

CONFERENCE REPORTS

PEOPLE AS PRODUCTS: THE ETHICAL, LEGAL AND SOCIAL ISSUES IN REPRODUCTIVE TECHNOLOGIES AND OTHER PROCEDURES INVOLVING THE COMMERCIALIZATION OF BODY PARTS AND TISSUES, Boston, Massachusetts, 6 and 7 November, 1989.

Public Responsibility in Medicine and Research (PRIM&R), a Boston-based nonprofit organization, sponsored this "People as Products" conference, with co-chairs Judy Norsigian from the Boston Women's Health Book Collective (BWHBC) and Gary Ellis from the U.S. Congress's Office of Technology Assessment (OTA). PRIM&R aims to promote research "that will both improve the quality of life and benefit society" and is not unreceptive to feminist views. They frequently sponsor conferences, and they educate members of institutional review boards (the committees in each U.S. hospital that must approve clinical experiments).

The conference structure comprised three keynote addresses and four plenary panels, with each panel followed by five concurrent workshops. Of the 24 workshop co-facilitators (many of whom were assigned to two or three workshops), eight were women. Women who co-facilitated three workshops were Dr. Patricia McShane, Medical Director of IVF Australia-Boston, Judy Norsigian of BWHBC, and Robyn Nishimi of the OTA. A book of "educational materials"—34 photocopied papers — was provided to participants. Only 12 were on NRTs and only 4 were feminist.

Many came especially to hear the announced keynote address by Representative Ron Wyden, member of Congress, whose Committee on Small Business is currently investigating consumer issues in IVF, but — as so often happens — he didn't appear. George Annas, liberal attorney from Boston University, spoke in his stead.

The first panel dealt with clinical research use and ownership of cells, tissues, and organs from adults, fetuses, and anencephalic infants. Charles Weiner of the Massachusetts Institute of

Technology denounced the U.S. Supreme Court's 1980 ruling that essentially anything may be patented, a decision (he claimed) aimed mainly at enhancing the United States' competitive advantage worldwide. He deplored the breakdown of open, informal communication between scientists, the lack of thorough evaluation of research in the haste to obtain patents, and the failure to use ethics committees when scientists work in secrecy. Kevin O'Connor from the OTA, taking a low-key pro-technology stance, provided lists and questions showing why the U.S. Congress is interested in biotechnology, "the last great technology of the 20th century." Then Dr. Eugene Redmond from Yale, an active clinical researcher using fetal brain tissue transplants in attempts to cure Parkinson Disease, advocated more harvesting of brains from aborted fetuses (not from miscarriages because those fetuses are defective). Yale, he claims, has adequate safeguards which ensure that women don't become pregnant just in order to have abortions so as to facilitate his research. However, no one's results have shown that such transplants really work, because Parkinson patients regularly have slight remissions and relapses.

At a plenary lunchtime address, disability rights advocate Adrienne Asch spoke on "Why We Have Children." Our reasons blend altruism and narcissism, she said, and she then wondered how *one* parent can be *so* interested in the genetic connection that he/she would go outside the marriage to get genetic material.

Then a panel on aspects of biotechnology and genetics covered sequencing the human genome, genetic testing, and eugenics. Robyn Nishimi described a current OTA review, to be published November 1990, on genetic testing and screening, including forensic uses of DNA. Jonathan Beckwith was deeply concerned about "genetic discrimination." In this category, he included eugenic policies in employment, insurance companies' plans to screen all policyholders for genetic disease, and a reduction in the study of

environment as a cause of disease. He deplored the attitude that the “essence” of human being will be known when we know the DNA sequence. Gary Ellis analyzed ethical and social issues raised by the use of recombinant-DNA-produced growth hormone to cure hypopituitary dwarfism. He described several advantages (e.g., no virus contamination) and disadvantages (e.g., heightism in society and sexism when parents are more likely to bring boys than girls for treatment). Feminist philosopher Caroline Whitbeck raised questions about what information is worth having, the connection between control and happiness, and some feminist issues such as the centrality laid on the relationship between a *man* and *his* genetic offspring. One of the workshops that followed this panel was “Feminist Critiques of the New Reproductive Technologies,” led by Ruth Hubbard and Judy Norsigian.

In the second-day keynote address, “Bits and Pieces and Civil Liberties,” feminist sociologist Barbara Katz Rothman asked “WHY?” i.e., why do we do NRTs and prenatal diagnosis? “What is the point?” she asked, and answered: our underlying ideology, that is, capitalism and the market system, a technological world view (body as machine), and patriarchy. Saying “state-of-the-art babies” and putting price tags on body parts show our market view. Assigning rights to those body parts and thinking of birth as separation *rather than* bonding show the machine mindset. She gave many examples of doublespeak – one is “therapeutic” abortion for eliminating a *wanted* fetus precisely because no therapy exists.

Rothman’s address was followed by a panel on assisted reproductive technologies. Dr. Kenneth Ryan, Chair of Obstetrics and Gynecology at Harvard, gave the to-be-expected pooh-poohing of those who see problems with assisted reproduction. “Society sees no problem.” “Donated eggs are getting more and more common.” There are, he admitted, a few questions still, such as paying egg donors, disclosing information, testing sperm. Neonatologist Michael Epstein discussed “principles” for deciding about compromised newborns in the intensive care nursery. It was good to hear his strong advocacy of the greater role of parents, particularly mothers, in neonatal decision-making. Judy Norsigian closed the panel. Although at times she took a more liberal view than most

FINRRAGE members, nevertheless she made important feminist points that this audience needed to hear. In her analysis of surrogate motherhood, she described a recommendation in a magazine for hospital administrators – that hospitals needing a source of revenue set up their own surrogacy matching services.

In the final panel on the role of government in forming policy, Robert Cook-Degan, from the OTA, reviewed the checkered history of three recent U.S. national advisory commissions on bioethics. Adrienne Asch described the rather amazingly effective work of a state commission, the New Jersey Bioethics Commission. A Massachusetts state senator, Edward Burke, active in health legislation, discussed such issues as rationing health care and reported that he was proud to have sponsored the bill that now requires insurance companies to cover IVF in Massachusetts.

What would FINRRAGE members have gained from this conference? They would have accepted most of the views of Norsigian, Asch, Rothman, and Whitbeck, and would have been pleased that these women were featured in plenary sessions where an audience of some 130 people was exposed to their views. In the workshops people with vested interests in the NRTs and fellow-traveling philosophers argued politely with those who questioned parts or all of the NRT paradigm. I had two gentle confrontations with the mild-mannered president of Serono Laboratories (producers of the best selling fertility drug Pergonal). But the status quo stayed quo. The “why” questions remained unanswered. How depressing to see our consumer society put so much energy into babies as carefully designed products for the “haves” – who happen to “not have” babies – while this same society ignores basic health needs of the “have nots” who happen to “have” undesigned and sometimes unwanted babies.

The conference papers have been collected in a book to be ready in July 1990, costing U.S.\$20.00. Add \$5 postage for orders out of North America. Send checks to: PRIM&R, 132 Boylston Street, 4th floor, Boston, MA 02116, U.S.A.

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