Medicine and Social Justice

Essays on the Distribution of Health Care



ROSAMOND RHODES
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ANITA SILVERS

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Essays on the Distribution of Health Care

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and Human Difference: Genetic Testing, Health-Care, and Disability, with Robert Wachbroit and Jerome Bickenbach, and Harming Future Persons: Ethics, Genetics, and the Nonidentity Problem with Melinda Roberts.

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Introduction

Medicine and Social Justice

Essays on the Distribution of Health Care

The essays in this volume—written by philosophers, doctors, lawyers, bioethicists, political scientists, and economists-challenge and deepen understanding of issues of social justice through a detailed examination of both philosophical theory and health care policy and practice. Since the publication of the first edition of Medicine and Social Justice a decade ago, there have been shifts in the understanding of social justice, both in philosophical and political theory, and in practice in the health care domain. There have been significant changes in health care institutions and policies as well. Biomedical science has advanced, social institutions have been transformed, and some issues that were barely noticed or not even on the horizon in 2002 have now come to be pressing. Profound concern about the adequacy of health care funding-for both present and future populations' needs-has prompted initiatives across the globe aimed at providing health services more efficiently and effectively, without compromising justice in regard to access to care. All these developments call for somewhat altered approaches to justice in health care decision-making.

The second edition of *Medicine and Social Justice* represents a significant update of the previous volume in both content and organization. The second edition still addresses, but with revised and new essays, the basic concepts and key issues of justice that arise in the allocation of health care. Two of the original chapters from the first edition are included, together with 19 considerably revised chapters, and 21 chapters that are entirely new to this volume.

This second edition of Medicine and Social Justice continues to raise and try to resolve farreaching difficult questions: What is justice? What is it for a health care system to be ideally just? What conditions of social justice or injustice in the background society affect justice in health care? What does justice require if health care must be allocated under conditions of injustice? Which choices and tradeoffs made within health care systems are just, and which ones are not? What requests from patients seeking access to specific forms of health care does justice require to be answered positively—does their personal history or the situation of their social group matter? Or their prognosis or the anguish of their desperation?

The collection serves two purposes: it both explores a wide range of different approaches to the issues of justice in health care, and it also probes the connections between theoretical accounts of justice and observations of justice (and injustice) in practice. It does not impose a single way of looking at justice; rather, readers will be introduced to the repleteness of theory and the many ways that different understandings of justice frame the problems facing policymakers and clinicians. Readers thus are invited to observe how theory is used to guide practice, and is itself shaped and changed by the conditions of practice.

The relevant theoretical discussion of justice draws on Aristotle, whose viewpoint is still influential and insightful. Aristotle defines "justice" as treating like cases alike and different cases differently. This is a formal principle of justice, and it still holds for all of the specific forms of justice: distributive justice (how to parcel out goods among parties who deserve them), procedural justice (how to maintain fairness in resolving disputes or differences in points of view), retributive justice (how to respond to a party who caused an offense), compensatory justice (how to repair harms done to parties undeserving of such treatment), and so on. Although other spheres of justice play a role as well, distributive justice is central to discussions of health care justice because health systems virtually always operate under conditions of scarcity. Thus the most frequent question regarding justice in health care is about how providers should allocate care among patients who need or want it when there are not enough

resources to provide for what everyone ideally should or would like to have.

The term "social justice" refers to relationships between a society and the individuals and groups it comprises. Social justice sets out what the society owes to its members and, concomitantly, what people owe to the community as a whole. Social justice can be contrasted with an individualistic conception of justice that focuses on what persons owe to one another (e.g., a doctor to a patient, a parent to a child, neighbors to each other), rather than what the collective community owes and is owed. While the term "social justice" is used in different ways, it usually incorporates the various forms of justice, but places particular emphasis on distributive justice sought in a context of opportunities and deprivations. Social justice is the ultimate goal of the forms of justice as they might be practiced interactively, in concert, on behalf of society as a whole.

Many discussions of health care and social justice are framed in terms of health and disease. Health is often defined as the biological condition that enables normal species functioning. Grounding decisions about the allocation of health care resources in the value of health makes allocation dependent on whether or not the prospective recipients' health states are classified as illnesses or disease: resources are provided primarily for cure or mitigation of disease.

In spite of the familiarity of this line of argument, health may not be the single appropriate goal for designing a health care system. It is hard to make sense of the notion of a right to health, as it is unclear against whom or what such a claim to be provided with health (as distinct from receiving services to maintain or restore health) reasonably could be lodged. Also, the skills and knowledge of medicine as it now is practiced are not restricted to preventing and curing disease.

Of course, every undesirable biological state with which medical professionals concern themselves might be subsumed under the idea of disease. But to do so would be to beg real questions about whether being old, heavy, infertile, or not immune to certain infections counts as being diseased. Yet these all are conditions for which physicians' services are offered in our health care system. Further, the broadly construed health care system encompasses much beyond effecting cures: immunization and other prevention programs, long-term caregiving, design and distribution of many kinds of durable equipment and prosthetic devices, medical analytics and informatics, and

even patient transportation, not to mention professional education and licensing for many kinds of service-providing and caregiving roles. Discussions in this volume reflect the presence of such extensions of health care systems, expanding the volume's focus beyond the traditional physician-patient relationship.

Four groupings of chapters make up the volume. First, the chapters in Part I address theoretical issues about the nature and requirements of justice. Some draw on John Rawls's influential theory of justice, a theory that, particularly in the application by Norman Daniels, has shaped much of contemporary thinking about justice in health care. Daniels emphasizes the importance of health in equalizing people's abilities to pursue opportunities in the world; he also develops the "lifespan" approach to justice in health care, according to which the young, the middle-aged, and the old are not seen as groups in competition for scarce health resources, but as individual persons at different stages of their lives. Other chapters in this section are non-Rawlsian in their conception of justice and their views of justice in health care. The chapters of this section, sometimes in agreement and sometimes in tension with one another, explore and expand the grounds for health care justice.

The chapters in Part II examine the justice of various proposals about priorities for allocating health care resources. This section begins to wrestle with the theories of justice explored in Part I. As rationing may be required in the real world of scarce resources, authors try to identify the just bases for making hard decisions. Some authors address the fundamental issue of whether a just system may give considerations of efficiency a dispositive, or at least weighty, role in deciding which individuals should have access to health care, and what quality and quantity of health care each should receive. Some of the chapters discuss the magnitude of the obstacles—economic, political, and ideological—to the achievement of justice in actual health care situations and systems, both at a national and on a global level. Some of the chapters in Part II point to dilemmas and inadequacies in the systems they examine, and to failures to reach or even to approximate justice in the distribution of health care resources. Others identify policies and practices that may approach a condition of genuine justice in health care.

The chapters of Part III pose some of the most pressing political challenges concerning justice in health care: these essays consider the claims and needs of disadvantaged groups, including the