Public Hearing

before

COMMISSION ON SEX DISCRIMINATION IN THE STATUTES

"Testimony on possible incidents or common practices that encourage sex discrimination in the health field and in the delivery of health care"

LOCATION: AB Auditorium
St. Barnabas Medical Center
Livingston, New Jersey

DATE: February 28, 1994
11:00 a.m.

MEMBERS OF COMMISSION PRESENT:

Senator Wynona M. Lipman, Chair
Cathy L. Waldor, Esq., Acting Vice-Chair
Patricia Atkins, Esq.
Phoebe Seham, Esq.

ALSO PRESENT:

Melanie S. Griffin, Esq.
Executive Director
Caroline W. Jacobus
Assistant Director For Research
Commission on Sex Discrimination
In the Statutes

Hearing Recorded and Transcribed by
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State of New Jersey

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NOTICE OF PUBLIC HEARING

The Commission on Sex Discrimination in the Statutes will hold public hearings on Tuesday, February 1, 1994 at 10:00 A.M. in Room 9 of the Legislative Office Building, Trenton, and on Wednesday, February 9, 1994 from 11:00 A.M. to 6:30 P.M. in the AB Auditorium at St. Barnabas Medical Center, Livingston.

The purpose of these public hearings is to discover whether there are incidents or common practices that encourage sex discrimination in the health field and in the delivery of health care. The Commission is mandated to examine the laws of New Jersey and to suggest revisions to the statutes that will correct discriminatory language or application.

The hearings are expected to focus on the following areas:

- The impact of health care reform and insurance on women's health care
- Coordination of women's health care
- Occupational safety and reproductive hazards
- Violence against women: the health care response
- Adolescent health care
- Health care of incarcerated women
- Research on women's health issues
- The health care needs of older women
- Cancer in women: breast, cervical, ovarian
- Cardiovascular disease in women
- Mental health services for women
- Pregnancy and addiction

These topics do not preclude other relevant testimony, and your testimony does not have to be limited to one category. Because of the large number of witnesses who will wish to testify, we ask that you limit your testimony to 10 minutes. The Commission will be pleased to accept any additional written materials you may wish to provide.

Anyone wishing to testify should contact Caroline Jacobus at the Commission at (609)633-2768.

Anyone wishing to submit written testimony to the Commission is requested to bring 10 copies to the hearing or to mail it to the Commission office by February 23, 1994.

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CATHY L. WALDOR, ESQ. (Acting Vice-Chair): Excuse me, I'd like to call this hearing to order so we don't run too much later. My name is Cathy Waldor. I am not Senator Lipman. Senator Lipman has been delayed.

I'd like to make a few opening remarks, but keep in mind that Senator Lipman did open the first session -- this is the second day of hearings -- on February 1. Obviously, we're all here with the same thing in mind. Health care reform is a major topic of conversation nationally and within the State of New Jersey. We're here today together to carefully examine women's health issues, to keep open dialogue concerning women's health issues. As we know, women's health issues have been fragmented as compared to other areas of society; with respect to insurance, with respect to violence, with respect to the family, and the economy. Hopefully, if we, again, all keep this dialogue going we can have a great impact again nationally, as well as statewide in legislation.

We welcome everybody here, and this hearing will last till about 5:00 or 5:30. Many people have put a lot of time and effort into preparing statements, studies, and written papers as well as, I'm sure, the wonderfully prepared oral statements that we'll hear. We want you to know-- The Commission wants you to know that we propose to put all of this testimony together -- oral and written -- and write legislation or aid in writing legislation that will somehow help all of us, and somehow defragmentize the issues that I've discussed and that we will all discuss today. So, with that, I hope I've covered it all. I'm not too good at ad-libbing.

Thank you again for coming, and perhaps we can get started.

MS. JACOBUS: Our first witness is Dr. Gloria Bachmann. Dr. Bachmann is from UMDNJ; she is the Director of the Women's Wellness Center at Robert Wood Johnson Medical Center.

G L O R I A A. B A C H M A N N, M.D.: Well, first of all, I'd like to thank you very much for inviting me. I have been involved with women's health care issues for about 20 years now, and I can say that I've been involved with them on four fronts:

The first is, obviously, the academics, where I am involved in the teaching of medical students, residents, nurses, psychologists, social workers, physicians' assistants, etc., etc.

Another is research. I'm involved with many research protocols involving women, especially those involved with menopause, with abuse, and with the aspects of hysterectomy.

The third front is, obviously, clinical services. I have a large population of women where I am their obstetrician/gynecologist.

The last is that I serve on many national and international committees involved with the health care of women. I was one of the founding members of the International Menopause Society, as well as sitting on the Gynecologic Practice Committee of the American College of Obstetricians and Gynecologists, which looks at the practice of gynecology and obstetrics in the United States.

I would like to just offer two observations regarding this topic of women's health. The first is that I support the creation of an Office of Women's Health in New Jersey. The second is that I support the creation of comprehensive women's health centers that would not only provide preventive health services, but would also provide coordinated multidisciplinary intervention services as well.

Obviously, all of us here are aware of the unique problems of women. I shouldn't call them problems; I should say unique health care needs of women. These range from the first menstruation -- the menarche -- to pregnancy, lactation, the perimenopausal period, the menopausal period, and, of course, the geriatric period.

I think that this has really received a lot of attention in these past few years because of the very rapidly growing, increased female population in the geriatric years. All of us are aware that, although the life expectancy of the woman is about seven years longer than a man, these later years are marked by a high prevalence of physical disabilities and mental problems that result in increased frequency of medical office visits, hospitalizations, and residency in nursing homes. This is where I feel that by early intervention -- early preventive measures -- and coordinated health care, we can obviously stem this tide.

Women have a higher incidence of urinary stress incontinence, chronic cystitis and other problems of the urinary system, constipation and other intestinal conditions, anemia, osteoporosis, and varicose veins, to name a few. In addition, contrary to public belief, older women lose their advantage of a lower risk of cardiovascular disease. Women also tend to have more atherosclerotic strokes, use more medications for hypertension, and have a twofold increase in operative mortality with bypass surgery than men.

I believe that the health care needs of women are not totally being met by the traditional health care delivery programs that we have in existence today. Many of the disabilities and chronic health problems that may be ameliorated, and in some instances prevented, are frequently not thoroughly addressed. Because of this, the long-term results appear to be increased health care costs, increased prescription drug usage, short-stay hospitalization increase, as well as a high, and in certain instances, inappropriate institutionalization.

Primary and secondary prevention directed to women with early diagnosis and treatment of common disorders may decrease certain chronic illnesses, cut health care expenditures, and add productive and, obviously, pleasurable years to the woman's life.

I'll just bring up one example, and that is urinary stress incontinence: Through early kegele exercise programs, through early bladder training of care of the bladder, pharmacologic interventions, hormonal interventions, and even in some instances, early surgical intervention when there is low operative risk, would really prove ideal and would stem the problem of this high incidence of incontinence that we have among women in our society today.

The traditional delivery of health care to women, especially older women, also poses problems. A trend toward over-prescription of medication and under-diagnosis of medical problems often occurs because women may visit several health care providers in different specialities and clinical settings, without coordination of clinical care or a close follow-up.

Also, there are no coordinated databases that really examine various interventions, their short- and long-term outcomes and their costs, and that look at the cultural and racial differences in outcome.

Delivery of health care with emphasis on prevention, both primary and secondary, and the coordination of services would optimize care and continuity of treatment and discourage duplication of services. In addition to the improved health care and enhanced quality of life that may result, there is also a benefit from a cost point of view in this era of limited resources.

What are we doing at UMDNJ, Robert Wood Johnson Medical Center, and our Women's Wellness Center? What I'd like to do now is give you a thumbnail sketch of some of the programs that we have implemented or are implementing at this time.

We have four components of our program: the delivery of clinical services, the delivery of community services, education, and research. Under clinical services there are seven components:

The first is a multidimensional health evaluation including: computer-driven history, physical examination, laboratory and radiologic screening. The content of each evaluation is determined by the woman's age and prior history, and is adapted from the guidelines set by the U.S. Preventive Service Task. Obviously, this is the book that outlines very clearly the clinical services that women should have, and for at-risk women, additional services.

The second is education and counseling women regarding common diseases and their prevention: incontinence, obesity, osteoporosis, cardiovascular, etc., as well as individualized counseling according to each patient's needs.

The third is the outpatient management of common medical and gynecologic conditions including: osteoporosis, hormone replacement therapy, urinary and fecal incontinence, osteoarthritis, uncomplicated hypertension, diabetes, and infections.

The fourth is onsite referral for outpatient specialty care by scheduled consulting periods.

The fifth is the overseeing of referral for tertiary outpatient care and inpatient care.

The sixth is psychological support by trained therapists, established volunteer groups -- we use volunteer groups that already extant -- and social interactions at functions sponsored by the Women's Wellness Center.

The seventh is outreach services by the Center of Personnel, in cooperation with home health care and community organizations.

The second aspect is community services.

The first is the provision of medical leadership and expertise to the many volunteer and community organizations serving women.

The second is library services with up-to-date, patient-oriented material and, of course, this material has to be appropriate for the education of the woman and for the language of the woman.

The third is annual health fairs.

The fourth is ongoing seminars, lectures, and roundtables for interested women and their families.

The third component is education.

The first is training of students involved in female health care. These are not necessarily physicians, but nurses, social workers, psychologists, dietitians, etc.

The second is a one-year fellowship in female ambulatory care which is offered to physicians completing training in either obstetrics and gynecology, family medicine, or internal medicine. Dr. Kate Thompson, who, I believe, will be offering a written statement for these hearings, is our first Women's Wellness Center Fellow, I am very happy to say.

The third is the postgraduate educational programs that we sponsor with national and international faculty and audience.

The fourth component of the Women's Wellness Center is, obviously, research.

We are very involved, number one, with clinical research on medical problems common in women. We are one of the vanguard centers of the Women's Health Initiative that is sponsored by NIH. Dr. Norman Lasser is the principal investigator and he is located at Newark. This is a joint venture between the Newark campus and the New Brunswick campus of the University of Medicine and Dentistry of New Jersey.

We do research on new pharmacologic agents for the prevention and treatment of many conditions and diseases common to women, and many times we are using cutting-edge types of pharmacologic agents that are not available to women other than through these research protocols.

The third is research on psychosexual and social needs of women. Again, we had in the past, I think, ignored these issues and we're seeing the importance of this.

The fourth is database research on the health problems of women with the ability to assess outcomes of various interventions and their costs.

In summary, I feel that we need a coordination of women's health services and this could probably best be accomplished through an Office of Women's Health. I think that we have to look at the delivery of health care to women through comprehensive service centers. I believe that with these two pieces in place there would be a multitude of benefits to the health care of women, their children, and their families.

Thank you very much.

MS. JACOBUS: Thank you very much, Dr. Bachmann.

Our next witness is Lois Hull, from the New Jersey Division on Aging, with the Department of Community Affairs.

L O I S H U L L: Thank you. My name is Lois Hull and I currently serve as the Director of the New Jersey Division on Aging. Thank you for inviting us here today to focus attention on sex discrimination in the health field and in the delivery of health care.

According to the recent census, New Jersey's older population totals 1.4 million people -- that's using 60 as the age, which we do in our Division -- of whom 60 percent, more than 800,000, are women. In the fastest growing segment of the older population -- those over 85 -- women outnumber men 2 to 1.

Older women have lower incomes, more long-term health problems, higher rates of morbidity, are more likely to live alone or to be widowed, and are less likely to have pensions or health insurance than men. These older women are often caring for functionally impaired older relatives, grandchildren, or disabled younger dependents. Paid caregivers, too, are most

often women earning minimum wages with no health insurance or pension coverage. These women, who bathe, feed, dress, and care for our disabled and aged parents are earning less than zookeepers or parking lot attendants. You'll forgive me for being melodramatic, but it's one of my most passionate concerns.

If deteriorating health, loss of loved ones, poverty, institutionalization, and loneliness are its hallmarks, then living longer is a mixed blessing at best. With the exception of longevity, women are relatively disadvantaged along most of the demographic parameters.

In New Jersey, 70 percent of all reported adult abuse and neglect involves either elderly or disabled women. Self-neglect and caregiver-neglect constitute almost 80 percent of our reports. Such neglect is largely due to inadequate resources for, and access to, in-home and community-based services. More than 60 percent of the elders who are severely impaired and living in the community are women; 75 percent of institutionalized elders are women; 41 percent of older women live alone, while only 16 percent of older men live alone. After age 75, the poverty rate for women is twice that for men. Widows are the poorest Social Security beneficiary group in this nation.

The various effects of an aging population disproportionately affect women, and unless we can change policies and attitudes these effects will continue to increase the hardships for many women, particularly for women of color. Older women face serious obstacles in gaining access to needed health care because of cost. Older women spend a higher percentage of their incomes on health care than men, reflecting gaps in coverage for chronic conditions experienced by women and women's lower median income. In addition, women are less likely to have health insurance than men for a number of reasons: higher rates of part-time work, more frequent moves in and out of the labor force, and a tendency to work in jobs that are less likely to insure employees.

Over a lifetime, reduced access to medical services and preventive health care has serious consequences for older women's health. Old women are here to stay, and we will be here in increasing numbers and for increasing lengths of time. We ignore the crucial need for preventive care and affordable care at our peril and at the risk of devastatingly high rates of disability and intolerable health care costs.

Health demographics and access/cost concerns are two statistical realities in any discussion of health care for older women, but caregiving is the vital human reality. For many women, life is a lifetime of caregiving. For the woman whose child is born at the age of 23 and whose parents begin to need help when they are about 65 years old -- when she is about 45 years old -- there is little time in life that is not involved in caregiving. If her spouse is disabled, she will begin to care for him when she is between 55 and 65, and probably continue that care until she is in her 70s, that is, until he dies. For more than half of all women, paid employment continues throughout these caregiving years.

As much as 90 percent of the community-based, long-term care provided to functionally impaired older people is provided by family or informal caregivers, 72 percent of whom are women. The emotional, physical, and financial strain borne by caregivers can be severe. Caregivers are more prone to depression, and suffer higher levels of stress and stress-related diseases than the general population. Many women caregivers are unable to continue working, many have high absenteeism, many can only work part-time, many lose salary, health benefits, and pension benefits. Paid caregivers -- mostly women -- such as home health aides, nursing aides, and homemakers, working for low wages and often without benefits, repeat the cycle which leaves older women alone and in poor health. Remedies, such as removing the disincentive for men to share in both paid and informal caregiving responsibilities,

and a more family-responsive workplace which might include options for dependent care and flexible work time, should be more widely available.

Thus far, the enormous social and economic impact of an aging population has been felt disproportionately by women. Conventional patterns have not been eradicated. Most women continue to work at relatively low paying jobs; Social Security and pensions continue to favor continuous employment. The imbalance between men and women among older Americans will continue because of the life expectancy advantage of women over men. With no significant policy changes to break the cycle, and despite improved educational and job opportunities for some, large numbers of younger women may find that they are old, alone, and poor eventually.

First, in order for women to safeguard their own old age, and to provide properly and safely for their parents, the workplace must offer them equity in jobs, salaries, and benefits so that they might be able to save and enjoy retirement benefits similar to those of men.

Second, cost-effective prevention initiatives will alleviate the incredible disability burden we will increasingly face as the population ages. Three examples:

1) Estimates of $7 billion to $10 billion annually are quoted as the national cost of follow-up care for frequently preventable hip fractures among older women.

2) Virtually all deaths from cervical cancer are preventable, assuming early detection and current technology, yet 41 percent of all cervical cancer deaths occur in women aged 65 and over.

3) We need a rational, equitable, and accessible home and community-based, long-term care program for all people with chronic illnesses and disabilities. For women, the major providers, as well as the major consumers of long-term care, implementation is essential to avert an impending disaster.

Ageism and sexism have combined to make older women the most disposable commodity in our society. A different role is possible. A different future is possible, perhaps for us, but surely for our daughters. In addressing the health care needs of older women, we will all move toward a health care system which includes preventive care and home and community-based, long-term care, that can meet the needs of our entire population.

Thank you for your attention. I wish you great success. If you have any questions, I'd be happy to answer them.

MS. JACOBUS: Thank you very much.

Do any of the Commissioners have any questions? (no response)

Thank you very much, Lois Hull.

Our next witness is Lisa Brooks, who is a toxicologist from Bell Laboratories.

L I S A B R O O K S, Ph.D.: Thank you. I am Lisa Brooks, Environmental Health and Safety Manager -- toxicologist by training -- for AT&T's Bell Laboratories. I have been asked to give you some insight on our approach to occupational health, specifically, reproductive and developmental hazards in the workplace.

I have provided some materials for you, and I'd just like to spend a few minutes walking you through them. I certainly hope that you take the opportunity to review them in detail. We feel there is a great deal of excellent information in there for you.

The first reprint that we've provided is a publication in which we did a benchmarking study of primarily R&D -- research and development -- organizations to determine whether reproductive hazards were being addressed in the workplace; if so, how; and what impact, if any, the Johnson Controls decision had on those programs?

Twenty-nine companies agreed to share information with us, only three of which had a formal, written program addressing reproductive hazards in the workplace. Two of those three companies indicated that they would be eliminating their written program in light of the Johnson Controls decision. The third was a fetal protection policy and they would be -- that particular company -- revising the fetal protection policy to be more in line with Johnson Controls.

Four of the 29 companies said in light of Johnson Controls they would develop a policy, but there were no timetables or specific assignments set out for the development of those programs. Fourteen companies felt that using something such as the OSHA Hazard Communication Program was sufficient to address reproductive and developmental hazards in the workplace.

Of the 29 companies that shared information with us, only six had any sort of written training or education materials that they were willing to share with their employees.

I've also provided you two pieces of information regarding the AT&T Bell Laboratories' program. One is a paper which is scheduled for the April issue of the "American Industrial Hygiene Association Journal," and that provides the background and rationale for the development of a comprehensive reproductive and developmental hazards program for the workplace. In that paper, we describe many of the key features of our program and certainly encourage readers to similarly develop programs for their specific workplaces.

I'd like to point out for you a couple of the key points of this comprehensive program. For one thing, it targets both men and women. Reproductive and developmental hazards, when they've been considered in the workplace, have long been considered pregnancy related; men don't have anything to do with it. That is not true. That sort of discrimination

is not appropriate, so we make a very sincere effort to target men as well as women in the workplace. At the locations where we are fortunate enough to have a male nurse, we have more success because men are more willing to talk to men about reproductive issues. But we do, very strongly, focus on men as well as women.

We have a focus on preconception awareness. Once a woman has confirmed her pregnancy in the workplace, the critical six- to eight-week, first period of gestation is probably already gone, and any hazards that may have been present were present during that critical time, so we focus on preconception awareness.

We also include lifestyle and environmental considerations. Much of the time there are workplace hazards, but much of the time the environmental and lifestyle hazards are far more significant: smoking, drinking, air pollution, all the typical environmental concerns. We try to use the workplace to educate women in that regard.

Finally, we have a mandatory program for education and training of our health service providers. If individuals come to us as subject matter experts, we want to be sure that we're fully prepared with all the technical knowledge and counseling skills that are appropriate to address the questions and concerns in the workplace. So there is a mandatory, inservice training program for the nurses and physicians. It addresses the basics of reproductive health and counseling skills, toxicology and legal guidelines, and everything that is appropriate to understanding a comprehensive reproductive hazards program in the workplace.

I've also provided for you what we have as our introductory pamphlet for the employees. It took a great deal of time in writing this to, hopefully, target men and women of all educational and cultural backgrounds. We use this as our introductory piece of information to get people some of the

answers they may originally need and to encourage them to approach us to go further into the program for more specific details.

I hope these materials are helpful to you. I would certainly be glad to entertain any questions now, or at any time in the future.

MS. JACOBUS: Dr. Brooks, as a result of your survey of the 29 companies, what was your feeling coming out of that? Did you feel discouraged, hopeful? What did you feel was the-- Now, these were all larger corporations?

DR. BROOKS: For the most part. You'll see a breakdown of the size of the company in the article.

MS. JACOBUS: So these were corporations that had a certain amount of resources, more than your small businesses or your medium-size businesses?

DR. BROOKS: Yes.

MS. JACOBUS: What was your sense coming out of that survey? Were these corporations prepared to invest in this? It didn't sound that way to me.

DR. BROOKS: No, it did not come out that there was a great push to make the financial and resource -- people resource -- available to generate the program. One of the things that you'll see in some of this information is that the benefits of a successful program are often very difficult to quantify. For many businesses and many environmental health professionals justifying how they deploy their resources, the benefits must be tangible in order for the company to support the program. It's very difficult to quantify things such as, decreased time off for sick child care. If you have healthier children, you should have healthier employees spending more time in the workplace, but it is exceptionally difficult to quantify that. So the tangible aspects required for a massive push for occupational health for reproductive hazards in the workplace is not really there at the moment.

The other aspect, I think, is that, as you know, Johnson Controls says that no matter how well-intentioned we are as employers, we can't make decisions for the employees. I think that scares a number of people away. "If I can't be well-intentioned, how can I do my job?" is sort of a prevailing question that we find out there. We understand all those concerns and limitations, but we at AT&T feel very strongly that education and training can be accomplished and can be a very productive aspect without a massive deployment of resource.

MS. JACOBUS: Do you think that there is any support at AT&T Bell Labs for a longitudinal study of the financial -- the economic -- benefits of putting in place a program such as you have?

DR. BROOKS: I think there would be support. We have geared our program to facilitate computerization of our information. That's our approach for our overall occupational health program and we hope to develop the ways and means of tracking, at least internally, the sorts of dollars that are associated with some of these issues. So once those concepts are fully implemented, we should be able to help deploy the information elsewhere.

MS. JACOBUS: Publish it so that other people can share it. Thank you.

Are there any other questions? (no response)

DR. BROOKS: Thank you.

MS. JACOBUS: Thank you very much, Dr. Brooks.

Our next witnesses are Dr. Patricia Klein, who is the Chair of the Committee on Women in Medicine, at the Medical Society of New Jersey, and Beverly Lynch, from the Medical Society of New Jersey.

B E V E R L Y J. L Y N C H: Good morning. I'm Beverly Lynch with the Medical Society of New Jersey. I'm here just

simply to introduce Dr. Klein, who is a neurologist in Bergen County, and most importantly to us, Chair of the Committee on Women in Medicine for the Medical Society.

P A T R I C I A G. K L E I N, M.D.: Thank you. Good morning. Basically, the first issue that the Committee on Women in Medicine of the Medical Society of New Jersey is concerned about is the level of the health benefits in the five insurance plans that had been devised by the Small Employer Health Benefits Program of the State of New Jersey. There are five basic benefit packages that are supposedly going to be the benefit packages that everyone will have to buy, whether you're an individual purchaser of health insurance, or a small employer. We reviewed these five plans, especially to look at the benefits for women and children.

The first issue that we found was the amount of coverage that was allowed in the plans for care of the child in the first year of life. In Plan A, which is called the bare-bones plan, this was limited to $100. In Plans B through E, it was limited to $500. We believe that this is inadequate to cover the cost of immunizations in the first year of life, as recommended by the American Academy of Pediatrics, and for the routine office evaluations of well-babies through the first year of life. The pediatricians on our Committee felt that a figure of approximately $1000 for the first year of life care would be more appropriate.

There also needs to be clarification about coverage for pregnant women. One issue is coverage of fetal surgery for gastrointestinal or cardiac birth defects, for which the fetus can have surgery before the baby is born. There is some question about whether insurance companies will cover that issue, and we feel that needs to be clarified. We also heard of one case where a child was born with a congenital defect and the insurance company refused to pay for the surgery because they considered it a preexisting illness.

The next major issue for us is the allotment for primary and preventive care for the remainder of the family. We feel that these amounts are set at woefully low levels, especially at a time when our nation is reiterating the importance of primary care and preventive medicine as being essential for the health of our citizens. These plans would allow only $100 in Plan A, and $300 in Plans B through E, for primary care and preventive care for the rest of the family. This would not even cover the amount needed for routine mammograms and pap smears for the woman in the family in Plan A, which is the bare-bones plan. This issue needs to be carefully reconsidered.

Next are mental health issues and the treatment of drug abuse. In Plan A there is no coverage whatsoever for mental health. In Plans B through E, it's limited to $5000 per year and $25,000 lifetime. We believe that it is most important for the women of this State to have the availability for coverage for mental health and that this should certainly be covered to some degree in all the Plans, not just Plans B through E.

The last issue that concerns us is coverage of what some insurance companies may consider experimental treatment. We're specifically worried about coverage for bone-marrow transplants in selected cases of metastatic breast cancer. The American Cancer Society supports reimbursement under appropriate protocols for this treatment, and we feel that it should be part of the coverage for all of the Plans. That's the first issue I wanted to speak about.

The second one, another critical issue to us, is related to domestic violence, which should be recognized as a critical health epidemic. About 30 percent of emergency room visits made by women, and about half of all the murders of women, are the result of domestic violence. The Medical Society of New Jersey's Subcommittee on Violence, which is part of the Council on Public Health -- and the Subcommittee is made

up of a diverse group of private- and public-sector organizations -- is working with many well-established State agencies to help identify and treat victims of spousal and child abuse. The Medical Society of New Jersey has highlighted this issue in the Department of Health budget hearings and to the Whitman transition team.

Last year, the Society launched an advertising and public service announcement campaign which called domestic violence, "A family tradition worth breaking." Highlighting the role the physicians play in providing advice and support to victims and encouraging the victims and their families to come forward, was an important part of this project.

Here with us today, we have posters of ads that appeared in magazines throughout New Jersey; there was also radio advertising on the same subject. There were basically three sections: elder abuse, child abuse, and domestic violence, or spousal abuse. We have also established physicians' guidelines for assessing and responding to violence, which are included in our Medical Policy Manual, and we have a copy of that to give to you today.

The Medical Society of New Jersey is committed to working with the Commission on Sex Discrimination and other groups to help solve these critical health problems.

Thank you very much.

MS. JACOBUS: Thank you very much, Dr. Klein.

Do any of the Commissioners have any particular questions? (no response)

Thank you very much for the time you spent on your analysis of the five standardized programs -- that's going to be very helpful -- also for underlining the problem of violence against women, which is probably the greatest health issue for women in the nation.

DR. KLEIN: Thank you.

MS. JACOBUS: Is Joan Bertin here?

J O A N E. B E R T I N, ESQ.: Yes.

MS. JACOBUS: Joan Bertin, is the Codirector of the Center for Gender, Science, and Law at the School of Public Health, at Columbia University.

MS. BERTIN: Hi. I have some copies. (indicating written testimony)

MS. JACOBUS: Thank you.

MS. BERTIN: I was just learning some important information myself from one of your prior witnesses.

I came this morning to talk a little bit about reproductive hazards in the workplace.

MS. JACOBUS: I think the other mike is the one that is going to--

MS. BERTIN: Oh, sorry.

MS. JACOBUS: She needs both of them.

MS. BERTIN: Both?

MS. JACOBUS: Both.

MS. BERTIN: All right. Am I plugged in properly? (affirmative response) Okay, thank you.

I am pleased to be here today to participate in these important hearings. For many years, I have been an advocate for the rights of women workers. A particular concern of mine -- and I gather of yours -- is the health of women workers, including pregnant workers, and that is the subject that I want to speak to today.

The employment rights of women workers is an issue that has evolved greatly during my own professional lifetime, and it is still evolving. This is a fact that we sometimes forget. Not very long ago, women were openly fired when they got married or became pregnant. Then, as now, unemployment or underemployment represented a major threat to women's health and well-being and to that of their families. Notwithstanding Federal and State laws prohibiting sex discrimination -- which have been in force at the Federal level since 1965 -- as late as

1978, Congress had to clarify that discrimination on the basis of pregnancy was, per se, sex discrimination.

Even that clear mandate, however, has been very difficult to enforce. Until recently, many employers maintained policies that limited the employment opportunities of fertile women, in order to prevent the possibility of injury to a fetus from workplace conditions if the woman were to become pregnant. These so-called fetal protection policies were justified on apparently benign grounds -- the desire to prevent fetal harm -- but they exacted a terrible price from women. Some women submitted to surgical sterilization to preserve their right to lucrative employment, while other women lost good jobs and health benefits because they wished to preserve their right to have children.

Fetal protection policies suffered from other flaws as well. By arguing that the fetus was hypersusceptible to the effects of workplace conditions, such policies ignored or minimized other equal opportunity health risks and created the illusion that adult workers were safe. They relied on the fiction that all women are always potentially pregnant until proven otherwise, and they shifted the responsibility to ensure fetal well-being to individual women -- who were charged with avoiding unsafe workplaces -- rather than placing the obligation on employers to maintain adequate workplace conditions.

After more than 12 years of litigation over the legality of such policies, in 1991 the Supreme Court ruled in UAW v. Johnson Controls that fetal protection policies violate Federal law against employment discrimination in virtually all circumstances.

The facts of that case are simple. In 1982, apparently on the advice of its company physician, Johnson Controls adopted a policy to prevent all women of childbearing capacity from exposure to lead, on the ground that it was necessary to prevent fetal harm.

The policy excluded fertile women of all ages from any job in a department in which any worker had a blood lead reading in excess of 30 micrograms per deciliter of whole blood during the proceeding year, in which there was an air lead reading in excess of 30 micrograms per cubic meter, or a job in which the line of promotion would lead to any such job.

The policy applied to all women capable of conceiving, regardless of marital status, sexual preference, use of birth control, childbearing intentions, or any other individual factors. At least one woman involved in the case submitted to surgical sterilization to secure her employment rights. A male employee who also challenged the validity of the policy, asserted that he had requested a low-lead job to reduce his blood lead level in anticipation of fatherhood, but that his request was denied.

The company defended its policy asserting that the fetus is sensitive to the effects of lead at occupational levels that are not hazardous to adult workers. In the lower court, the debate revolved around the question of differential sensitivity. The Supreme Court, however, resolved the matter not as the employer urged, on the basis of current but incomplete scientific knowledge, but with a legal and policy determination about sex discrimination in employment.

The Court's resolution avoided the potential for conflicts among the lower courts based upon choosing which expert to believe by concluding that such policies are inherently discriminatory and unlawful. The Court recognized that an employment policy that creates different rules or practices for women workers is discriminatory, even if the intent is to achieve some beneficial goal. In other words, the employer's intent is irrelevant to the question of discrimination when a policy openly discriminates on the basis of sex or pregnancy. Even taking the employer's contentions at face value, the Court held that an employer may not pursue a

laudable goal through a discriminatory means. Instead, employers are required to avoid foreseeable harm to the fetus or the worker, independent of the equally important obligation of avoiding discrimination.

Recognizing that the policy caused women workers to choose between having a child and having a job, the Court rejected any moral and ethical concerns as a justification. The Court explained that, "Decisions about the welfare of future children must be left to parents who conceive, bear, support, and raise them. It is no more appropriate for the courts than it is for individual employers to decide whether a woman's reproductive role is more important to herself and her family than her economic role. Congress has left this choice to the woman as hers to make."

The Court acknowledged both the significance of employment to women's well-being and the welfare of their families, and the concern that lead exposure could be equally harmful to males and potentially to their offspring. While the decision relied exclusively on law not science, the Court nonetheless clarified employers' obligations with regard to occupational safety and health.

The Court held, "Title VII plainly forbids illegal sex discrimination as a method of diverting attention from an employer's obligation" -- I'm underscoring -- "<u>to police the workplace.</u>" The plain import of the decision is that employers may not shift the obligation to women workers to ensure a safe workplace by removing themselves from recognized risks, or by any other burden-shifting means.

The Court held that fetal protection policies, like Johnson Controls' policy, could never be justified under Title VII. They concluded that no defense was available; that such policies do not further the kinds of business interests that Title VII recognizes as providing a defense to intentional discrimination, because they are totally divorced from the

employer's legitimate interest in job performance. The nondiscrimination law permits only one defense, the Court acknowledged, and that is the Bona Fide Occupational Qualification defense. Such a defense might apply, for example, to the job of clothing model.

Since there is no dispute in this case that women could make batteries as well as men, the critical element of the defense was missing -- the occupational qualification element. In order to constitute a defense under the statute, the Court concluded, an employer would have to demonstrate that the policy was connected in some way to women's ability to perform the job.

The policy failed to meet Title VII standards in other respects as well. Justice White, concurring, observed that the BFOQ -- or Bona Fide Occupational Qualification defense -- must be "reasonably necessary to the normal operation of the business" to meet the statutory standards. Therefore, the level of protection or the degree of risk avoidance that the employer applies to fetal risk, must be consistent with how the business normally deals with health risks. In other words, an employer is not permitted to use a different, higher standard of protection to avoid risk to fetuses than it normally applies to other health risks incident to its operation. In this case, Johnson Controls permitted its employees and customers to be exposed to some degree of risk from its operations and products, and it protected its own interests presumably by purchasing insurance or by self-insuring. This would establish the normal operation of the business with regard to risk avoidance.

The Court also rejected the argument that additional costs associated with employing women to improve workplace conditions or for other reasons, could justify discrimination. The Court rejected any cost-based defense, holding that employers must, "shoulder any extra cost of employing women

workers." With regard to liability-based concerns, the majority observed -- and this is a quote -- "OSHA established a series of mandatory protections which, taken together, should effectively minimize any risk to the fetus and newborn child. If under general tort principles, Title VII bans sex-specific fetal-protection policies, the employer fully informs the woman of the risk, and the employer has not acted negligently" -- I underscore that phrase -- "the basis for holding an employer liable seems remote at best." It is highly significant that the Court has recognized that any negligence does lead to liability, as well it should.

Consequently, the employer would have to implement nondiscriminatory mechanisms to meet its multiple legal obligations; the obligation imposed by Federal safety and health law to maintain, "safe and healthful working conditions for every working man and woman," and the desire to avoid or minimize the risk of tort liability. The obvious way to achieve these goals, noted the Court, is by observing the requisite duty of care. In other words, by reducing known risks and providing adequate warnings as to foreseeable but irreducible risks. In this fashion, the Court indicated its intent that employers' duties to workers and their future children should be governed by these standards: the obligation to comply with safety and health laws and regulations, the duty not to be negligent, and the duty to warn.

The decision does not, in and of itself, achieve a safe workplace for women or for men, but it was a necessary precursor to the effort to upgrade workplace conditions for both. As long as employers could avoid the necessity to abate reproductive risks in particular, by alleging that the risks were confined to a class that could be excluded, there was little incentive to improve those conditions. It is time, however, for the legal and policy debate to move to the next level, to ensure that the right to equal employment opportunity is not the right to an equally hazardous job.

Fetal protection policies were commonplace in Fortune 500 companies in the petrochemical industry, pharmaceuticals, battery manufacturing, and other major industries, many of which have facilities in the State of New Jersey. Unfortunately, there has been little systematic effort to characterize corporate reactions to the UAW decision -- and I was delighted to hear Dr. Brooks on that subject. Consequently, very little comprehensive information is available detailing corporate response.

Anecdotal reports suggest that some employers have failed to comply with the Supreme Court decision, and have continued to deny women certain employment opportunities, although the discrimination has surely become more subtle. There have been no reports, for example, of women getting sterilized to keep their jobs. Instead, there are indications that some employers try to steer women into certain jobs or provide biased assessments of occupational health risks. One woman was required to provide medical certification that it was safe for her to continue to work. She filed a lawsuit which was settled. That is a New Jersey case.

One practice bears special mention. Some women report being required to provide a waiver of the right to sue in the event of future injury to self or child. There is considerable doubt about the enforceability of such a waiver, if it is extracted as the price of employment. Given its questionable legal status, requiring workers to sign waivers could function to mislead or to intimidate them. If a waiver was obtained in such a fashion and were enforceable, however, the ramifications would be serious indeed. Employees would be sacrificing legal rights as the price of employment -- similar to sacrificing their fertility as the price of employment -- and as a result employers would once again escape liability even for negligent or otherwise wrongful conduct. These consequences, or

potential consequences, are sufficiently serious that evaluation of the prevalence of waiver requirements is, in my opinion, a high priority.

Employers who previously enforced fetal protection as a method of reducing work-related risk to reproduction have essentially admitted that the work environment was hazardous for pregnant women. At one time, they were prepared to document that view in order to defend against charges of discrimination. Having made such an admission, it is essential to know what they have done since to make the workplace safe enough for fertile and pregnant women who are entitled to employment. If the substantive risks were serious enough to cause employers to ban women from work, it is incumbent on them now to demonstrate that the risks have been abated, and it is incumbent on the State to ensure that as well.

The State of New Jersey could perform an invaluable service, both for the workers of this State and others, by surveying industry policies and practices in Fortune 500 companies that had previously imposed fetal protection as a method of health protection. The purpose is to inquire about prior occupational reproductive health practices and the changes, if any, that have been instituted in response to the Supreme Court decision. Some employers have undoubtedly modified their policies to address comprehensively the needs of workers, including those who are pregnant, and these employers could serve as models to demonstrate that this can be effectively accomplished and how it can be done. Other employers are likely to be in violation of either equal employment laws or occupational safety and health laws. Documenting the extent and nature of noncompliance is critical to any effort to craft a regulatory or legislative response. A legislative response would be particularly appropriate if the survey discloses widespread resort to legal waivers as a response to reproductive risk.

In conclusion, women need to work and they're entitled to work. If doing so extracts an unacceptably high cost in terms of health effects, the burden is felt by the entire community in the incidence of work-related illness, disability, and injury; in the incidence of birth defects; and in the overall decline in well-being. The State has much to gain by enforcing the twin obligations not to discriminate and to maintain a safe and healthful work environment. Enforcement of these obligations across-the-board diminishes the likelihood that the responsible, conscientious employer will suffer a competitive disadvantage from meeting its obligations fully. The true cost of the product or service will be reflected only when any expense associated with nondiscrimination and safety and health are incorporated, and this, in turn, will permit more rational consumer choices.

I urge you to undertake this important work, and offer whatever assistance I can provide to advance your efforts. Thank you.

MS. JACOBUS: Thank you very much, Ms. Bertin.

Are there any questions? (no response)

I did want to let you know that, largely through the efforts of this Commission, there is such a study on a small scale beginning; working with Dr. Howard Kipen--

MS. BERTIN: Oh, I know him. Yes, great.

MS. JACOBUS: --at the Rutgers Environmental and Occupational Science Center, to survey workplace policies in occupational safety reproductive hazards in New Jersey in the wake of the Johnson Controls case. So keep in touch with us on that and we will certainly keep you informed.

I have a question: What do you think, from a legal standpoint -- perhaps a tort standpoint -- might make it easier for individuals to sue companies, or to find some legal redress if it's not through suit, for negligence in the workplace safety, given that OSHA does not seem to have a very large budget for enforcing existing laws?

MS. BERTIN: Are you talking about injury to workers themselves?

MS. JACOBUS: Or to their children.

MS. BERTIN: Well, you're going to have to reform the Workers' Comp system if you want to create a course of action for workers themselves or, of course, the State courts or the State Legislature can expand on the grounds for suit against employers for intentional acts by defining those to include: gross negligence, willful misconduct, or something of that sort. That has been done in some jurisdictions. Workers themselves are, by and large, as you know, bound by the exclusive remedy through the Workers' Compensation system. Suits by the children of male and female workers alleging that the parents' exposure caused an injury to the child are theoretically more feasible, but as a practical matter extraordinarily difficult to prove simply because causation is very difficult in such cases.

You may be interested to know that of the cases that are reported in the legal reporting system, there are more cases brought by the children of males than the children of females alleging preconception injury to parents that caused a genetic injury that was passed on to the child. Very few of these cases win; in fact, I don't think there is a winner on the books. But if companies are concerned simply about having to defend, the prospect of having to defend exists with regard to both male and female.

The issue of recovery for any kind of reproductive injury, regardless of whether it is workplace induced or otherwise -- especially an injury from exposure to toxic chemicals -- is a very difficult one, and many of those cases face similar problems in terms of proof of causation. In the absence of what they call a signature effect, it is extremely difficult to obtain a recovery.

So, of course, if one wanted to look at compensation for reproductive injury one might want to look at more novel approaches having to do with, perhaps, establishing liability on the basis of negligent conduct that could have caused reproductive risk without a necessity to prove causation precisely, or some other form of no-fault -- or a form of no-fault, not some other -- that would not be a no-fault solution.

I personally endorse a legal analysis that in these kinds of situations where causation cannot be demonstrated because of the lack of scientific data to do it -- a legal analysis that examines negligent conduct and then permits the defendant, if you will, to rebut the inference of liability that would create.

For the lawyers in the group, what I would propose is shifting the burden of proof. If you can establish a biological, plausible connection between the injury and the effect, and if you can establish negligent conduct that could have led to the event, then the burden of proof would shift to the defendant to prove that its conduct did not cause the injury. Because the current allocation of burdens of proof is such that plaintiffs simply can't win if the causation issues are unclear -- scientifically unclear -- even if they can demonstrate negligence.

In my view, this is why you see juries going off in the direction the courts don't want them to go off in, because when they observe negligence they find for the plaintiffs, but those cases are often reversed on appeal.

MS. JACOBUS: Do you see a movement in that direction from the court system in the land, that they accept that situation more?

MS. BERTIN: I don't know that. A movement is, perhaps, too strong. There is no groundswell. I think there is a growing recognition that toxic tort cases across-the-board

and other more complicated personal injury cases -- that are not slip and fall or direct cause and effect kinds of cases -- require some modification in analysis. We have seen modification in analysis, for example, in the DES cases; with the enterprise liability theory or some variation on the enterprise liability theory.

I think that the recent decision in the Supreme Court in the Daubert v. Merrell Dow -- the Bendectin case -- has alerted many more members of the Bar and members of the judiciary to the fact that we are really stretching the tort law system out of shape in some of these cases that involve very complex issues of causation; where the science has not caught up with the need to provide remedies to injured individuals, and where there is an enormous amount of tension because you have, on one hand, a blameless person who has been injured, and you have, on the other hand, a defendant who may not have violated any current legal norms, but nonetheless there is sympathy on both sides. So I think that as a result of the Daubert litigation and decision there has been a great deal of energy gone into trying to craft some new responses to these problems. I am hopeful that that will actually evolve into some movement toward tort reform in this area, which I think is badly needed.

MS. JACOBUS: Thank you very much.

Dr. Paulette Stanford, Associate Director of Adolescent Medicine at New Jersey Medical School, who has prepared her testimony in conjuction with Robert Johnson.

MS. JACOBUS: I see that Senator Wynona Lipman has arrived, so perhaps we could wait a few moments. Also Phoebe Seham, another one of our Commissioners.

By the way, there is some lunch at the back of the room for people who would like to have some. It's all for you, so please feel free to go and get some.

SENATOR WYNONA M. LIPMAN (Chair): Hello. Please proceed.

P A U L E T T E S T A N F O R D, M.D.: Good morning, or should I say, good afternoon? My name is Dr. Stanford. As Associate Director of the Division of Adolescent and Young Adult Medicine at the University of Medicine and Dentistry in Newark, and at the Children's Hospital of New Jersey, and also as the Medical Director of the START Program -- a program for HIV positive adolescents and teens, and teenagers with AIDS -- I would like to strongly encourage the State of New Jersey to enact specific legislation to permit adolescents to receive HIV testing without parental consent.

The growing tragedy of HIV infection in New Jersey, as well as in the nation, and our as yet ineffective attempts to arrest are apparent to all. The Human Immunodeficiency Virus may be the major threat to the well-being of the adolescent population in the next century.

Acquired Immunodeficiency Syndrome is rapidly becoming one of the leading causes of death among adolescents. It is already the sixth leading cause of death among 15- to 24-year-olds in the United States. As of June 1993, 3000 cases of AIDS had been reported to the Centers for Disease Control in adolescents aged 13 to 21. Unfortunately, the number of adolescents who are HIV positive and do not have AIDS is not known. Seroprevalence can only be estimated on the basis of a variety of studies on various subgroups. As an example, the rate amongst adolescent entrants into the Job Corps is about 4 HIV positive teenagers per 1000, but there is a higher seroprevalance among homeless and runaway youths. The estimate amongst this group is 6 percent to 16 percent of runaway teenagers are HIV positive.

Although adolescents represent only 1 percent to 2 percent of the total cases of AIDS throughout the United States and New Jersey, the number of adolescents diagnosed with AIDS

has doubled every 14 months since 1988. The official figures reported by the CDC include only those teenagers who display specific criteria for AIDS and do not include teenagers who are positive and don't meet the criteria. These numbers also don't include teenagers who are positive and ignorant of their serostatus. Because the incubation period from time of exposure until clinical manifestation is about 8 to 10 years, many of the HIV young adults probably were exposed to the virus during their adolescent years. Of the over 300,000 cases of AIDS in the United States, and the 19,000 cases in New Jersey, about 20 percent occur in patients between the ages of 20 and 29, which means that a fifth of all the cases of AIDS may have had their exposure during the adolescent period.

Adolescents are particularly high risk for HIV infection given that the majority of today's teenagers are engaging in high risk behaviors such as unprotected sexual activities and drug and alcohol use and abuse. Behaviors that put teens at risk are as follows:

The most common risk factor associated with HIV transmission among teenagers is unprotected sexual intercourse. For teenage girls between the ages of 15 and 19 in the United States, the average age of sexual intercourse is 16. In many urban areas, the average age may be as young as 13, and many of our teenagers admit to first exposure at age 11 or 12. By the age of 20, 80 percent of males and 70 percent of females have had a least one episode of sexual exposure, and we're familiar with the fact that consistent condom use is not practiced amongst this age group.

Other sexual practices that put teens at high risk, such as oral and anal intercourse, are practiced with regularity in this population; 10 percent to 20 percent of both male and female teens practice anal intercourse, and oral intercourse may be practiced in certain groups more frequently than vaginal intercourse.

Having multiple partners and older partners places a teen at increased risk; 40 percent of males and 20 percent of females between the ages of 18 and 24 have three or more partners in a given year. Male partners of homosexual male teens tend to be seven years older on average, and male partners of teenage girls tend to be two to three years older on average.

Sexual abuse poses another risk for HIV transmission; 3 percent to 10 percent of all teenagers have experienced some form of sexual abuse, many never reporting the incident. Over 50 percent of all rape victims are adolescent women. It is not known how many of these sexual assaults have resulted in the transmission of this deadly virus.

Pregnancy rates are obvious indicators of noncondom use and HIV exposure. It is estimated that one in every ten sexually active teenage girls becomes pregnant. There are nationally one million pregnancies a year in the United States among teenage girls. In 1990, New Jersey averaged 41 pregnancies per 1000 teens between the ages of 15 and 19, and in the county with the highest rate, there were 89 pregnancies per 1000 teens. If the above estimate is to be believed, then in that particular county 890 girls out of 1000 are sexually active.

Other health risk behaviors that help adolescents acquire this virus are sexually transmitted diseases. We know that sexually transmitted diseases have been found to be highly correlated with the prediction of HIV infection. According to the United States Centers for Disease Control, adolescents between the ages of 15 through 19 have the highest rates of gonnorhea, syphilis, chlamydia, and rates of hospitalization for pelvic inflammatory disease.

Drug use behaviors amongst teens is another important risk factor. The prevalence of needle sharing, injection, and intravenous drug use in the United States among teenagers is

about 1 percent to 2 percent, but 13 percent of all teens with AIDS have become positive because of needle use activities. We are all familiar with the high prevalence of alcohol and drug use and abuse among adolescents; 90 percent of all high school seniors have used alcohol and about 20 percent of them have used cocaine. The use of drugs puts teens at increased risk for the HIV virus because they are disinhibitors and promote risky sexual behaviors. As an example, crack use has been found to be associated with the high risk behaviors of trading sex for crack or sex for money to purchase crack.

There are also numerous barriers that adolescents face within the health care system that interfere with general health care maintenance and the ability to access HIV testing. The most important one is the legal impediment.

Currently, teens in New Jersey are allowed to consent to the diagnosis and treatment of STDs, pregnancy and related care, and substance abuse treatment. The extension of these rights was based upon the legislative concerns that adolescents might delay or avoid treatment for those important morbidities because of fear of parental retribution.

Nationally, many states, realizing the enormity of this epidemic, have enacted laws that give minors the right for HIV testing without parental consent. There are 10 states that have specific laws that permit minors to consent to HIV testing. There are three states that have specific laws that allow minors to consent to both HIV testing and AIDS treatment. Because many states have classified HIV as an STD, communicable, or contagious disease -- and minors can consent to treatment of these diseases -- there is a grand total of 27 states that allow adolescents to consent to HIV testing without parental consent, and in 22 states minors can give consent for HIV care.

Nationally, New Jersey has the third highest seroprevalence for HIV, but has enacted no legislation to

provide for the population whose numbers are increasing at an alarming rate; 17 percent of all AIDS cases in New Jersey occur in young adults between the ages of 20 and 29. As mentioned previously, given the long latency of this virus, it is likely that many of these young adults were infected as teenagers.

Confidentiality issues are also very important. Confidentiality is most important in encouraging an adolescent to seek out health care related to sexual or drug use behaviors. Many health plans require that the beneficiaries identify themselves with a card or adult signature, and often a bill is sent home to the parent with a list of the tests performed. In my experience, this barrier has often led teenagers to avoid bringing pressing issues to medical attention, such as symptoms of STD or possible pregnancy.

Financial access: Adolescents face the same financial access issues that plague all Americans, and many in my community have no coverage for HIV screening. Many of the free State testing services are not sensitive to adolescent issues, do not counsel in a "developmentally friendly" manner, and do not understand that adolescents perceive this epidemic differently and process information about AIDS differently than adults do. Approaching teenagers with risk reduction and educational initiatives must be unique and different from the initiatives used for adults.

There is also a failure of comprehensiveness. The failure of the health care system to provide comprehensiveness also creates a barrier to the adolescent. The teen is a whole person who does not experience his or her problems in isolation. The high risk young man who is seen in an urban emergency room for trauma, usually is not given a follow-up appointment for comprehensive care; a sexual history is never asked; and the availability to ask about health care concerns in that setting is nonexistent. That may be that adolescent's only health care contact, and he leaves without any

intervention concerning his multiple sexual contacts, his STD symptomatology, his history of sexual abuse as a child, or his drug use behaviors.

There are a variety of other barriers such as geographic, attitudinal, and communication gaps that prevent teens from receiving comprehensive health care and HIV testing.

One must remember that adolescents' perceptions are different from adults and this is a dynamic period of psychosocial change. Adolescents are often omnipotent, concrete thinkers who are greatly influenced by peer pressure and are often in a state of denial. All of our risk reduction educational efforts may be in vain as we are challenged by the overwhelming and abundant sexual messages in television, print, and movie media. What messages do we give the typical American teenager who averages 24 hours of TV a week, and according to the Nielsen data, sees an average of 14,000 instances of sexual material a year? Afternoon soaps, which happen to be a favorite of teens, contain the highest sexual content, with 35 sexual instances per hour. We are all aware that explicitness has replaced suggestiveness. All of these messages versus a few hours of State-mandated, family life education, that is, for those teenagers who attend school.

We would like to see enacted specific legislation to allow teens to receive HIV testing without parental consent.

Thank you very much.

MS. JACOBUS: Thank you, Dr. Stanford.

Do any of the Commissioners have specific questions?

MS. SEHAM: Would you add to allow teenagers to receive HIV treatment also without parental consent?

DR. STANFORD: Yes, I would allow that also. Definitely.

SENATOR LIPMAN: You were saying that teenagers do not go to testing centers because they are not situated for teenagers?

DR. STANFORD: Well, they're not developmentally sensitive. Very frequently-- If they are centers where they do pre and posttest counseling, very often they don't see to specific adolescent needs and requirements. Very often, developmentally and intellectually adolescents don't understand a lot of the pre and posttest counseling. In our particular program, we try to do pre and posttest counseling and educational efforts in sort of, you could say, an intellectual/developmentally sensitive manner. I think teenagers take to that a little bit easier than the adult approaches.

SENATOR LIPMAN: Is this at UMDNJ?

DR. STANFORD: It's at the University of Medicine and Dentistry, and at Children's Hospital of New Jersey.

SENATOR LIPMAN: Have you ever visited one of the school clinics that have now opened in Newark?

DR. STANFORD: Yes, I have.

SENATOR LIPMAN: You have?

DR. STANFORD: Yes, I have.

SENATOR LIPMAN: There is no testing, education, or training--

DR. STANFORD: There is no testing. There may be some education, but there is no testing done in the school itself. No, none at all.

SENATOR LIPMAN: Thank you.

MS. GRIFFIN: If a teenager went in for an anonymous test, would they be denied a test?

DR. STANFORD: Well, no, they wouldn't be denied a test.

MS. GRIFFIN: I know the counseling isn't good, but just in terms of the absolute medical testing.

DR. STANFORD: Yes, they would be allowed a test, but the problem with anonymous testing is that, again, adolescents don't clearly understand all the ramifications of being

positive. What happens is, there is no support with these services. They're told they are positive and usually that's it. The patient goes on to maybe become very depressed about it. We had one or two patients who were suicidal who had gone to anonymous testing sites. There was no follow-up. There was no support. There was no program. We have a program for HIV positive teenagers and we also have a program for teenagers who have AIDS -- clinical AIDS. We're better able to support -- and I am sure there are other programs like us throughout the State, I think there were one or two other ones -- patients after they find out the news that they are HIV positive. But we don't really believe in anonymous testing for teenagers. We do believe in confidential testing for teenagers, with support, because I think it's important that they understand what it means to be HIV positive.

MS. GRIFFIN: Yes, I think there is a problem there because I know that the HIV community is very concerned that anonymous testing be available because of the discrimination that people experience, and they don't quite trust the system to confidence about their status. That is not a concern for you? You trust the system more than some people?

DR. STANFORD: Well, I trust the system if it's a confidential testing site and if there is confidentiality that is assured, and usually there is for the most part. I also think it would probably be better for adolescents to go to specific sites where there is adolescent sensitivity. I think there are a number of centers -- at least three that I can think of -- in this State where there is adolescent sensitivity. But, again, I think that adolescents need support when they find out that they are HIV positive. They also need to be followed. We found out, from creating a liaison with another program in Newark that has very high risk teenagers, that many of them found out that they were HIV positive and then nothing else happened. They weren't followed. They're

not in any kind of medical care right now. They're in Newark, still having sexual -- regular sexual intercourse with numerous people, and not using any safe sex practices. So we think it is important that in addition to confidential centers, these centers are also supportive centers.

MS. JACOBUS: Dr. Stanford, given the fact that most adolescents do not have the motivation, ready transportation, the money, or the information about these three centers in the State to access this kind of very good care that you're providing, how could those three centers better network with all of the high schools in the State to develop a whole network, so that students from any high school in the State could have better access and more assured access to one of these three programs?

DR. STANFORD: Well, what we're doing now in the Essex County area is to-- We have an outreach program where we give information. We not only do some educational initiatives, but we give information about our program. We have a hot line number -- a 1-800 hot line number -- teenagers are allowed to call. If we can arrange it -- sometimes it's difficult because of insurance and transportation right now -- we usually try to arrange for them to come to our center and get tested with pre and posttest counseling and follow-up. I'm sure that statewide that can be done. I think that it is fairly easy to do outreach and to have a center that adolescents can access. We arrange transportation. We are grant-funded. We have a Ryan White grant. We do have a transportation budget. We can bring kids to our center for testing, evaluation, and educational information. That can be done statewide. I don't think it would cost that much money.

MS. JACOBUS: Thank you. Do you think that Ryan White funds will remain a source of money to expand these grant-funded programs, or do you think that source is drying up?

DR. STANFORD: I think that source will eventually dry up, I really do. I think we'll have to take some State initiatives.

MS. JACOBUS: Thank you.

Are there any further questions of Dr. Stanford? (no response)

Thank you very much.

DR. STANFORD: Thank you.

SENATOR LIPMAN: Dr. David Beck. He is President of the Coriell Institute.

D A V I D P. B E C K, M.D.: Senator Lipman, members and staff of the Commission, I am David Beck, President of the Coriell Institute for Medical Research in Camden, New Jersey. I am pleased to have the opportunity to tell you about a very important need in New Jersey and a project that is being designed to meet that need.

The New Jersey State Cancer Registry tells us that New Jersey ranks fourth in the nation in the incidence of breast cancer and second in the nation -- after only the District of Columbia -- in mortality from breast cancer. We could speculate for a long time about the reason for this sad state of affairs in New Jersey, but the simple fact is that these numbers translate into 42,000 newly diagnosed cases of breast cancer per year. This is an enormous burden for the women of New Jersey to carry, and great efforts are being made to improve the health care network to care for these patients. That, however, is not the long-term solution.

It is clearly recognized that we need to know more about the origins of breast cancer, its cell biology, its molecular genetics, and how this information can be applied to treat and prevent the disease. We must have more research. Very exciting and substantial progress has been made in understanding cancer in the last several years. We now understand that cancer is, in fact, a genetic disease, that

it's caused by a derangement of our genes. We know that it takes several incidents of genetic damage to cause cancer, and a number of cancer genes have now been isolated and studied. Indeed, the first gene associated with breast cancer was isolated by Dr. Mary Claire King in California.

This is a great beginning, but there is a long way to go before the problem is solved. A major impediment is the availability of breast cancer tissues and cell cultures from breast cancer patients and their families to be used in this kind of research. In addition to its great expertise in cancer research, the Coriell Institute -- which was established in 1953 -- has a long history of collecting such materials from patients with a wide variety of diseases. The usefulness of this kind of tissue has been demonstrated many times over, over and over again. Examples of the success include studies with diseases such as: a patient with Huntington's Disease, cystic fibrosis, hypercholesterolemia, and on and on. To study breast cancer, Dr. King had to establish cell cultures from breast cancer tissue. But she simply couldn't establish enough cultures from enough tissues to satisfy the whole research field, and she certainly couldn't spend time away from her research efforts distributing those cultures to research labs in New Jersey. The Coriell Institute, in fact, has a long track record of doing exactly that.

But we need something else in addition to just access to the tissue, and that is access to the patients and a method for getting those tissues from them. Our colleague, Dr. Jack Goldberg, head of The Cancer Center of Southern New Jersey at Cooper Hospital in Camden, and American Cancer Society Professor of Clinical Oncology, has put together a clinical network that will provide access to a large number of patients. This network reaches throughout the State of New Jersey including, at this point: hospitals in Princeton, Newark, Monmouth, Atlantic City; an oncology practice in

Vineland; and several hospitals in and around Camden, including Cooper, Our Lady of Lourdes, West Jersey, etc. This network will allow us to collect large amounts of tissue, and especially important -- as it has been a major failing in much of the research done thus far -- allow us to collect tissue from an ethnically diverse population. In particular, black and Hispanic women have not been adequately represented in the studies done so far, and that imbalance must be redressed immediately.

In this collaboration between Cooper Hospital and the Coriell Institute, patients will be identified, their tissue and blood collected, and these biomaterials stored at the Coriell Institute. In addition, histories will be collected to build a valuable family database. We expect that the New Jersey State Cancer Registry will be involved in this project. Families are very useful in tracking a gene that has been associated with a certain disease through several generations. The New Jersey Cancer Institute will also be involved both in helping with family and tissue collections, and in being a major user of the tissues collected for its own research programs.

In addition to providing a much needed and extremely valuable resource for breast cancer research which will facilitate progress in this field, establishing such a collection will also likely be beneficial to other cancer research. This is because it has now been demonstrated that families in which breast cancer appears also have, unfortunately, an increased incidence of colon, ovarian, and prostate cancers. Thus, we will seek blood samples from collateral family members and be well on the way to building a resource that is valuable for other diseases as well.

There is a strong scientific rationale for this project, and the proposal has been formalized in a request for support for this work from the New Jersey Cancer Commission, as

well as from other resources. But we need public support and enthusiasm for such a project to work. We need patients with breast cancer to contact Dr. Goldberg at Cooper Hospital and to involve their families in this project, and we need everyone who learns about the project to encourage their friends and neighbors to help us achieve the goals of this work. I also hope that another outcome of this Commission's deliberations will be -- as hard choices are made in the budget cycles ahead -- to make the funding pleas necessary to assure that research in underfunded areas of women's health, especially in this case breast cancer, are properly encouraged.

Thank you for the opportunity to tell you about this project. I'd be glad to amplify on any parts which I have treated too briefly.

MS. ATKINS: I have a question: Dr. Beck, could you speak to the issue of the disparity in tissue samples from black and Hispanic women?

DR. BECK: Yes. Many of the studies that have been done have focused on the population which is easily available. In the major medical centers those tend to be white, middle-class women. Many of the studies that have been done -- this is probably all too familiar to you -- in a variety of areas, in heart disease, for example, have treated white men. A longitudinal study that studied aging at the National Institute on Aging, has studied white men. Unfortunately, far too few of these kinds of studies have incorporated a broad spectrum of the patients affected.

The exciting thing about the project that we're putting together, and the network that Dr. Goldberg has assembled, is that it reaches into many of the medical centers serving the minority populations and, indeed, underserved populations, so these people will be seen and their tissues will be incorporated (short passage missing due to malfunction of machine) scientifically for this to occur. Intuitively,

I'm sure it's quite obvious that studying only one kind of tissue doesn't tell you about the great cross section of the occurrence of a disease, and, in fact, scientifically one needs to have comparisons between kinds of tissues and different occurrences of a disease to learn as much as one can about that disease. So this is a very important thing to do for a lot of reasons.

MS. JACOBUS: Dr. Beck, to your knowledge, is there any way that the Medicaid or Medicare funding system might be used to encourage the gathering of these scientific materials? For instance, might there be Medicaid or Medicare reimbursement to doctors and hospitals who gather these samples for you and send them to you?

DR. BECK: That's a hard question. I'm not sure I can answer it. From the point of view of the research project, we will be approaching people who are already in the system or being encouraged to enter the system through the kind of network that Dr. Goldberg has constructed. The funding that we need really is to support the actual banking of the tissue, the distribution of the tissue, and, indeed, to actually have someone standing outside of the operating room, if you will, with a vat of liquid nitrogen -- which is how we preserve this tissue -- waiting for the tissue to be released to us. I'm not sure I can see how to use -- although I'm not an expert in these other mechanisms -- how they might be used to encourage this. It may be possible, and perhaps clever people like you, who have the broader perspective, can figure out a way to do that, and if so, I hope you will.

MS. GRIFFIN: Yes, I just had a question: Your database will include a lot of information, I take it, about each patient who submits samples?

DR. BECK: Yes, and family.

MS. GRIFFIN: Will that include environmental, occupational, and lifestyle, such as smoking, those kinds of risks that we know are out there, or will that be--

DR. BECK: That's an excellent question, and the answer is, without a doubt, yes. What has happened actually-- I was interested to hear one of the earlier bits of testimony about knowing where the approximate cause of a particular disease was, whether in some environmental/occupational exposure. Increasingly, the ability to distinguish the sources and the causes of disease-- As our knowledge of molecular genetics becomes more sophisticated, this knowledge will allow us to actually distinguish what the cause of a disease was. It is now possible, in fact, with one particular type of colon cancer that is caused by mutation in a gene called P-53 -- it's been very much in the news-- One can actually distinguish the kind of mutations that occur in P-53 and distinguish exactly what the source of that mutation was; whether it was from eating contaminated peanuts, smoking, or some other kind of occupational exposure. So that will increasingly be the case and we will need to have a very, very good, very sophisticated database for this particular kind of information to enable us to extrapolate in the studies of the disease itself.

MS. GRIFFIN: Thank you. With respect to the Cancer Registry in the State, will your database feed into that or are these separate efforts?

DR. BECK: We haven't worked out all the details of that. I expect that they will be very closely linked. The Cancer Registry will be helpful to us in identifying families. I can't emphasize strongly enough the importance of having family information. The way a gene responsible for a disease is found is by tracking that disease through a family -- through multiple generations of a family -- and trying to find what genetic characteristics follow with that disease; then extrapolate that to the actual molecular genetic foundation of the disease.

MS. GRIFFIN: Is that Registry in financial trouble do you know? I know that there is a bill that has been introduced by Assemblyman Warsh to add $100,000 to its funding. I just wondered if you had any inklings of debts?

DR. BECK: I can't speak entirely to the situation of the finances of the Cancer Registry, but I can tell you that most of the research mechanisms -- research organizations -- are having extreme difficulties these days because of cutbacks in Federal support. We shouldn't always look to the State to pick up that support, but where there are very important State interests involved, such as in the situation I described, the statistics on breast cancer in New Jersey, I would say that we need to do everything we can to defend ourselves. That is basically what it boils down to.

MS. JACOBUS: To my knowledge, the Cancer Registry hasn't been updated since 1988 and, in fact, the State of New Jersey has lost Federal funding in certain great opportunities because, we have been told, our Registry is not up-to-date.

SENATOR LIPMAN: Thank you very much, Dr. Beck.

Is Anita Curran present? (no response) Ann Fade? (no response)

Well, in that case, I think we'll just have a small break for lunch right in here for a few minutes.

(RECESS)

AFTER RECESS:

SENATOR LIPMAN: Are we ready to begin? We'd like to get started again.

Dr. Anita Curran, Assistant Dean of the Robert Wood Johnson Medical School.

Yes, please. Thank you.

L O I S A. G R A U, R.N., Ph.D.: Unfortunately, I'm not Dr. Anita Curran.

SENATOR LIPMAN: We don't allow that. (laughter)

DR. GRAU: I'm Dr. Lois Grau from the Robert Wood Johnson Medical School, here to read Anita's testimony. Unfortunately she had a conflict that she was not able to resolve.

SENATOR LIPMAN: All right.

DR. GRAU: I'll read her comments verbatim.

SENATOR LIPMAN: Could we have a copy, please?

DR. GRAU: Yes, I've got about 10 extra copies.

"Honorable ladies and gentlemen of the Committee, thank you for the opportunity to speak before you today. My name is Anita Curran, M.D., M.P.H.. I am Associate Dean for Community Health of the UMDNJ-Robert Wood Johnson Medical School. I am also the Executive Director of the Eric B. Chandler Health Center, a federally qualified, community health center operated by the Robert Wood Johnson Medical School. Prior to my present position, I was Commissioner of Health for Westchester County, New York, for approximately 11 years, and I currently Chair the Residency Review Committee's Council for the Accreditation Council on Graduate Medical Education.

"These past and present positions have given me the opportunity to observe and analyze firsthand, the broad health and social needs of diverse communities, both locally and nationally. Today I wish to speak about those, particularly as they relate to women, and the graduate medical education and research efforts required to address those needs.

"While many here today will be talking about women's health in general, I will focus my remarks to the issues concerning the population with which I am currently working -- the low-income and minority women of our inner cities. Despite an overall improvement in most health status indicators throughout the country and State, this improvement has not reached the poor and the minorities in our inner cities.

"For example, preliminary statistics for 1991 show that while 81 percent of all pregnant women in New Jersey began prenatal care in the first trimester, in the City of New Brunswick, this figure was 70 percent; in Perth Amboy it was 62 percent; in Trenton it was 57 percent; and in Atlantic City it was only 45 percent. Our rural areas show similar statistics. For example, for all of Cumberland County, only 63 percent of pregnant women received prenatal care in the first trimester, and in Salem County it was as low as 46 percent.

"Using 1990 census data, New Jersey ranked among the lowest 10 states in births to teenagers, with adolescent fertility rates of 1 per 1000 for those under 14, and 40 per 1000 for women between the ages of 15-19. But, the rate was as high as 11 per 1000 for 10 to 14 year olds, and 180 per 1000 for those 15 to 19 in Atlantic City, and in many of our other major cities the rates were only slightly lower. Of particular concern is that in 1990, approximately 360,000 of the 500,000 births to teenagers in New Jersey under the age of 20, 68 percent were to unmarried mothers.

"Many, if not most, of these young mothers live in poverty. Many have dropped out of school, have few job skills, and little opportunity to improve their future quality of life. Poverty, adolescent pregnancy, and lack of prenatal care contribute directly to low birth weight and ultimately to the unacceptably high infant mortality rate seen in many of our cities. While this is a society issue, it is also clearly a women's issue.

"On the national level, statistics recently released by the Centers for Disease Control and Prevention highlight another aspect of the problem; the disproportionately severe impact relatively common conditions have on the death rates of black and minority women. The age-adjusted death rate from diabetes nationally for white women is 13 per 100,000; for black women it is 33, almost 3 times higher; and for Hispanic

women it is 24, just about double. The cervical cancer death rates are 2.7 for whites, 7.6 for blacks, and 4.7 for Hispanics. The death rates from all infections show the same bias: 37.7 for white women; 56.3 for black women; and 36.4 for Hispanics. The AIDS death rate is 10 times higher in black women, and 4 times higher in Hispanic women, than it is in white women. Even excluding AIDS and pneumonia, black female, age-adjusted death rates from infections are 2 times higher than for white females.

"Obviously there is no one factor that is responsible for these negative health status indicators, but major causative variables are:

1) Reduced access to health care, and late entry into care.

2) Lack of information and health education on the part of the patient.

3) Misunderstanding of the impact made by psychosocial, cultural, economic, and educational variables on the outcomes of medical care on the part of the providers.

"Access does not just mean having an HMO on the corner, or even mandating that all HMOs enroll their share of poor and underserved populations. It means health care that is acceptable and affordable with adequate transportation, culturally sensitive health care providers, very low or no copay and deductibles. It means the presence of knowledgeable outreach workers and social workers who reach out to these women and expedite their entrance into care. It means comprehensive -- including preventive -- coordinated and continuous care, not just episodic acute and urgent care. It means managed care, not just managed cost. Health education and health information sharing must be an integral part of each patient visit.

"National health care reform is on the horizon, but implementation will be a time-consuming process. What can we in New Jersey do in the meantime? From my point of view, there are at least two areas that I believe can be addressed immediately:

1) The restructuring of graduate medical education and how it is funded.

2) The development of a strong program in health services and outcomes research.

"Since the early 1900s, a system of health care delivery and medical education has evolved in the United States which has largely been hospital-based. It began in the last quarter of the 19th century with the founding of the Johns Hopkins University. This institution brought the medical student to the bedside.

"It became institutionalized at the end of the Second World War when it was decided that the university-affiliated hospital represented the most favorable environment for biomedical research. This decision had the effect of solidifying the hospital as the workshop for the academic physician. He was able to practice medicine, conduct research, and educate the students all under one roof.

"The growth and use of the hospital has been paralleled by the increasing dependency of medical education upon the use of hospitalized patients. Medical centers emerged as the proprietors of ultra-sophisticated medical services and, in turn, they became the most desirable places in which to receive a medical education. Subsequently, as health insurance, with its inpatient orientation, became more available, it was quite easy to attach the education cost of hospital-based training programs to the overall cost of doing business.

"Throughout the 20th century, medical students and residents have learned about the natural history and physiologic manifestations of disease, diagnostic and

therapeutic rationales, and developed their "bedside manner" through interactions with patients in hospital settings. With increasing technology, the biomedical model became more and more entrenched as the methodology for both delivery of health care services and the education of the next generation of physicians and health care providers. This approach literally separates the patient from the disease, and diseases are viewed almost in isolation from their patient victims. But as George Engel states, "The crippling flaw of the model is that it does not include the patient and his attributes as a person and as a human being." The biomedical model can make provisions neither for the person as a whole nor for data of a psychological or social nature.

"Now, several events force us to rethink how we deliver care and train physicians. Since the mid-1960s, health care costs have been skyrocketing. Subsequently, cost containment for medical expenditures began to drive policy, and the management of health care costs has become a major goal of the 1990s. Medical centers have been, and will be, finding themselves under increasing pressure to conserve resources, reduce costs, and shift activity to less expensive alternative settings. As a result there is an increasing trend toward the delivery of care in an out-of-hospital, ambulatory setting.

"At the same time, new medical technologies have caused inpatient lengths of stay to shorten, comprehensive evaluations and diagnostic workups to be done on an outpatient basis, and measures of severity of illness and intensity of services required by hospitalized patients to increase. The modern teaching hospital has become a large intensive care unit where medical students and residents have access to patients who represent only a small, although very ill, portion of the total spectrum of medical practice.

"Thus, medical students and residents are often unaware of the impact made by psychosocial, cultural, economic, and educational variables on the outcomes of medical care. As a

result, many medical schools and postgraduate training programs are producing very talented, technically competent, highly trained physicians with little understanding of, or sensitivity to the demands of the day-to-day environment in which their patients live. This is particularly problematic for the elderly, the chronically ill, the disabled, the economically and educationally disadvantaged, ethnic and cultural minority groups, and for other special needs populations. Consequently, the suitability of using inpatient settings -- which tend to reduce patients to one common denominator -- for the preponderance of students' education, has been questioned.

"Training in an ambulatory setting has become essential not only because it provides the opportunity for students to perform high quality, cost-effective medical evaluations, follow the course of a disease, and evaluate different therapeutic interventions, but also because it requires them to confront the realities of the impact of the disease upon the patients and their families. The goal is to broaden the focus of health care from an emphasis on the individual and his or her disease, to a wider social and population perspective.

"However, to accomplish this there must be appropriate funding for graduate medical education not tied to inpatient revenues. Today, in New Jersey, there are no dedicated funds for graduate medical education. This makes it very difficult to modify or to give added weight to the educational requirements of the training programs as opposed to the hands-on service delivery requirements of the hospitals.

"The training of residents relies primarily on learning acquired through the process of providing patient care under supervision. Educational quality and patient care quality are interdependent and must be pursued in such a way that they enhance rather than interfere with each other. Hospitals play, and will continue to play, a critical role in

this process, but a proper balance must be maintained so that a program of graduate medical education does not rely on residents to meet patient care needs at the expense of educational objectives.

"Nationally, the Council on Graduate Medical Education -- which was established to advise Congress, the Secretary of the Department of Health and Human Services, the Physician Payment Review Commission, as well as foundations, advisory bodies, and other professional and academic organizations -- has suggested strategies by which payments for the direct costs of graduate medical education can be made to other entities in addition to teaching hospitals such as, medical schools, medical school/hospital consortia, and the residency programs themselves in order to encourage training in sites outside the teaching hospital. The creation of additional ambulatory care training sites that are culturally sensitive, consider the demographics of the community, and are affordable will increase access. The goal is to develop a broad construct of health that emphasizes social and personal resources, as well as physical capacity through an integration of population and clinical perspectives into education, research, and service programs.

"The second area that can be addressed immediately is the need for a strong State-sponsored program in health services research. By health services research, I mean outcomes research, not health policy research. There are a number of institutions in New Jersey and elsewhere that are already deeply involved in health policy research. What are needed are population-based research studies -- area specific when appropriate -- that define and measure outcomes, and then to apply the results of those studies to health care and to the education and training of new health professionals.

"As an example, Dr. John Wennberg, Director of the Center for the Evaluative Clinical, Dartmouth, provides an example of how outcomes research can affect clinical care and

enhance patient choice. At a recent American Association of Medical Colleges meeting, Dr. Wennberg described an outcomes study he conducted to determine the effectiveness of prostate surgery which went beyond answering biomedical treatment questions and delved into patients' quality of life concerns.

"This knowledge enabled the team to present patients with detailed information about the various outcomes they could expect and allowed them to become active partners in their own care. Gail Wilensky, Ph.D., former HCFA administrator, amplified Dr. Wennberg's conclusions by saying, "Outcomes research is about empowering patients just as much as assisting doctors." The same might be said for breast cancer.

"Thank you for the opportunity to make this presentation.

SENATOR LIPMAN: Thank you.

Do the Commissioners have any questions? (no response)

Ann Fade, is she here?

A N N F A D E, R.N. ESQ.: Yes.

SENATOR LIPMAN: Yes, she's here. From Choice In Dying, Inc.

MS. FADE: Hello, my name is Ann Fade. I'm a nurse and a lawyer, and I am Director of Legal Services at Choice In Dying, a nonprofit organization that is headquartered in New York City. We are a not-for-profit organization that advocates for patients' rights at the end of life. We're best known as the creators of the Living Will in 1967, and we're the nation's largest distributor of free advance directives.

Approximately 60 percent of Choice In Dying's membership is female. We keep a Living Will registry in which people can give us their advance directives, and if something happens to them, they're on file -- they have a number. Ten thousand individuals registered in our registry; of the 10,000, 70 percent are female. In addition, the majority of caregivers

for those who are sick or too old to care for themselves are women. Even when caregiving is shared with men, women do the majority of the work and they do it longer.

Choice In Dying has approximately 3500 members here in New Jersey. New Jersey's advance directive laws authorize individuals who complete both an instruction directive and a proxy directive. The instruction directive is your Living Will, which allows people to write out, in advance, instructions for the type of medical treatment they would want at the end of life if they are unable to make decisions for themselves. The proxy directive allows an individual to appoint another person to make decisions on their behalf if they become too ill to make those decisions for themselves.

While this statutory scheme provides fairly broad protection for end-of-life treatment decision making, the fact remains that the majority of people do not fill out advance directives. There may be special problems for women who have not completed advance directives, especially if the courts are called upon to make the decisions about discontinuing life-sustaining treatment. There is evidence to suggest that courts do not apply the law equally to men and women when end-of-life treatment issues are at issue.

There are two researchers who have made a study of court decisions that reached the Appellate level or higher in 1990. They discovered that of eight cases involving decisions for male patients, the court found sufficient evidence of the patient's treatment wishes from prior statements made by the patient in six of the eight cases. Of the 14 cases involving women, the court found sufficient evidence of the patient's treatment wishes from prior statements in only two cases. Many of the courts characterize past statements made by female patients as irrational, emotional, unreflective, or immature, while the male patient's statements were viewed as rational.

Some of the courts never even mentioned prior statements made by the women, but just made decisions in what the court said was, "their own best interest."

To ensure that those closest to a patient have a voice in end-of-life decision making, and to prevent cases from ever going to court in the first place, New Jersey should enact what is known as a surrogate decision-making statute. Twenty-three states and the District of Columbia already have enacted this type of legislation. In the event that a person is unable to make his or her own medical treatment decisions, this statute sets forth a list of those who would be authorized to make decisions on the patient's behalf; usually close family members, but it may include even a close personal friend. The law usually sets out a prioritized list of decision makers and if the person first on the list is not available, it moves on down the list. The laws generally say that the decisions are to be made based on the patient's wishes if known, and if the patient's wishes are not known, then they are to be made in the patient's best interest.

Now, this is essentially the formula that New Jersey courts have endorsed for cases that have come before them, but Choice In Dying frequently receives calls from New Jersey residents who are having difficulty getting health care facilities to accept a loved one's wishes. Most health care professionals do not understand the legal system and they don't know-- Either they do not know about the court rulings, or they don't know that they have the same effect as a law. Therefore, many health care professionals remain uncertain about the role of family members when it comes to making decisions about terminating medical treatment. A surrogate decision-making statute would put an end to this uncertainty.

The second law that we would advocate for New Jersey to consider is a Nonhospital/Do Not Resuscitate order. New Jersey should be aware that advance directives are not honored

in an emergency setting. Many people who have a terminal illness or are frail and elderly, mistakenly believe that if they have filled out an advance directive that says, "No CPR" on it, that that will prevent them from being resuscitated in the event of an emergency, but that's not the case. EMF personnel are mandated by law to attempt resuscitation any time they are called to a person, even if that person is technically dead. They are not allowed to honor advance directives.

To date, 17 states have passed Nonhospital/DNR laws that allow individuals who are not good candidates for CPR to complete a specialized, written advance directive refusing emergency resuscitation, and emergency personnel are required under the law to honor a Nonhospital/DNR that's been provided to them.

Generally these laws require that a person's physician sign the order which would ensure that only appropriate candidates have the forms filled out. There is a growing need for these Nonhospital/DNR orders, because more and more people are opting to die at home and sicker patients are being released from the hospital earlier and earlier.

In conclusion, New Jersey has been in the forefront of recognizing the right of individuals to be free from unwanted medical treatment. In order to stay in the forefront, it should consider enacting surrogate decision making and Nonhospital/DNR laws that will ensure all of New Jersey's citizens -- particularly women -- that they have adequate legal protection of their right to refuse treatment.

Thank you.

SENATOR LIPMAN: Thank you.

Are there questions?

MS. GRIFFIN: Do you have citations for the studies about the Appellate decisions regarding women and men's wishes?

MS. FADE: Yes, I just have it briefly here, but I can call and give you the complete cite.

MS. GRIFFIN: That would be great, thanks.

MS. WALDOR: Does New York have a surrogate decision-making statute?

MS. FADE: New York does not. They have one that right now has been introduced into the legislature, but it has not been voted out of the Health Committee. They do have a Nonhospital/DNR law in place, though.

MS. WALDOR: Do you have samples with you of the proposed legislation in New York for a surrogate decision-making statute, or could you fax us or get us them, so we can have a reference guide?

MS. FADE: I'd be more than happy to.

MS. WALDOR: Thank you very much.

MS. JACOBUS: Thank you. That would be very useful.

SENATOR LIPMAN: Yes, it sure would.

Anyone else? (no response)

Anna Hoffman? (no response)

MS. JACOBUS: Margaret Smith is here.

SENATOR LIPMAN: Margaret Smith, is she here? (affirmative response) Good.

She's a researcher for the Institute of Criminal Justice Ethics. She is the Managing Editor of Criminal Justice Ethics and a criminal justice doctoral candidate from Rutgers University.

M A R G A R E T L E L A N D S M I T H: I would like to say that I am a member of the Prisoners Self-Help Legal Clinic at Seton Hall Center for Social Justice. I welcome this opportunity to talk about health concerns of incarcerated women from ethical research and from the point of view of the women themselves.

I am going to make some specific recommendations and then some general considerations about health care for incarcerated women. Edna Mann Correctional Facility houses between 830 and 840 women in New Jersey; has one staff doctor,

who was trained as a pediatrician, and a gynecologist for approximately two to three hours per week. Six percent of women nationally enter jail and prison pregnant. In New Jersey, there are usually between 12 and 15 women in Edna Mann pregnant at any given time. You can see that the consequence of this is that their prenatal considerations and care will absorb almost all of the two to three hours of gynecological care per week.

The experience related to me by a prisoner who experienced-- A woman prisoner, who, this past year in 1993, experienced pelvic pain intense enough to disable her and prevent her from working, and who was unable -- for a period of four months -- to gain access to an appointment with the gynecologist, inspired me to take a look through the "American Journal of Public Health" records of some of the prevalence of gynecological illness among incarcerated women in New York.

I am not aware of studies being conducted in New Jersey, so I am going to report to you what three researchers found about the prevalence of sexually transmitted disease -- gynecological problems -- among women in New York's incarcerated population.

Michelle Holmes, in April of 1993, reported on women at Rikers Island. She tested a fairly large sample and found: 8 percent infected with gonorrhea, 16 percent infected with syphilis, and 27 percent infected with chlamydia. Chlamydial cervical infection is associated with: infected uterus, infertility, ectopic pregnancy, and chronic pelvic pain. A prevalence of even 5 percent in a population would warrant testing and treatment.

In 1991, Perry Smith sampled a survey of women in New York prisons looking for associations between indications of HIV, syphilis, hepatitus B, and tuberculosis. He found in 1991 that 18.8 percent of women prisoners in New York State of his sample were HIV positive.

Mina Bickell, in 1991, again, two years earlier than Michelle Holmes, looked at women at Rikers Island, and her findings are consistent: 7 percent carrying gonorrhea, 22 percent positive for syphilis, and 35 percent positive for the human papilloma virus, which is often associated with abnormal paps. Nine percent of the women she tested had abnormal paps.

So I would make the case for two things immediately: significant survey of the medical care needs of women at Edna Mann Correctional Facility, and the immediate provision of increased gynecological care.

I'm going to read an excerpt from a letter written to the Governor by the woman who waited four months to have an appointment with the gynecologist. She was subsequently diagnosed with endometriosis and is being treated now.

MS. JACOBUS: Which is cancer of the lining of the uterus.

MS. SMITH: She wrote to the Governor-elect, "If you'd really like to save tax dollars, may I suggest a suitable replacement be found for the medical personnel who cause countless numbers of lawsuits to be filed? They spend more time, effort, and valuable resources in not treating the problems, and in the end the original complaint needs to be addressed in addition to the damage caused by the mistreatment. This doesn't detract from the fact that the supervising physician at Edna Mann is a pediatrician who purportedly came to us via community service for welfare fraud, supposedly after he was investigated when it was alleged he gave a baby the wrong type of medication and it died as a result. He refuses to touch staff and prisoners alike during the course of examination and he is excellent at invalidating a person's complaint."

I only report this to give you a sense that women's testimony about their own state of health is rarely listened to. Prisoners who are women are listened to much less than

just women who are residents in the street. We know, as women, that we know the state of our bodies better than anyone else. We have to provide a way at Edna Mann so that women's concerns about their health can be responded to in a different fashion than is being done now.

I would also like to comment, and I'm sure other people have spoken to this point, women who give birth -- sentenced prisoners who give birth -- are required to give up the custody of their children within 24 hours of birth to a designated foster care representative, or then the State takes charge. This is a situation which, despite the statute-- The statute, I believe, provides for a three- to six-month period of letting the infant remain with the mother, but this is not being carried out.

In New York, at Bedford Hills, there is provided a period of a year of nursery care. This certainly could be done on the grounds of Edna Mann. There are physically cottages there which could be transformed to provide nursery care. Again, this does not talk about or speak to a large proportion of the women, but it is an acute concern for a mother being separated from her infant a day after birth. The experience of several women with whom I have spoken directly about their efforts to appoint or designate a person -- not the father, mother, or sister -- as a guardian-- These women have reported extensive difficulties in negotiating the bureaucracy and found that it was-- It may seem as though all one needs to do is write a letter naming someone as the foster parent, but this is a much more complicated procedure than it appears to be, and it is not one in which the women feel they have any support from the institutional structure of child welfare in New Jersey.

I would like to come to one point which we as criminologists can report: One of the few things that we can say with certainty is, there is only one thing which is positively associated with an increased ability to stay out of

prison, and that is family ties. In light of that consideration -- and this has been shown since 1945 until 1990 in countless studies of probation, parole violation, and recidivism -- the only thing that consistently shows up is family connection to reduce a person's likelihood of returning to prison.

In light of this piece of information, I ask you if we can talk about providing health care to women separated from their children in any ethical understanding of what the term health care should mean to us as women and as people? So I ask you to think whether punishment ought not to be considered in terms other than incarceration. We're not in the habit of thinking about punishment in any other way but incarceration. But it seems to me that there are many things that we would be able to do to place facilities in communities where women could continue to be in touch with families and children, and not do the additional damage of separating women from their children for incarceration purposes, when what we know is that that only increases the likelihood of their returning to prison.

Thank you very much for this opportunity.

SENATOR LIPMAN: Thank you.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Questions? (no response)

MS. JACOBUS: Thank you very much.

SENATOR LIPMAN: Jane Porro?

MS. JACOBUS: Janet.

SENATOR LIPMAN: Janet, I'm sorry.

J A N E T L. P O R R O, ESQ.: That's okay.

SENATOR LIPMAN: She is the Chair of the Task Force on Eliminating Violence Against Women and Children, in the National Organization for Women of New Jersey.

MS. PORRO: Thank you.

On behalf of the NOW-New Jersey Task Force on Eliminating Violence Against Women and Children, I would like

to thank the Commission for this opportunity to testify. My testimony here today is the culmination of the Task Force's findings as corroborated by my experience as a licensed attorney specializing in the litigation of women's issues including: domestic violence, sexual harassment, and sexual abuse.

An estimated four million women are battered each year by their husbands and partners. Violence will occur in at least two-thirds of all marriages. In the United States, statistics show that a woman is more likely to be raped, assaulted, or killed by her male partner than by another type of assailant.

Research suggests that wife-beating results in more injuries that require medical treatment than rape, automobile accidents, and muggings combined. Each year more than one million women seek medical assistance for injuries caused by battering. Despite this, many of our health care professionals lack any experience or training in domestic violence. Few truly understand what clinicians refer to as the battered women's syndrome, and even fewer are apprised of the resources available to women who are victims of the crime of domestic violence.

The Prevention of Domestic Violence Act, N.J.S.A. 2C:25-17, as amended in 1991, was initially viewed as a major victory for advocates of the elimination and prevention of domestic violence. The law, as enacted, provides individuals with a number of rights and avenues for relief when subjected to an act of domestic violence, which has been broadly defined to include a significant number of crimes including: assault, sexual assault, terroristic threats, and harassment. In theory, New Jersey has one of the strongest Prevention of Domestic Violence Acts in the country. In reality, however, the Act has not proved as effective as advocates had originally envisioned.

In practice, women in domestic violence situations are unaware of the safeguards afforded to them. In other instances, they are too fearful to exercise their rights under the statute.

Women suffering from battered women's syndrome have typically been demeaned, demoralized, battered, and even raped over a period of many years. They have come to believe their abuser's derogatory epithets. These victimized women are frequently told that they are the ones that are crazy. They are the ones who are at fault, they deserve to be beaten. Others are threatened with their life if they attempt to leave. These women are frequently raped by their partners, who view them as objects for sexual gratification. They feel trapped, hopeless, and there appears to be no way out of this living hell. Their desperation manifests itself in depression, anxiety, suicidal tendencies, or a lashing out at their perpetrators, for which the victims are often chastised, held up for public ridicule, and punished.

Sadly enough, some women in domestic violence situations do not even recognize themselves as being abused, for this is the life they have come to know and to accept without question.

As cited earlier, it is estimated that in excess of one million women per year seek medical assistance for injuries related to domestic violence. For many women who have been isolated from their friends and family by their abusers, the medical profession is the one and only link they have to social services which can help them break free of their chains; the one group of individuals who can recognize the agony they are enduring, who can perhaps open their eyes, assist them in coming to the realization that they do have self worth and do not need to fall prey to another individual's control and power over them.

Unfortunately, what battered women have experienced in their contact with the medical profession are individuals who have not been trained to recognize an abused woman. Thus, these women return home after receiving medical treatment to the same desperate situation, now feeling even more helpless than before.

I personally had the experience where a client relayed to me that while in a hospital she conveyed to the nurse that her husband had continually raped, verbally abused her, and beaten her over the seven years of the marriage. She feared for her life, as well as those of her young children. What was the nurse's response to this desperate woman's plea for help, her searching for reassurance and validation? The response was, "If you stayed with this man all those years, you must be as sick as he is." I submit that this was totally inappropriate, yet nevertheless, representative of what women have been encountering in the medical profession.

The Prevention of Domestic Violence Act specifically provides for the filing of a complaint by law enforcement officials where the victim exhibits signs of domestic violence, or where there is probable cause to believe that an act of domestic violence has been committed. This includes the exhibiting of any signs of injury, physical pain, or impairment by the victim. In that most victims are terrified of their abusers, and thus reluctant to file a complaint, this was a major step forward for women who were abused. No longer are they required to make the initial decision to press charges. Such is made by a third party, the law enforcement official.

It is the recommendation of the NOW-New Jersey Task Force that the Act be amended in such a way as to impose mandatory reporting provisions upon all physicians and health care officials, requiring reporting to law enforcement authorities immediately when rendering medical care to an individual whom they, in their professional opinion, feel has

been abused. This would be similar to the reporting of child abuse cases as mandated by statute. Such would be a significant amendment to the law which would further the legislative purpose of the Act, that being to assure that victims of domestic violence have the maximum protection which the law can afford.

Such a measure, however, presupposes that there are health care professionals who are trained to recognize the indicia of domestic violence. Accordingly, it is recommended that the Act be further amended to mandate training for those in the health care field. Provisions exist in the Act for a training course and curriculum by the Division of Criminal Justice and the Administrative Office of the Courts, to provide educational programs to law enforcement officials and the judiciary alike. It is submitted that a similar program should be instituted for the medical profession. Such should include mandating of a curriculum in colleges and medical schools prior to licensing, as well as postgraduate training.

As a prerequisite, the health care individual should be provided with training as to the psychology involved in abusive situations. This ignorance of adverse psychological impact upon women who are abused in the household setting, which is prevalent in the health care field, is additionally visible in other areas in which health care professionals interact with women who are victimized and violated, such as sexual harassment and rape. All too often, victims are treated for their physical symptoms and no attention is paid to the trauma which they are undergoing psychologically. Frequently this aspect is overlooked or minimized.

I recall a statement made to me by a psychologist in connection with my representation of two young children who had been heinously sexually molested and penetrated by their father. I was told that, "Children do not suffer from post traumatic stress disorder. Rather than have the children

continue in therapy, continually bringing up the incidents of incest, they should just forget about it and move on." I found this to be an absolutely incredible diagnostic plan, one which was espoused by an individual who, despite his degree, had absolutely no insight into the psychological trauma which individuals who are violated and victimized suffer.

Psychological trauma is a reality, whether it be childhood sexual abuse, abuse in domestic violence settings, or victimization by a stranger. The health care professionals should be better trained to deal with this aspect of victimization, and at the very least direct the individual to qualified professionals.

Stop the silent suffering that these women of domestic violence must endure. Provide the Prevention of Domestic Violence Act with mechanisms to protect victims. Mandate training for health care professionals so that they can recognize the indications of domestic violence. It is just as crucial that the Prevention of Domestic Violence Act be further amended to provide for reporting of all suspected incidents of domestic violence.

Domestic violence is a serious crime. Women are beaten, raped, verbally abused, and tortured on a daily basis. NOW-New Jersey urges you to make the protections established by the Prevention of Domestic Violence Act a reality.

I would be happy to discuss the Task Force's position on other issues of victimization of women. We also deal with sexual harassment and sexual abuse, if there are any questions.

MS. GRIFFIN: I just wanted to say something on the record about this, because I know that the Coalition for Battered Women and other advocacy groups are dead-set against mandatory reporting by anyone, partially because of empowerment of victims and partially because there is no way to protect those women once the report is made. Do you have suggestions

as to how you would protect a woman who doesn't feel it is time to report, but her doctor reports, and law enforcement gets in touch with her husband who then threatens her?

MS. PORRO: Well, the protection would be the issuance of a temporary restraining order.

MS. GRIFFIN: Yes, we all know that that is--

MS. PORRO: Right. It's a piece of paper, exactly.

MS. GRIFFIN: Without the woman's consent, is that any use at all?

MS. PORRO: I think one of the major problems in this area is that a lot of women are not aware of what services and service organizations are out there, such as battered women's shelters.

MS. GRIFFIN: So would it serve your purposes just as well to have doctors better trained -- obviously that is something that we've always been advocating -- and then have it mandated that they instruct women about their options?

MS. PORRO: Or go a step beyond that; instruct women about their options and perhaps have a representative of a battered women's shelter come in contact with them at the hospital. Obviously they can't come in contact with them at the home, and to send a woman home to that setting-- A lot of these women don't even feel that they're abused, which is the sad part; they've come to accept that. So have some representative come in from a battered women's shelter, for example, and say, "Hey look, this is an incident of domestic violence and you don't have to tolerate this. There are ways you can get free. There are ways we can help you. We have shelters where you can go where we'll help you get back on your feet."

MS. GRIFFIN: So I take it you would advocate for more funding for the shelter programs?

MS. PORRO: We would. However, I think in reality that is a difficult thing to get -- additional funding.

MS. GRIFFIN: Thank you.

SENATOR LIPMAN: Phoebe.

MS. SEHAM: That was the concern that I had, too, so thank you for bringing it up.

MS. PORRO: Thank you for your time.

MS. JACOBUS: Thank you very much.

SENATOR LIPMAN: Nadine Taub, Director of the Women's Rights Litigation Clinic, Rutgers.

N A D I N E T A U B, ESQ.: Well, as I think a number of you know, I'm Nadine Taub from Rutgers Law School, Women's Rights Litigation Clinic. Evelyn Hernandez, who has worked closely with me on this, is here with me. We're here for the Clinic, the National Center for Public Interest Law at Rutgers, and also for the New Jersey Coalition Against Reproductive Hazards in the Workplace, a group which has fought long and hard, and strongly supports our testimony today.

Let me say, first of all, that we're sorry that our colleague, Erica Wade, who also helped us greatly, couldn't come. Evelyn Hernandez will be presenting the testimony. Let me call your attention -- in addition to our written testimony -- to the letter from Dr. Maureen Paul which is attached. She'll be referring to it. There is also an additional letter from Drs. Mohr and Gochfeld from UMDNJ, which won't be mentioned, just to call your attention to it. After Ms. Hernandez finishes, if you have any questions we'll try to answer them together.

I just have to tell you briefly about my own health calamity in January. I seem to have had a temporary loss of hearing, so if I can't hear you and you shout, I think she'll help me out.

Thank you.

E V E L Y N H E R N A N D E Z: Good afternoon. Our testimony today concerns reproductive hazards in the workplace; one aspect of a large and, at times, discriminatory obstacle to

safe, continued employment. As you no doubt know, the United States Supreme Court with its 1991 decision in United Auto Workers v. Johnson Controls made it clear, at least in theory, that fertile women cannot be excluded from the workplace in the name of fetal protection.

The result of that decision, however, was to make women, as well as men, free to be exposed to reproductive hazards in the workplace. The need to eliminate such exposures must remain in the forefront of our minds. But while we are seeking and implementing ways to meet this crucial need, we must ensure that workers are not forced to choose between their health and the health of their offspring on the one hand, and their incomes on the other. It is that short-term problem of ensuring continued income to workers, pregnant women workers in particular, who must temporarily leave their jobs and the dangerous exposures they entail, that we address today.

Right now, the State of New Jersey refuses to allow such women to receive disability payments. It, instead, insists that pregnant women whose physicians tell them to avoid exposures to chemicals and other hazards while they are pregnant, can only get unemployment compensation. In other words, the State is telling them that they must quit their jobs and receive assistance. With this approach the State deprives them of all medical benefits associated with their employment and any right to seniority if they are able to return to their previous jobs.

We first became aware of New Jersey's rigid policy last spring when the Clinic received a call from a woman employed as a chemical analyst by a company that recycles hazardous wastes, whose doctor had told her not to continue her position at work now that she was pregnant. The company did not have any other work for her and wanted to put her on disability, but the State said, "No." Our repeated calls and

letters on her behalf simply confirmed the denial of disability benefits, though it did spur disability personnel to help her secure the unemployment benefits to which she was presumably already entitled.

The New Jersey Temporary Disability Law does not say anything about denying pregnant workers disability benefits if they choose to follow their physician's instructions to avoid on-the-job exposures to hazards while they are pregnant. Instead, this restriction on the availability of benefits is contained in a document issued by the State disability agency called: "Interpretation, IMT-185, Service Guide No. 18, Subject: Adjudication of Pregnancy-Related Disability Cases Under the State Plan and Disability During Unemployment." In our view, that Guide, which we submit herewith, is totally irrational and impermissibly discriminatory.

The document makes clear that a pregnant woman may receive temporary disability benefits from the State of New Jersey, "if she is too disabled to work due to medical complications associated with her pregnancy." The Guide also makes clear that, "Heavy lifting or any other strenuous work is disabling for most women in the first trimester of pregnancy." However, the document makes equally clear that a pregnant woman will not receive benefits, "if she leaves work because of the potential effect of toxic fumes, or other chemical or x-ray exposures, on her fetus."

It is very hard to understand any basis for the State's distinction. It is possible that the State is confusing the nature of the risk and its degree of seriousness. However, it is simply not true that heavy lifting and strenuous activity jeopardize a pregnancy in the first trimester more than exposure to high levels of certain toxins and x-rays. The Guide states the Supervising Medical Examiner has found the risk due to ergonomic strains unacceptable in the first trimester. The Examiner likewise should find that

exposure to developmental or reproductive toxins that pose an unacceptable risk of miscarriage, stillbirth, or birth defects is also a disabling complication of pregnancy.

Another possible explanation for the distinction is that the State somehow has the idea that the chemical exposure situation is unlike the ergonomic problem in that it involves risk to the fetus only. However, the chemical exposure situation endangers the woman and her pregnancy just as heavy lifting and other strenuous activities do. Doctors who advise their pregnant patients to leave work because the exposure poses a high risk to their pregnancy are acting out of an understanding that certain toxins, in fact, pose grave threats to pregnancy. In short, both the ergonomic and the chemical exposure situations can be disabling.

A third possible basis for treating the two situations differently is that in the chemical and x-ray exposure case, the State regards the injury a doctor seeks to forestall as an injury to the fetus, whom it sees as distinct and separate from the woman. This, however, is inconsistent with both State and Federal law. In a case directly on point, the New York Appellate Division awarded disability benefits to a woman exposed to hazardous chemicals while pregnant. In so doing, the court made clear that the cognizable harm was to the pregnancy and therefore a harm to the woman herself. The court explicitly stated that, "Since it could rationally be concluded that claimant's work area was never cleared of paint fumes and the claimant had been admonished by her physician not to remain in such an environment due to her pregnancy, there was ample basis to support the board's determination that claimant was disabled in connection with her pregnancy." That was cited in Pond v. Oliver, a 1985 case.

The United States Supreme Court has also made clear that a fetus is not a person distinct from the pregnant woman carrying it. As it said, "A fetus is not a person within the

meaning of the 14th Amendment or within the meaning of any other provisions of the U.S. Constitution," cited in Roe v. Wade. The New Jersey courts have reached the same conclusion in a variety of contexts; for instance, in wrongful death, abortion, and homicide.

Like New York, New Jersey must find a woman's inability to work in an occupation where exposure threatens fetal deformity is disabled in connection with her pregnancy. Simply put, the harm is to the woman. A woman should be granted disability benefits under the New Jersey Temporary Disability Benefit Law if her position at work poses harm to the fetus, since the fetus is part of her and is not a separate person.

Even if the State does not share our view that inability to work due to dangers posed to the fetus renders a woman eligible for disability benefits, it must acknowledge that the very same toxins that cause a fetal deformity also cause miscarriages. Thus, it would make no sense to a policy of only awarding disability benefits where the pregnancy is compromised.

We commend to your attention the opinion letter of Dr. Maureen Paul, the Director of the Occupational Reproductive Hazard Center, University of Massachusetts. She is an expert in these problems. Dr. Paul makes plain the scientific basis for the analysis we have presented today.

We very much hope that bringing the improprieties in a statutory interpretation announced by the State Department of Labor and Industry (sic) to your attention will help prompt correction of the State's policy and practice. Obviously, it would be preferable to resolve these matters without additional legislation and out of an adversary context. We appreciate your interest in this matter and stand ready to assist you in any efforts you my undertake to achieve change.

Thank you.

MS. TAUB: Let me just add that I think we all understand that in New Jersey, exposure to chemicals and other toxins during pregnancy is a very real problem. That's unfortunately the state of our State. Also, I think you would like to know that we actually sent a letter very similar to our testimony today to the Commissioner of Labor. Dr. Paul's letter went with it. We have not received an answer to date. I believe the date of our letter is the date of her letter, which you have before you. It was before the change of the year. Maybe we're talking about change of administration, but we think this is a problem that could use your help.

Thanks.

SENATOR LIPMAN: Thank you. Do you think it is a decision that the Commissioner himself can make, or his staff?

MS. TAUB: You know, this is an example of where I'm going to need help from my friend, because I have so much trouble hearing.

SENATOR LIPMAN: I'm asking if the Commissioner himself could grant this sort of -- could solve this problem?

MS. TAUB: Well, I think that the new legislation probably is not required. I think that the Commission can help get the Department of Labor to clear up its false interpretation, and to announce that disability is available to women who have to leave their jobs temporarily. If the Department of Labor is resistant, then I guess what would be necessary is legislation, and I think you have been the source of some very good legislation. I think you probably understand the politics in this State better than we do. In principle and theory, the Labor Department doesn't need to have this irrational interpretation that, frankly, hurts pregnant women. How to get them to see that, I think I have to leave to the experts.

MS. SEHAM: But what about a new letter to the new Commissioner of the new administration? They don't necessarily pass their correspondence along.

MS. TAUB: Well, I think it makes a lot of sense for us to do that. It would be very nice if accompanying that letter there was some more visible expression of concern. I think that might-- We don't have to assume they'll do the wrong thing--

MS. WALDOR: Come on now. (laughter)

MS. TAUB: --but with a little urging they might be more eager to do the right thing. It's not a really difficult matter in terms of costing a lot of money and in terms of not forcing them into quitting their jobs, not having to go for unemployment, etc. It can be a politically desirable thing to do and maybe we can have some informal conversations about how to coordinate our statements.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Anybody else? (no response)

Thank you very much.

MS. TAUB: Thank you.

SENATOR LIPMAN: Dr. Carole Sheffield, Political Science and Women's Studies, William Paterson College, former Director of the Women's Center.

C A R O L E J. S H E F F I E L D, Ph.D.: Senator Lipman, Executive Director Griffin, and members of the panel, I thank you for the opportunity to address this panel and to contribute in any way to the important and vital work you are undertaking. My testimony is going to be quite different from all that you've heard today.

I am a Professor of Political Science and Women's Studies, and a researcher in the area of sexual violence, but I am here today to talk about my experience as an ill woman and as a consumer in the health field.

I became seriously ill two years ago with muscular-skeletal, common, and possibly cluster migraines. With a particularly violent episode in April of 1992, I began a nearly two-year journey through the medical system which left

me quite disheartened about the ability of ill women to secure nonsexist, competent, and safe health care. With each doctor I saw, mostly on referral from the previous doctor, I had to wonder not only would she or he have an answer to these mysterious headaches, or at least an effective remedy, but whether I would be listened to and treated respectfully.

I would like to report on a few of the experiences I had, at least two of which were life-threatening, and a third which prompted me to seek redress from the New Jersey Medical Society. Some of the incidents were overtly sexist and harmful; others were, at best, arguably sexist, but clearly revealed an incompetence and uncaring in the delivery of health care. In the latter, the question is whether the incompetence resulted from sexist medical beliefs and practices, and I believe they did.

A neurologist at a headache clinic in New Jersey prescribed Stadol, a synthetic narcotic, although he did not tell me this. He did tell me to consult with him before taking the drug. I called him several times over a three-day period, each time telling the nurse/receptionist of the excruciating pain I was experiencing and repeating the doctor's instructions that I consult with him prior to using the drug. After three days, with no response from the doctor, no relief from the pain, and in total desperation, I read the drug insert and administered it myself. After several minutes, I passed out cold for a period of five hours. I was home alone. It was springtime, my dog was in the yard, and my back door was unlocked. I don't know whether I used the drug incorrectly or whether the drug was simply too strong for me, but not having had any guidance, I was certainly not prepared for what happened. This left me in a vulnerable and potentially dangerous situation.

I immediately found another neurologist. Last June, she prescribed Imitrex, the new, highly touted, patient-injectable medication. She carefully went over the

insert with me, found nothing in my medical history to suggest I might have an adverse reaction to it, and even administered the first dose in her office to monitor me for side effects.

A few weeks later, I needed to use it at home. I followed her instructions precisely. Getting no relief, and finding the headache worsening, I called her office. She was unavailable. It took several more calls by my spouse to get one of her partners to respond. He questioned me about the pain and the other medications I had been prescribed, all of which had failed. I emphasized to him that this headache was very different from all of the others in the type of pain, as well as its intensity. Since I had experienced significant medicinal failure, he said there was nothing he could do for me, and hung up. I then asked my spouse to take me to the hospital, where it was determined that my blood pressure was dangerously high. If I had accepted his advice that, "Nothing can be done," I would have suffered a stroke or I would not have lived.

Three weeks later, again with a terrible migraine, I called my doctor. She was away on vacation, so one of her partners spoke to me. He disagreed with her instructions to avoid Immitrex and suggested instead that I drive myself to my local hospital -- in the throes of a horrible migraine -- sit in the waiting room of the emergency room, and inject myself with Imitrex. He said to me, and I quote, "That way, if I am wrong and you do have a stroke, you'll already be at the hospital." I said, "Thanks, but no thanks."

A month later, after a two-week migraine, my doctor prescribed a 14-day trial of a steroid called Decadron. After four days of being on the drug, I could not walk unassisted, and could not swallow due to profound weakness. My hands and feet began to burn and I started to tear at my flesh. I called my doctor right away, as the "Physicians' Desk Reference" cautioned that one should seek medical attention immediately if severe itching or a rash developed.

Again, my doctor was unavailable and one of her partners returned my call. I explained what was happening. He told me it was "impossible to have a bad reaction to Decadron," and that I was "just tired." I told him that I don't dig at my flesh when I was tired and he commented then that I "must be depressed." I told him he was wrong, that I wanted to go off the drug, and asked how to do it safely. He said he would not authorize me to go off the drug and would not give me instructions for doing so.

Why didn't he take 30 seconds to look up Decadron in the PDR? If he had, he would not have concluded that I was just tired or just depressed, and would have realized that my life was in jeopardy if I continued on the drug as prescribed. Like the long-standing medical belief that menstrual cramps were a figment of a woman's imagination, I believe this doctor's response fits a classic pattern of dismissing a woman's complaints as that of a whining neurotic. While migraine headaches are not an exclusively sex-specific illness, three out of four migraine sufferers are female.

I took myself off the drug cold turkey. Two days later, my lungs filled with fluid and I developed a cough which lasted for three months and was severe enough to damage my chest wall and my ribs. I also developed a frozen shoulder. As a result of this, I had to take a leave of absence for the entire fall semester, using up a majority of my accumulated sick leave.

My neurologist, concerned about the severe cough, referred me to an internist. After seeing me twice, he referred me to his partner, a pulmonary specialist. This doctor's attitude and behavior towards me was so offensive and blatantly sexist, that I contacted the New Jersey Medical Society to file a complaint.

I will briefly summarize the salient points from the letter of complaint, and will be happy to provide a copy to the Commission if it is interested.

He yawned continuously during the 20 minutes he saw me. He was very inattentive and repeatedly asked the same questions. For example, he asked at least four times whether Decadron had helped the headache.

He asked not a single, substantive question about my cough, and remember, he's a lung specialist.

As he leafed through my file, he asked whether among the doctors I had seen recently, had I seen a psychiatrist? I said, "No," and told him that I did not wish to do so or to pursue this discussion. He became focused only on this issue and despite my repeated rejection of his advice, he persisted. He absolutely refused to take my "No," for an answer.

While admitting to me that he doesn't know very much about migraines, he asked, "Isn't is strange to wake up at 4:00 a.m. with such a terrible headache? Surely, this is evidence of a deep-seated problem." I told him that 30 percent of migraine sufferers get them in the middle of the night. He also insisted that since the MRI and CT-Scan that I had had were negative and that I had not responded well to migraine drugs then, "Surely the problem is psychological." He made insinuations about my marriage, and even said to me that my husband must be sick of me having headaches.

When he returned from reviewing my chest x-ray, he gave me the name of a psychiatrist written on a prescription pad.

I left his office very angry and upset. In spite of the fact that his treatment did not jeopardize my physical health to the same degree as the doctor who refused to believe that I could have an adverse reaction to a potent steroid, his behavior and attitude were so humiliating and degrading that I decided to file a complaint.

Apparently filing a complaint against a doctor is a well-kept secret in New Jersey. I first contacted the county office in which the doctor practiced. They told me I had to

write a letter to the doctor and wait for his response. If I was not satisfied with his response, I should then contact them.

I was not happy with this; I found the doctor to be emotionally abusive, a poor listener, and clearly one of those who believe that migraines in women are purely psychological. Several times I said, "No," clearly and directly to his insistence that I see a psychiatrist. In fact, the more I said, "No," the more he insisted. The experience with him was demeaning. I wanted to file a complaint against him and did not believe that correspondence with him would be beneficial.

I then called the State office, which only referred me back to the county office. I told them that I had already done that and that I was uncomfortable with the procedures, although I would follow them if I found out I had no other options. When I told them what the county office had instructed me to do they agreed it was not appropriate, and after a few phone calls, they told me to write a letter to the judicial committee of the county.

I wrote the letter, which basically included a summary of why I wanted to file a complaint -- based on notes I had made when I returned home from the doctor's office -- and I asked specifically for an explanation of the complaint process. All I received from them was a note that the matter had been referred to the judicial committee on the basis of my initial letter, and that I would hear from them when they had investigated the matter. I also had to sign two forms: a release of medical records and a disclaimer of legal action.

I was given no further explanation of the process. For example, is there a complaint form -- since I was given no guidance for constructing the letter? Who was on the judicial committee? Not necessarily their names, but since this was, in effect, a sex discrimination complaint, I wanted to know the gender makeup of the committee. How did they investigate?

Would there be an opportunity for a hearing? Is there an appeal process should I be dissatisfied with the results at the county level? These are obvious questions that anyone would have about a complaint process, but I received no information about it whatsoever.

I filed the complaint in early October, 1993. In December, after writing again to inquire about the status of the complaint, I received a response from the judicial committee. The response itself illuminated the nature of the investigation process. That is, the doctor about whom I complained wrote his response to my letter to the committee and the committee came to a determination. That the process is weighted in favor of the doctor is evidenced, in part, by the fact that he was given ample time to respond to my letter, but I was not given the opportunity to respond to his.

I quote the last two sentences from the county judicial committee's letter to me: "The committee can only say that it finds your recounting of details at variance with Dr. _____'s recollection. Since you two were the only parties to the encounter, we are unable to form a conclusion. In conclusion, the committee finds Dr. _____'s care for you to be professional and ethical."

I daresay the latter sentence contradicts the former. Finding Dr. _____'s care for me to be professional and ethical is most certainly a conclusion, a finding of fact. In other words, the committee, in a position where it is the patient's word against the doctor's, chooses to believe the doctor. End of story. No further information, no advice about other options, etc.

Why would anyone file a complaint if that is the position of the judicial committees of the medical societies? Well, perhaps that is their objective after all.

As a Professor of Political Science and Women's Studies, I have had considerable experience with drafting and implementing complaint procedures at my college and in hearing

complaints. I know it is not easy. However, as it is currently structured, the complaint process for the New Jersey Medical Society is mysterious, intimidating, and frustrating. I had to persist, insist, and persevere in order to file a complaint, and I believe that it is designed to be this way. Many times along the way I wanted to forget about it and give up. If women find the process indecipherable and give up, the medical profession can laud itself for the lack of complaints against its doctors.

To redress sexism in the medical profession is a daunting and multifaceted task, to be sure. However, the establishment of a fair and open complaint process is absolutely essential to any attempt at reform.

The Medical Society needs, at a minimum, to have a written policy which clearly delineates the complaint process, including appeals, and which should be provided immediately to the complainant. It should include guidelines for drafting the complaint and for substantiating it. Judicial committees of medical societies also need to realize that perhaps, given the clear and well-documented history of differential and substandard health care that many women receive, they are often not the best judges of sexism in their profession and need outside consultants, or perhaps an outside agency to assist them in these matters.

I hope my participation in these hearings will be helpful to you, and I thank you again for your time.

MS. WALDOR: How are you?

DR. SHEFFIELD: Not much better. I had to go back to work because I ran out of sick days, and I'm not much better.

MS. WALDOR: So there is no resolution, so to speak?

DR. SHEFFIELD: There is no resolution. After the experience with Decadron, I went to a doctor of oriental medicine and acupuncture, and I was treated for the fall semester. I found it enormously helpful; however, my insurance

company will not pay for it anymore and I can't afford the treatment, so I am back to having no treatment for the migraines. Most doctors whom I have seen told me that as a result of the extensive medicinal poisoning I had, I cannot take any more drugs.

SENATOR LIPMAN: Astounding.

MS. WALDOR: That's pretty horrible.

DR. SHEFFIELD: Yes. Yes, it is.

MS. WALDOR: I mean I couldn't even imagine living like that.

DR. SHEFFIELD: Yes, it is. I thank you because as I sat here all day impressed and fascinated with all the testimony -- which was also scholarly -- I thought, well maybe my testimony isn't going to be helpful to you. But I thank you for the opportunity to present it, because we must never forget when we're talking about policy and so forth, that we're talking about real human beings.

MS. JACOBUS: And if an enormously intelligent woman, who knows the ropes, is finding it this difficult, what does the other 99.9 percent of the female population do?

DR. SHEFFIELD: Yes, yes. I would be dead if I didn't listen to my own body and disobey the male doctors that I've seen in the last two years.

MS. WALDOR: Have you--

DR. SHEFFIELD: Then I get punished for disobeying the male doctors, so it becomes a very vicious circle.

I'm sorry.

MS. WALDOR: I didn't mean to interrupt you, but I also got the impression that it wasn't just the male doctors, although they were much more obvious. But if your own doctor, who was a female -- the neurologist -- didn't call you back--

DR. SHEFFIELD: She was often away. I don't know if it was-- They would not tell me why she was away. Once, I know it was vacation; other times they just told me she was

unavailable. I don't know what that means. Is she at the hospital doing surgery, whatever? But that is also a problem that I've noticed in the practice she is in, she is the only female. It is a large, very highly reputable firm -- or doctors' practice -- and there are six or seven male doctors. Although I have always been satisfied with her care, if she's not available, I get one of these guys. So I feel that I need to-- Even though I like her, I need to find another situation, but I've not been able to get up the courage to go to another doctor.

MS. WALDOR: I can't say that I blame you.

DR. SHEFFIELD: Thank you.

SENATOR LIPMAN: Thank you very much.

MS. WALDOR: Good luck.

DR. SHEFFIELD: Thank you.

SENATOR LIPMAN: Is Karen Mittleman here, please?

K A R E N D. M I T T L E M A N, Ph.D.: Yes.

SENATOR LIPMAN: Will you come up?

She's from the Department of Exercise Science at Rutgers University.

DR. MITTLEMAN: Hello.

Dear members of the Commission, I am here before you as a State-employed faculty member of Rutgers University; as a Fellow of the American College of Sports Medicine; and most importantly, as the stepmother of two adolescent girls.

The importance of physical activity in promoting health is widely documented for adults. It is no longer just a positive belief, but a documented fact that regular physical activity helps to protect against the development of cardiovascular disease, obesity, noninsulin-dependent diabetes mellitus, and osteoporosis, as well as promote psychological health. The prevention of these diseases could have a tremendous impact on the cost of health care of the nation. The U.S. national health promotion and the disease prevention

objectives -- or Healthy People 2000 -- have also established that the physical activity behavior of children and youth is an important health issue.

For example, it has been suggested that adolescence is a crucial time in terms of accruing bone density and that active adolescents have better skeletal health than their less active peers. This may be extremely important in terms of the future development of osteoporosis; a disease which is most prevalent in women. It has been estimated that over one-third of all women over the age of 65 will experience an osteoporotic fracture in their lifetime. In addition, osteoporosis has been documented to incur health care costs of over $6 billion annually in the United States.

In June 1993, an international consensus conference on physical activity for adolescents was convened. With the conference coordinator's permission, I would like to share with you some of their findings and recommendations from the consensus statement which is in the process of being published; which is why I don't have a copy of my statement for you.

Several of these findings reveal sex differences which may have a tremendous impact on the future health of adolescent girls. The consensus statement highlights two health-related rationales for adolescent physical activity:

1) The promotion of physical and psychological health and well-being during adolescence.

2) The enhancement of future health by increasing the probability of remaining active in adulthood.

As a result of this conference of experts and representatives of scientific, medical, and government agencies, two guidelines have been proposed for the general adolescent population:

The first is that all adolescents should do some physical activity on a daily basis as part of their lifestyles.

The second guideline is that adolescents should also engage in three or more sessions, each week, of activities lasting 20 minutes or greater. Each session should require moderate to vigorous levels of exertion.

According to the consensus statement, present data suggests that most U.S. adolescents probably meet the first guideline; however, the amount of activity is minimal. Only about 50 percent of boys, and only 25 percent of girls, are meeting the second guideline of three, 20-minute, moderate exercise sessions each week. By the end of high school, only about half of adolescents are enrolled in physical education classes, and most of these classes do not provide adequate amounts of physical activity to meet the second guideline.

In addition, adolescents traditionally have gotten most of their physical activity outside of school through sports. However, sports participation declines during adolescence in girls. The data suggests that the majority of girls are not sufficiently active. The consensus statement states, "The sex differences in physical activity indicate that effective interventions are especially needed for girls." The downward trend of time spent in physical activity during adolescence continues into adulthood, increasing the risk of becoming sedentary adults.

When you look across the nation, New Jersey is one of only six states that requires physical education during all four years of high school. However, the mandate of 150 minutes per week is a combination of comprehensive health education, safety education, and physical education. According to data from the National Children and Youth Fitness Survey, only about one-third of the time spent in physical education is dedicated to physical activity, which means that, in reality, less than 30 minutes per week is spent moving. There is also a growing concern that the State fiscal crisis may lead to a waiver of physical education requirements.

What should be done? There is a need to integrate the efforts of health care providers, education specialists, and state legislatures to ensure that adolescents, and especially adolescent girls, are provided with the opportunity to be physically active.

In addition, programs that encourage and promote regular physical activity for adolescent girls, whether competitive or recreational, must be supported. The promotion of healthy lifestyles in the first two decades of life can ultimately impact health care costs; savings of billions of dollars per year in osteoporosis treatment alone, as well as impact the quality and quantity of life for all citizens.

I would like to express my appreciation to Dr. Barbara Long of San Diego State University for allowing me to discuss the results of the consensus conference, and to Carolyn Jacobus, for inviting me to speak.

Thank you for your attention.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you very much.

Any questions? No? (no response)

Thank you for coming.

Well, we can have a little intermission here while we're waiting for our next speaker to come in.

(RECESS)

AFTER RECESS:

SENATOR LIPMAN: Okay, I think we'll get started.

I'll call Dr. Pamela Moss, Co-Medical Director of the Center for Trauma Disorders, formerly Carrier Clinic.

P A M E L A F. M O S S, M.D.: I'd like to speak today to the issue of sexual misconduct by mental health professionals. The ethical guidelines of the American Medical Association and the

American Psychiatric Association explicitly state that sexual activity with a patient is unethical. This opinion is shared by the American Psychological Association and other mental health organizations. It's not only unethical and unacceptable behavior, but more often than not, it is malpractice.

The patient is automatically presumed to be damaged, generally leaving only the degree of damage to be determined by litigation. Surveys have been conducted to assess the extent of the problem of sexual misconduct. Between 5 percent and 10 percent of mental health professionals admit to sexual contact with their patients. Because a survey depends upon the clinician admitting to unethical behavior, the estimate is thought to be low.

Recent studies indicate that sex-related charges now rank eighth on the list of causes of medical malpractice against psychiatrists. Educational background does not decrease the risk of sexual misconduct. In the specialties of psychiatry, psychology, and social work the occurrence is believed to be about the same. Sexual contact is known to occur not only with adult patients, but also with minors. The number of false allegations appears to be low.

What we know about clinicians who engage in sexual misconduct is that, by far they tend to be male therapists victimizing female patients. They tend to be significantly older than their patient. They have sexually victimized a previous patient. They have engaged in boundary violations with the patient prior to engaging in sex.

In the treatment setting the concept of boundary violations may not be self-explanatory. Most understand that sexual intercourse is a boundary violation, but so may be going to lunch with a patient, offering up personal conversation during a therapy session, or selling a car to a patient. The concept of boundaries is complicated. Generally, there are numerous minor violations within the treatment setting prior to the onset of sex.

The harm in therapist/patient sex is considerable. There may be exacerbation of existing symptoms or development of a major psychiatric illness such as: drug abuse, major depression, or post traumatic stress disorder. The patient may be left with intense feelings of mistrust, guilt, anger, and confusion about sexuality and boundaries. Treatment where sexual misconduct has occurred creates numerous complications for any subsequent clinical interventions. The patient often has extreme difficulty engaging with the next clinician, which she so badly needs to do if she is to recover from the damages of the previous treatment.

A therapist's best and only role is that of being a therapist. When they step out of that role and start on the continuum of boundary violations, they no longer maintain the role of being a therapist. When this occurs it is an indication that the therapist is professionally and personally impaired. The sexual abuse of patients is a flagrant manifestation of deficiencies in character and competence.

The American Psychiatric Association directs psychiatrists to, "Strive to expose those physicians deficient in character or competence." Yet in addition, mental health professionals have the responsibility to protect a patient's confidentiality and privacy. These two ethical obligations can come into play at the same time, hence, creating a dilemma.

If the patient who has been sexually abused by her therapist is ultimately unwilling to file a complaint with, for example, the appropriate licensure board, what should be done? Should the new treating therapist file notice of the allegations of sexual misconduct, breaching confidentiality? Appreciating that a patient may have been harmed, others may be at risk, and a colleague may be personally and professionally in grave trouble. Today we do nothing beyond working therapeutically with the victimized patient. Confidentiality in the State of New Jersey still overrides exposing the colleague.

I recommend to the Commission that this dilemma be examined. I recommend that a committee be formed to explore mandating education for professionals and patients alike regarding appropriate treatment boundaries. Explore the reporting process of alleged sexual misconduct, and explore treatment and licensure requirements once a professional has been found guilty of sexual misconduct.

Thank you.

SENATOR LIPMAN: Thank you.

Any questions?

MS. JACOBUS: Have you ever had any knowledge of-- Is it the licensing board to whom one would complain, or would it be the Medical Society of New Jersey?

DR. MOSS: I think that for a physician it would be the Board of Medical Examiners; psychologists, the Board of Psychological Examiners. In the social work field it's more complicated, because as of yet they don't have a--

MS. JACOBUS: Licensing board.

DR. MOSS: That's correct.

MS. JACOBUS: What have been the anecdotal experiences of women who have brought such allegations to these boards? Have they been listened to? Has any action taken place as a result of their complaints?

DR. MOSS: Absolutely. The complaints are taken very seriously and often they result in action. The investigation is initiated and often there is action. The false allegations appear to be very low. The only difficulty with the boards is that it takes a considerable period of time from start to finish. Often we really are looking at a year or more.

SENATOR LIPMAN: What kinds of actions are taken?

DR. MOSS: If a physician is found guilty of sexual misconduct, they are often asked to close their practice for a period of time. Sometimes that's a relatively short period of

time; it can be anywhere from several months to a number of years. They may be asked to enter into therapy and they are often asked to be-- It is mandatory that they supervised by colleagues.

MS. WALDOR: That's in a noncriminal situation, not where there is a companion criminal situation.

DR. MOSS: Yes.

MS. GRIFFIN: In the situation where the boundaries are being violated but there hasn't been a sexual violation, do you know of any cases where people have complained and anything has been done?

DR. MOSS: I don't know of any cases where someone has complained. I think often what happens is, there are many violations -- many minor violations -- and the clinician may not even be appreciating the violations. The patient is also not appreciating the violations. What can often happen is a patient will leave therapy. What's more important, though, is that almost-- My understanding is that in almost 100 percent of these cases where there is sexual misconduct, that prior to the sex, there have been numerous, numerous violations; flagrant violations, more minor violations. So being able to intervene at a much earlier point would be extremely important -- that there is evidence that the treatment is straying from what is considered appropriate care.

MS. GRIFFIN: Would you advocate at some point, if it became somehow feasible to do so legally, overriding the confidentiality? You were kind of hinting that you would want to override confidentiality if a patient reported to the next therapist that there had been sexual abuse or sexual contact. You would think there would be circumstances under which that would be warranted.

DR. MOSS: Yes.

MS. ATKINS: Dr. Moss, you had spoken to the education of both patients and physicians with regard to boundary issues. How would you foresee this being done in terms of educating patients?

DR. MOSS: Pamphlets in offices regarding what is appropriate treatment and what a patient can insist upon.

MS. JACOBUS: Could it be mandated that a physician must give, in the course of initiating treatment, such an explanatory policy or pamphlet to the patient?

DR. MOSS: Absolutely. I think what you're finding is--

SENATOR LIPMAN: We're discussing psychiatrists and psychologists now, aren't we?

DR. MOSS: As well as social workers. Mental health professionals.

SENATOR LIPMAN: Mental health professionals.

MS. WALDOR: We interrupted you, you were starting to say something about mandatory pamphlets?

MS. JACOBUS: That the giving of this policy statement be mandatory as a part of initiating treatment with any new patient. So that it would be on the books that the professional had given the statement to the new patient.

MS. WALDOR: That leaves room for subjectivity, though.

MS. JACOBUS: At least it's on the books that both parties were aware it was an issue.

MS. GRIFFIN: To your knowledge, is there any training in medical and psychologist's training -- training regimens -- about these issues? Has this become a topic of conversation in medical schools or graduate schools?

DR. MOSS: I think it does come up, but I think that generally it does not come up in a formal way, and it is minimized. Certainly the consequences of committing boundary violations and sexual misconduct are overlooked in training.

SENATOR LIPMAN: Anybody else? (no response)

Thank you very much.

Okay. Ms. Gretel Weiss, please, from the Older Women's League.

G R E T E L D. W E I S S, Ph.D.: Senator Lipman and members of the Commission, thank you for giving me the opportunity to speak on behalf of midlife and older women. I am Gretel Weiss, and I represent the Older Women's League. It is a national, grassroots advocacy organization with members and chapters in New Jersey. I'm the Mid-Atlantic Region Representative on OWL's Board of Directors.

I was happy to note that concerns of midlife and older women have been addressed by others during these hearings, and being late on the agenda, I hope that my comments will complement and reinforce what has already been said.

In our youth-oriented society, we sometimes tend to forget that the health care needs of midlife and older women differ from those of their younger sisters. In the 20th century we have seen remarkable advances in medicine and public health. While American women live longer today, they do not necessarily have longer periods of good health. For example, aside from the diseases unique to women, heart disease is a leading cause of death, but it is not acknowledged, recognized, and treated as early and as aggressively as it is in men. Women's health needs are different than those of men, and as they age, women become more susceptible to both acute and chronic problems.

We all know that there is a correlation between economic status and access to quality health care. In theory, and ideally, retirement income for the elderly rests on the three-legged stool of savings, pensions, and Social Security. But the work history of today's older woman, marked by job segregation, labor force discontinuity, low wages, limited benefits, and sex and age discrimination render that stool

extremely wobbly. Nearly twice as many women over the age of 65 live in poverty than men; 15.5 percent for women and 7.9 percent for men, and of course, that is much higher for minority women.

For older women still in the workforce, for example, only 30 percent of female sales workers have group health insurance, and for women service workers the situation is worse; only 24 percent have coverage. These are the positions many midlife and older women occupy, and their situations are often exacerbated by divorce and widowhood. Thus, health insurance often is a precious and elusive commodity resulting in neglected health and inadequate treatment.

The long-term care needs of older women are of particular concern. Women live longer than men, and as they age into their 80s and 90s they are likely to become increasingly frail. Most older women live alone and there is a desperate need for community-based support services, as well as for institutional services, if needed. Private long-term care insurance, which is often described as the panacea of the long-term care problem, is not the answer.

In 1992, the median annual income for women over age 65 was $8044 and the average annual premium for long-term care insurance was $1071. Whatever health care plan we enact, be it on the Federal or State level, provisions for long-term care in the community, as well as in an institutional setting, are essential.

In the State we must also improve our provisions for adequate resources for the spouse of an institutionalized partner. This is truly a women's issue. In almost all cases, the spouse in the community who becomes impoverished is a woman. As pointed out before, because of her interrupted and low-paying work history, her resources in old age are very limited. Whereas, if her husband is the spouse in the community, he can draw on a far larger income.

Related to long-term care concerns is the fact that the safety net for American families is the paid and unpaid caregiver, who typically is the midlife and older woman. If unpaid, her caregiving duties often keep her out of the workforce or restrict her participation, and the safety net may not be there when she herself needs care. We need support for family caregivers, as well as for chronic care workers who have low wages and no job mobility. One study found that 32 percent of home health aides are without health insurance coverage, and 68 percent have only minimal coverage.

To sum up briefly, some of the inequities confronting midlife and older women in securing health care and the need to recognize and correct them are as follows:

Older women have special health needs; health insurance is often inaccessible to midlife women, and coverage is inadequate for older women; lack of long-term care support services in the community and in an institution; need of economic protection for the community spouse; and support and improved working conditions for paid and unpaid caregivers.

Thank you for providing this opportunity to testify for the Older Women's League.

SENATOR LIPMAN: Could I ask you a question?

DR. WEISS: Sure.

SENATOR LIPMAN: Do you know about Clinton's plan for health care?

DR. WEISS: Yes.

SENATOR LIPMAN: I have heard that long-term care has been left out. Is that true?

DR. WEISS: Well, the Clinton plan does have some provisions for long-term care. It is community-based care, and it is -- aside from the single-payer program, which is the McDermott/Wellstone bill -- the only plan that has any kind of provisions for long-term care. None of the other plans, be they Cooper, Michael, or Chafee, address the long-term

question at all. Now, we feel that there is a recognition on the part of President Clinton that there is a need, and that's a start. It's not enough, but it's a start.

MS. JACOBUS: Will the Older Women's League come out nationally for Clinton's plan.

DR. WEISS: Well, that's a very good question. We've got a Board meeting coming up this coming weekend and that's one of the big questions on the agenda. I'll tell you what our position has been thus far. We are basically supporters of a single-payer system; however, we have analyzed President Clinton's plan. We have applauded his efforts to bring the whole issue to the forefront. We like many of the things in his plan. We feel it falls short in other areas, and this is what we're going to have to address.

By the way, one of the things that's a very important aspect of the Clinton plan is the ability to provide health insurance for early retirees. What we're talking about is women, again. Very often women -- not only women, but a preponderance of women between the ages of 55 and 65 -- who have been dependent on their husband's health insurance in many cases, who are either widowed or divorced, who have no job or health insurance, or cannot get health insurance because of preexisting conditions -- that they will be able to get health insurance. Also the fact that there are provisions for part-time workers which, again, is a very big issue for women.

SENATOR LIPMAN: Health benefits for part-time workers.

MS. JACOBUS: Proportional?

DR. WEISS: Right, that's a very important aspect of the Clinton health plan that is not in the other health plans.

SENATOR LIPMAN: Any other questions?

MS. GRIFFIN: I'm just remembering something someone told me recently, and I want to check it out. If a man is married to a woman who is 10 years younger than he is and she is dependent on his health insurance-- For example, she is a

waitress or has some other traditional pink-collar, ghetto job where she doesn't get health insurance on her own. If he retires and is eligible for Social Security--

DR. WEISS: And Medicare.

MS. GRIFFIN: And Medicare, isn't there some gap before-- She has to qualify in her own right? There is a vulnerability there, too.

DR. WEISS: That's right. She is not eligible until she reaches the age of 65 and you've got, again, this tremendous gap which affects women disproportionately, obviously.

MS. JACOBUS: And that is the same period in which she may be called upon to diminish or even cease working in order to care for him.

DR. WEISS: Exactly. Right. The other issue which I've touched upon here -- and I don't know whether anyone else has mentioned this -- is the whole issue of spousal impoverishment, which affects women again. It's really a women's issue. New Jersey has not yet come up to what is federally permissible. There has been a bill in the Legislature, but it hasn't gone anywhere. We feel very strongly that we should at least come up to the Federal permissible levels, so that women whose husbands then become eligible for Medicaid, if they are institutionalized, are not left impoverished.

SENATOR LIPMAN: You're speaking Federal now, a Federal bill?

DR. WEISS: There is a Federal bill which is enacted on the State level. All states have to come up to a minimum, but they can raise it to the maximum allowed by the Federal government. It was the only thing that was left from the Catastrophic bill which didn't go anywhere a number of years ago.

MS. GRIFFIN: As I understand it, that's a cost issue. They see it as very expensive to implement that, to up the level.

DR. WEISS: Yes, that again depends on who you listen to.

MS. GRIFFIN: But that's the excuse that is given.

DR. WEISS: Right. That's right.

MS. GRIFFIN: Well, if you have anything that would refute their numbers, we would love to have it, because certainly we would love to put that in as a recommendation.

DR. WEISS: Okay.

SENATOR LIPMAN: Thank you very much.

MS. JACOBUS: Thank you, Dr. Weiss.

DR. WEISS: If you want copies, I also gave you a copy of OWL's Mother's Day Report on Health, and a pension booklet which we're just working on.

Thank you.

SENATOR LIPMAN: Thank you.

Are you Dr. Santoro?

C H E R Y L J. T I C E: No. Cheryl Tice.

SENATOR LIPMAN: You're Cheryl Tice, Associate Vice President for Strategic Development from UMDNJ.

MS. TICE: Good afternoon.

SENATOR LIPMAN: Hello there.

MS. TICE: Honorable Senator, members of the Commission, I was listening to Dr. Weiss' testimony and I think she has probably highlighted a lot of the positions I wanted to make today, although quite honestly, I'm here to talk to you a little bit about the impact that these Federal bills might have upon the State of New Jersey. I'm going to highlight what's in my written comments, because I know you've heard a lot of this already. I think in terms of my discussion, I want to just focus on a couple of areas.

As you've heard over these last few days -- and they've obviously been disjointed due to the weather conditions -- health care reform and its impact have received more attention than any other single entity, excepting perhaps the economy, over the past year.

To date, over 40 bills have been introduced in the House and Senate. Within the current decade, these reforms are expected to transform the American health care delivery system into one based upon increased competition and reliance on managed care, achieve an unprecedented degree of integration among providers and levels of care, and profoundly influence the numbers and types of future health care practitioners needed, and the ways in which they must be educated. As you know, I represent the University of Medicine and Dentistry of New Jersey, the nation's largest health sciences institution, and we are particularly interested in this issue.

Of particular interest to you, of course, are women's health issues and that's what we're here to talk about today. I don't need to belabor the statistics; I'm sure you've heard them already. Amongst the 39 million people who are currently uninsured, approximately 16 million are women. Those also represent a vast majority because of their employment statistics, many being part-time employees. Fifteen million women of reproductive age have no coverage for maternity care. Nearly 25 percent of pregnant women do not receive adequate prenatal care, and this number is even higher among minority women.

It is estimated that one in nine women in the United States will develop cancer -- breast cancer; that number equates to about 46,000 women this year. In addition, the National Cancer Institute estimates that seven in ten deaths from cervical cancer could have been prevented if women had had earlier care.

The other issue of concern for us at the University is the deficiency of research in women's issues. No more apparent and obvious is that than in a recent study that was done in terms of heart patients, when a study was done that included over 22,000 men and no women. As you know, heart disease is a major killer of women as well.

UMDNJ -- I'll use that for short, it's a lot easier -- supports the major goals of health care reform as proposed by President Clinton, and in his plan, which was recently introduced by Dick Gephardt, and Senator George Mitchell. The major goals include: security, controlling costs, enhancing quality, and expanding access, while streamlining bureaucracy and reducing fraud and abuse. We believe guaranteed, lifetime coverage for all Americans -- which is already enjoyed by citizens of virtually every other country -- is long overdue. The Health Security Act mandates coverage for all Americans through a system of regional health alliances, as you well know.

We are encouraged that in this plan there is coverage for a broad range of services, including many that have been overlooked by traditional insurance mechanisms. In particular, women's health issues are highlighted with the inclusion of preventive services such as cancer screening, family planning, and health education classes. The emphasis on prevention is reinforced through the proposed increased investment in public health initiatives such as enhancing access for high-risk and underserved groups.

As you are probably aware, over the past few months the frequency of coverage for mammograms and pap smears with the Clinton plan has generated much controversy and, in essence, the administration has expanded the coverage of mammograms and pap smears in the Health Security Act.

With reference to other pieces of health care legislation, I would propose that there are three bills currently in Congress; two that are Democratically sponsored,

and one that is a Republican alternative to the Clinton plan. They are the three major alternative proposals. There are others that have been mentioned, some that have been proposed, but these three are the ones that seem to be generating the most interest.

Representative McDermott's bill -- which is the leading single-payer health care reform proposal on Capitol Hill -- advocates mandatory coverage and does have language in it regarding women's health, although the difficulty that we see with these bills is that much of what is written is very vague and is being left up to various boards that will be formed if and when these bills are passed. That language-- This failure, actually, to specify exactly what is covered under the basic benefits package is of concern to women looking for assured access to reproductive care.

Since it is generally believed that bipartisan support and collaboration will be necessary, efforts in Congress are likely to focus on identifying common elements of these bills and the positions of major health care leaders and organizations, in order to develop a compromise proposal. As early as late March, we expect, congressional committees could record the first votes on whether abortion services should be covered as part of a full range of reproductive rights for all women.

Relegating the abortion decision to the states or rendering it entirely optional for insurance companies are fast becoming politically palatable compromises for some lawmakers. Congressman Cooper has recently suggested the idea of excluding abortion from any benefits package and treating it as an optional benefit, requiring women to pay additional insurance premiums if they want to be covered for these services. According to the American Public Health Association, the Cooper proposal is aimed at discriminating against one service in what should be a full spectrum of women's reproductive health care.

We expect that there will be some action in the upcoming session. The fate and the final form of these bills is obviously fluid and is going to change over the next several months. The most popular prediction is that some type of reform bill is likely to pass Congress; however, none of the bills have any complete support or enough passage in both the House and Senate.

Historically, women's health has been treated as an afterthought. Women have been systematically excluded from medical research studies, received less aggressive treatment for heart disease and other serious conditions, and lacked access to important preventive services. This is not a political debate over abortion or contraception, but rather a critical debate over health equity for women. Who will be covered, how coverage will be financed, and how costs will be contained remain the thorniest issues. Conventional wisdom holds that support is there for universal coverage; however, on a slower timetable and with a narrower package of benefits than what is initially in the Clinton plan.

While the Clinton plan is not perfect, we urge all participants in this Commission to work together to develop reasonable, workable alternatives that support a health care reform package that treats women's health equally to men's. We look forward to working with the Commission and other colleagues on this health care system that offers women equal access to comprehensive health care.

I thank you for your time today.

MS. JACOBUS: It sounds as if you and the other executives at UMDNJ are in the thick of the strategy -- the national strategy -- for positioning in this health reform effort. What do you think are the most effective means for the voices of women in the nation to be most effectively heard in this debate?

MS. TICE: Well, I can tell you that there is a congressional caucus for women's issues that has been very vocal and it has taken a stand. They've outlined eight principles that they are advocating in support of women. We, at the University -- some of my colleagues -- have talked about some of the issues that we've been involved in in promoting women's health. We have Women's Wellness Centers now at several of our campuses, and have been very much involved in some of the studies that are bringing more women into the research areas. There is great concern that women have been left out historically from these research areas. With components such as the division in NIH, that is on women's issues, we find more and more that the focus-- I believe that the Clinton administration has also focused more attention on women than may have been done in the past.

As you may be aware, our own President has served on the task force that did help advise initially, when Mrs. Clinton and her task force were developing their plan.

SENATOR LIPMAN: Any other questions? (no response)

Thank you so much for coming. We appreciate it.

MS. TICE: Thank you.

SENATOR LIPMAN: I think we have a little break coming.

(RECESS)

AFTER RECESS:

SENATOR LIPMAN: Dr. Meredeth Turshen, who is from the School of Urban Planning and Policy Development, Rutgers University.

M E R E D E T H T U R S H E N, Ph.D.: I really just wanted to talk to you today about some research that I've done on sex harassment and sex discrimination, and to try and tie it down to what's happening in New Jersey. I'm looking at these issues

as they affect women's health care, research on women's health, and the education/training of women in the health professions.

I'm especially concerned about the findings on minority women, and I want to point out that it is very hard to track them because of lack of data. Most of the studies address the problems of either minorities without regard to sex, or they compare black and white, or white and nonwhite, as they sometimes do, or they look at women's problems in comparison to men's without regard to race. So black women just sort of fall out of these studies and it is very hard to find out precisely what their experience is. I would like to recommend that this Commission make sure that all publications of the State data cross-tabulate according to race and sex or ethnic affiliation.

I would like to look first at the impact of sexism on women's employment in the health professions, because the medical gender gap is really striking.

Nationally, only 8 percent of surgeons and 16 percent of physicians are women. Women doctors earn one-third less than their male colleagues; that's even lower than women across-the-board in all professions nationally. Few women are deans of medical schools or chairs of medical school departments, and just 21 percent of medical school faculty are women. That's the national figure. Now, UMDNJ does slightly better than that national average in New Brunswick, where 33 percent of faculty are women, but only 1.6 percent of New Brunswick faculty are black women. Camden is more like the nation; 21.5 percent of the faculty are women and there are no black women on that faculty. That seems to me an egregious omission, especially given the population of the City of Camden.

Nationally, in 1990, 36 percent of medical school students were women. I was surprised to find that UMDNJ-RWJ ranks 76th in the country. That means that there are 75 schools that do better than we do in having women in medical

school. NJMS ranks 72nd. In 1993, 39 percent of students enrolled at UMDNJ-RWJ -- and that's Camden and Piscataway campuses combined -- were women; only 6 percent were African-American women, and 3.5 percent were Hispanic women. That's far lower than the representation in the State population. At NJMS, 40 percent of students were women, 5.8 percent were African-American women, and 4 percent were Hispanic women.

I teach in the New Jersey graduate program in public health, which enrolls more women than men in the Masters program, but as of 1993, had graduated only three African-American women -- the program has been in existence for almost 10 years -- only one Cuban-American, no Puerto Rican women, and no Mexican-American women. Here, again, I would guess that one could make demands on the school to do a bit better in its recruitment. It seems to me that the conclusion is inescapable, that sexism and racism are still the rule in medicine.

The picture is hardly brighter in other university faculties, where women are still underrepresented. Men compose 72.6 percent of all faculty, women 27.4 percent. One could look at the personnel practices and account for this limited picture in change over the last decade. More white men are hired in beginning tenure-track positions than women or minorities. The tenure rate for white men is higher; their promotion rate is more rapid. Minority women are particularly underrepresented, with a percentage of African-Americans decreasing over the years and that of Latino faculty remaining minuscule. Women's salaries are lower than men's in every academic rank, and too few women hold administrative posts where budget and policy decisions are made.

We fear that the gains of the 1970s in terms of tenure and promotion of women and minorities may disappear as the

older generation of academics retires or dies, unless good-faith efforts are made to hire, retain, and promote new women and minorities.

Financial cutbacks now endemic at State universities and colleges have a disproportionate impact on women, many of whom are vulnerable because they serve as part-time faculty or in administrative posts that are not protected by tenure. University programs that nurture women students, such as Women's Studies, are typically underfunded, vulnerable, and they're unrewarding to the faculty in terms of tenure and promotion.

If university policies do not begin to reward devoted teaching and student advisement, fewer and fewer women faculty -- and especially minority women faculty -- will offer these important services. They tend, in fact, to get swamped. They tend to be the token person on every single committee and it's far beyond what they can keep up with, do their research, and get promoted.

If women students are to enter the sciences, including medical science, institutional changes and more scholarships are needed to encourage them to select these fields, because they've not felt welcome in them in the past.

Repeated studies show that affirmative action programs do improve the access of minorities and low-income people to health care. More blacks and other minority physicians train in primary care specialties and serve in inner-city areas. Admission to the medical profession is more than a moral issue or a test of democratic principles or equity; it resonates with social need and the distressing inequity of the health of minority groups. Can't we do better in New Jersey? We need more minority women in health care, in medical research, in medical training, and university education. The need is especially acute today given the changing population and demographics in our State.

Throughout the 1980s, the social service literature documented the growth of poverty among women. Although women fared better in New Jersey than in the nation, 32.8 percent of female-headed households with related children lived below the poverty level in New Jersey. A higher percentage of blacks, over 19 percent, Hispanics, also 19 percent, than whites, only 5 percent, live below the poverty level in our State.

Gender bias affects the type of health services extended to minority women, and their needs differ from those of the majority. Because minority populations are growing at a faster rate than the white majority, minority women need more maternal and child health care, more family planning, more adolescent services, probably more mental health services, and especially, protection from domestic abuse. With the exception of affluent blacks, who have a lower birthrate than whites, minorities are having more babies and Hispanics have very high birthrates. The 1990 census shows enormous growth in the Hispanic population in New Jersey, up over 50 percent from 1980, but nothing comparable in the training of Hispanic women in the health professions in our State.

Faster population growth rates also affect the age structure of populations and translate as a need for different kinds of service. Minorities are younger than the white majority. Latinos, for example, are one of the youngest populations in America, with a median age of 26 years. That compares to 27 as the median for African-Americans; for whites it's much higher at 33. Yet everywhere in health circles, the talk about the aging American population and the health system has shifted to meet the needs of geriatric patients. In New Jersey, indeed, we have a large population over 65 -- it's over 13 percent -- but we also have a very important population under 15 years old -- almost 20 percent.

I'd like to turn now specifically to sexual harassment and bias against women, which are two of the greatest hindrances to the professional advancement of women physicians

and medical students. A study was done by the American Medical Women's Association in Massachusetts that found that 54 percent of respondents encountered some form of sex discrimination; 27 percent experienced sexual harassment; and 24 percent complained of discrimination related to parenthood. I'd like to see a similar study carried out on our medical campuses. That study did not look at minority women, and I think if we do such a study, we should specifically look at minority women and single out their problems.

The two areas of health care most affected by gender bias are the different treatment of female and male patients and the lack of research on women's health issues. In a review of clinical decision making, the AMA Medical Council -- not known to be particularly progressive on this issue -- found that, although women received more health care than men overall, women's health care consisted of drug prescriptions and routine checkups; whereas, men received major diagnostic tests and therapeutic interventions. The effect of the disparity can be life-threatening. For example, doctors order more tests to diagnose lung cancer for male smokers than for female smokers, and more cardiac catheterizations, which are a prerequisite for coronary bypass surgery, for men than for women.

Social attitudes including sterotypes, prejudices, and other evaluations based on gender roles, rather than biological differences between women and men, account for gender disparities in rates of cardiac catheterization, kidney transplantation, and lung cancer diagnosis. This is actually the conclusion of the AMA Council on Ethical and Judicial Affairs.

Physicians, they said, were more likely to attribute women's health complaints to emotional rather than physical causes. They don't believe women when they complain, in other words. Male practitioners share a general perception that

men's social role obligations and their contributions to society are greater than women's. This means that doctors believe it's harder for men to take time off from work and accommodate health care, and they consider their financial contribution to the family more critical than women's. We just earn pin money, right? Therefore, they are more likely to perform a kidney transplant -- which is much less cumbersome than dialysis -- on men than on women. Unfortunately, again, the AMA report -- this is, as I said, typical -- does not address the additional problems that minority women may encounter.

The trend in gender bias in health care continues despite strong protests from women themselves. In New Jersey there is a chapter of the National Women's Health Network. We have had a meeting on gender discrimination in the health care system in New Jersey, where we had women come forward and testify as to the kind of experiences they had encountered. The Women's Health Initiative, and the creation of the Office of Research on Women's Health in the National Institutes of Health, are national attempts to fill the gender gap left by research done mostly on middle-aged, white men. I'd like to see an office in the State that fulfills the same function -- overseeing women's special health needs.

I'd like to finish now with some new questions about affirmative action. Health care institutions need a clear policy on discrimination against women and mechanisms for handling grievances and the resolution of bias cases. At Rutgers University we're in the process of adopting new wording for precisely this issue of sex bias, sex harassment, and how to handle grievances.

Health care providers also need to have the will to enforce antidiscrimination policy. Minority women patients often complain of disrespectful staff, and a feeling that they are pressured to conform to majority values. The problems of

ethnocentricity may be overcome by inservice training and cultural awareness by the recruitment of minorities in decision-making positions, community outreach programs, community participation, and input into management. Institutional leadership that sets the right tone can also help. I notice that Dr. Goldstein, for example, at the Environmental and Occupational Health and Safety Institute, routinely puts out notices about these issues to remind the staff that sexual harassment is a real issue.

Despite what we know, opposition to affirmative action has grown considerably since the 1978 Bakke decision focused national attention on medical school policies for the recruitment of minorities. We need to clarify that affirmative action also refers to gender bias against white and minority women. We need to reinvigorate the purpose of affirmative action, enlarge its meaning, examine it in the context of all preferential practices in education and employment, ease minority students' transition from secondary school to university and from university to medical school, provide more scholarships for women and minorities, nurture historically black institutions, integrate multiculturalism and diversity in the curriculum, and expand affirmative action down to the level of preschool programs.

Thank you.

SENATOR LIPMAN: Seems pretty thorough.

DR. TURSHEN: My written testimony has a lot more details in it, so I'll just submit that for the record.

SENATOR LIPMAN: Thank you very much.

MS. JACOBUS: Thank you, Dr. Turshen.

SENATOR LIPMAN: Any questions?

MS. SEHAM: I'd just like to add something. At a cocktail party, a doctor approached me who was on the administrative committee of his hospital and said, "What should our hospital be doing about sex discrimination -- sexual

harassment -- any kind of sex discrimination?" I gave him a few thoughts on it and he was polite. But when I mentioned that I had a case in which a woman complainant had been awarded a large financial settlement, he paid much more attention to what I had to say than he had before. So I think maybe there are all kinds of good reasons for having affirmative action, but I think maybe we need the carrot and the stick to let these people know. Maybe some of the bulletins that are handed around should be what some of the latest settlements have been.

DR. TURSHEN: A good project for a woman student who is studying for law in either Camden or Newark, to take a look at what awards have been made in the State. Do a little paper on it and circulate that. It would be interesting to do that.

MS. GRIFFIN: They could certainly do that in the area of malpractice.

DR. TURSHEN: Right.

SENATOR LIPMAN: You're being rough.

Anybody else? (no response)

Thank you very much, Dr. Turshen.

Dr. Howard Holtz from St. Barnabas.

H O W A R D H O L T Z, M.D.: Hi. This was nice, one time I didn't have to travel to go anywhere. (laughter)

MS. JACOBUS: Well thank you very much for this facility. It's been very good today.

DR. HOLTZ: I'm glad it worked out for you.

I'd like to just open my remarks with two experiences. I'm an Associate Director in Medicine here at St. Barnabas, but for the last eight years I've been Director of a domestic violence prevention project, which I originally started over at the medical school and brought with me from Newark to St. Barnabas. The purpose of that project is to educate health care professionals about domestic violence, to augment their identification rates, and to improve the way they manage and refer victims of violence in their practices. We

also provide service through some of the shelters in New Jersey. We have a nurse practitioner who is at a shelter site and refers to St. Barnabas. We have about 70 doctors here who have agreed to see women from shelters on a pro bono or insurance-only basis, and we do some research in domestic violence -- health care service research.

When I first got started in this about eight years ago, there was very little in the health care field about domestic violence. I remember when I spoke about domestic violence to a grand rounds recently, at a suburban hospital in this area, an internist raised his hand at the end of the program and said, "But I can't understand why you are focusing so much of your energy and attention on domestic violence. I've been in practice for 25 years and I have seen one woman who has experienced domestic violence." So I diplomatically translated that back to him as saying what an inadequate job we all have been doing in identifying victims of domestic violence in the health care field.

That's unusual now, because the American Medical Association, the American College of Physicians, and the American College of Obstetrics and Gynecology have all given a lot of attention and publicity to this in medical literature and in the journals which they distribute to their membership. So it's unusual to find somebody like that, but I'm not so sure how much practice standards have changed when you get into the room, into the clinic, or into the cubicle of an emergency room. Even when we do identify domestic violence, the response in our coordinating with other agencies can be less than optimal.

Back in Newark -- and this is the second anecdote before I get into the formal part of the presentation -- a resident that I was supervising clinic for, identified a woman who was beaten and who was ready to leave her violent relationship, which is unusual. We usually see women who are

not at that point in the clinical setting yet. But she had done all the things she would have been counseled to do on her own. She had packed, she had saved money, she had prepared to leave, and she needed somewhere to stay to pick up her paycheck in two days. Then she was going to leave and go back to her native country in the Caribbean.

We called a shelter, they had room for her, and she was going to stay there for a couple of days, but she needed a restraining order for two days so that she would be able to get her paycheck and not have her abuser interfere with that.

So we called the police station to say-- I said, "This is Dr. Holtz. I'm over at University Hospital and we have this woman here who needs a restraining order." He said, "Well, bring her right over." So it was the end of clinic -- this woman had gotten there by bus -- I took her over and in my most officious, professional voice said, "I called earlier, this is Ms. So and So, and she is here to get a restraining order." The police desk sergeant -- I guess it was at the time -- looked at me and said, "Dr. Holtz, you don't know what goes on with these women. It's Friday afternoon, she will be back with him on Monday. Tell her to come back on Monday. If she's still interested in this, we'll see what we can do."

That kind of opened my eyes outside of the academic world of health care delivery to domestic violence to almost what it feels like, I guess, to come into a situation -- a professional situation, whether it be the police, an attorney, a physician -- and have somebody totally invalidate what you've been through and the kinds of things that you've endured. Because I'm real nervous in police stations, it was a good lesson for me. I told him about the Prevention of Domestic Violence Act, and we got the restraining order that night.

But we sometimes, in trying to teach about domestic violence to physicians, have to get across that there is a network out there that is ready to help these women once we

refer them; that's the police, the shelters, the counseling services. That's part of what we do and part of what we stress in our education.

Specifically related to this Commission's charge of sex discrimination in the statutes, I have thought about what could be done legislatively to improve the health care response to domestic violence. On the whole, the health profession probably identifies anywhere from 5 to 10 percent of victims correctly that come into a health care setting, which means that we do not identify 95 percent of patients. We know that protocols, when placed in emergency rooms or clinic settings, increase the identification rates. We know that education is helpful. So the question I asked myself is: "What do we do legislatively to make sure those protocols are in place, to make sure that doctors have the proper education?"

After thinking about that long and hard, I thought that there should be no mandatory curriculum that's legislated, either in medical schools or postgraduate medical education. This is something that the medical schools and the residency programs have to see as an important issue for themselves. I think we have had the lesson that you just can't legislate practice behavior. So I think that's a job for the medical schools -- through the initiative of the educators, through private foundations -- to address.

On a practice level, should there be mandatory reporting of patients who have experienced domestic violence? Again, I think not. I don't think that competent women who have experienced violence, who go to their doctors and depend on that trust and confidentiality, should have the specter of mandatory reporting to some adult protective service agency. This isn't the model of child abuse. We're not dealing with developmentally or cognitively incompetent patients, and after thinking about it long and hard, I am very much against any

kind of mandatory reporting other than for statistical purposes, on an anonymous basis, about domestic violence in clinical situations.

In New York, there is mandatory training when you go for your license or your renewal of your license, in domestic violence, and that encompasses child abuse, adult battering, and elder abuse. This is a possibility that-- Since traditionally domestic violence -- as opposed to many other social problems that have health care significance, like alcoholism -- has received little curricular time in undergraduate and postgraduate education, that is a possibility, requiring practitioners on renewal of their licensure to have some convenient, continuing medical education credit available to them to make sure that they have some working knowledge of the issues of domestic violence. I'm not totally convinced that that's a good idea, but I bring that up for your consideration.

Being a doctor, as well as a domestic violence advocate, it is, again, something where there are probably scores of health care for social interests that bear upon the medical profession and we can't, certainly, legislate all of them. But I think if you look at the time that we spend on geriatrics, that we spend on child abuse, that we spend on alcoholism, that we spend on mental illness -- problems with clear social connections in the medical curriculum -- we really have a disproportionate lack of training in domestic violence.

My project surveyed all North American medical schools back in the 1987-88 academic year, and found that 53 percent had absolutely nothing on domestic violence. That was with a very liberal definition of what curriculum in domestic violence could be. That was, if anybody mentioned anything during a course or a preceptorship on domestic violence, we counted it. Still, at that time, the majority of medical schools in North America had nothing. We're redoing that survey this year and

hopefully we will find an improvement. But I am sure that we will still find a major lack in that kind of education.

Certainly, that is discrimination if doctors don't know how to recognize one of the major public health issues for women in this country. It is as blatant as the kind of more publicized discrimination we've seen in women's health care research issues. We do have regulations in the State of New Jersey that the Department of Health adopted for guidelines -- quality of care guidelines -- for emergency rooms, on how to take care of, how to identify, and how to manage women who have experienced violence.

The national accrediting organization for hospitals, the Joint Commission on Accreditation of Health Care Organizations -- JCAHO -- came out with those first, and we very strongly advocated that similar guidelines be adopted in the State of New Jersey, and they were. I think that's something on an enforcement level that certainly can be done at this time. When the State does their hospital inspections -- in emergency rooms -- they look at a number of different things, but we know right now that the compliance with those regulations -- the national and the State regulations -- is not what it should be. I don't want to give you the data. They're from the Family Violence Project in California, and they haven't been published yet. They surveyed emergency rooms -- I believe 89 in New Jersey -- and one thing we can do right now to make sure that women get the kinds of options, education, and sensitive care that they deserve in New Jersey's emergency rooms, is to make sure that those existing guidelines are enforced when they come and do State inspections of our emergency rooms.

That's about all I have to say formally. I would be glad to answer any questions.

MS. JACOBUS: You've given this some long and hard thought, and you've had a great deal of experience that lies behind you're saying that the "stick" approach is perhaps not

too useful in trying to get doctors to identify domestic violence. What about the "carrot" approach? This is pie in the sky, but would a small amount of money sitting throughout the State Department of Health to be awarded to those hospitals which most improve their identification of domestic violence in the ER site be at all useful? What sort of carrots could we offer to emergency rooms?

DR. HOLTZ: I think that's an excellent idea. I think whether it be money, an acknowledgement, a certification, or an award to emergency rooms that have protocols in effect and that, most importantly, network with existing community agencies, emergency rooms that call the shelters, that call the counseling agencies, that have the hot line numbers and the shelter program information available in the emergency room, would be an excellent idea.

MS. JACOBUS: I spoke to the gentleman at the Joint Commissions who is in charge of gathering the data on compliance with the domestic violence protocols being in emergency rooms, and it didn't sound as if, at this point, they were in effect in any major way. They were sitting there and not a whole lot of data was being gathered on it; if it was, it really didn't impact on the accreditation of the facility. Do you see very much effort being put into strengthening that "stick"?

DR. HOLTZ: Well, that "stick" needs to be strengthened most probably through sanctions from the JCAHO. They're probably giving some leeway, because they are fairly new guidelines, to give health care organizations time to adopt and develop their own protocols. But it's been a couple of years now and I think if ERs start to get sanctioned by the JCAHO for not having those in place, that's obviously the next step to go. It seems when you look at this in a qualitative way and not a quantitative way, when somebody is there who is identified in the emergency room as the domestic violence

person, who is committed to it, and does the inservice trainings over and over again, as opposed to just coming in doing an inservice-- You know, the turnover in health care facilities is enormous, and in six months you've got to search all over again, "Who put the domestic violence-- Where is the domestic violence protocol?"

MS. JACOBUS: I think in a number of facilities in New Jersey there is no designated person.

DR. HOLTZ: Right. I think a key issue that probably doesn't cost anything, is that one person in an emergency room is designated as being responsible for making sure that the policy-- Because you'll probably find the policy, but it's underneath some lab work, or underneath the drawer where the syringes are, or whatever.

MS. WALDOR: Do I understand you to say that you are philosophically opposed to legislation because you don't think that behavior modification, so to speak, in recognizing domestic violence can be legislated, that it has to be learned?

DR. HOLTZ: No, I don't think that-- I'm not against legislation for, for example, mandatory reporting because I don't think it would change behavior. I think that, you know, if you look at child abuse, that really changed behavior.

MS. WALDOR: Putting mandatory reporting aside, I think that's a different issue.

DR. HOLTZ: Okay. Because that's a different clinical issue.

MS. WALDOR: I agree. I think that's a totally different issue. But what about legislation that would somehow make it easier in the medical schools? There are still general practitioners, aren't there, in community neighborhoods?

DR. HOLTZ: We call them primary care doctors nowadays. Yes. That's the buzzword.

MS. WALDOR: Primary care doctors. You know, your family kind of doctor. I imagine in cities you have more primary care doctors, perhaps, than in the suburban areas?

DR. HOLTZ: Actually the opposite. It's hard to get primary care doctors into inner cities because of issues like Medicaid reimbursement and things like that.

MS. WALDOR: How do you get primary care doctors to recognize domestic violence signs without an emergency room situation? How do they familiarize themselves with the signs if medical schools aren't teaching them?

DR. HOLTZ: Well, education in the health professions is ongoing. Everything that I learned in medical school 15 years ago is pretty much wrong anyway, so doctors continually have to read journals and go to continuing medical education courses, etc. But that's a slow process because there are many people who don't update themselves.

When the usual channels for education in the health professions are used -- and that's usually through whatever health care professional organization that person is affiliated with, whether it's the American Academy of Family Practitioners, the Association of Emergency Room Docs, the internists, the obstetricians, the gynecologists, they all have their own clubs and organizations that do a lot of teaching, setting practice guidelines, sending out bulletins, and things like that-- We've done a lot of work through that. The American Medical Association for some of its lack of -- as I heard earlier -- progressive attitude on some of these issues, has developed a national resource center on family violence, and has publicized this over and over again in the "Journal of the American Medical Association." So now, as opposed to 10 years ago, it is unusual to find somebody who doesn't understand this as a health issue.

MS. WALDOR: But it's still treated-- I mean, you hear these horror stories in these general care, primary care situations where it's repeated abuse, as child abuse used to be.

DR. HOLTZ: Right.

MS. WALDOR: The same situation, I think, exists in domestic violence, wife abuse, or if husband abuse exists, that situation as well, where willingness to recognize the symptoms, if you will, or the signs just doesn't seem to be there.

DR. HOLTZ: Well, that's certainly a problem and if there were a malpractice suit tomorrow, where the wrong kind of care was administered, the patient's safety was not taken into account, and something happened-- I think that kind of thing, when that gets publicized -- as was mentioned earlier -- is very important. How to change practice behavior legislatively for adult medicine--

MS. WALDOR: That's what I'm talking about. Wouldn't that be a more efficient way to kind of force education?

DR. HOLTZ: Yes, but what I really brought up for discussion was, how would you do that? Why would child sexual abuse not have the same requirements? Why would eating disorders not have the same requirements for legislated continuing medical education? I brought up the New York model of when you have to get your license--

MS. WALDOR: Right.

MS. SEHAM: How frequently is that, by the way, in New Jersey? How frequently does the license have to be renewed?

DR. HOLTZ: Every three years, I believe. Is that right? I just send in the check.

MS. SEHAM: Don't doctors in New Jersey have to have a certain number of hours of continuing medical education every year? No?

DR. HOLTZ: No. It depends. Some of them need that more and more now because the HMOs are requiring it, or the hospitals are requiring it for them to have staff privileges. So increasingly, yes, and it's hard to find somebody who doesn't have continuing medical education credits. That would be somebody who belongs to no managed care networks that are

requiring it -- which is becoming more and more unusual -- or belongs to a hospital that doesn't require any continuing medical education to stay on the staff.

MS. SEHAM: So your suggestion was that a possible avenue was to require that all doctors have some continuing medical education in not only recognizing, I think, the signs of physical violence -- domestic violence -- but I think perhaps learning something about resources in the community so that referrals could be made -- that that kind of education be made a requirement for license renewal? You'd get everybody within a three-year span that way.

DR. HOLTZ: You would get everybody, but then you would have a legitimate argument by the Medical Society of New Jersey, and other groups, which would say, "Why not 15 other social reasons? You're starting to legislate curriculum for doctors."

MS. SEHAM: Not in the medical schools, but for renewal of the license.

DR. HOLTZ: Right, not in the medical schools.

MS. SEHAM: Renewal of the licenses. I mean, that's kind of known as a parade of the horribles; if you did this, look at all these other terrible things that would happen. But if we decide that this is a major concern for the State of New Jersey, then we could go ahead and do it. Then the other people who would come along and want their pet disease or pet ailment taken care of, would have to make their arguments with the Legislature.

DR. HOLTZ: In some ways, the government could foster and facilitate education that is already in place. We teach all of New Jersey's fourth-year medical students in part of a required course at UMDNJ. I go over there and a social worker from one of the shelters goes over there. We spend a couple of hours with the students. If that were made more standardized through UMDNJ -- through the health care -- then you wouldn't

have the argument later on -- if you pass legislation like that -- of the male urologist who specializes in male infertility saying, "Why do I have to learn about domestic violence for four hours CME credit to get my license?" That's just the kind of argument you're going to get.

One other thing I neglected to mention before, which I don't know if anybody else has testified to: Through the Pennsylvania Coalition for Battered Women, we've become aware of cases of health insurance companies which are denying coverage to women based on the fact that they might have domestic violence histories, not just for health insurance, but for mortgage insurance and life insurance. I'm certainly happy to see that the insurance companies realize that this is an actuarial risk for your health, as far as being in a violent relationship, but it's kind of like blaming somebody for walking on the street when they get hit by a drunk driver.

MS. SEHAM: It's kind of an assumption of being accident prone, isn't it?

DR. HOLTZ: Yes. I think if there was one thing -- as I was reviewing these -- that could be legislated or regulated, it would be through the insurance agency in the State, to make sure that any history or anywhere where it is written in a medical record that an insurance company gets a hold of, that this person has experienced domestic violence, or they just get that from the individual themselves, that that cannot be used to deny insurance coverage for health insurance, life insurance, or anything else. I think that that's something that is clearly within the realm of what government should do for battered women.

SENATOR LIPMAN: Thank you, Doctor, very much.

DR. HOLTZ: Thank you.

SENATOR LIPMAN: Dr. Elaine Leventhal, please. Department of Gerontology, UMDNJ.

E L A I N E A. L E V E N T H A L, M.D., Ph.D.: I want to thank you for inviting me to come. Now, at what I gather is at the end of your hearings, I'm going to talk to you about the end of a woman's life span. That's of particular concern to me as a physician who deals with the aging, and certainly with aging women, because, as you know, the population demographics as projected into the next century very clearly show that there are more and more older women living to be older and older. The difference in the life span between men and women is continuing to remain significantly longer for women.

At this time, since I was asked to address the issue of the potential impact of health care reform on older women-- This very critical issue-- Women have a greater life span. They suffer higher rates, however, of morbidity, which means illnesses throughout their lives. They use the health care system and if they accumulate more illnesses as they get older, their impact on the health care system continues to be great. If the basis of the current reform movement is to control health care costs -- which is obviously the bottom line -- and yet supposedly guarantee access to everyone, there is certainly, from my point of view, the potential for actually rationing health care for older women on strictly a chronological and, as I see it, irrational basis.

We ration health care now, as you all know. We ration it strictly on the basis of who has access to entitlements or other forms of health care insurance. Women who have not worked -- and certainly this is the elderly cohort now -- did not have access to other forms of health insurance except primarily that supplied through Medicare, unless they have had various other accesses through their husbands. The numbers of women who have inadequate health care in this particular cohort is great. Medicare benefits, if you look at them globally, average approximately 40 percent of medical expenses incurred by the over 65-year-old woman.

I've been very interested in health care delivery that has been based primarily on gender and on age. There is growing literature now as the Federal government has been concerned about women's health care issues, and as there is now a women's health care initiative, there has been concern, as I mentioned, about the fact that women have not had equal access to health care as they've gotten older.

From the research point of view, women have been systematically excluded from research which drives health care delivery patterns -- treatment. So they have been excluded on the basis of gender and on the basis of age. Much of our health care given to older women is extrapolated from research done on men and older men. We are biologically different with respect to when we get sick, how we get sick, and how we respond to treatment. We are now beginning to see that and we don't always have the knowledge base on which to then deal with the older woman.

I have collected several articles looking at hospitalization rates, and looking at differences in diagnostic procedures for women for the most common illnesses, which are heart disease and cancer. Women develop heart disease later than men, because they are protected by their estrogens during the menopause and they don't begin to present disease until approximately 10 years after a man will have the same illness. They do not get diagnosed at the same rate. They do not get referred for diagnostic procedures such as angiography, which would then determine if they are candidates for surgery or other kinds of invasive procedures. When and if they do get these procedures, they do less well. They do less well for reasons which we think we're beginning to understand: because they are older, sicker, and there is a greater delay before they are treated.

The same holds true for cancer of various types, in particular, breast cancer in which we have more and more evidence that treatment does prolong the life span of a woman

and does prolong the life span of an older woman. If you look, however, both here and abroad, older women get much less aggressive care, much less definitive care, and if you read or try and determine why, it is clearly that they are being discriminated against on the basis of age.

Now, this I see is truly going to be the dilemma of the next couple of decades. I anticipate that if there is not a very clear and vigilant attitude to look at how health care policy is designed, to try and protect women's access to health care as she gets older, we will continue to see rationing based on gender and on age for this particular population.

There are other components of the health care reform movement that are also particularly relevant for older women; that is, at this particular time, the willingness to postpone providing moneys for long-term care. Women provide the bulk of long-term care and then when they are in need of it themselves, there is no one to provide it for them. Indeed, there may be relatively very limited resources in order to ensure that they get care without being totally destitute. Again, I would urge that there is attention to these issues in terms of legislation in this State.

Finally, what is probably even more important, we have never traditionally been willing to pay for prevention and health maintenance. We've always been quick to jump on the crisis and pay for the catastrophic problems, which is probably why health care is so high. What must be built into reform of health care is reimbursement for prevention and for health maintenance. Prevention of the loss of function is really the key to controlling health care costs; the key to also controlling quality of life as women age. I'm not urging that we be overly aggressive if we have no opportunity of providing some benefit to an older woman, but they should not be denied access to health care that could, indeed, prolong their life at a level of quality and function which is dignified.

Thank you.

SENATOR LIPMAN: Thank you.

Are there any questions?

MS. JACOBUS: Dr. Leventhal, I have one question: From your very global view of the impact of health care reform on older women's health and health in general, do you believe that the growth of HMOs -- where many of them function by awarding a certain amount of money to health care professionals regardless of the amount of care that will be needed in the outflow -- will result in greater emphasis on prevention to lower costs, or simply in greater refusal to pay for needed care?

DR. LEVENTHAL: Well, I think both of the above. I think there will, indeed, be more emphasis on prevention and attempts at interventions that may have some long-term affect, though we don't really have good research that demonstrates which interventions applied when, really have an impact on long-term outcome.

There is an enormous interest in cholesterol. Everybody wants to know what their cholesterol levels are. The older my patients are the more they want to know what their cholesterol levels are, and they want to do everything to lower it even though they have extensive vascular disease from here (indicates) all the way down to their toes. They will not buy anything in terms of life span prolongation -- perhaps two or three days -- if they take these lipid lowering drugs for five years. Yet, they put themselves at jeopardy for problems with the liver as well as the cost incurred at monitoring their cholesterol levels, and yet "prevention" in that arena is misplaced. Prevention in that arena at a 30-, 40-, or 50-year-old will buy something down the line.

So I am not sure that HMOs necessarily will be putting their money in the best place when they put it in prevention, because, as I said, we don't have as much data as we should. But it is also very clear, if you look at studies of referral

patterns from people enrolled in HMOs, and those are fee-for-service, the HMOs certainly do triage and ration health care. That may be perfectly appropriate if we know that outcomes will be minimal in terms of certain aggressive treatment.

I have no problem with saying that everyone is not a reasonable candidate for surgery. Not everyone should go to intensive care units when they become deathly ill in the hospital, because many people don't come out of it. Doing cardiopulmonary resuscitation on an old person does not work. The number who actually leave the hospital is so small -- it is 1 percent to 2 percent -- that offering it indiscriminately is something that's wrong ethically and morally, yet the public expects that it should be offered. We have a massive education challenge on our hands if we are willing to confront it, and if we are really going to reform health care. But I do think that HMO rationing per capitation does, indeed, represent a diversion of people who are assumed to be at risk for not benefiting or costing the agency too much money -- being diverted away from health care.

MS. JACOBUS: Do you see the possibility that these capitation policies may be able to be discriminatory toward women and minorities?

DR. LEVENTHAL: Yes.

MS. JACOBUS: So that women and minority diseases such as, let us say, lupus or some other diseases, may be rationed out of the system or have lower accessibility?

DR. LEVENTHAL: I think that's a definite risk and we have to be very vigilant about that. Yes, I do, and it's a concern to me because I would want decisions about health care not based on general criteria, but rather based on the individual's particular status and opportunity to benefit from treatment. I mean, that's really the bottom line: How much

can this individual really benefit? We have to be willing to address that issue and also put resources into trying to understand more about natural history, so we make, again, reasonable decisions.

MS. JACOBUS: Thank you very much.

SENATOR LIPMAN: Thank you, Doctor.

Our last speaker is Donna Miller, who is Chair of the Women and Health Task Force of NOW-New Jersey, and a research scientist at a major New Jersey pharmaceutical corporation.

D O N N A S. M I L L E R: (distributes literature) There are also some resource materials there for you.

First, I'd like to just thank the Commission for this opportunity to speak to you today. We appreciate your existence. You've done a lot of good work for women in this State, for all people in the State, so thank you very much.

My name is Donna Miller, and I am Chair of the Women and Health Task Force of NOW-New Jersey. I represent the membership of NOW-New Jersey -- about 12,000 women and men who work to advance women's issues. I also speak for women of New Jersey who need a stronger voice to effect change and progress for health-related issues, something that will affect every woman in this State. My Task Force, its members, and the leadership of NOW-New Jersey, are trying to change the current status quo of health care for women in New Jersey for the better.

As all of you know, there is a problem in dealing with women's health issues in the United States and the problem doesn't stop at the border to New Jersey. Unfortunately, women, as a class, face discrimination of various kinds in both access to health services and health research; this even though women make up 52 percent of the United States population and comprise approximately 4 million of New Jersey's population. Traditionally, women have been treated as second-class citizens in science and medical research, as well as medical practice. Increasingly, their health care is being compromised by

political or religious issues like those surrounding contraception and abortion.

New Jersey, with its extensive pharmaceutical industry and its high-quality medical schools, could, and should, serve as a model to the rest of the country in changing the way things are to the way they should be. New Jersey could help end the gender gap in medical services, access, and research. In this testimony, as well as the other testimony you've received, you'll start to see a blueprint emerging that I think can help -- be used -- to achieve the goals of equality. It's by no means a complete picture of what could, or should, be done to make things progress, but it is a skeleton that we hope this Commission, this State, and our Governor will use to embrace, enhance, and build on to make New Jersey a better place for women and men.

In the following testimony, I'm really going to focus on two areas of concern to our Task Force, as well as the women of New Jersey. Those are the issues of coordination of women's health care access issues, and women's health research. I'm really going to briefly present this, because it is going to be a summary of the written testimony, and to try to get this in, in 10 minutes or less, is a little difficult. So I ask you to please look at the written testimony, and I am sure you will.

Access issues, coordination issues: Access and coordination obviously cover a lot of ground and I am sure you're aware of that. From services, to training, to provision, and a lot of other things, they are most important. Without access, we have no effective coordination of health care in New Jersey or anywhere else.

One area I've personally heard about is mammography centers -- physical access. I've heard of women who are physically challenged, in other facilities also, but I specifically heard about a woman having trouble gaining access to a mammography facility either because the facility people --

the nurses and doctor there -- didn't have the training to deal with somebody in a wheelchair or there were just problems in terms of training. They claimed it was the machines, that they couldn't deal with a woman in a wheelchair. So obviously that should be dealt with with the American Disabilities Act, but apparently, in some cases, it still hasn't been. This needs to be addressed. Also, some facilities have very difficult, heavy doors to open. Physically, it's very difficult for even a healthy person to get some doors open in different facilities, and this is something that I think still needs to be addressed by whatever way that can be addressed in the State.

We all know of problems in terms of schedules regarding health clinics. Further work must be done to coordinate women's health care with busy schedules and child care needs. More mobile vans and innovative locations for provisions of health care might be further investigated such as using supermarkets -- a place almost everybody frequents -- for example, as a place for immunizations or other very noncomplicated care. It is something we should be doing more of.

A way to get early care done and better control over several epidemics in our society would be the institution of school-based clinics. This would help deal with the epidemic of teen pregnancy and the lack of care that a number of teens, especially low-income teens, receive at the present time. Many don't see doctors for many, many years and they have health problems that are long-standing and could be dealt with this way; including the TB epidemic -- that's a problem.

Coordination of care for women is another issue of importance. Action must be taken to ensure that all women receive all the care they need throughout life. Health services utilization by women is really a blocked box at this time. Experts tell us they need more data to develop a better system of health care for women. Alternative providers, like

nurse practitioners and physician assistants, might be used for more services than they are currently being used for to lower costs -- for more use of health services in general.

Services that women obtain from their doctors are, in many cases, fragmented. They're lacking because women are bounced from one doctor to another to obtain care. Their problems are spread out among various specialties, while no doctor really specializes in women's care. So women are basically forced to choose which doctor they're going to stick with and a lot of them decide to use their obstetrician/gynecologist.

My own physician apparently is dealing with a lot of this. She is dealing with primary care for most of her patients at this point. They're using her as their primary doctor and, as a result, she's super busy. She feels that her care for her patients might be lacking just from time constraints alone.

Often these doctors are also not trained to deal with the totality of women's health care. Some experts have suggested that a specialty dedicated to women's health would be a good idea, but others argue that this would be segregating care rather than an acknowledgement that all doctors should be dealing with all issues of women's health.

Physician's training is another area that needs attention. Curriculum needs to be looked at to eliminate sources of discrimination. One area that is just beginning to receive attention is the training of doctors and nurses to recognize domestic violence. It's a serious problem in this State, as well as in others. It basically accounts for more trips to emergency rooms than any other single thing in the United States. The priorities need to change on this issue and more people need to be taught about it.

Access to women's health services is also compromised by the lack of physician training. You just need to look at

the training of doctors to perform one of the most common surgical procedures in this country; the training in terms of abortions. Residents' training has declined more than 21 percent in recent years, with only 12 percent of new doctors receiving training as a mandatory part of their education. That such training is not mandatory is discrimination against women. New Jersey should investigate the programs of its medical schools and ensure that such training is required to erase the stigma the antiabortion zealots have tried to pin on this particular piece of medical care. Not training in this area allows marginalization of doctors and continues the violence to be perpetrated against doctors.

Insurance issues have become a major point of contention in New Jersey regarding access. Insurance companies try to avoid payment for care they consider experimental, while other doctors consider it to be normal care. I'm talking about bone marrow transplants, especially for breast cancer patients. Insurance companies tend not to want to pay for these, but they have in the past paid for this treatment for diseases in men. We need to watch this issue. I'm sure we've dealt with this in the recent past in the Legislature. Again, another issue of discrimination insurance-wise is a lack of coverage for birth control by many insurance companies; discriminatory, because most women deal with birth control.

Another issue is the silent, growing problem of insurance coverage for women's health clinics. Several incidences have recently come to light where insurance has been pulled from clinics or has been threatened to be pulled. This needs to be investigated further. We think it's something that is going to be a crisis for New Jersey, as in several other states.

MS. JACOBUS: Do you mean liability insurance? Insurance of the buildings?

MS. MILLER: Both liability for buildings and physicians performing abortions particularly, but also physicians who have worked in women's health clinics that don't do abortions, from what I understand. I'm not sure if that has happened in other states, but it has happened here. I'm sorry. I'm not positive that it's happened in New Jersey for physicians that work at these clinics that do not perform abortions, but in other states that has happened. Just because they are working at a women's health clinic which does abortions, their insurance has been pulled. So it's a problem.

Physical access is also a problem in New Jersey and has been for some time, just like in the rest of this country. Threats, pickets, blockades, stalking, and bombings have all occurred in New Jersey in the recent past. Denial of access discriminates against women because they are the only ones that get pregnant and must deal with it. Support of both State and Federal legislation to intervene in this situation should proceed and be strengthened. Terrorists should not be allowed to get away with what they've gotten away with in the past.

The issue of parental consent and notification is another area of concern to us at NOW-New Jersey, because it will definitely severely impact upon the health of young women. Because of this, NOW-New Jersey has a "no compromise" position on this issue and a number of you are aware of this. We see these laws as teen endangerment, laws rather than protection laws. We cannot legislate communication. We've begun to see this; Governor Whitman also understands this and we're very happy about that. The law also would discriminate against women because it singles out this one procedure from the law and would also single out the woman and not talk about the person who got her pregnant.

Clinical trial access has been a problem for the women of New Jersey. This gap affects women's health adversely because the latest treatments are often done in clinical

trials, this despite New Jersey's poor position in cases of breast cancer and AIDS, which is basically one of the worst in the nation. Often women wanting to participate in clinical trials have had to leave New Jersey because there has been a lack in the past of an NCI cancer center. We have examples in the Taxol trial and the Tamoxifen prevention trial. Communication is also a problem. I've personally called the Department of Health and not been able to get information as quickly as I would like or as complete. Residents need to know about the opportunities to participate in trials and other things, but often face doctors who do not know because they can't obtain information. Perhaps the addition of a hot line to receive trial information in New Jersey, partly funded by State and industry, would help that.

Another area is getting information from the Department of Health, like I said. My attempts to do that tell me that the State might need an 800 number which, according to the Department of Health, does not exist at this time -- to receive booklets and information. The Department of Health should also seek out more modern sources of information distribution, such as computer networks, PSAs, things like that, which so far I have not seen them doing personally, on cable or network.

Research issues: A gender gap exists not only in research that is done but also in the dollars allocated, the training of female scientists and doctors, and in the care that women get from the health care system. There is something wrong when clinical trials address female problems by testing drugs on men. There is something wrong when aspirin to prevent second heart attacks is studied in over 20,000 men, but not one woman. The data is then extrapolated to women even though women have much more complex hormonal considerations that can, and do, cause effects of medication. This has happened with many other trials such as migraine studies and others.

There is something wrong when only two women serve as deans of medical schools in the whole country. We believe it affects research priorities, and changing the faces may help change the priorities. To that end, we suggest that New Jersey require all medical boards, commissions, State boards, advisory councils, and others dealing with health related issues, to have a 50-50 male/female representation on them. State action might also push the private sector and academia to follow.

Women's health has suffered over the years because companies and academia have shut women out of clinical trials, preferring to deal with male subjects who do not have female cycling or menopause to worry about. Pregnancy concerns have also been a roadblock, even though pregnant women do, and must, take certain drugs during pregnancy.

One special area of concern in terms of women's health research is the area of contraceptive research. Political and legal questions have almost brought this area to a standstill. We've gone from 13 major companies, 9 in the U.S., doing R&D in 1970 to only one in 1994 -- Ortho. It's a serious problem and contraceptives should be treated like the serious medical care they are.

For many women, pregnancy is the most life-threatening condition they'll face in their lives. Over one-half of the six million pregnancies each year are unintended, and women go to serious lengths to change their lot and to survive. Many seek illegal abortion; one woman every three minutes worldwide dies in an illegal, botched, or self-induced abortion. Legal abortion is up to 11 times safer than childbirth, but many abortions would not even be needed if there were better contraceptives available.

We certainly support more research being done so less abortions need to be performed, but those contraceptives also need to be better. They need to be made more widely available, more widely discussed; otherwise, nothing happens. Many STDs

would also be lowered, and teen pregnancy in New Jersey and other states would also be lower. Liability and political pressures have combined to produce a crisis for research. Clearly one company is not enough; liability issues need to be dealt with by the industry and by the State, along with community groups working together to create reform of the system. We believe that New Jersey has a special responsibility to help promote this increased research, because many of the world's top pharmaceutical companies call New Jersey home. Tax incentives and the like might be a "carrot" to promote them to do this research.

Research into AIDS must also be accelerated -- women in New Jersey have one of the highest rates and death rates in the country. Less gender bias in research would also help this area.

Political issues need to be addressed also, and these are harder. Many companies do not do the contraceptive research or abortion research, like I said, because of political issues, violence threats from antiabortion groups, and recent battles -- obviously we've seen the RU-486 issue. The drug is available in France and Britain, but not to women in America. First we went through Reagan and Bush. Now we've got a very supportive President, but we still don't have the drug in the U.S. The pharmaceutical company is scared to death to bring it here because of liability issues and also threats from extremists, even despite the promising results with Cushings disease, breast cancer, menigiomas, glaucoma, endometriosis, and a number of other serious diseases. Never mind that it would also be a very early abortifacient -- before the first 49 days of pregnancy -- as well as a possible once-monthly contraceptive.

We can't allow a breakthrough class of drugs to be held hostage to politics. New Jersey can act like several other states and formally encourage the company to market

RU-486. Further, it can encourage breast cancer trials emphasizing New Jersey as a possible site if we get the status of a cancer research area. It could also support research into this class of drugs and stand up for scientific progress.

In conclusion, much needs to be done and much can be done in the area of women's health research, women's health access to care, the coordination issues. Action is needed immediately to remedy problems that we've had in the past and injustices. The future really is at stake and we need to spend time on this. I went over a little bit, I'm sorry.

SENATOR LIPMAN: No, that's all right. You were very comprehensive. Thank you.

MS. JACOBUS: That's fine, thank you. It was very global.

MS. MILLER: I appreciate this. Thank you very much. Any questions?

SENATOR LIPMAN: Any questions? Melanie?

MS. GRIFFIN: No.

Thank you very much.

SENATOR LIPMAN: Caroline.

MS. JACOBUS: Thank you very much. It was very comprehensive.

SENATOR LIPMAN: Thank you very much.

I think this brings our testimony to an end, doesn't it?

MS. JACOBUS: Yes, it does.

SENATOR LIPMAN: All right, then I will entertain a motion to adjourn.

MS. JACOBUS: I so move.

MS. ATKINS: I second the motion.

SENATOR LIPMAN: All right, it has been properly moved and seconded, and we will adjourn, ladies.

(HEARING CONCLUDED)

APPENDIX

AT&T Bell Laboratories

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Caroline Jacobus, M.S.W.
Director of Research
State of New Jersey Commission on
Sex Discrimination in the Statutes
226 West State Street, CN 095
Trenton, New Jersey 08625-0095

February 28, 1994

re: 1994 Public Hearings on Issues of Health Care in New Jersey

Dear Ms. Jacobus:

Thank you for the opportunity to testify at the Commission's hearings on occupational safety and reproductive hazards. AT&T Bell Laboratories' Environmental Health & Safety and Health Services organizations believe strongly in proactive education and training as an effective approach to identification and control of reproductive and developmental hazards in the workplace.

Benchmarking

We have recently completed a benchmarking of reproductive health programs in research and development (R&D) organizations and have provided for your reference our article published in the Semiconductor Safety Association (SSA) Journal. Twenty-nine companies shared information on their approach(es) to reproductive and developmental health programs/policies and on the impact of the *Johnson Controls* decision.

- Only three (3) companies had a formal, written policy on reproductive health. In light of *Johnson Controls*, one of these companies revised a "fetal protection policy" and the other two companies indicated that specific programs/policies would be eliminated and that general hazard communication would be the forum for addressing reproductive hazards.

- Four (4) companies reported plans to develop a written program/policy.

- Fourteen (14) companies reported using a surrogate program/policy.

- Six(6) companies provide training and/or training materials.

AT&T Bell Laboratories' Comprehensive Reproductive Health Program in the Workplace

As part of a comprehensive occupational health and safety program that ensures a safe and healthy work environment, AT&T Bell Laboratories' Environmental Health & Safety and Health Services organizations have developed a Reproductive Health Program to focus specifically on reproductive and developmental health. For your reference, we have provided a pre-print of our article scheduled for publication in the April 1994 issue of the American Industrial Hygiene Association (AIHA) Journal and our general introductory pamphlet geared for employees of diverse backgrounds and education levels.

The R&D Reproductive Health Program targets employees of both sexes, focuses on pre-conception awareness, and addresses lifestyle and environmental considerations in addition to workplace issues. It goes beyond a "fetal protection" policy in that it addresses all aspects of reproductive and developmental health. Program elements include a mandatory in-service curriculum for occupational health nurses and physicians and a voluntary program for employees.

- The in-service curriculum was developed for the corporation's approximately twenty-five occupational health nurses and physicians to ensure that these service providers are comfortable with the subject material and that each employee's initial encounter with Health Services is a positive one. Subjects covered in the curriculum include toxicology, legal guidelines, and counseling skills.

- The reproductive health program for employees includes an informational booklet, private confidential interviews with a trained nurse or physician, and information, recommendations, and referrals as indicated. Consultations and workplace evaluations are conducted by appropriate professionals, most commonly industrial hygienists, toxicologists, and health physicists. Employee confidentiality is a prime consideration at all times.

Benefits of a Successful Program

An effective comprehensive reproductive and developmental health program bolsters existing wellness and industrial hygiene and safety programs through employee awareness of work practices and of potential health hazards. Among the tangible measures of program success are an increased number of worksite evaluations, an increased number of appropriate referrals to subject matter experts and private physicians, and an increase in pre-conception evaluations relative to post-conception evaluations. The improvement in risk counseling skills of the nurses and physicians also greatly enhances the ability to counsel employees in other potential high risk/high anxiety situations such as asbestos exposures.

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Benefits of a Successful Program *(cont.)*

Equally important although less easily quantified results include decreased disability absences during pregnancy, decreased absences for sick child care, reduced spending for medical expense claims, and avoidance of litigation.

AT&T Bell Laboratories' Environmental Health & Safety and Health Services organizations hope that the information provided today is of value to the Commission. Please do not hesitate to contact me at (908)582-7157 if you have any questions on our Reproductive Health Program.

Lisa Brooks, Ph.D.
EH&S Manager

Attachments (3)

Copy (w/o Att.) to:
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L. Shoner

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Testimony of Joan E. Bertin

Attorney at Law and
Clinical Professor of Public Health
Columbia University • Faculty of Medicine • School of Public Health

on Women's Occupational Health Issues

Before the

New Jersey Commission on Sex Discrimination in the Statutes

February 28, 1994

A program of the Center for Population and Family Health

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I am pleased to be here today to participate in these important hearings. For many years, I have been an advocate for the rights of women workers. A particular concern is the health of women workers, including pregnant workers, and that is the subject I want to address today.

The employment rights of women workers is an issue that had evolved greatly during my professional lifetime, and is still evolving -- a fact that we sometimes forget. Not too long ago, women were openly fired when they got married or became pregnant. Then, as now, unemployment or underemployment represented a major threat to women's health and well-being and that of their families. Notwithstanding federal and state law prohibiting sex discrimination, which has been in force at the federal level since 1965, in 1978 Congress had to clarify that discrimination on the basis of pregnancy was *per se* sex discrimination.

Even that clear mandate was difficult to enforce. Until recently, many employers maintained policies that limited the employment opportunities of fertile women, in order to prevent the possibility of injury to a fetus from workplace conditions if the woman became pregnant. These so-called fetal protection policies were justified on apparently benign grounds -- the desire to prevent fetal harm -- but they exacted a terrible price from women. Some women submitted to surgical sterilization to preserve their right to lucrative employment, while other women lost good jobs and health benefits because they wished to preserve their right to have children. There was something terribly

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misguided about an employment policy that made women choose between their fertility and their economic security.

Fetal protection policies suffered from other flaws as well. By arguing that the fetus was hypersusceptible to the effects of workplace conditions, such policies ignored or minimized other "equal opportunity" health risks and created the illusion that adult workers were safe. They relied on the fiction that all women are always potentially pregnant until proven otherwise. And they shifted the responsibility to insure fetal well-being to individual women, who were charged with avoiding unsafe workplaces, rather than placing the obligation on employers to maintain adequate workplace conditions.

After more than twelve years of litigation over the legality of such policies, in 1991 the Supreme Court ruled in UAW v. Johnson Controls that fetal protection policies violate federal law against employment discrimination.

The facts of the case are simple. The Johnson Controls Company manufactures lead-acid batteries, among other activities. In 1982, apparently on the advice of its physician, the Company adopted a policy intended to prevent all women of childbearing capacity from exposure to lead on the ground that it was necessary to prevent fetal harm. The policy excluded fertile women of all ages from any job in a department in which any worker had a blood lead reading in excess of 30mg/dL[1] during the preceding year, in which there was an air lead reading in excess of $30mg/m^3$, or in

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which the line of promotion would lead to any such job. The policy applied to all women capable of conceiving, regardless of marital status, sexual preference, use of birth control, childbearing intentions, or any other individual factors. At least one woman involved in the case submitted to surgical sterilization to secure her employment rights. A male employee who also challenged the validity of the policy asserted that he had requested a low lead-job to reduce his blood lead level, in anticipation of fatherhood, but that his request was denied. (International Union UAW v. Johnson Controls, 1984 E.D.Wis., No. 84-C-0472, Complaint ¶79.)

The company defended its policy asserting that the fetus is sensitive to the effects of lead at occupational levels that are not hazardous to adult workers. In the lower courts, as in other prior cases, the debate revolved largely around this question of differential sensitivity. The Company and its supporters claimed that other health risks of lead exposure were not as well documented and quantified as the risk to the fetus, and that it was therefore justifiable to adopt a policy aimed to reduce this risk alone. The union and its members and supporters claimed that the policy ignored other significant health risks for all workers from occupational exposure to lead, and that the discrimination should be cured by lowering exposure levels to make the jobs safer for both males and females.

The Supreme Court resolved the matter, not as the employer urged, on the basis of current but incomplete scientific knowledge, but with a legal and policy determination

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about sex discrimination in employment. Indeed, the prospect that judges would have to resolve this and other similar disputes, by choosing among conflicting expert opinions in private court cases, created the specter that national occupational reproductive health policy would become distorted and confused as a result. Johnson Controls' own policy was already subject to two diametrically opposite judicial responses: the California courts had reviewed the policy under California anti-discrimination law and had found the company's defense unacceptable, while the federal appellate court had upheld the policy.

The Court's resolution avoided the potential for such conflicts among the lower courts, and even among experts, by concluding that such policies are inherently discriminatory and unlawful. Consistent with earlier cases, the Court recognized that an employment policy that creates different rules or practices for women workers is discriminatory, even if the intent of the employer's conduct is to achieve some other goal or to benefit women. In other words, the employer's intent is irrelevant to the question of discrimination when a policy openly creates a sex or pregnancy-based distinction. In this and other similar cases, employers claimed that since protecting fetuses was a legitimate employer objective, their "fetal protection" policies should be legal, even though they had a discriminatory effect on women. The Court rejected that argument. Even taking the employer's contentions at face value, the Court held that an employer may not pursue even a laudable goal through a discriminatory means. Instead, the Court acknowledged the propriety, indeed necessity, of avoiding foreseeable harm -- to the fetus or worker -- but noted that the obligation exists independent of the equally

compelling obligation not to discriminate.

Recognizing that the policy at issue forced women workers "to choose between having a child and having a job," the Court rejected Johnson Controls' "professed moral and ethical concerns" as a justification for discrimination. The Court explained that "decisions about the welfare of future children must be left to the parents who conceive, bear, support and raise them rather than to employers who hire those parents." The Court explained that:

> [it] is no more appropriate for the courts than it is for individual employers to decide whether a woman's reproductive role is more important to herself and her family than her economic role. Congress has left this choice to the woman as hers to make.

The Court acknowledged both the significance of employment to women's well-being and the welfare of their families, and the concern that lead exposure could be equally harmful to males and potentially to their offspring. While the decision relied almost exclusively on law, not on scientific opinion or expert testimony, the Court nonetheless clarified employers' obligations with regard to occupational safety and health. The Court held that "Title VII plainly forbids illegal sex discrimination as a method of diverting attention from an *employer's obligation* to police the workplace." (Emphasis added.) The plain import of the decision is that employers may not shift the obligation to women workers to insure a safe workplace, by removing themselves from recognized risks or by any other burden shifting means.

The Court held that "fetal protection" policies like Johnson Controls' could *never* be justified under Title VII. The Court concluded that no defense was available: "fetal protection" policies do not further the kind of business interests that Title VII recognizes as providing a defense to blatant discrimination, because the policies are totally divorced from the employer's legitimate interest in job performance. The non-discrimination law, the Court noted, permits only one defense to intentional discrimination, and that is when the employer can prove that sex is a "bona fide occupational qualification" ("BFOQ") for a particular job, as it might be for a clothing model, for example. Since there was no dispute that women could make batteries as well as men, a critical element of the defense was missing -- the *occupational* qualification element. In order to constitute a defense under this statute, the Court concluded, an employer would have to demonstrate that the policy was connected in some way to women's ability to perform the job.

The Johnson Controls' policy failed to meet Title VII standards in other respects, as well. Justice White, concurring, observed that a BFOQ must be "reasonably necessary to the *normal* operation" of the business to meet statutory standards. Therefore, the level of protection or the degree of "risk avoidance" that the employer applies to fetal risk must be consistent with how the business normally deals with health risks. In other words, an employer could not use a different, higher standard of protection to avoid risk to fetuses than it normally applies to other health risks incident to its operation. In this case, Johnson Controls permitted its employees and customers to be exposed to some degree of risk from its operations and products,[2] and protected its own interests

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presumably by purchasing insurance or self-insuring. This would establish the "normal operation" of the business with regard to risk avoidance.

The Court also rejected the argument that any additional costs associated with employing women could justify discrimination. Such costs might include both the expense of implementing workplace improvements and the costs of potential liability to the future children of workers. The Court, however, rejected *any* cost-based defense, holding that employers must shoulder any "extra cost of employing" women workers. With regard to the liability-based concern, the majority observed:

> . . . OSHA established a series of mandatory protections which, taken together, 'should effectively minimize any risk to the fetus and newborn child'. . . . If under general tort principles, Title VII bans sex-specific fetal-protection policies, the employer fully informs the woman of the risk, *and the employer has not acted negligently,* the basis for holding an employer liable seems remote at best. [Emphasis added.]

Consequently, the employer would have to implement non-discriminatory mechanisms to meet its multiple legal obligations: the obligation imposed by federal safety and health law to maintain "safe and healthful working conditions" for "every working man and woman," and the desire to avoid or minimize the risk of tort liability. The obvious way to achieve these goals, noted by the Court, is by observing the requisite duty of care, in other words by reducing known risks and providing adequate warnings as to foreseeable but irreducible risks. In this fashion, the Court indicated its intent that employers' duties to workers and their future children should be governed by these standards: the obligation to comply with safety and health laws and regulations, the

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duty not to be negligent, and the duty to warn.

This decision does not in itself achieve a safe workplace for men or women, but it was a necessary precursor to the effort to upgrade workplace conditions. As long as employers could avoid the necessity to abate reproductive risks, by alleging that the risks were confined to a class that could be excluded, there was little incentive to improve working conditions. It is time, however, for the legal and policy debate to move to the next level, to assure that the right to equal employment opportunity is not the right to an equally hazardous job.

Fetal protection policies were commonplace in Fortune 500 companies in the petrochemical industry, pharmaceuticals, battery manufacturers, and other major industries, many of which have facilities in New Jersey. Unfortunately, there has been no systematic effort to characterize corporate reactions to the UAW decision, and consequently no comprehensive information detailing corporate response is available. Anecdotal reports suggest that some employers have failed to comply with the Supreme Court decision, and have continued to deny women certain employment opportunities, although the discrimination has surely become more subtle -- there have been no reports of women getting sterilized to keep their jobs. Instead there are indications that some employers try to steer women into certain jobs or provide biased assessments of occupational health risks. One women was required to provide medical certification that it was safe for her to continue to work -- she filed a lawsuit which was settled.

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One practice bears special mention. Some women report being required to provide a waiver of the right to sue in the event of future injury to self or child. There is considerable doubt about the enforceability of such a waiver, if it is extracted as the price of employment. Given its questionable legal status, requiring workers to sign waivers could function to mislead or to intimidate workers. If a waiver obtained in such a fashion were enforceable, however, the ramifications are serious: employees would be sacrificing legal rights as the price of employment (similar to sacrificing fertility as the price of employment), and as a result employers could escape liability even for negligent or otherwise wrongful conduct. These consequences are sufficiently serious that evaluation of the prevalence of waiver requirements is a high priority.

Employers who previously enforced "fetal protection" as a method of reducing work-related risk to reproduction have admitted that the work environment was hazardous for pregnant women. At one time, they were prepared to document that view in order to defend against charges of discrimination. Having made such an admission, it is essential to know what they have done since to make the workplace safe enough for fertile and pregnant women who are entitled to employment. If the substantive risks were serious enough to cause employers to ban women from work, it is incumbent on them now to demonstrate that the risks have been abated, and it is incumbent on the state to insure that result.

The State of New Jersey could perform an invaluable service, both for the workers

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The State of New Jersey could perform an invaluable service, both for the workers of this state and others, by surveying industry policies and practices in this area. The purpose is to inquire about prior occupational reproductive health policies and practices, and the changes, if any, that have been instituted in response to the Supreme Court decision. Some employers have undoubtedly modified their policies to address comprehensively the health needs of workers, including those who are pregnant, and these employers could serve as models to demonstrate how this can effectively be accomplished. Other employers are likely to be in violation of either equal employment laws or occupational safety and health laws. Documenting the extent and nature of non-compliance is critical to any effort to craft a regulatory or legislative response. A legislative response would be particularly appropriate if the survey discloses widespread resort to legal waivers as a response to reproductive risk.

Women need to work, and they are entitled to work. If doing so extracts an unacceptably high cost in terms of health effects, the burden is felt by the entire community, in the incidence of work-related illness, disability and injury; in the incidence of birth defects; and in the overall decline in well-being. The state has much to gain by enforcing the twin obligations not to discriminate and to maintain a safe and healthful work environment. Enforcement of these obligations across the board diminishes the likelihood that the responsible, conscientious employer will suffer a competitive disadvantage from meeting its legal obligations fully. The true cost of the product or service will be reflected only when any expenses associated with non-

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discrimination and safety and health are incorporated, and this in turn will permit more rational consumer choices.

I urge you to undertake this important work and offer whatever assistance I can provide to advance your efforts.

Notes

1. The Occupational Safety and Health Administration (OSHA) issued a Final Standard for Occupational Exposure to Lead, which recommends that pregnant women maintain their blood leads below this level. The OSHA Standard and Appendices also recommend that men intending to become fathers maintain blood lead levels below 30mg/dL, because of evidence that lead may effect the offspring of exposed male animals and humans. (29 C.F.R. §1910.1025).

2. For example, at the time the case went to the Supreme Court, the company was appealing from a judgment of $9.1 million awarded to a motorist who had been severely injured when one of its batteries exploded. (Jones, et al., v. Sears & Roebuck Inc., Globe Union, Inc., et al., No. 585-427 (Cal. Super. Ct., San Diego County May 17, 1987), appeal filed No. D009904 (Cal. Ct. App., 4th App. Dist., Div. 1, filed Apr. 10, 1990). The company also had a significant history of workers' compensation claims relating to employee lead exposure. International Union, UAW v. Johnson Controls, Inc., (7th Cir. 1988) Brief of Plaintiffs-Appellants, p. 27 n. 11).

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CHOICE IN DYING, INC.
Formerly Concern for Dying and the Society for the Right to Die

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WOMEN AND END-OF-LIFE DECISIONS

The right to refuse medical treatment at the end of life is not the same for women as it is for men. Advance directive laws in individual states often explicitly limit the applicability of living wills or durable powers of attorney for health care during the course of a woman's pregnancy. Even when the law is the same for men and women, there is evidence to suggest that the courts apply that law differently for the two sexes.

Pregnancy Exclusions

"Pregnancy exclusion" -- the definition given to state law restricting a woman's choice to refuse unwanted life support through a living will or durable power of attorney for health care while she is pregnant -- illustrates this imbalance.

In the landmark right-to-die case Cruzan v. Director, Missouri Department of Health, the United States Supreme Court recognized that competent adults have the constitutional right to refuse medical treatment, even if that treatment is necessary to sustain life. This right can be preserved through advance directives such as living wills and durable powers of attorney for health care in the event the individual loses the ability to make decisions for herself.

Roe v. Wade and more recently, Planned Parenthood of Southeastern Pennsylvania v. Casey, the U.S. Supreme Court ruled that a woman's decision to end her pregnancy is a "liberty interest" protected against state interference by the Fourteenth Amendment prior to viability of the fetus.

Combined, these cases clearly state that, at least prior to viability of the fetus, no state may force a pregnant woman to receive unwanted medical treatment.

State laws do not follow suit:

Of the 47 states and the District of Columbia that have living will statutes,

- Thirty-four states explicitly forbid withdrawal of or withholding life support under a woman's living will if the woman is pregnant;
- Ten states and the District of Columbia make no mention of pregnancy in their living will statute, implicitly allowing her to refuse life support during pregnancy;
- Only three states permit the woman to choose to refuse life support if she is pregnant.

Of the 37 states and the District of Columbia that have durable power of attorney for health care or health care proxy statutes:

- Seven states explicitly forbid a health care agent from ordering the withholding or withdrawal of life support from pregnant patients;
- Twenty-six states and the District of Columbia are silent on the issue of whether an agent may order the withholding or withdrawal of treatment from a pregnant patient, implicitly allowing her to refuse life support during pregnancy;
- Only four states permit the woman to choose whether her agent can withhold or withdraw life support in the event she is pregnant.

Right-to-Die Court Cases

Women may also be subject to unequal treatment by the courts when end-of-life medical treatment is at issue. Two researchers (Miles and August, 1990) studied the outcomes of all right-to-die cases decided by state appellate courts involving patients without advance directives.

This study found:

- Out of eight cases involving men, the court found sufficient evidence of the patient's treatment wishes from prior statements in six cases;
- Out of 14 cases involving women, the court found sufficient evidence of the patient's treatment wishes from prior statements in only two cases;
- Many courts characterized past statements made by male patients as "rational." The female patients' statements were characterized as "unreflective, emotional, or immature;"
- Some of the courts never even mentioned the women's prior statements.

Other Facts

- Approximately 60 percent of Choice In Dying's membership is female.
- Of the 10,000 individuals registered in Choice In Dying's Living Will Registry, 70 percent are female.

# # #

Call 1-800-989-WILL for more information

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RECOMMENDATIONS FOR NATIONAL HEALTH LEGISLATION

The Patient Self-Determination Act (PSDA) is a legislative attempt to broaden public understanding among Americans of their legal rights to direct their health care at the end of life. This statute has fallen short of its legislative mandate to educate the public about advance directives. For this reason, Choice In Dying has proposed that the following recommendations be included in any health care reform legislation.

- Encourage all health care clinicians to discuss end-of-life medical choices and preferences with their patients during a standard medical history. Clinicians should be encouraged to ask whether a patient has completed an advance directive and thus beginning what must be an ongoing conversation with the patient about end-of-life medical choices and decisions.

- Establish "advance directives" as a check-off item on the proposed National Health Security Card. Since the health security card is an ideal vehicle to reflect vital patient data such as health insurance or organ donor preferences, it is appropriate to include a check-off for advance directives. This information will give health care providers essential direction about the end-of-life medical wishes of a patient.

- Include facts about advance directives in the information made available to eligible enrollees by regional alliances. Public education is an integral component of effective implementation of PSDA. Laws regarding end-of-life decisions vary from state to state and health care facilities alone should not bear the full burden of public education.

- A definitive study to assess whether the PSDA is being effectively implemented. The research has been limited and results are conflicting. While the PSDA continues to be hailed as breakthrough legislation, early returns indicate that providers are either confused by or reticent to comply with the requirements of the statute. In addition, there is considerable concern that health care facilities are not fulfilling their mandate to educate staff and local communities about advance directives.

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NEW JERSEY HIGHLIGHTS

New Jersey Advance Directives for Health Care Act, N.J. Stat. Ann. §§26:2H-53 to -78 (West Supp. 1992).

Significant Features of the Advance Directives for Health Care Act:

- With an advance directive, life-sustaining treatment may be withheld or withdrawn when it is experimental and likely to be ineffective or futile and is likely merely to prolong an imminent dying process; when the patient is permanently unconscious or in a terminal condition; when the patient has a serious irreversible illness or condition and the likely risks and burdens associated with the medical treatment outweigh the likely benefits; or when imposition of the medical treatment on an unwilling patient would be inhumane.

- Advance directives may be either "proxy directives" used to appoint health care representatives or "instruction directives" or both.

- "Terminal condition" is defined as the "terminal stage of an irreversible fatal illness, disease or condition." A determination of life expectancy is not required as a precondition for a diagnosis of a "terminal condition." However, a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, is deemed to constitute a terminal condition.

- "Life-sustaining treatment" is defined to include "any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increase the expected life span of a patient."

- A female declarant may include information in her advance directive as to the effect the advance directive shall have if she is pregnant.

- Attending physicians are required to make affirmative inquiries of patients, family and others concerning the existence of an advance directive.

- If an instruction directive provides clear and unambiguous guidance, it must be honored. If the instruction directive is not specific as to the patient's condition and treatment alternatives, family members or others acting on the patient's behalf are to exercise reasonable judgment to effectuate the patient's wishes.

- Physicians or nurses who decline to participate in the withholding of measures utilized to sustain life, in accordance with sincerely held personal or professional convictions, must inform the patient and health care representative and institutional officials as soon as practicable and effect a timely transfer of care. The patient's medical records, including the advance directive, must also be transferred.

- Health care institutions are to adopt policies and practices to provide for routine inquiry concerning the existence and location of advance directives, to educate patients, families,

health care representatives and to inform health care professionals of their rights and responsibilities under the act. Health care institutions may also adopt dispute resolution processes.

- Intentional failure by a health care professional or institution to act in accordance with the act's requirements subjects the health care professional to discipline for professional misconduct and the institution to a fine of not more than $1,000.

- Prior to withholding or withdrawing life-sustaining treatment, the attending physician may seek consultation with an institutional or regional reviewing body or approval from a public agency recognized by law for this purpose.

- Do not resuscitate orders may be issued.

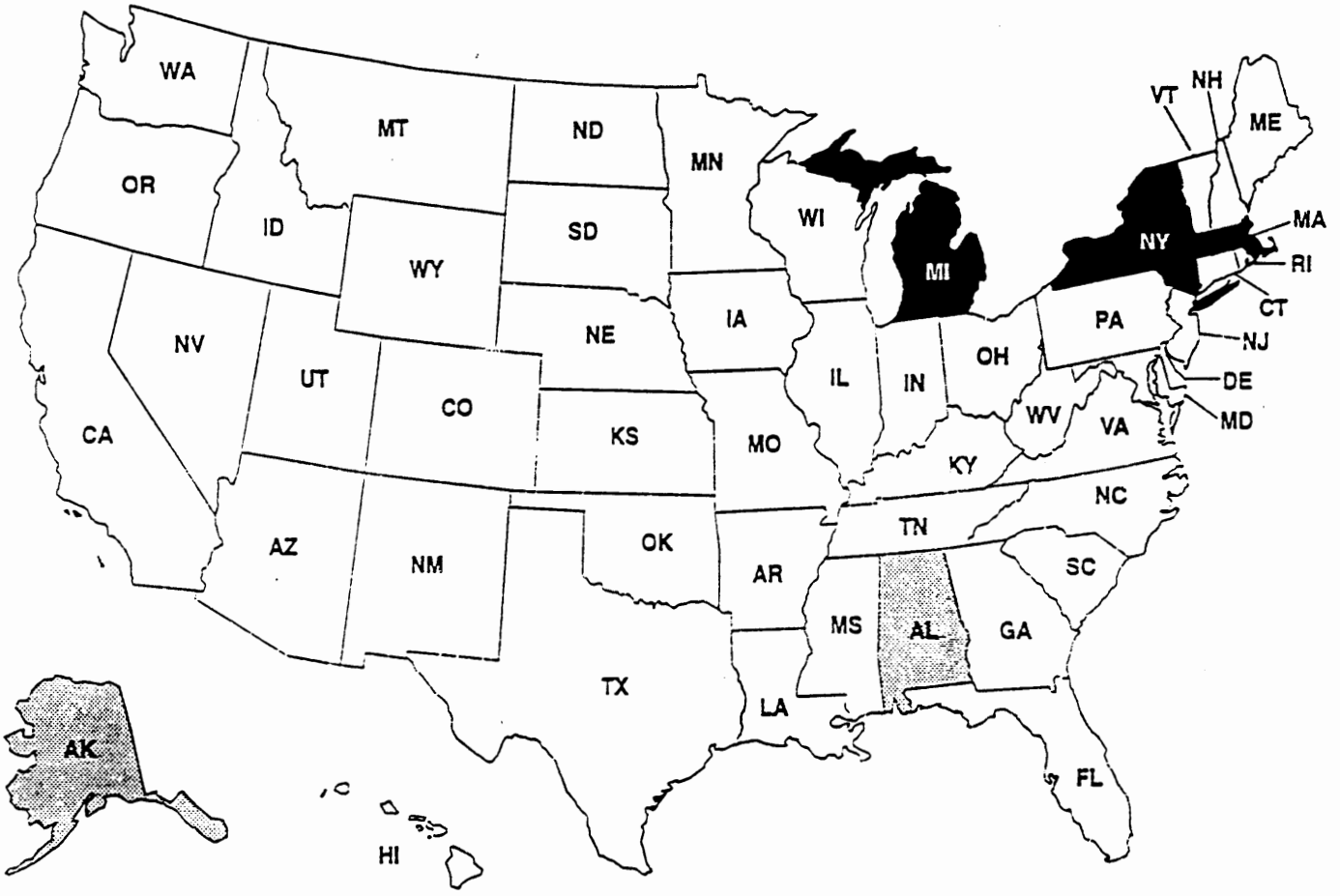
- Emergency personnel need not withhold or withdraw emergency care where there is no reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of a patient.

- An out-of-state or foreign country advance directive is valid if executed in compliance with the laws of that state or country or the laws of New Jersey.

- The State Department of Health shall establish rules and regulations to implement the act and to require health care institutions to adopt specific policies and practices.

June 1993

State Statutes Governing Living Wills and Appointment of Health Care Agents



Jurisdictions with legislation that authorizes both living wills and the appointment of a health care agent (**the District of Columbia and 45 states: Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin and Wyoming**).

States with legislation that authorizes only living wills (**2 states: Alabama and Alaska**).

States with legislation that authorizes only the appointment of a health care agent (**3 states: Massachusetts, Michigan and New York**).

Note: The specifics of living will and health care agent legislation vary greatly from state to state. In addition, many states also have court-made law that affects residents' rights. For information about specific state laws, please contact Choice In Dying.

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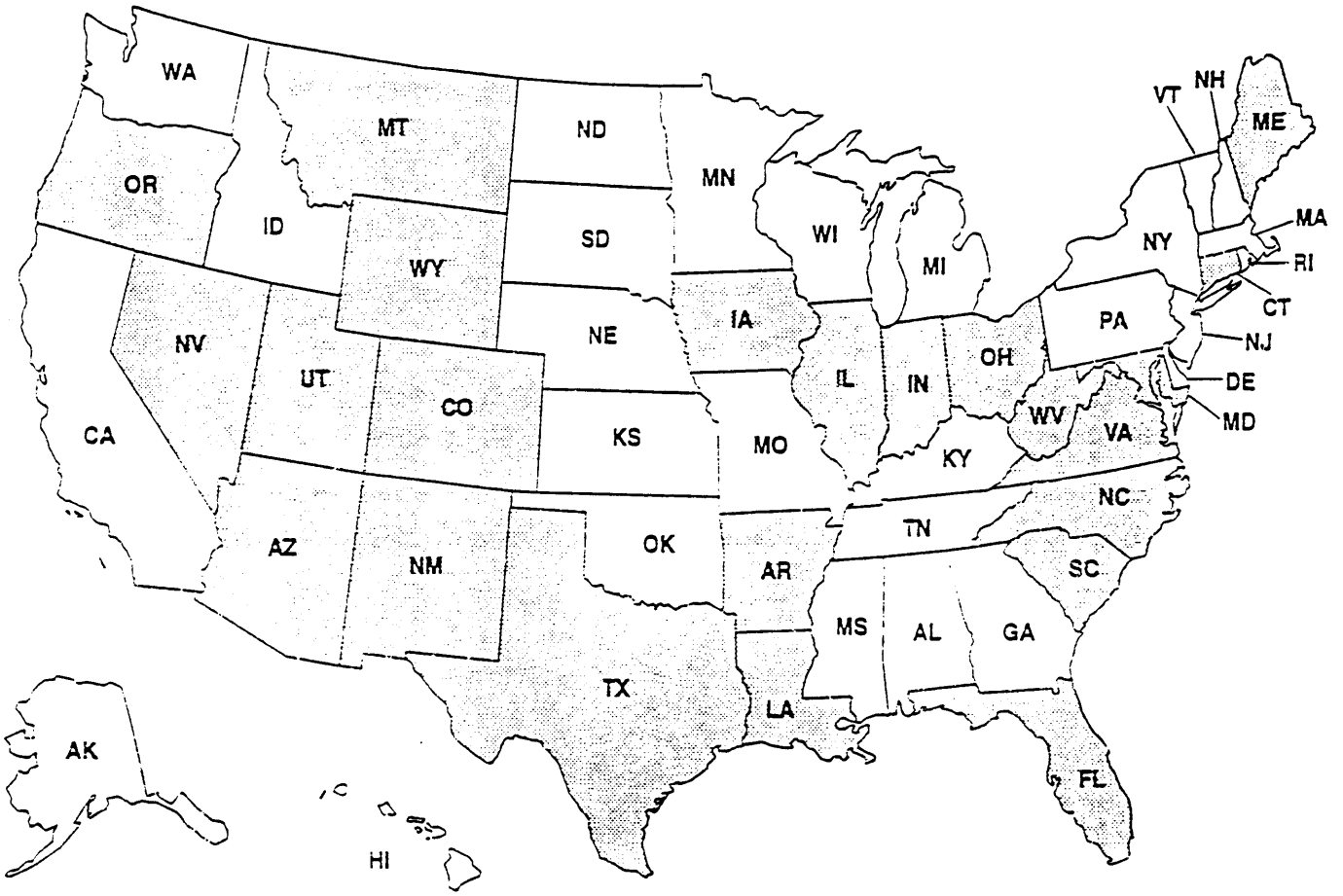
State Statutes Governing Surrogate Decisionmaking



Jurisdictions with statutes authorizing surrogate decisionmaking in the absence of advance directives (**the District of Columbia and 23 states: Arizona, Arkansas, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Montana, Nevada, New Mexico, North Carolina, Ohio, Oregon, South Carolina, Texas, Utah, Virginia, West Virginia and Wyoming**).

States without statutes authorizing surrogate decisionmaking (27 states: Alabama, Alaska, California, Delaware, Georgia, Hawaii, Idaho, Kansas, Kentucky, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Tennessee, Vermont, Washington and Wisconsin).

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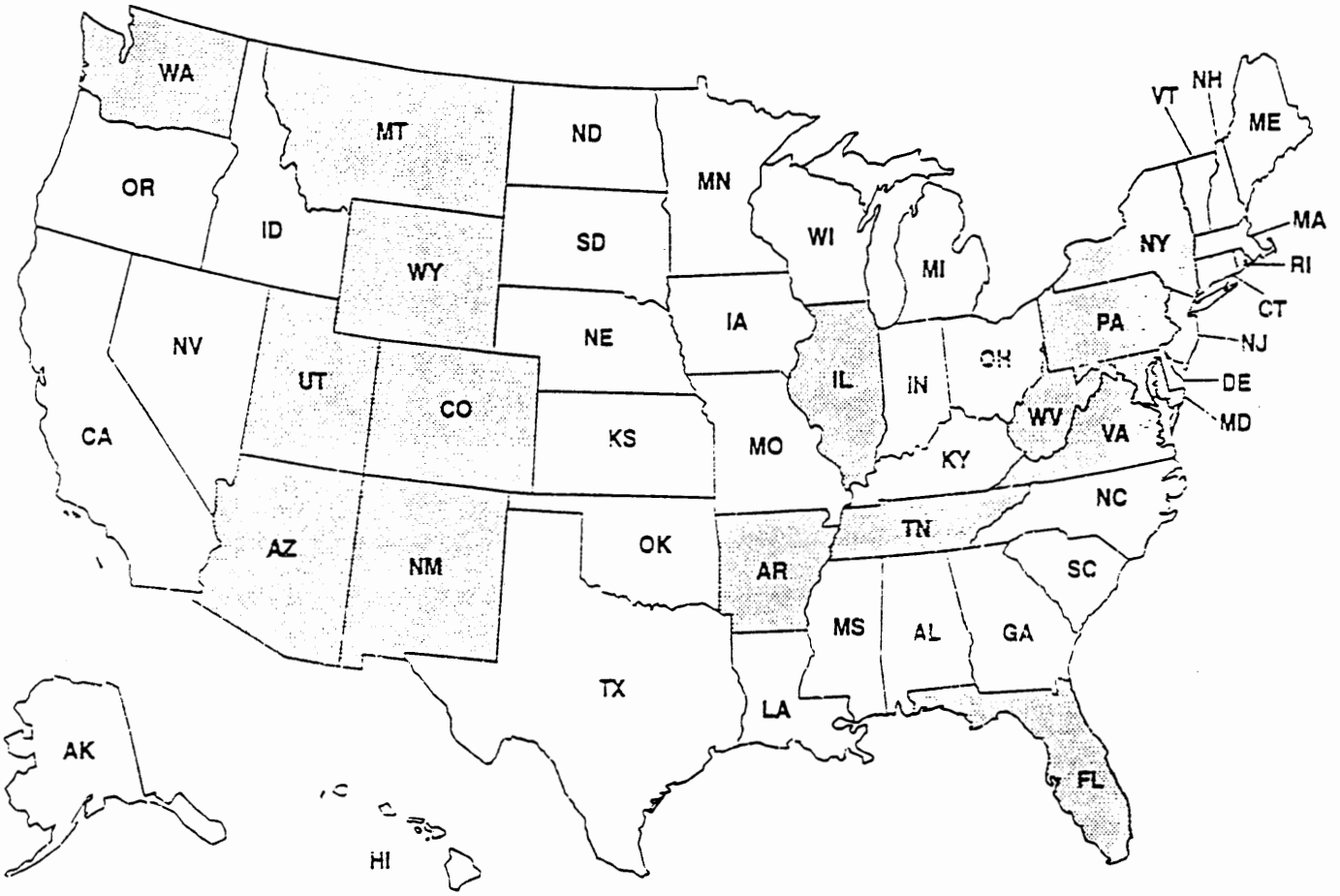
State Statutes Governing Nonhospital Do-Not-Resuscitate Orders



States with statutes authorizing nonhospital DNR orders (**17 states: Arizona, Arkansas, Colorado, Florida, Illinois, Maryland, Montana, New Mexico, New York, Pennsylvania, Rhode Island, Tennessee, Utah, Virginia, Washington, West Virginia and Wyoming**).

Jurisdictions without statutes authorizing nonhospital DNR orders (**the District of Columbia and 33 states: Alabama, Alaska, California, Connecticut, Delaware, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Vermont and Wisconsin**).

Note: This map refers to statutes that address DNR orders in the nonhospital and interfacility settings only. Some of these same statutes explicitly apply also to inpatient situations. However, most hospitals already have institutional policies regarding DNR orders, in compliance with the accreditation standards of the Joint Commission on Accreditation of Hospitals. Thus, we have not provided any information in this publication concerning DNR orders within health care institutions. For information about specific state laws, please contact Choice In Dying.

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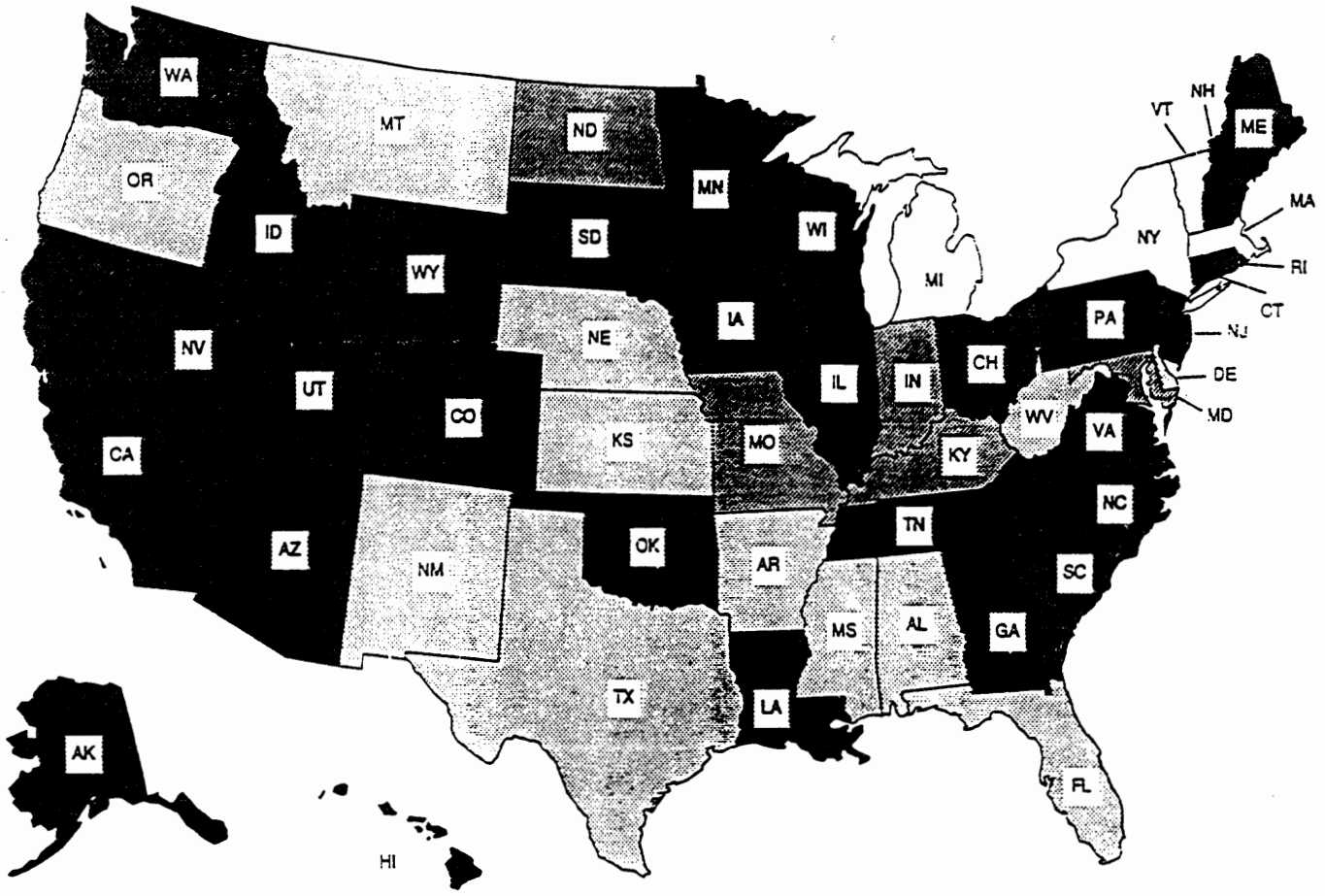
March 1993

Artificial Nutrition and Hydration in Living Will Statutes



States with living will statutes that **permit** individuals to refuse artificial nutrition and hydration through their living wills (**29 states: Alaska, Arizona[1], California, Colorado, Connecticut, Georgia, Hawaii, Idaho, Illinois[2], Iowa, Louisiana, Maine, Minnesota, Nevada, New Jersey, New Hampshire, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Virginia, Washington, Wisconsin and Wyoming**).

States with living will statutes that **require** the provision of nutrition and hydration except in very limited circumstances (**5 states: Indiana[3], Kentucky, Maryland[4], Missouri[3] and North Dakota**).

Jurisdictions whose living will statutes do not explicitly permit the refusal of, or explicitly require the application of artificial nutrition and hydration (**the District of Columbia and 13 states: Alabama, Arkansas, Delaware, Florida, Kansas, Mississippi, Montana, Nebraska, New Mexico, Oregon, Texas, Vermont and West Virginia**).

States without living will statutes (**3 states: Massachusetts, Michigan and New York**).

[1] The authority to withhold or withdraw artificial nutrition and hydration is only explicitly mentioned in the sample document.
[2] Artificial nutrition and hydration cannot be withheld or withdrawn if the resulting death is due to starvation or dehydration.
[3] The medical power of attorney statutes in Indiana and Missouri permit appointed agents to refuse artificial nutrition and hydration on behalf of the principal.
[4] Although the act requires the "administration of food and water," a Maryland Attorney General's Opinion has stated that artificial nutrition and hydration may be refused through a living will.

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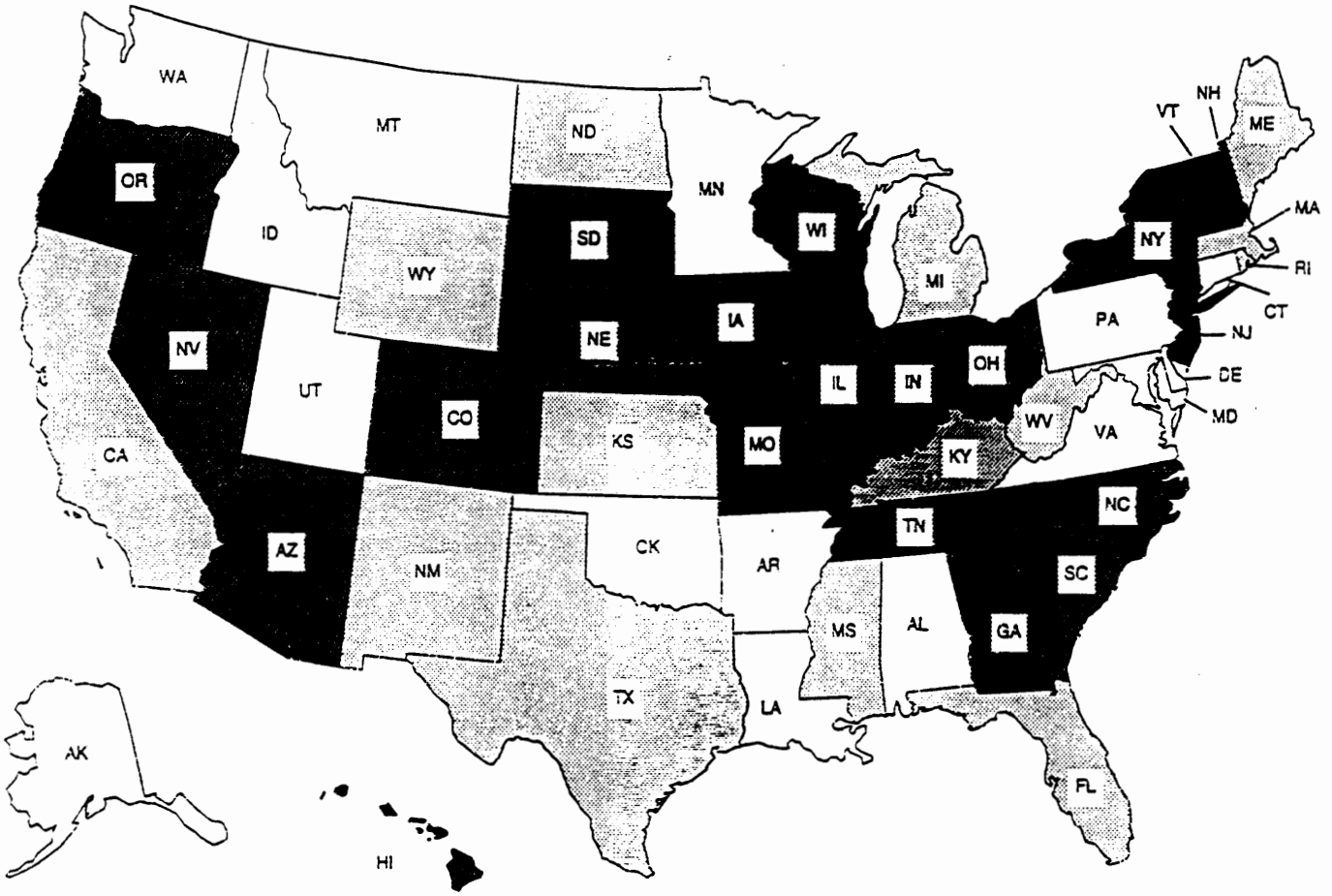
Artificial Nutrition and Hydration in Medical Durable Power of Attorney Statutes



States with medical power of attorney statutes that **permit** health care agents to order the withholding or withdrawal of artificial nutrition and hydration (**21 states: Arizona, Colorado, Georgia, Hawaii, Illinois, Indiana, Iowa, Missouri, Nebraska, Nevada, New Hampshire, New Jersey, New York[1], North Carolina, Ohio, Oregon[2], South Carolina, South Dakota, Tennessee, Vermont and Wisconsin**).

States with medical power of attorney statutes that explicitly **require** the provision of nutrition and hydration except in very limited circumstances (**1 state: Kentucky**).

Jurisdictions whose medical power of attorney statutes do not explicitly permit the refusal of, or explicitly require the application of artificial nutrition and hydration (**the District of Columbia and 13 states: California, Florida, Kansas, Maine, Massachusetts, Michigan, Mississippi, New Mexico, North Dakota, Rhode Island, Texas, West Virginia and Wyoming**).

States without medical power of attorney statutes (**15 states: Alabama, Alaska, Arkansas, Connecticut, Delaware, Idaho, Louisiana, Maryland, Minnesota, Montana, Oklahoma, Pennsylvania, Utah, Virginia and Washington**).

[1] Agents are permitted to order the withholding or withdrawal of artificial nutrition and hydration only if they know the wishes of the principal concerning such action.

[2] Agents are permitted to order the withholding or withdrawal of artificial nutrition and hydration only if the principal had expressly rejected artificial nutrition and hydration before incompetence.

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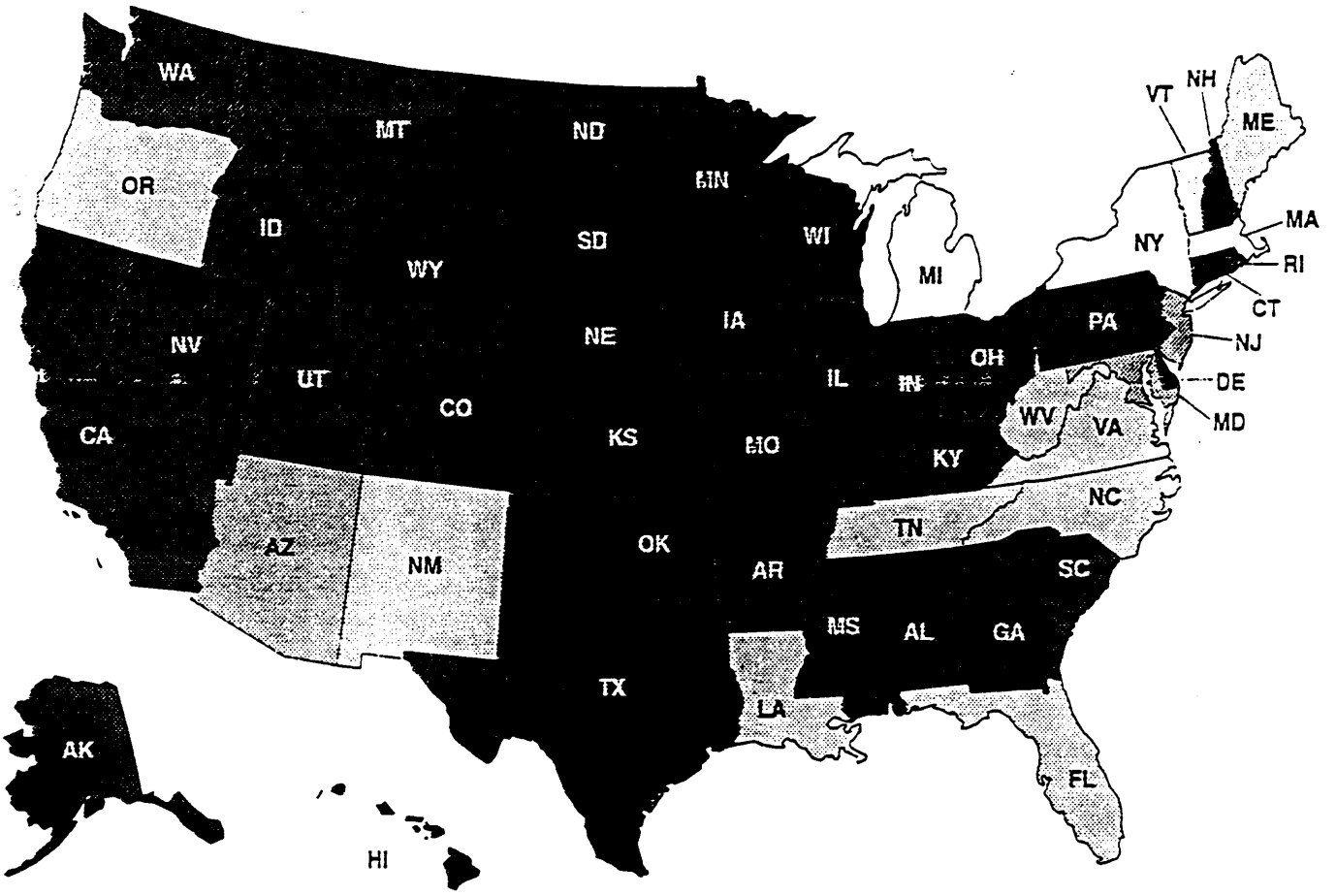
Pregnancy Restrictions in Living Will Statutes



States with living will statutes that explicitly forbid the withholding or withdrawal of life support from pregnant patients (34 states: **Alabama, Alaska[1], Arkansas[1], California, Colorado[2], Connecticut, Delaware, Georgia[3], Hawaii, Idaho, Illinois[1], Indiana, Iowa[1], Kansas[1], Kentucky, Minnesota[1], Mississippi, Missouri, Montana[1], Nebraska[1], Nevada[1], New Hampshire, North Dakota, Ohio, Oklahoma, Pennsylvania[1], Rhode Island[1], South Carolina, South Dakota[1], Texas, Utah, Washington, Wisconsin and Wyoming**).

States with living will statutes that permit the principal to choose to refuse life support if she is pregnant (**3 states: Arizona, Maryland and New Jersey**).

Jurisdictions whose living will statutes make no mention of pregnancy (**the District of Columbia and 10 states: Florida, Louisiana, Maine, New Mexico, North Carolina, Oregon, Tennessee, Vermont, Virginia and West Virginia**).

States without a living will statute (**3 states: Massachusetts, Michigan and New York**).

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[1] Life support cannot be withheld/withdrawn if the fetus can develop to the point of live birth with continued life support.

[2] Life support cannot be withheld/withdrawn if the fetus is viable.

[3] Explicitly permits individuals to choose to have living will honored during pregnancy, but only until the point of viability.

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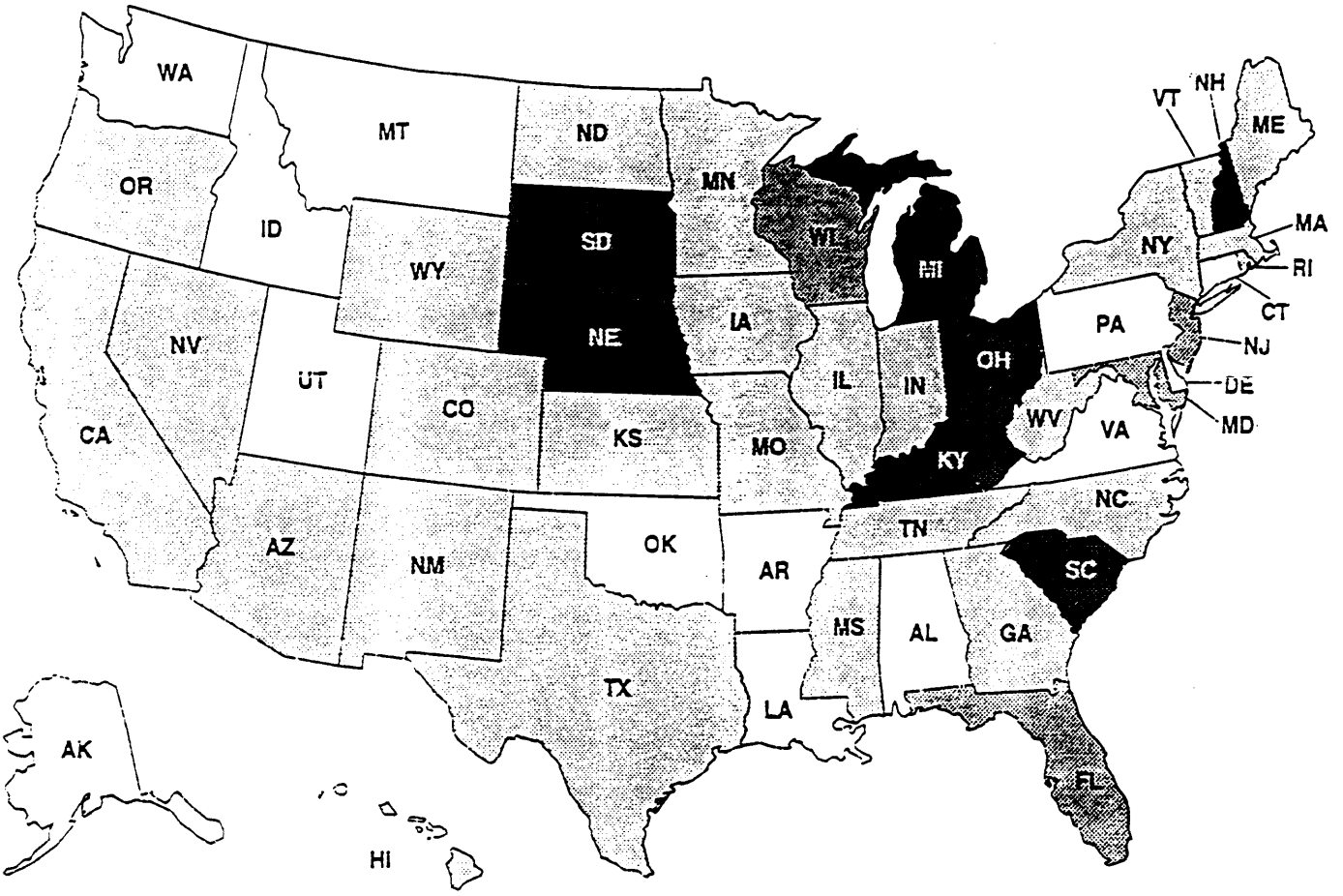
September 1993

Pregnancy Restrictions in Medical Power of Attorney Statutes



States with medical power of attorney statutes that explicitly forbid a health care agent from ordering the withholding or withdrawal of life support from pregnant patients (7 states: **Kentucky*, Michigan, Nebraska*, New Hampshire*, Ohio*, South Carolina and South Dakota**).

States with medical power of attorney statutes that permit the principal to choose whether her agent can withhold or withdraw life support if she is pregnant (4 states: **Florida, Maryland, New Jersey** and **Wisconsin**).

Jurisdictions whose medical power of attorney statutes make no mention of pregnancy (the **District of Columbia** and 26 states: **Arizona, California, Colorado, Georgia, Hawaii, Illinois, Indiana, Iowa, Kansas, Maine, Minnesota, Massachusetts, Mississippi, Missouri, Nevada, New Mexico, New York, North Carolina, North Dakota, Oregon, Rhode Island, Tennessee, Texas, Vermont, West Virginia** and **Wyoming**).

States that do not have medical power of attorney statutes (13 states: **Alabama, Alaska, Arkansas, Connecticut, Delaware, Idaho, Louisiana, Montana, Oklahoma, Pennsylvania, Utah, Virginia** and **Washington**).

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* Life support must be continued unless it is unlikely that the fetus will develop to the point of live birth.

Note: This publication addresses only health care agents appointed through medical power of attorney statutes. Some living will statutes also permit the appointment of health care agents; however, these agents would then be bound by any pregnancy restriction contained in the living will act.

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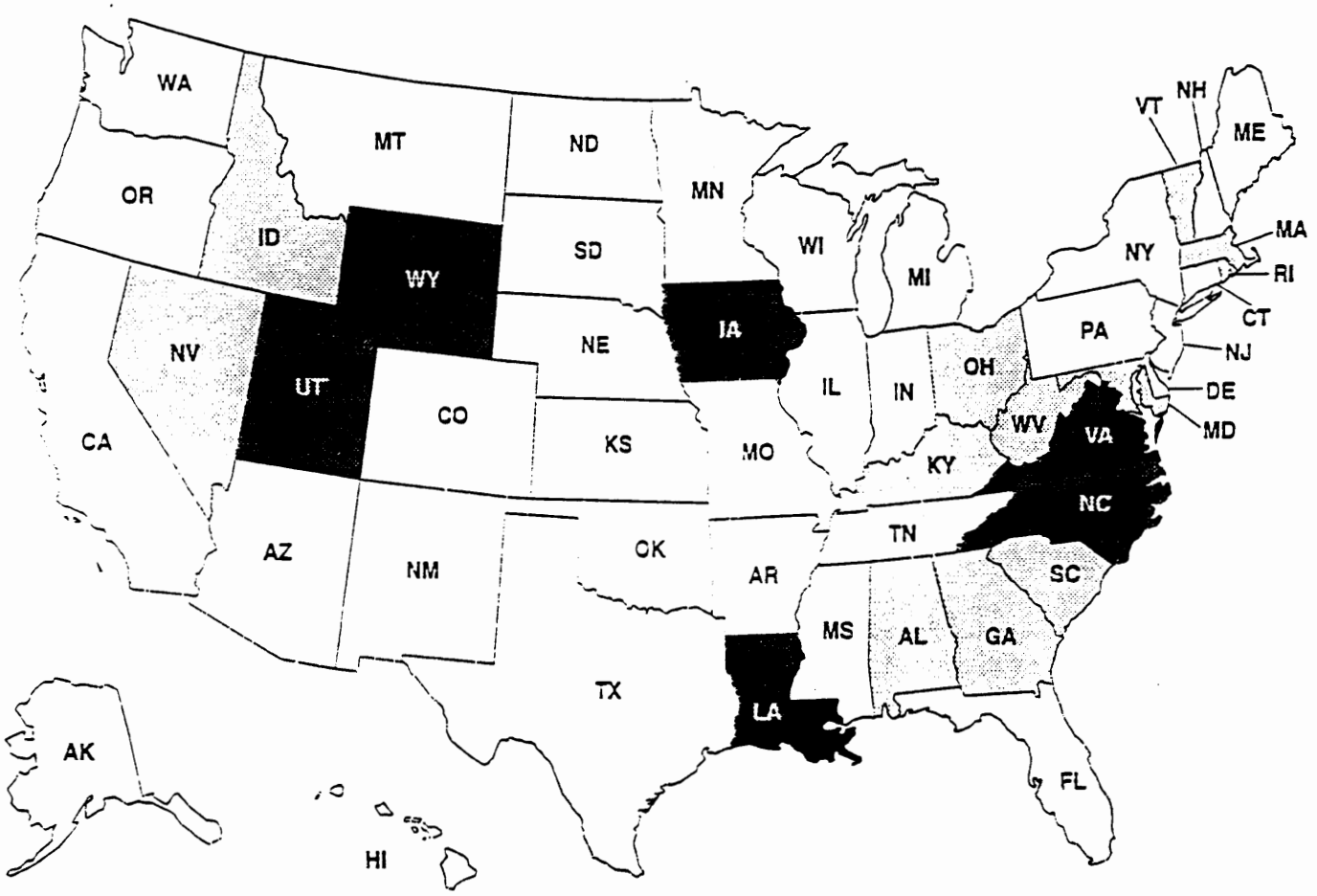
Assisted Suicide Laws in the United States



States with statutes that explicitly criminalize assisted suicide: (**32 states: Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Hawaii, Illinois, Indiana, Kansas, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, Washington and Wisconsin**).

Jurisdictions that criminalize assisted suicide through the common law (**the District of Columbia and 12 states: Alabama, Georgia, Idaho, Kentucky, Maryland, Massachusetts, Nevada, Ohio, Rhode Island, South Carolina, Vermont and West Virginia**).

States in which the law is unclear concerning the legality of assisted suicide (**6 states: Iowa[1], Louisiana[2], North Carolina[3], Utah[3], Virginia[1] and Wyoming[3]**).

---

[1] Case law exists which may or may not be applicable to assisted suicide.

[2] State constitution stipulates that "no law shall subject any person to euthanasia."

[3] State has abolished the common law of crimes and therefore does not explicitly prohibit assisted suicide.

63X

Produced by Choice In Dying, Inc.
200 Varick Street, 10th Floor New York, NY 10014-4810 (212) 366-5540

CHOICE IN DYING

Formerly Concern for Dying and the Society for the Right to Die

The New Jersey Advance Directives For Health Care

In 1991 New Jersey enacted a law on life-sustaining treatment, effective as of January 1, 1992. The form we are sending you complies with this law. It includes a section for appointment of a health care representative, and a section called an "instruction directive." We recommend that you complete both sections.

You will need <u>either</u> two adult witnesses, or a notary public, or an attorney to sign the advance directive at the same time that you sign it.

The New Jersey Health Care Representative Directive

The first part of the New Jersey document allows you to appoint another adult (called your "health care representative") to make medical decisions for you when you cannot make such decisions yourself. Your health care representative can make any medical decision that needs to be made, including — but not limited to — decisions about life-sustaining treatment.

Instructions for appointing your health care representative are on the form. **Please read it carefully before you sign it.**

Make sure you tell your health care representative that you have appointed him or her to make medical decisions for you when you cannot make such decisions yourself. Also be sure to discuss your wishes with your health care representative.

The New Jersey Instruction Directive

The second part of the New Jersey document is an "instruction directive." This section allows you to record your personal wishes about receiving or refusing life-sustaining treatment. There are several places where you are asked to initial those statements on the form that express your own desires, and other areas where you must fill in the spaces provided with statements that reflect your wishes. **Be sure to follow with care the instructions for initialing the form and filling in the blanks. If you do not comply with the instructions, this section of your directive may be legally invalid.**

What to Do with Your Document

Give photocopies of the completed document to your health care representative, if you name one, and to your doctor(s) and family members or close friends who might be concerned with your medical care. Keep the signed original document in a safe place that will be easily accessible to others in case of an emergency — **not** in a safe deposit box — and let someone know where it is.

Be sure to keep your health care representative and health care provider(s) up to date with your wishes about medical treatment, especially if your medical condition changes.

Other Services from Choice in Dying

Choice in Dying maintains a Living Will Registry. The one-time fee for registering advance directives is now $35 for members, $40 for nonmembers. We are happy to send more information about the Registry upon request.

(over, please)

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Choice in Dying's publications provide further information about various aspects of the right to refuse treatment. Please use the form on the enclosed list to order.

The annual membership fee of $15 entitles you to the latest information on right-to-die developments, including any changes in the law that might affect you; a subscription to our Newsletter, published quarterly; a wallet-size membership card, to alert people in case of an emergency that you have an advance directive; and a discount on all our publications, videos and special services.

By contributing, you will join the ranks of supporters who have kept this organization in the vanguard of the patients' rights movement for over 50 years. Your donation will help us to distribute more advance directives and so protect the right of all Americans to a natural and dignified death.

Thank you.

12/91

65X

NEW JERSEY
ADVANCE DIRECTIVE FOR HEALTH CARE

[Combined Health Care Proxy and Instruction Directive]

I understand that as an adult able to make my own decisions I have the right to make decisions about my health care. I know that a time may come when I am unable, because of physical or mental incapacity, to make my own health care decisions. If that happens, those caring for me will need direction concerning my health care. I understand that health care decisions which are in my best interests will be made and that my best interests will be ascertained by looking into what is known about my wishes. I am completing this document to give instructions, guidance and the authority needed to make health care decisions on my behalf.

I, _____, direct that this advance directive for health care shall take effect in the event I lose the capacity to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any physician(s) confirming that determination, if necessary. I direct that this document become part of my permanent medical records.

In completing Part One of this advance directive, you will appoint a person you trust to act as your legally recognized health care representative to make all and any health care decisions for you in the event you are unable to make decisions for yourself. You may choose any competent adult, except that you may not appoint an operator, administrator or employee of a health care institution in which you are a patient or resident unless the operator, administrator or employee is related to you. Your physician may be appointed but cannot serve as your physician and representative at the same time.

In completing Part Two of this advance directive, you will provide instructions concerning your health care preferences and wishes to your health care representative (if you choose to appoint one) and others who will be entrusted with responsibility for your health care, such as your physician, family members and friends

You may choose to complete only Part One or only Part Two, or you may complete both Parts.

Part One: Appointment of a Health Care Representative

CHOOSING A HEALTH CARE REPRESENTATIVE:

I hereby appoint:

Name _____

Address _____

City _____ *State* _____

Telephone _____

to be my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, and decisions to provide, withhold or withdraw life-sustaining treatment. I direct my health care representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, or if a situation arises that I did not anticipate, my health care representative is authorized to make decisions in my best interests.

I have discussed the terms of this appointment with my health care representative [and alternate representative(s) if I have appointed one/them] and my representative(s) has/have willingly agreed to accept the responsibility for acting on my behalf. I understand that it is important to keep my health care representative(s) up to date with my wishes if they change. I am confident that my health care representative(s) is/are able to act in my best interests.

(over, please)

66X

State below the limitations, if any, to be placed on the authority of your appointed health care representative(s), including the limitations, if any, which you wish to be applicable only when you are pregnant:

_____

_____

_____

_____.

ALTERNATE REPRESENTATIVES:

If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *Name* _____

Address _____

City _____ *State* _____

Telephone _____

2. *Name* _____

Address _____

City _____ *State* _____

Telephone _____

Part Two: Instruction Directive

In Part Two, you can provide instructions concerning your future health care. In so doing, you will make important choices. Before completing your instruction directive we advise that you discuss these matters with your health care representative, doctor, family members or others who may become responsible for your care.

Please note that if you have both an instruction directive and a health care proxy directive, as you will have if you complete both Part One and Part Two of this advance directive, then your representative must consult your instruction directive (Part Two) when carrying out your wishes.

GENERAL INSTRUCTIONS:

To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial ONE of the following two statements with which you agree:

1. _____I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2. _____There are situations (descriptions of which I initial below) in which I would not want my life to be prolonged by medical treatment. In these circumstances, no life-sustaining treatment* should be started and if it has been started, should be ended. I recognize that this is likely to hasten my death.

*"Life-sustaining treatment" means the use of any medical device or procedure, including artificially provided fluids and nutrition, drugs, surgery or therapy, that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increases the expected life span of a patient.

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If you have initialed statement 2, please initial each of the statements (a, b, c) with which you agree:

a. _____ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition. If this occurs, and my attending physician and at least one additional physician who has personally examined me determine that my condition is terminal, I direct that life-sustaining treatment which would serve only to artificially prolong my dying be withheld or ended. I also direct that I be given all medically appropriate treatment and care necessary to make me comfortable and to relieve pain.

In the space provided, write in the bracketed phrase with which you agree:

To me, terminal condition means that my physicians have determined that:

[I will die within a few days]
[I will die within a few weeks]
[I will die within a few months]
[I have a life expectancy of approximately _____ or less *(enter, for example, 6 months, or 1 year)]*

b. _____ If there should come a time when I become **permanently unconscious**†, and it is determined by my attending physician and at least one additional physician with appropriate expertise who has personally examined me, that I have totally and irreversibly lost consciousness and my ability to interact with other people and my surroundings, I direct that life-sustaining treatment be withheld or discontinued. I understand that I will not experience pain or discomfort in this condition, and I direct that I be given all medically appropriate treatment and care necessary to provide for my personal hygiene and dignity.

c. _____ I realize that there may come a time when I am diagnosed as having an **incurable and irreversible** illness, disease or condition **which may not be terminal**. My condition may cause me to experience severe and worsening physical or mental deterioration and/or a permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

*(Paragraph **c**. covers a wide range of possible situations. If you wish, in the space provided below you may specify in more detail the exact conditions in which you would choose to forego life-sustaining measures. You might include a description of the faculties or capacities, which, if irretrievably lost would lead you to accept death rather than continue living, for instance the ability to talk with your family or to enjoy food or sunlight. You may want to express any special concerns you have about particular medical conditions or treatments, or any other thoughts which would provide guidance to those who may become responsible for your care.)*

Conditions which I find **unacceptable** include, among others:

_____

_____

_____

d. _____ If, however, I am pregnant at the time that I am diagnosed as having any of the conditions described in (a) - (c) above, I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition, but only for the duration of the pregnancy.

SPECIFIC INSTRUCTIONS: Artificially Provided Fluids and Nutrition; Cardiopulmonary Resuscitation (CPR).

In the previous section of Part Two you provided general instructions regarding life-sustaining treatment. In this section of Part Two you are asked to give specific instructions regarding two types of life-sustaining measures – artificially provided fluids and nutrition, and cardiopulmonary resuscitation. It is important that you complete this section.

†"Permanently unconscious" means total and irreversible loss of consciousness and capacity for interaction with the environment and includes a persistent vegetative state and an irreversible coma.

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In the space provided, write in the bracketed phrase with which you agree:

1. In the circumstances I initialed above, I also direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion,

_____

[be withheld or withdrawn and that I be allowed to die]
[be provided]

2. In the circumstances I initialed above, if I should suffer a cardiac arrest (a heart attack), I also direct that cardiopulmonary resuscitation (CPR)

_____

[not be provided and that I be allowed to die]
[be provided]

3. If you wish to add more about your wishes about either of these two kinds of life-sustaining treatment, please write your wishes below.

_____

_____

_____

ADDITIONAL GENERAL INSTRUCTIONS:

(You may use this space to provide additional information about your health care preferences that is important to you and that may help those concerned with your care to implement your wishes. If you are or believe you may become pregnant, you may wish to state specific instructions. If you need more space than is provided here you may attach an additional statement.)

_____

_____

_____

_____

BRAIN DEATH:

(The State of New Jersey recognizes the irreversible cessation of all functions of the entire brain, including the brain stem (also known as whole brain death), as a legal standard for the declaration of death. However, individuals who do not accept this standard because of their personal religious beliefs may request that it **not** *be applied in determining their death.*

Initial the following statement only if it applies to you:

_____ To declare my death on the basis of the whole brain death standard would violate my personal religious beliefs. I therefore wish my death to be declared solely on the basis of the traditional criteria of irreversible cessation of cardiopulmonary (heartbeat and breathing) function.

AFTER-DEATH ANATOMICAL GIFTS:

(It is now possible to transplant human organs and tissue in order to save and improve the lives of others. Organs, tissues and other body parts are also used for therapy, medical research and education. This section allows you to indicate your desire to make an anatomical gift and if so, to provide instructions for any limitations or special uses.)

Initial the statements which express your wishes:

1.____ **I wish** to make the following anatomical gift to take effect upon my death:

A.____ any needed organs or body parts

B.____ only the following organs or parts:

_____

for the purposes of transplantation, therapy, medical research or education, or

C. ____ my body for anatomical study, if needed.

D. ____ special limitations, if any:

_____

If you wish to provide additional instructions, such as indicating your preference that your organs be given to a specific person or institution, or be used for a specific purpose, please do so in the space provided below:

_____

_____

_____

_____

2.____ **I do not wish** to make an anatomical gift upon my death.

Part Three: Signature and Witnesses

COPIES:

The original or a copy of this document has been given to the following people *(NOTE: If you have chosen to designate a health care representative and alternate representative, it is important that you give your representative(s) a copy of your directive.):*

1. *Name* _____

Address _____

City _____ *State* _____

Telephone _____

70X

2. *Name* _____

Address _____

City _____ *State* _____

Telephone _____

SIGNATURE:

By writing this advance directive, I inform those who may become responsible for my health care of my wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I have discussed the terms of this designation with my health care representative(s) and my representative(s) has/have willingly agreed to accept the responsibility for acting on my behalf in accordance with this directive and my wishes. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ day of _____ 19 _____.

Signature _____

Address _____

City _____ *State* _____

Your signature must be witnessed by <u>either</u> (a) two adult witnesses, neither of whom is your designated health care representative or alternate representative; <u>or</u> (b) a notary public; <u>or</u> (c) an attorney at law. Use one of the two forms of witnessing your signature that appear below:

WITNESSES:

I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, **and am not designated by this or any other document as the person's health care representative.**

1. *Witness* _____

Address _____

City _____ *State* _____

Signature _____

Date _____

2. *Witness* _____

Address _____

City _____ *State* _____

Signature _____

Date _____

ACKNOWLEDGEMENT BY NOTARY PUBLIC OR ATTORNEY AT LAW:

On , _____ (date) before me came _____ (name of declarant) ,
whom I know to be such person, and the declarant did then and there execute this declaration.

Sworn to before me this _____ day of _____ , 19 _____ .

_____

Notary Public ❑ Attorney at Law ❑ (check one)

71 X

This document will be revoked if you 1) notify your health care providers, in words or in writing, that you intend to revoke it, 2) complete and sign and have witnessed a subsequent advance directive, or, with regard to the health care representative portion, (3) by divorce or legal separation if you have appointed your spouse as a health care representative.

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Choice In Dying **NEWS** *Excerpt*

FROM THE SPRING, 1993 ISSUE OF *Choice In Dying News*.

STATES ARE CREATING A NEW FORM CALLED A "NONHOSPITAL DNR ORDER." HERE'S WHY.

An Ohio member wrote to us recently about a traumatic experience: "My husband had a seizure on December 1st and was gone before the paramedics arrived. As they came in I said he was no longer breathing and had no pulse, to which one of them agreed. I also said that we had living wills. They said something to the effect of, 'Oh, you do?' Nonetheless, they proceeded to give him CPR, [including] electric shock to the heart. They had him breathing, I could see that.

They proceeded to the hospital, where they continued working on him. I immediately told the nurse about our living wills. She replied, 'I'm so glad you told me.' She spun on her heels and entered the cubicle in which they had my husband; shortly thereafter we were informed he was gone.

My question is, what do I have to do, have my living will tattooed on my forehead??? How can I be sure I will not be resuscitated?"

PARAMEDICS *MUST* START CPR

Unfortunately, this was no aberration. In most states, if you call for paramedics and they find that the victim's heart has stopped, they are legally required to perform CPR (cardiopulmonary resuscitation). They must do this even if the patient has already died—that is, stopped breathing—when they arrive. And they cannot stop CPR based on a living will or an appointed proxy's request, because *advance directives do not apply in medical emergencies*.

TIME AND EXPERTISE

There are valid reasons for this rule. Emergency medical technicians (EMTs) have one specific job: to keep someone alive long enough to get to an emergency room. And since paramedics are not physicians, they can't make medical diagnoses. Living wills or health care proxies take effect only after the patient is diagnosed as unable to make medical decisions. Emergency medical personnel don't have the time or the training to make that judgment.

ENTRENCHED MISUSE

At the same time, there are clearly cases where the use of CPR makes no sense at all. CPR was created for people, such as accident victims, who are basically in good health and have a good chance of recovering. It was not meant for very frail or dying people. Like other forms of life support, CPR came to be used automatically, whatever the patient's condition.

It is this use of CPR for patients who are already near death—a misuse that is now entrenched in the thinking of most medical facilities—that creates the need for Do-Not-Resuscitate (DNR) orders. Until recently, though, DNR orders were valid only within medical facilities, not outside of them.

TWO SOLUTIONS

As a result, some EMT groups and other organizations are lobbying for "nonhospital Do-Not-Resuscitate orders." A nonhospital DNR order is an advance directive that specifically refuses *emergency* CPR. Thus, it is valid anywhere. So far, seven states have passed nonhospital DNR legislation (see "The New DNR Laws," on back).

Unlike a living will or proxy appointment, a nonhospital DNR order is *not* something everyone should rush right out to get. It is meant only for people whose frailty or ill health gives them little chance of surviving and recovering from CPR. In those cases, however, DNR orders can avert the surreal situations created by current standards for emergency resuscitation.

The other solution is to try to avoid calling the paramedics at all. People who are dying at home can, with the help of medical professionals, plan ahead so their caregivers know who to call instead of the EMTs. However, since loved ones may, understandably, panic at the moment of death, a nonhospital DNR may still be the best safeguard of the patient's wishes. ■

(See back for more.)

73X

As of the spring of 1993, Arizona, Colorado, Florida, Montana, New York, Rhode Island and Virginia have enacted "nonhospital DNR" laws to allow people to refuse emergency resuscitation. These laws attempt to solve the problem of people receiving unwanted emergency treatment.

All of the laws require that a non-hospital DNR (do-not-resuscitate) order be on an official form prepared by the state department of health. These forms are made to look distinctive, so that Emergency Medical Technicians (EMTs) can identify them quickly; for example, Arizona's form is on orange paper. The patient (or his or her health care proxy) and a doctor are usually required to sign the order. In some states, the DNR order can be noted on an identification tag worn as a necklace or bracelet, or on a wallet-size card.

COMPLIANCE WITH AN ORDER

Since paramedics in most states *must* resuscitate unless they see a DNR order, people who do not want cardiopulmonary resuscitation (CPR) should carry the order with them at all times. An EMT must stop resuscitation efforts whenever a nonhospital DNR order form is presented (unless the order has been tampered with, or the EMT knows it was revoked). Paramedics who comply with an official DNR order cannot be sued later for failing to provide care.

SOME CONFUSION REMAINS ...

These laws do have some problematic features. One of the most glaring is the question of who can complete such an order; most of the laws are simply vague on this point. In some states, such as Virginia, only patients diagnosed with a terminal or irreversible condition have the option to fill out a nonhospital DNR order. Other states, including New York, place no such restrictions on competent patients. (New York does, however, say that a health care proxy may complete a nonhospital DNR order on a patient's behalf only if that patient is terminally or irreversibly ill, or permanently unconscious.)

... AND BASIC IGNORANCE

At the moment, however, publicity may be the biggest problem of all. Since these laws are new, the information is still little known to health care professionals, and even to emergency medical personnel. You may now know more about nonhospital DNR orders than your doctor does. And with most states relying on doctors to educate their patients, instead of informing the public directly, publicity is crucial.

If you live in a state with one of these laws, you can educate your community by writing to the newspapers, and by asking your care providers and medical facilities what they know about the new system.

And if, like most of us, you live in one of the states that do not have this kind of mechanism, you can send copies of these articles to your state legislators and EMT societies, and urge them to push for a nonhospital DNR law. ■

Choice In Dying News *is a publication of Choice In Dying, Inc., the nation's leading nonprofit organization working for the rights of patients to make their own decisions about medical care at the end of life.*

Choice In Dying advocates the recognition and protection of individual rights at the end of life. It educates the public, health care professionals and lawmakers to the needs of people who are dying.

For more information, contact:

Choice In Dying, Inc.
200 Varick Street
New York, NY 10014-4810

1-800/989-WILL, or
212/366-5540.

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TESTIMONY OF NADINE TAUB WITH THE ASSISTANCE OF EVELYN HERNANDEZ AND ERICA WADE BEFORE THE NEW JERSEY COMMISSION ON SEX DISCRIMINATION'S HEARING ON WOMEN'S HEALTH ON BEHALF OF THE RUTGERS WOMEN'S RIGHTS LITIGATION CLINIC, THE NATIONAL CENTER FOR PUBLIC INTEREST LAW AND THE NEW JERSEY COALITION AGAINST REPRODUCTIVE HAZARDS IN THE WORKPLACE.

Livingston, New Jersey

February 9, 1994

Good afternoon.

Our testimony today concerns reproductive hazards in the workplace, one aspect of a large and at times discriminatory, obstacle to safe, continued employment. As you no doubt know, the United States Supreme Court with its 1991 decision in United Auto Workers v. Johnson Controls made clear at least in theory that fertile women cannot be excluded from the workplace in the name of "fetal protection." The result of that decision, however, was to make women as well as men free to be exposed to reproductive hazards in the workplace. The need to eliminate such exposures must remain in the front of our minds. But while we are seeking and implementing ways to meet this crucial need, we must ensure that workers are not forced to choose between their health and the health of their off-spring on the one hand and their incomes on the other. It is that short-term problem of ensuring continued income to workers, pregnant women workers in particular, who must temporarily leave their jobs and the dangerous exposures they entail that we address today.

Right now the State of New Jersey refuses to allow such women to receive disability payments. It instead insists that pregnant women whose physicians tell them to avoid exposures to chemical and other hazards while they are pregnant can only get unemployment compensation. In other words, the State is telling them they must quit their jobs to receive assistance. With this approach, the State deprives them of all medical benefits associated with their employment and any right to seniority if they are able to return to their previous jobs.

We first became aware of New Jersey's rigid policy last spring when the Clinic received a call from a women employed as a chemical analyst by a company that recycles hazardous wastes whose doctor had told her not to continue in her position at work now that she was pregnant. The company did not have other work for her and wanted to put her on disability, but the State said no. Our repeated calls and letters on her behalf simply confirmed the denial of disability benefits, though it did spur disability personnel to help her secure the unemployment benefits to which she was presumably already entitled.

The New Jersey Temporary Disability Law does not say anything about denying pregnant workers disability benefits if they choose to follow their physicians' instructions to avoid on-the-job exposures to hazards while they are pregnant. Instead, this restriction on the availability of benefits is contained in

a document issued by the state disability agency called Interpretation, IMT-185, Service Guide No. 18, Subject: Adjudication of Pregnancy-Related Disability Cases Under the State Plan and Disability During Unemployment. In our view, that Guide (which we submit herewith) is totally irrational and impermissibly discriminatory.

The document makes clear that a pregnant women may receive temporary disability benefits from the State of New Jersey "if she is too disabled to work due to medical complications associated with her pregnancy." The Guide also makes clear that "heavy lifting or any other strenuous work, is disabling for most women in the first trimester of pregnancy." However, the document makes equally clear that a pregnant women will not receive benefits "if she leaves work because of the potential effect of toxic fumes [or other chemical or x-ray exposures] on her fetus."

It is very hard to understand any basis for the State's distinction. It is possible that the State is confusing the nature of the risk and its degree of seriousness. However, it is simply not true that heavy lifting and strenuous activity jeopardize a pregnancy in the first trimester more than exposure to high levels of certain toxins and x-rays. The Guide states the Supervising Medical Examiner has found the risk due to ergonomic strains unacceptable in the first trimester. The

Examiner likewise should find that exposure to developmental or reproductive toxins that pose an unacceptable risk of miscarriage, stillbirth or birth defects is also a disabling complication of pregnancy.

Another possible explanation for the distinction is that the State somehow has the idea that the chemical exposure situation is unlike the ergonomic problem in that it involves risks to the fetus only. However, the chemical exposure situation endangers the woman and her pregnancy just as the heavy lifting and other strenuous activity do. Doctors who advise their pregnant patients to leave work because the exposure poses a "high risk" to their pregnancy are acting out of an understanding that certain toxins in fact pose grave threats to pregnancy. In short, both the ergonomic and the chemical exposure situations can be disabling.

A third possible basis for treating the two situations differently is that in the chemical and x-ray exposure case, the State regards the injury a doctor seeks to forestall as an injury to the fetus who it sees as distinct and separate from the women. This, however, is inconsistent with both state and federal law. In a case directly on point, the New York Appellate Division awarded disability benefits to a woman exposed to hazardous chemicals while pregnant. In so doing, the court made clear that the cognizable harm was to the pregnancy and therefore a harm to the woman herself. The court explicitly stated that

"since it could rationally be concluded [claimant's] work area was never cleared of paint fumes and the claimant had been admonished by her physician not to remain in such an environment due to her pregnancy, there was ample basis to support [the board's] determination that claimant was disabled in connection with her pregnancy." Pond v. Oliver, 111 A.D.2d 1059, 1059-60; 490 N.Y.S.2d 358, 360 (1985).

The United States Supreme Court has also made clear that a fetus is not a person distinct from the pregnant women carrying it. As it said, a "fetus is not a person within the meaning of the 14th Amendment or within the meaning of any other provision of the U.S. Constitution," Roe v. Wade 410 U.S. 113, 156-159 (1973). New Jersey's courts have reached the same conclusion in a variety of contexts. See Giardina v. Bennett, 111 N.J. 412, 420-422 (1988) (Wrongful Death Act); State v. Loce, 267 N.J. Super 10, 630 A.2d 792, (App. Div. 1993), cert. den. appeal dismissed (---N.J.--- Oct. 21, 1993) (abortion); State in the Interest of A.W.S 182 N.J. Super 278 (App. Div. 1981) (homicide).

Like New York, New Jersey must find a woman's inability to work in an occupation where exposure threatens fetal deformities is disabled in connection with her pregnancy. Simply put, the harm is to the woman. A woman should be granted disability benefits under the New Jersey Temporary Disability Benefit Law if her position at work poses harm to the fetus since the fetus is

part of her and is not a separate person.

Even if the State does not share our view that inability to work due to dangers posed to the fetus renders a woman eligible for disability benefits, it must acknowledge that the very same toxins that cause to fetal deformity also cause miscarriage. Thus, it would make no sense to a policy of only awarding disability benefits where the pregnancy is compromised.

We commend to your attention the opinion letter of Maureen Paul, M.D., M.P.H., F.A.C.O.G., Director, Occupational Reproductive Hazard Center, University of Massachusetts Medical Center submitted herewith. An expert in these problems, Dr. Paul makes plain the scientific basis for the analysis we have presented today.

We very much hope that bringing the improprieties in statutory interpretation announced by the State Department of Labor and Industries to your attention will help prompt correction of the State's policy and practice. Obviously, it would be preferable to resolve these matters without additional legislation and out of an adversary context. We appreciate your interest in this matter and stand ready to assist you in any efforts you may undertake to achieve change.

Thank you.

80X

University of Massachusetts

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December 8, 1993

Mr. Michael P. Malloy, Director
Commissioner, New Jersey Department of Labor
Division of Program
Department of Labor, John Fitch Plaza
CN-058
Trenton, New Jersey 08625-0058

Dear Mr. Malloy:

I am a Board-certified obstetrician-gynecologist and occupational health physician (a copy of my curriculum vitae is attached). I have been asked by Nadine Taub to review "Interpretation IMT-185, Service Guide No. 18, Adjudication of Pregnancy-Related Disability Cases under the State Plan and Disability during Unemployment" and to render an opinion regarding the medical and scientific issues relevant to determinations of eligibility of pregnant women for disability and unemployment benefits. An integral part of my work as Director of the Occupational and Environmental Reproductive Hazards Center at the University of Massachusetts Medical Center involves evaluation of pregnancy-related disability claims, and I am therefore intimately involved in the subject addressed by the Interpretation document.

Determinations about pregnancy-related disability must be consistent with criteria for disability as they have been applied in cases of injury and illness generally. The definition of disability expressed in your Division's Interpretation document is indeed one quite universally applied to disability determinations, i.e., that disabling conditions are those which render a worker "unable to perform the duties of his or her regular job". In the case of injury (e.g., a broken leg) or incapacitating illness (e.g., a severe viral illness), this definition of disability is applied quite literally, since a worker with such a condition is clearly physically unable to work. However, disability also encompasses conditions that are not always literally incapacitating, but that entail significant threat of harm. For example, disability benefits are typically granted to truck drivers with angina or machinists with diabetes, even if these illnesses are medically controlled. Although workers with these conditions are technically able to perform the work tasks required of their jobs, the rationale for allowing disability is that such work might result in serious harm to the worker or others.

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Consistent with the above, a pregnant woman, while physically able to perform her job in a literal sense, would be likewise eligible for disability if continuation of work threatened serious physical harm, such as miscarriage (spontaneous abortion) or fetal deformities. Indeed, the case of the pregnant waitress described in the Interpretation document is such a case. While there are normally no physiologic changes in the first trimester of pregnancy that interfere with a waitress' actual physical ability to lift 30 pounds, disability benefits were allowed because "heavy lifting" increases the risk of an adverse outcome - in this case, spontaneus abortion. The Interpretation indicates that disability should be granted in the first trimester to all pregnant women whose jobs require strenuous work and whose physicians advise discontinuation of such work. I should note, however, that limiting this to the first trimester is inconsistent with a considerable body of scientific evidence that suggests that strenuous work may also be hazardous later in pregnancy, particularly with regard to increasing the risk of preterm delivery (1). A pregnant woman should be eligible for disability at whatever point in pregnancy her physician determines that such activity poses an unacceptable risk of miscarriage or other complication of pregnancy.

The failure of the state of New Jersey to extend disability benefits to cases of pregnant women exposed to chemicals or ionizing radiation is wholly inconsistent with the principles stated above and is incongruent with sound scientific principles. There is at least as much, if not more, scientific data to support an increased risk of spontaneous abortion from certain chemical exposures as there is for heavy lifting or other strenuous work. Examples include occupational exposure to organic solvents such as the ethylene glycol ethers, chemotherapeutic agents, ethylene oxide, and waste anesthetic gases (2). There is no logical scientific basis for treating spontaneous abortion differently from other adverse developmental outcomes. In fact, it is a well-established scientific principle that the same toxic exposure during pregnancy may result in a variety of adverse outcomes ranging from spontaneous abortion to birth defects to fetal growth deficits to functional abnormalities, and that the particular manifestations of abnormal development depend on a number of factors such as genetic susceptibility and the timing and dose of exposure (2-6). Ionizing radiation is a prototypical example in that, depending on the conditions of exposure and other factors, any of the above abnormalities may result from exposure. Moreover, aberrant developmental outcomes are highly interrelated. For example, malformed fetuses are more likely to be growth retarded and to spontaneously abort (3,7). Due to the numerous factors that can influence outcome, many of which are unknown or incompletely understood, it is usually difficult, if not impossible, to predict which adverse outcome (miscarriage, birth defects, etc.), if any, will result from exposure to a developmental toxicant (4).

It makes no sense from a scientific perspective to consider strenuous work disabling during pregnancy, but not exposure to high levels of ionizing radiation or to serious chemical reproductive hazards. Neither does it make sense to distinguish between the consequences of these exposures and award disability benefits for one consequence (i.e., the risk of spontaneous abortion) and not for others (e.g., the risk of birth defects). These outcomes are inextricably interrelated and equally serious in nature; furthermore, which outcome will actually occur in a given individual or in a given situation is usually impossible to predict.

Finally, it is extremely important to recognize that the current occupational limits established by the Occupational Safety and Health Administration (OSHA) are not usually designed to protect against adverse reproductive and developmental effects specifically (8). In fact, of the tens of thousands of chemicals in widespread industrial use in the United States, only three chemicals currently have OSHA standards that at least partially consider reproductive effects, i.e., dibromochloropropane, ethylene oxide, and lead (5). (OSHA also recently proposed reduced exposure limits for the ethylene glycol ethers based specifically on their reproductive effects, but these are not yet adopted). Moreover, these limits are, in the case of lead, in grave need of revision based on recent scientific evidence of lead's toxicity as low doses. Therefore, a significant risk of reproductive harm may exist with occupational exposures well below OSHA limits, and physicians may justifiably advise pregnant women not to work with hazardous chemicals even when exposures do not exceed permissible limits.

In summary, it is my medical opinion that New Jersey's temporary disability provisions for pregnant women are seriously flawed and scientifically irrational. Rather than providing "seamless service" to pregnant women, these provisions represent a grave disservice by denying women eligibility for disability benefits for cases in which their exposure to ionizing radiation or chemicals may result in serious reproductive harm, ranging from miscarriage to birth defects. In addition, by withholding from pregnant women benefits that are typically provided to other individuals with medical conditions that pose a threat to one's health or safety, the provisions appear inconsistent with anti-discrimination statutes whose intent is to assure that pregnant women are treated the same as other similarly-situated individuals.

I urge the state of New Jersey to seriously reconsider its eligibility criteria for pregancy-related disability and to bring its provisions in line with current scientific knowledge. I am more than willing to be of assistance in this endeavor. If you have any questions regarding this letter, please do not hesitate to contact me at 508-793-6255. Thank you very much.

Sincerely,

Maureen Paul MD, MPH

Maureen Paul MD, MPH

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UMD
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675 Hoes Lane
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February 9, 1994

Mr. Michael P. Malloy, Director
Commissioner, New Jersey Department of Labor
Division of Programs
Department of Labor, John Fitch Plaza
CN-058
Trenton, NJ 08625-0058

Dear Mr. Malloy:

In the Division of Occupational health, we run a clinic in which we are asked to see and evaluate pregnant women and their workplace exposures every week. Because of our familiarity with the many dilemmas of these problems, we have been asked by Nadine Taub to review "Interpretation IMT-185 Service Guide No. 18, Adjudication of Pregnancy Related Disability Cases under the State Plan and Disability During Employment".

Upon review of this document, we find that the granting of disability to pregnant women who work for the state of New Jersey is whimsical and quite simply not based in scientific fact. How can it be that disability can be granted to a worker at high risk for miscarriage due to heavy lifting (the waitress required to lift 30 lbs) but not to a worker at high risk for miscarriage due to chemical exposure (for example a nurse-anesthetist exposed to anesthetic waste gas)?

In addition to the distinction make by the state regarding physical versus chemical and radiation hazards, we see no scientific rationale for granting disability to women for threatened miscarriage but not for high risk for fetal malformations. The fetus is a part of the mother until time of delivery; chemical and radiation hazards known to cause fetal malformations do harm to the pregnant woman in many ways beyond the physical sense of the word. Please remember too that the primary cause for miscarriage is fetal genetic aberrations. A knowledgeable and caring public will not tolerate the state's demands that the pregnant worker blithely accept these risks in order to keep her job.

We urge you to reconsider work as a process and not as a tally

of isolated physical traumas and chemical or radiation exposures. It is our moral duty to make the workplace as safe as possible for all workers. Nevertheless, should a worker become pregnant and for whom carrying on the process of work would clearly place her health and/or the health of the fetus at risk, alternatives must be found. In our clinic we urge each employer to find safe, alternative duties that the pregnant woman can perform with no loss of seniority, pay or benefits. If alternative duties cannot be found or if the woman's condition is such that it would be medically unwise for her to continue in the workforce at all, she should be placed on temporary disability until she is delivered or can otherwise safely return to work.

The state of New Jersey must reconsider the criteria for pregnancy-related disability among its workers and bring the policy in line with current practical and scientific guidelines. We recommend that disability coverage be extended to pregnant women who are at high risk for adverse reproductive outcome due to work conditions regardless of their nature. Finally, please remember that an ounce of prevention now may be worth pounds of needlessly spent health care dollars in the future and tons of heartache by the families involved. Please do not hesitate to contact us at 908-932-0180 if we can provide any additional information.

Sincerely,

Sandra N. Mohr, M.D.

Sandra N. Mohr, M.D.
Assistant Professor, Occupational Health Division

Michael Gochfeld, M.D., Ph.D.
Professor and Director, Occupational Health Division

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Testimony: NJ Commission on Sex Discrimination in the Statutes
St. Barnabus Hospital, Livingston NJ
February 28, 1994

Commission Chairwoman Senator Lipman,
Ms. Griffin, Executive Director and Members of the Panel:

I thank you for the opportunity to address this panel and to contribute in any way to the important and vital work that you are undertaking.

My name is Carole Sheffield. I am a professor of political science and women's studies. I became seriously ill two years ago with muscular-skeletal, common migraine, and possibly cluster migraine headaches. With a particularly violent episode in April, 1992 I began a nearly two year journey through the medical system which left me quite disheartened about the ability of ill women to secure non-sexist and competent, safe health care. With each doctor I saw, mostly on referral from another doctor, I had to wonder not only whether he/she would have an answer, or an effective remedy for the crippling pain I was experiencing, but whether I would be listened to and treated respectfully.

I would like to report on a few of the experiences I had; at least two of which were life-threatening, and a third which prompted me to seek redress from the New Jersey Medical Society. Some of the incidents were overtly sexist and harmful; others were at best, arguably sexist, but clearly revealed incompetence and uncaring in the delivery of health care. In the latter, the question is whether the incomptence resulted from sexist medical beliefs and practices. I believe they did.

1. A neurologist at a Headache Clinic in NJ prescribed "Stadol"--a synthetic narcotic (although he did not tell me this). He did tell me to consult with him before using the drug. I called him several times over a three-day period, each time telling the nurse/receptionist of the excruciating pain I was experiencing and repeating the doctor's instructions that I consult with him prior to using the drug. After three days, with no response from the doctor, no relief from the pain and in total desperation, I read the drug insert and administered it myself. After several minutes, I passed out cold for a period of five hours. I was home alone; it was springtime and my dog was in the yard and the backdoor was unlocked. I don't know whether I used the drug incorrectly or whether the drug was simply too strong for me. Not having had any guidance, I was certainly not prepared for what happened. This left me in a vulnerable and potentially dangerous situation.

2. I immediately found another neurologist. Last June, she prescribed "Imitrex" --the new, highly touted patient-injectable medication. She carefully went over the insert with me, found nothing in my medical history to suggest I might have an adverse reaction to it, and even administered the first dose in her office to monitor me for side-effects.

A few weeks later, I needed to use it at home. I followed her instructions precisely. Getting no relief, and finding the headache worsening, I called her office. She was unavailable. It took several more calls by my spouse to get one of her partners to respond. He questioned me about the pain and the other medications I had been prescribed--all of which had failed. I emphasized to him how this headache was very different from all the others--in the type of pain as well as its intensity. Since I had experienced significant medicinal failure, he said was that there was nothing he could no for me and hung up. I then asked my spouse to take me to the hospital, where it was determined that my blood pressure was dangerously high.

If I had accepted his advice--"nothing can be done"--I might suffered a stroke or I might not have lived.

3. Three weeks later, again with a terrible migraine, I called my doctor. She was away, so one of her partners spoke to me. He

disagreed with her instructions to avoid Imitrex and suggested instead that I drive myself--with a horrible migraine--to my local hospital, sit in the waiting room and inject myself with Imitrex. That way, he said, if I am wrong and you do have a stroke, you will already be at the hospital. I said thanks, but no thanks.

4. A month later, after a two week migraine, my doctor prescribed a 14-day trial of a steroid, "Decadron." After 4 days of being on the drug I could not walk unassisted and I could barely swallow, due to profound weakness. My hands and feet began to burn and I started to tear at my flesh. I called my doctor right away--as the PDR cautioned that one should seek medical attention immediately if severe itching or a rash developed.

Again, my doctor was unavailable and one of her partners returned my call. I explained what was happening. He told me it was "impossible to have a bad reaction to decadron" and that I was "just tired." I told him that I don't dig at my flesh when tired and he commented that I was "just depressed." I told him he was wrong and that I wanted to go off the drug and asked how to do it safely. He said he would not authorize me to go off the drug and would not give me instructions for doing so.

Why didn't he take 30 seconds to look up decardon in the PDR? If he had, he would <u>not</u> have concluded that I was just tired or just depressed and would have realized that my life was in jeopardy if I continued on the drug as prescribed. Like the long-standing medical belief that menstrual cramps were a figment of a woman's imagination, I believe this doctor's response fits a classic pattern of dismissing a woman's complaint as that of a whining neurotic. While migraine headaches are not an exclusively sex-specific illness, three out of four migraine sufferers are female.

I took myself off the drug--cold turkey. Two days later, my lungs filled with fluid and I developed a cough which lasted for three months and was severe enough to damage my chest wall and ribs. I also developed a frozen shoulder. As a result of this, I had to take a medical leave of absence for the entire fall semester, using up a majority of my accumulated sick-leave.

5. My neurologist, concerned about the severe cough, referred me to an internist. After seeing me twice, he referred me to his partner, a pulmonary specialist. This doctor's attitude and behavior towards

me was so offensive--and blatently sexist, that I contacted the New Jersey Medical Society to file a complaint.

5a. I will briefly summarize the salient points from my letter of complaint (and will provide a copy to the Commission if it so desires):

---He yawned continuously during the twenty minutes he saw me . He was very inattentive and repeatedly asked the same questions. For example, he asked at least four times whether "decadron had helped the migraine."

---He asked no substantive questions about my cough.

---As he leafed through my file, he asked whether among the doctors I had seen recently, had I consulted a psychiatrist? Even after I said no and told him that I did not wish to do so, he became focused only on this issue and despite my repeated rejection of his advice, persisted.

---He absolutely refused to take no for an answer.

---While admitting to me that he doesn't know very much about migraines, he asked "Isn't it strange to wake up at 4:00 a.m. with such a terrible headache. Surely, this is evidence of a deep-seated problem." Further, he insisted that since the MRI and CT-Scan were negative and I had not responded well to migraine drugs then "surely the problem is psychological." He made insinuations about my marriage; even stating that my husband must be sick of me having headaches.

---When he returned from reviewing my chest x-ray, he gave me the name of a psychiarist written on a pad.

I left his office very upset and angry. In spite of the fact that his treatment did not jeopardize my physical health to the same degree as the doctor who refused to believe that I could not have an adverse reaction to a potent steriod, his behavior and attitude was so humiliating and degrading that I decided to file a complaint against this doctor.

6. Filing a Complaint:

Apparently, filing a complaint against a doctor is a well-kept secret. I first called the county office in which the doctor practiced. They told me I had to write a letter to the doctor and wait for his response. If I was not satisfied with it, then I should contact them.

I was not happy with this; I found the doctor to be emotionally abusive, a poor listener, and clearly one of those who believe that migraines are purely psychological. Several times, I said no, clearly and directly, to his insistence that I see a psychiatrist. In fact, the more I said no, the more he insisted. The experience with him was demeaning. I wanted to file a complaint against him and did not believe that a correspondence with him would be benefical in any way.

I then called the state office--which only referred me back to the county office. I told them that I had already done that and was uncomfortable with their procedures. When I told them what the county office had instructed me to do, they agreed that it was not appropriate and after a few telepone calls, told me to write a letter to the judicial committee of the county.

I wrote the letter, which basically included a summary of why I wanted to file a complaint (based on notes I had made when I returned home from the doctor's office), and asked specifically for an explanation of the complaint process. All I received from them was a note that the matter had been referred to the judicial committee on the basis of my initial letter and that I would hear from them when they had "investigated" the matter. I also had to sign two forms: a release of medical records and a disclaimer of legal action.

I was given no further explanation of the process: for example, is there a complaint form (as I was given no guidance for constructing the letter); who was on the judicial committee (not necessarily their names, but since this was in effect a sex discrimination complaint, I'd want to know the gender makeup of the committee); how did they "investigate"?; would there be an opportunity for a hearing; is there an appeal process should I be dissatisfied with the results at the county level? These are obvious questions that

anyone would have about a complaint process but I was given no information about it whatsoever.

I filed the complaint in early October, 1993. In December, after writing yet again to inquire about the status of the complaint, I received a response from the judicial committee. The response itself illuminated the nature of the investigation process--that is, the doctor about whom I complained wrote his response to my letter to the committee and the committee came to a determination. That the process is weighted in favor of the doctor is evidenced by the fact that he was given ample time to respond to my letter, but I was not given the opportunity to respond to his.

I quote the last two sentences from the county judicial committee's letter to me: ...."the committee can only say that it finds your recounting of details at variance with Dr. ___'s recollection. Since you two were the only parties to the encounter, we are unable to form a conclusion. In conclusion, the Committee finds Dr. ___'s care for you to be professional and ethical."

I daresay the latter sentence contradicts the former. Finding Dr.___'s care for me to be "professional and ethical" is most certainly a conclusion, a finding of fact. In other words, the committee, in a position where it is the patient's word against the doctor's, chooses to believe the doctor. End of story. No further information, no advice about other options, etc.

Why would anyone file a complaint if that is the position of the judicial committees of the medical society? Well, perhaps that is their objective afterall.

As a professor of political science and women's studies, I have had considerable experience with drafting and implementing complaint procedures at my college and in hearing complaints. I know it is not easy. However, as it is currently structured, the complaint process for the NJ Medical Society is mysterious, intimidating and frustrating. I had to persist, insist and perservere in order to file a complaint. And I believe that it is designed to be this way. Many times along the way I wanted to forget about it and give up. If women find the process indecipherable and give up, the medical profession can laud itself for the lack of compliants against its doctors.

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To redress sexism in the medical profession is a daunting and multi-faceted task, to be sure. However, the establishment of a fair and open complaint process is absolutely essential to any attempt at reform. The medical society needs, at minimum, to have a written policy, which clearly delineates the complaint process, including appeals and which should be provided immediately to the complainant. It should include guidelines for drafting the complaint and for substantiating it. Judicial committees of medical societies also need to realize that perhaps, given the clear and well-documented history of differential and sub-standard health care that many women receive, they are often not the best judges of sexism in their profession and need outside consultants to assist them in these matters.

I hope my participation in these hearings will be helpful to you. Thank you again for your time.

Carole J. Sheffield, Ph.D.
Professor of Political Science/Women's Studies

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Statement by Ms. Cheryl J. Tice,
Associate Vice President for Strategic Development
University of Medicine and Dentistry of New Jersey

for
Commission on Sex Discrimination in the Statutes
February 28, 1994

The Honorable Wynona M. Lipman, Chairperson, members of the Commission, invited guests, it is my pleasure and honor to testify before you today regarding issues of health care with particular emphasis on federal health care reform and its impact on the delivery of health care within our state. No single entity has received more attention during the past year than the health care reform initiatives currently underway at the state and federal level. To date, more than 40 bills have been introduced in the House and the Senate. Within the current decade, these reforms are expected to transform the American health care delivery system into one based upon increased competition and reliance on managed care; achieve an unprecedented degree of integration among providers and levels of care; and profoundly influence the numbers and types of future health care practitioners needed, and the ways in which they must be educated.

Of particular interest to this group are how women's health issues will be affected and/or influenced as health care reform goes before the Congress this year. As Congress moves toward action on health care reform, it is vital that women's health care needs are addressed. A simple set of statistics bears this out:

- Of the 39 million uninsured in the nation (approximately 900,000 in New Jersey), sixteen million are women;
- Women are more likely to be employed part-time or by small businesses therefore lessening their chances to receive health insurance through their jobs;
- Fifteen million women **of reproductive age** have no coverage for maternity care -- nearly twenty-five percent of pregnant

women do not receive adequate prenatal care and this number is even higher for many minority women;

o It is estimated that one of every nine women in the United States will develop breast cancer, a statistic that equates to nearly 46,000 women dying from breast cancer this year. In addition, the National Cancer Institute estimates that at least seven in ten deaths from cervical cancer could be prevented if more women had regular Pap smears;

o The deficiency of research on women's health has led to less appropriate and less effective care for women. While heart disease is the leading killer of American women, a 1988 study demonstrating that small doses of aspirin effectively prevented heart disease included over 22,000 men and **no** women.

The University of Medicine and Dentistry of New Jersey (UMDNJ), New Jersey's university of the health sciences, endorses the major goals of health care reform as advanced by the plan proposed by President Bill Clinton and introduced in Congress by co-sponsors Rep. Richard Gephardt (D-MO) and Sen. George Mitchell (D-ME) as the Health Security Act of 1993(S.1757/H.R.3600): creating security, controlling costs, enhancing quality, expanding access to all citizens and legal residents by 1998, streamlining bureaucracy, and reducing fraud and abuse. As educators of future health care professionals and providers of health care, we recognize that our system must be made more rational and efficient if we are to improve our nation's economic competitiveness in the global marketplace. We believe guaranteed, lifetime coverage for all Americans--which is already enjoyed by the citizens of virtually all other developed countries--is long overdue. We also are pleased that, as well as universal coverage, the latest draft of the Clinton plan provides for increased choice for all Americans.

The Health Security Act mandates coverage for all Americans, through a system of regional health alliances, which contract with state-certified health plans to offer a comprehensive benefits

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package. The plans, in turn, contract with providers for the actual delivery of care. Health plans must utilize community rating, and must provide services to all eligible persons.

We are encouraged that the plan includes coverage for a broad range of services, including many that have been overlooked by traditional insurance mechanisms. In particular, women's health issues are highlighted with the inclusion of preventive services such as cancer screening and family planning and health education classes; mental health and substance abuse services; home health and extended care services; and prescription drugs are likely to improve the health status and quality of life for Americans, while controlling health care costs. The emphasis on prevention is reinforced through the proposed increased investment in public health initiatives, such as enhancing access for high risk and under-served groups, reducing the incidence of infectious diseases, and addressing environmental health problems--all major challenges here in New Jersey.

As we are already aware, the frequency of coverage for mammograms and pap smears within the reform plan has already generated controversy among Members of Congress and women's health advocates. In response to those concerns, the administration has expanded the coverage of mammograms and pap smears in the Health Security Act.

The plan calls for vigorous measures to limit the growth of premium costs of the proposed health alliances, and aggressive savings in Medicare, Medicaid, and other federal programs. We share the concerns that have been raised by both economists and legislators, who concede that the financing plan is theoretically possible, but question whether the identified spending cuts and cost controls can be implemented as aggressively and rapidly as targeted. Without financial viability, the plan will not be politically viable, and its important goals will not be achieved.

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While numerous pieces of health care reform legislation were introduced into the last Congressional session, in addition to the Health Security Act, three bills--one sponsored by Conservative Democrats Sen. John Breaux (D-LA) and Rep. Jim Cooper (D-TN) (Managed Competition Act, S. 1579/H.R. 3222), single payer legislation sponsored by Rep. Jim McDermott (D-WA) and Sen. Paul Wellstone (D-MN) (American Health Security Act, S. 491/H.R. 1200) and the other by Republicans Sen. John Chafee (R-RI) and Rep. Bill Thomas (R-CA) (Health Equity and Access Reform Today Act, S. 1770/H.R. 3704)--appear to represent the major alternatives to the President's proposal.

The McDermott bill, the leading single-payer health care reform proposal on Capital Hill, advocates mandatory coverage by 1995 with government sponsoring and financing all health insurance through employer payroll taxes and a variety of sin taxes. The other two bills seek to expand insurance coverage toward the goal of universal access, without an employer mandate, and rely upon increased competition, rather than government controls, to effect cost containment. With reference to women's health, the McDermott bill lists coverage for prenatal care, periodic screening mammograms and pap smears, family planning services and abortion as a medically necessary and appropriate service, although the periodicity for health screening tests is to be determined by a professional body established under the Act. Language within the Cooper bill suggests something similar and includes "preventive health measures with respect to breast and cervical cancers", however, the actual determination of standard benefits will be left to a National Health Board to formulate and recommend to Congress for final approval. This failure to specify precisely what is covered under the basic benefits package is of concern to women looking for assured access to reproductive care.

Since it is generally believed that bipartisan support and collaboration will be necessary to enact health care reform

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legislation, efforts in Congress are likely to focus on identifying common elements of these bills, and the positions of major health care leaders and organizations, in order to develop a compromise proposal. As early as late March, congressional committees could record the first votes on whether abortion services should be covered as part of a full range of reproductive rights for all women.

Relegating the abortion decision to the states or rendering it entirely optional for insurance companies are fast becoming politically palatable compromises for lawmakers. Congressman Cooper has suggested the idea of excluding abortion from any benefits package and treating it as an optional benefit, requiring women to pay additional insurance premiums if they want to be covered for abortion services. According to the American Public Health Association (APHA), the Cooper proposal is aimed at discriminating against one service in what should be a full spectrum of women's reproductive health care.

Action within the upcoming session is possible, but by no means guaranteed, and the need to achieve broad-based support for national health care reform must be balanced against the potential negative effects of delay. Despite numerous state reform initiatives designed to increase access, recent data indicate that the number of Americans without health insurance increased by 2.3 million from 1991 to 1992, to 38.9 million. This is a larger increase than in the previous two years, probably due to high rates of unemployment. Secondly, and equally critical, none of the changes to date appear to have affected the escalation of health care costs, which, in 1992, totalled $838 billion--more than 14 percent of the gross domestic product.

Historically, women's health has been treated as an afterthought. Women have been systematically excluded from medical research studies, received less aggressive treatment for heart disease and

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other serious conditions, and lacked access to important preventive services. This is not a political debate over abortion or contraception but rather a critical debate over health equity for women. Who will be covered, how coverage will be financed, and how costs will be contained remain the thorniest issues. Conventional wisdom holds that support is there for universal coverage but on a slower timetable and with a narrower package of benefits than Clinton has proposed.

Clearly, another set of concerns springs from fears about the impact of the plan on various states. The premium caps are based upon the historic price and volume of health care in each state prior to the introduction of Clinton's legislation, therefore the budget targets will vary dramatically across states. Critics say that penalizes states that have been leaders in cost containment while giving a financial break to states where spending remains high.

While the Clinton plan is not perfect, we urge all participants in this Commission to work together develop responsible, workable alternatives that support a health care reform package that treats women's health equally to men's. We look forward to working with the Commission and other colleagues on a health care system that offers women equal access to comprehensive health care. Thank you.

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New Jersey Commission on Sex Discrimination
in the Statutes 28 February 1994

The Impact of Sexism on Women's Health and Health Care

Meredeth Turshen, PhD
Edward J. Bloustein School of Policy and Planning
Rutgers University, New Brunswick, NJ

In the past decade we have seen, simultaneously, an erosion of affirmative action, increasing poverty among women, and declining standards of public health care in the United States. The purpose of this testimony is to address issues of sexual harassment and sex discrimination as they affect women's health care, research on women's health, and the education and training of women in the health professions.

Tracking the impact of the erosion of affirmative action on minority women is difficult because publications consistently present data either by race or by sex, but rarely break them down by both race and sex. Most articles in the literature address either the impact on minorities without regard to sex, or the impact on women without regard to race. My first recommendation is that the State cross tabulate all data on employment, education, and training by race and sex.

The Impact of Sexism on Women's Employment

The medical gender gap is striking: nationally, 0% of medical school deans are women, 2% of medical school department chairs are women, 8% of surgeons are women, and 16% of physicians are women.[1] Female doctors earn only 62.8% of what male doctors earn, in part because they are clustered in the lowest paying specialties. The top ranks of the American Medical Association and the American College of Obstetricians and Gynecologists are virtually devoid of women. Just 21% of medical school faculty are women; this represents an increase of only 7% since 1967. UMDNJ does better than the national average in New Brunswick, where 33% of faculty are women, but only 1.6% of the faculty are black women; Camden is more typical of the nation--21.5% of the faculty are women and there are no black women on the faculty (1993 data from Associate Dean of Academic Affairs).

Nationally, in 1990, 36% of medical school students were women, the only proportion that has grown considerably in recent years. UMDNJ-RWJ ranks 76th in the country, NJMS ranks 72nd (Feminist Majority Foundation 1991:4). In October 1993, women accounted for 39% of students enrolled in UMDNJ-RWJ (Camden and Piscataway combined); 6% are African-American women and 3.5% are Hispanic women. At NJMS, 40% of students are women, 5.8% are African-American women and 4% are Hispanic women. The New Jersey Graduate Program in Public Health enrolls more women than men in

the master's program, but as of 1993 had graduated only 3 African-American women, 1 Cuban-American and no Puerto Rican or Mexican-American women. In contrast to physicians, nationally 98% of nurses are female. Eleanor Smeal, head of the Feminist Majority Foundation, concluded that "sexism is still rampant throughout medicine." (Science 1991, 253:1352)

The picture is hardly brighter in other university faculties. Nationally, women are still under-represented in tenured faculty, with discrepancies greatest for full professors. Men compose 72.6% of all faculty, women 27.4%. Personnel practices account for the limited change in this picture: (i) more white men are being hired in beginning tenure-track positions than women or minorities; (ii) the tenure rate for white men is higher and their promotion rate is more rapid; (iii) minority women are particularly under-represented: in general the percentage of African-Americans has decreased and the percentage of Latino faculty has remained minuscule; (iv) women's salaries are lower than men's in all types of institution and for every academic rank; and (v) women are still under-represented in the upper reaches of administration, particularly where budget and policy decisions are made. Lillian Robbins, Chair of Committee W of the New Jersey American Association of University Professors, concludes, "Twenty years of Affirmative Action have not been successful at dramatically improving the situation of women and minorities. The gains of the seventies, in terms of tenure and promotion, may disappear as the older generation of academics retires or dies, unless good faith efforts are made to hire, retain and promote new women and minorities." (New Jersey AAUP Newsletter Fall 1991, 12(1):1-2)

Financial cutbacks are now endemic at state universities and they may have a disproportionate impact on women already employed. Many women serve as part-time faculty and in the lower levels of university administration: they are the most vulnerable group because they are not protected by tenure and they may be hurt by stereotypes that project women as not needing to work or unlikely to fight back. University programs that nurture women students, such as Women's Studies, are typically underfunded and again vulnerable. To serve in such programs is often a labor of love, because research productivity counts much more for tenure and promotion. If university policies do not begin to reward devoted teaching and student advisement, there will soon be few women faculty, and especially minority women faculty, to offer these important services. And, if women students are to enter the sciences, including medical science, institutional changes are needed to encourage them to select these fields in which they have not felt welcome in the past.

Taking this analysis back one step further to the stage of access to higher education, we note that rising tuition and reduced financial aid are greater handicaps for women and minority entrants. If families must choose between sending a son or a

daughter to college or medical school, they may give preference to the son.

Repeated studies show that affirmative action programs do improve the access of minorities and low-income people to health care: blacks and other minority physicians serve or expect to serve in inner-city areas and more of them train in primary care specialties. As George Silver wrote in the Lancet on the subject of affirmative action, admission "to the medical profession is more than a moral issue or test of the democratic principle of equity. It resonates with social need and the distressing inequity of the health of minority groups." (Oct. 6, 1990) Can't we do better in New Jersey? The need for minority women in health care, medical research, medical training, and university education is especially acute today, given the changing population and health demographics in our State.

The Changing Demographics

Throughout the 1980s the social service literature documented the growth of poverty among women; although women fared better in New Jersey than in the nation, 32.8% of female-headed households with related children lived below the poverty level in 1989 in New Jersey.[2] A higher percentage of blacks (19.3%) and Hispanics (19.1%) than whites (5%) live below the poverty level in our State.

Gender bias affects the type of health services extended to minority women. Bias and prejudice preclude accurate planning to meet the health needs of minority women, which differ from the majority in a number of ways. For example, minority populations are growing at a faster rate than the white majority. With the exception of affluent blacks, who have a lower birth rate than whites, minorities are having more babies and Hispanics have very high birth rates. The 1990 census shows enormous growth in the Hispanic population in New Jersey (up 50.4% from 1980).

Another result of faster growth rates is that the age structure of minority populations is different. Minorities are younger than the white majority. Latinos, for example, are one of the youngest populations in America with a median age of 26 years. For African-Americans that figure is 27 years; for whites it is 33. Yet everywhere in health circles the talk is about the aging American population, and the health system has shifted to meet the needs of geriatric patients. In New Jersey, people over 65 years old accounted for 13.4% of the population in 1990; children under 15 years accounted for 19.5%. Minority women need more maternal and child health care, family planning, and adolescent services.

Sexual Harassment and Gender Bias

Sexual harassment and bias against women are two of the greatest hindrances to the professional advancement of women

physicians and medical students. According to a study of 193 members of the American Medical Women's Association carried out in 1989 by Lenhart et al. in Massachusetts, 54% of respondents in their sample encountered some form of sex discrimination; 27% experienced sexual harassment; and 24% complained of discrimination related to parenthood.[3] Unwanted sexual attention not viewed as sexual harassment was experienced by 55%. Other forms of discrimination reported were age (22%), sexual preference (20%), and race (7%). The study group included practicing physicians, medical school faculty, researchers, interns, residents, and medical school students. The number of minority women participating in the study was not reported.

The two areas of health care most affected by gender bias are differential treatment of female patients and research on women's health issues. This Commission has previously heard testimony on the barriers to health care created by sex discrimination.[4] A report of the AMA Council on Ethical and Judicial Affairs reviewed evidence of disparities in clinical decision making.[5] Although it found that women receive more health care than men overall, women's health care concerned drug prescriptions and routine checks--more examinations, laboratory tests, blood pressure checks, and return appointments--whereas major diagnostic and therapeutic interventions were more frequently performed on men. The effect of this disparity can be life threatening: for example, doctors order more tests to diagnose lung cancers for male smokers than for female smokers; one study found that men were twice as likely as women to have cytologic studies of sputum ordered. More men who need kidney dialysis and transplants are likely to receive them than women. In yet another example, doctors order cardiac catheterizations (a prerequisite for coronary bypass surgery) at a rate disproportionately higher for men than women--6.5 times higher. They are more than twice as likely to attribute cardiac symptoms of women with abnormal results from nuclear test scans to somatic, psychiatric, or other noncardiac causes. The Council concluded that "Real biological differences [between women and men] cannot account for the gender disparities in rates of cardiac catheterization, kidney transplantation, or lung cancer diagnoses."

In searching for possible explanations, the Council pinpointed "social attitudes, including stereotypes, prejudices and other evaluations based on gender roles [which] may play themselves out in a variety of subtle ways." Physicians are more likely to attribute women's health complaints to emotional than to physical causes. Male practitioners share a general perception that men's social role obligations and their contributions to society are greater than women's; such stereotypes may fuel disparities in major diagnostic and therapeutic interventions such as kidney transplantation. For instance, male doctors may view taking time off from work to accommodate health care as more difficult for men than women; and overall, they may consider men's financial contribution to the family more critical than women's. Therefore,

they are more likely to perform a kidney transplant, which is much less cumbersome than dialysis, on men than on women. Unfortunately, the report does not address the additional problems that minority women may encounter.

This trend in gender bias in health care continues despite strong protests from women themselves. The Women's Health Initiative and the creation of the Office of Research on Women's Health in the National Institutes of Health are national attempts to fill the gender gap left by research done mostly on middle-aged white men. Is there an office in the State that fulfills the same function, overseeing women's special health needs?

Rethinking Affirmative Action

Health care institutions need a clear policy on discrimination against women and mechanisms for handling their grievances and for the resolution of bias cases. Health care providers also need to have the will to enforce antidiscrimination policy. Minority women complain of disrespectful staff and of feeling that they are being pressured to conform to majority values. When women come for prenatal care, they don't want to be lectured on family size, though they may welcome postpartum information on contraception. The problems of ethnocentricity may be overcome by inservice training in cultural awareness, the recruitment of minorities in decision-making positions, community outreach programs, and community participation and input into management. Institutional leadership that sets the right 'tone' can also help.

Opposition to affirmative action has grown considerably since the 1978 Bakke decision focussed national attention on medical school policies for the recruitment of minorities. We need to clarify that affirmative action refers to gender bias against white and minority women. We need to reinvigorate the purpose of affirmative action, enlarge its meaning, examine it in the context of all preferential practices in education and employment, ease minority students' transition from secondary school to university and from university to medical school, provide more scholarships for women and minorities, nurture historically black institutions, integrate multiculturalism and diversity in the curriculum, and expand affirmative action down to the level of preschool programs.[6]

Acknowledgments

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Endnotes

1. Data are for 1986 (latest available year) from the Feminist Majority Foundation (1991) "Empowering Women in Medicine."

2. Hughes, J.W. and C.O. Hughes. (1993) "A 1990 Census Profile of New Jersey". Working Paper No. 20. Princeton University.

3. Lenhart, S. A. et al. "Gender Bias Against and Sexual Harassment of AMWA members in Massachusetts." JAMWA 1991, 46:121-125. They carried out this study in 1989 and reported on women's experience in the past year; they made no comparison to prior decades.

4. "Sex Discrimination in Health Care" Summary of Testimony June 20, 1990 and June 26, 1990. Hearings before the New Jersey Commission on Sex Discrimination in the Statutes.

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NEWS FROM
MWW/STRATEGIC COMMUNICATIONS

THE JERSEY JOURNAL

JERSEY CITY, NJ DECEMBER 7, 1993

Fighting back

The woman came to a New Jersey clinic complaining of chronic headaches, but seemed to have no serious medical problem. Then she told a sympathetic young doctor that the pains began after her husband beat her weeks earlier.

Dr. Howard Holtz was supervising in the clinic in Essex County that Friday when the resident doctor, whom he had trained to spot signs of domestic abuse, sought his advice.

"She's at the point where she wants to leave her abuser. What can we do to help?" the resident asked Holtz. "She was afraid that if (her husband) got wind of her plans she would be in danger," Holtz recalls.

After talking with the doctors, the woman, a Caribbean native, decided to get a restraining order and go to a shelter. But first she needed to retrieve money, belongings, her passport and other papers from home.

The local police wouldn't pick her up, so Holtz drove her to the police station, where the desk sergeant stunned him by suggesting the woman go home and come back Monday — if she still wanted the restraining order.

"It was an education for me," Holtz says.

He insisted the sergeant arrange a hearing before a judge.

"She got a restraining order that night," Holtz says, "got a police escort to get her things, went to a shelter and three days later was on a plane back home."

Holtz can recall many other cases since that one seven years ago when his staff has detected abuse and helped the victim. But, he says, far more often doctors don't spot signs of family abuse — because they haven't been trained for it.

Holtz helped found the seven-year-old Domestic Violence Prevention Project at St. Barnabas Medical Center in Livingston. It is funded by the Geraldine R. Dodge Foundation.

He works on the Medical Society of New Jersey's task force of doctors, nurses and state and community social service experts, which is trying to reduce violence within families.

According to the American Medical Association, domestic violence touches a quarter of all American families, costing an estimated $5 billion annually for medical care, plus $5 billion in lost productivity due to absenteeism. Spousal abuse is responsible for more than one-third of all female murder victims and 35 percent of emergency room visits by women.

Last week, acting Attorney General Fred DeVesa announced that reported domestic violence offenses for the first six months of the year were down 26 percent from the same period last year, to 20,463 cases.

DeVesa attributed the drop to better police training and public education, and the state's tough domestic violence law. But advocates for battered women said calls for help to shelters and counseling centers are up.

"We hope the decrease is because victims of family violence are not using the police," said Barbara Price, director of the state Coalition for Battered Women. "They're going in for service before they reach a crisis point."

The state medical society's year-old campaign against abuse of spouses, children and elderly relatives aims to teach experienced doctors and those now in training how to detect abuse, convince patients to open up, and get them to agencies that can help.

Doctors say diagnosing domestic violence can help cut medical costs by preventing future attacks on patients and by eliminating unneeded diagnostic tests on patients who conceal the cause of injuries and health problems.

"As we talk about capping

Doctors battle family abuse

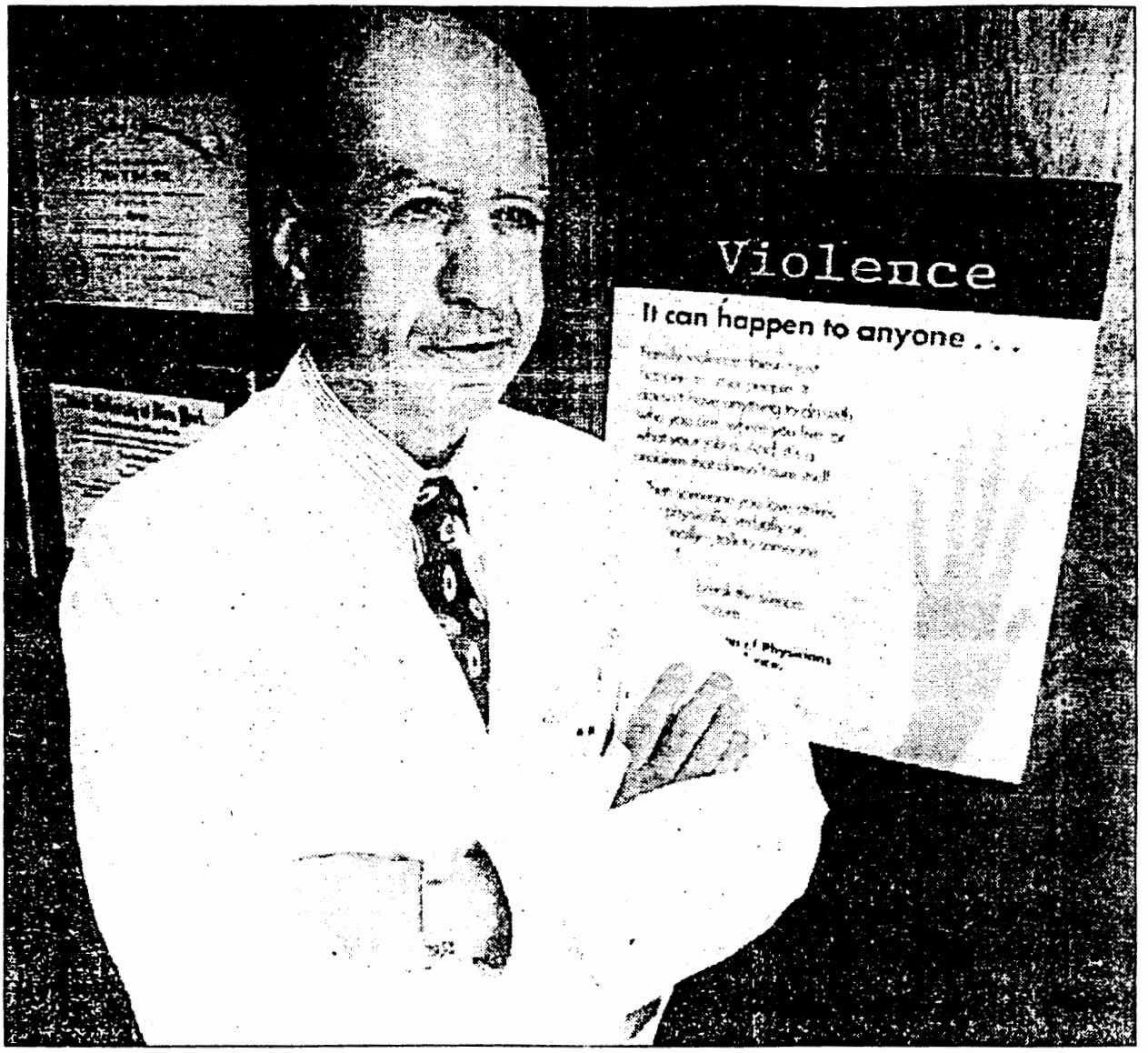

Photo by Mike Derer/AP

Dr. Joseph Micale, president of the Medical Society of New Jersey, has hung a poster about family violence in his North Bergen office. Doctors statewide are trying to be more attuned to abuse to better serve their patients.

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our costs, as we talk about budgets, it's very difficult to do unless you cap the violence," says Dr. Robert McAfee, the AMA's president-elect. "It's as major a public health problem as AIDS."

In the midst of the health care reform debate, McAfee makes half his speaking engagements to groups asking for information on family violence. He says more people are focusing on the problem, which the AMA has been publicizing for two years.

"It's a long-term fight," says internist Dr. Joseph Micale of North Bergen, president of the state medical society. "People who are abused try to cover it up. When they hit the emergency room, there's always an explanation for their injury" or their child's.

To change that, the medical society last spring and summer ran a series of newspaper, radio and television ads encouraging victims to seek help.

The society has written about the issue in its monthly magazine — sent to 10,000 of New Jersey's 16,000 doctors — and devoted about one-fifth of the latest edition of its medical policy manual to how doctors can assess for abuse and where to send victims for help.

The campaign's most ambitious aspect will kick off early next year after task force members finish writing a domestic violence curriculum. Doctors will then teach the subject at hospitals throughout the state during "grand rounds" — weekly guest lectures that hospitals hold for their interns, residents, staff doctors and those with admitting privileges.

Holtz, an internist who teaches about domestic violence at New Jersey Medical School in Newark, says more education is sorely needed. A 1988 survey he did, later published by the Centers for Disease Control, found 53 percent of U.S. medical schools required no instruction on the topic.

That means few doctors can do the detective work needed to figure that a woman with unexplained hearing loss, for example, might have sustained inner ear damage from frequent beatings about the head. Many doctors instead look for a complicated medical explanation for unusual symptoms.

Pediatrician Barry Prystowsky, chairman of the task force, wants all medical schools to squeeze domestic violence into their already crowded curriculum, something the AMA also is urging.

"There should be family violence centers to handle anyone (abused) in the family and they should be regionalized throughout the state," he adds.

Prystowsky said social service experts on the task force — officials from the state departments of health, education, human services and community affairs, plus private agencies for the elderly and battered women — value the chance to coordinate their scarce resources and work with doctors and psychiatrists.

"We're real pleased with the progress that we're making," says Price, a member of the task force.

"If doctors respond and women are getting help from doctors as well as the police and social services," she says, "we have a much better chance of early intervention. If you intervene earlier, you're going to cut down on the level of violence."

NOW-NJ

NATIONAL ORGANIZATION FOR WOMEN OF NEW JERSEY

WOMEN AND HEALTH TASK FORCE

Testimony before the Commission on Sex Discrimination in the Statutes
Presented by Donna S. Miller
Chair, NOW-NJ Women and Health Task Force
February 28, 1994
Saint Barnabus Hospital, Livingston, New Jersey

My name is Donna S. Miller and I am the Chairperson of the Women and Health Task Force of NOW-NJ. I represent the membership of NOW-NJ -- 12,000 women and men in New Jersey who work to advance women's issues. I also speak for the women of New Jersey who need a stronger voice to effect change and progress for health-related issues, something that will affect every woman in this state. My task force and the members and leadership of NOW-NJ are trying to change the current status quo of health care for women in New Jersey for the better.

As all of you know, there is a problem in dealing with women's health issues in the United States and the problem does not stop at the border to New Jersey.

Unfortunately, women as a class face discrimination of various kinds in both access to health services and women's health research. This even though women make up 52% of the United States population and comprise approximately 4 million of New Jersey's population. Traditionally, women have been treated as second-class citizens in science and medical research as well as medical practice. Increasingly, their health care is being compromised by political or religious issues like those surrounding contraception and abortion.

New Jersey, with its extensive pharmaceutical industry and its high quality medical schools, could and should serve as a model to the rest of the country in changing the way things have been done to the way things should be done. New Jersey could help end the "gender gap" in medical services, access, and research. In my testimony, as well as other testimony that you will receive, you will start to see a blueprint emerging that may be used to achieve our goals of equality. It is by no means a complete exposure of all that is wrong or right about the system or a complete solution, but it is the skeleton that we hope this Commission, this state, and our Governor will embrace and enhance and build on to make New Jersey a better place for women and men.

In the following testimony, I will focus on two areas of concern to the NOW-NJ Women and Health Task Force as well as the women of New Jersey. They are the issues of coordination of women's health/access issues and women's health research. This testimony is not a complete discussion of these issues, but it will be a start -- a start to eradicating the inequities that women face in the United States and New Jersey.

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COORDINATION OF WOMEN'S HEALTH CARE/ACCESS ISSUES

A number of issues need to be addressed in this area. Since women cannot have coordination of care if they do not first have access to facilities, I will first address access to facilities, access to clinical trials, and access to information.

First, physical things have been noted that affect access in New Jersey and elsewhere. In the area of mammography facilities, I recently talked to a woman whose friend was having difficulty obtaining care because she was confined to a wheelchair and the mammography equipment was either unable to accommodate her or the technician was insufficiently trained to deal with that type of situation. Also, it has been noted, both by myself and individuals that I know, that some doors on some health care buildings are very difficult to open; they are not power equipped and are difficult for some people to open. This should have been dealt with by the American Disabilities Act legislation, but some facilities still have not remedied the situation and this is a problem for both women and men. The state should investigate these facility access issues.

Access to health care for women may also be hampered by lack of transportation and/or childcare. State funded centers like UMDNJ should have on-site child care available for women and men who use their facilities. Also, times of operation of clinics that are state subsidized should be investigated. Under utilization may be improved by change of times of operation; not all people are available during normal business hours. Mobile health vans should be considered by the state for screening tests and immunizations. Also, novel sites like supermarkets might be considered for vaccinations and the like. This would make more services available to more people.

Another way to make health care accessible to all is the introduction of school-based clinics. This makes possible much preventative care that many young people do not get, especially in less affluent communities. Such clinics can spot potential problems in children early, and probably lower overall healthcare costs compared to later diagnosis. It is probable that many pharmaceutical companies would be willing to supply needed equipment to such centers so that state expenditures would be reduced, and the state of health in New Jersey would be improved. They may also be used to detect sexually transmitted diseases (STDs) earlier; STDs are an epidemic in this country with 1 in 5 people infected which disproportionately impacts women in later life.[1,2] They may be avoided or caught early, reducing chances of women having to deal later with infertility problems that cost society in numerous ways.[1] Such programs, including STD clinics, need to focus on women and undetected infections, a major problem in the United States. A recent Atlanta clinic study showed that 24% of teens who had visited the clinic and practiced unprotected sex with one partner had a chlamydia infection, one of the more serious and undetected STDs which may cause pelvic infections leading to infertility.[1,2] It is estimated that 100,000-150,000 women per year are rendered infertile as a result of an STD.[2] Some of these women may also be more vulnerable to AIDS infection because of practices leading to the infection as well as because of tissue damage at the site of infection.

An issue related to the coordination of services is the type of services that are provided. No good survey exists nationally that provides data on how services are utilized by women.[3] Maybe this is a good place to start to get an idea of what women need and how they need it. This data also helps establish a base for development of agendas for future research. Population-based data on how all income level women access the health system throughout life is needed to insure they get comprehensive care throughout life. Besides the basics of hours of operation and the like, it is time to investigate whether women are getting the services they need in the way health services are currently organized in this country and in New Jersey. Also, the use of health providers other than physicians should be explored as well as the New Jersey certification process for nurse practitioners and physicians assistants. Many of the screening services that doctors now provide might be done by other health professionals.

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Generally, the care that women receive from the medical system is lacking. In general, women need and want less fragmentation of their health care. This is not just our belief, but that of the experts and the women who receive care from the current system. Evidence the recent study published in the New England Journal of Medicine showing that female doctors tend to treat women patients better than their male counterparts for preventative care; that they follow up better with patients and are more likely to order screening tests for women than male doctors of similar specialty, especially if not obstetricians/gynecologists (ob/gyns).[4] Or another study that shows that women doctors spend more time with their patients of both genders, give them more information and collect more, and encourage greater patient participation in care decisions.[5,6,7] Generally, both sexes rate female physicians better than their male counterparts.[8] These and other inequities have led various women's health and medical groups to investigate whether women need a specialty dedicated to women's health. Some say is it would segregate women while others say that if pediatrics and geriatrics are specialties than surely women should also be one.[9,10] For many women, their ob/gyn has become their primary doctor. Many think this is because these doctors most directly address a good number of women's health concerns, better than a general practitioner or internist. Experts caution though that ob/gyns may not be accustomed to dealing with the full range of health care that women need.[3]

Physician training is another area needing attention. A number of topics need to be included in the curriculum of medical schools and residency programs that have been missing in too many places in the United States. One of those topics is the teaching of recognition of domestic violence and ways to deal with the situation if it is found. Too many programs ignore the single greatest source of trips to the emergency room in this country.[11] In New Jersey alone, there were 52,321 reported instances of violence in 1992 -- only the tip of the iceberg because experts estimate these numbers only account for 10% of actual cases.[12,13] Changes in medical school curriculums are needed to address women's health issues. Reasons for this are obvious. According to the American Medical Women's Association, which has developed an Advanced Curriculum in Women's Health, these reasons include: women's health fragmentation, differences between women's and men's health, women's dual role as distributor and receiver of health care, morbidity and mortality consequences, the role of women doctors, and gender bias.[14]

Physician training, or lack of it, is also a problem for women in the area of abortion services and their access. Right now, new doctors are failing to be trained to learn how to perform abortions. Physicians that want to be trained in this important area of women's health care often cannot get such training. Also, ob/gyn resident training has declined more than 21% in recent years with only 12% of new doctors receiving this training as a required part of their education.[15] This even though abortion is one of the most common surgical procedures in the United States.[2] That it is not a required part of the residency program is discrimination against women. Voluntary training rates of around 50% are not good enough for this important part of reproductive care because no time is scheduled for already busy resident schedules.[16] New Jersey might consider implementing a program where incentives are provided to medical students, or residents and to the medical schools and the teaching hospitals so that each would be given an incentive to learn the procedure and provide for it to be taught. The state might require all ob/gyn residents in NJ receive such training before they receive their medical license. Requirements such as these put this common surgical procedure back into the mainstream of medicine and demonstrate to doctors-in-training that the procedure is not at all like what is portrayed by the rhetoric of those against abortion.

The issue of insurance is an important one that also affects access and coordination of services. Some insurance companies doing business in the state of New Jersey have refused to pay for treatments they consider "experimental" even though the doctors treating their patients do not and studies have shown efficacy. This is wrong. But it is discrimination when similar treatments are paid for male patients but not female patients. I am referring to bone marrow transplant for breast cancer and several other disorders. Bone marrow transplants are essentially done to rescue a person after intense chemotherapy and radiation. So insurance companies essentially are not willing to pay for treatment that is proven but taken to the next level. Especially, it seems, when

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they may have to pay for the larger numbers of breast cancer patients. Recent legislation has dealt with this problem, but New Jersey must be ever vigilant about insurance companies and women's health issues. Another area of discrimination in insurance is the lack of reimbursement by most companies of prescription birth control devices or drugs, especially since women tend to be responsible for contraception. Basic issues that are important health considerations. Legislation in this area might be possible.

Increasingly there is another insurance problem, one that is sure to come up regarding universal coverage. The issue is primary care doctors. Many women consider and use their ob/gyn as their primary doctor. Most women do not want to change that, especially if they see only one doctor. Increasingly, HMOs and other insurance providers have changed their policies so that ob/gyns are considered specialists that require a "gatekeeper" referral to use. This hurts women because ob/gyns often deal more and better with women's health issues than internists or GPs; they should also be considered primary care doctors for women.

Another related issue is that of women in the Medicaid program facing problems with coverage. Many cannot find a doctor they can use because of unwillingness of many providers to accept Medicaid.[17] This is partly because New Jersey has one of the lowest reimbursement rates in the country[18]. Also, lower-income women and men in New Jersey should be able to get health insurance partly subsidized by the state, possibly with policies designed for certain levels of income so that they can access care before their problem leads them to the emergency room at high cost to them and the state.

Political issues affect access and coordination of care in this state and others. Access to reproductive services like birth control and abortion are severely threatened all over the country. For too long clinic violence has been ignored. It has taken until 1994 to have federal legislation that will even begin to protect access to clinics. New Jersey is no exception. In recent years, women's clinics have been blockaded, bombed and picketed. Doctor's offices and homes have been picketed as well as staff and patients being threatened and stalked by anti-abortion extremists. In recent years at least 3 fire bombings occurred, and at least 5 major blockades occurred in 1993 in addition to almost constant picketing at clinics.[19] Additionally, two board members of Life Advocates, an organization that supports the actions of Michael Griffin who killed Dr. David Gunn in Florida, call New Jersey home and help organize actions by antiabortion activists.[19]

Denial of access to clinics discriminates against women because they are the only class that can get pregnant. It also prevents women from receiving services other than abortions that many clinics provide.

Also concerning access issues is the growing, silent problem of insurance coverage being dropped or threatened to be dropped for women's clinics and physicians that perform abortions in New Jersey. Problems have already surfaced with two doctors that I am aware of and several clinics. This concerns both building and malpractice insurance. Without insurance, these doctors and centers cannot operate. It seems that the heat has been turned up on the insurance companies by antiabortion groups to cause such sudden cancellations containing specious reasons. The state must somehow step in to make it much harder to cancel such policies or the women of New Jersey will soon face a crisis in terms of reproductive care.

Another area where women may soon have access problems is with the national health care program. If state or regional health care cooperatives are part of the plan that passes, New Jersey women will have to fight to keep reproductive services in the plan. Governor Whitman and legislative leaders should take a leadership role in this so that women are not discriminated against in this way.

New Jersey's young women may also soon face a threat from the legislature regarding parental notification and consent laws. We have a very strong no compromise position on this issue. We feel that such parental involvement laws are actually teen endangerment laws because they put

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young women in a position that make them likely to explore alternatives to the legal routes to abortion like Becky Bell did in Indiana.[11,19] We believe such laws do not work because communications cannot be legislated. If the young woman could talk to her mother or father she would. Common sense says a law cannot make dysfunctional families functional and so we believe it puts the young woman into an even more desperate situation that may force decisions that will cause her harm. The law also would tread on the state statute regarding emancipated minors and would except only the abortion decision from decisions pregnant minors can make about their pregnancy. Other, more risky surgeries could be consented to by the young woman, but not the decision to have an abortion. Also, the law would discriminate because males also responsible for the pregnancy would not have to tell their parents either about continuing the pregnancy or about the abortion.

Another major issue of access to health care affecting women is the dearth of clinical trials available in New Jersey. This affects women's health care because the latest treatments are tested in clinical trials and often these treatments increase the survivability of cancer and other diseases.

In 1990, only slightly greater than 4% of cancer patients receiving care in New Jersey were involved in clinical trials, an even smaller percentage being women.[20] This despite the fact that New Jersey is the home to 67 pharmaceutical companies.[21]

This also despite the fact that breast cancer is at epidemic levels in the United States affecting 1 out of every 8 women in their lifetimes and gynecological cancers affected approximately 67,000 women in 1993.[22] In 1992, 175,000 women were diagnosed with breast cancer and more than 44,000 died of the disease.[22] New Jersey had 40.5 cancer deaths/100,000 women in NJ in 1990, the highest in the nation.[24] It also had 17.6 AIDS cases/100,000 women in 1991, the highest rate in the nation as well as the highest death rate.[13]

Women in New Jersey have to face even dimmer statistics when it comes to cancer. Annual cancer rates in a recent NJ compilation show 14,976 white females and 1,391` African-American women were diagnosed with breast cancer.[23] New Jersey women have a higher incidence of breast cancer than comparison groups in the Surveillance Epidemiology, and End Results Program (SEER) of the National Cancer Institute (NCI). New Jersey women have 7% higher incidence of breast cancer for white females and a 6% higher incidence for African-American women for breast cancer. Of more concern is that white females have a 24% higher death rate for breast cancer in NJ and African-American women have a 15% higher death rate for the same disease.[23,24] Additionally, the 5-year survival rates for women in New Jersey are always lower than comparison groups in SEER. Higher mortality rates and lower 5-year survival rates were also seen for other female cancers such as endometrial, ovarian and cervical cancers.[23,24]

New Jersey women have had difficulty gaining access to clinical trials in New Jersey. since no NCI designated cancer center existed in New Jersey. Thus, women wanting or needing to participate in clinical trials had to travel outside of New Jersey to participate; something not possible for many women because of poverty, childcare, transportation or other obstacles.

One recent example of the difficulties is the Taxol clinical trial for ovarian cancer. Even though Bristol-Myers Squibb, which manufactures the drug, has several major facilities in New Jersey it only distributed Taxol through NCI designated centers in New York and Philadelphia. After some time and prodding by advocacy groups, Cooper Hospital/University Medical Center in Camden received Taxol for <u>one</u> ovarian cancer protocol.[24] Clearly New Jersey has to work to develop a greater ability for clinical trials in the state. Some efforts have already started by the Commission on Cancer Research, but clearly a lot has to be done.

In another case, the trial of tamoxifen for breast cancer prevention was available to New Jersey women in two Fox-Chase affiliated hospitals in western NJ even though larger, medical-school

affiliated hospitals were not chosen to be part of the trial. Access has been limited in this state and these are just two examples.[24]

Another problem with clinical research in New Jersey which affects both women and men seems to be communications to the public regarding opportunities. To my knowledge, these trials were not promoted by the state health department even though they received a lot of publicity nationally. In fact, I saw only one newspaper article discussing the New Jersey trials of tamoxifen. People I knew in the health field were not aware that these clinical trials existed at all in New Jersey.

You may say that this is not an area of discrimination against women in health care, but it is. Because women suffer more discrimination in health care in general, incomplete or hard to get information results in further delays and inequities for women facing disease; women do not find the few trials that are available. This can result in increased mortality and morbidity. And it makes distribution of literature about various topics to prevent illness or inform people difficult because there is no one-stop shopping.

This brings us to another area of importance to the women of New Jersey vis-a-vis access. This is the problem of communications.

To my knowledge,[25] New Jersey has no central place to call and find out about clinical trials that are available in New Jersey for various diseases. Nor a central number to get publications of all kinds. Instead, fragmentation exists. Each disease or condition is a separate entity to the Department of Health and each controls and distributes its own literature and statistics. Phone calls to each separate department are required to obtain information or pamphlets. And toll calls are required at that. Also, no complete listing of all NJ Department of Health publications exists, according to employees at the Department of Health.[25] In other words, one has to make multiple phone calls using a toll number to find out basic health information to which all residents of NJ should have access. This needs to be changed. In fact, health department employees expressed this sentiment to me over the phone and said they have wanted changes on this level for years.

Other, more modern ways of informing the public should be sought such as forums on computer networks. Cable and network television public service ads and programs should also be investigated. To my knowledge, the NJ Department of Health does not have an 800 number for clinical trial information. This should be investigated, possibly partly subsidized by the industry or groups involved with the trials. An 800-number hotline for information could also be created. Public service ads should be made available to NJN, cable television and networks for important messages on AIDS, breast cancer, teen pregnancy and a whole host of other critical areas. The Department of Health should also create a comprehensive listing of doctors and their specialties and expertise areas, hospital and surgicenters quality and programs as well as all mammography and breast centers and their accreditation and expertise. It should be available to New Jerseyans even if for a small fee. Another suggestion is to consider creating an advisory board that deals with women's health issues as well as coordinates, innovates and suggests solutions to problems for the department. The New Jersey Department of Health should serve as a central part of the community in New Jersey. Instead, it just seems like another state agency. It is and should be more than this.

RESEARCH ISSUES

We believe that a health "gender gap" exists in the United States and in New Jersey. Clearly, we see evidence of inequities existing in research dollar allocations by industry and scientific centers as well as health focuses in the United States and New Jersey. These inequities result in a lower standard of care for women in our health care system. We believe some research for strictly female diseases is simply not done because those diseases never affect men and males make most of the decisions to fund or not fund biomedical research in this country.

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Contributing to the problem is a medical and scientific community that perpetrates inequities by keeping female researchers, doctors and others under a glass ceiling. Few women nationally or in New Jersey hold leadership roles as heads of departments in industry or academia. Fewer women still hold positions of authority like dean or department heads at medical schools -- only 2 nationwide as dean and 2% hold department chairs.[11,26] We believe such inequities affect the kind and amount of research that is done in this country. We believe that if more women were in decision-making roles in industry and medicine then more would be done in the area of women's health research. It is not only our belief. It is shared by the American Medical Women's Organization and many prominent individuals.[5,11,14,27,28] We believe that changing the players will change the priorities and attitudes. As a result, research will become less biased toward the male model. To this end, we support efforts to include women's health curriculums in medical schools.

To that end, we suggest that all state boards, commissions, advisory councils, and authorities dealing with health issues should be composed of equal numbers of male and female members. New Jersey should take a leadership role to lead the state to greater equality as far as state health decisions are concerned and may serve as a model for industry and academia to follow.

Attitudes toward women have also affected women's health research. Paternalistic attitudes toward women affected the willingness to allow women to participate in clinical trials. Unwillingness to deal with normal female cycles also has also occurred and its existence compromises research and women's health. Often, researchers have created trials that studied heart disease or any number of other diseases using tens of thousands of males but not one female.[28] Data was then extrapolated to say women also probably had the same effect from the drug or device. Often this is not the case. Women can and do have different reactions to drugs [14,29] Concerns about effects on the fetus have also restricted women's participation in trials. Only recently has this restriction been lifted, at least partly.[29]

Another important area of research related to women's health is that of contraceptive research. It too has been lacking. Two major reasons for this are liability and controversy.

Lawsuits concerning the IUD, the Pill, and other drugs and devices as well as political pressure from anti-abortion forces have sharply curtailed the number of pharmaceutical companies doing research and development in the contraceptive area in the United States. It also resulted in fewer methods being available to women in the United States In 1970, there were 13 major pharmaceutical companies engaged in contraceptive R&D, nine in the United States. Only one company in the United States (Ortho) and four worldwide remain.[30,33]

This despite the fact that contraception is an important health area for women. It is imperative to the rights of women that they have control over their reproduction. It is also imperative to their health. Over half a million women die from childbirth or in pregnancy each year. One woman every three minutes dies from an illegal, botched, or self-induced abortion.[30,31] This even though legal and properly performed abortions are almost 11X safer than childbirth.[2,30] With improved contraceptives, the need for many abortions would be obviated as well as lead to reduction of the teen pregnancy problem. A serious problem in New Jersey as well as in the U.S., both for health and other reasons. Clearly, having only one company performing this research is not enough. We believe that the state can and should promote this type of work just like it promotes other industries. The state of New Jersey should offer financial incentives to companies that take on these problems. Other states should be doing it too but NJ has a special responsibility because it is home to so many of the worlds pharmaceutical companies. Liability issues certainly can be dealt with on a state or federal level or both. New Jersey could form a study group made up of women's health advocates and industry representatives that could look at reforms that could make it possible for liability issues to be addressed and dispatched fairly.

Contraceptives need to be treated like the necessary medical care that they are and not as unimportant. For many women, pregnancy is the most life-threatening condition that they will face

in their lives. It should be treated seriously. About one half of the 6 million pregnancies that occur annually are unintended and about 1/2 of these result in abortion.[2,31,33] The problem is particularly acute among teens with 5 of 6 of the over one million annual teen pregnancies being unintended.[32] Many of the current methods are either too expensive, have too many side effects, are too difficult or inconvenient to use. Many also have high failure rates. Women need better care than this.

Health would also be improved because barrier methods could help control sexually transmitted diseases. Every year about 6 million women, about half teens, are infected with an STD. Increased condom use and development of new devices should be encouraged to slow the rate of AIDS and other STDs in the population. Currently, women are the group that is seeing the largest increase of AIDS cases in the United States and New Jersey.[13]

Research must also be increased for women with AIDS because up until recently there were virtually no studies of women and AIDS. And research that was done seemed to focus on women as vectors of disease rather than as patients to be treated. Prevention strategies were also limited. Little work was done on the progression of AIDS in women or women's unique problems with the disease (cervical disease, increased yeast infections). Women have also faced discrimination in care that this is based on their gender and childbearing potential when trying to get into drug treatment, clinical trials, or treatment.

Political issues are another thing. Recent years have found companies facing numerous attacks from anti-abortion groups that have chilled willingness to conduct research in the areas of birth control and abortion. Witness the recent battles over the drug RU-486 discovered by scientists at Roussel-Uclaf in France.

RU-486 should already be available to women here. Safety is high. Data on over 200,000 women is available from France and England where the drug is available.[11,34] Politics have stalled its introduction to the United States as seen in the stalling by a company afraid to face a small group of extremists attempting to prevent it's introduction here. This despite studies that show that RU-486 produces significant other benefits beyond its use as an abortifacient. RU-486 and drugs in its class have shown significant benefits for patients with Cushings syndrome and may be useful for breast and ovarian cancers, endometriosis, menigiomas and other progesterone-dependent diseases.[34,35,36] It could also prove to be a once monthly contraceptive.[34,36] Other such drugs exist in this class and may even be more useful to treat diseases that affect women, yet it is held hostage to the politics of abortion. Can we let this class of drugs or any other that are abortifacients be held hostage to politics and religion? This needs to stop. New Jersey can encourage its introduction in the United States by encouraging the company to start breast cancer studies in New Jersey using RU-486. It could also support other research studies on this class of drugs.

CONCLUSIONS

In short, much needs to be done and much can be done in the area of women's health regarding access issues/coordination of care and women's health research. Action is needed immediately to remedy the injustices of the past.

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Reproductive Health of U.S. Women
FACT SHEET

In comparison to women in developing countries, United States women have access to a broad range of health care and reproductive services. Many women in the United States, however, do not have access to these services, contraceptive methods and medications because of economic, geographic, cultural and medical barriers.

HEALTH INDICATORS

•**The United States ranks 23rd among industrialized nations in number of infants dying in first year of life.** Japan has the lowest infant mortality rate of all industrialized countries. (U.S. Dept. of Health and Human Services, 1993)

•The infant mortality rate of African-American infants is 18 deaths per 1,000 live births compared to 7.6 per 1,000 for white babies. (U.S. Dept. of Health and Human Services, 1993)

•Early and continuous pre and post-natal care is a key factor to preventing low birthweight and infant mortality. **Twenty percent of white women, 40% of African American women, 39% of Hispanic women and 39% of Native American women do not receive pre-natal care in the first trimester of pregnancy.** (U.S. Dept. of Health and Human Services, 1993)

BARRIERS TO HEALTH CARE

•**8 million women (14%) of reproductive age (15-44) have incomes under the federal poverty level.** (National Council of Negro Women, 1990)

•**19% of women of color cannot afford birth control.** (National Council of Negro Women, 1990)

•68% of Latinas in a John Hopkins study did not seek pre-natal care because they lacked information about services and financial assistance. Consequently, none of these women sought either pre-natal care in their first trimester or immunizations for their existing children. (Johns Hopkins University, 1993)

•**Because of provider bias and lack of information regarding the IUD, U.S. women represent only 1% of the 100 million women in the world using this method**, which has been proven safe and effective. (Alan Guttmacher Institute, 1993) In addition, the IUD is not available to some women because fear of lawsuits has prompted the manufacturer to require that the user be over 25 years of age, have had a child, and not have a prior history of Pelvic Inflamatory Disease.

•Although the Clinton Administration intends to overturn the Hyde Amendment prohibiting funding for abortions for women on Medicaid, there is a fight in Congress to keep this restriction and prevent poor women from obtaining abortions. **Currently, only 13 states fund abortion under Medicaid.** (Alan Guttmacher Institute, 1993)

•**In the United States, contraceptives may be more expensive and difficult to obtain than in developing countries.** A wider range of contraceptives that are affordable should be made available to women of all socio-economic groups. The following figures show the average cost in 1989 for the first year of some methods of birth control in the United States:

*Female Sterilization	$385-$1,600
*Male sterilization	$285-$600
*The Pill	$330
*Male Condoms	$50
*Spermicides	$75
*Norplant	$500
*IUD	$250

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•RU-486, a safe, effective method of early abortion which also is a possible treatment of some forms of breast cancer, endometriosis, Cushing's syndrome and meningiomas remains unavailable to U.S. women.

FEMALE CONTRACEPTIVE USE

•3.4 million pregnancies occuring annually are unintended; the result of contraceptive misuse, method failure and nonuse. (Alan Guttmacher Institute, 1993)

•The 1992 Women of Color Reproductive Poll found that only **48% of women received information about birth control from their doctors, and 16 % never received information about birth control. Fifty-nine percent of women of color at risk of becoming pregnant reported never using birth control, compared to 90% of American women overall reported to use contraceptives.** (National Council of Negro Women, 1990)

•The 1992 Women of Color Reproductive Health Poll found that only 6% of women of color report sterilization as their chosen method of birth control, yet sterilization rates run up to 65% for Latinas in some parts of the U. S. (National Women's Health Network, 1991)

•Depo Provera, an injectable contraceptive recently approved by the FDA , is apromising method of fertility control. However, some groups fear that it poses the risk of inappropriate and coercive use and has potentially irreversible long term effects (i.e. breast cancer, excessive bleeding and weight gain), which would disproportionately affect poor women and women of color. (National Black Women's Health Project, 1991)

ABORTION

•More than 50% of pregnancies among American women are unintended - half of these are terminated by abortion. (Alan Guttmacher Institute,1993)

•There are 500,000 maternal deaths each year world- wide. **Approximately 20% of maternal mortality is caused by unsafe abortion practices - more than 100,000 deaths each year world wide** - yet a well- performed abortion carries almost no risk. In fact, under safe conditions, abortion is 5 to 10 times safer than childbirth. (Journal of American Medical Association, 1992)

•Medicaid recipients are 3 times more likely than women who are not covered by Medicaid to have an abortion even though Medicaid will not pay for abortions in most states. In addition, **even though women of color constitute just 33% of Medicaid recipients, they constitute 82% of deaths from illegal abortions.** (Alan Guttmacher Institute, 1993; Center for Reproductive Law and Policy, 1993)

•Latina women are 60% more likely than non-Latina women to have abortions. In comparison, because black women experience unintended pregnancies 2 1/2 times more often than white women, they are twice as likely to have abortions. Two-thirds of women having abortions say they cannot afford to have a child. (National Women's Health Network, 1992; Alan Guttmacher Institute, 1990)

ADOLESCENT REPRODUCTIVE HEALTH

•85% of U.S. teens who give birth did not want to become pregnant. (Center for Population Options, 1988)

•U.S. teenagers have one of the highest pregnancy rates in the western world - twice as high as in England and Wales, France and Canada; 3 times as high as in Sweden; and 7 times as high as in the Netherlands. (Alan Guttmacher Institute, 1993)

•25% of all African- American babies are born to teen mothers. (Zero Population Growth, December 1990)

•On average, secondary schools offer only 6 1/2 hours a year on sex education - fewer than 2 of those hours focus on contraception and the prevention of sexually transmitted diseases. (Alan Guttmacher, 1993)

•Fifty-five percent of students in schools with school- based reproductive health programs have no other means of primary health care.

CONTRACEPTIVE RESEARCH

•The budget for the National Institute of Health's Contraceptive Developement Branch decreased from approximately $16 million in 1992 to $9 million in 1993. (Scientific American , April 1993)

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•In 1970, there were 13 pharmaceutical companies in contraceptive research worldwide, today there are 3. Of the 13, 7 of them were in the U.S. - currently only one remains.

FEMINIST MAJORITY FOUNDATION REPORTS ON RU486

• HIGHLIGHTS •

RU486 AND ABORTION

Developed by Roussel Uclaf, a French pharmaceutical company, RU486 (or mifepristone) is the first in a new generation of fertility control agents that can cause the interruption of early pregnancy.

RU486, taken in pill form, has been used by over 120,000 women worldwide and found to be both safe and effective as a method of early abortion during the first nine weeks of pregnancy. Research shows that RU486, taken in conjunction with tablets of prostaglandin, is now 99% effective.

A woman can take RU486 as soon as she knows that she is pregnant. RU486 is the only method of abortion available to women during the first seven weeks of pregnancy. Surgical abortions generally cannot be performed until after this period.

Many women prefer RU486 because the procedure is more private and allows them greater psychological control over the termination of pregnancy. Due to its popularity, RU486 eventually could replace 50% of vacuum aspiration abortions.

The administration of RU486 is non-invasive, has less risk of infection, and does not require anesthesia. A vacuum aspiration abortion is invasive, has a slight risk of infection, and is commonly performed with local anesthesia in the United States. RU486 eventually will be less expensive than surgical abortion.

RU486 AND WOMEN IN DEVELOPING NATIONS

For women in poor nations in Asia, Latin America, and Africa, RU486 represents a significant and potentially life-saving discovery. According to the World Health Organization, an estimated 200,000 young women die each year (one every three minutes) in these countries as a result of unsafe and illegal abortions.

The vast majority of women in poor nations terminate their pregnancies outside the formal health sector using unsafe methods that often result in bleeding and infections.

In hospitals in developing nations, dilation and curettage (D&C), although twice as risky as either the use of RU486 or vacuum aspiration abortion, remains the most frequently employed means of ending a pregnancy.

The availability of better technology, already used in wealthy nations, could vastly improve the quality of care women receive.

RU486 is a safe and less expensive fertility control alternative.

RU486 AND BREAST CANCER

Breast cancer is an epidemic. In 1993 over 182,000 women will be diagnosed with breast cancer in this country alone. This year 46,000 women will die of breast cancer in the United States.

As an anti-progestin, RU486 blocks the action of progesterone, and therefore may be effective in treating progesterone-dependent breast cancers. Experts estimate that RU486 may be a treatment for 40% of breast cancer tumors.

In animal studies in the Netherlands, RU486 reduced breast cancer tumors as well as tamoxifen. In the trials, the administration of both tamoxifen and RU486 reduced tumor size more than each drug alone.

A French clinical trial found that RU486 also may be a second-line treatment for tumors that have become resistant to tamoxifen. In addition, this study reported that RU486 reduced the pain from the metastasis of cancer cells to the bones.

Trials are now underway in Canada to test RU486 as a treatment for women who have breast cancer recurrences, but have not been treated with any other hormones or drugs during the recurrence.

RU486 AND MENINGIOMA

Meningiomas account for between 15% of all primary brain tumors, and 12% of all spinal cord tumors. Meningiomas occur two times more frequently in women than in men.

Meningiomas may enlarge or become symptomatic during pregnancy or the menstrual cycle, and are positively associated with breast cancer. These indications suggest that the hormones estrogen and progesterone influence tumor growth. By binding with progesterone receptors, RU486 may inhibit the growth of, or actually reduce meningioma.

In a study by Dr. Grunberg *et al* at the University of Southern California School of Medicine, RU486 was found to have some efficacy in the treatment of patients with inoperable meningioma.

The National Cancer Institute has begun a multi-center U.S. trial on the use of RU486 as a treatment for meningioma that will include 200 patients.

RU486 AND CUSHING'S SYNDROME

Cushing's Syndrome results from an over-production of cortisol. Too much cortisol can be fatal. The vast majority of Cushing's Syndrome victims are women, primarily in their 20's - 40's.

Some forms of Cushing's Syndrome, a deadly disease, can be treated with the new French pill RU486.

The RU486 compound is an anti-glucocorticoid: it binds to glucocorticoid receptors in the body and thus prevents the hormone cortisol from binding. One important National Institutes of Health (NIH) study has shown that when people gravely ill with inoperable tumors were given RU486, over half experienced actual reversal and control of the disease as well as complete regression of the Syndrome's features.

RU486 already has helped patients with advanced Cushing's Syndrome symptoms. Two such survivors testified before Congress in 1990 that RU486 saved their lives.

RU486 AND ENDOMETRIOSIS AND FIBROID TUMORS

Ten to twenty percent of American women of child bearing age have endometriosis.

The new French pill RU486 shows promise as a treatment for endometriosis, a chronic, long-term, painful disease that can affect women for their entire reproductive lives.

In addition to being an anti-progestin and an anti-glucocorticoid, RU486 is a non-competitive anti-estrogen. RU486 blocks the capacity of the endometrial tissue to grow in response to estrogen. As such, RU486 is a possible new hormonal treatment for endometriosis.

Through a similar mechanism, RU486 may be a treatment for uterine fibroid tumors.

Fibroid tumors, which affect about 30% of women, are a leading cause of hysterectomies.

Clinical trials at the University of California-San Diego found that RU486 reduced the mean size of uterine fibroid tumors and that RU486 was well-tolerated by the women in the study.

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THE FIGHT TO MAKE RU486 AVAILABLE TO U.S. WOMEN

• A CHRONOLOGY IN BRIEF •

RU486 – a pill that can be used for safe, effective early abortion, as well as a "morning-after" pill. RU486 may also be effective in treating breast cancer and several other serious diseases. Developed by the French firm Roussel Uclaf (parent company: Hoechst AG of Germany), RU486 is a medical breakthrough that continues to be denied to American women because RU486 manufacturers have been reluctant to market the medication in the U.S. for fear of anti-abortion protests.

1983

Clinical trials on the use of RU486 as a method of early abortion begin in the United States at the University of Southern California.

1988

Anti-abortion forces threaten Hoechst AG with economic reprisal if RU486 is marketed in the United States. In March of 1989 Hoechst informs abortion opponents that "it is not our intention to market or distribute RU486 outside of France." *(RU486 had become available in France in October 1988, after the French Minister of Health ordered Roussel Uclaf to return RU486 to the market following the company's decision earlier in the fall to withdraw the drug in the wake of anti-abortion pressure.)*

JUNE 1989

The U.S. Food and Drug Administration responds to pressure from anti-abortion Congressional representatives by banning the importation of RU486 for personal use.

JULY 1990

A ten-member Feminist Majority Foundation delegation, comprised of feminist leaders and prominent scientists, travels to Paris and Frankfurt to meet with officials of Roussel Uclaf and Hoechst AG, respectively, to urge introduction of RU486 to the U.S. At these meetings, which include a five-hour discussion with Roussel Uclaf CEO Edouard Sakiz, the delegation present over 115,000 petitions from American citizens in support of RU486. Hoechst AG officials argue that the U.S. political climate was not conducive to U.S. distribution.

NOVEMBER 1990

Congressman Ron Wyden holds hearings on RU486 before the House Small Business Committee. Leading scientists testify that the import alert has hindered research on non-abortion indications of RU486, including its use as a possible treatment for breast cancer. Following these hearings, Congressman Ron Wyden introduces legislation to remove the import alert.

FEBRUARY 1991

The American Association for Advancement of Science (AAAS) endorses the testing and use of RU486.

Having secured the support of AAAS, the Feminist Majority Foundation aggressively and successfully pursues endorsements of RU486 from almost every scientific and medical organization in the country. In addition, the Feminist Majority Foundation collected over 3000 petitions from individual scientists in support of RU486.

MAY 1991

New Hampshire becomes the first state in the nation to pass a resolution urging the commencement of clinical trials of RU486 in that state. Subsequent resolutions are passed in Hawaii, California, Maine, and Colorado and introduced in a dozen other states.

SEPTEMBER 1991

Feminist Majority Board Chair Peg Yorkin announces an historic $10 million dollar endowment and gift to the Feminist Majority Foundation and Fund. The donation is especially targeted for the Foundation's Campaign for RU486 and Contraceptive Research.

FEBRUARY 1992

A second Feminist Majority Foundation delegation led by Eleanor Smeal meet with officials from Hoechst AG to urge marketing of RU486 in the U.S. At this meeting, Smeal delivered an additional 110,000 petitions supporting RU486.

APRIL 1992

Feminist Majority Foundation announces its *Web of Influence Campaign* to educate the public on U.S. companies and

institutions that do business with Hoechst AG and Roussel Uclaf, to encourage those companies to ask that RU486 be distributed here.

Feminist Majority Foundation holds picket in favor of U.S. distribution of RU486 at Treviera Twosome race in New York City, sponsored by Hoechst Celanese and Nike.

JULY 1992

In the first direct challenge to the FDA import alert on RU486, a pregnant American woman, Leona Benten, returns from Europe with a prescription of RU486. Customs officials seize the RU486 upon the arrival of Benten and Larry Lader of Abortion Rights Mobilization at JFK Airport.

Despite a lower court ruling in favor of Benten's right to RU486, the Supreme Court refuses to order Customs to return the RU486 to Benten, and refuses to order the FDA to overturn the import ban.

OCTOBER 1992

New England Journal of Medicine study concludes that RU486 is a safe, effective post-coital contraceptive, which has fewer side effects and is easier to use than the current "morning-after" pill.

NOVEMBER 1992

Bill Clinton is elected as President of the United States. During the campaign, Clinton had pledged his support for bringing RU486 to this country.

The Feminist Majority Foundation immediately sends a letter to Roussel Uclaf CEO Edouard Sakiz and Hoechst AG CEO Wolfgang Hilger informing them that with Clinton's election and the election of more women and pro-choice members of Congress the political obstacles to RU486 in this country had effectively been removed.

DECEMBER 1992

The FDA announces that a review of RU486 for U.S. distribution could be completed in as short a time as six months. FDA Commissioner David Kessler writes to Roussel Uclaf encouraging the company to submit an application to license RU486 in the U.S.

JANUARY 1993

President Clinton issues an executive order instructing the FDA to re-evaluate the RU486 import alert and directing the Secretary of Health and Human Services to "assess initiatives ... [that can] promote the testing, licensing, and manufacturing of RU486 or other anti-progestins."

FEBRUARY 1993

Larry Lader announces that the Peiking Union Medical College has given Abortion Rights Mobilization permission to test the Chinese clone of RU486. (Because China doesn't recognize patent law, this is not a violation of the patent on RU486).

APRIL 1993

Larry Lader, along with Eleanor Smeal and Molly Yard of the Feminist Majority Foundation, announce a strategy to remove Roussel Uclaf's patent on RU486, using an existing law that allows Congress to remove patents on products not being marketed in the U.S. Lader also announces that the RU486 compound has been replicated by scientists in New York State.

At a press conference sponsored by Physicians for RU486, Congressman Ron Wyden promises to hold a Congressional hearing on removing the RU486 patent from Roussel Uclaf if there is no agreement to commence U.S. trials in three months.

Hoechst AG and Roussel Uclaf announce agreement allowing the Population Council to test and manufacture RU486. However, Hoechst AG continues to prohibit Roussel Uclaf from selling RU486 to a U.S. distributor in the interim, while an American manufacturer is established and gains FDA approval. These restrictions could delay making RU486 available for U.S. women by three or more years.

Stating that "unnecessary delays could lead to indefinite delays," Feminist Majority President Eleanor Smeal sends a letter to Hoechst AG CEO Wolfgang Hilger urging the company to permit the sale of RU486 to the U.S. during the interim period. Smeal's letter was accompanied by another installment of 100,000 RU486 petitions.

MAY 1993

Population Council announces that Oregon will be the site of the first clinical trials on RU486. Trials will include 2000 women at Oregon Health Sciences University in Portland and other locations.

A *New England Journal of Medicine* article reports that RU486, in combination with an oral prostaglandin in pill form, is now 99% effective in terminating pregnancy during the first nine weeks. This oral prostaglandin, already used in France, replaces an injection formerly used with RU486. This new procedure eases the administration of RU486.

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than the risk to women in their 20s. In fact, for a young teen to have a baby, it is 24 times more dangerous than to have an early abortion.

High Social Cost for Teenage Pregnancy

Over one million U.S. teenagers become pregnant each year. One in four teenage mothers drops out of high school and only 1 in 50 finishes college. Children of teens are *twice* as likely to die in infancy than those born to women in their 20s or 40s. The total cost to American taxpayers for families started by teenage women is $20 billion annually in AFDC, food stamps and medicaid benefits.

The Adoption Myth

Some people believe the answer to these social costs is adoption. In fact, the most likely woman to place a child for adoption is a white teen under 18.

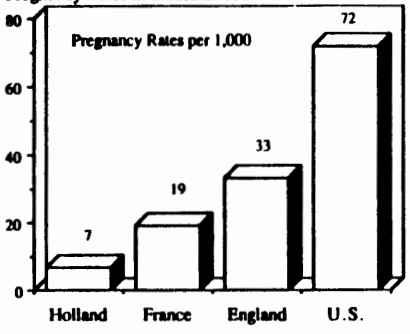
Yet, there are some 35,000 children waiting to be adopted with no homes in sight. Adoptive parents usually seek white, healthy infants, often paying large fees to baby brokers or agencies, while infants of color and disabled children wait, often indefinitely, for homes.

In fact, brokers can charge up to $100,000 for a healthy white infant, and fees of $30,000 are standard. Most adoption agencies are more moderate, but fees vary from agency to agency and frequently by type of infant. Agency fees can go to a high of 12% of the adoptive parents' gross annual income. In some agencies, fees for white, healthy infants are higher than for minority or special needs children.

It is worth noting that some anti-abortion groups operate adoption agencies.

Also, America's foster care system is breaking down. There are now 450,000 children who have been temporarily removed from their families and, by the year 2000, there will be one million.

Pregnancy Rates in Industrialized Nations for Women 15-17



A Worldwide Killer

The U.S. teen pregnancy rate is the highest among developed nations. It is more than double that of England, triple that of France, and 10 times greater than Holland. The teenage sexual activity rates are equal, but other countries have better sex education, access to contraception and birth control information.

The U.S. ranks tenth among 15 industrialized countries in the availability of birth control to minors, behind countries such as Canada, Italy, and Czechoslovakia.

Worldwide, 1 woman dies every 3 minutes from illegal abortion and young women rank high among the casualties. Throughout the world, denial of sex education, birth control, and abortion shatters the lives of young women and girls.

ABORTION DENIED

Shattering Young Women's Lives

Key facts about the one law that is killing the women it was meant to protect ...

In 1973, safe, legal abortion became every American woman's right. Thousands of senseless deaths from unsafe, illegal abortions stopped. Since then the Supreme Court, in a series of decisions upholding repressive state laws, has chipped away abortion rights -- first for low-income women, then for seriously ill women and *now, for young women.*

Shattering Young Women's Lives

In June 1990, the Supreme Court upheld two more harsh anti-abortion laws dramatically restricting a young woman's right to legal abortion.

While laws requiring a teenage woman to notify or get permission from her parents for abortion may seem reasonable, *the overwhelming evidence shows that parental consent and notification laws are devastating to young women.*

Lethal Impact of Laws

In 1988, Becky Bell, 17 years old, was a victim of Indiana law PL-106 which demands parental consent for an abortion for women under 18. Becky was intimidated by Indiana's law that blocks access to legal abortion.

Panicked by the legal requirement that she tell her parents -- because she did not want to disappoint them -- and believing she could not obtain a judge's waiver through a court hearing, she instead obtained an illegal abortion.

Becky was killed by a massive deadly infection -- the result of that back-alley abortion.

A Growing National Threat

Parental consent and notification laws have passed in 34 states. Though many have been blocked by the courts, 14 states now enforce these laws. The recent Supreme Court decisions upholding the Ohio and Minnesota laws invite many more states to follow suit. Both types of laws have exactly the same dangerous impact -- *they risk young women's lives.*

Young women often cannot tell their parent(s) for a host of compelling reasons: *fear of abuse, physical violence, being thrown out of the house, or tarnishing their image with their parents.*

In restrictive states, young unmarried women under 18 years old who want an abortion must:

1) seek parental notification or consent;
2) travel long distances to an unrestricted state;
3) petition for a court bypass; or
4) obtain an illegal abortion.

And although 50% of young women *do* voluntarily go to one or both parents, those who feel they cannot will risk almost anything, including their lives, to avoid exposure.

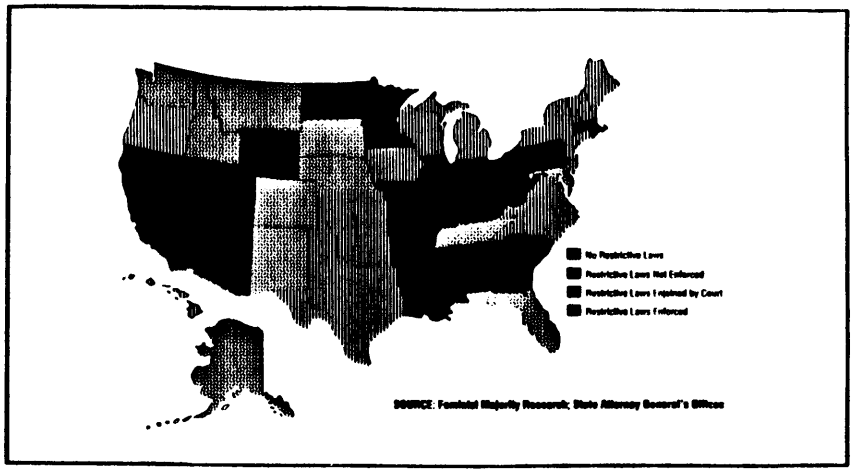
Failure of Court Bypass

The court bypass procedure, which forces young women to convince judges that they can't involve their parents(s), is discriminatory and frequently does not work. Young women seeking a bypass tend to be white, suburban, middle-class, college bound, and self-confident.

Young women must reveal their personal lives to the scrutiny of stranger(s), chiefly older white, male attorneys and judges. The legal maze they must maneuver is intimidating and is especially discriminatory against women of color and those with low incomes.

Teenage women are denied their right to privacy and often have to face up to 23 people in the process. Many have reported harassment from anti-abortion judges.

The court bypass delays essential medical care and causes many young women to enter the second trimester of a pregnancy.



Status of State Laws Restricting Young Women's Right to Abortion

After the Minnesota law passed, the percentage of teenage women needing riskier, more costly second trimester abortions *increased* by 26.5%. Even so the U. S. Supreme Court said this was not an undue burden.

Court bypass hearings are not easy to come by. In Massachusetts, many judges refuse to hear abortion cases. In Minnesota, court hearings and abortions are available in only two locations. In Ohio, the bypass process could take 22 days, but the U.S. Supreme Court still approved the law.

An analysis of court bypass procedures indicates that a young woman's right to abortion is dependent on where she lives.

For instance, an extensive clinic survey in Indiana reveals that permission has been *granted only about a dozen times per year* in the 4 years the law has been in effect.

In comparison, in Minnesota and Massachusetts thousands of court waivers were granted in that same time period.

Medical Opposition to Forced Parental Consent

Medical and health professionals do not support parental consent and notification on abortion. Organizations filing court briefs against the Minnesota and Ohio laws included:

*Amer. College of Ob/Gyn (ACOG)
*Amer. Acad. of Child and Adolescent Psychiatry
*Amer. Acad. of Pediatrics
*Amer. Medical Women's Assn.
*Amer. Nurses Assn.
*Amer. Psychiatric Assn.
*Nurses' Assn. of Amer. College of Ob/Gyn
*Society for Adolescent Medicine

In most states, teenagers do not need parental consent nor notification to receive treatment for drug or alcohol abuse, venereal diseases, nor to carry a pregnancy to term.

Adolescents are 200% more likely to die in childbirth than women in their 20's -- and adolescents under the age of 15 face the highest risks. Their risk of death in childbirth is 1000% greater

129X

THE STATE UNIVERSITY OF NEW JERSEY
RUTGERS

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January 30, 1994

Ms. Caroline W. Jacobus, M.S.W.
Commission on Sex Discrimination in the Statutes
228 West State Street
CN 095
Trenton, NJ 08625-0095

Dear Ms. Jacobus,

Thank you for accepting the enclosed testimony. I have included original sources for much of this information.

I apologize for not presenting this testimony in person, as the recent weather has forced me to change my schedule. Please let me know if I can provide additional information or clarification for what I have included.

Best of luck with your work.

Sincerely,

Fern Goodhart

Fern Goodhart
Director of Health Education

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Testimony, Fern Goodhart, 2/1/94

Thank you for accepting this testimony, which describes the prevalence of risk-taking, health-compromising behavior in adolescents. I rely on the expertise of the Commission to analyze how we, as a state, can create an environment which protects these adolescents by correcting gender bias in our statutes, and by making recommendations to the appropriate public agencies to correct other discrepancies.

Adolescence is often characterized by increasing rates of many problems. Mental health problems, especially depression, increase significantly. Other behavior, such as alcohol use and sexual expression, occur earlier than we as a society would prefer. Other behavior is problematic at any age, such as illicit drug use, smoking, and expressions of violence.

I'd like to focus on four main areas which affect adolescents: violence, alcohol and other drugs, smoking and sexual health. However, I noticed from the witness list that others will be addressing violence, so I will only briefly mention this.

VIOLENCE

Homicide is the second leading cause of death among 15-19 year olds. The 1991 YRBS (youth risk behavior survey) indicated that 26% of students in grades 9-12 reported carrying a weapon at least once during the past 30 days. Suicide is a leading cause of death for adolescents

Suicide rates for adolescents 15-19 years of age have quadrupled since 1950, to 11.3/100,000 in 1988. Attempted suicide,a potentially lethal health event in itself, is a predictor of other health problems, such as substance abuse, depression or stress. Suicide is a greater problem among females than males.

1/7 adolescents report having attempted suicide - many adolescents, particularly girls, experience depression and have difficulty coping with stress; and many adolescents have been in fights or were victims of violence.

4/10 boys and 1/4 girls report being able to obtain a handgun if they wanted one; The leading cause of death in both black and white teenage boys in gunshot wounds. 30% of women killed in the U.S. die at the hands of a husband or boyfriend. In studies of emergency department visits, 22% to 35% of women presenting with any complaint were there because of symptoms relating to partner abuse.

ALCOHOL AND OTHER DRUGS

Despite the fact that the legal drinking age in this country is 21 years, a recent national study of graduating high school seniors indicated that 93% of students had tried alcohol at least once, with 66% reporting drinking alcohol at least once in the last month.

This underage drinking continues into college, where, in one national survey,

80% of college students reported drinking alcohol in the previous month. In New Jersey, one university found that 80% of students drank alcohol in the previous month, and nearly half had had five or more drinks at a time (the definition of heavy drinking) within the last two weeks. More often (50% vs. 34%) these heavy drinkers are white males.

Use of alcohol and other drugs is associated with the leading causes of death and injury (e.g., motor-vehicle cashes, homicides, and suicides) among teenagers and young adults. Alcohol-related problems on college campuses include vandalism, fighting, injuries, STDs, unplanned pregnancies, and sexual assault. Is sexual assault increasing, or just the attention paid to it? It's hard to say, but regardless, the prevalence of unwanted sexual contact is epidemic. Conservative estimates put 1/4 of college women being the targets of rape or attempted rape.

Nearly 30% of all students will drop out before high school graduation, and youth who have dropped out of high school have higher rates of drug use than those in school.

Drug and alcohol abuse are major co-factors in HIV and STD transmission. While IV drug use provides a direct route for HIV transmission, non-injection drugs and alcohol can compromise judgment, reducing the likelihood that a teenager will make health-promoting decisions for sexual expression..

30% of gay and lesbian youth have problems with alcohol. And steroid use is a large problem which seems to remain undercover.

SMOKING

In 1990, use in the past month for adolescents aged 12-17 years were: 8% for illicit drugs, 24% for alcohol and 12% for cigarettes, although lifetime use for the same ages were 23% for illicit drugs, 48% for alcohol and 40% for cigarettes. [Society for Adolescent Medicine]

1/5 adolescents smoked cigarettes during the past month; 1/10 smoked marijuana.
4/10 10th grade students, and 1/3 8th grade students said that they recently rode with an intoxicated driver [National Adolescent Student Health Survey]

Girls are still starting to smoke more than boys. Much of the tobacco advertising is especially targeted at girls. Most cigarettes are purchased in small convenience stores, where the age restrictions for tobacco sales seem least likely to be observed.

SEXUAL HEALTH

Adolescents are engaging in sexual expression, starting this experimentation at younger ages, reporting regretting or having unwanted sexual contact, and often having sex while drunk or high.

By age 17, 48% of boys and 27% of girls have already had sexual intercourse. 2/3 do not use contraceptives all the time, often citing "unexpected sex" as their reason for not doing so, as well as not thinking pregnancy would occur, not knowing where to get birth control, and not feeling

comfortable going into a strange clinic (among other reasons).
72% of high school student have had sex by their senior year:

by grade 9 - 40% report having had sex
by grade 10 - 48%
by grade 11 - 57%
by grade 12 - 72%

The average age of first intercourse is 16 years (16.2 for girls, 15.7 for boys - 11.8 for inner city Black youth). Many adolescents initiate sexual activity before being adequately taught about sex education in the schools. And 1/6 sexually active high school girls has had at least 2-4 different sexual partners. 4/10 females become pregnant before they turn 20 years old.

On average, 1/3 of women under age 20 who give birth receive inadequate prenatal care, either because they start care late in their pregnancy or because they have too few medical visits.

By age 20, studies show that 77% of females and 86% of males report having experienced sexual intercourse. More than 90% report engaging in vaginal intercourse in the past year. More than one third have had multiple partners, putting them at increased risk for sexually transmitted diseases (9% report having had five or more partners in the last year).

The Centers for Disease Control and Prevention (CDC) recently reported that: More than half of high school students have had sex (less than half of whom use a condom). And although the rate of teenagers talking with their parents about, for example, AIDS, has not changed significantly, the availability of school instruction has increased by 50%.

Every year 2.5 million U.S. teenagers are infected with an STD, 1/6 of every sexually active teens, and 1/5 of the national STD cases. One study found 38% of sexually active teens examined were infected with HPV (human papilloma virus, which causes genital warts, sterility and cancer). This is consistent with college student data. 2/3 of all STDs occur in people under 25 years of age.

STD rates have become epidemic, and are increasing faster in the African American community (gonorrhea among Black youth 15-19 were almost 36 times the rate of white youth (5597 vs. 156 per 100,000). The rate of primary and secondary syphilis has increase 75% between 1985-1990, most notably in black heterosexuals men. According to the U.S. Public Health Service: women bear an inordinate share of the burden of STDs: 10-15% of women aged 15-44 years have had at least one episode of pelvic inflammatory disease (PID), more than half of which is STD related. PID among other things, contributes to infertility.

Women are the fastest growing group of persons with AIDS in the U.S., and in New Jersey. Because of the latency of HIV, 1/5 of New Jerseyans with AIDS were probably infected as teenagers.

More than 900,000 youth, 2/3 female, are involved in prostitution; their average age is 15. Nearly 4/5 of adolescent female prostitutes are thought to be runaways.

STD prevention requires: postponing the initiation of sexual activity, using latex barriers when having sexual contact, limiting the number of sexual partners, and acquiring a multitude of complex interpersonal skills needed to protect and promote their own health. Often these skills are not taught by parents or teachers, not learned from friends, and unfortunately left to be acquired through trial and error. In this case, the "error" part of practicing can have tragic consequences.

HIV/AIDS education must be started before the onset of sexual experimentation, and with the full range of knowledge, attitude and skill-building components recommended in the literature. We must teach our teachers how to facilitate successful learning, and begin this instruction on the pre-service level, while these future teachers are college students themselves. As this education is part of comprehensive health education programs and services, we will only increase the likelihood of success.

The same is true for how we prepare our health care providers, teaching them the skills they need to gain the confidence of adolescents, how to ask questions and not make assumptions about the probable pathology these adolescents will be seeking help from them with.

Among first-year college students, 51% of males and 23% of females reported having had intercourse while under the influence of alcohol. Among students over 21, 81% reported having had sex under the influence. Of the students who were sexually active, 29% of the men and 32% of the women said that at least half of their sexual activity was associated with alcohol.

1/2 women having abortions were using a contraceptive method in the month during which they conceived. According the Guttmacher Institute, NJ is one of 10 states with the largest number of women at risk of unintended pregnancy, yet we are not one of the 10 states with the greatest total public expenditures for contraceptive services.

CONCERNS

Based on the picture these facts present, I'd like to make the following observations:

1. Anonymous HIV testing must remain available, since adolescents rarely seek services which are not. In addition, STD treatment must remain available to adolescents without parental permission. There has been inadequate funding for HIV and other STD prevention for adolescents; for boys who don't get adequate health care where they reveal the scope of their risk-taking behavior, and for girls, who bear the burden of health needs - by contracting an STD and having no symptoms, or becoming pregnant, have an eating disorder, mental health or substance abuse problem.

2. Adolescents are reluctant to seek needed health care, either because they require parental consent for gaining access to needed services, or their only way to pay for services is through their parents' health insurance coverage. Services must remain accessible, confidential, affordable and convenient. This especially affects females, as the vast majority of health care needed by adolescents relates to reproductive health, nutritional health, and mental health.

3. Especially for adolescent girls, affordable routine health care is limited, and there is grossly insufficient funding for school-based clinics.

4. Pressure to weaken the family life mandate already on the books has been demonstrated by recent legislation. Family life education must be supported with resources which provide a safe environment for students to learn the skills necessary to make safe, health-promoting choices before they have already initiated health-compromising behavior. For example, sex education about pregnancy and STD prevention must teach skills before girls (who, in general, reach puberty earlier and socialize with older boys), are already dating and beginning sexual activity. Statutes must support the existing family life mandate, reinforcing (not weakening) it.

5. Risk reduction tools, such as latex condoms, need to be available and accessible at low
cost. This includes in community health agencies, public schools, and other public places where adolescents gather.

6. Termination of pregnancy requirements for parental notification - burden on the pregnant female. Termination of pregnancy must be the decision of the pregnant woman, not her partner or parents, as the burden for the long-term consequences fall on her, alone. Lack of safe access to termination of pregnancy facilities also makes exercising this right often dangerous.

7. Lack of insurance coverage for prescription contraception - burden on the female. Insurance should cover oral contraception.

8. Weak statutes make sexual aggression difficult to prosecute. We must take seriously the legal definition of sexual assault, overcome our cultural myths about sexual expression, and not allow the burden of proving innocence to remain on the female. We need safe places for females to live, study, work and recreate without fear of assault. And we need adequate housing, child care and food (and other essential services, such as health care and transportation) to enable females to do this.

9. There is currently inadequate child care for teenage girls who have children and want to work or go back to school.

10. Pap smears and mammography are needed as part of routinely covered women's health care.

11. The need for Adequate, acceptable, affordable, accessible, available contraceptive options, including RU 486, depo provera, female condoms, contraceptive implants (Norplant).

12. Inadequate mental health and physical health services for adolescents, and the need for: affordable, confidential, and targeted to girls and boys needs.

13. Systematic exclusion of women from clinical trials for drugs presents problems when treating women with drugs never tested on them..

14. Women are often poorer than men, often have inadequate health insurance, and bear the majority of child-rearing responsibilities.

15.Violations of Title IX in terms of access to opportunities for physical activities and adequate sports medical care.

16. Access to tobacco through cigarette vending machines or unenforced laws whereby tobacco (and alcohol) is easily purchased by minors over-the-counter.

17. Alcohol and smoking marketing targeted at adolescents (e.g., smoking ads at girls), especially connected to sports, on products sold to minors, and at places where girls and boys particularly gather or identify.

18. Public places, especially places where adolescents (and children) gather should be entirely smoke-free (schools, sporting arenas, bowling alleys, for example).

Adolescents need access to complete and accurate information (such as sex education taught by well-trained teachers), services (such as school-based clinics, confidential counseling and anonymous HIV testing) and the tools to protect their health (e.g., condoms and psychosocial and interpersonal skills). In addition, they need barriers to limit their access to alcohol, guns and tobacco (such as enforced laws and eliminated cigarette vending machines).