From the Desk of your Coordinators:

We are looking forward to seeing as many of you as possible in Brazil for the Tenth Anniversary of FAB as well as our Fourth Biannual Meeting. The Co-Chairs of the Program Committee, Debora Diniz and Sue Sherwin, have been pleased by the quality and quantity of submissions. We will have a major opportunity to focus our collective thoughts on the theme of gender and justice; to ask each other how we can work together to reduce the disparities between those of us who live in developed nations and those of us who live in developing nations; and to ponder how we can persuade our governments that balancing the scales of justice rather than brandishing the weapons of war is the way to reduce the violence, terrorism, and hate that spoils the world which we cohabit.

Many thanks are due not only to the Co-Chairs of the Program Committee but also to its other members: Laura Shanner, Susana Sommer, Rosie Tong, Mary Rorty, and Gwen Anderson. We are also grateful to Debora’s local arrangements committee consisting of Maureen Alexandra Sampaio, Fabiana Paranhos, and Marilena V. Correa. Our understanding is that opportunities to travel to other parts of South America from our base in Brasilia will be many and quite convenient.

Thanks to Volnei Garrafa and Léo Pessini, FAB’s plenaries and several of its concurrent sessions will have the benefit of simultaneous translation: English, Spanish, and Portuguese. Every effort is being made to enhance our ability to communicate with each other. Wendy Rogers has been working hard behind the scenes to organize a Country Representatives panel. The members of the panel will voice their concerns about women’s health, education, work, and welfare in their respective nations. They will also report on upcoming FAB-related activities in their home countries.

Because this is a major anniversary year for FAB, we intend to present a Distinguished Service Award to one or two of our members at the Business Meeting. The agenda for the Business Meeting is likely to be full. In particular, we need to continue our discussion of how we fund ourselves, distribute our grant monies, and determine our policies. We need to further enhance our web page, to continue to utilize our Listserv; and to contribute even more to our Newsletter. FAB’s members are impressive publishers and energetic activists. The more we know about each others’ ideas and work, particularly grassroots and service work, the more we can assist each other. Please feel free to contact Rosie Tong with issues you wish to have discussed at the Business Meeting.

If you are able, consider staying for the IAB’s 6th World Congress, entitled “Power and Injustice.” Several FAB members are among its speakers, and there will be a round table on Feminist Bioethics. Sue Sherwin and Fátima Oliveira will discuss how issues of gender, race, ethnicity, and poverty shape the theory and practice of feminist bioethics.

The contents of the Newsletter are particularly rich thanks to Maggie Little, its editor, and Hilde Nelson, its Book Review editor. Many thanks to Becky Holmes for compiling an impressive bibliography of FABsters’ publications. We remain grateful to the Kennedy Center at Georgetown University, USA for its support of the Newsletter. We are also thankful for those members of FAB who have contributed monies to the Audre Lorde Fund. In order to function as effectively as possible, FAB needs our financial support as well as our energy, enthusiasm, and commitment.

Best wishes,

Sue Sherwin and Rosie Tong, Coordinators
Several members of FAB were invited to Beijing, to speak at the First Beijing Symposium on Feminist Bioethics. Professor Renzong Qiu of the Institute of Philosophy in the Chinese Academy of Social Sciences, Beijing, arranged this meeting with the support of the Ford Foundation.

There were approximately 50-60 participants at the symposium, the majority of whom were Chinese speaking. All the papers (except for those given by the invited speakers) were given in Chinese, with simultaneous translation to English. The programme was very full, with 26 papers over two days. The programme included sessions on theoretical issues in feminist bioethics, sex and gender, theory and practice, genetics, reproduction, sexuality, and issues in health care.

Two major themes in feminist bioethics were represented at the symposium. The first of these was the crucial feminist task of bringing to the foreground those implicit assumptions that frame central issues and determine whose voices are heard. The second theme was how to make global bioethics more inclusive of the voices of the marginalised as well as those of the privileged.

A third theme which emerged from the conference was the importance of the link between theory and practice, and the need for practical strategies and solutions. This last theme is particularly important in China where bioethics historically has been a very theoretical field with few links to either policy makers or practitioners.

Discrimination was a recurrent topic. In China, one of the main social divides is between the urban and rural populations. The rural population is very disadvantaged by urban standards across all parameters, with poor infrastructure, low incomes, poor health care, and lower life expectancies than urban people. Feminist analysis was seen as a valuable tool for examining discrimination against rural people as a form of social injustice rather than as a given ‘misfortune.’ Apart from contraceptive services, health care services are fragmented and rudimentary in many parts of rural China. The barefoot doctor programme has been abandoned and there are difficulties in getting doctors to move to rural areas. Even where services are available, the cost is beyond the means of many people. To my surprise, I found that China does not have a free health care system; patients have to pay for services. There is a state insurance scheme, but this does not provide universal cover.

Discrimination against prostitutes was discussed in a couple of papers. Prostitution is illegal in China. Despite this, there are many prostitutes, who form one of the most disadvantaged groups. Many of these women are from rural areas who come as illegal immigrants to the cities to earn income for their families (and to pay for the education of their brothers). As rural women and prostitutes, they suffer double discrimination. There was a lot of discussion about the appropriate terms for describing their activities. Sex worker was deemed inappropriate as ‘work’ is a term reserved for higher status activities (for example rural labour is not classified as work). There was also discussion about the moral acceptability of prostitution and whether extreme deprivation and the need to survive could justify ‘immorality.’ An interview study with disadvantaged women including prostitutes found high levels of ignorance about available resources.

HIV/AIDS is a growing problem. There are 26,000 official cases and approximately 600,000 unofficial cases. The majority of infected people are male, but the ratio of males to females is decreasing. Transmission is thought to be predominantly through blood products, shared needles and unsterilised medical equipment. There is a lot of discrimination against people with HIV. The issue of openness about HIV is problematic. Partners of people with HIV (in practice these are usually female partners) are not informed, and use of condoms is left to the discretion of the infected person (usually male). In a well publicised incident, a rural community was infected with HIV following the use of unsterilised equipment when collecting blood donations. Following identification of the community, the people were unable to sell any of their produce or to find marriage partners for fear of infection. Amongst prostitutes, there are high levels of ignorance about HIV and poor knowledge about preventive measures. Some women have monthly penicillin injections in the mistaken belief that this will prevent HIV infection.

Provision of care for increasing numbers of people with HIV/AIDS has not been addressed. It is...
likely that the burden of caring will fall disproportionately upon women.

Papers on contraception raised interesting issues. The one-child policy has been in effect for 20 years and is widely accepted in urban areas. However, in areas populated by particular ethnic groups, the premium placed upon having several children (especially boys) has proved difficult to alter. The problem is seen as that of implementing policies which have been developed for the Han people (the dominant ethnic group in China) amongst ethnic minorities who are suspicious of the elite coming to dispense ideas. The lack of success with family planning was attributed to lack of suitable propaganda, people being too poor to pay fines, and lack of alternative activities in isolated areas(!). Successful family planning programmes have been linked to land distribution policies which do not reward families with more children.

A programme to increase the informed choice of rural women about contraception was presented. Prior to the informed choice campaign, women were offered IUDs or sterilisation, with sterilisation being mandatory after the birth of a second child. The informed choice programme aimed to provide women with information about alternative methods of contraception, and about sexual health in general. Cost of alternative methods and lack of support from families were barriers to using alternative methods. The investigators found high rates of STDs with little access to treatment. Husbands were not interested in contraception, which is seen as a female concern, thus largely ruling out use of condoms.

An interesting paper comparing birth control in India and China highlighted similarities and differences. Both countries have a culture which prefers male to female children, and both have experienced coercive population control strategies, although this has tempered to some extent in India. However, in India, contraceptive services are not free and are not widely available as in China. The rate of illegal abortion is very high in India, including selective abortions of female foetuses (2 million per year). It is estimated that there are 32 million women missing in India today.

Discussion of genetic issues revolved around questions of women’s autonomy with regard to choice, examination of the assumptions implicit in genetic testing and counselling, the impact of genetic testing on women, and issues of power and control with regard to genetic testing. There are several factors operating in China which raise doubts about the possibility of women’s autonomous choices about genetic testing. The current construction of families discriminates against women, whose wishes are often subservient to their husbands or in-laws. Women are expected to make decisions in compliance with family wishes rather than their own. Fertility and child-bearing are seen as a gift from the woman to her husband, decreasing the extent to which women are free to make their own decisions. The one-child policy creates pressure to accept genetic testing to ensure the ‘best possible’ child. Use of new reproductive technologies may be seen as demonstration of woman’s love for husband and as her duty to preserve family relationships.

Overall my impressions were that many of the issues engaging Chinese bioethicists are similar to those engaging western feminist bioethicists. Superimposed upon this similarity are important contextual differences, including differences in the status of women, differences in cultural beliefs and expectations about morality, and significant material differences. The scholars we met with are working to improve conditions for women by exploring theoretical approaches and through developing practical strategies for urgent problems, such as HIV/AIDS. As in the west, the gap between the advantaged and the disadvantaged seems to be widening. Globalisation and the introduction of information technology are compounding these differences, further disenfranchising some women, in particular rural women.

FAB members who gave papers at the symposium were:

Ruth Chadwick, Professor of Bioethics, Lancaster University
Barbara Nicholas, Researcher, New Zealand
Wendy Rogers, Research Fellow, University of Edinburgh and Flinders University
Krishnaraj Shanti, Professor, Department of Econometrics/Centre for Gender Studies, University of Madras
Jing-Bao Nie, Otago Bioethics Centre, Dunedin, New Zealand.

Papers presented at this meeting will be published in a bi-lingual collection.

Wendy Rogers, University of Edinburgh
I, like most of you, periodically get an invitation from Rachel Ankeny, FAB country-representative for Australia, to take part in this conference and help organize a FAB section. With great pleasure (and the help of a Fab grant) I accepted the invitation and traveled sixteen hours by airplane from the winter in Germany to the sunny Down Under. Because I had never been to Australia before, it was a great experience. The people there live in a different way—you could even feel this in the conference organization: every speaker had forty-five minutes and we were given frequent breaks for rest and personal discussion. Since we did not have to rush we had ample opportunity to exchange ideas and opinions!

The conference was titled “Global Bioethics: Exploring Alternative Approaches.” I have met the title “Global Bioethics” often at conferences, but this was the first one I took part in that was really global. Many of the speakers were from different cultures or minorities and we were speaking with them and not about them. The conference began with a paper by Tristam Engelhardt (US), primarily an interpretation of American bioethical discussion. It became obvious later in the conference that the western standards of medicine and ethics he characterized did not work in this part of the world (e.g. it is not clear what informed consent means when the client does not understand the whole procedure followed by western medical methods). On the other hand, I was very surprised to discover the respects in which western medicine does confirm with other traditions. Professor Pranee Liamputtong told us a story from the School of Public Health at La Trobe University in Melbourne. In my own words events happened this way. A woman from a minority group, after giving birth to five children at home, has to have her sixth in a hospital. Afterwards she feels very sick but the clinics’ doctors could not find anything wrong. After one year she took part in a socio-empirical research study and she told the interviewer that she was sick because she forgot one of her souls in the operating theater. The only way to get it back would be to do some kind of procedure with a shaman involving a living chicken. The interviewer contacted the hospital manager and one Sunday morning the whole procedure took place, and afterwards the woman was healthy again. Can you imagine a hospital manager allowing such a procedure with a living chicken in one of your western hospitals? I certainly can’t in Germany, but I was happy to hear about the wise decision of the Australian manager, particularly his respect for her wishes.

We used this case not only to discuss the combination of western and non-western conceptions of healing but also to explore questions about research guidelines:

Is it allowable (or morally right) for interviewers to interfere to promote the medical and/or social welfare of their clients?

What does autonomy mean for clients, especially if they do not understand the research procedure?

What does autonomy mean when the inhabitants of a whole island are used for research? Lopeti Senituli told us about the Tongan people whose DNA-codes were sold by their Minister of Health. What do democracy and self-determination mean in such cases?

What about using third world or Australian people in research studies when the results of the research are used primarily for European or American people?

...
The conference included a number of panels and talks of interest to FAB members. Empowerment, recognition of the impact of socio-cultural factors on patient care and choices, attention to context, recognition of the complexity and inadequacy of autonomy, and issues in reproductive technologies were common threads in many of the talks. Below is a description of some of the highlights; the author’s inability to be in two places at once accounts for the limited number of panels described.

Susan Wolf participated in a panel discussion on pre-implantation diagnosis (PID), with an emphasis on the creation and selection of stem cell donors. She emphasized the importance of demanding that such innovative therapy be subject to the same protective oversight measures as therapeutic research. Using a theory of nascent parentalism and professional responsibility, Susan suggests the following measures to protect against commodification of resulting children. PID should medically benefit the resulting child. The therapeutic use of stem cells should not be the only motive for PID. PID should address a serious and life-threatening problem. The resultant child should be wanted and loved, and the physical burden to the resulting child should be minimal. Finally, it is important to recognize that parents have conflicting interests, and parental consent is thus morally complicated.

There was an added session on the stem cell debate. The panelists raised many issues, including the need for consideration of the language used, since even the “experts” disagree on how to define terms like “embryo.” Points were made about the stem-cell debate’s focus on rescue medicine and the influence of lobbying groups in creating new technologies while the poor and marginalized in society go without basic care. Cynthia Cohen pointed out the need for a national oversight body to look at the issues involved in the creation of embryos, including women’s health issues. Aline Kalbian continued discussions on the role of women’s health in assisted reproductive technologies (ART) in general by questioning the adequacy of patient autonomy in the consent process for ART.

Two interesting discussions of personal narrative identity were given by Hilde Nelson and David DeGrazia. Hilde discussed the difficulties transgendered persons experience due to the master narratives of one’s culture that identify transgendered persons as not wholly male or female. In this context, the complex issue of “passing” becomes a central one. David gave an entertaining discussion of various views of personal identity in the context of a coffee house chat.

The International Network on Feminist Approaches to Bioethics Affinity Group Meeting took place early Saturday morning. The meeting was well attended, by both FAB members and interested others. Several issues were raised during the discussion, including the possibility of a joint meeting in the future with the Lesbian, Gay, Bisexual, and Transgender Affinity group. While responses were generally positive toward joint projects, meeting participants felt that two separate meetings increases the presence of both groups at ASBH. The meeting then turned to a discussion of possible topics for future discussions, perhaps even a panel at a future ASBH. Possibilities ranged from the definition of feminism, particularly the next generation of feminism, to the new contributions of feminist bioethics to various areas of ethical research, to the notion of evil, and whether it is an appropriate category for feminist theory. There was some discussion of putting together a proposal for a panel at the next ASBH.

There were many other interesting talks and a strong presence of FAB members and panelists. Of course the best part of the conference was seeing old friends and making new ones. Hopefully next year’s conference will continue to expand the variety of voices and topics presented.

Connie Perry, MCP Hahnemann University
Ruth Groenhout, Calvin College
A DECADE OF BOOKS BY MEMBERS OF
THE INTERNATIONAL NETWORK ON FEMINIST APPROACHES TO BIOETHICS
Compiled by Helen (Becky) Holmes

This is a copy of the bibliography that was distributed at the FAB International Conference in London, September, 2000 (with a few errors corrected). It is comprised only of books with publication dates from 1991 through 2000, with at least one author or editor who was a FAB member before June, 2000. Not limited to topics in bioethics, its goal is to honor our members and their unique contributions. Also included are anthologies edited by nonmembers if any such book contains at least three contributions by FAB members. Please send suggestions for future lists to Becky at fholmes@pltpath.umass.edu.

BASICS: CORE BOOKS in the DEVELOPMENT of FEMINIST MEDICAL ETHICS


BOOKS BY FAB MEMBERS: ALPHABETICAL BY AUTHOR OR EDITOR


WHAT IS FAB?

The Origin Of The International Network on Feminist Approaches to Bioethics

Launched in 1992 at the Inaugural Congress of the International Association of Bioethics, the International Network on Feminist Approaches to Bioethics (FAB) by 2000 has approximately 350 individual members in 28 countries and exchanges information with many organizations whose missions overlap our own. FAB aims to develop a more inclusive theory of bioethics encompassing the standpoints and experiences of women and other marginalized social groups, to examine presuppositions embedded in the dominant bioethical discourse that privilege those already empowered, and to create new methodologies and strategies responsive to the disparate conditions of women’s lives across the globe.

FAB is committed to a non-hierarchical model of organization and seeks to include all who share our goals and will strive to advance them. Academics, professionals, grassroot activists, and concerned persons from all fields are welcome to join FAB. We are supported by members’ biennial contributions to our (tax-deductible) Audre Lorde Memorial Fund for Bioethics Research, which is used principally to subsidize conference participation by women from developing countries. By 2000 we have country representatives in Argentina, Australia, Austria, Brazil, Canada, Colombia, France, Germany, India, Italy, Japan, the Netherlands, New Zealand, Pakistan, the Philippines, Switzerland, the Ukraine, the United Kingdom, and the U.S.A. Country representatives assemble and disseminate news from their regions and seek opportunities to extend the mission of the Network.

Our semiannual newsletter, currently subsidized by the Kennedy Institute of Ethics, has been published since 1993. Included in the Newsletter are short essays from Network members that explore and develop feminist approaches to bioethics or suggest collaborative projects for groups to pursue; reviews of recent books relevant to the Network; information about national and international events and policies that bear on Network interests; upcoming conferences, calls for papers, manuscript requests, and relevant books and articles. We also maintain a listserv and this web page (www.fabnet.org), and we organize panels at national and international bioethics conferences and symposia.

Information on joining FAB can be found below, and by following the “FAB Membership” link on our website menu. You may also sign on to our listserv at LISTSERV@LIST.MSU.EDU. Include only the following in the body of your message: SUBSCRIBE FABLIST Your Name.

Our founders and first coordinators were Anne Donchin and Helen Bequaert Holmes. From 1996 to 1998 Gwen Anderson replaced Becky Holmes. From 1998 to 2000 Rosie Tong and Laura Shanner were coordinators. The 2001 to 2002 coordinators are Rosie Tong and Sue Sherwin (listed below).

In 1996 in conjunction with the Third World Congress of the International Association of Bioethics, in San Francisco, we organized our own conference, which was attended by over one hundred participants. Our second international conference, Globalizing Bioethics, took place in Japan in November 1998. Our third conference took place in London in September 2000. Plans are progressing for our fourth conference, Gender, Power and (In)Justice, to be held in Brasilia, November, 2002. Anthologies from the first two conferences are:

♦ San Francisco: Embodying Bioethics: Recent Feminist Advances, Anne Donchin and Laura Purdy, eds., Rowman and Littlefield, 1999. $63.00 cloth; $23.95 paperback

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or follow the “FAB Membership” link from www.fabnet.org.

To CONTRIBUTE to our work:
Send a check payable to “The Audre Lorde Fund for Bioethics Research” It can be mailed to the FAB Treasurer, Anne Donchin or be included with your membership form to Lenore Kuo:
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FAB is a not-for-profit organization.

Can autonomy account for feminist theories of a social self? Should feminists bother trying to revive the notion of autonomy at all? What would a feminist theory of autonomy look like? These are some of the questions the collection of essays in *Relational Autonomy* tries to answer and, in doing so, the authors begin to move beyond critiques of autonomy and start to offer more constructive accounts. While the authors sometimes disagree on specific points, all agree that any account of autonomy must attend to the social self and that “autonomy” is not an all-or-nothing category. Autonomy can come in degrees and can be expressed in some situations while being absent in others.

The book itself is divided into two sections: “Autonomy and the Social” and “Relational Autonomy in Context.” The first, longer section offers various theoretical approaches to autonomy, while the second, shorter section looks at how our conception of autonomy affects our approach to certain concrete situations. Of the four essays in this second section, three deal with bioethics. These essays focus, in turn, on the stranglehold autonomy has had on bioethical theory (Susan Dodds), a nonhierarchical model of informed consent using genetic counseling as an example (Anne Dochin), and the connections between oppression and autonomy within the healthcare system (Carolyn McLeod and Susan Sherwin). In the fourth essay, Susan Brison looks at how relational accounts of autonomy relate to the issue of hate speech.

Many of the authors try to rethink autonomy by looking at previously neglected relationships. For example, Lorraine Code uses concrete examples of advocacy to develop her theoretical conception of autonomy, and Genevieve Lloyd examines how responsibility is related to autonomy by looking at instances of collective responsibility, as well as at persons’ taking responsibility for things that are beyond the scope of their individual agency.

All of the authors are sensitive to the previously neglected contextual nature of autonomy and, therefore, offer examples of a better way to approach discussions of autonomy. As Marilyn Friedman points out in the first chapter, autonomy is always expressed or asserted in relation to some other individual or group. In this way, autonomy is inherently a relational concept. However, the most innovative aspect of this collection is the way these authors begin to formulate an alternative theory of how to conceive of autonomy itself. While none of the authors develops a comprehensive theory of autonomy (nor could they be expected to do so within the space of single essays), taken together the papers begin to sketch out a framework for what such an alternate theory should take account of and, perhaps, look like. Consider the following.

Natalie Stoljar argues against a completely procedural account of autonomy. She points out that often feminists have what she calls a “feminist intuition” that certain decisions are not autonomous even if they seem to follow a rational and reasonable procedure. The implication is that just because a decision or action is rational does not mean that it is autonomous, because often the factors that went into the rational decision were a creation of oppressive norms.

Similarly, Paul Benson discusses how autonomy can also be undermined by self-doubt. He argues that a certain amount of self-worth and an ability to connect decisions to one’s values systems are necessary for a decision to be autonomous. In this way, being able to see oneself as someone who is able to take/have responsibility for certain actions or decisions is crucial to whether or not those actions can be considered autonomous.

Although this is not her primary purpose, Diana Meyers’s essay on intersectionality further elaborates the issues raised by both Stoljar and Benson. Meyers asks how an intersectional theory of the self relates to a conception of autonomy and comes up with a new set of “competencies” by which to judge autonomy. Traditional conceptions of autonomy have relied on a unified theory of the self as well as on a certain rational procedure or ordering of desires. Meyers takes these conceptions a step further by arguing that autonomy must also factor in various levels of self-knowledge and a self-definition that does not rely on a unified notion of the self. Indeed, Meyers focuses on the often conflicting nature of the intersectional self as one way to gain self-knowledge and develop the skills necessary for autonomy.
Meyers’s theoretical account of autonomy speaks to both Stoljar’s and Benson’s concerns. Part of Stoljar’s feminist intuition is that oppressive influences will go unrecognized and, thereby, unduly influence a person’s actions or decisions. Meyers accounts for this in her discussion of self-knowledge as a requirement for autonomy. The self-knowledge of one as oppressed (possibly in various ways) will help a person recognize oppressive influences in her own decision-making. Similarly, if a person’s self-definition does not include a notion of herself as someone who can be responsible or accountable for certain things, then it is hard to say that the person is autonomous in relation to those same things—which addresses Benson’s concern about how self-worth affects competency in deciding and acting.

I do not mean to imply that all of these essays fit neatly together to ultimately provide a tentative theory of autonomy. Indeed, many authors disagree on the usefulness of the concept itself and where, when, and how it should be applied. All the same, this collection is not simply a more refined and detailed set of the usual feminist criticisms of traditional liberal notions of autonomy, but a fine example of constructive work in feminist ethics as well.

Sonya Charles, Michigan State University


Many FAB members have written or edited books with feminist analyses of ethical issues raised by the new reproductive technologies; Davis continues in this tradition. Genetic Dilemmas is distinctive in that it discusses in depth only six issues and does not skim over a spectrum of technologies.

One theme throughout is Davis’s goal of putting the child in “center stage,” that is, to focus on the best interests of the child who results from a genetic ‘choice,’ a theme rarely emphasized by the myriad of authors on these topics. Pregnant women, as they make decisions on the choices now available in countries with Western medicine, may also “expand or limit the choices that will be available to their children as the latter grow up.” To be ethically acceptable, Davis contends, techniques must not diminish a “child’s right to an open future.”

The longest chapter, on genetic counseling, is comprehensive, perhaps in some places an overdose. Davis meticulously reviews the practice of nondirective counseling, with lucid explanations of how it developed, and quotes a wide range of critics. She then discusses the concept of raising children so that they’ll receive good parental guidance but also be allowed to have an open future. Intermixed with this is a somewhat rambling analysis of individual, family, and community autonomy.

In her chapter on harm, Davis wrestles with the harm conundrum (problem of wrongful life/wrongful-handicap problem): should parents bring into the world a child who is physically or mentally damaged so that she or he has more suffering than normal children? In this philosophical (rather than legal) analysis, Davis cites and evaluates the best-known work on this issue. Her conclusion that harm, but not harm to that child, has been done when such a child is born does not, in my view, clear the air for discussions later in the book.

On the next three topics, Davis’s reasoning leads her to firm conclusions. In “Choosing for Disability” she develops a forceful argument that deaf parents ought not to choose to have a deaf child, because deaf children miss out on too many of life’s pleasures and job opportunities. In “Childhood Testing for Genetic Traits” she argues that (unless there are definite curative measures available) children should not have genetic tests for carrier status or adult-onset diseases until they are old enough to make informed decisions. As counselors protect the privacy of adults by not divulging results of genetic tests, so should they also protect the privacy of children. Each of these chapters is well fleshed out, presents diverse views, and provides the reader with excellent sources.

Similarly in the next chapter, Davis develops convincing arguments against sex selection. In her strong concern about sex stereotyping, she even disapproves of pregnant women being told the sex of the child they’re carrying: she believes stereotyping can begin before birth and that grandparents can aid and abet it. An excellent set of appropriate literature is cited, including many works by FAB members.
After the strong stances that Davis has taken up to this point, views expressed in the chapter on cloning are surprising: Davis does not conclude that human cloning ought to be out-and-out banned. The first several pages are valuable to a nonbiologist with their lucid explanations of what cloning is. Cloning is not blastomere separation, the careful separation of cells in a very early embryo, which can make identical twins, quadruplets, etc. Also, any egg cell with a selected nucleus inserted into it can become a ‘clone’ only after undergoing successful gestation in someone’s womb. But Davis moves onto shaky ground in her distinction between cloning for ‘logistical’ and for ‘duplicative’ motivation. Logistical reasons mean that the prospective rearing mother has no other way to produce a baby biologically related to her and her living or dead husband. Duplicative motivation means that one chooses a nucleus from someone with characteristics one wishes for one’s child. First, I find that most of Davis’s specific examples do not fall neatly into either of those two pigeonholes; next, although she seems to approve ‘logistical’ reasons, she then spots acceptable and unacceptable reasons for cloning in examples from each pigeonhole. For example, if a woman has a basketball player’s nucleus inserted in her egg (duplicative cloning), and feels then entitled to a son who plays basketball, she closes the child’s future; but if she simply lets him grow up (with, perhaps, a basketball hoop in the back yard), then she has left his future open.

Those of us who teach, write, or research these sub-areas would do well to consult this book, both for Davis’s perceptive analyses and for her guidance to other insightful literature. Also refreshing are the many spots where Davis is explicitly feminist.

Becky Holmes, Amherst, Mass.


From Detached Concern to Empathy grew out of the author’s experiences and reflections. Jodi Halpern’s experiences included work as a medical student, a medical intern, and a psychiatric resident. In the course of her work, she saw how often physicians fail to empathize with patients or empathize with them in the wrong way. She reflected on her experiences, including her own failures to empathize with patients in helpful ways, and supplemented her reflections with philosophical studies. Her reflections and studies cover a lot of ground: from the limits of detached insight to the need for emotional communication, from the role of reasoning to the nature of emotions, from phenomenology to psychoanalysis.

Halpern notes how physicians have always been emotionally moved by the people they treat, but she also recounts how and why the idea of emotional engagement came to be replaced by the ideal of detached concern. A detached attitude was supposed to help physicians avoid errors of over-involvement and to promote a better, more objective medical judgment. As an added bonus, emotional detachment was supposed to prevent burn-out and allow professionals to perform necessary but repugnant procedures. So medical students came to be taught and physicians tried to practice a form of detached concern. The idea was to adopt a detached stance, to observe the patient (including her emotional states), to make accurate judgments, and then use these judgments for the patient’s good.

What’s wrong with the ideal of detached concern? As Halpern shows, it’s based on bad philosophy and leads to bad medicine. That we should adopt a generalized stance of detachment because our emotional engagement sometimes leads to errors is a crazy idea. It’s like giving up eating because sometimes we eat too much or eat something that makes us sick. Of course, sometimes we do feel too much, or too little, or the wrong things; and sometimes we don’t know how to deal with our feelings. But in these cases, we need a much more Aristotelian approach: a discussion of what it’s like to have various “feelings at the right times, about the right things, toward the right people, for the right end, and in the right way” (Nicomachean Ethics, 1106b). Indeed, I wish more physicians felt angry about the frequency of domestic violence, the number of uninsured people, and the state of public health.

The ideal of detached concern is based on a false picture of human life. This ideal tends to picture human beings as detached observers who function best by representing the world in the form of theoretical knowledge. This ideal tends to take theoretical knowing as the paradigm form of human experience. But as Dewey, Heidegger, and Wittgenstein pointed out (in different ways, with different political sympathies), we human beings are practical, interested, emotional, engaged par-
was disappointed. Changes. Let me try to explain what I mean and why I think it will take large structural changes, not small curricular changes. Let me try to explain what I mean and why I was somewhat disappointed with her book. The subtitle set me to thinking about what might be needed to humanize medical practice in the United States. I think we need to change social structures and actual experiences. Of course, Halpern is right to say that the point of view is that of a physician—indeed, that of a psychiatric consultant called to evaluate acutely ill patients who are refusing medical care. What’s wrong with that? Nothing in itself, but a lot gets left out: the point of view of the clerk, the office manager, the nurse’s aide, the nurse, the nutritionist, the physical therapist, the social worker, the home health care aide, and the primary care physician. In an odd way, even the point of view of the patient and the family get neglected. The emphasis is on the physician’s clinical understanding of the patient’s experience of acute illness, not on the patient’s overall experience in the health care system. But if we want to humanize medical practice, we need to understand all the difficulties that patients experience: worrying about money, deciding whether to see a doctor, paying for care, getting time off work, traveling to a clinic, waiting and waiting (while trying to manage restless children), interacting with professionals, understanding what people say, dealing with illness, getting medication, worrying about money, asking family members for support, providing care at home, and so on.

Although Halpern mentions structure, power, and gender in a footnote or two, the emphasis in her book is on the emotional response of physicians. I wonder if that’s the crucial point to emphasize. I am not an ideologue who believes that all relationships are strictly determined by the economic structure, but I do believe that relationships and attitudes are influenced by social structure and organization. Think about the following changes: suppose people went to clinics in their neighborhoods, and the doctors who worked at the clinics lived in those neighborhoods; suppose doctors made house calls and saw patients in their homes; suppose doctors routinely attended meetings of patient-support groups; suppose doctors earned salaries that were about average in their communities; suppose all medical students were former nurses. My point here is not to argue for any of these changes. I hope that other people can devise and discuss better ideas. My point is to shift the focus from the humanistic training of physicians to the social and economic conditions that are often left in the background.

Perhaps I’m more pessimistic than Halpern, but I think we need to change social structures and actual experiences. Of course, Halpern is right to say that empathy does not require that people have the same actual experiences. Empathy depends on possibilities.
and imagination. But between existential possibilities that all humans face—like illness, loss, and death—and the specific experiences that individuals have, there are ranges of experiences that are socially shaped. Think of the experiences of these people: a man, a woman, a black woman, a black working-class woman, a black working-class lesbian woman, a black working-class lesbian woman who wants to start a family.

What concerns me is that most patients and doctors have quite different ranges of social experiences. If we are going to humanize medical practice, we may need to reduce the gap between patients and doctors—the gap in their actual experiences, social problems, effective power, and life prospects. If we are going to create a decent and democratic society, we may need to reduce the gap between different groups. Sure, we need more empathy, but we also need better politics.

James Dwyer, New York University


In 1995, with little fanfare, the Joint Commission for the Accreditation of Healthcare Organizations introduced a standard for “organization ethics” to its requirements for accreditation. The term has been simultaneously a Rorschach blot test and a rallying call to people in a variety of professional and academic positions. What is organization ethics, actually, and what does this new accreditation standard require of us? In the last few years a variety of interpretations and applications have been offered in books and articles.

Robert Hall’s Introduction to Healthcare Organizational Ethics presents a wry, judicious and comprehensive answer to this question. What, he asks, are the ethical requirements on the health care organization—simultaneously a provider of a crucial service and a business, an employer and a coalition of professionals, and a member of a community?

In health care organizational ethics the central questions have to do with the nature and function of the institution. They arise from considerations of the mission of the organization, its role in society, and its relationship with many people in addition to patients—employees, administrators, the community, suppliers, professionals and other providers. (p. 6)

Brief methodological chapters at the beginning and end of the book address, respectively, two possible models for ethical analysis of organizational ethics decisions (according to organizational goals, and a stakeholder analysis) and alternative ways in which an organization ethics program can be incorporated into the operations of a hospital. The other ten chapters are thoughtful, contextualized, realistic appraisals of the challenges facing the hospital as an ethical agent under current conditions. They typically begin with a general overview of the ethical issues germane to the topic, focus in on the problems most likely to arise in the specific area of healthcare delivery, often include case studies illustrating various complexities of the issue, and conclude with specific recommendations about what is most worthy of the attention of healthcare administrators in the current healthcare climate. Hall makes good use of examples as he sketches out details of the ways in which hospitals are businesses like any other—and ways in which the problems common to all businesses are inflected by the history and goals of healthcare in America.

Hall explicitly defines organization ethics as a “managerial perspective,” and considers healthcare organizational ethics analysis an “essential skill of healthcare administration.” The book is aimed at “students in health services management, healthcare professionals, and healthcare administrators who are facing these issues,” and cannot fail to be illuminating to readers from any of those groups. For students of business administration in general, the book’s focus on healthcare highlights the ways in which healthcare as a business is subjected to multiple goals, of which financial success is only one, and involves multiple ethical perspectives. For beginning healthcare professionals, or for practicing professionals subjected to increasing responsibility for cost containment, the presentation of the administration perspective may be useful. In discussing the organization goals model of ethical analysis, for instance, Hall not only gives examples of 10 actual mission statements from HCOs, but offers some gentle criticisms of ways in which mission statements can go wrong—as well as offering a model statement that avoids some of those pitfalls. The same chapter discusses codes of conduct in the same critical and informative way, and an appendix offers a
I was particularly charmed by the chapter on program development, not least because of the various cautionary notes it sounded. As healthcare organizations struggle for financial survival in a rapidly changing and increasingly competitive market, introduction of new service lines becomes a tempting option, but one not without its dangers. Hall presents some of these dangers in an extended case study: the introduction in one hospital of an organ transplantation program. Following a general summary of organ procurement procedures, Hall presents a case detailing the impact on the various physicians and staff members of morale, coordination, and role assignment over a two-year period of the program implementation. Ethical analysis as a “normal dimension of organizational management” is needed to help in anticipating problems, meeting them when they arise, and preventing their reoccurrence.

Many of the issues that arise in clinical ethics have their counterparts on the organizational level. Confidentiality of medical records is a typical and often discussed example. Treating confidentiality as if it were the sole responsibility of the individual clinician is both frustrating and inappropriate, as Hall’s chapter on medical records makes clear. Equally to the point is his chapter on managed care, where he highlights the conflict of interest that care providers face when negotiating their responsibilities to the plan that reimburses care vs. their responsibilities to the patients cared for—a structural and systemic conflict which he suggests will only be able to be solved on the political level. “Reliance on the professional commitment of individual physicians to overcome the economic pressure exerted by MCOs may be somewhat naïve,” he comments. “Medical professionalism is up against a very powerful opponent. I wouldn’t bet on Hippocrates” (p. 82).

The most Frequently Asked Question in this area, after “What Is It?” is, “How does my institution develop an organization ethics program?” In his final chapter Hall addresses this question in the context of the JCAHO accreditation standards. He suggests five models for such programs, including expanding the existing hospital committee. Two of his other four suggestions involve committees as well. An ethics officer or consultant, the organizational-ethics equivalent of the designated clinical ethicist, is his fourth suggestion, and he discusses as well the pros and cons of assigning the organization ethics function as an additional duty of the compliance program. Several strategies for systematic ethical analysis are briefly discussed, but Hall acknowledges that most decisions for instituting and developing organization ethics programs will be institution-specific.

Coming from a feminist and clinical ethics background, my own approach to organizational ethics tends toward a grass-roots, bottom-up approach. Hall’s book is an illuminating example of an alternative approach, and a valuable how-to book for a program that is established from any of the 5 routes he discusses.

Mary V. Rorty, Stanford, Calif.


In Citizenship and the Ethics of Care, Selma Sevenhuijsen attempts to provide an adequate model for an ethics of care. In general, Sevenhuijsen characterizes her view as a “postmodern form of humanism” (p. 28). As such, her theory emphasizes social practices and individual perspectives. In fact, she believes that normative theories can only be improved through dialogue between individuals with differing moral perspectives (p. 87). In addition to her general discussion of the ethics of care, Sevenhuijsen devotes two chapters of the book to the topics of child custody and public healthcare policies. These specific examples are intended to provide an analysis of existing Dutch policy and demonstrate how a dialogue that pays attention to the ethics of care and gender assumptions would have a positive impact on social practices.

Like many other authors promoting an ethics of care, Sevenhuijsen accepts that the proper image of self is a relational one that emphasizes responsibilities, and she rejects any ethical theory that does not focus on specific individuals and their circumstances when making judgments. What makes her version of this theory different from some others is that, according to Sevenhuijsen, the ethics of care is inseparably tied to the practice of democratic citizenship (p. 66). She believes we cannot develop an adequate ethics of care outside the context of political discussions in a democratic environment. This
means that public debate is crucial to achieving adequate decisions concerning the quality and type of care provisions that are desirable. She also points out that the common view that political judgments require an “objective” stance that is free from personal relationships disempowers the language of care. Consequently, public discourse must be used to challenge the very language of ethical discussions so that care will no longer be marginalized.

Sevenhuijsen’s argument that justice and care are not opposed to each other provides an additional contrast with several other versions of the ethics of care. Because she denies that opposition, her theory does not require the rejection of traditional liberal concepts that have been associated with theories of justice (p. 34). Instead, she believes that such concepts must be re-evaluated from an ethics of care. She further claims that justice itself requires that a variety of individuals participate in public discussions (pp. 145-46). So, for example, a truly representative democracy would have the ability to develop adequate health care policies because it would include all voices, especially those that were previously marginalized. She also notes that to ensure just decisions, discussions of health care would have to include those who are in need of care (p. 135). Justice requires that these individuals, who are typically rendered powerless in current discussions, participate in the determination of such things as what is to count as necessary care.

The fifth and final chapter of the book focuses on health-care issues. Sevenhuijsen approaches this topic by providing an analysis of a public policy document, entitled Choices in Health Care, published in 1991 by the Dutch government. This document was intended to provide a method for public involvement in decision-making concerning the availability of, and access to, health care. Sevenhuijsen’s analysis of the document proves valuable not only in the Dutch context, but more widely as well. In this chapter, she successfully demonstrates that this policy document identifies certain preferred modes of speaking and making judgments, declaring these modes to be authoritative in public discourse (p. 123). Consequently, alternative modes, including the ethics of care, are disempowered. Needless to say, any document that involves this approach to public discussion has limited the debate and cannot be expected either to find the best available solutions to health care concerns or to vary from the social status quo in any significant way.

Choices in Health Care also assumes that citizens are health care consumers who meet their health care needs through a market system operating in accordance with the principles of supply and demand (p. 132). While this assumption is currently a common one, Sevenhuijsen points out that it entails an approach to health care that is problematic. For example, it sets individuals with health care needs in competition with others who have similar needs or with the community as a whole, since the community may be interested in conserving these resources (p. 133). Additionally, it marginalizes an ethics of care by not considering caring activities as socially and individually significant (p. 132). The document privileges discussions that are aimed at providing objective, universal, and economically rational solutions (p. 134), but if it truly advocated wide public discussion of health care, such aims would be impermissible. The market approach is one of the models that must be scrutinized as part of an open and fully participatory discussion of health care within any society.

Sevenhuijsen’s analysis also points out that unwarranted gender assumptions pervade the document. For example, she notes that a policy of determining when needs are serious enough to need professional attention forces upon women, who provide a vastly disproportionate share of the unpaid care-giving in every society, the role of preventing unnecessary demands on the health care system (p.136). Such gender biases must also become part of the public debate, and women must be given an equal voice in these discussions.

Sevenhuijsen is correct in claiming that public policy documents such as Choices in Health Care provide us with the opportunity to notice what is included and excluded in the public discourse about health care. However, her book provides few suggestions for achieving the kind of open discussion that she claims is necessary to an adequate ethics of care. Simply analyzing policy and legal documents from an outside, disempowered, position does not seem to offer much hope for success. As she recognizes, democratic citizenship, to date, has not prevented the marginalization of women’s voices and the ethics of care. Consequently, some ideas concerning how to prevent an existing power structure from limiting debate would be valuable, especially since it is not clear how to go from the current political situation to Sevenhuijsen’s ideal.

Julia J. Bartkowiak, Clarion University
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Calendar of Events

May

**Neuroethics: Mapping the Field**, May 13-14, 2002, Golden Gate Club, San Francisco, CA. The conference will bring together neuroscientists, bioethicists, public policy makers and scholars in the humanities for discussion and debate on these issues. Registration is $100.00. To register please call the Continuing Medical Education Department at LDS Hospital, 408-1976 or 1-800-842-5498. The agenda for the conference is listed on the website: www.med.utah.edu/ethics/conference2002.

Registration material will be available on-line soon.

For more information about the program, please email Dr. Judy Illes, illes@stanford.edu. For information about conference logistics and an application, please email jprasad@stanford.edu or call Joyce Prasad, Conference Co-ordinator, Tel: (650) 498-6958, Fax: (650) 725-6131, Stanford Center for Biomedical Ethics, 701 Welch Rd., Palo Alto, CA 94304-5748.

**Telling the Truth in Health Care: 13th Annual Intermountain Medical Ethics Conference**, May 31, 2002. Salt Lake City, Utah. The Division of Medical Ethics is sponsoring its 13th Annual Intermountain Medical Ethics Conference at the LDS Hospital Education Center. The conference will explore truth telling in various aspects of health care, including prognostic information, direct-to-consumer advertising by the pharmaceutical industry, medical mistakes and health plans. For more information about the program, please email Dr. Judy Illes, illes@stanford.edu. For information about conference logistics and an application, please email jprasad@stanford.edu or call Joyce Prasad, Conference Co-ordinator, Tel: (650) 498-6958, Fax: (650) 725-6131, Stanford Center for Biomedical Ethics, 701 Welch Rd., Palo Alto, CA 94304-5748.

June


**Intensive Bioethics Course XXVII: Difficult Choices, Ethical Decisions**, June 4-9, 2002, Kennedy Institute of Ethics, Georgetown University, Washington, DC. Sponsored by The Joseph and Rose Kennedy Institute of Ethics, one of the world’s premiere institutes for research in bioethics. Special topics such as “Ethics Committees,” “Teaching Bioethics,” “Ethics of Care,” “Careers in Bioethics,” “NBAC,” and “Feminist Bioethics,” will be offered in small forum sessions. Specific aims for the course are to introduce participants to the philosophical underpinnings of bioethics and current major topics in the field, and to provide them with the skills to define and describe various principles and approaches to bioethics. For more information visit www.georgetown.edu/research/kie/courses/ibc02.htm

**Narratives of Power in Health Care**, June 8-13, 2002, Hiram College, Hiram, OH. The Tenth Annual Summer Seminar sponsored by The Center for Literature, Medicine and the Health Care Professions, a collaborative project of Hiram College and Northeastern Ohio Universities College of Medicine. For further information, contact Carol Donley, Mahan House, Hiram College, Hiram, OH 44234. Tel: 1-330-569-5380. Fax: 330-569-5449. Email: donleycc@hiram.edu, or visit www2.umdnj.edu/ethicweb/upcome.htm.

**Ethics of Research with Humans: Past, Present, & Future**, June 17-21, 2002, University of Washington, Seattle, WA. Summer Continuing Education Courses in Bioethics. Sponsored by the University of Washington School of Medicine. The course reviews the origins and development of the ethics and regulation of human research. For more information contact: Marilyn J. Barnard, Continuing Education Program, University of Washington, Department of Medical History and Ethics, Campus Box...
26th Annual Health Law Teachers Conference, June 7-8, 2002, Indiana University School of Law. This two-day conference is intended for professionals who teach law or bioethics in schools of law, medicine, public health, health care administration, pharmacy, nursing, and dentistry. ASLME’s Annual Health Law Teachers Conference combines presentations by experienced health law teachers with the opportunity for discussion among conference participants. Continuing Legal Education is available. For more information or to register online please visit www.aslme.org/conferences.

July


August

NASHP’s 15th Annual State Health Policy Conference, August 4-6, 2002, Philadelphia, PA. For more information visit www.nashp.org/meetings.htm


Summer Seminar in Health Care Ethics, August 5-9, 2002, Seattle, WA. This annual one-week seminar provides an intensive introduction to the concepts, methods, and literature of health care ethics. For more information contact: Marilyn J. Barnard, Continuing Education Program, University of Washington, Department of Medical History and Ethics, Campus Box 357120, Seattle, WA 98195-7120.

September

ASLME Annual Meeting, September 20-21, 2002, John Hancock Center, Boston, MA. For more information or to register online please visit www.aslme.org/conferences.

October


November

This Year’s Nominating Committee, which is responsible for soliciting nominations to FAB’s Advisory Board, are Anne Donchin, Susana Sommer, and Laura Shanner. You can expect to hear from them soon on the Listserv, asking for interested parties and encouraging you to vote in the next FAB election.

Get Involved In FAB

To Join FAB
Members receive the semi-annual newsletter which contains helpful announcements of upcoming events and opportunities, book reviews, and articles of interest to those working in feminism and bioethics. To join, send a request for a membership form with your name and address, either by mail or electronically to Lenore Kuo (address on Contact page). Or print a membership form from the FAB website: www.fabnet.org

To Contribute to the Newsletter
We welcome contributions of all sorts: articles, announcements of upcoming events, information about articles or books you have published or find useful, reviews of books. Book reviews are organized by Alison Brookes. Any other contribution should be forwarded to Maggie Little (both addresses on Contact page). It’s particularly helpful if you can send them in electronically. Deadline for submissions to the next newsletter is September 15, 2002.

Change in FAB Book Review Editor
FAB would like to express its deep gratitude to Hilde Nelson for her many expert efforts as FAB Book Reviewer for the past several years. We extend our delighted thanks to Alison Brookes for her willingness to take on the new role. Welcome Alison!

This Year’s Nominating Committee, which is responsible for soliciting nominations to FAB’s Advisory Board, are Anne Donchin, Susana Sommer, and Laura Shanner. You can expect to hear from them soon on the Listserv, asking for interested parties and encouraging you to vote in the next FAB election.

Feminist Approaches to Bioethics