Genetic disease and birth defects pose a unique set of concerns for affected individuals and their families. The need of these individuals for pastoral care—guidance for difficult decisions, bereavement counseling, and support—has opened a new area of ministry for pastors and pastoral counselors of all faiths. This ministry occupies the intersection of the disciplines of pastoral care, bioethics, and genetic counseling. This bibliography is intended both to introduce pastors, pastoral care workers, and educators to this unique dimension of health care and to assist them in extending their knowledge of the field. With the exception of a few classic articles, only material from the last ten years is included in this edition. The bibliographies are classified into four chapters: (1) "New Frontiers in Biology: Ethical, Legal, and Theological Concerns"; (2) "Clergy Involvement in Genetic Counseling"; (3) "The Religious Community and Persons With Disability"; and (4) "Support for Families." (YP)
RESOURCES FOR CLERGY IN HUMAN GENETIC PROBLEMS

A Selected Bibliography

1988 Edition

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NCEMCH
National Center for Education in Maternal and Child Health
Resources for Clergy in Human Genetic Problems

A Selected Bibliography

Second Edition
May 1988

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Resources for Clergy in Human Genetic Problems

A Selected Bibliography

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Preface

Genetic disease and birth defects pose a unique set of concerns for affected individuals and their families. The need of these individuals for pastoral care—guidance for difficult decisions, bereavement counseling, and support—has opened a new area of ministry for pastors and pastoral counselors of all faiths. This ministry occupies the intersection of the disciplines of pastoral care, bioethics, and genetic counseling. The demand for clergy familiar with genetics who can provide this new ministry has been dramatically stimulated by the rapid expansion in the diagnosis and treatment of birth defects and genetic disorders.

However, an immense and growing body of literature exists in the various disciplines that comprise this new ministry. Keeping abreast of this literature is a difficult job for the already busy pastor or pastoral care worker. Moreover, many of the journals and books are not readily available, except at major medical centers or universities. This bibliography is intended both to introduce pastors, pastoral care workers, and educators to this unique dimension of health care and to assist them in extending their knowledge of the field.

The Division of Genetics at Georgetown University School of Medicine has long had an interest in familiarizing clergy with genetics and in preparing them for more adequate ministry in this field. The first edition of this bibliography evolved from the course, "Clergy Education in Human Genetics Problems," which was sponsored by the March of Dimes Birth Defects Foundation and presented by the Division of Genetics during the summer of 1984. The bibliography has supplemented subsequent sessions of this course which have been held yearly since 1984.

The response to the first edition was very gratifying, indicating that this bibliography does indeed meet an educational need. The publication of many new articles and books in the four years since the first edition has necessitated a new edition. Over two hundred new references have been included. Since this publication is for practicing clergy rather than scholars, citations more than ten years old were deleted, with a very few exceptions for classic books. No bibliography is ever complete, and important sources can be overlooked. Therefore I welcome suggestions from readers for material that should be included in the next edition.

Frank D. Seydel, Ph.D., M.Div.
Acknowledgements

I would like to express my deep appreciation to the Bureau of Maternal and Child Health and the March of Dimes Birth Defects Foundation, whose financial support has made this bibliography possible from its inception through this second edition. I would also like to thank Robert C. Baumiller, Ph.D., S.J., Chief of the Division of Genetics at Georgetown University Medical Center, who conceived the Program for Clergy Education in Genetics, from which this project arose, and who has energetically promoted this project. In addition, the staff at the National Center for Education in Maternal and Child Health deserve thanks for their extensive editorial and literature search efforts.

F.D.S.
All items in this bibliography have been annotated. Citations follow the American Psychological Association style manual. The bibliography has been organized topically. Each topic has been further divided into two sections: the first section contains books and periodical articles arranged alphabetically by author; the second section lists journals and periodicals that frequently contain articles on the topic. Many works, especially the proceedings of meetings, touch on several of the topics listed. However, each item is cited only once, under the topic which seems most appropriate.

The bibliography is intended to acquaint clergy and pastoral care workers with current information. Thus, with the exception of a very few classic articles, only material from the last ten years is included in this edition. All items are currently in print. Journals and books should be available from major libraries by interlibrary loan. Emphasis has been placed on the role of religion in general and the role of clergy in particular in dealing with concerns in human genetics. Additional material on such topics as bereavement, bioethics, genetics, pastoral care, and social work can be obtained by consulting references in those fields.
Chapter 1
New Frontiers In Biology: Ethical, Legal, and Theological Concerns

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**General Bioethics**

**Books and Articles**


The why, what, and who of ethics committees, covering membership, structure, religious perspective, history of the *Ethical and Religious Directives for Catholic Health Facilities*, corporate decision making, committee meetings, and evaluation. Available from Catholic Health Association of the United States, 4455 Woodson Road, St. Louis, MO 63134-0889.


An introductory survey of current medical ethics topics, emphasizing their complexity.


A criticism of the Uniform Declaration of Death Act with a survey of recent proposals for definitions of death, and an alternative definition of death as the persistent cessation of consciousness.


Basic primer in medical ethics. The chapters on prenatal diagnosis and applied genetics are especially pertinent.


A collection of essays on the philosophy of nature. Contains five essays on reproductive technology (some originally published in the early 1970's) and four on medical ethics.


A comprehensive reference, with listings from abortion to zygote.


Provides a history and overview of bioethics; discusses the resolving of bioethics dilemmas; surveys the legal system, issues of privacy, confidentiality, and liability. Contains seven appendices including "Religion and Health Care Ethics." Includes a multimedia bibliography and an index. Available from American Hospital Association, 211 East Chicago Avenue, Chicago, Illinois 60611.

Offers an overview of the ethical questions created by biotechnology. Includes a chapter on genetic engineering. Each section contains questions for discussion and resources for further study.


Surveys and discusses the issues of eugenics, reproductive technologies, and genetic engineering. Provides an overview of the scientific background and data for each issue discussed.


A yearly compendium of citations in the field of bioethics. The bibliography is produced at the Kennedy Institute of Ethics, Georgetown University. Contents also available in an online database, BIOETHICSLINE, in the National Library of Medicine's MEDLARS network. Vols. 1-9 are available from Gale Research Co., Book Tower, Detroit, MI 48226.

**Journals and Periodicals**

*Bioethics Quarterly*. Human Science Press, 72 Fifth Avenue, New York, NY 10011.

Multidisciplinary consideration of bioethical dilemmas, including those of concern in the practice of genetics. Published quarterly.

*The Hastings Center Report*. 255 Elm Road, Pleasantville, NY 10510.

An interdisciplinary, bioethics journal devoted primarily, but not exclusively, to secular bioethics. Published monthly.

*Journal of Medical Ethics*. Tavistock House East, Tavistock Square, London, England WC1 H9JR.

This journal includes papers on medical ethics, analyzes ethical concepts and theories, and features case conferences and comment on clinical practice. Published quarterly.


Deals with the philosophical foundation for the nature of medical practice; occasionally has articles on genetic health care. Published quarterly.


This journal gives a broad, philosophical view of the interaction of science and religion. Published quarterly.

*Kennedy Institute Newsletter*. Kennedy Institute of Ethics, Georgetown University, Washington, DC 20057.

Provides short essays and an annotated bibliography of recent publications in bioethics. Published bimonthly.

*New Titles in Bioethics*. Kennedy Institute of Ethics, Georgetown University, Washington, DC 20057.

A listing of the Kennedy Institute's bioethics bibliographies. Published annually.
### Books and Articles


A systematic examination of the theological foundation for contemporary health care. Chapters include The Health Seeker, The Healing Profession, Bioethical Decision Making, Difficult Bioethical Decisions, and Pastoral Ministry in Health Care. The book provides a thorough background for the practice of genetic health care from the Roman Catholic point of view. Much of the presentation can be extended to other traditions as well. Available from Catholic Health Association of the United States, 4455 Woodson Road, St. Louis, MO 63134-0889.


The fourth monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines mental and physical health, marriage and procreation, abortion, aging, and right to life from the fundamental Jewish perspective of the Torah.

**Franck, I. (1983).** *Moral dilemmas that are acute within a religious tradition: A Jewish perspective.* *Hospital Practice, 18*(7), 192-196.

Considers the Jewish imperative to preserve life in regard to five genetic dilemmas: the risks and benefits of group screening for Tay-Sachs disease, the desire of two mentally retarded persons to marry, medical intervention for affected newborns, the definition of death, and the use of prenatal diagnosis.


Special 50th year anniversary issue dealing with the range of medical ethics. Topics covered include *in vitro* fertilization, abortion, genetics and amniocentesis, and the treatment of chronically ill infants.

**Hauerwas, S. (1986).** *Suffering presence: Theological reflections on medicine, the mentally handicapped, and the Church.* South Bend, IN: University of Notre Dame Press.

A three-part discussion. The first covers medicine and the church, professional authority in medicine, and suffering and death. The second addresses suicide, brain death, the ethics of experimentation with human subjects (including children), and *in vitro* fertilization. The third covers ethical issues involved in preventing, and in caring for persons with, mental retardation and other disabilities.

The sixth monograph in a ten-part series dealing with central themes in health and medicine from the perspectives of different faiths. This volume deals with healing, suffering, dying and death, morality, stages of life, sexuality, caring, and well-being from the Methodist focus of the journey towards holiness.


This issue of the theological quarterly of the Church of the Brethren consists of seven articles on medical genetics and biotechnology.


An anthology of 105 contemporary essays on medical ethics, most from religiously informed perspectives. Chapter topics include: religion and medicine, theology and medical ethics, professional integrity, the sanctity of life, health and healing, death and its dignity, the mastery of nature, patients and their suffering, respect for persons, contraception, reproductive technology, genetic control, abortion, euthanasia, neonatal care, the physician-patient relationship, psychiatric care, research ethics, and distributive justice. Includes work by Karl Barth, Hans Jonas, Leon Kass, C.S. Lewis, Paul Ramsey, Paul Tillich, and Robert Veatch.


The first monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different religious faiths. This volume covers wellness and illness, caring and curing, and passages in life from the perspective of the "world centeredness" of the Lutheran tradition.


The introductory volume for a ten-part series dealing systematically with core themes in health and medicine from the perspectives of different religious faiths.


The third monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines morality, justice, sexuality, and dignity as they relate to health issues from the Roman Catholic perspective of well-being and totality.


McCormick compares the Roman Catholic moral imperative to preserve life with the pastoral need to place the imperative within the content of particular lives.


Tackles several issues of interest in human genetics, including test-tube babies and pregnancy termination. Tay-Sachs disease is presented as a case study for the ethical concerns in screening.


Discusses the spectrum of theological, ethical, and pastoral issues raised by contemporary biological research.

*Medical Ethics and Religious Tradition*

Provides suggestions for resolving conflicts arising from questions about the nature and quality of life and the beginning of individual life.


The fifth monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different religious faiths. This volume deals with mortality, decisions about death, and sexuality and new life from the perspective of the central Anglican theme of communion or sharing.


The second monograph in a ten-part series dealing with core themes in health and medicine from the perspectives of different faiths. This volume examines issues surrounding the nature of humanness, such as well-being, suffering, sexuality, healing, and mortality, from the central Reformed perspective of redemption.


Discusses the Jewish legal concepts of goses (being in the state of imminent death), trefa (being in the state of having a fatal organic disease), and pikuach nefesh (the duty to save life), as they apply to the Quinlan case. However, these concepts apply as well to such arenas as the neonatal intensive care unit.

**Journals and Periodicals**


Deals with broad ethical concerns from the perspective of religious traditions. Occasionally deals with medical ethics. Published biannually.

**Medical Genetics and the Law**

**Book and Articles**


Provides an overview of the laws that affect clinical and research aspects of medical genetics. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.


Covers legal issues of fetal research, amniocentesis, genetic counseling, genetic screening, *in vitro* fertilization, artificial insemination, surrogacy, adoption, contraception, sterilization, abortion, human experimentation, and sale or rental of human organs.


From the National Symposium on Genetics and the Law. Extensive updating and supplementing of Volume I. Volume II discusses the legal and ethical issues in government control of science, genetic counseling and screening, eugenics, the control of genetic disease, family law, and the regulation of mutagens and teratogens.


From the National Symposium on Genetics and the Law. Includes discussion of genetic mass screening, human experimentation, eugenics, genetic counseling, the status of the newborn, in vitro fertilization, and other related topics.


A report of the Institute of Medical Ethics working group on the ethics of clinical research investigations on children. Glossary and index are included.

**Journals and Periodicals**

*American Journal of Law and Medicine.* American Society of Law and Medicine, 765 Commonwealth Avenue, Boston, MA 02215.

A number of legal-medical articles touch on issues of interest to the practice of genetics, including the fetus as a patient, pregnancy termination, confidentiality, and parents’ right to know the risk of birth defects. Published quarterly.

*Journal of Legal Medicine.* American College of Legal Medicine, Inc., 801 North Rutledge Street, Suite 2149, P.O. Box 3926, Springfield, IL 62708.

Discusses various legal aspects of health care with many articles focusing on genetics and medical ethics.

*Law, Medicine, and Health Care.* The American Society of Law and Medicine, 765 Commonwealth Avenue, 16th floor, Boston, MA 02215.

Deals with the intersection of medical practice, law, and ethics. Many issues apply to a variety of medical specialties including genetics. Occasionally, articles deal specifically with reproductive and genetic concerns. Published bimonthly.


Discusses current international legal thinking on medical issues. Topics with implications for the practice of genetics include euthanasia, abortion, malpractice, medical ethics, and medicine and religion. Published quarterly.
Reproductive Technologies

Books and Articles


A discussion of in vitro fertilization, artificial insemination by donor and gender selection in Japan, and the ethics discussion provoked by these technologies.


Reports on the debate over whether Catholic hospital officials should discourage the surrogate mother from choosing their institutions for delivery.


Includes chapters on genetic concerns such as host mothers, gender pre-selection, genetic screening, test tube babies, and abortion.


A discussion of the views and statements of medical professionals, Parliament, and the Anglican and Catholic churches about artificial insemination, surrogacy, and abortion. Available from SPCK, Holy Trinity Church, Marylebone Road, London NW1 4DU.


An overview of the ethics of reproductive technology, with a useful bibliography.


Examines the constitutionality of legislation that might be used to regulate human genetic experimentation. One chapter (and its attendant appendices) presents the results of interviews with regulators, cloners, and campus biosafety committees. Includes bibliography (including court cases) and index.


Provides a critical evaluation of the ethics of reproductive and other technologies.


Surveys legislation covering surrogacy in the United States, Canada, the United Kingdom, and Australia; the ethics of surrogacy; and guidelines for resolving conflicts between the (biological) father and (biological) surrogate mother over pregnancy termination, prenatal care, and custody.


Provides an overview of the politics and political economy of reproductive technology in France.

A report on controversy in Britain over the Warnock Commission report on the ethics of human embryology experiments.


Surveys the Italian response to the Vatican proclamation on in vitro fertilization.


Ramsey's classic book has served as the basis for much subsequent discussion in this field. He presents a carefully developed rationale for restricting a number of the new technologies such as artificial insemination and cloning.


Reports on the regulatory history of reproductive technology in Israel, and on the implications of this technology for the question of Jewish identity.


Discusses the technical and ethical aspects of in vitro fertilization, surrogacy, and sex selection, and such still futuristic topics as cloning, ectogenesis, and genetic engineering. Appendices include statements and reports from Australia, the United Kingdom and the United States, and results of a survey of Australian couples who have undergone in vitro fertilization. Includes a bibliography and index.


Covers recombinant DNA, in vitro fertilization, surrogacy, cloning, and the moral dilemmas posed by biotechnology.


Reports on abortion and in vitro fertilization in Poland.


Provides an overview of the legal climate for reproductive technology in Australia.


Surveys statements on reproductive technologies by bioethics committees in Australia, Great Britain, Canada, West Germany, Spain, France, the Netherlands, and the United States.


Warnock provides a summary of the report of the British committee of inquiry which she chaired. This landmark committee recommended more stringent regulation of artificial insemination by donor, the criminalization of the organizational promotion of surrogate motherhood; and licensing, regulation, and inspection of facilities that conduct research on human embryos.
Gene Therapy and Genetic Engineering

Books and Articles


A review of existing legislation and an attempt to apply the arguments of contemporary political philosophers in resolving conflicts arising from the distribution of genetically engineered superior talents.


A critical evaluation of recombinant DNA technology and its impact on society.


A statement which raises many questions proposed for further study, and which offers some cautions, but which basically takes a permissive attitude to all non-military applications of genetic technology.


Extensive review of the controversies surrounding the possibility of the therapeutic alteration of DNA in both somatic cells and gametes.


Rifkin is perhaps the best known exponent of the thesis that modern genetic practices, especially gene-splicing, are dangerously meddlesome and tantamount to playing God.


Presents the scope and limits of contemporary medical genetics, the interest in genetic engineering which these limits arouse, and the ethical and social concerns anticipated by these experimental new techniques for the lay person.


Adopted from a study report of the Panel on Bioethical Concerns of the National Council of the Churches of Christ/USA, this book is useful as a resource for church study groups. Discussion questions and suggestions for group leaders are provided at the conclusion of each section.


An examination of genetic engineering with some theological answers and suggestions for involvement by the different denominations in the Council.

Provides a systematic examination of the types and techniques of gene therapy and their medical applications. It discusses the issues which could arise from clinical application, including parental responsibilities, trade secrets, social implications such as alteration of the gene pool, and the federal role in this new technology. Available from Government Printing Office, Superintendent of Documents, Washington, DC 20402. Ask for publication no. 052-003-00906-4.


This study carefully examines the social and ethical issues in light of the limitations and potential of current research.


Examines the motivations for current genetic manipulations, and briefly looks at two major types, cloning and recombinant DNA.


Part of the *What are they saying about...?* series. Gives an overview of several contemporary developments in genetics and the ethical issues accompanying them.


An overview of the techniques, prospective commerce, and research ethics of human gene therapy, especially single gene germ line therapy for inborn errors of metabolism.

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**Genetic Screening, Prenatal Diagnosis, and Fetal Therapy**

**Books and Articles**


A group study guide on genetic screening, fetal therapy, and reproductive technology, written by officials of the Episcopal Church.


A report on the debate over whether to screen "intellectually handicapped" children to determine whether they have fragile X syndrome, and whether to offer screening to the families of those who are found to have this disorder.

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A discussion of the morality of providing needed fetal therapy against the will of the mother.


A study of the attitudes of 490 pregnant women towards pregnancy termination due to abnormalities revealed through genetic screening. Three hundred of the women were participants in a prenatal screening program for neural tube defects.


Examines the status of the major ethical debates accompanying prenatal diagnosis and fetal therapy.


Specific ethical issues are discussed, as well as the history of genetic counseling and its applications.


A survey of the current and prospective means for identifying genetic markers for disease, longevity, IQ, depression, alcoholism, schizophrenia, etc. The potential uses and abuses of this information by employers, governments, medical professionals, insurers, and others is discussed.


Presents the basic concepts of genetics but also covers social controversies arising from genetic screening and engineering.


Addresses genetic screening from the standpoint of Catholic moral theology.


Provides a comprehensive description of current screening services, including carrier, newborn, and prenatal screening, and of associated ethical concerns including confidentiality, autonomy, disclosure of knowledge, public and professional education, well-being, and equity. Uses cystic fibrosis as a case study for application of the various issues discussed.


Reflections on prenatal diagnosis and pregnancy termination.


Examines the unique aspects of genetic disease, including the dilemmas for patients and families.

*Gene*c Screening, Prenatal Diagnosis, and Fetal Therapy

The moral decisions faced by a family concerning further testing and treatment are examined in terms of perceived obligations and rights.


A report on California's maternal serum alpha-fetoprotein screening program.


Discusses the implications of intrauterine diagnosis and therapy for decisions regarding pregnancy termination and the mother's right to refuse medical treatment beneficent for the fetus.

**Critically Ill Newborns**

**Books and Articles**


This volume, in the format of a looseleaf, spiral notebook, represents the results of a workshop offered in San Francisco, Washington, and Chicago, sponsored by the University of Illinois College of Medicine, Carle Medical Communications, and the Carle Foundation. Covers treatment of critically ill newborns, whether parents have the right to make decisions about the child-patient, the roles of family and doctor in decision making, criteria for withholding or withdrawing life-sustaining care, the American Academy of Pediatrics' guidelines for bioethics committees, the American Nurses' Association's code, ethical dilemmas, the legal and ethical issues about withholding treatment from the critically ill newborn, and judicial and administrative rulings and legislation. Includes a bibliography.


The authors cover the roles of professionals working in neonatal intensive care units, clinical decisions, and the family, and survey neonatal intensive care in the United States and abroad. Includes bibliography, glossary, and index.


This anthology covers ethical issues in neonatology, as well as other life and death issues.


The author discusses the role of families and doctors in decisions about critically ill newborns in Japan.


Contains one contribution each on Jewish and Catholic perspectives on passive euthanasia. Several chapters discuss the Baby Doe case and the general issue of life-sustaining measures for infants born with life-threatening disorders.

The author cover current Canadian practice, and legal and ethical aspects of treatment of critically ill neonates. Includes bibliography, table of cases, and index.
Chapter 2
Clergy Involvement in Genetic Counseling

Clinical Genetic Counseling

Books and Articles


An annotated collection of twenty-four varied genetic counseling cases provided by twenty-six professionals and one client. Provides insights into the work of the counselor and the different responses of patients to the counseling experience.


Discusses why church-related medical institutions have shied away from genetic counseling and genetic testing.


This volume is a multilanguage translation dictionary of genetic terminology. The first section is an alphabetized and numerically indexed list of almost 3,000 terms in English. Each term is followed by its equivalent in French, Spanish, Italian, German, and Russian, without definition. The remainder of the volume consists of alphabetized lists of terms segregated by language, each term followed by the index number for its equivalent in the English language section.


Discusses the history of genetic counseling, counseling as related to the concepts of genetic disease and health, the role of the counselor within the medical profession, professional qualifications, and ethics, including autonomy and confidentiality. Several specific ethical issues are also presented, including responsible parenthood, the relationship of prenatal diagnosis to selective abortion, and the withholding of treatment to critically ill newborns.


A synthesis of philosophy and medical case experience.


Presentation of various components of genetic counseling. Emphasizes psychological impact of genetic disease upon the family.


Topics discussed include anxiety, anger, the effect of genetic counseling on self-concept, non-verbal communication, parental response to uncertainty, a guide for amniocentesis decision making, and presentation and perception of risk.


A comprehensive text on medical genetics which presupposes no background in the field.


Provides a comprehensive view of genetic counseling. Also includes a chapter on basic human genetics.


Provides a listing of genetic service providers in many countries.


Integrates medical and genetic information with the psychosocial aspects of genetic counseling. Written in non-technical language and is primarily concerned with communication between counselor and counselee.


Examines the psychological factors present in persons with a high risk of, or who currently have, a serious genetic disease in themselves or their families. Attention to these factors enables counselors to communicate information more effectively and better help their patients deal with their concerns.


The major counseling tactics alleviating or reducing feelings of guilt and shame are outlined and case illustrations are provided.


Transcripts of genetic counseling sessions were analyzed to determine communication difficulties concerning information on risk and consequences.


The two chapters on building supportive counseling relationships and on genetic counseling, which discuss the patient’s needs and the means to remain open to the patient’s point of view, are particularly helpful for pastors. Case studies included.

The benefits of preamniocentesis counseling, regardless of whether pregnancy termination is contemplated, are examined.


This text is written to introduce medical students to human genetics. It presupposes little or no background in genetics. Each chapter is referenced and many of the nineteen chapters have problems at the end. Answers to problems are provided in the back of the book. Glossary and index are included.

Journals and Periodicals

Genetics Digest. Foundation for Blood Research, P.O. Box 190, Scarborough, ME 04074.

A digest of recent literature in human genetics. Published monthly.

Genetics in Practice. March of Dimes Birth Defects Foundation, Professional Education Department, 1275 Mamaroneck Avenue, White Plains, NY 10605.

A brief update on major themes in clinical human genetics. Intended primarily for health professionals, the information presented is summarized adequately to be helpful to clergy. Published quarterly.

Pastoral Counseling About Genetics

Books and Articles


This work is the result of an interdisciplinary Task Force on Genetic Diagnosis and Counseling assembled by the Pope John Center to examine the moral issues engendered by genetic counseling.


Brief discussion of the opportunities open to clergy to work closely with families and individuals who are at risk for or affected with a genetic disorder.


Proceedings of a conference held at Georgetown University. The conference faculty explored the problems caused by the reproductive options given to individuals and couples by advances in medical genetics and medical technology and the need for faith groups to prepare their counselors and pastors to advise families competently.


Written by a pastor who became interested in genetics after the birth of his two children affected with a genetic condition. The article suggests pastoral roles on a genetics team.

A commentary on the expanding role of clergy in supporting persons with genetic disorders and their families.


A guide for clergy who must counsel couples who already have or are at risk of having a child affected with a genetic disorder. Many sections of the book are also informative for those interested in genetic counseling and in the dilemmas created by genetic technology.


A compendium of genetic disorders among Jewish groups including Ashkenazi, Oriental, and Sephardic Jews. Contains a section on common misconceptions about diseases which affect Jewish persons.


Itemizes the diseases especially common among this ethnic group. Provides much technical detail on genetic patterns, clinical manifestations, and treatment.


A report on clergy involvement in counseling affected individuals and their families.


Developed as a workbook of exercises and reflections to be used as a resource in a congregational study group. The book has three sections: The Power to Be a Parent, Parenthood and the "Quality" of Children, and Making Decisions and Getting Involved.


Addresses the many ways that clergy can participate in resolving ethical conflicts for patients and professionals.


A brief article in a United Methodist publication, intended to acquaint clergy with this new area of ministry.


Includes articles and books from professional literature and audiovisual materials produced by voluntary organizations and professional film makers. References cited are meant to assist health professionals to respond to the unique problems faced by individuals and families who are at risk for or have a genetic disorder. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057


Surveys psychological literature to provide insights for ministers in crisis counseling. Covers theory and methods of crisis counseling, intervention procedures, family crises, grief, pathological grief, divorce, suicide, and congregational and community services. Includes footnotes and index.

Presents a permissive approach to contraception, sterilization, and abortion, and a much less permissive approach to euthanasia and the obligation to provide information about inherited disorders.


Examines practical and religious counseling concerns from a Jewish perspective.

**Journals and Periodicals**

*Journal of Pastoral Care*. Journal of Pastoral Care Publications, Kutztown Publishing Company, P.O. Box 346, Kutztown, PA 19530.

Carries articles on counseling, decision-making, and coping with grief and mourning relevant to genetic illness and genetic counseling. Published quarterly.

*Journal of Religion and Health* Human Sciences Press, Inc., 72 Fifth Avenue, New York, NY 10011.

Includes articles on topics relevant to genetic illness and genetic counseling. Published quarterly.
Chapter 3
The Religious Community and Persons with Disability

Books and Articles


An annotated bibliography of publications suitable for use in various religious educational services for the disabled.


Guidelines for instructing the disabled in the Catholic faith. Also available in Spanish as Acceso a los Sacramentos de Iniciación y Reconciliación para Personas Inhabilitadas. Available from Liturgy Training Publications, 1800 Hermitage Avenue, Chicago, IL 60622-1101.

Association for Retarded Citizens. (No date given.). Congregational awareness program. Arlington, TX: Association for Retarded Citizens.

Suggestions for a program to acquaint congregations with the presence of mentally retarded persons within their constituency or neighborhood areas and to help them see possibilities for expanding the congregation's programs to include mentally retarded persons and their families. Available from Association for Retarded Citizens, 2501 Avenue J, P.O. Box 6109, Arlington, TX 76011.


Personal anecdotes from Baptists and Anglicans in the United Kingdom and Australia who are working with mentally disabled relatives and congregants. Available from Baptist Union, 4 Southampton Row, London WC1B 4AB.


Catholic clergy and lay people address the role of the Church, the medical profession, financial planning, special education, residential services, sexuality, and parent advocacy.


A guide for the workshop director, including scripts for lectures and audiocassettes. Available from Special Pastoral Services, Archdiocese of Portland in Oregon, 8716 S.E. Ellis, Portland, OR 97266.

Sermon ideas, bibliography, and a directory of Mennonite organizations working with persons with disabilities. Available from Developmental Disability Services, Box 370, 500 South Main, Elkhart, IN 46515.

Division for Parish Services. (No date given.). T'ps for congregations working with disabled persons. Philadelphia: Lutheran Church in America.

This loose-leaf folder contains inserts on the moderately mentally retarded, those with hearing, speech, vision, and physical disabilities, the emotionally disturbed, and the autistic. Available from Division for Parish Services, Lutheran Church in America, 2900 Queen Lane, Philadelphia, PA 19129.


An extensive listing of resources for religious education and worship programs that include persons with disability. Available from E.A.C.H., 4805 Manion Street, Annandale, VA 22003.


A collection of position papers by Protestant and secular groups on persons with disabilities. Also contains worship materials, suggestions for group use, and a bibliography. Available from National Council of the Churches of Christ, Education for Christian Life and Mission, 475 Riverside Drive, New York, NY 10115.


An exploration of the role of the minister, church, and wider community in ministering to the mentally retarded.


Discusses the issues of church accessibility, clergy as spokespeople and as advocates, existential questions arising from disabilities, clergy as service providers, and the need for an expansion of PL 94-142 to cover religious education for those who desire it.


Discusses programs and services by churches to meet the needs of disabled persons for worship and education.


This booklet contains sermon plans and mimeograph masters for teaching about the disabled.


A booklet on ministering to the disabled, with an extensive bibliography of audiovisuals and print material, and a directory of organizations. Available from Division for Parish Services, Lutheran Church in America, 2900 Queen Lane, Philadelphia, PA 19129.

The author recounts the grieving process of her sister, who has Down syndrome, after the death of their grandmother.

Theological, historical, and psychological essays, including coverage of the issues of religious instruction and family dynamics. Available from Mennonite Central Committee Canada, 134 Plaza Drive, Winnipeg, Manitoba R3T 5K9.

Discusses ministry to the deaf as an example of cross-cultural ministry.

Discusses the importance of a sense of space and time in the development of human beings, especially persons with mental disabilities. Concludes that the socioaffective development of mentally retarded persons makes it possible to enlarge their sense of space by bringing them into the Christian community.

Using the experience of preparation for the First Communion as an example, the author presents appropriate methods for presenting religious instruction to mentally retarded children. The emotions of the parents are also discussed.

Suggestions for how a congregation can help the family with a disabled family member. Available from Mennonite Disabilities Committee, 1712 W. Clinton, Goshen, IN 46526.

Discusses myths about the disabled.

Discusses L'Arche communities (which integrate persons with and persons without mental disability), their disclosure of the value of persons with mental disability, their facilitation of mutual relationships, their provision of a sense of community, and their illumination of the spirituality of both those with and those without mental disability.


**Journals and Periodicals**

*Breakthrough*. Bethesda Lutheran Home, 700 Hoffmann Drive, Watertown, WI 53904. A newsletter that can be used in religious education for the mentally retarded. Published quarterly.

*The Caring Congregation*. The Healing Community, 139 Walworth Avenue, White Plains, NY 10606. An interfaith newsletter for clergy and religious educators working with disabled persons. Published quarterly.

*NAMRP Quarterly Publication* and *National Apostolate with Mentally Retarded Persons Newsletter*. NAMRP Publication Office, 100 East Eighth Street, Cincinnati, OH 45202. Publications available to members of the National Apostolate for Mentally Retarded Persons. Published quarterly and bimonthly.

*Religion Division Newsletter*. American Association on Mental Retardation, 1719 Kalorama Road, N.W., Washington, DC 20009. Available to Association members only.

*SPRED*. Special Religious Education Division, Archdiocese of Chicago, 2956 South Lowe, Chicago, IL 60616. (312) 842-1039. A newsletter for those involved in the religious education of persons with mental retardation. Published monthly.
Chapter 4
Support For Families

Coping with Grief

Books and Articles


Discusses whether children should be shielded from death, whether children understand death, how one tells children about death, and whether children should attend the funeral and cemetery services. Though some of the material is specifically Jewish information, all is presented in a way that would be instructive to both Jews and non-Jews. Available from Jewish Funeral Directors of America, 122 East 42nd Street, Suite 1120, New York, NY 10168.


Discusses the various circumstances that can precipitate mourning including abortion, birth of a disabled child, death of a child, and death due to terminal illness. Ways of helping the family are provided, including the role of religion.


This rabbi's answer to the question of theodicy became a best seller. This question is frequently asked when a genetic or congenital defect is diagnosed.


Written for bereaved parents from the personal viewpoint of a mother who lost her ten-year-old son. Discusses the funeral, grief, and attitudes about religion.


Discusses children's attitudes about death and ways to counsel children who encounter death, whether it be the child's own impending death, that of a sibling, or that of a relative or friend. One chapter specifically discusses the role of the pastoral counselor. Its annotated bibliography of books for children and adults, and its comprehensive annotated list of audiovisual resources available for educating children about death make this book an exceptionally useful resource.

Journals and Periodicals

*Caring Concepts*. Centering Corporation, P.O. Box 3367, Omaha, NE 68103.

A newsletter by and for bereaved families.
Perinatal Bereavement

Books and Articles


Includes prayers, services, and articles to assist clergy in providing pastoral care to those with special needs, including parents who have experienced a pregnancy loss.


Discusses the grief experiences of parents caused by miscarriage, stillbirth, abortion or infant death, and discusses the role of the clergy and of support groups in helping bereaved parents cope. The appendices provide lists of national and regional support groups and of organizations and resources available for assistance.


Covers the responses in mourning of the couple, the community, the mother, caregivers, and siblings. Includes notes, bibliography, index, and a directory of local parent support groups.


Discusses types of pregnancy loss, the bereavement experience, and planning for future pregnancies. Includes bibliography, index, and a directory of parent support groups and adoption organizations.


This guide was developed in collaboration with the National Perinatal Bereavement Alliance, and presents an annotated collection of information on perinatal loss, including materials on hospital programs, curricula, audiovisuals, and organizations. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.


Provides texts of prayers for bereaved family members.


Discusses grief, tensions between husband and wife, the role of the physician, funeral arrangements and grave visits, subsequent pregnancy, and the need for support groups. Includes list of organizations and bibliography.


Early description in medical literature of the grief associated with pregnancy loss.


Contains a chapter on spiritual needs of the grieving. Includes directory of support groups, bibliography, and index.

A manual and directory of resources for those planning to organize a parent support group for the bereaved. Available from St. John's Hospital, 800 East Carpenter Street, Springfield, IL 62769.


Discusses grief, anger, the feelings of husbands and siblings, postpartum nutrition and exercise, mood swings, and subsequent pregnancies. Two chapters discuss spiritual themes.

**Journals and Periodicals**

SHARE Newsletter. St. John's Hospital, 800 East Carpenter Street, Springfield, IL 62769.

A newsletter by and for lay people and clergy dealing with bereavement. Published bimonthly.

**Coping with Disability within Families**

**Books and Articles**


Covers having a child diagnosed, finding other parents with disabled children, learning about the disability, genetic counseling and abortion, choosing doctors and therapists, institutionalization, early intervention, financial aid, special education, advocacy, life after high school, and sexuality. Includes bibliography and list of organizations.


Three physicians discuss helping parents of children with Down syndrome deal with anger, denial, guilt, and sorrow.


Discusses technique of obtaining parents' early memories of their child's disabling condition to uncover the true feeling of parents, identify critical concerns, and predict future difficulties for the families.


A detailed examination of the emotions and interactions of family members in response to the birth and development of a seriously disabled child.


Lester has collected articles by pastors, therapists, community mental health workers, and professors of psychiatry and of child education. Articles cover children's needs for religious instruction and support from adults during divorce of parents, bereavement, hospitalization, and terminal or chronic illness, after abuse, or when possessed of disabilities, stress, or anxiety.

Discusses the problems (impoverishment, marital stress, social isolation) of parents of a child with mental retardation, and the resources (socioeconomic status; religious belief; supportive, especially rural or religious, communities) that help families deal with these problems. In her opening remark the author expresses her belief that parents of the child with mental retardation often turn to the clergy before seeking other professional services. Available from The Joseph P. Kennedy, Jr Foundation, 1350 New York Avenue, N.W., Suite 500, Washington, DC 20005-4709.


Examines, according to the developmental sequence, problems parents of disabled children will encounter. Later chapters discuss strategies for obtaining assistance, including financial assistance, from agencies within the community.


Proceedings from a national symposium. Extensive discussion of concerns in, and strategies for, dealing with illness and death of children by parents and siblings, and by the family’s helping professionals, including nurses, teachers, and clergy.


Chronicles the experiences of one family’s coping with the unexpected birth of a Down syndrome child. Though different Down syndrome children will vary, and family conditions will also vary, the realistic presentation of problems and negative emotions and reactions by family, friends, and community provide reassurance and help define reasonable expectations for other parents with a disabled child.


Exploration of a multitude of ethical, religious, legal, and counseling concerns by geneticists, genetic counselors, clergy, social workers, lawyers, educators, and parents.


Provides information about the importance of social work services for the disabled, their families, and communities.

**Journals and Periodicals**

*Especially Grandparents.* King County Association for Retarded Citizens. 2230 Eighth Avenue, Seattle, WA 98121.

A newsletter for the grandparents of children with disabilities. Published quarterly.
Support Groups

Books and Articles


Traces the genesis of self-help groups from religious institutions, and the continued interrelations of the two groups, and then codifies five roles for the clergy: referrals, developing local groups, providing meeting space, motivating religious institutions to develop groups, and developing support groups that serve clergy. Includes a directory of self-help groups.


Written by genetics service providers, organizers of voluntary groups, and parents. Designed to help established organizations as well as new support groups.

Directories


Lists over 150 support groups and voluntary organizations for genetic disorders. Gives a statement of purpose for each organization and lists available educational materials. Available from the National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.


A bibliography and directory of organizations covering autism; cerebral palsy; epilepsy; mental retardation; hearing impairments; learning disabilities; mental and emotional illnesses; physical, social, and visual disabilities; and the gifted and talented. Available from the National Council of Churches of Christ, Education for Christian Life and Mission, 475 Riverside Drive, New York, NY 10115.


Provides a comprehensive reference to organizations with maternal and child health interests. Includes support groups for families, self-help clearinghouses, and professional organizations. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057.


A directory of university affiliated programs; state, regional, and Federal maternal and child health agencies; and advocacy groups.

Support Groups