

City University of New York

Rachel N. Grob, *Testing Baby: Parents' Perspectives on Genetic Diagnosis*. Barbara Katz Rothman, adviser. 2006.

This dissertation examines the impact of diagnostic processes on parents, with particular focus on how newborn screening is changing the way they perceive and experience their children's genetic disorders. What is the effect of knowing one's child has such a disorder at birth, and how is this experience different from that of knowing later, after symptoms of the disease emerge? How is it different from knowing earlier, before birth? How is newborn screening changing the relationship, for affected families, between medically defined "disease" and socially defined "illness"? In qualitative interviews with parents who learned about their child's genetic disorder in various ways—i.e., prenatally, through newborn screening, or after the emergence of symptoms—the author asked how the diagnostic process unfolded for them, and how their lives were changed as a result. She also asked more specifically about whether and how the diagnostic process influenced their perception of their child, their parenting practices, and their relationships with health care professionals. Her analysis draws heavily on the sociology of families, sociology of science, and sociology of health and illness. Recently, technology has emerged that makes it easy and inexpensive to screen infants' heel blood for large numbers of disorders. Eagerly, and with unprecedented speed, policy makers have seized the opportunity to add more and more new conditions to state newborn-screening panels. The manifest function of newborn-screening policy in 2005 is still to prevent

disease or, when that is not possible, to lessen its effect. But the author's interviews with parents highlight many other consequences of testing, including its substantial influence over the entire context of early parenting, over intrafamilial relationships, and over the balance of power and the process of collaboration between parents and their health care providers. This dissertation research illuminates underexamined aspects of the current technological shift in childhood genetic diagnostics, gives voice to a broader range of parental narratives about their experience of this shift than is generally found in either the popular or the scientific literature, and examines newborn screening as an increasingly important aspect of the "new public health" and its prevailing discourse about risk.—Abstract from *Dissertations Abstracts International*, publ. no. AAT 3204973, DAI-A 67/01 (July 2006): 354.

Duquesne University

Andrew W. Getz, *The Role of Christian Faith In Public Moral Discourse: A Comparison of Selected Works from H. Tristram Engelhardt, Jr., Stanley Hauerwas, and Richard A. McCormick*. David F. Kelly, adviser. 2006.

This dissertation asks, What is the proper role of the Christian and the Christian community in the ethical arena of a pluralistic society? The social nature of human beings means that all ethical judgments regarding right and wrong and the good of the human person have social implications. This dissertation examines how faith "in-formed" ethical judgments function in a society of diverse faith commitments by examining some of the different understandings of the role of

faith in the ethics of Engelhardt, Hauerwas, and McCormick. It illustrates the impact that their different understandings of the role of Christian faith in ethics have on the way that they understand Christian ethics functioning in the public moral discourse. To examine the issue of the role of religiously “informed” ethical judgments within a religiously pluralistic society, this dissertation examines the ethical methodology of the three ethicists, their views of Christian ethics, their understanding of how religiously informed ethical judgments function in the wider society, and their treatment of the issues of euthanasia and universal health care. The comparison of the ethicists begins with an examination of their understanding of the nature of ethics. It then examines how each of these ethicists answers fundamental questions regarding the role of Christian faith in ethics. The final section of this methodological consideration examines their understanding of “public theology.” Following the methodological section, the dissertation examines the authors’ positions on the issues of euthanasia and universal health care. It illustrates how the different methodological approaches of these three authors are manifested in the actual treatment of contemporary ethical issues. The unique contribution to theology that it makes is a thorough examination of the effect that different positions regarding the role of faith in ethical judgments have on the understanding of the proper role that the Christian and the Christian community ought to play in the ethical arena of contemporary pluralistic society.—Abstract from *Dissertations Abstracts International*, publ. no. AAT 3238541, DAI-A 67/10 (April 2007): 3846.

Fordham University

Brooke Myers Sorger, *Decision-Making Capacity in Terminally Ill Cancer Patients*. Barry Rosenfeld, adviser. 2005.

Little research has focused on the ability of terminally ill patients to make end-of-life decisions. The purpose of this study was to

explore the decision-making capacity of elderly, terminally ill cancer patients and better understand factors that may affect this ability. The researcher hypothesized that elderly patients with terminal illness were likely to have compromised decision-making skills as compared to a healthy group of comparison participants. Decision-making capacity was measured by use of the Hopkins Competency Assessment Kit, the Bechara Gambling Task, the Concept Assessment Kit, and the Mini Mental Status Exam. The author further hypothesized that symptoms of depression, level of physical functioning, and extent of physical symptomatology would have negative effects on decision-making skills. These variables were measured respectively by the Hamilton Depression Rating Scale, Karnofsky Performance Rating Scale, and the Memorial Symptoms Assessment Scale. The author also believed that significant relationships exist among decision-making tasks. Two groups were evaluated, elderly terminally ill cancer patients (n = 43), and healthy elderly comparison participants (n = 35). The results revealed significant impairment in the decision-making skills of those with terminal cancer compared with healthy comparison participants with regard to all measures except the Bechara Gambling Task. General demographic factors such as age, race, and education could not explain these differences in performance. Significant relationships among decision-making tasks were also revealed. The clinical variables described above did not effect decision-making skills as expected. Suggestions and insights are offered as to why the original hypotheses were not supported. Limitations regarding sample and measurement choices are discussed. Implications for significant findings including clinical and policy issues are explored, and future research directions are addressed.—Abstract from *Dissertations Abstracts International*, publ. no. AAT 3169403, DAI-B 66/03 (September 2005): 1738.

**Pontifical and Royal
University of
Santo Tomas (Philippines)**

Rev. Thomas Haake, O.M.V., *Documents on Bioethical Matters by the Congregation for the Doctrine of the Faith (1968–1995): Their Contribution to a Theology and Culture of Life.* Rev. Fausto Gomez, O.P., adviser. 2007.

By its nature, bioethics is a matter of vital concern for the welfare of the human person and the community at large. Although broad in scope, its principal focus is on the determination of the proper respect which should be accorded to human life. Religion is involved deeply in the process of evaluating the ethical standards which are to be applied in this field. Thus, this study seeks to analyze some of the major teachings of the Catholic Church in this subject area. To do so, a clearly delineated time period (1968 to 1995) has been selected. This span of twenty-seven years is framed by two highly germane papal encyclicals, *Humanae vitae* and *Evangelium vitae*. The chief doctrinal body of the Church, the Congregation for the Doctrine of the Faith (CDF), also issued four particularly relevant documents about bioethics during this period. These documents constitute the major area of concentration in this research. The topics covered in the documents are procured abortion, sexual ethics, euthanasia, and respect for human embryos and procreation. Part One of the dissertation provides observations about the history of the CDF and its role in the magisterium along with comments on the theological tensions present during the years under investigation. Part Two begins with an exposition of the effects of Church teaching in the encyclical on the regulation of births (*Humanae vitae*) and then proceeds to analyze the four CDF documents as to their doctrinal sources, content, solutions offered, and related issues arising after the publication of each document. Theoretical and practical associations are discovered among the topics of the documents them-

selves and the cultural context within which they were promulgated. The synthesis of the research presents links between the doctrinal teachings and the encyclical on life issues (*Evangelium vitae*). Thus, the comprehensive and consistent teaching of the Catholic Church is seen as significantly appreciable in fostering proper attitudes and behavior respectful of human dignity in bioethical matters.—Abstract received from the author, December 9, 2007.

**State University of
New York at Albany**

Melinda M. Denham, *Experiences of In Vitro Fertilization Donor Egg Recipients: The Impact of Technology on Reproduction.* Lawrence Schell, adviser. 2005.

Donor egg in vitro fertilization (DE), first developed in the early 1980s, severs female biological reproduction into genetic (egg donor) and gestational (egg recipient) components. Because of its high cost, in the United States DE is primarily used by white, middle- and upper-class women. In the media, infertile women who utilize this assisted reproductive technology have been variously caricatured as desperate, irrational, selfish, feminist career women, too old, or the cause of their own infertility. Yet amid the clamor of numerous stakeholders, the voices of egg recipients have often been absent. This research project emerged as a means of addressing this silence by listening to and contextualizing egg recipients' experiences as told. Semi-structured open-ended interviews were conducted with egg recipients recruited for this project through two U.S. infertility clinics (2001–2002) and one online listserv (2003). Political economic and interpretivist traditions in anthropology are drawn upon to frame egg recipients' experiences in broader social-cultural-historical matrices, and to understand how recipients develop and use body narratives as they navigate the worlds of infertility and DE. DE shares common features

with several other procreative technologies, such as non-normative reproduction, public reproduction, religious implications, and issues of disclosure of origins to children, family, and friends. However, DE departs from the experiences of IVF, surrogacy, donor insemination, and adoption in key ways that have framed this research project, including simultaneously non-genetic yet biological mothering, motherhood at a later age, high and highly variable cost of treatment and donor fees, and embodied knowledge on the part of recipients of what donors experience. In their narratives, egg recipients both challenge and accommodate cultural beliefs and norms, particularly regarding age-appropriate mothering, kinship definitions, consumption practices, and the commodification of children. At the core of egg recipients' narratives is motherhood. Egg recipients variously adopt, reject, and reconstitute powerful cultural idioms about motherhood in asserting and normalizing their own status as mothers. Finally, egg recipients' narratives offer new vantage points from which to consider such crosscutting and politically charged themes as "good" vs. "bad" mothers, maternal nurturance and sacrifice, and the contested terrain of fetal personhood.—Abstract from *Dissertations Abstracts International*, publ. no. ATT 3196109, DAI-A 66/11 (May 2006): 4073.

University of Chicago

John D. Carlson, *The Case for Limited Justice: Human Nature, Irony, and Transcendence in Political Ethics*. Jean Bethke Elshtain, adviser. 2005.

Justice is a perennial virtue that frames the most pressing ethical concerns in political life. John Rawls and other scholars, whose treatments of justice have dominated moral and political thought for the last thirty years, have largely ignored questions of moral anthropology and transcendence; omission of such features once central to "classical"

notions of justice has skewed our appreciation of this vital pursuit. This dissertation departs strongly from recent approaches by illustrating how views of human nature and God or "the sacred" deepen our appreciation of the many faces of justice, including the preservation of political order, retribution, reconciliation, and the proper ordering of human relations. After tracing historically the loosening of justice's "anthropological" and "transcendent" moorings in the modern era, the author suggests why these root ideas experienced decline in contemporary thought. Examinations of Plato, Calvin, Hobbes, and Marx show that a reliance on human nature and notions of transcendence is associated with overly ambitious or "unlimited" forms of justice. Justice, when made "ultimate" or "absolute" ironically begets injustice, eliding critical scrutiny and jeopardizing vital human endeavors. This overreach no doubt engendered an overreaction, resulting in the jettisoning of vital anthropological and theological resources for conceiving justice. As a correction, I draw upon Augustine, Reinhold Niebuhr, and Albert Camus to craft a position called "limited justice"—a more modest approach that accounts for human error, allows sufficient latitude to make amends and, in the end, provides for more substantive achievements of justice. Limited justice recognizes the irony and danger of pursuing a vision of justice that human frailty and finitude make impossible to achieve. Surprisingly, perhaps, such insights emerge when one reclaims the anthropological and transcendent underpinnings of justice. This dissertation bridges the roots of Western political thought with contemporary practical issues. From this conceptual treatment emerges a form of practical reasoning that sharpens debates surrounding capital punishment, crimes against humanity, and the justifiable use of force. For without a clear understanding of the human possibilities and limitations of achieving justice, we are not likely to arrive at satisfactory resolutions to these or other exigent ethico-political dilemmas of our time.—Abstract from *Dissertations Abstracts International*, publ. no. ATT 3168327, DAI-A 66/03 (September 2005): 1030.

University of Illinois at Urbana-Champaign

Russell H. Horwitz, *Assessment of Informed Consent Understanding: HIV Vaccine Trials in Port-au-Prince, Haiti*. Janet Reis, adviser. 2006.

The informed consent process has served as the cornerstone of research ethics since the end of World War II. The process of informing potential volunteers of the nature of research in which they will participate has undergone several changes. An HIV/AIDS clinic in a resource-limited area of Port-au-Prince, Haiti, conducts NIH-sponsored HIV vaccine trials. Ethical issues regarding the HIV vaccine trials raise several potential concerns, and the clinic has begun innovative methods of conducting the informed consent process. In addition to creating novel methods of informing individuals, the clinic has begun to assess potential participant understanding of key issues introduced in the consent form. Educational sessions were implemented for individuals interested in joining the HIV vaccine trials. The sessions discussed information regarding the experimental nature of research and highlighted information in the consent form. The sessions included one-on-one and group counseling. The assessment of informed consent understanding integrated [true/false], Likert-scale, and open-ended question formats, and predictors of passing the informed consent assessment were examined. The tendency of participants to view the HIV vaccine study with high perceived benefits and low perceived risk was analyzed. The informed consent process, in an effort to ensure participant understanding, excluded less-educated individuals. The first HIV vaccine trial conducted in Haiti found that the exclusion criteria inadvertently selected for higher educated individuals, $F(4,652) = 2.75$; $p = 0.028$. The second and most recent HIV vaccine trials revealed that level of education predicted performance on the assessment (OR = 1.60; $p = 0.000$, and OR = 4.87; $p = 0.000$ respectively). Finally, an increased understanding of voluntarism

correlated with participant recognition of risk (OR = 1.66; $p = 0.003$). Introducing the HIV vaccine trials to research-naive populations, particularly those in resource-limited settings of less industrialized countries, may include many obstacles. The aim of the informed consent process is to inform potential participants; however, measuring the efficacy of this process remains a vital means of protecting vulnerable populations. Higher levels of education predicted successful performance on informed consent assessments. Efforts to measure appreciation in lieu of information retention of informed consent may mitigate the effects.—Abstract from *Dissertations Abstracts International*, publ. no. ATT 3223618, DAI-B 67/07 (January 2007): 3736.

University of Iowa

Sara Lynn Baker Imhof, *Promoting a "Good Death": Determinants of Pain Management Policies in the United States*. Brian Kaskie, adviser. 2006.

Persons dying from terminal and chronic illnesses can, and should, experience a "good death." However, most Americans do not die this way, and many die in pain. Pain management is an end-of-life care priority because it is desired universally yet remains notably underapplied in many health care settings despite advancements in the field, including clinical best practice guidelines. The literature suggests that the varied and inadequate treatment of pain may stem more from the lack of public policies—or from policies that are outdated and scientifically flawed—and less from problematic clinical and organizational policies. Primary authority for public pain policies lies with the states, specifically with state medical boards. The purpose of this study was to examine the determinants of medical board pain policies, which establish the parameters for the organizational and clinical policies that ultimately drive patient care. First, four reliable

and valid measures of medical board pain policy making were constructed. Second, explanatory models—including economic, external demands, political systems, and institutional characteristic variables most likely to influence medical board pain policy decisions—were constructed. Finally, event history analysis was used to examine the relationships between the medical board pain policies and these predictor variables over a fifteen-year period. This analysis found that medical boards with more legal counselors had higher rates for adopting the four pain policies considered in this dissertation. Boards that previously had adopted more pain management policies than other boards consistently had a lower hazard rate for adopting these policies. Higher state general revenues, more conservative state government ideology, the previous adoption of an Intractable Pain Treatment Act, and having more neighbors with pain policies increased a medical board's hazard rate for adopting a pain policy, while having more frequent annual medical board meetings decreased the hazard rate. These results contribute to fields of comparative state policy and health services and policy research, and also make available valuable information for advocates and policy makers working to improve pain-management-enhancing policies across the states. This dissertation provides a foundation for future research to assess how improved public policies can positively affect patient outcomes.—Abstract from *Dissertations Abstracts International*, publ. no. ATT 3225625, DAI-B 67/07 (January 2007): 3680.

University of Minnesota

Susan Marie Rensing, *Feminist Eugenics in America: From Free Love to Birth Control, 1880–1930*. Sally Gregory Kohlstedt, adviser. 2006.

This dissertation examines the development of “feminist eugenics”—the advancement of social policies aimed at improving the hereditary quality of the human race through empowering and emancipating women in the United States from the 1880s into the 1920s. The historical narrative of feminist eugenics in America falls into three phases. The first phase marks the formation of feminist eugenics within the context of the suffrage, social purity, and free love movements. Research for this period centers on the writings of Elizabeth Cady Stanton in the 1880s, Moses Harman's free love periodical *Lucifer, the Light Bearer*, which began in 1890 and would eventually become the *American Journal of Eugenics* in 1907, and the social purity *Journal of Heredity*, which was funded by the Women's Christian Temperance Union throughout the 1880s. This section argues that the scientific writings of Francis Galton on eugenics were used by these reformers as part of a larger campaign of scientific social reform in late nineteenth-century America. The second phase begins when feminist eugenics clashed with the mainstream eugenics movement, which began to formulate a much different agenda around 1900. Eugenacists like Charles Davenport attempted to define eugenics along racial instead of sexual lines. Thus, the process of institutionalizing eugenics entailed a conscious, directed effort to exclude women's reforms from the eugenic platform. In the third stage, prominent feminists such as Charlotte Perkins Gilman and Margaret Sanger negotiated between feminist eugenics and the increasingly more established twentieth-century eugenics discourse.—Abstract from *Dissertations Abstracts International*, publ. no. ATT 3220029, DAI-A 67/06 (December 2006): 2297.

University of Notre Dame

William P. Bolan, *Conceptual Frameworks for Evaluating Negative Moral Formation: Problems and Contributions of Catholic Moral Theology since Vatican II*. Maura A. Ryan, adviser. 2005.

Since Vatican II, various Catholic moral theologians and schools of moral theology have taken different approaches to the question of the influence of poor upbringing and damaging environments upon moral agents. On the one hand, various papal encyclicals and apostolic exhortations of the Catholic magisterium have emphasized that these impediments do not ordinarily prevent a person from fulfilling the Church's teachings. Even when facing the "gravest of hardships," they claim, God's grace can always sustain the moral agent. On the other hand, in varying degrees "revisionist" moral theologians such as Bernard Haring and Charles Curran have insisted that significant negative moral formation can present a formidable obstacle to living a more ideal moral life. In many cases, they claim, factors of upbringing and environment can effectively and understandably prevent an agent from realizing moral norms. However, in making these claims, "traditionalists" and "revisionists" alike have focused primarily on the effect of negative formation on an agent's subjective guilt, her moral obligations, and the objective wrongness (or correctness) of violating moral norms. These juridical analyses have been pursued to the exclusion of examining the influence of upbringing and environment in its own right. They have not provided a comprehensive means of understanding when and why some moral agents are or are not effectively prevented from leading more ideal lives. Moreover, both traditionalists and revisionists have been unable to provide a fitting framework for counseling the victims of negative formation. The dissertation explicates these claims, and as an alternative to primarily juridical approaches, explores the adequacy of several contemporary ac-

counts of Christian virtue ethics. It proposes that their central concern with moral formation, considered in itself, provides a better means of both understanding and advising [in cases of] negative formation.—Abstract from *Dissertations Abstracts International*, publ. no. AAT 3159313, DAI-A 65/12 (June 2005): 4601.

University of Pennsylvania

Susan Nolte, *Predictive Correlates of Prophylactic Oophorectomy in Genetically High-Risk Women*. Deborah McGuire and Lorraine Tulman, advisers. 2005.

Women who have a breast cancer genetic mutation (BRCA) are at a significantly increased risk for the development of ovarian and breast cancer. Prophylactic oophorectomy is effective in reducing ovarian cancer risk and is recommended for genetically high-risk women. However, the demographic and health factors predictive of having preventive surgery for this condition are not known. This study was a secondary analysis of an ongoing international study examining the effect of prophylactic surgery on risk reduction and mortality from ovarian and breast cancer. The study sample included 276 women with a BRCA mutation, of whom 121 (43.84 percent) had a prophylactic oophorectomy, and 155 (56.16 percent) did not. Key variables identified by a review of the literature relating to women's decision to undergo genetic testing and preventive surgery guided the study: age, Jewish ethnicity, BRCA1/2 status, family history of ovarian/breast cancer, gravidity, smoking status, and personal breast cancer history. Logistic regression analysis, controlling for study site, revealed that older age at disclosure of genetic test results, having two term pregnancies, and having a high percentage of second-degree relatives with breast cancer were predictors of prophylactic oophorectomy. Subjects from the Dana Farber Institute

were also more likely to have prophylactic oophorectomy than subjects at other study sites. Cox regression analysis, controlling for study site, revealed that having both BRCA1 and BRCA2 mutations, a positive previous smoking history, older age at disclosure of genetic test results, and a high percentage of second-degree relatives with breast cancer were associated with a greater likelihood of having prophylactic oophorectomy during the time interval that women were followed. Subjects from the Dana Farber Institute, Yale University, and the University of Pennsylvania also had a greater likelihood of prophylactic oophorectomy than those from other study sites during the time interval of follow-up. Jewish ethnicity, personal breast cancer history, and family history of ovarian cancer were not predictors of prophylactic oophorectomy. Kaplan-Meier analysis demonstrated that Jewish ethnicity, a personal history of breast cancer, and having both BRCA1 and BRCA2 mutations were associated with a shorter time to having prophylactic oophorectomy following disclosure of genetic test results. Current smokers had a longer time to prophylactic oophorectomy than women who never smoked.—Abstract from *Dissertations Abstracts International*, publ. no. AAT 3165739, DAI-B 66/02 (August 2005): 817.

Uppsala University (Sweden)

Sofia Källemark Sporrang, *Ethical Competence and Moral Distress in the Health Care Sector: A Prospective Evaluation of Ethics Rounds*. Janine Morgall Traulsen, adviser. 2007.

Ongoing structural and financial changes in the health care sector have resulted in increased risks for ethical dilemmas and moral distress. It is purported that increased

ethical competence will help staff manage ethical dilemmas and hence decrease moral distress. To enhance ethical competence several approaches may be used—theoretical education, and methods focusing on reflection and decision-making abilities. Ethics rounds are a widespread systematic method hypothesized to improve ethical competence, nurture a reflective climate, and help in ethical decision making. Despite its popularity, its effects on moral distress have hitherto never been evaluated in a controlled study. The purpose of this thesis was to evaluate the effects of an intervention, including ethics rounds, the hypothesis being that the intervention would decrease perceived moral distress. An additional aim was to explore the concept of moral distress in various health care establishments, including pharmacies. Focus groups were conducted to explore the concept of moral distress. To evaluate the intervention, a scale assessing staff-perceived moral distress was designed, validated, and implemented. Results showed that moral distress is evident in diverse health care settings. Some factors associated with this were lack of resources, conflicts of interest, and rules that are incompatible with practice. An expanded definition of moral distress was presented. The training program was much appreciated by participants. However, no significant effects on perceived moral distress were found. Reasons could be that the intervention was too short or otherwise ineffective, there is no association between ethical competence and moral distress, the assessment scale was not sensitive enough, or management was not sufficiently involved. There is a need to further refine the various aspects of ethical dilemmas in clinical settings, and to evaluate the most efficient means to enhance skills for dealing with ethical dilemmas, for the benefit of staff, patients, institutions, and society.—Abstract from Uppsala University Theses, DiVA no. 7493, <http://publications.uu.se/abstract.xsql?dbid=7493>.