrative of most state recovery limits:

First, the recipient must have been sixty-five years of age or older when the benefits were received. Second, the Department may recover only from the estate of the recipient, i.e., only upon the death of the recipient. Third, the Department must await the death of the recipient's spouse, if any. Fourth, it must await the death or majority of any surviving child who is under age twenty-one, or the death of a surviving child who is blind or permanently and totally disabled.¹⁹¹

Because the latter three events will eventually occur in all cases, their only function would be to govern the timing of recovery.¹⁹² These events have no bearing on the existence of the state's claim to recovery, only when that recovery may be sought.¹⁹³ However, "not all recipients of medical assistance will be age sixty-five or older when they receive aid."¹⁹⁴ Thus, the threshold issue of age at the time of receipt is the only means of completely avoiding the existence of a recovery claim at the time of death.

Applying similar principles, the court in *Estate of Cripe*¹⁹⁵ recently found that the estate of a deceased Indiana Medicaid recipient was liable for expenditures made on her behalf, despite the argument by representatives of her estate that her ability to pay arose only after her death.¹⁹⁶ Representatives of the estate relied on a statute purportedly limiting the state's recovery claim against assets to the amount of assistance paid after those assets were acquired.¹⁹⁷ The court rejected

188. *See id.*

189. *See id.* at 87. *But see In re Estate of Hoover*, 251 N.W.2d 529, 531 (Iowa 1977) (finding that the state's claim to recovery of assistance accrued at the time of death, not receipt).

190. N.D. CENT. CODE § 50-24.1-07 (1997).

191. *Hooley*, 521 N.W.2d at 86 (citing N.D. CENT. CODE § 50-24.1-07).

192. *See id.* at 87 (citing *Department of Public Welfare v. Anderson*, 384 N.E.2d 628, 633-34 (Mass. 1979)).

193. *See id.*

194. *Id.* at 87 (quoting *Anderson*, 384 N.E.2d at 633-34).

195. 660 N.E.2d 1062 (Ind. Ct. App. 1996).

196. *See id.* at 1064.

197. *See id.* at 1063-64. The estate relied upon IND. CODE § 12-5-3-14 (repealed 1983), a statute which is better understood as pertaining to responsible relative claims, rather than claims against the decedent recipient's estate. *See id.*; *supra*

this proposition, finding that the state's recovery claim is not limited to the amount of assistance paid after the recipient obtains resources.¹⁹⁸ The court also rejected the estate's argument that the state could not have a claim against the recipient's resources if the recipient herself could not have "assigned or sold her expectancy interest" in the assets, as lacking legal authority.¹⁹⁹ This notion comports with OBRA 93's expansion of the definition of estate to encompass assets that may not have actually been available to the recipient during his or her lifetime.²⁰⁰

In *Citizens Action League v. Kizer*,²⁰¹ the Ninth Circuit Court of Appeals held that "estate" within the estate recovery statute did not include property formerly held in joint tenancy²⁰² and that allowing recovery of Medicaid from a surviving joint tenant was therefore impermissible.²⁰³ In enacting OBRA '93, Congress attempted to eliminate this avenue of recovery by allowing states simply to redefine "estate" to include, among other things, property held in joint tenancy.²⁰⁴ Nevertheless, the language of the statute allows recovery from "any other real and personal property and other assets in which the individual had any legal title or interest at the time of death."²⁰⁵ Ironically, the statute allows states to include property held in joint tenancy, tenancy in common, life estate, and other forms.²⁰⁶ These two phrases appear contradictory on their face, because under state law at the time of death, an individual generally has no legal or equitable interest in property formerly held in joint tenancy prior to death or in a life estate.²⁰⁷

notes 155-67 and accompanying text (briefly discussing responsible relative statutes).

198. See *Cripe*, 660 N.E.2d at 1064.

199. See *id.*

200. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-661, § 13612(c), 107 Stat. 312, 628 (codified as amended at 42 U.S.C. § 1396p(b)(4) (1994)).

201. 887 F.2d 1003 (9th Cir. 1989).

202. See *id.* at 1006.

203. See *id.* at 1008.

204. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-661, § 13612(c), 107 Stat. 312, 628 (codified as amended at 42 U.S.C. § 1396p(b)(4)(B) (1994)).

205. 42 U.S.C. § 1396p(b)(4)(B).

206. See *id.*

207. See JOHN E. CRIBBET ET AL., *PRINCIPLES OF THE LAW OF PROPERTY* 106 (3d ed. 1989).

D. Recovery and Estate Planning

Because of the comprehensive nature of estate recovery programs, the best way to avoid the effect of these programs is through effective long-range planning.²⁰⁸ Although Medicaid eligibility requirements are exacting and demand careful attention to detail, it is possible to avoid the harshest effects of estate recovery through proper planning. Perhaps the best strategy for the elderly person with sufficient income is the purchase of quality long-term care insurance to avoid the Medicaid trap altogether.²⁰⁹

Legislators, alert to the widespread use of Medicaid planning,²¹⁰ have done much to limit the ability of elders to avoid estate recovery by imposing harsh penalties for asset transfers in the period preceding application for Medicaid. Thus, OBRA '93 instituted a longer look-back period of thirty-six months for scrutinizing transfers occurring after August 10, 1993, in order to limit the ability of elders to transfer assets.²¹¹ The transfer of assets by an applicant for less than market value will be considered to be a transfer to achieve eligibility for benefits.²¹² Any such transfer will result in a penalty of a period of ineligibility, the length of which is determined by a formula which considers the amount transferred and the prospective cost of long-term care.²¹³ Recent legislation has even gone so far as to impose a criminal penalty on those who advise a person about such transfers for a fee.²¹⁴

The previously existing thirty-month cap on ineligibility penalties also was eliminated by OBRA '93.²¹⁵ As a result, applicants may be severely penalized for asset transfers made in violation of existing regulations. It is possible for a very large asset transfer to preclude

208. A detailed description of estate planning techniques, either for Medicaid eligibility or for avoidance of estate recovery, is certainly beyond the scope of this note. What follows is therefore intended to introduce certain planning considerations regarding the assets that may remain in the estate of a Medicaid recipient as they relate to estate recovery.

209. See Brian E. Barreira, *Long-Term Care Insurance—A Necessary Option to Consider*, NAELA NEWS, July 1995, at 1 (considering the importance to elder law attorneys of examining long-term care insurance as an option to meet their client's planning needs).

210. See SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 186-90.

211. See 42 U.S.C. § 1396p(c)(1)(B)(i).

212. See Gary Mazart, *Protecting the Home in Government Benefits Planning*, N.J. LAW, Oct. 1994, at 34, 35.

213. See *id.*

214. See Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4734, 111 Stat. 251, 706 (1997) (codified as amended in 42 U.S.C. § 1320a-7b(a)(6)).

215. 42 U.S.C. § 1396p.

permanently an applicant from achieving Medicaid eligibility.²¹⁶ Thus, estate planners should be extremely careful in considering the Medicaid eligibility consequences of any asset transfer.

Although trusts are an integral part of estate planning generally, they are of lesser value in protecting the assets of Medicaid recipients from recovery. One method which has been frequently employed by estate planners is the creation of a revocable *inter vivos* trust. Assets held in a revocable trust continue to be considered to be within the control of the Medicaid recipient under current law.²¹⁷ Thus, for example, in *Belshe v. Hope*,²¹⁸ a California appellate court recently found that the estate of a recipient included non-probate transfers upon death made from a revocable *inter vivos* trust.²¹⁹ The court reasoned that trust assets were subject to Medicaid liens for expenditures.²²⁰

A strategy that may prove effective in certain circumstances is the outright transfer of the home to a healthy spouse. Such a transfer continues to be exempt under Medicaid.²²¹ If, however, eligibility was based on receipt of cash assistance, a period of ineligibility might still result because the husband and wife are treated separately for such purposes.²²² Nevertheless, if the spouse who is healthy at the time of transfer later becomes ill and requires long-term care, the benefit of the transfer may be lost entirely.²²³ Moreover, in many cases, unless the at-home spouse enrolls in some sort of long-term care insurance, such action may simply delay the inevitable.

Because of these complex planning considerations for the elderly with sufficient means, long-term care insurance may be the simplest and most dependable strategy for avoiding estate recovery. By providing for the eventuality of long-term nursing home or in-home care, elders can avoid the impoverishment that drives many to rely upon Medicaid. Indeed, as noted earlier, one of Congress's main goals was to encourage elders to obtain long-term care insurance.

216. See James C. Peart, *Medicaid Nursing Home Financing and OBRA 1993 Changes*, ADVOCATE, May 1994, at 14.

217. See 42 U.S.C. § 1396p(d)(3)(A).

218. 38 Cal. Rptr. 2d 917 (Cal. Ct. App. 1995).

219. See *id.* at 175.

220. See *id.*

221. See Mazart, *supra* note 212, at 35.

222. See *id.* at 38.

223. See *id.*

E. Possible Changes in Medicaid Legislation

There have been several proposals to alter the Medicaid estate recovery program at the federal level. Although very different from one another, all of the proposals suggest an increasing role for estate recovery. At least one proposal considered by Congress would turn Medicaid over to the states through so-called block grants.²²⁴ Such a plan would leave states free to structure Medicaid programs with minimal or no federal guidance,²²⁵ forcing states to create their own estate recovery programs. Projected funding cuts would provide a strong incentive for states to make maximum use of recovery. In doing so, legislators should be mindful both of the need for reducing Medicaid expenditures and of the emotional—and politically delicate—nature of estate recovery for elders and their families. The current federal estate recovery scheme²²⁶ provides a solid foundation on which to build, but this foundation may certainly be improved. Additionally, various budget proposals have suggested a tightening of recovery procedures to help reduce Medicaid costs, while alternative proposals seek increased limits on recovery.²²⁷ Other proposals have included extending recovery expenditures for such things as home- and community-based care within the existing administrative framework of Medicaid.²²⁸

IV. Resolution

States should enact estate recovery programs which maximize recovery while having the least possible impact on recipients or their surviving spouses. This requires an aggressive approach to recovery that demands significant administrative resources,²²⁹ as well as the willingness to endure strong political opposition in some cases. The necessary changes could be made primarily by a shift in focus from the age of the recipient at the time that aid was received to the wealth of the recipient at the time of death. As a result, estate recovery programs would do more to distinguish between well-off recipients who

224. H.R. 280, 104th Cong., §§ 2100-2175 (1995).

225. *See id.* § 2135(g).

226. *See* 42 U.S.C. § 1396p (1994).

227. *See, e.g.,* H.R. 2491, 104th Cong. § 2135(g) (1995).

228. *See, e.g.,* S. 86, 104th Cong. (1995) (a proposal by Senator Feingold to give states the option of seeking recovery for home- and community-based services for individuals over age 55).

229. *See* Dunlop et al., *supra* note 2, at 536.

are simply hiding assets and poor recipients who have managed to hold on to only a small core group of assets accumulated over a lifetime such as their homes. Federal law currently requires recovery only from the estates of recipients age fifty-five²³⁰ or older. A better method of recovery would prohibit the use of liens on the property of any living recipient or spouse, by confining the definition of estate to the property subject to administration in the probate estate and by requiring that Medicaid recipients or their representatives to be fully informed of the possible effects of recovery. Finally, the institution of a minimum estate value for recovery would ensure that poor recipients are not penalized excessively for resorting to Medicaid.

Limiting recovery to estates of a certain size would prevent an excessive penalty against poor Medicaid recipients and fulfill the original aims of the estate recovery programs. Preventing financially capable elders from utilizing Medicaid as a type of long-term care insurance was one of the primary reasons for the passage of OBRA '93 and the institution of estate recovery programs.²³¹ The injustice of financially comfortable elders exploiting Medicaid sparked outrage among the public as well as numerous commentators.²³² Even after passage of OBRA '93, at least one commentator believes that "prosperous people with access to the right legal and financial advice will continue to find ways to qualify for Medicaid nursing home benefits without spending down and without estate recovery liability."²³³

One way of ensuring that Medicaid is reserved for indigent individuals is by structuring an estate recovery scheme that begins with estates with a value of, for instance, \$10,000.²³⁴ Under such a system, only those individuals whose estate value exceeded the threshold would be required to pay the state for the expenditures made on their behalves. A minimum recoverable estate value is already utilized in

230. *But see supra* note 63 (considering whether the change from 65 to 55 years of age may have been a scrivener's error).

231. *See* SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 186-90 (discussing Medicaid estate planning techniques as studied by the GAO and noting that OBRA '93's amendments to Medicaid were made "in response to concerns of State officials about estate planning activity, as well as concerns of the private insurance industry that the ability of persons to transfer assets undermines the growth of the long-term care insurance market").

232. *See, e.g.*, STEPHEN A. MOSES & LTC, INC., *THE FLORIDA FULCRUM: A COST SAVING STRATEGY TO PAY FOR LONG TERM CARE* (1994).

233. *Id.* at 56.

234. In 1993, the average Medicaid applicant had \$38,202 in assets, including the home, and \$14,875 in assets other than the home. *See* SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 188.

some states,²³⁵ but the minimum employed is insufficient to prevent recovery even from genuinely poor elders. If estate recovery is intended to prevent elders with sufficient means from abusing the Medicaid system, then its focus should be more particularly directed at that group. By reaching individuals who leave meager estates of three or four thousand dollars, for instance, recovery provisions deprive indigent individuals of the ability to pass on any inheritance whatsoever to friends or relatives. It is axiomatic that the desire to pass on an inheritance, to leave something of oneself behind, is of great concern to many elders.²³⁶ To be sure, those who have genuinely turned to Medicaid for their care will likely have proven themselves unsuccessful at amassing such a heritage for their progeny. Certainly, it may be argued that the complete deprivation of the right to pass on assets is the appropriate consequence of finding oneself indigent and turning to the state for support in the months or years before death. This reaction seems unnecessarily punitive. Medicaid is a program aimed at providing medical assistance to those "whose income and resources are insufficient to meet the costs of necessary medical services."²³⁷ By enlarging the scope of estate recovery, Congress was intending to ensure that the program continued to fulfill that mission, while preventing well-advised and comparatively wealthy elders from receiving its benefits.²³⁸ This necessary and compassionate goal should not deprive indigent individuals of the prospect of passing on more than a memory of destitution to their loved ones.

Rather than focusing on the age of the recipient at the time benefits were received, recovery should depend upon the size of each former recipient's estate when that person dies, with states recovering where the estate exceeds the established threshold. By seeking recov-

235. See, e.g., N.J. REV. STAT. § 30:4D-7.2a (1997) (excluding recovery or liens upon estates with a gross value of less than \$3000). This low amount suggests that the purpose of the statute is simply to prevent the wasting of administrative resources on de minimis recoveries, rather than concerns of equity toward impoverished elders and their heirs.

236. See, e.g., Marshall B. Kapp, *Options for Long-Term Care Financing: A Look to the Future*, 42 HASTINGS L.J. 719, 719 (1991) (noting that "financial impoverishment with . . . its dampening of an elder's ability to leave a significant financial inheritance to his or her heirs is perhaps the most feared result of the aging process."); see also *Proverbs* 13:22 (New American Standard) ("A good man leaves an inheritance to his children's children, and the wealth of the sinner is stored up for the righteous.").

237. 42 U.S.C. § 1396 (1994).

238. See SPECIAL SENATE COMM. ON AGING, *supra* note 68, at 186-90.

ery of assistance paid on behalf of all recipients, regardless of age, states would maximize recovery and avoid the perceived unfairness that results under present law.²³⁹ Currently, states only seek recovery of assistance paid on behalf of individuals who are fifty-five years of age or older or those who have been inpatients in long-term care facilities.²⁴⁰ This is an unnecessary and arbitrary distinction. Except to the extent that eligibility requirements are relaxed for elderly applicants, elderly recipients should be treated as are other adult recipients. Removal of the distinction would almost certainly increase the overall amount of recovery.²⁴¹ Moreover, insofar as estate recovery fulfills a perceived desire to see recipients of government welfare expenditures give something back to the system,²⁴² it will presumably be of even greater efficacy when applied to younger recipients. Consider the example of an indigent fifty-four year old who receives substantial Medicaid expenditures for successful treatment of cancer. If his good fortune continues, and he later comes into a substantial inheritance, he need not concern himself with reimbursing the state for its Medicaid expenditures on his behalf. Of course, our fortunate fellow would be in a very different situation if the expenditures were made after his fifty-fifth birthday. In that case, the state would have a claim against

239. Admittedly, seeking recovery from the estates of all one-time recipients of Medicaid would present administrative challenges, but these do not seem insurmountable in light of other records that follow one throughout life, such as Social Security data. Indeed, perhaps recovery could be better achieved by including a record of the existence of a claim in the individual's Social Security file. The suspension of Social Security payments would almost certainly require the agency to be notified of the recipient's death and would, therefore, place them in a position to notify the state of its need to seek recovery, even if that need arose several decades after the assistance was received.

240. See *supra* notes 106-07 and accompanying text. The inclusion of recipients who are inpatients in nursing facilities along with recipients aged 55 or older may suggest that states are attempting to limit recovery to those who are near death at the time of receipt and are using age as a proxy for such proximity to death. It is questionable, however, whether such a proxy would represent the kind of ageism that federal policy has generally opposed, particularly as embodied in the Age Discrimination in Employment Act of 1967, 29 U.S.C. §§ 623-637 (1994). However, in light of the lowering of the threshold age of recovery from 65 to 55—in spite of increasing life expectancies—it remains unclear whether the distinction represents any policy apart from simple fiscal expediency. For a brief discussion of equal protection challenges to estate recovery, see *supra* notes 173-74 and accompanying text.

241. Although a substantial proportion of Medicaid expenditures are made on behalf of those aged 65 and over (approximately 55% in 1994), 45% of expenditures are made by those under 65, and 22.5% of Medicaid expenditures were made on behalf of those aged 21 to 65. See HEALTH CARE FIN. ADMIN., *supra* note 37.

242. See, e.g., Sastry, *supra* note 122, at 95 (recalling colonial attitudes toward social welfare programs).

his estate for the entire value of the expenditures made on his behalf. Such a scenario is the indefensible result under current law. Though such inequities are the inevitable result of many bright-line distinctions made in the law, they should not simply be disregarded without careful scrutiny. If the aim of recovery programs is to see the state reimbursed for its expenditures, for purely fiscal reasons, that goal will be achieved more fully by having the fifty-four-year-old recipient—or twenty-four year old for that matter—pay. Moreover, if the goal of recovery is instead to achieve some measure of perceived social justice by having those who are able reimburse the state for its expenditures, it obviously will also be fulfilled by having younger recipients pay.

Furthermore, limiting the placement of liens on the property of living recipients would reduce the burden of estate recovery on the recipient and his or her family members. The state currently may not place a lien on a recipient's property unless it appears reasonably certain that the recipient will not be released from a medical institution.²⁴³ Nevertheless, such an approach cannot help but put unnecessary pressure on recipients or their families as they approach the decision of whether to enter a long-term care facility or to remain at home. Because of the state's ability to learn of the recipient's death,²⁴⁴ the need for placement of a lien is limited. Rather than burden the recipient with a lien, the state should look to improve its ability to learn of recipients' deaths in a timely manner. The imposition of liens for assistance correctly paid should be limited to the rare instances where the state agency makes an affirmative showing that there is unacceptable risk to the states future interest in recovery. Factors that might be considered are the value of the home, the location of the home (an isolated or rural location might make learning of the recipient's death in a timely manner impracticable), or any past attempts to defraud the state by either the recipient or an individual with power of attorney for the recipient. Unless such an affirmative showing can be made, imposition of a lien places a small but unnecessary burden on the recipient and should be prohibited.

Confining the definition of "estate" from which recovery is sought to only that property subject to administration in the probate estate under state law would prevent the unfairness of recovery from

243. See *supra* notes 96-100 and accompanying text.

244. See *supra* notes 135-40 and accompanying text.

assets that were not, in fact, available to the recipient. The expanded definition of estate works an injustice against Medicaid recipients and their heirs by allowing recovery from assets that may not have been available to fund the care of the recipient during his or her lifetime. It is HCFA's position that these are resources that were properly available to the state at the time the recipient received the assistance.²⁴⁵ Under this view, it is merely the state's benevolent forbearance that allows the recipient to maintain these assets after death, not any positive lack of entitlement to them.²⁴⁶ If, prior to the expansion of the estate definition, a deceased recipient and a surviving spouse were formerly joint tenants of certain real property, that property could not be used to reimburse the state for the recipient's Medicaid debts.²⁴⁷ This is a just result because the recipient may not have been able to use those assets while living. Moreover, such a disposition comports with the traditional understanding of joint tenancy with right of survivorship. In that case no interest actually passes at the time of one joint tenant's death; the interest of the other joint tenant(s) simply expands or continues, unaffected by the deceased joint tenant's interest.²⁴⁸ Thus, nothing passes from the deceased joint tenant to the surviving joint tenant. For the state to obtain recovery in a case where the recipient did not have access to the asset prior to death and where the surviving joint tenant did not legally receive any property of the recipient upon the recipient's death seems an inconsistent and inequitable result. In acknowledging this inherent unfairness, some state statutes have specifically omitted joint tenancy from estate recovery even though states are authorized by federal law to include such property.²⁴⁹ Nevertheless, others have gone even further, including property formerly held by the recipient as a life estate or in a living trust within the recoverable estate.²⁵⁰

245. See 42 C.F.R. § 433.310 (1996).

246. See *id.*

247. See *Demille v. Belshe*, No. C-94-0726-VRW, 1994 WL 519457, at *15 (N.D. Cal. Jan. 12, 1995).

248. See CRIBBET ET AL., *supra* note 207, at 106 (noting that no interest actually passes to remaining joint tenants or tenants on the death of other joint tenant); see also ROGER A. CUNNINGHAM ET AL., *THE LAW OF PROPERTY* 194 (2d ed. 1993) (noting that at common law, the last surviving joint tenant became the sole owner because his original interest in the entire estate was the only interest left after all other joint tenants died, rather than because the deceased joint tenants' interests passed to the remaining joint tenant).

249. See, e.g., ME. REV. STAT. ANN. tit. 22, § 14(2-I)(f) (West Supp. 1996).

250. See, e.g., IDAHO CODE § 56-218(4)(b) (1995); IOWA CODE § 249A.5(2)(c) (1994).

Placing greater emphasis on full disclosure of Medicaid estate recovery and its possible effect on the recipient's estate would allow recipients and their representatives to make an informed decision to accept or reject Medicaid assistance. The example of one Maine homeowner who is a Medicaid recipient is instructive. She reported being completely surprised that the Medicaid payments accepted by her would create a debt of her estate.²⁵¹ In most states, notice is given to recipients at the time they apply for benefits. Typically, a recipient is notified by a statement acknowledging the possibility and import of estate recovery, which the recipient must read and sign before receiving benefits,²⁵² or through an explanation by the case worker during the public aid intake procedure.²⁵³ In a case in which a lien is sought for assistance properly paid, notice will necessarily be provided by the process of determining that the individual cannot reasonably be expected to return home from an institution.²⁵⁴ However, because of age or infirmity, the ability of many Medicaid recipients to understand the consequences of estate recovery or alternatives to Medicaid may be relatively limited. Thus, states should provide counseling to recipients or their representatives, including a description of the estate recovery program and its probable impact in the recipient's case based upon a review of the recipient's individual circumstances. Additionally, the state should take steps to publicize the existence and operation of estate recovery programs so that elders are made aware of the potential consequences of accepting Medicaid well before they require it. Most importantly, a clear statement of the alternatives to accepting Medicaid, if any, should be provided to the recipient and his or her representatives. Obviously, educating recipients as to alternatives is likely to be important only in cases where noncritical procedures are to be undertaken. Nevertheless, these seem appropriate safeguards in light of the potentially dramatic effects of estate recovery. The indigent recipient should be given every opportunity to avoid recovery by foregoing aid where that is a reasonable option.

251. See *Medicaid Recovery*, BANGOR DAILY NEWS, July 18, 1995, available in 1995 WL 8764776.

252. See, e.g., HEALTH CARE FIN. ADMIN., ESTATE RECOVERY PROVISIONS (Aug. 5, 1997) <<http://www.hcfa.gov/medicaid/obs1.htm>> (last updated Nov. 15, 1996).

253. This is the procedure followed in Illinois. Schultz Interview, *supra* note 18.

254. See *supra* text accompanying notes 96-100.

V. Conclusion

In light of the rapidly increasing cost of Medicaid²⁵⁵ and its growing share of state budgets,²⁵⁶ estate recovery will likely continue to be an important tool for cost-conscious state governments. Until public policy takes account of the need for long-term care, elders will have their life savings exhausted by its expense and will be compelled to turn to Medicaid for support. Thus, it is essential to consider carefully the objectives of estate recovery and to evaluate the methods employed to achieve those ends. Estate recovery is an innovative approach to Medicaid budget problems, but its relatively minor impact on fiscal integrity may ultimately undermine its success. The current federal statute and HCFA regulations prevent substantial abuse and do much to safeguard the interests of recipients and their families. Nevertheless, by limiting recovery to estates of a certain size, providing adequate notice to recipients, and limiting the definition of estate to the probate estate, states can minimize the impact on recipients and their heirs, while still aiding the long-term fiscal integrity of Medicaid. Furthermore, by shifting the focus of recovery from the age of the recipient to the amount of the estate, recovery programs will improve their efficiency and will become more politically palatable.

255. See HEALTH CARE FIN. ADMIN., *supra* note 2.

256. See *id.*

THE RIGHT TO LIVE

Leigh B. Middleditch, Jr. and Joel H. Trotter

As medical technology has developed to enable doctors to keep incompetent patients alive on life-support systems, the legal issue relating to the authority to discontinue medical treatment has grown. In this essay, Messrs. Middleditch and Trotter address the right to live: the issue of whether a doctor should be able to discontinue the medical treatment of an incompetent patient against the wishes of the patient's guardian.

Messrs. Middleditch and Trotter analyze three cases where doctors wanted to disconnect the life support system of an incompetent person against the wishes of the patient's guardian or family members and find that courts differ in their approaches to the problem. The authors hypothesize that the right-to-live issue stems partly from our culture's denial of death's reality, partly from our reverence for patient autonomy, and mostly from economic concerns. Finally, the authors describe several proposals advanced by those in the medical and legal community which aim to clarify and resolve right-to-live issues. These proposals include: that the medical community should deny treatment defined to be futile; that the presumption of treating persons in a persistent vegetative state should be changed to a presumption of not treating such persons; and, that limits on disproportionately expensive treatments should be acknowledged and defined.

A look into the future shows us a society in which more and more people are "kept alive" both with machines replacing vital

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organs and computers checking from time to time to see if some additional physiologic functionalities have to be replaced by electronic equipment. Centers may be established in increasing numbers where all the technical data is collected and where a light may flash up when a patient expires in order to stop the equipment automatically.

Elisabeth Kübler-Ross, M.D.¹

This prediction might seem less plausible now than two decades ago, when Dr. Kübler-Ross first ventured her "look into the future." Back then, the right to die had yet to emerge on the national agenda. Today, after the intervening high-profile legal wrangles that sought to turn off Karen Quinlan's ventilator,² disconnect Nancy Cruzan's gastrostomy tube,³ and crank up Jack Kevorkian's suicide machine,⁴ the future does not readily disclose "increasing numbers" of automated life-support centers. In the present social climate, the mind can more easily imagine burgeoning suicide clinics. By most accounts, the vast majority of Americans would prefer to discontinue medical treatment rather than remain in a persistent vegetative state.⁵ Very few people would choose to live the existence Kübler-Ross described: to have machines and computers keeping them alive.

Some people, however, might choose such a fate. If a physician decides to discontinue the treatment of a terminally ill, incompetent patient while the patient's guardian insists on continuing the treatment, does the patient have the right to live? Courts have established, of course, that a mentally competent patient can always exercise one form of the so-called right to die—the right to refuse life-sustaining medical treatment—and, for the most part, so can the guardian of a terminally ill, incompetent patient.⁶ Recently, the obverse right—the right to live—has begun to receive attention. This essay discusses the most visible right-to-live cases to date, examines causes that may underlie the recent emergence of the right to live, and identifies potential developments in right-to-live legal doctrine.

1. ELISABETH KÜBLER-ROSS, ON DEATH AND DYING 14 (1969).

2. See *In re Quinlan*, 355 A.2d 647, 653-55 (N.J. 1976).

3. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 267 (1990).

4. See *Kevorkian v. Thompson*, 947 F. Supp. 1152, 1156 (E.D. Mich. 1997).

5. See, e.g., George J. Annas, *The "Right to Die" in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875, 889 (1996).

6. See, e.g., *Cruzan*, 497 U.S. at 279 (acknowledging "a liberty interest in refusing unwanted medical treatment").

I. Right-to-Live Case Law

At present, the right to live denotes a certain factual pattern rather than any developed legal doctrine. Although noteworthy authors have theorized about whether the right to live might assume a constitutional dimension,⁷ that development seems especially remote as of yet. The U.S. Supreme Court has already bypassed deciding a constitutional right to die,⁸ and most recently the Court similarly declined to announce a constitutional right to physician-assisted suicide.⁹ The right to live remains undeveloped today, though a mature jurisprudence may emerge in time. So far only three cases have attracted widespread attention for their right-to-live implications.¹⁰

A. *Gilgunn v. Massachusetts General Hospital*

In May 1989, Catherine Gilgunn fell and broke her hip for the fourth time.¹¹ The seventy-two-year-old woman from Charlestown, Massachusetts, had suffered from numerous maladies for years.¹² Diabetes, Parkinson's disease, stroke, heart disease, chronic urinary tract infections, and breast cancer had all taken their toll on her health.¹³ After Mrs. Gilgunn's admission to the Massachusetts General Hospital, she experienced repeated seizures that caused brain damage and rendered her comatose.¹⁴ Mrs. Gilgunn's husband and children agreed that Joan Gilgunn, Mrs. Gilgunn's daughter and primary

7. See Yale Kamisar, *When Is There a Constitutional "Right to Die"? When Is There No Constitutional "Right to Live"?*, 25 GA. L. REV. 1203, 1229 (1991); John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1148 (1991).

8. *Cruzan*, 497 U.S. at 279, 284 (assuming "for purposes of this case" that "a competent person [has] a constitutionally protected right to refuse lifesaving hydration and nutrition" to conclude merely that "a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state").

9. See, e.g., *Vacco v. Quill*, 117 S. Ct. 2293 (1997); *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

10. For an account of additional cases, see Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. a Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1249-52 (1993) (identifying five lesser-known cases implicating the right to live).

11. See Alexander Morgan Capron, *Abandoning a Waning Life*, HASTINGS CENTER REP., July-Aug. 1995, at 24; Gina Kolata, *Court Ruling Limits Rights of Patients*, N.Y. TIMES, Apr. 22, 1995, at A6. For additional summaries of Mrs. Gilgunn's case, see also John Ellement, *Jury Sides with Doctors on Ending Woman's Life Support*, BOSTON GLOBE, Apr. 22, 1995, at 18.

12. See Capron, *supra* note 11, at 26.

13. See *id.*

14. See *id.*

caregiver, would become Mrs. Gilgunn's surrogate decision maker.¹⁵ Joan Gilgunn informed her mother's physicians that Mrs. Gilgunn had always wanted aggressive medical interventions; she wanted her doctors to do "everything possible."¹⁶

After several weeks of treatment, Mrs. Gilgunn's physicians determined that further medical care was futile.¹⁷ The hospital's ethics committee and Mrs. Gilgunn's attending physician issued a do-not-resuscitate order, despite Joan Gilgunn's objection, because they believed that CPR would be "medically contraindicated, inhumane, and unethical."¹⁸ The attending physician then began to reduce Mrs. Gilgunn's ventilatory support.¹⁹ Three days later, on August 10, 1989, Mrs. Gilgunn's breathing stopped, and she died.²⁰

Joan Gilgunn sued the hospital and the physicians for negligently inflicting emotional distress on her by refusing to resuscitate her mother.²¹ The case went to trial in April 1995 before a jury in the Superior Court of Suffolk County, Massachusetts.²² The judge asked the jury first to decide whether Mrs. Gilgunn would have wanted resuscitation and, second, to determine whether the doctors correctly refused to resuscitate her.²³ After a two-week trial, the jury deliberated for two hours before saying "yes" to both questions.²⁴ The media called the lawsuit the first case "to test whether doctors must provide treatment that patients have requested, even when the doctors believe that the care would be futile."²⁵

Others have commented that the case represents a more limited principle. For example, Professor George J. Annas warns of *Gilgunn* that "many physicians have over-interpreted this case, saying it means they can now do whatever they want, that they can decide when treatment is futile, and it doesn't matter if patients want to be treated or not, if the doctors say they shouldn't be treated—you can't."²⁶ Thus,

15. *See id.*

16. *See id.*

17. *See id.*

18. *Id.*

19. *See id.* at 25.

20. *See id.*

21. *See id.* at 24.

22. *See Ellement, supra* note 11, at 18.

23. *See Annas, supra* note 5, at 888.

24. *See Kolata, supra* note 11.

25. *Id.* (reporting that the verdict means that "a hospital and its doctors need not provide care they deem futile, even if a patient has asked for it").

26. Annas, *supra* note 5, at 888.

he says, the concept of medical futility threatens to "bring us back to medical paternalism which is where we started."²⁷

B. *In re Conservatorship of Wanglie*

In December 1989, eighty-six-year-old Helga Wanglie slipped on a rug at home and fractured her hip.²⁸ During her recovery, her breathing failed.²⁹ Her physicians placed her on a respirator and transferred her to a long-term care facility.³⁰ There, she had a heart attack in May 1990.³¹ Although doctors revived her, she suffered irreversible brain damage from oxygen deprivation.³² Mrs. Wanglie was returned to the hospital, where her physicians determined that she was in a persistent vegetative state (PVS) without any awareness of her surroundings or hope of recovery.³³ Mechanical devices sustained her breathing and supplied her nutrition.³⁴

Mrs. Wanglie's physicians concluded, in light of her extraordinarily poor prognosis, that her care brought her no medical benefit and should cease.³⁵ However, Mrs. Wanglie's husband of fifty-three years and the rest of her family strongly disagreed with the physicians and insisted on continuing all treatments.³⁶ Mr. Wanglie maintained that "only God can take life and . . . doctors should not play God."³⁷ Repeated discussions between hospital personnel and family members failed to resolve the matter.³⁸

In February 1991, the hospital filed a petition in the Probate Court Division of the Fourth Judicial District for the County of Hennepin, Minnesota, asking the court to appoint a conservator who would

27. *Id.*

28. See Ronald E. Cranford, *Helga Wanglie's Ventilator*, HASTINGS CENTER REP., July-Aug. 1991, at 23. For further discussions of Mrs. Wanglie's case, see also JAMES M. HOFER & BRIAN E. KAMOIE, *DEATHRIGHT: CULTURE, MEDICINE, POLITICS, AND THE RIGHT TO DIE* 61-63 (1994); Annas, *supra* note 5, at 887-88; Alexander Morgan Capron, *In re Helga Wanglie*, HASTINGS CENTER REP., Sept.-Oct. 1991, at 26; Daar, *supra* note 10, at 1241-45; Robert J. Dzielak, *Physicians Lose the Tug of War to Pull the Plug: The Debate About Continued Futile Medical Care*, 28 J. MARSHALL L. REV. 733, 748-50 (1995). See generally Steven H. Miles, *Informed Demand For "Non-Beneficial" Medical Treatment*, 325 N. ENG. J. MED. 512 (1991).

29. See Cranford, *supra* note 28, at 23.

30. See *id.*

31. See *id.*

32. See *id.*

33. See *id.*

34. See *id.*

35. See *id.*

36. See *id.*

37. *Id.*

38. See *id.*

recommend a decision in Mrs. Wanglie's "best interest."³⁹ In July 1991, after a four-day trial, Judge Patricia L. Belois appointed Mr. Wanglie as his wife's guardian because he could best "investigate and act upon Helga Wanglie's conscientious, religious and moral beliefs."⁴⁰ Three days after Mr. Wanglie won guardianship, his wife died of multi-system organ failure.⁴¹

The Wanglie case presents an interesting dichotomy to the Karen Quinlan case. Karen Quinlan's family went to court to remove her ventilator while doctors insisted on continuing ventilation indefinitely.⁴² Conversely, Helga Wanglie's doctors sought court approval to discontinue ventilation while her family insisted on keeping her ventilator running,⁴³ prompting one author to remark that "if *Cruzan* is properly pegged as a case about the 'right to die,' *Wanglie* surely stands as a contrasting . . . case about the 'right to live.'"⁴⁴

Professor George Annas identified the *Wanglie* case as "the first time in the United States" that doctors argued in court "that it was wrong to treat someone in a persistent vegetative state once the diagnosis was certain."⁴⁵ This "was a very difficult argument to make," Annas explained, because "we know that at least 10,000 people are now being treated that way in the United States."⁴⁶ Given that such treatment is now customary, Annas argued that *Wanglie* demonstrates the need "to change medical custom."⁴⁷

C. *In re Baby K*

In October 1992, Stephanie Keene, who "will be forever better known as 'Baby K,'" was born at Fairfax Hospital in Fairfax, Virginia.⁴⁸ Keene had anencephaly, a congenital defect "in which a major portion of the brain, skull, and scalp are missing."⁴⁹ She lacked a cerebrum and remained permanently unconscious, unable to "see, hear, or

39. *In re Conservatorship of Wanglie*, 7 ISSUES L. & MED. 369 (Minn. Dist. Ct. Prob. Div. July 1, 1991).

40. *Id.*

41. See HOEFLE & KAMOIE, *supra* note 28, at 63.

42. See *In re Quinlan*, 355 A.2d 647, 648 (N.J. 1976).

43. See Capron, *supra* note 28, at 26.

44. Daar, *supra* note 10, at 1244.

45. Annas, *supra* note 5, at 887.

46. *Id.*

47. *Id.*

48. John G. Carlton, *Cases that Focused Attention on Sustaining Life*, ST. LOUIS POST-DISPATCH, May 5, 1996, at 5B; see also Marylou Tousignant & Bill Miller, *Death of "Baby K" Leaves a Legacy of Legal Precedents*, WASH. POST, Apr. 7, 1995, at B3.

49. *In re Baby K*, 16 F.3d 590, 592 (4th Cir. 1994).

otherwise interact with her environment."⁵⁰ At her mother's insistence, Keene's doctors placed her on a respirator whenever she experienced difficulty with unaided breathing.⁵¹

After Keene stabilized, the hospital transferred her to a nursing home, but respiratory problems forced Keene back to the hospital three times.⁵² The hospital filed suit in the U.S. District Court for the Eastern District of Virginia,⁵³ seeking a declaratory judgment that the hospital had no obligation "to provide emergency medical treatment to Baby K that it deems medically and ethically inappropriate."⁵⁴ Keene's guardian ad litem and her father sided with the hospital, but Keene's mother, Contrenia Harrell,⁵⁵ contested the hospital's law suit.⁵⁶ Judge Claude M. Hilton denied the hospital's request.⁵⁷

On appeal, the U.S. Court of Appeals for the Fourth Circuit upheld Judge Hilton's decision.⁵⁸ The Fourth Circuit found that "a straightforward application" of federal law "obligates the Hospital to provide respiratory support to Baby K when she arrives at the emergency department."⁵⁹ Specifically, the Emergency Medical Treatment and Active Labor Act⁶⁰ prevents hospitals from "'dumping' patients . . . by either refusing to provide emergency medical treatment or transferring patients before their emergency conditions [are] stabilized."⁶¹ Because the hospital had conceded that Keene required respiratory support to stabilize her condition, the court concluded that the hospital should have provided that assistance.⁶² The court remarked that "the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants" simply lies "beyond the limits of our judicial function."⁶³

Despite the court's ostensible unwillingness to consider the "moral or ethical propriety" of the treatment at issue, morality and

50. *Id.*

51. *See id.* at 593.

52. *See id.*

53. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993).

54. *Baby K*, 16 F.3d at 593.

55. *See Carlton, supra* note 48.

56. *See Baby K*, 16 F.3d at 593.

57. *See In re Baby K*, 832 F. Supp. 1022, 1031 (E.D. Va. 1993).

58. *See Baby K*, 16 F.3d at 598.

59. *Id.* at 594.

60. *Id.* (citing 42 U.S.C. § 1395dd (1994)).

61. *Baby K*, 16 F.3d at 593 (quoting *Brooks v. Maryland Gen. Hosp., Inc.*, 996 F.2d 708, 710 (4th Cir. 1993)).

62. *See id.* at 594-95.

63. *Id.* at 598.

ethics may have influenced the court's "straightforward application" of the statute at hand. Some twenty years before *Baby K*, Professor John A. Robertson discussed treatment options available to an anencephalic infant and observed that, arguably, "it is necessary to withhold treatment in order to save the infant from the horrible existence that would follow from caring for his many defects."⁶⁴ Presciently anticipating *Baby K*'s outcome, Robertson then added: "But lacking precedents for making such a quality-of-life judgment, it is unlikely that a court would be willing to deviate from respecting the value of human life."⁶⁵

II. Recent Emergence of Right-to-Live Litigation

Analysis of these cases has yet to yield consensus on precisely what has changed since *Quinlan*⁶⁶ that would explain the recent emergence of right-to-live litigation. Three possible explanations merit discussion. These explanations include the increasing denial of death, heightened attention to patient autonomy, and changes in economic incentives facing doctors.

A. Society's Increasing Denial of Death

First, our culture's persistent denial of death's reality may have driven patients and their families to an unprecedented level of resisting death. Freud cautioned four decades ago that "in our civilized attitude towards death we are once more living psychologically beyond our means,"⁶⁷ and Kübler-Ross pointed out the "fantastic degrees of denial that some people require in order to avoid facing death as a reality."⁶⁸ Advances in medical technology have magnified the problem. Perhaps the Preacher of *Ecclesiastes* would never have posited a "time to die"⁶⁹ in our age of mechanical ventilators and gastrostomy tubes. If Shakespeare's Julius Caesar had only seen an intensive care unit, he might have thought twice before saying that death "[w]ill come when it will come."⁷⁰

64. John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 242 (1975).

65. *Id.* (footnote omitted).

66. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

67. SIGMUND FREUD, *Thoughts for the Times on War and Death*, in 4 COLLECTED PAPERS 288, 316 (1959).

68. KÜBLER-ROSS, *supra* note 1, at 15.

69. *Ecclesiastes* 3:2.

70. WILLIAM SHAKESPEARE, *JULIUS CAESAR* act 2, sc. 2.

Rather than accede to death's inevitability, we vainly engage death in battle. As Sherwin B. Nuland notes, "the prevailing temperament of our times" considers death "a grim adversary to be overcome," and so we deploy "the dramatic armaments of high-tech biomedicine" against that adversary.⁷¹ "Many doctors," he further observes, "especially those who spend much of their time in laboratories, share with statisticians the disbelief in the necessity of death from old age."⁷² Despite their disbelief, Nuland counters, "life does have its natural, inherent limits."⁷³ Finally, when those limits approach, "life, even in the absence of any specific disease or accident, simply sputters out."⁷⁴

The right-to-die controversy has shown that many people do accept life's "natural, inherent limits." Those who do accept death can defeat Nuland's "grim adversary" through "conscious acquiescence" to death's power.⁷⁵ Acquiescence, Nuland observes, "evokes the serene style for which present usage has invented a term: 'Death with Dignity' is our society's expression of the universal yearning to achieve a graceful triumph over the stark and often repugnant finality of life's last sputterings."⁷⁶ The right-to-live debate embodies a clash between these two approaches—"dramatic armaments" on the one hand, and a "graceful triumph" on the other.

B. Heightened Attention to Patient Autonomy

Second, the right-to-die debate has elevated the notion of patient autonomy,⁷⁷ which could account for the appearance of right-to-live litigation. Mentally competent patients always have the right to refuse life-sustaining medical treatment, due largely to the paramount value of individual autonomy.⁷⁸ On this view, assertions of the right to live resulted in part from changes in the process by which doctors and patients reach treatment decisions.⁷⁹

71. SHERWIN B. NULAND, *HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER* 10 (1994).

72. *Id.* at 70.

73. *Id.*

74. *Id.*

75. *Id.* at 10.

76. *Id.*

77. See, e.g., Edmund D. Pellegrino, *Ethics*, 270 JAMA 202 (1993). "What is currently being debated is how far the patient's right of participation extends." *Id.*

78. See Robertson, *supra* note 7, at 1140.

79. See, e.g., Pellegrino, *supra* note 77, at 203 (noting that the futility debate "underscores a growing ethical conflict between the autonomy of the physician and of the patient").

An autonomy-based rationale may present logical difficulties for the right to live because the asserted right arises exclusively with incompetent patients.⁸⁰ Such patients no longer possess autonomy, and any effort "to approach the incompetent patient through the lens of autonomy ignores the reality of the incompetent patient as a nonautonomous individual."⁸¹ Consequently, some theorists have argued that a decision by the patient's surrogate ought not piggyback on the patient's supposed autonomy.⁸² "A guardian's or family member's judgment," the argument goes, "is not entitled to the special deference arising from the autonomy principle, for it is a judgment that one person makes about another, not a judgment that the patient makes about herself."⁸³

C. Economic Incentives Facing Doctors

Finally, assertions of the right to live may have less to do with societal conceptions of death or the legal doctrine of patient autonomy and more to do with money. Robert Taylor and John Lantos identify economic factors as the root cause, explaining that "changes from cost-based reimbursement to prospective payment or managed care put doctors and hospitals at financial risk for providing expensive and marginally beneficial treatment," which has forced health-care providers to "correlate costs with outcomes."⁸⁴ For example, hospitals today often lose huge sums when they provide artificial ventilation or nutrition because managed care networks must allocate their scarce resources by producing "clear economic incentives" against those types of "expensive, marginally beneficial therapy."⁸⁵ Thus, economic

80. See Robertson, *supra* note 7, at 1140.

81. *Id.* at 1143; *cf. id.* at 1197 ("When all cognitive and sapient function is irretrievably lost, it is a reasonable judgment that the patient has lost the capacity to have interests at all."); see also *Cruzan*, 497 U.S. at 275 (citation omitted) (recounting another court's acknowledgment that "to claim that [a patient's] 'right to choose' survives incompetence is a legal fiction at best").

82. See Kamisar, *supra* note 7, at 1229.

83. Ira Mark Ellman, *Cruzan v. Harmon and the Dangerous Claim that Others Can Exercise an Incapacitated Patient's Right to Die*, 29 JURIMETRICS J. 389, 395 (1989).

84. Robert M. Taylor & John D. Lantos, *The Politics of Medical Futility*, 11 ISSUES L. & MED. 3, 7 (1995); see also Sidney H. Wanzer et al., *The Physician's Responsibility Toward Hopelessly Ill Patients*, 310 N. ENG. J. MED. 955, 956-57 (1984) ("In the past, cost was rarely an important factor in decision making, but today, as society tries to contain the soaring cost of health care, the physician is subject to insistent demands for restraint, which cannot be ignored.").

85. Taylor & Lantos, *supra* note 84, at 8.

changes—not “increased emphasis on patient autonomy”—more directly caused the present debate over the right to live.⁸⁶

III. The Future of Right-to-Live Cases: Recommendations

The outlook for the right to live remains uncertain. Right-to-live cases arise infrequently, and so far the three leading cases have offered little doctrinal guidance for future adjudications of the right. According to one recommendation, the medical community should adopt a universal definition of futile treatment—namely, treatment that “merely preserves permanent unconsciousness or cannot end dependence on intensive medical care”⁸⁷—and doctors should apply that definition to determine when treatment becomes futile and whether to discontinue the futile treatment.⁸⁸

Another recommendation urges that we change from presumptively treating patients in a persistent vegetative state to presumptively discontinuing such treatment, because public opinion dramatically rejects continued treatment under the circumstances.⁸⁹

With persistent vegetative states and other diseases that result in severe brain damage, you're not dead. Nonetheless, you're in such bad shape that we know by surveys that 90% of Americans would not want continued medical treatment in a PVS. The presumption in these cases should be changed. It's wrong to continue the presumption in favor of continued treatment in someone in a persistent vegetative state when we have overwhelming evidence that Americans don't want to continue to live like that.⁹⁰

If these polling data are accurate, then the current presumption may well point in exactly the wrong direction, and we should replace it with a presumption in favor of discontinuing aggressive treatment for any patient in a persistent vegetative state.⁹¹

86. See *id.*

87. Dzielak, *supra* note 28, at 764 (quoting Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS OF INTERNAL MED. 949, 951 (1990)).

88. See *id.* at 764-66. The author further argues that “courts must provide physicians with a rebuttable presumption to determine when treatment is futile,” *id.* at 765, and that the patient’s decision makers could rebut the presumption “by showing that treatment will improve the patient’s condition and correspondingly the patient’s quality of life,” *id.* at 766.

89. See Annas, *supra* note 5, at 889.

90. *Id.*

91. See also Kristi E. Schrodde, *Life in Limbo: Revising Policies for Permanently Unconscious Patients*, 31 HOUS. L. REV. 1609, 1649 (1995) (concluding that “denying treatment to permanently unconscious patients is a reasonable starting point” in setting limits to health care resources).

Ultimately, the “critical question confronting our health care system . . . is whether we can create fair mechanisms to limit the use of expensive but marginally beneficial therapies in order to assure adequate care for all our citizens.”⁹² To do so, we should avoid “disguising these decisions as simple futility assessments” and, instead, acknowledge and define limits on “disproportionately expensive” treatments in which the “costs of therapy are high and the expected benefit is low.”⁹³ Assuredly, this presents a “more ethically complex and politically troublesome task” than merely declaring some treatments futile.⁹⁴ However, this approach would frame the issues in a meaningful way and thus assist lawmakers in directly confronting the right to live.

92. Taylor & Lantos, *supra* note 84, at 11.

93. *Id.* at 12.

94. *Id.*

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