

Bibliography

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An Annotated Bibliography on Bioethics

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The field of bioethics continues to grow in importance and influence. At the same time the literature on bioethics also continues to grow. This annotated bibliography can only be an introduction to the field. It is a place to begin.

Allen, Garland E. (1986) The Eugenics Record Office at Cold Spring Harbor, 1910-1940. *Osiris*, 2d Series, 2: 5-42. A history of the American eugenics movement using the historical records at their national office.

Amundson, Ron. (2000) Against Normal Function. *Studies in History and Philosophy of Biological and Biomedical Sciences*, 31(1): 33-53. An excellent analysis of the concepts of normal and abnormal which form the basis of the deficit model of disability. Normal and abnormal are social judgments of what are acceptable biological variations and functioning. When people with disabilities are classified as abnormal, these value judgments are used to justify the disadvantages which confront them.

Amundson, Ron. (1992) Disability, Handicap, and the Environment. *Journal of Social Philosophy*, 23(1, Spring): 105-18. An excellent attempt to deal with the ambiguity of the terms disability and handicap and to establish a moral framework for discussing the provision of health care. After defining abilities in a normative way he defines disabilities as the absences of "basic personal abilities." That is, the lack of some ability on the part of some individual. Health care has moral importance in regard to a person with a disability because disability leads to the loss of opportunity. (He does not deal with the fact that a disability can open doors to opportunity previously closed.) As he writes: "...the avoidance of disability per se is at the moral core of health care." He then presents the environmental concept of handicap. A person with a disability is handicapped only in a specific environment in regard to a specific goal.

Andrews, Lori B. (2001) *Future Perfect: Confronting Decisions About Genetics*. New York: Columbia University Press. Looks at the ethical, legal, and social implications of

genetic technology including people with disabilities.

Astrue, M.J. (1994) Pseudoscience and the Law: The Case of the Oregon Medicaid Rationing Experiment. *Issues in Law and Medicine*, 9(4, Spring): 375-96. Using quality of life in the Oregon experiment introduces a social utilitarian calculus in health care delivery overriding individual autonomy and informed consent and moving toward using societal choice instead.

Banks, Judith L. (1986) Rehabilitation Act - Department of Health and Human Services May Not Interfere in Medical Treatment Decisions Regarding Handicapped Infants. *Cumberland Law Review*, 16(3): 607-25. A discussion of the case *Bowen v. American Hospital*, 106 S. Ct. 2101 (1986).

Barnes, David S. (1994) *The Making of a Social Disease: Tuberculosis in Nineteenth-Century France*. Berkeley: University of California Press. Using both popular and scientific views the author demonstrates how moral meanings are given to disease.

Barnett, W. Steven. (1986) The Transition from Public Residential Schools for Retarded People to Custodial Facilities: An Economic Explanation. *Disability, Handicap & Society*, 1: 53-71. Argues that it was for economic reasons that custodial facilities were created and not just because of discriminatory attitudes.

Bell, Terrel H. (1986) Education Policy Development in the Reagan Administration. *Phi Delta Kappan*, 67: 487-93. A clear exposition of the eugenic basis for US education policy during the Reagan administration.

Berns, Walter. (1953) *Buck v. Bell: Due Process of law? Western Political Quarterly*, 6: 762-75. A discussion of how the landmark eugenics case clearly violated Carrie Buck's right to due process.

Bernstein, P. (1991) Termination of Parental Rights on the Basis of Mental Disability: A Problem in Policy and Interpretation. *Pacific Law Journal*, 22(4): 1155-85. A discussion of the legal merits of several cases in which parental rights were terminated because of a mental disability.

Blackford, Karen A. (1993) Erasing Mothers with Disabilities Through Canadian Family-Related Policy. *Disability, Handicap & Society*, 8: 281-94. How the Canadian policy removed mothers with disabilities from consideration as fit parents.

Bock, Gisela. (1983) Racism and Sexism in Nazi Germany: Motherhood, Compulsory Sterilization, and the State. *Signs: Journal of Women in Culture and Society*, 8: 400-21. Traces the Eugenics Movement in Germany in the 1920's and into the Nazi era. The Nazis passed the Law for the Prevention of Hereditary Diseased Offspring which had nine categories of diagnoses which could lead to sterilization: five concerned psychiatric "invalidity," three to physical "invalidity," and the ninth one was alcoholism. Much more on sterilization of women is presented.

Bogdan, Robert; Biklen, Douglas. (1977) Handicapism. *Social Policy*, March-April: 14-19. A very important article which defines handicapism in a manner similar to racism and sexism using the terms prejudice, stereotype, and discrimination. Handicapism results in discrimination based upon presumed physical, mental, or behavioral differences.

Bogdan, Robert; Taylor, Steven. (1987) Toward a Sociology of Acceptance: The Other Side of the Study of Deviance. *Social Policy*, Fall: 34-39. An argument that prejudicial attitudes result in the label of deviant for persons with disabilities.

Bogdan, Robert; Taylor, Steven. (1989) Relationships with Severely Disabled People: The Social Construction of Humanness. *Social Problems*, 36: 135-48. A full development of the position presented in Bogdan & Taylor (1987).

Bosk, Charles L. (1992) *All God's Mistakes: Genetic Counseling in a Pediatric Hospital*. Chicago: University of Chicago Press. Discusses how health professionals work with colleagues and patients [sic] in genetic counseling based on fieldwork in a medical center.

Boston Women's Health Book Collective. (1985) *The New Our Bodies, Ourselves*. Second edition, revised; New York: Simon and Schuster. This revised edition of the feminist groundbreaker includes (for the first time) disabled women and details on the concerns of disabled women and girls.

Bowling, Ann. (1997) *Measuring Health: A Review of Quality of Life Measurement Scales*. Second edition, Briston, PA: Open University Press. A review of a large number of QOL scales.

Brantlinger, Ellen. (1995) *Sterilization of People with Mental Disabilities: Issues, Perspectives, and Cases*. Westport, CT: Auburn House. Argues that sterilization advances the sexual freedom of people with the label mentally retarded. Although it can be viewed as an eugenic tool, some women with disabilities need to prevent pregnancy permanently for a variety of reasons. Presents and discusses some relevant case studies.

Brown, Hilary; Smith, Helen. (1989) Whose 'Ordinary Life' Is It Anyway? *Disability, Handicap & Society*, 4(2): 105-19. A trenchant review of community care policy and normalization from the feminist viewpoint showing the parallels between clients and women in the ways in which they are viewed and treated which results in common oppression. Strategies for change are discussed and the inconsistencies of the values of individualism, competition, and self-reliance (upon which most community care policy is based) are shown to be incompatible with the integration of disabled people into the community.

Brown, Roy I. Editor. (1988) *Quality of Life for Handicapped People*. London: Croom Helm. In discussing the concept of "quality of life" this book demonstrates how uncertain it is. The reality referred to by the term is far too complex for a simple definition. A number of illustrations of the varying ideas are provided.

Burgdorf, Robert; Burgdorf, Marcia. (1977) The Wicked

Witch Is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons. *Temple Law Quarterly*, 50: 995-1034. Argues that Buck v. Bell is no longer the law of the land. However, they fail to state that it has never been explicitly over ruled and still must be considered the ruling case.

Burleigh, Michael. (1995) *Death and Deliverance: "Euthanasia" in Germany c. 1900-1945*. New York: Cambridge University Press. The history and the ideology of the Nazi program which executed some 200,000 people with disabilities from 1939 to 1945.

Caplan, Arthur L. (1989) The Meaning of the Holocaust for Bioethics. *Hastings Center Report*, July/August: 19(4): 2-3. The author, who is the director of the Center for Biomedical Ethics, presents the substance of papers given at a conference on the Holocaust and bioethics. One paper argued that German biology and medicine contained the theories of racial hygiene long before Hitler came to power. A second paper said that Nazi scientists followed five norms two of which still exist in contemporary medical research. Another one reviewed the rationalizations of Nazi physicians including utilitarianism, obedience to the state, and advancing the war effort. A fourth one drew parallels between the justifications for Nazi euthanasia and present day arguments. A fifth one contended that the results of the Nazi experiments should be available to help others. Two survivors, Susan Seiler Vigorito and Eva Kor, said that it would be complicity with the Nazis to do so. Another survivor said that those studies had no contribution to make. Discussion made it clear that the claims of the Nazis had already entered contemporary science. An important question is why it took forty years for the question of their use to come forth.

Churchill, L.R. (1985) Which Infants Should Live? On the Usefulness and Limitations of Robert Weir's Selective Nontreatment of Handicapped Newborns. *Social Science and Medicine*, 20: 1097-1102. A review of Selective Nontreatment of Handicapped Newborns by Robert Weir (1984) which is described as the first systematic treatment of the problem. The implications of Weir's book are presented for several current instances.

Cohen-Almagor, Raphael (2002) *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law*. Rutgers: Rutgers University Press. Defends physician assisted suicide based on active and passive euthanasia.

Dworkin, Ronald. (1993) *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A. Knopf. An analysis and attempted reconciliation of conflicting views of abortion and euthanasia.

Evans, Daryl. (1989) The Psychological Impact of Disability and Illness on Medical Treatment Decisionmaking. *Issues in Law & Medicine*, 5(3): 277-99. Although originally predisposed to think otherwise, Evans found that parents of newborn infants with spina bifida were equally influenced by positive and negative emotions about disability and disabled

people.

Fancher, Raymond E. (1985) *The Intelligence Men and the I.Q. Controversy*. New York: W.W. Norton & Company. Examines the persons who originated the concept of I.Q. and some of the controversy surrounding its use.

Field, Martha A.; Sanchez, Valerie A. (2000) *Equal Treatment for People with Mental Retardation: Having and Raising Children*. Cambridge: Harvard University Press. A study of past and present laws and policies restricting the rights of people labelled mentally retarded to have children and to raise them as parents. It says that they must be allowed to make their own decisions and that they have the right to do so.

Gerry, Martin H. (1985) The Civil Rights of Handicapped Infants: An Oklahoma 'Experiment'. *Issues in Law & Medicine*, 1: 15-66. Discusses the ethical and moral issues of withholding treatment from severely disabled infants, the Oklahoma experimental program which led to the death of 24 infants with spina bifida, and the applicability (in this type of case) of Section 504, of federal civil rights laws such as 18 USC 241-42, and of recent federal legislation.

Glover, Noreen M.; Glover, Samuel J. (1996) Ethical and Legal Issues Regarding Selective Abortion of Fetuses with Down Syndrome. *Mental Retardation*, 34(4, August): 207-14. Discusses the legal and ethical issues surrounding the abortion of a fetus with Down Syndrome when so called "healthy" fetuses are not aborted.

Gostin, Larry. (1985) A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates. *American Journal of Law and Medicine*, 11: 31-78. A discussion of the legal, ethical, and social aspects of nontreatment of severely disabled newborns. A new moral standard is proposed based on personal interests. After reviewing the Child Abuse Amendment of 1984 the author suggests that his work will assist the courts in balancing the disabled child's right to privacy with the law's requirements.

Gould, Stephen Jay. (1985) *The Flamingo's Smile: Reflections in Natural History*. New York: W.W. Norton & Company. This very readable work is a collection of Gould's essays which first appeared in *Natural History Magazine*. One of the themes is that the world can be explained in evolutionary terms: "The proof that our world is Darwinian lies in the large set of adaptations arising only because they enhance reproductive success but otherwise both hinder organisms and harm species." (page 45) Essay 4 (pages 64-77) is a curious discussion of whether persons joined and sharing bodies are one or two individuals. It is a type of disability pornography because he treats them as objects. Essay 20 (pages 306-18) is the best available discussion of *Buck v. Bell* showing - among other things - that Carrie Buck and her daughters were not mentally retarded and that Carrie was the victim of sexism. Essay 21 (pages 319-32) discusses Cyril

Burt's fraudulent claim that 80% of intelligence is inherited. Gould also says in this essay that IQ does not measure intelligence, that nature and nurture interact, and that biological determinism is blaming the victim (of social evils).

Groce, Nora Ellen; Chamie, Mary; Me, Angela. (1999) Measuring the Quality of Life: Rethinking the World Banks' Disability Adjusted Life Years. *International Rehabilitation Review*, 49(1 & 2): 12-15. A very stringent criticism of the DALYs with excellent arguments.

Gross, Richard H.; Cox, Alan; Tatyrek, Ruth; Pollay, Michael; Barnes, William A. (1983) Early Management and Decision Making for the Treatment of Myelomeningocele. *Pediatrics*, 72(4): 450-58. Describes the program for the selection and treatment of newly born with spina bifida. While acknowledging the difficult ethical concerns, it presents the use of class data to arrive at a quality of life measurement as to whether or not to treat the infant.

Haller, M.H. (1963) *Eugenics: Hereditarian Attitudes in American Thought*. New Brunswick: Rutgers University Press. A history of the eugenics movement in the US.

Hasian, Marouf A., Jr. (1996) *The Rhetoric of Eugenics in Anglo-American Thought*. Athens, Georgia: University of Georgia Press. How the language and the ideas of Eugenics penetrated social thought in the nineteenth and twentieth centuries.

Hirst, M. (1985) Young Adults with Disabilities: Health, Employment and Financial Costs for Family Carers. *Child: Care, Health and Development*, 11: 291-307. Mothers of disabled youths are more likely to have a severe chronic illness, to have symptoms of psychiatric problems, to have less work force involvement, fewer hours of work, and lower earnings than mothers of non-disabled youths.

Hollander, Russell. (1989) Euthanasia and Mental Retardation: Suggesting the Unthinkable. *Mental Retardation*, 27(2, April): 53-62. After reviewing the Eugenics Movement in the nineteenth century he concludes that the same reality - killing people labeled mentally retarded - exists in this century. It could increase if protests do not occur.

Holtzman, Neil A. (1989) *Proceed with Caution: Predicting Genetic Risks in the Recombinant DNA Era*. Baltimore: Johns Hopkins University Press. Although the recombinant DNA procedures can be beneficial, there could be a danger in that there will be pressure on pregnant women to abort fetuses which might be at risk. Testing should be neither curtailed nor imposed on anyone. More knowledge of probability and genetics is needed by everyone.

Hubbard, Ruth. (1990) *The Politics of Women's Biology*. New Brunswick: Rutgers University Press; 1990. Discusses the political and social assumptions of biology, especially genetics.

Huefner, Dixie Snow. (1986) Severely Handicapped Infants with Life-Threatening Conditions: Federal Intrusions into the Decision Not to Treat. *American Journal of Law & Medicine*,

12(2): 171-205. An extensive discussion of *Bowen v. American Hospital* (1986).

Humphry, Derek. (1986) The Case for Rational Suicide. *Euthanasia Review*, 1(3): 172-76. Rational suicide is justifiable for terminally ill or severely disabled persons provided that the individual is mature, seeks medical help, makes all legal provisions necessary, avoids criminal liability for others, and leaves a written explanation. There is also a discussion of how rational suicide is a form of self-control.

Kane, F.I. (1985) Keeping Elizabeth Bouvia Alive for the Public Good. *Hastings Center Report*, 15: 5-8. Completely misunderstands the ethical import of the Bouvia case by asserting that personal autonomy in such situations must give way to the primary principle of respect for life.

Kane, F.I. (1985) What Nurses Profess: The Elizabeth Bouvia Case. *Health Progress*, 66 (July-August): 52-54, 68. Nurses are bound by a moral code or set of ethical principles which would keep them from assisting Bouvia in her suicide. They are concerned with protecting life, public health, and the general welfare and thus are committed to assisting disabled and ill persons. Nurses must reflect upon their ethical standards and go beyond mere tolerance, technical proficiency, and a therapeutic understanding of the patient's needs. They must reaffirm the sacredness of life and health.

Kaplan, Robert M. (1994) Using Quality of Life Information to Set Priorities in Health Policy. *Social Indicators Research*, 33(1-3, August): 121-63. Sets forth the General Health Policy Model as an instrument for making health policy decisions. The Model sets 1.0 as perfect health and 0.0 as death and provides only negative aspects for the judgement. These negative aspects reflect the common stereotypes of disability. The author of this abstract calculated that he was over half way to death - primarily because he uses a wheelchair.

Kapp, Marshall B. (1989) Rationing Health Care: Will It Be Necessary? Can It Be Done Without Age or Disability Discrimination? *Issues in Law & Medicine*, 5(3): 337-51. The author argues that rationing of health care on the basis of age is not constitutional nor ethical. He presents alternatives. Companion to article with identical name by Daniel Callahan.

Kent, Deborah. (1985) Public Policy and Ethical Choice: A Review of *Playing God in the Nursery*, by Jeff Lyon. *Journal of Visual Impairment & Blindness*, 79: 416-20. A trenchant review of Lyon's book which gives a biased presentation of the Baby Doe Case. Kent raises very good questions about determining whether disabled infants should receive medical attention on the basis of the supposed quality of the infants' future life. She exposes the biases in Lyon's presentation.

Kevorkian, Jack. (1991) *Prescription: Medicide - The Goodness of Planned Death*. Amherst, NY: Prometheus. His early and strident call for active euthanasia of persons with low

quality of life (as he sees it).

Koch, Tom. (1998) *The Limits of Principle: Deciding Who Lives and What Dies*. Westport, CT: Praeger Publishers. A critique of bioethics and offers a new approach.

Kolker, Aliza; Burke, B. Meredith (1998) *Prenatal Testing: A Sociological Perspective*. Westport, CT: Bergin & Garvey. Discusses the sociological, psychological, and ethical ramifications of prenatal testing using as data interviews with genetic counselors and women who were tested.

Komesaroff, Paul A. Editor. (1996) *Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics, and the Body*. Durham: Duke University Press. Covers abortion, physician-patient relationship, the social construction of illness, and other topics.

Kuhl, Stefan. (1994) *The Nazi Connection: Eugenics, American Racism, and German National Socialism*. New York: Oxford University Press. Demonstrates the links between the Eugenics Movement in the US and the racial hygiene movement in Germany.

Kuhse, Helga; Singer, Peter. (1985) *Should the Baby Live? The Problem of Handicapped Infants*. Oxford: Oxford University Press. A chilling discussion of why some babies - so-called severely disabled babies - should be allowed to die.

Laughlin, H. (1922) *Eugenical Sterilization in the United States*. Chicago: Psychopathic Laboratory of the Municipal Court of Chicago. The classic call for the sterilization of disabled persons written by the executive secretary of the eugenics movement in the US.

Longmore, Paul. (1985) Screening Stereotypes: Images of Disabled People. *Social Policy*, Summer: 31-37. How prejudicial attitudes toward people with disabilities are formed by discriminatory stereotypes.

Lund, Nelson. (1985) Infanticide, Physicians, and the Law: The 'Baby Doe' Amendments to the Child Abuse Prevention and Treatment Act. *American Journal of Law & Medicine*, 11: 1-29. Infanticide has reappeared in Western civilization in the neonatal intensive care unit where infants who are labelled mentally retarded, who have spina bifida, and/or who are born premature are allowed to die. The questions are who will decide on non-treatment and what will be the criteria. The author discusses the background and the likelihood for success of the new legislation.

Lusthaus, Evelyn. (1985) 'Euthanasia' of Persons with Severe Handicaps: Refuting the Rationalizations. *Journal of the Association on Severe Handicaps*, 10: 87-94. Examines and refutes the two most common arguments that severely disabled persons should be allowed to die: that they are not really people and that they lack a quality of life.

Lyon, Jeff. (1985) *Playing God in the Nursery*. New York: W.W. Norton & Company. A very disturbing book which presents a biased view of the Baby Doe case and then details the financial and emotional burdens of raising a disabled child.

He goes on to describe the life of disabled persons as being nothing else but suffering and pain. On the surface his presentation appears reasonable and leads to the position of withholding medical care to disabled infants as a solution to the "disability problem."

Markus, K. (1989) *The Nurse as Patient Advocate: Is There a Conflict of Interest?* *Santa Clara Law Review*, 29: 2-35. A discussion of the historical and institutional basis of the conflicts between a nurse's duty to patients, employers, and physicians. The courts have wrongly applied ethical principles in cases of conflicts because there are few guidelines available. State nurse licensure statutes need to provide protection for good faith acts of advocacy on behalf of patients by nurses.

Masters, Roger D. (1990) *Evolutionary Biology and Political Theory*. *American Political Science Review*, 84(1): 195-210. Using a Platonic ontology this simplistic essay points to several ambiguous "facts" about human behavior which leads him to conclude that a study of evolutionary biology and human behavior is necessary to understand and do political theory. The political theorist must understand that some people are inferior to others.

Mazumdar, Pauline. (1992) *Eugenics, Human Genetics, and Human Failings*. New York: Routledge. History of the British eugenics movement using new archival sources.

Merrick, Janna C. (1989) *Federal Intervention in the Treatment of Handicapped Newborns: Baby Doe Regulations and the 1984 Child Abuse Amendments*. *Policy Studies Review*, 8(2): 405-19. A history of the Baby Doe controversies which concludes that there was much debate and emotions, but not a problem to begin with nor any change afterwards.

Miringoff, Marque. (1989) *Genetic Intervention and the Problem of Stigma*. *Policy Studies Review*, 8(2): 389-404. An accepted social good (prevention and elimination of genetic conditions) can have a social cost in terms of reducing social tolerance for persons who have the genetic condition and for disabled persons in general. Not that the suffering and problems are good in and of themselves, but that we must take a careful approach as we make genetic advances. However, genetic intervention, in its most extreme form, says that we are afraid of that differentness and will prevent its appearance.

Miringoff, Marque-Luisa. (1991) *The Social Costs of Genetic Welfare*. New Brunswick: Rutgers University Press. Discusses the conflict between disability activists and those persons who want to prevent people with genetic based disabilities from being born. She characterizes the return of Eugenics as the change from social welfare to genetic welfare.

Morris, Jenny. (1991) *Pride Against Prejudice: Transforming Attitudes to Disability*. Philadelphia: New Society Publishers. The author begins by stating how feminism ignored its basic assumption (that the personal is political) in regard to disability and shows how the concept of normal

produces prejudice against people with disabilities. She discusses euthanasia and how people with disabilities are still threatened by it. In discussing abortion she says that abortion on demand because of a disabled fetus calls into question the right of all people with disabilities to live. She does favor abortion availability, however. In discussing quality of life she points out that living with a disability can be painful and difficult and to deny that is to deny part of the disability experience. And to say that the woman has the right to decide on abortion means that we ignore the constraints on women from society's prejudice toward and a lack of resources for people with disabilities. It also results in the woman having sole responsibility while there is a denial of social responsibility toward women and people with disabilities. A fetus with a disability which is viable outside of the womb and a newly born baby with a disability have the same civil rights as a non-disabled fetus or newborn. And to kill or to let die a fetus or newborn has a high cost to the people involved. The refusal to see people with disabilities as real people and as we actually are is the worst form of oppression. People with disabilities have the right to be both different and equal. Charity must be rejected and disability pride developed. People with disabilities must become empowered.

Munetz, M.R.; Lidz, C.W.; Meisel, A. (1985) Informed Consent and Incompetent Medical Patients. *Journal of Family Practice*, 20: 273-79. A patient who is mentally incapacitated requires a surrogate decision maker. The situation arises most frequently with a patient who was capable, but who slowly becomes incapable. It also arises with comatose, mentally retarded, mentally ill, and "physically handicapped patients." While standards of capacity are not clear, one way is to determine if the patient understands the physician's view and opinion of the best treatment. The surrogate decision maker should, if possible, be a family member.

Murphy, Robert F. (1989) Subjects and Objects. *Disability Studies Quarterly*, Spring: 1-4. As the author, a trained anthropologist, experienced a progressive disability, he became even more convinced that the observer and the objects of scrutiny merge ending all pretensions to objectivity. All social scientists have a political agenda and must operate with that in mind.

Nelkin, Dorothy; Tancredi, Laurence. (1989) *Dangerous Diagnostics: The Social Power of Biological Information*. New York: Basic Books. Diagnostic tests are "instruments of control" used by those in control to keep themselves in control. Covers biological and genetic technology, but mainly focuses on the political implications which concern autonomy, privacy, and discrimination.

Nussbaum, Martha C.; Sen, Amartya. Editors. (1993) *The Quality of Life*. Oxford: Clarendon Press. The chapters in this work discuss from the viewpoint of economics and philosophy what comprises quality of life. The chapters are very good,

but when disability is discussed it is usually on the level of the happy cripple. For example, one question concerns whether Tiny Tim should be denied a wheelchair because he is so happy even without one. Includes the chapter by Dan Brock which says that not much of depth can be gained from the fields of health care and medical ethics.

Offer, Avner. Editor. (1997) *In Pursuit of the Quality of Life*. New York: Oxford University Press. Analysis of objective circumstances and their subjective impacts on the quality of life of individuals.

Palomar, Joyce Dickey. (1985) School Health Services for Handicapped Children: The Door Opens No Further. *Nebraska Law Review*, 64: 509-36. Discusses the provision of health (as opposed to medical) services by public schools under PL 94-142 under the decisions in United States Irving Independent School District v. Tatro, 104 S. Ct. 3371 (1984), and Board of Education v. Rowley, 458 U.S. 176 (1982).

Parmenter, Trevor R. (1994) Quality of Life as a Concept and Measurable Entity. *Social Indicators Research*, 33(1-3): 9-46. The measures of quality of life are all flawed. In the medical arena there is a tension in the measures between the biomedical aspects and the need to open a dialogue between physician and patient.

Patrick, Donald L.; Erickson, Pennifer. (1993) *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation*. New York: Oxford University Press. This book masquerades eugenics as a public choice approach to resource allocation in the area of health care. The ideas in this book were used to produce the Oregon Plan for health resource allocation. Without belaboring the point, this approach is not truly public choice. One of the assumptions made by the authors and most persons writing about health care financing in the US is that the amount of money available will not significantly increase. While a cautious assumption, it is not necessarily correct. Another assumption made by the authors is that the cost of health care delivery can not be reduced and still have the same level of services. The concepts used to define good health and the process for assigning values introduce eugenics into the process.

Pearlman, Robert A.; Cain, Kevin C.; Patrick, Donald L. (1993) Insights Pertaining to Patient Assessments of States Worse Than Death. *The Journal of Clinical Ethics*, 4(4): 33-41. Based on interviews of 56 outpatients and well adults the authors write that conditions considered "worse than death" were permanent coma, severe dementia, loss of essential functional abilities such as feeding oneself, dying in an unfamiliar or institutional setting, being kept alive artificially, being a burden to others, experiencing hopelessness, depression, and chronic pain or suffering. They conclude that physicians need to talk with patients about their preferences, values, and concerns. They need to be able to determine when a patient views a situation as hopeless.

Pfeiffer, David. (1994) Eugenics and Disability

Discrimination. *Disability & Society*, 9(4): 481-99. Some of the most threatening discrimination against people with disabilities in the United States is based in state law. This paper discusses these past and present state laws in the area of domestic relations. The eugenics movement continues to be the force behind them. (Reprinted on the Web site of the Institute on Independent Living, <<http://www.independentliving.org>>.)

Pfeiffer, David. (2000) *The Disability Paradigm. Disability Policy: Issues and Implications for the New Millennium - A Report on the 21st Mary E. Switzer Memorial Seminar, Held September 1999*, edited by L. Robert McConnell and Carl E. Hansen. Alexandria, VA: National Rehabilitation Association, 81-82. Rejecting the social constructionist and oppressed minority models, a paradigm must be adopted which says that disability exists when discrimination is encountered. Equal protection and due process is a remedy for discrimination. Disability policy today is largely a failure and seen as terribly expensive and not always the morally correct thing to do. Until professionals, providers, family members, and policy makers recognize that people with disabilities have the right to equal protection and due process and have the right to be a part of the process, disability policy will remain a failure. Nothing about us without us.

Physically Disabled Parents' Rights. (1985) *Mental and Physical Disability Law Reporter*, 9: 435-36. Discusses the rights which disabled persons who are parents have in regard to keeping their children as found in two cases. In both instances the parent was a mother. In *Michigan Department of Social Services v. McDuel*, 369 NW 2d 912 (1985), the Michigan Court of Appeals reversed a lower court decision terminating the parental rights of a mother with multiple sclerosis with scathing remarks about the lower judge's misunderstanding of disability. In the other case, *In re Green*, 480 NE 2d 492 (1984), the Ohio Court of Appeals upheld the awarding of custody to a county agency of children of a mother who had uncontrolled petit mal seizures.

Powell, T. Hennessy; Hecimovic, Anton. (1985) *Baby Doe and the Search for a Quality Life. Exceptional Children*, January: 15-23. Discussion of the dimensions of the quality of life of severely disabled infants and how it can be improved. Improvements in service delivery which improve the quality of life must be made known to service providers, policy makers, and the public.

Proctor, Robert. (1988) *Racial Hygiene: Medicine Under the Nazis*. Cambridge: Harvard University Press. A review of the Nazi biomedical programs to "cleanse" the race including the sterilization law, the control of women, the death camps, and euthanasia. Even though there was resistance among the medical profession, they initiated and managed the Nazi programs.

Rafter, Nicole Hahn. (1989) *White Trash: The Eugenics*

Family Studies, 1877-1919. Boston: Northeastern University Press. Reprints with commentaries eleven studies from the American eugenics movement.

Reiser, Stanley J. (1986) Survival at What Cost? Origins and Effects of the Modern Controversy on Treating Severely Handicapped Newborns. *Journal of Health Politics, Policy and Law*, 11(2): 199-213. An extensive discussion of the question of the treatment of severely disabled newborn infants and who should participate in the decision making.

Rhoden, Nancy K.; Arras, John D. (1985) Withholding Treatment from Baby Doe: From Discrimination to Child Abuse. *Milbank Memorial Fund Quarterly/Health and Society*, 63: 18-51. Discussion of when withholding treatment becomes child abuse. Concludes that moving from a simplistic medical model way to answer the question of whether to withhold treatment to examining the question of the child's best interest is not much progress, but it is better than nothing.

Rock, Patricia J. (1996) Eugenics and Euthanasia: A Cause for Concern for Disabled People, Particularly Disabled Women. *Disability & Society*, 11(1, March): 121-27. Medical ethics and practices are threatening people with disabilities, especially women. Abortion of impaired fetuses is common. Euthanasia and forced sterilization is widely accepted. The idea that people with disabilities are less worthy or have a lower quality of life must be challenged.

Rothenberg, Karen H.; Thomson, Elizabeth J. Editors. (1994) *Women & Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio State University Press. Reviewed in *Disability Studies Quarterly*, Winter 1996, 16(1): A collection of essays on prenatal testing. One of the best is by Deborah Kaplan, "Prenatal Screening and Diagnosis: The Impact on Persons with Disabilities." She analyzes its justification and says that there is no causal connection between predictable genetic conditions and low quality of life. The other essays present comparable discussions.

Rothman, David J. (1991) *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. New York: Basic Books. During World War II many experiments endangered the subjects' health with no prospect of any general benefit and even without their knowledge or a chance to refuse. Experiments on persons with disabilities such as these cited helped destroy the assumption that the doctor knows best. Medicine had become depersonalized.

Sanderson, Stephen K. (1990) *Social Evolutionism: A Critical History*. Cambridge: Basil Blackwell. An excellent history of social evolutionism in the social sciences with comparisons with evolutionary theory in biology. Chapter Eight discusses the question of whether progress (in the sense that more recent changes are "better" than the earlier stages) is necessarily inherent in an evolutionary view of society. The answer is no.

Seery, John E. (1996) *Political Theory for Mortals: Shades of Justice, Images of Death*. Ithaca: Cornell University

Press. Presents a revised social contract theory for the discussion of life and death issues including abortion and euthanasia.

Silvers, Anita. (1995) Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities. *Hypatia*, 10(1, Winter): 30-55. Argues that preferring difference over equality and care over justice fails to recognize that it is not natural differences which cause marginal groups to be oppressed, but minority social status. The ADA tries to remedy this exclusion through equal access and not exceptional treatment.

Smith, George P., II. (1985) Genetics, Eugenics, and Public Policy. *Southern Illinois University Law Journal*, 1985: 435-53. Cites with approval *Buck v. Bell*. Accepts discredited eugenics theory and offers the Juke and Kallikak family histories as proof. He is very concerned that "...one out of every twenty babies [in the US] is born with a discernible genetic deficiency; of all chronic diseases, between twenty and twenty-five per cent are predominantly genetic in origin. At least half of the hospital beds in America are occupied by patients whose incapacities are known to be of a genetic origin. . . . [Modern medicine keeps alive persons who] can reproduce and thus may increase the number of defective genes in the gene pool." (435) Advocates restricting "...reproduction by those who, although not 'manifestly unfit' themselves, perpetuate human suffering by giving birth to genetically defective offspring." (447)

Smith, J. David. (1985) *Minds Made Feeble: The Myth and Legacy of the Kallikaks*. Rockville, MD: Aspen Systems Corporation. The classic history of the eugenics movement in the US and their accomplishments.

Snyderman, Mark; Rothman, Stanley. (1989) *The IQ Controversy, the Media, and Public Policy*. New Brunswick: Transaction Publishers. Even though public opinion does not support the position that intelligence can be measured and that genetics influences the level of intelligence, a sample of "experts" surveyed by the authors believe these two statements to be accurate. The authors conclude that inaccurate media coverage, liberalism, and the civil rights discussions along with a new strategic elite have produced this situation.

Stade, Nancy K. (1993) The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal. *Columbia Law Review*, 93(8, December): 1985-2021. The article covers the development of the Oregon Health Plan including the use of discriminatory attitudes which people hold about persons with disabilities and the use of the concept of quality of life. It analyzes the reasoning in the US Department of Health and Human Services rejection of the Oregon Health Plan because it violated the ADA. Then, assuming that there are scarce resources, it advocates the use of quality of life measures as the basis for the rationing of health care and what changes Congress would have to make in

the ADA for that to happen.

Stepan, Nancy Leys. (1992) *"The Hour of Eugenics": Race, Gender, and Nation in Latin America*. Ithaca: Cornell University Press. A comparison during the years between the two world wars of the development of eugenics and its influence on social reform in Argentina, Brazil, and Mexico with the same events in the US, Great Britain, and Germany.

Stratford, Brian. (1991) Human Rights and Equal Opportunities for People with Mental Handicap - with Particular Reference to Down Syndrome. *International Journal of Disability, Development & Education*, 38(1): 3-13. Discusses public attitudes toward people with mental disabilities and how they are treated. Reviews the concept of quality of life and a number of rights.

Thomson, Mathew. (1998) *The Problem of Mental Deficiency: Eugenics and Social Policy in Britain, c. 1870-1959*. New York: Oxford University Press. How the policy of institutionalism arose from eugenics.

Veatch, Robert M. (1986) *The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality*. New York: Oxford University Press. Rejecting a libertarian selfishness, Veatch focuses upon the situation of an individual who needs considerable assistance from society in a time of limited resources. Finding support in both the religious and the secular traditions of ethics, he concludes that minimizing inequalities and injustice is more valuable than personal liberty and autonomy.

Waitzman, Norman J.; Romano, Patrick S.; Scheffler, Richard M. (1994) Estimates of the Economic Costs of Birth Defects. *Inquiry*, 31(Summer): 188-205. Using 1988 California data the authors estimated that net per capita medical cost for babies born with spina bifida was \$99,000 and cerebral palsy was \$142,000. They estimated that total special education costs for persons with Down syndrome was \$37.1 million, for persons with cerebral palsy was \$28.6 million, and for persons with spina bifida was \$5.3 million.

Walters, James W. (1997) *What Is a Person? An Ethical Exploration*. Champaign: University of Illinois Press. Presents the concept of proximate personhood to be used to decide who has a claim to be kept alive.

Walters, James W. Editor. (1996) *Choosing Who's to Live: Ethics and Aging*. Champaign: University of Illinois Press. We must face the question of how rationing health care will protect or not protect elderly persons.

Wasserman, Gail A.; Allen, Rhianon. (1985) Maternal Withdrawal from Handicapped Toddlers. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 26: 381-87. Observing a sample of 12 disabled, 14 prematurely born and seriously ill, and 9 nondisabled children and their mothers at nine months, 12 months, 18 months, and 24 months, the study concludes that the mothers of the disabled children were more likely to ignore their children at 24 months than mothers of nondisabled children and that children with facial problems

were the most likely to be ignored. There was an associated drop in IQ for the children between 12 and 24 months.

Weindling, Paul. (1989) *Health, Race, and German Politics Between National Unification and Nazism, 1870-1945*. New York: Cambridge University Press. Traces the origin and influence of eugenics in German politics.

Wertz, Dorothy C.; Fletcher, John C. (1989) Fatal Knowledge? Prenatal Diagnosis and Sex Selection. *Hastings Center Report*, May/June: 21-27. Today many medical procedures are used solely for the purposes of sex selection. Not only is this use wrong, but it will lead to abuse in terms of aborting all but the "perfect" child. Medicine must not remain ethically neutral to sex selection procedures, but take a firm stand in opposition to them.

Wolfensberger, Wolf. (1981) The Extermination of Handicapped People in World War II Germany. *Mental Retardation*, 19: 1-7. The extermination of disabled persons in Nazi Germany was the precursor to the Holocaust. Present day parallels (like the Becker Case) are discussed.

Wolfensberger, Wolf. (1989) The Killing Thought in the Eugenic Era and Today: A Commentary on Hollander's Essay. *Mental Retardation*, 27(2, April): 63-66. Wolfensberger commends Hollander for bring forth evidence of the "killing thought" which is implicit in Eugenics. The final chapter has already started with 200,000 to 400,000 disabled or devalued persons killed each year. However, it is discussed in professional terms which is "obscene."

Zeitz, Kathleen. (1991) Employer Genetic Testing: A Legitimate Screening Device or Another Method of Discrimination? *Labor Law Journal*, 42: 230-38. Discusses the impact of cases brought under the Civil Rights Act with attention also given to the Rehabilitation Act of 1973 and the Americans with Disabilities Act.

Zola, Irving Kenneth; Asch, Adrienne. Editors. (1993) Genetics. *Disability Studies Quarterly*, 13(3): 1-59. Essays, book reviews, bibliography, and other resources on the topic of genetics and disability.

Note: Some of the annotations in this bibliography were previously published in: David Pfeiffer, 1991, An Annotated Bibliography on Bioethics, *Disability Studies Quarterly*, 11(2, Spring): 37-41; and in David Pfeiffer, 1993, Annotated Bibliography on Genetics and Disability, *Disability Studies Quarterly*, 13(3, Summer): 55-59. They are reprinted with permission.