II. RESEARCH

A. MAJOR PUBLICATIONS

BOOK: *Just Caring: Health Care Rationing and Democratic Deliberation*  
(Oxford University Press, 2009), 480 pages.


“Regulating Reproductive Technologies: Can We Trust Democratic Deliberation?” *Hastings Center Report*, 37 (July/August, 2007), 22-25.


“How Do You Create a Public Conversation about Behavioral Genetics?” chapter in *Wrestling With Behavioral Genetics: Implications For Understanding Selves and Society*, edited by Erik Parens, Audrey Chapman, and Nancy Press (Johns Hopkins University Press, 2005),
“Sharing Genetic Information: What is a Minimally Decent Sibling to Do?”
*Newsletter for Philosophy and Medicine*, American Philosophical Association
(Spring, 2004), pp. 35-39.

“Children and Organ Donation: Some Cautionary Remarks,” paper for special
issue of *Cambridge Quarterly of Healthcare Ethics*, edited by Mark Sheldon
Vol. 13 (Spring, 2004), 161-66.

“Genetics, Ethics, and Policy: Issues in Medical Practice,” Web essay for session 7 of

“Just Caring: Oregon, Health Care Rationing, and Informed Democratic
Deliberation,” reprinted (from 1994) in *Contemporary Issues in Bioethics*,
edited by Tom Beauchamp and Leroy Walters, Sixth Edition (Wadsworth, 2003),
100-06.

“Please Don’t Tell: Case and Commentary,” (reprinted from 1991) in *Ethical Issues
in Modern Medicine*, edited by John Arras and Bonnie Steinbock, Sixth Edition

“Ethics and Consent to Treat Issues in Acute Stroke Therapy,” (with Oliver Hayes),

“Last Chance Therapies: Can a Just and Caring Society Do Health Care Rationing When
Life Itself is at Stake?” *Yale Journal of Health Policy, Law, and Ethics*, 2 (Spring,
2002), 255-98.

(March/April, 2002), 35-36.

“Just Caring: Do Future Possible Children Have a Just Claim to a Sufficiently Healthy
Genome?” chapter for *Health Care and Social Justice*, edited by Rosamond Rhodes,
Anita Silvers, and Margaret Battin (Oxford University Press, 2002), 446-457.

“Health Care Justice and Rational Democratic Deliberation,” essay commenting on lead
paper by Norman Daniels titled “Justice, Health, and Health Care,” *The American

Review of “Pricing Life: Why It’s Time for Health Care Rationing,” by Peter Ubel in

“Just Caring: Managed Care and Protease Inhibitors,” *Ethical Issues in Modern Medicine*,
5th edition, edited by John Arras and Bonnie Steinbock (Mayfield Publishing, 1999),
679-86. This essay has also been reprinted in *Intervention and Reflection*, 6th

“Oh Being Genetically ‘Irresponsible’,” (equal author) with Judith Andre, Tom Tomlinson, Kennedy Institute of Ethics Journal, 10 (June, 2000), 129-46.


“Improving Our Aim,” with Judith Andre (lead author) and Tom Tomlinson, paper prepared for special issue of Journal of Medicine and Philosophy on the theme of bioethics and the media, edited by Haavi Morreim, 24 (1999), 130-47.


“Just Caring: The Moral and Economic Costs of APOE Genotyping for Alzheimer’s Disease,” in Apolipoprotein E Genotyping in Alzheimer’s Disease, edited by


"Just Genetics: A Problem Agenda," paper prepared for conference "Justice and the Human Genome," sponsored by the University of Illinois-Chicago College of Medicine (November, 1991). A revised and expanded version of this paper was completed in early 1992 and has been published as part of a volume of conference proceedings, Justice and the Human Genome Project, edited by Marc Lappe and Tim Murphy, (University of California Press, 1994), 133-52.


"Justice, HMOs, and the Invisible Rationing of Health Care Resources," in volume titled Efficacy in Health Care, essays from the First International Conference on Justice in Health Care, edited by Andrew Griffin (Chicago: 1990). This is a reprint (mostly) of the same paper published earlier in 1990 in Bioethics.


"Justice, HMOs, and the Invisible Rationing of Health Care Resources," Bioethics, 4 (April, 1990), 97-120.


"Surrogate Motherhood: Is It Morally Equivalent to Selling Babies?" Logos, 9 (1988), 135-145. This paper was originally delivered at a conference at the University of Santa Clara in April of 1988. The topic of the conference (and the theme of this issue of the journal) was "Manufactured Motherhood: The Ethics of the New Reproductive Techniques."

"Evaluating Executive Ethics: Is the ACHE Code Enough?" Michigan Hospitals, 24(December, 1988), 13-18. Earlier this paper was presented at a conference sponsored by The Ethics Center at Mercy College (Detroit) for health care executives.

"Moral Implications of the Shifting Power Equilibrium in Hospitals: From Medical Monopolization to Managerial Mandaranism," paper presented at the annual meeting of the Society for Health and Human Values in Chicago (November, 1988), 39 pp. in manuscript. This paper was the subject of the lead article in the newsletter Hospital Ethics, 5 (Feb. 1989) published by the American Hospital Association, under the title "Power Shifts Lead to Moral Twilight Zone for Hospitals."

Confidentiality, ethics module prepared for MERN and distributed to hospital ethics committees in Michigan (1990), 80 pp.

"DRGs: Justice and the Invisible Rationing of Health Care Resources," The Journal of Medicine and Philosophy, 12 (May, 1987), pp. 165-96. A shorter version of this paper was presented as a workshop at the Annual Meeting of The Society for Health and Human Values, New Orleans (October, 1986).


"Confidentiality: Moral Obligation or Outmoded Concept," Health Progress, 67 (May, 1986), pp. 17-20, 61. This paper has also been reprinted with permission in the Journal of the American Medical Records Association (1986).

Just Caring: Justice, Health Care, and the Good Society: An Agenda for Community Inquiry (Goshen Hospital Found., 1987), 36pp. This booklet was distributed to the Goshen community. It represented the results/recommendations from the original version of the "Just Caring" project (1985-87).


"Pricing Human Life: Moral and Public Policy Dilemmas," published in Making Medical Decisions, Edited by Patrick Herrmann (Northern Indiana Health Systems Agency, 1982), pp. 60-75. This volume represents the proceedings of a conference sponsored by the Health Systems Agency and the Indiana Committee for the Humanities.


"The Liberating Function of Philosophy in Education," Interdisciplinary Perspectives, 10 (Winter, 1979), pp. 2-11. This paper had been presented at the Annual Conference of the Association for General and Liberal Studies, Drake University (October, 1978).

"Abortion, Deformed Fetuses, and the Omega Pill," Philosophical Studies, 36 (October, 1979), pp. 271-283. This paper was first presented at a Philosophy Department colloquium at the University of Notre Dame, and subsequently at the Fall (1976) meeting of the Indiana Philosophical Association. By special request, the paper was later presented at a Philosophy Department colloquium at Purdue University (May, 1980).

"Mead on Knowledge and Action," presented before the American Catholic Philosophical
Association in Montreal (April, 1973). This paper was subsequently published in the Proceedings of the ACPA, Vol. 47, pp. 76-87.
B. MAJOR ACADEMIC PAPERS/PRESENTATIONS


“Rational Democratic Deliberation and Nanotechnology in Medicine: Ethical and Policy Challenges,” 20-page section of White Paper commissioned by the Director of NIH under the title “ELSI in Biomedical Nanotechnology.” The Hastings Center had the commission to create the paper. Tom Murray and Erik Parens asked me to write this section of the paper.


“Challenges to Conscience: Quarrels, Quibbles and Quips,” paper for ASBH conference in Denver (Oct. 2006).
“Priority-Setting, Health Care Justice, and the Least Well Off: Are Persons with Disabilities Vulnerable to Unjust Treatment?” paper for International Bioethics Conference, Vrije University Medical Center, Amsterdam (June, 2005). A version of this paper was also presented as part of a panel session at the ASBH conference in Washington D.C. (October, 2005).

“Pricing Human Life: Must Health Care Rationing be about Tragic Choices?” Faculty seminar for the Life Sciences and Values Program at the University of Michigan (May, 2004).

“Last Chance Therapies: Can a Just and Caring Society do Health Care Rationing When Life itself is at Stake?” Grand Rounds presentation at the University of Michigan Medical Center (Nov., 2003).


“Behavioral Genetics and Public Policy: The Role of Rational Democratic Deliberation,” presentation for meeting on behavioral genetics at The Hastings Center in Garrison, NY (June, 2002).


“Rational Democratic Deliberation: Scope, Methods, Objectives, and Other Practical Considerations,” for conference titled “Genetic Literacy and Civic Genetics” at The Hastings Center (Garrison, NY), (April, 2002).

“Genetics, Science Literacy, Social Values, and Democratic Deliberation,”
Presentation for three-part symposium on behavioral genetics, annual meeting of the American Academy for the Advancement of Science, Boston, MA (Feb., 2002).

“Communities of Color and Genetics Policy: The Role of Community Dialogue,” two Congressional seminars, one for staff/members of the House of Representatives, The other for staff/members US Senate, Washington D.C. (Feb. 2002). We also had a number of private meetings with various members of Congress aimed at disseminating the results of our NIH ELSI project.


“Last Chance Therapies: Can a Good Communitarian Do Health Care Rationing When Life Itself is at Stake?” 82 pp. paper for conference on Communitarianism and Bioethics, sponsored by NIH Department of Clinical Bioethics and George Washington University, in Washington D.C. (June, 2001.)


“The Ethical Challenges of Contemporary Academic Research,” lecture and workshop paper for conference titled Ethics Oversight at the Frontiers of Biomedical Research, sponsored by the University of Illinois at Chicago, Chicago (June 2001).


“Engaging Diverse Communities in Genetics Policy Dialogues,” workshop and panel presentation for Tenth annual meeting of the Association of Practical and Professional Ethics, Cincinnati (March, 2001). A similar presentation was also done at the Tenth Anniversary ELSI conference in Washington D.C. (Jan., 2001).


“Norms for Assessing Community Dialogue,” paper prepared for “Communities of Color and Genetics Policy Project,” National Advisory Board Meeting. This paper was also used as part of the training workshop I did for community dialogue facilitators in the “Communities of Color” ELSI project (Jan., 2000). This paper was also part of the resource material that I provided during a presentation I did at the Tenth Anniversary ELSI conference at NIH in Washington D.C. (Jan. 2001) under the title “Gene Themes.”

“Just Caring: Health Care Rationing and Rational Democratic Deliberation,” paper prepared for NIH seminar for staff and fellows of Department of Clinical Bioethics, Bethesda, MD (March, 2000).


“Priority-Setting, Managed Care, and Rational Democratic Deliberation,” paper prepared for APA Medicine and Philosophy Program in Chicago (May, 1998) under the program title “Priority-Setting in Health Care Today: From Managed Care to Moral Mayhem.”


“Non-Compliant Patients and Health Care Justice,” paper presented as part of workshop I chaired and organized under the title “Ethical Issues in Managed Care: Three Current Problems,” for the Medicine and Philosophy Committee, American Philosophical Association, Eastern Division Meeting, Atlanta (Dec., 1996).

"Rational Democratic Deliberation: Meeting the Challenges of Justice and Rationing," paper presented at the American Philosophical Association meeting in San Francisco, Medicine and Philosophy section, (March, 1995), 60 pp. in manuscript.


"Ethical Principles for Community-Based Health Reform," briefing paper for W. K. Kellogg Foundation Comprehensive Community Health Models Project (August, 1995).


"Just Health Care Reform: Democratic Decisionmaking Approaches," workshop

"Rights and Responsibilities of the HIV-Positive Physician or Medical Student," with Keith Apelgren, M.D. as co-author. This paper was presented at the national meeting of the Society for Health and Human Values in St. Louis (October, 1991).


Managing Medicaid for the 1990s: Balancing Equity and Efficiency (Two volumes). These volumes consist of seven chapters of readings, plus a leader's guide for each chapter designed to assist the reader in identifying and critically assessing the moral issues raised by Medicaid policy. These readings were used in conjunction with seven seminars that we conducted for the managers and administrators of the Michigan Medicaid program during June and September of 1989. There are about 600 pages in the two volumes.


"Justice and Age-Related Rationing in Health Care: A Defense," paper presented at a conference sponsored by the North American Society for Social Philosophy in
Montreal in August of 1989. Manuscript was 24 pages.


"Just Health Care: The Cost of Compassion," concept paper prepared for the Indiana Committee for the Humanities for statewide project that would address issues of justice and health policy.

Health Care Policy for the Future: Issues of Justice (two volumes). These are papers that were selected for reading by participants in seven workshops we designed for Medicaid managers and policymakers in Michigan under a grant from the Department of Social Services. Another volume contained the leader's guides we created for each of the seven seminars.


"Rawls, Reflective Equilibrium, and Justification: An Economic Model," (30 pp.), presented at the Western Division Meeting of the American Philosophical Association in April, 1984. I also presented this paper as a Philosophy Department colloquium in Sept., 1983 at Indiana University-South Bend. This paper was written during an NEH Summer Seminar at the University of Wisconsin under the direction of Professor Marcus Singer.

"Health Care, Justice, and Pareto Optimality," (38 pp.), presented at a meeting of the Indiana Philosophical Association at Depauw University (April, 1984).


"Aspirations for the '80s: The Social Responsibilities of Urban Universities," in Aspirations for the '80s: A Working Agenda, pp. 45-66. There is much discussion
today of corporate responsibility. This paper attempts to establish a framework for understanding the social responsibilities of universities in an urban setting. More specifically, this paper analyzes a major conflict built into our conception of the contemporary university: we believe that a university must be committed to both dispassionate intellectual stewardship and to passionate involvement as a creative force in the affairs of society. I argue for a new conception of the role of the university that resolves this conflict.

"Community Quality of Life: Corporate Responsibility," (10 pp.) in Aspirations for the '80s: A Working Agenda. This paper was presented at one of the workshops in the "Agenda for the '80s" community conference.

"Health Care for the Poor: A Moral Perspective," (18 pp.) in Aspirations for the '80s: A Working Agenda. This paper was presented at one of the workshops in the "Agenda for the '80s" community conference.

"Economic Development in Indiana: Zeroing out the Great Society/Penciling in the Poor," presented to the Indiana Academy of the Social Sciences, Annual Meeting, Wabash College, 1982 (22 pp.).


"Is a Right for a Wrong Ever Right? A Reparational Case of Capital Punishment," presented at a national conference on capital punishment at Georgia State University (April, 1980). This same paper was presented at a meeting of the Indiana Philosophical Association at Purdue University (November, 1980) as a Philosophy Department colloquium.

"Corporate Takeovers: The Selling of the University 1980 or the Bankruptcy of the Liberal Arts," as the first presentation in the Dean's Seminar Series at Indiana University at South Bend (October, 1980).


"Corporate Takeovers: The Selling of the University 1979 or the Bankruptcy of the Liberal Arts," for the annual meeting of the Association for General and Liberal Studies at Pennsylvania State University (November, 1979).

"Putting a Price on Human Life: Moral Dilemmas for the Public Policymaker," as the first presentation in the Dean's Seminar Series at Indiana University at South Bend (September, 1979).

"On the Rational Justification of Basic Ideals and Values," presented at the Philosophy Department colloquium at Indiana University at South Bend (May, 1978).

"An Introduction to an Inquiry into the Nature of the Humanities and their Role in Public Affairs," presented to the Indiana Committee for the Humanities in the Fall of 1976 as part of the project "Planning and Privacy: The Right to Health." This paper was 71 pages in manuscript form.
C. MAJOR ACADEMIC REPORTS

Communities of Color and Genetics Policy: A Summary Dialogue Report, for the NIH ELSI project @Communities of Color and Genetics Policy,@ 35 pp. (May, 2001).

Communities of Color and Genetics Policy Project: Community Dialogue Summary Reports. A total of fourteen reports were produced, one for each of the dialogue groups, each report being 10-15 single-spaced pages in length, (Summer/Fall, 2000)

The dialogue groups included:

- Alpha Kappa Alpha Sorority (Lansing, MI)
- Ann Arbor Bethel AME Church (Ann Arbor, MI)
- Castillo and Associates Latino dialogue group (Lansing, MI)
- Faith Access to Community Development (Flint, MI)
- La Salud Student Organization (Ann Arbor, MI)
- Latino Family Services (Detroit, MI)
- Omega Psi Phi Fraternity (Lansing, MI)
- The Tuskegee Orchid Club (Tuskegee AL)
- St. Andrew=s Episcopal church (Tuskegee, AL)
- Support Group for Individuals with Disabilities (Tuskegee, AL)
- Tri-City SER Jobs for Progress (Saginaw, MI)
- Tuskegee Church of Christ (Tuskegee, AL)
- Tuskegee Housing Authority Resident Council Executive Board
- Urban league of Flint (Flint, MI)

Genome Technology and Reproduction: Values and Public Policy (A Report and Analysis of the Spring Community Dialogues). East Lansing/Ann Arbor (Oct., 1997), 83 pp. [NIH, ELSI Program grant]

Genome Technology and Reproduction: Values and Public Policy (A Report and Analysis of the Fall Community Dialogues). East Lansing/Ann Arbor (June, 1997), 62 pp. [NIH, ELSI Program grant]

"Health Care Cost Containment in Indiana: The Dangerous Dilemmas of Equity and Efficiency," (110 pp. in manuscript). This paper was submitted to the Indiana Hospital Prospective Payment Study Commission in September, 1984. This committee was appointed by the governor to study alternative policies for health care cost containment.

Aspirations for the '80s: A Working Agenda (1982). This is a collection of 24 "working papers" from the 24 task forces that were part of the "Agenda for the '80s" project. These papers were presented at a community conference in Century Center in
South Bend, Indiana in May, 1982. I was responsible for compiling and editing these papers. This volume is about 600 pages in length.

Aspirations for the '80s: A Working Agenda (Summary version, 1982). This volume represents a 70-page condensation of the above volume. For the most part it contains the recommendations from the 24 working papers. It was created because it was felt that a briefer document would more readily stimulate the sort of community conversation that the "Agenda for the '80s" project was designed to generate and sustain.
D. MINOR PUBLICATIONS


“Objectivity, Integrity and Academic Freedom,” Research Integrity, 10 (Spring, 2007), pp. 8-9.


“Bioethics and Persons with Disabilities: Starting the Conversation,” in Ethics-In-Formation 11 (March, 2004), 1, 4-6.


“Case Commentary: Case of Sophia,” Journal of the Academy of Family Practice
(sometime in 2004).

“Can Rationing be Fair?” The Hastings Center Report 32 (Sept./Oct., 2002), 4-5.

“New MERN Summer Conferences,” essay in Ethics-In-Formation (March, 2003), 1, 4-5.

Review of Prenatal Testing and Disability Rights, edited by Erik Parens and Adrienne Asch in Philosophy and Medicine Newsletter (Spring, 2002), 165-66

Review of From Chance to Choice: Genetics and Justice, by James Buchanan, Dan Brock, Norman Daniels, and Dan Wikler in Medical Humanities Review (Spring, 2002).

Review of The Culture of Death: The Assault on Medical Ethics in America by Wesley Smith in Philosophy and Medicine Newsletter (Spring, 2001)

Response to angry letter by Wesley Smith in Philosophy and Medicine Newsletter (Fall, 2001), 159.


“From the chair,” column for Philosophy and Medicine Committee of the APA, published in APA Newsletter on Philosophy and Medicine, 00 (Fall, 2000), 126-27.
“Multicultural Citizen Engagement in Genetic Policymaking,” Abstract for 128th American Public Health Association Annual Meeting (Abstract # 5028.0), pp. 444-45, with Stephen Modell, Toby Citrin, Shelley Coe, Marian Secundy, and Tene Hamilton as co-authors.


“Ethical Issues in Managed Care: HIV and Protease Inhibitors,” Ethics-In-Formation, 7 (April, 1997), 3,6.


“Institutional Ethics Committees: The Next Generation,” Ethics-In-Formation, 8 (March, 1998), 1,4.


“How Would You Handle These Ethical Dilemmas?” Article by Anne Finger using scenario material and interpretation/analysis on ethics/reproductive genetics issues from our community dialogue project; in Medical Economics, 74 (Oct. 27, 1997), 105-17.

“How Would You Handle These Ethical Dilemmas?” article by Mark Holoweiko using material from community dialogue project; in Medical Economics, 74 (July 14, 1997), 101-03.


“MERN and the Human Genome Project: Reproductive Decisions,” Ethics-in-Formation


"Just Caring: Ethical Issues in High-Tech Home Care," Ethics-In-Formation, 6 (Jan., 1996), 1, 8-11.


"Update on Annual Meeting, Summer Ethics Conference, and Health Reform," Ethics-In-Formation (Feb., 1994), 1, 7.

"Notes from an Ex-President," Ethics-In-Formation (July, 1994), 4-5.


"Case Commentary: Crystal Barbier," Ethics-In-Formation, 4 (August, 1992), 4-5.


"Review of Pharmacy Ethics, [edited by Mickey Smith and others]," Ethics, 103 (April, 1993), 619.

"The Cancer Drug Works: Do the Insurance Rules?" Ethics-In-Formation, 3 (Feb., 1991), 4-5.

"Assisted Suicide: Why it Deserves Serious Discussion," Ethics-In-Formation, 3 (March 1991), 1,4,11.

"Aids and Confidentiality: A Case Study" Ethics-In-Formation, 3 (March 1991), 10.

"Just Caring: Justice, Resource Allocation, and the Terminally Ill" Ethics-In-Formation, 3 (July 1991), 5-7.


"If We Are Merciful, We Must Help Others Die With Dignity" The Detroit Free Press, (June 7, 1991), 9A.


"HIV-Infected Health Professionals: What to Do?" Ethics-In-Formation, 3 (September, 1991), 1, 6-7.

"Limits to Medical Care: Who Will Decide?" Ethics- In-Formation, 3 (September, 1991), 5.

"Oregon and Health Care Rationing: The Debate Continues," Ethics-In-Formation, 3 (September, 1991), 8, 14.


"Case Commentary: Conceiving Children to Use for Tissue Transplantation," Medical Humanities Report, (Spring, 1990), 4-5.


Commentary on medical ethics case titled "Spending Down" for the journal *PA88: Physician Assistants in Primary and Hospital Care*, 5 (Jan., 1988), 19.

Commentary on medical ethics case titled "Minor Referral" for the journal *PA88*, 5 (April, 1988), 111-112.


"What to Do When a Patient Refuses Medical Care" *Ethics-in-Formation*, 1 (Feb., 1989), 5.


As part of the project "Just Caring: Justice, Health Care and the Good Society," I did a series of seven essays that were published in the *Goshen News* during the spring of 1986. Six more essays were done in the fall. Each essay was 8-10 pages in manuscript form. The essays appeared every other week and were designed to stimulate a broad-based community conversation regarding justice and health care policy. The essays were titled:

"Just Caring: Justice, Health Care, and the Good Doctor," (February 24).

"Human Life is Priceless--Or is it?" (March 13).

"Allocating Scarce Life-Saving Resources: Equity vs. Efficiency," (March 27).

"Justice, Health Care, and the Poor: Is Minimally Decent Care Enough?" (April 24).

"Making Moral Choices: The Terminally Ill," (May 7).


Review of Just Health Care by Norman Daniels for The Journal of Medical Humanities and Bioethics (Fall, 1987).


