Introduction

I. THE QUESTION

How ought decisions to be made for those who are not competent to decide for themselves? That is the question this book seeks to answer. Our focus will be on medical treatment decision making for incompetent patients. We will mention decisions about other matters such as financial affairs, living arrangements, or participation in research either to clarify our theory for medical decisions or to show important contrasts between medical decision making and these other areas.

The scope of the problem of decision making for incompetent individuals is vast. If one focuses only on the elderly who are incompetent and, among the elderly incompetent, only on those who are incompetent due to Alzheimer's dementia, the number may be as high as two million in this country alone, and increasing. But this is only one group. When all forms of dementia are included, the total is between three and six million.[1] At the other end of life is the largest group of incompetents—those who are not competent to decide for themselves by virtue of their immaturity. In addition, there are those who are incompetent due to mental retardation, brain damage from trauma, stroke, and alcoholism, and those whose mental illness renders them incompetent to make at least some decisions, and in some cases all decisions.

Over 80 percent of Americans die in hospitals.[2] Among

those who die in hospitals, many, indeed perhaps most, are incompetent or are treated as such, for some period of time before their deaths. Ironically, the much-lauded advances of modern health care and medical intervention have swelled the ranks of the incompetent in three ways: first, by reducing the frequency of early death due to the major communicable diseases (largely through better sanitation and diet, inoculation, and, to a much lesser extent, the use of antibiotics); second, through medical interventions that prolong the lives of incompetent individuals; and third, by the use of medications (such as some highly toxic cancer drugs) which impair decision-making capacities and devices (such as respirators) that can limit the patient's ability to communicate. For these reasons, incompetence is a pervasive condition, not a special problem for a certain group. All of the readers of this book were incompetent in their earliest years, and most will be incompetent prior to their deaths. The great majority of us will be confronted with the problem of decision making for an incompetent loved one.

II. THE HISTORY OF THE PROBLEM

In this work, we focus on decisions concerning medical treatment. We do so in the conviction that the problem of decision making for incompetents is one of the most, if not the most, urgent problems of contemporary bioethics. It is not much of an exaggeration to say that from its first flowering fifteen or twenty years ago, the modern bioethics literature has focused chiefly on articulating, justifying, and implementing the rights of the competent individual. In one sense this battle has been largely won: the courts, the great bulk of writers in bioethics, and the official codes of ethics of the major health care professional organizations all explicitly recognize that the competent individual has the right to accept or refuse medical care and treatment, as well as participation in experimentation. In

another sense, the struggle still continues: what is accepted in principle is still sometimes not honored in practice.[3] Nevertheless, as far as competent individuals are concerned, there is a strong convergence of opinion, grounded in a good deal of systematic ethical theorizing and a fairly solid grasp of the institutional realities.[4]

The time has come to redirect the focus of bioethics toward the problem of the incompetent patient. In this volume we build on existing work in bioethics to provide a systematic account. Many of the issues explored in this book are simply basic problems of social and political philosophy and of ethical theory, even if their most dramatic and visible instantiation lies in the area of medical care and treatment. In keeping with the constitutive idea of the series in which this volume appears, we have attempted to provide a deeper and more systematic conceptual and ethical grounding for evaluating and developing different practical approaches to the problem than is usually encountered in the bioethics or health policy literature.

Just as bioethics has tended to concentrate primarily on the rights of the competent patient, so philosophical work has centered on the rights of competent persons, and the grounding of these rights in utility or in autonomy, rather than on decisions for those who are incompetent. Most philosophical work on paternalism has been directed toward the question of whether paternalistic intervention in the choice or action of *competent* persons is ever justified.[5]

John Stuart Mill's neglect of the problem of decision making for incompetents is, unfortunately, quite representative of most contemporary work on paternalism. Mill simply acknowledges that we are justified in interfering with the liberty of those who are incompetent, in order to promote their own good or prevent them from harming themselves, and adds that we may sometimes justifiably interfere temporarily with an individual's risky behavior

long enough to determine whether he is competent. Mill offers no account of the principles which should guide decision making on behalf of the incompetent, nor does he offer a theory of what competence and incompetence are, or of how we are to ascertain them.

III. ETHICS AND THE LAW

Courts and legislatures have not been as successful as philosophers in evading either the problem of decision making for incompetents or the threshold issue of what competence is. But neither the law nor legal scholarship has provided an adequate theory of decision making for incompetents or a satisfactory analysis of competence. The greatest single weakness in the law and the legal literature is that they fail to develop systematically the ethical basis of our treatment of incompetents, and, perhaps to a lesser extent, fail to articulate fully the law's valuable insights into the nature of competence.

This allegation may be somewhat unfair, however. Perhaps law need not itself explicitly incorporate a particular, developed ethical theory. But the law should at least be compatible with and supported by plausible ethical theory. Thus our work here might best be viewed not so much as an implicit criticism of the law as being incomplete, but more as an attempt to ground the law more firmly in ethical theory. At certain points in the analysis, however, our ethical theory, along with what we believe to be an accurate appreciation of the institutional realities, leads us to criticize some aspects of existing law.

The distinction between ethical and legal analysis warrants further elaboration. There are two good reasons for resisting the all-too-common temptation to reduce ethical issues to legal issues. First, the law is itself insufficiently developed to provide sure guidance for some of the most urgent problems in this area. In particular, the law has frequently responded belatedly and inadequately to prob-

lems concerning the termination of sophisticated life-sustaining systems for competent as well as incompetent patients. Even fundamental and long-standing legal concepts—including the legal concept of death—have been strained and in some cases rendered obsolete by rapid technological developments.[7] Where old law must be adapted to new circumstances, and where new law must be developed, ethical guidance is essential.

Second, and just as important, there may be weighty ethical reasons for *not* attempting to extend the law into some areas.[8] Whether or not the law is an appropriate instrument for dealing with a particular problem is itself in part an ethical issue. Further, existing law, even when it clearly applies to the problems under consideration here, cannot be regarded as fixed and sacrosanct. The law itself can and should be subjected to ethical criticism.

It has been our intention, therefore, to strike a middle course between two equally inappropriate attitudes toward the law: on the one hand, a failure to evaluate the law critically from an ethical standpoint, and on the other a utopian disregard of the real constraints law places on individual choice and social policy. Law is a rather highly evolved, though of course imperfect, institutionalized form of practical reasoning about how to cope with conflicting interests. The appropriate attitude for the ethical theorist who wishes to bring theory to bear on practical problems is to recognize the power of law as an institution and the resources of law as a mode of practical reasoning, while maintaining a critical, revisionist attitude toward both.

IV. ETHICS AND PUBLIC POLICY ANALYSIS

A second error this volume is designed to combat, one which is perhaps even more common than that of reducing ethical problems to legal ones, is the mistaken assumption that "policy matters" and "ethical issues" can be separated

neatly, especially at the outset of an analysis. What this assumption overlooks is that most serious policy issues, whether in health care or in other areas, involve an ethical component, often at their core. Policy analysts may not see this, perhaps because they have not made their own ethical assumptions explicit, are not trained in the analysis of forms of ethical reasoning, and mistakenly believe that their own techniques (including risk/benefit, cost/benefit, and cost/effectiveness analysis) are ethically neutral.[9]

Indeed, the distinction between ethical issues and those that are *purely* matters of policy makes sense only after a great deal of ethical analysis has been successfully completed. For example, once we have fulfilled whatever ethical responsibilities we have (both as individuals and collectively) to provide health care for those who cannot afford it, society might simply as a matter of social policy decide to spend a great deal of additional money on social support for the indigent. But the problem that must be solved before we could identify these further allocational decisions as being "merely" a matter of social policy rather than of ethics is the daunting one of delineating the scope and limits of our ethical obligations to provide health care for the indigent. Assuming a facile distinction between ethical and social policy matters can have unfortunate methodological consequences. Fundamental ethical issues may simply be overlooked, or ethical analysis may appear belatedly as a reaction to policy rather than as a vital component of policy analysis and formation.

For these reasons we have attempted to articulate a comprehensive but sensitive ethical framework for evaluating current social policy on decision making for incompetents and for developing recommendations for change. However, the ethical analysis is not restricted to social policy. It examines problems of individual ethical choice as well, and takes as one of its fundamental tasks the problem of demarcating the proper boundary between matters of individual choice and responsibility, and those

of collective responsibility and social policy. Our goal, however, is to provide the ethical and conceptual framework for enlightened public policy and individual choice, not to advance comprehensive, highly specific policy proposals or to offer definitive answers or exhortations to the individual faced with hard, concrete ethical choices.

We believe work in ethical theory itself can also be greatly enriched by closer attention to matters of applied ethics and public policy. Ethics matters in the real world and reflection on real world ethical problems can also deepen our understanding of largely theoretical issues. The more applied and public orientation of much philosophical work in ethics over the last two decades, a period of renewal and broadened focus for academic work in ethics, provides many examples of the deepening of theory. There are several instances in the present work in which grappling with concrete, practical problems prompted theoretical advances. We cite just two examples here. Our account of competence and incompetence in Chapter 1 has important implications for and helps illuminate the problem of paternalism at the deepest levels of ethical theory. Our evaluation in Chapter 3 of the challenge to advance directives from common philosophical accounts of personal identity bears on broader theoretical issues concerning the implications of theories of the person and personal identity for moral theories generally. Ethical theory has been and will continue to be deepened and enriched by work in more practical or applied areas such as bioethics.

V. THE METHOD

The best way to understand our conception of ethical theory is to see it exemplified in the ethical theorizing presented in the chapters that follow. However, a preliminary, rough characterization of how we understand ethical theory is in order, even if only a rather incomplete

and unfortunately abstract sketch can be offered at this point. First, our approach is thoroughly anti-Cartesian. We do not start from scratch, attempting to boot-strap an ethical theory and then use that theory as an external standard for the evaluation of institutions and policies. We begin *in medias res,* utilizing, roughly, what Rawls calls the method of wide reflective equilibrium.[10] The goal of this method, as the name implies, is to achieve a stable system of ethical beliefs and attitudes, but one whose stability is grounded in reflection and self-critical reasoning, not unexamined custom, prejudice, or blind feeling. The process is that of attempting to achieve a match between a rather small but powerful set of general ethical principles and our firmest considered moral judgments not only about the subject matter at hand, namely the treatment of incompetents, but also about other important moral issues to which the same general principles apply. The qualifier "wide" is used to signal two things: first, that the ethical principles we explore can be drawn not only from contemporary popular morality and current law, but from the history of ethical theorizing and of jurisprudence as well; second, that besides ethical principles and more particular ethical judgments, theory here draws on related conceptions, such as conceptions of the person.

A second important feature of the conception of ethical theory deployed in this volume is that it takes very seriously the *institutional* aspects of ethical problems and their solutions. Russell Hardin put the point rather archly but well when he remarked that the greatest advances in contemporary ethics have come when a number of thinkers came to realize that any ethical theory that was developed to cope with moral dilemmas involving (at most) two persons and a runaway trolley in an unspecified time and place, is likely to be of very limited value.[11] In other words, casuistical reasoning about the isolated decisions of individuals abstracted from institutional frameworks should give way to a more nuanced and multi-dimensional

analysis of moral problems as institutionally embedded. This is especially true for decision making in health care, which takes place in such complex and powerful institutional contexts as hospitals, nursing homes, organized professions such as medicine, and the law. The chapters that follow proceed on this methodological assumption and should help to confirm its value. It has been our aim, then, both to enrich ethical theory by "institutionalizing" it and to further the evaluation and refinement of the relevant institutions by bringing systematic philosophical thinking to bear on the problems that arise within them.

VI. THE PLAN

Any theory of decision making for incompetents must begin by examining the notions of competence and incompetence. For Chapter 1 we formulate five questions:

(1) What is competence?
(2) Given an analysis of the appropriate concept of competence, what *standard* (or standards) of competence must be met if an individual is to be judged to be competent?
(3) What are the most reliable *operational measures* for ascertaining whether the appropriate standard is met?
(4) *Who* ought to make a determination of competence?
(5) *What sorts of institutional arrangements* are needed to assure that determinations of competence are made in an accurate and responsible way?

Chapter 1 focuses primarily on the first three questions; the fourth and fifth are examined in later chapters. The foundation of the first chapter is a *decision-relative* analysis of the concept of *competence as decision making capacity*. We articulate its implications and defend it against several rival analyses. We argue that the key function of the competence determination is to ascertain whether the patient's decision making capacity is sufficiently defective to war-

rant transferring decisional authority to a surrogate. Setting the proper level of decision making capacity for competence requires balancing respecting the patient's self-determination and protecting his or her well-being. Consequently, a variable standard of competence for different decisions is necessary.

Chapter 2 sets forth the primary ethical framework for decision making for incompetents. The primary framework, we contend, should be patient-centered in the fundamental sense that considerations of the incompetent's own well-being and (where possible) self-determination, as opposed to the interests of others, should be the primary focus. The analysis distinguishes among different types of principles that together constitute the primary ethical framework.

Ethical value principles: principles that specify the basic ethical values that are to be served in dealings with incompetent individuals (these include individual well-being and self-determination, as well as justice).

Guidance principles: principles that provide substantive direction as to how decisions are to be made. These include:

- *Advance directive:* implementing a valid advance directive, such as a "living will" or durable power of attorney, that the individual executes while competent.
- *Substituted judgment:* acting according to what the incompetent individual, if competent, would choose.
- *Best interest:* acting so as to promote maximally the good (i.e., well-being) of the incompetent individual.

Authority principles: principles that identify appropriate surrogate decision-makers for incompetent individuals.

Intervention principles: principles specifying the conditions under which the courts, representatives of