ETHICAL FOUNDATIONS BRIEFING BOOK TABLE OF CONTENTS

I. BACKGROUND

II. ISSUES

III. RECOMMENDATIONS

A. Universal Access
B. Comprehensive Benefits
C. Equal Benefits
D. Fair Burdens
E. Generational Solidarity
F. Wise Allocation
G. Effective Treatment
H. Quality Care
I. Efficient Management
J. Individual Choice
K. Personal Responsibility
L. Professional Integrity
M. Fair Procedures

IV. QUESTIONS AND ANSWERS

V. APPENDIX

1 A. Ethical Foundations of the New Health Care System: Briefing Paper
   AUTHORS: Dan W. Brock, Ph.D. and Norman Daniels, Ph.D.

1 B. The Preamble
   Section 1. For the public
   Section 2. For policy discussions

2. Privacy and Security of Health Care Information

3. The Physician-Patient Relationship


5. Baily, Mary Ann, "Rationing Medical Care"
6. Brock, Dan W., "The Problem of Low Benefit/High Cost Health Care"

7. Brock, Dan W., "Medicine and Business: Unhealthy Mix?"

8. Buchanan, Allen, "Justice A Philosophical Review"

9. Daniels, Norman, "In surability and HIV Epidemic: Ethical Issues in Underwriting"

10. Daniels, Norman, "Is the Oregon Rationing Plan Fair?"

11. Daniels, Norman, "Justice and Health Care"

12. Daniels, Norman, "Why Saying No to Patients in the United States Is So Hard."

13. Garland, Michael, "Justice, Politics, and Community: Expanding Access and Rationing Health Services To Oregon"


15. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Recommendations.

16. Welch, H. Gilbert, "Should the Health Care Forest Be Selectively Thinned By Physicians or Clear Cut By Payers?"

17. Wikler, Daniel, "Personal Responsibility for Illness"

18. Priester, Reinhard, "A Values Framework for Health Reform"


21. President's Commission on Ethical Problems in Medicine: Chapter 1

22. ETHICAL FOUNDATIONS WORKING GROUP MEMBERS
A. THE MORAL IMPORTANCE OF HEALTH CARE

Attention to ethical issues in the new system reflects awareness and commitment to the moral traditions of our nation which are grounded in concern for equality, justice, liberty, and community.

The central values/principles of equality, justice, liberty and community should be applicable in all aspects of our lives. They are significant relative to health status because they affect so many of us in very basic and fundamental ways. Inequalities in the health care system at either levels of access or delivery seriously undermine our capacity to achieve a just and caring community.

Health care is considered of fundamental moral importance in that it protects the opportunities open to us to pursue our life goals, reduce our pain and suffering, prevent premature loss of life, etc. These moral ideals also serve to affirm our values as members of this society.

The health of a nation is a measure of its greatness. Preventable diseases, untreated illness, and neglected disabilities tear at the fabric of society. The well being and sense of security of the citizenry depends upon an effective health care system. When individuals lack care, the promise of our common life together is diminished.

Our current health system violates many of the principles of equality, justice, liberty, and community which undergird our nation. It does not provide security for the people. It does not offer sufficient primary, preventative, mental health, or long-term care. There are too many specialists. People are burdened with excessive costs. Prices for medications are exorbitant. Vast numbers of people are uninsured or in jeopardy of losing insurance. Generations are artificially pitted against generation in a competition for resources.

We acknowledge health care as not the only social good. We recognize, therefore, the necessity of "trade-offs" and compromises. We accept the conditions of limits and scarcity and
observe that justice demands wise allocation and prudent resource management.

Health Care Reform should see that care is delivered to all, and that it will secure and enhance life, liberty, and welfare. We must commit ourselves to universal and comprehensive health care as a way to fulfill our national promise to all of our people.
B. ETHICS AND PUBLIC POLICY ANALYSIS

"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." (Buchanan, Allen and Brock, Dan W. DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING, Cambridge University Press, 1989, p.5-6). We must attempt to delineate the scope and limits of our ethical obligations to provide health care. In addressing ethics and health care reform, we have made every effort to see that fundamental ethical issues are not overlooked or ethical analysis function solely as a reaction to policy rather than as a vital component of policy analysis and formation.

Ethical analysis is not restricted to social policy. "It examines problems of individual ethical choice . . .and takes as one of its tasks the problem of demarcating the proper boundary between matters of individual choice and responsibility, and those of collective responsibility and social policy" (Buchanan, p.5-6).
II. ISSUES

PRINCIPLES AND VALUES WILL CONFLICT DUE TO DIFFERENCES BETWEEN PEOPLE PHILOSOPHICALLY, CULTURALLY, RELIGIOUSLY, AND POLITICALLY.

Ethical "trade-offs" are necessary in the development and implementation of Health Care Reform. Examples are among the following:

· PHASE-IN OF UNIVERSEAL ACCESS

Although a phase-in might be politically and/or economically feasible, it may compromise the principle of justice and its demands.

· See Tab 4. Bach, Marilyn, "Ethics and Medicaid"
· See Tab 21. President's Commission on Ethical Problems in Medicine

· EQUALITY

To ensure that competing health plans do not produce an unacceptable tiering, specific steps are necessary at both the federal and state levels. These steps may restrict choice in favor of equality.

· See Tab 9. Daniels, Norman, Insurability and HIV Epidemic
· See Tab 10. Daniels, Norman, "Is the Oregon Rationing Plan Fair?"
· See Tab 11. Daniels, Norman, "Justice and Health Care"

· COMPREHENSIVE BENEFITS VS. WISE ALLOCATIONS

The more comprehensive the package, the less likely the realization of cost savings. The dilemma faced is in the concern for quality and fair distribution of burdens.

· See Tab 13. Garland, Michael, "Justice, Politics and Community..."

See Tab 9. Daniels, Norman, "Insurability and the HIV Epidemic"
INDIVIDUAL CHOICE VS. WISE ALLOCATION

It is not possible to have unlimited individual choice if we are to fulfill our responsibility to wise allocation. The new system should allow for a range of more effective choices.

See Tab 5. Baily, Mary Ann, "Rationing Medical Care"

See Tab 12. Daniels, Norman, "Why Saying No to Patients in the United States is so Hard"

See Tab 19. Caplan and Priester, "Ethics, Cost Containment, and the Allocation of Scarce Resources"

See Tab 16. Welch, H. Gilben, "Should the Health Care Forest be Selectively Thinned"

See Tab 17. Wikler, Dan, "Personal Responsibility for Illness"

GENERAL SOLIDARITY VS. INDIVIDUAL CHOICE

As people age, they can pass through the system at step stages of life and thus have a common stake in meeting our needs at each stage. Emphasis on individual rights only reinforces an "us" vs. "them" view that conflicts with solidarity across the community and across generations.

See Section V, Questions and Answers, #4
A. UNIVERSAL ACCESS

- Recommendation: -

Universal access is the soul of reform. Access for all citizens is essential. Such access should not depend upon job status, ability to pay, prior medical background, race, age, genetic background, sexual preference, disability, geographical location, etc.

- Rationale:

Justice is most efficiently served by creating appropriate security for America's citizens. Having health care available to all serves to affirm our moral status as full members of society and the moral community. We must remove the barriers to access arising from linguistic and cultural differences, geographical distance, prejudice, residence in economically deprived or underserved areas.

Access to Health care is a necessary condition to pursue nearly all of the goals around which people organize their lives.

B. COMPREHENSIVE BENEFITS

- Recommendation:

Mi plans should offer a comprehensive package of benefits, acceptable to the majority of Americans and should be inclusive of primary care, preventative, chronic, and long term care.

- Rationale:

A comprehensive package for all will serve the interests of justice and equity. This recommendation attempts to meet the needs of the people. We cannot assure equality of opportunity without ensuring that this principle is satisfied.
C. EQUAL BENEFITS

· Recommendation:

The benefits package should be standardized across all plans. The quality and availability of Health Care services should reflect only differences in our health care needs, not other individual or group differences.

· Rationale:

The principle of equality would dictate that the new health care system must not continue or create two or more tiers of care. By their very definition, tiers of care have been unequal and unfair. In order to avoid violation of this principle, the quality of care to all must be comparable. Equality of opportunity is acknowledged as a moral right.

Fair treatment in the access to benefits requires that the distribution of basic social goods reflect only morally relevant, non-arbitrary differences between people.

D. FAIR BURDENS

· Recommendation:

The costs of meeting needs created by the health care system should be spread equitably across the entire community. A community rating is necessary. Ability to pay is to be factored in. Taxes and other financing mechanisms must be progressive. The poor must be subsidized.

· Rationale:

Adherence to the principles of justice and equality come into play here. Differences in our risks of becoming ill and in the costs of meeting our needs are largely underserved and beyond our control. Protecting equality of opportunity is a shared obligation. Fairness requires spreading the costs of insurance across the entire community. What we pay for health care should be based upon what we are able to pay. Fair or just treatment of individuals involves the distribution of burdens as well as benefits.
E. GENERATIONAL SOLIDARITY

Recommendation:
We must share the benefits and burdens of the health care system fairly across the generations.

Rationale:
We all have a common stake in a health care system that meets our needs. The values of social solidarity and a communitarian ethic prevail here. Our children and their children must come to understand their responsibility to others. We cannot assure equality of opportunity without ensuring that this principle is satisfied. A common health care system that serves and cares for us will also bind us together in a broader national community.

F. WISE ALLOCATION

Recommendation:
We must limit the growth of health care expenditures. We must balance what we spend on health care with other national priorities.

Rationale:
A central value of health care is its preservation of our opportunities to pursue the other things we care about in life. If we can limit the growth of our health care expenditures, we will be in a better position to meet our other needs. Since we do not value all health care services equally, we must give priority to services that meet our most important needs.

G. EFFECTIVE TREATMENT

Recommendation:
We support "outcomes" research and research that can lead to new treatments in order to assess effectiveness of various services and benefits.

Rationale:
Limited data and perverse incentives to over-utilize services lead to use of
unnecessary care that does not benefit patients. We support expansion of services beyond acute care and new technologies which are beneficial and warrant any additional costs.

H. QUALITY CARE

· Recommendation:

New quality measures must be developed to ensure that quality is maintained for individuals and for the system. Effective grievance systems must be developed. Unethical and incompetent practitioners must be weeded out.

· Rationale:

The new system should strive to eliminate waste and yet not compromise quality of care to those who need it. In the interests of caring for all and making the system work, mechanisms must be put in place to assure quality at all levels.

I. EFFICIENT MANAGEMENT

· Recommendation:

The health care system must be organized simply and minimize administrative costs.

· Rationale:

Such organization will be less wasteful and will not interfere with quality care or divert resources from effective delivery of services to those in need. Administrative burdens should not be added to the burdens of illness or disability. Providers do not need administrative burdens which interfere with appropriate patient care.

J. INDIVIDUAL CHOICE

· Recommendation:

The system must allow and respect reasonable patient and provider choice which encourages personal responsibility, protects professional integrity, and
ensures accountability using fair procedures. These choices should be inclusive of plan, provider, treatment alternatives and reflect an informed consumer/patient.

· Rationale:

Respect for persons, their needs and values is important in that it reflects and demonstrates our adherence to the national values of liberty and individual self-determination. The requirement that medical care not be rendered without the free and informed consent of a competent patient is deeply and firmly embedded in American professional practice and in our legal system. Liberty is not unlimited, however. It is necessary to, on occasion, limit people's choices in order to carry out desirable social purposes.

K. PERSONAL RESPONSIBILITY

· Recommendation:

The health care system should provide information, education, counseling and treatment that empowers patients to make effective choices. However, access to health care should not be denied because of unhealthy behaviors.

· Rationale:

This recommendation is supportive of our commitment to liberty and individual self-determination within limits.

L. PROFESSIONAL INTEGRITY

· Recommendation:

The health care system must respect the clinical judgments of professionals and protect the Integrity of the professional/patient relationship while ensuring that professionals fulfill his/her public responsibilities. Appeal procedures are essential for patients and for providers.

· Rationale:

The sanctity of the patient/provider relationship is critical. Trust and integrity
must be maintained and supported to fulfill the fundamental aspects of this relationship. The liberty of the provider is essential for the maintenance of professional integrity if that liberty is exercised with responsibility and accountability to others.

M. FAIR PROCEDURES

· Recommendation:

Decision making and dispute resolution within the new system must take place within an atmosphere of fair and open democratic procedures.

Rationale:

Fair and democratic procedures will protect all of the moral principles espoused. Even in a just and caring society, reasonable people will disagree about how to translate our moral ideals, principles and values into a well functioning health care system. Of fundamental importance here is the concept of respect for persons. An aspect of justice applicable here recognizes that fair procedures are necessary to achieve fairness.
IV. QUESTIONS AND ANSWERS

1. Is health care a good of special moral importance? Do we have rights to healthcare?

Allen Buchanan, in *Justice: A Philosophical Review*, suggests how different theories of justice (egalitarian, libertarian, utilitarian) might approach the distribution of health care. Libertarian views argue for a minimalist view of the state and leave little room for redistributing wealth to make health care available to all. Utilitarian views can support a decent basic minimum of health care, but they make individual claims on health care depend very much on how the health care system promotes aggregate well-being in society; individuals can be left quite vulnerable.

In *Just Health Care* and his overview paper, *Justice and Health Care*, Norman Daniels argues that health care is of fundamental moral importance because of its ability to protect equality of opportunity. Disease and disability shrink the range of opportunities open to people; health care protects that range. Rights to health care become a special case of rights to equality of opportunity. Though health care is of special moral importance, it is comparable to education, which also protects equality of opportunity; it is not the only important good and reasonable resource limits must be placed on what we spend on health care. The view supports universal access, the provision of comprehensive health care benefits whose importance is judged by their efficacy in addressing needs, and limitations on benefits as a result of resource limitations only if they are fairly applied to everyone and publicly justified. This book has been influential in Canada, the Netherlands, Norway, Denmark, and elsewhere, where government commissions have been thinking about health care reforms under budget constraints.

Ezekiel Emmanuel’s *The Ends of Human Life* articulates a communitarian approach to health care distribution, arguing that basic choices about the distribution of health care require choices made by small communities that share fundamental values. He argues that liberal theory cannot answer these questions about the goals of medicine. Other communitarian approaches to health
care are reflected in works by Daniel Callahan, author of *Setting Limits: What Kind of Life*.

An opposing view to the claim that health care is of special moral importance, and that there are social obligations to provide it, can be found in libertarian works such as Tristram Engelhardt's *Foundations of Bioethics*. 
The ethical discussion in the President's Commission Report On Securing Access to Health Care (1983) grounds the special importance of health care in its effects on opportunity, its role in reducing pain and suffering, and the information and assurance it provides us. This language is reflected in the ethical principles which the Ethics Working Group has provided.

2. What ethical considerations affect decisions about benefits?

The "Ethical Foundations" paper argues that benefits must be comprehensive and that the principle for distributing medical services must be responsive to medical need, not other differences among individuals or groups. It takes a strong stand against arbitrarily omitting or reducing coverage for whole categories of services (mental or preventive), and it takes a strong stand against permitting unequal tiers of medical insurance that trap low income people in low quality health plans.

There is strong support for these views in Just Health Care and in Daniels' AinImy Pare nts' Keeper. Arbitrary categorical distinctions among kinds of services (preventive vs curative, acute vs chronic or long term, mental vs physical, which have often influenced the content of insurance benefit packages, have no moral standing and are arbitrary. Mental health services, if they are effective and meet important needs, have the same impact on the opportunities and welfare of individuals as physical health services, and should not be discriminated against in benefit packages. Similarly, long term care services restore normal function, prevent further losses of function, or compensate for losses of normal function, just as do acute care services; they must not be given secondary status in thinking about benefits. To our knowledge, there is no literature that argues an opposing view.

3. Is health care insurance just like other kinds of insurance?

The marketing of private health care insurance in the United States has generally behaved like all other insurance markets: standard underwriting practices are used to exclude those at
high risk from insurance and to risk-rate insurance groups. Insurers have even argued that they are morally required to behave this way in order to market "actuarially fair" insurance. Daniels' article on insurability uses the HIV epidemic to highlight what is morally unacceptable about these practices. Because of the fundamental importance of health care, the social function of health insurance, whether it is private or public, must assure access to services.
The Daniels article on exclusionary underwriting practices cites literature that offers an opposing view. The main motivation for insurers, however, is not moral but economic, that is, to protect themselves from adverse selection. The social costs of these exclusions are unacceptable.

4. How should the burdens of providing health care be shared?

Should those who are sick or at higher risk pay more for insurance? Daniels article on HW and insurability argues for community rating.

We have provided no literature specifically discussing the ethical issues involved in more vs less progressive forms of financing. Both utilitarian and egalitarian approaches to public policy would generally support more rather than less progressive financing: general revenues rather than pay taxes, though payroll taxes could be supplemented by "health taxes" on unearned income and taxes rather than premiums. Sin taxes are often regressive in their effect, though they provide incentives to healthier behavior.

A key obstacle to sharing the burdens of financing health care fairly are divisions that emerge between "us" and "them". The problem is particularly long term care, which is often (incorrectly) seen as a problem of the young vs. the old. Since we all age, however, we have a common stake in designing a health care system that meets our needs at each stage of life and for sharing the economic burdens of doing so. Daniels elaborates this argument in AmA my Parents' Keeper?, claiming that we treat people in different age groups fairly if we design systems that involve prudent allocations across stages of life.

It is sometimes argued that those who engage in unhealthy lifestyle choices should bear the burden of their choices, either by having to pay more for their health care or by being denied some services. The "Ethical Foundations" paper rejects this position. Support for its stance can be found in Wikler's paper on Coercion and Lifestyle Choices.
5. How can we protect doctors and patients under pressure to contain costs?

When DRG's were introduced, American physicians began to complain loudly that "bureaucrats" were interfering with appropriate clinical care. The theme is echoed in response to micro management of clinicians by different insurance schemes. There is a growing
literature on the ethics of these institutional pressures on clinicians and patients. Daniels' *why Saying No Is So Hard in the United States* is an early piece on this problem. It argues that physicians must believe a system is fair and that their participation as gatekeepers works to the advantage of patients overall before their inclination to "game" the system can be reduced. Where incentives work to make providers offer less treatment, the incentives should not directly impact on the physicians, but should be spread through larger groups of providers.

The Ethical Foundations policy paper argues for establishing grievance procedures within health plans and health alliances so that doctors and patients can oppose what they take to be unreasonable or unfair constraints on treatment. Time has prevented us from gathering supporting literature on such procedures, but the detailed Guidelines produced by the Ethics Working Group cover many of these issues.
RECOMMENDED READING


Emmanuel, Ezekiel. The Ends of Human Life_.

Engelhardt, Tristram. Foundations of Bioethics_.

Reich, Warren, Editor. The Encyclopedia of Bioethics_.
