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PUBLIC HEARING

before

COMMISSION ON SEX DISCRIMINATION  
IN THE STATUTES

"To discover whether there are incidents or common  
practices that encourage sex discrimination in the health  
field and in the delivery of health care"

June 26, 1990  
State House Annex  
Room 341  
Trenton, New Jersey

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Janice M. Newman, Esq.  
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ALSO PRESENT:

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## State of New Jersey

### COMMISSION ON SEX DISCRIMINATION IN THE STATUTES

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## NOTICE OF PUBLIC HEARING

The Commission on Sex Discrimination in the Statutes will hold public hearings on Wednesday, June 20, 1990 at 10:00 a.m. in Room 341 of the State House Annex and on Tuesday, June 26, 1990 at 12:00 noon in Room 334 of the State House Annex.

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:

- Access to health care
- AIDS
- Detection and treatment of domestic violence by health care professionals
- Differences in the way men and women are treated as patients
- Drug treatment programs
- Fetal protection policies in employment
- Hospital and laboratory practices
- Insurance-rates, denials, COBRA terminations
- Medical education
- Medical/Clinical research
- Mental health care and treatment
- Nursing practice and education
- Prevention and treatment of fetal alcohol syndrome
- Prenatal, pregnancy, and childbirth services and practices
- Prosecution for child abuse/neglect during pregnancy
- Video display terminal workers and other possibly hazardous employment conditions

These topics do not preclude other relevant testimony, and your testimony does not have to be limited to one category.

Anyone wishing to testify should contact Jodi Danis, Research Intern at the Commission at (609)633-7098.

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 July 3, 1990.



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**JEANNE FOX, ESQ:** (Acting Chairperson) Hi, I'm Jeanne Fox, one of the new Commissioners. I'm glad that you made it here today and that you're all on time, which we aren't. Several of the other Commissioners will probably be coming in later. This hearing is being transcribed and they'll read the transcripts before we make our recommendations and have our discussions.

Health issues have been in the forefront of the national attention over the past few years. Health has also become a particularly important concern in our State, New Jersey, and the Governor's Commission on Health Care Costs has been a means to address problems arising from the increasing costs of obtaining health care. Sex discrimination in the health field and in the delivery of health care also presents an important area of study.

Women often face additional barriers in the health care system because of discriminatory practices and because of women's economic status. The increasing difficulty of obtaining adequate health insurance has taken an especially hard toll on women, and access to low-cost prenatal and pregnancy care remains a problem.

Women may also not receive the same health care options and quality of care as do men. Women are often not studied in certain areas of medical research, and existing medical models often do not include the experience and needs of women.

Many witnesses have come today to testify on these important issues. The Commission on Sex Discrimination in the Statutes hopes that the information from these hearings will be considered by the Governor in his study of health care in New Jersey.

Our first witness today is Hazel Staats-Westover. Please come forward.

**H A Z E L   S T A A T S - W E S T O V E R:** It is appropriate for the testimony on domestic violence to be the first report today, as our former Surgeon General of the United States Public Health Service in the United States Department of Health and Human Services, C. Everett Koop, considers domestic violence to be women's number one health problem in the United States. It affects more women's health than all automobile accidents, rapes, and muggings combined. Domestic violence is a serious social, legal, and health problem. Those who inflict violence on their partners come from every imaginable race, class, profession and occupation, age, geographic, and religious group. Abusers continue to abuse because society ignores, accepts, or fails to prosecute their behavior.

A specific focus on the physical care of the abused and the medical caregivers will be testified on later in the afternoon. As a United Church of Christ clergywoman, I have been working part-time the last 15 months as the Lead Consultant for the Clergy Project under the Division on Women and would like to speak on some of the issues that I have observed in regard to family life when domestic violence is present.

Twenty years ago, Americans assumed that rape, incest, and wife beating rarely occurred. Because of the women's movement, we know now that they're not at all uncommon.

The statistics are chilling. From a book soon to be published by New Jersey author Flora Davis, she writes, "An American woman stands one chance in three of being sexually abused before the age of 18, usually by a relative or friend of the family. When she reaches college age, the chances are one in five that she'll be raped on a date." I'm also the United Church of Christ Chaplain at Princeton, and have been called by women students to help them through the terror and trauma in the aftermath of acquaintance rape or date rape. They experience violent acts. Sometimes their heads get knocked

against the wall. Ms. Davis continues her statistics on women and violence, "Nine out of ten women have been sexually harassed on the job. Roughly seven out of every 100 women have been kicked, punched, or choked by the man they live with; some are beaten repeatedly."

As 85% of the abused are women, there is an apparent sex discrimination going on in family life behavior. What can we say to help people understand the way our sexist society works against women for equality? One has to be an historian with a sensitivity toward the patterns of behavior throughout history to really see how, since at least biblical times, women have been considered property of men along with their cattle, land, and so forth.

Ms. Davis writes, "Though legally women are no longer property, some men still feel that they are. The proof lies both in the fact that sex crimes and violence are so common, and in the way the criminal justice system has resisted changes designed to protect the abused and punish rapists and batterers."

As a clergyperson I am very conscious of the wrong religious nurture that reaped a society of sexual inequality, one in which there is confusion between the sexes in regard to dominance, control, and submission while couples work out hoped for loving, balanced relationships.

The epidemic proportions of violence against women calls all of us to be advocates for prevention of domestic violence in all aspects of the larger society, as well as immediate care for the abused. Knowing how total health; mental, psychological, physical, and spiritual-- is all of the same piece, we have a new understanding of how in a society where so much violence occurs, women are the recipients of 85% of the domestic violence. Specifically in New Jersey, we must not have 49 deaths and just under 52,000 calls for help or violence offenses as we had in 1989.

The time is past when the crimes of sexual and domestic violence are made only an issue of private, rather than public, concern, which allows the abuser to be protected. Last month I attended the inauguration of the Center for Global Issues and Women's Leadership at the Eagleton Institute at Douglass College. Margarita Papandreaou, the wife of the President of Greece, spoke on violence and human rights. She reminded us that if such an act of violence took place on the street, a policeman would be called and there would be an arrest. The criminal justice system has been less effective because of the institutionalized attitudes of sexism, racism, and class consciousness.

Improvements in response to society's growing awareness of the evil of domestic violence is seen in New Jersey as one of the states that has specially trained police units that effectively help handle cases of spouse or partner abuse. Our State has also modified our laws to make it easier to arrest batterers. It has been found that arresting an offender is far more effective in preventing future assaults than the two other common police approaches, which were ordering the offender to leave the house for eight hours and offering counseling.

Change has come slowly. Only a small percentage of those arrested are ever prosecuted because the charges are reduced to minor infractions of the law, or suspended sentences are recommended to the court by prosecutors, and judges in domestic violence cases often impose either a light sentence or no sentence. Nor can court orders of protection always safeguard battered women, since police do not provide a 24-hour-a-day guard to women who have been granted a protection order. Many of the deaths from domestic violence occur during this time.

Nevertheless, this is a quote from the NOW Legal Defense and Education Fund and Renee Cherow-O'Leary, in "The

State-by-State Guide to Women's Legal Rights,": "While sexist attitudes and other serious problems still prevail in many cases, if a woman does decide to go to court, she will find there is more public and judicial support than ever for prosecuting violence against women." There is also a greater likelihood of finding doctors, lawyers, judges, police, and counselors who can deal sensitively and effectively with the problem of domestic violence, press charges, and appear as witnesses.

Sexual, as well as domestic violence, constitutes criminal behavior. It is a crime for anyone to have forced sexual contact with another adult, or for any adult or teenager to have sexual contact with a child, either by force or with consent. Reporting sexual assaults helps both the victim and others. Sex offenders almost always repeat their crimes and seldom seek treatment voluntarily, so criminal prosecution is, in all probability, the most effective method of countering sexual assault.

Justice-making for victims of sexual and domestic violence involves our legal system, as well as social service agencies, religious institutions, and mental health services. This statement is directed toward the most effective use of our legal system to protect the abused and end domestic violence, including sexual violence.

In the funding and supportive services, include:

A policy of nondiscretionary arrests in domestic violence cases, which means that a police officer has no choice but to arrest, if she or he believes violence has occurred. These programs have been effective in reducing battering. Some cities sponsor community intervention projects along with the mandatory arrest. Female and male volunteers provide immediate counseling for both the abused and the abuser. The goodwill and support are important.

The police also need training programs for dealing more effectively with domestic and sexual violence, including crisis intervention techniques, legal guidance for fully informing battered women of their rights, and fuller coordination with other agencies trying to protect and help victims.

I was one of the founders of the Keyport Center where we had 300 women come for help the first year. Feminists always felt that shelters must somehow empower battered women to feel a part of a community of women who could help each other. Then when they left, they'd be resilient human beings who could control their own lives.

Courts should strive to cut red tape and eliminate delays in victims obtaining restraining and protective orders, peace bonds, and so forth.

Legal aid programs should increase services to battered spouses who seek divorce and custody.

Stronger, more effective laws governing domestic violence are still needed.

Legislation for appropriations is needed to adequately fund improvements in preventing and remedying domestic and sexual violence. In New Jersey this means support of moneys regardless of our present day cuts in the budget. My own belief about this issue is that it might be the most important issue of all, if we are truly concerned for our future society, as we know that children were present or involved in 54% of the reported offenses in 1989, and therefore psychologically and emotionally disturbed even when they have not been physically abused. But it means the next generation will have been trained for violence.

All court personnel, judges, lawyers, and court officers, should be trained in further sensitivity to the issues of sexual and domestic violence, and to the fact of bias against women in our court system.

To sum up my testimony on violence against women as the number one health problem, I believe it will require a network of all of our social systems to get at the root cause of the imbalance between women and men and equalizing power between males and females. We need a system where all women are no longer men's dependents, underpaid and undervalued, and therefore undervaluing themselves; one of freedom, security, and peace for all women. The legal statutes should reflect that need.

MS. FOX: Thank you. How do you feel at this point in time -- I don't know nearly as much about this as you obviously do -- how the training of the court system, the court personnel, is at this point in time in this State?

MS. STAATS-WESTOVER: It isn't enough.

MS. FOX: The active programs in some areas?

MS. STAATS-WESTOVER: I have been working in the feminist movement since the very beginning, and until I worked at this job -- as the Lead Consultant in the Clergy Project -- I had no idea how prevalent it was; it's massive. I mean, it is everywhere, and it is global as well as just in our country. It seems to me that there can't be enough education and training for dealing with this.

While I was on the Keyport Center staff, I helped train the police, years ago, in the care of rape victims, and did the training for Monmouth County. They are a different organized group now. It pays off. I mean, they have real sensitivity and appropriate ways of talking to the victims of rape and of dealing with going into the homes where violence is being perpetrated. All we need is more, I think, but there has to be funding to help this happen.

MS. FOX: And the funding for that program was by--

MS. STAATS-WESTOVER: It's ending at the end of this month.

MS. FOX: --by the county, or was it State funded?

MS. STAATS-WESTOVER: Oh, that. That was special HEW project money that we had gotten for an experiment in developing programs in the community for women -- to help.

MS. FOX: Is that continuing, that programs?

MS. STAATS-WESTOVER: That Center is still going. It's one of our 29 centers in the State.

MS. FOX: And where does that funding come from?

MS. STAATS-WESTOVER: It comes from several different sources. It's partly under the Division on Women and reaches out.

MS. FOX: Okay, thank you.

Our next witness is Diane Palladino, from New Jersey Women and AIDS.

D I A N E P A L L A D I N O, Ed.D.: Hi. I'm the Coordinator of the New Jersey Women and AIDS Network, a statewide organization which is now based in New Brunswick.

The mandate of the New Jersey Women and AIDS Network is to make visible the issues affecting women who are at risk for, and who are infected with HIV and AIDS. To create this visibility, we sponsor public education forums, disseminate information on the impact of HIV infection on women and in women's bodies, and monitor policies which regulate care and service delivery to HIV infected individuals.

Since the inception of the HIV epidemic, New Jersey has had the largest percentage of women with AIDS in the United States. As of May 30 of this year, 1813 women, or 21% of the total number of people diagnosed with AIDS in New Jersey are women. This means, conservatively speaking, that over 27,000 additional women are currently infected with HIV. Well over 50% of these women are women of color, poor women, and urban women. For a State that ranks fifth in the country in the number of diagnosed adult AIDS cases, women have been, and still are worse than second-class citizens in health care services and constructive public policy. They are invisible.

Before I present the specific problem areas in HIV/AIDS services to women, let me make clear that the discrimination is couched in the institutional responses to women and HIV.

The subtlety of the discrimination rests in the fact that women are ignored as victims of HIV infection, as people who get HIV infection, and as individuals whose bodies become sick because the virus exists in those bodies. The lack of positive responses to women as people who can, and do become infected with HIV is accompanied by the framing of women only as transmitters of the virus to men and to fetuses. Women are perceived as "vehicles of infection." In the latter role, women are projected as beings whose sexual activities must be controlled, as if the control of women's bodies will result in the ability of the State to control the transmission of HIV infection. Public policy has been formulated around this negative perception of women's role in the epidemic rather than towards providing women with the essential health services they urgently need.

The key areas which require immediate attention are as follows:

- 1) In Essex and Hudson Counties, where 61% of all women with HIV and AIDS reside in New Jersey, there is one clinic specifically for women with HIV. This is the only women's clinic in the entire State. The other 29% of women with diagnosed AIDS and HIV infection have no such facility near them.

- 2) There is no medical protocol in New Jersey for the treatment of HIV infected women. There is a protocol for "people" with HIV infection. This protocol does not include the gynecological manifestations of HIV which, by definition, are female specific. It fell to the New Jersey Women and AIDS Network to do the research and produce literature dealing with the medical manifestations of HIV in women. The literature was

produced through a small grant from Hoffmann-La Roche, with no support of public funds or public institutions. Since the literature was made available on June 4 of this year, we have had requests for over 100,000 copies from groups within New Jersey and for over 25,000 copies from groups in other states. We are now trying to find additional funding to accommodate the additional printings.

3) There is no medical protocol in New Jersey for pregnant women who are HIV infected. We have heard reports that many obstetricians do not want to work with HIV infected pregnant women and attempt to refer them to "HIV specialists." The reality of the situation is that obstetricians can treat these women as well as they can treat non-HIV infected women and, in fact, many physicians have, unknown to them, treated women patients who are infected. All primary care physicians must commit to self-education about HIV disease and must participate in the medical response to the epidemic. That's another reason why we produced the literature. The literature that was produced has a pamphlet for physicians, health care workers, and one pamphlet for women with AIDS and HIV.

4) The Centers for Disease Control does not include any reference to female specific symptoms in its current definition of AIDS. When asked the reason for this, Mr. Curran has replied that there's not enough "research" on women to generate hard data. Of course, there are minimal funds available to support such research, so the data cannot be generated in the "scientifically acceptable ways," which produce the hard data necessary to justify the expenditure of funds for research.

When we were doing research -- as an aside -- on the medical manifestations literature, the researcher that we hired contacted all of the research projects in the country that were researching the effects of HIV infection on women. She didn't have a hard job; there were 10. That's an increase over the last few years.

Another effect of the limited definition of AIDS is that many women have been misdiagnosed, and as a result, die unclassified as having AIDS. The result of this non-AIDS classification is twofold: 1) women remain undercounted in the epidemic and the lack of resources is justified on the "small number" of women who have HIV/AIDS; and 2) women who are not accurately diagnosed with AIDS do not qualify for entitlement programs, which require an AIDS diagnosis for participation.

5) There are no clinical trials in this country which study the effects of experimental drugs on women's bodies. Up until recently, many trials excluded women because the results from women "skewed" the data, and many women of childbearing age are still, in fact, not allowed into trials. They are afraid of what might happen to the fetus, and that's even if the woman is not pregnant. They're still afraid of what's going to happen to the fetus. In trials for AZT, the most widely tested antiviral drug, only 7% of the participants were women. The truth is that we do not know the effects of AZT on women.

6) There are currently two open trials for pregnant women who are HIV infected, protocol 082, and C121. The goal of both of these trials is to study the effects of specific drugs on 1) the transmission -- once again we're back to the transmission -- of HIV from mother to fetus or neonate, and, 2), on the HIV status of the newborn; in other words, blocking transmission to the newborn. Neither trial -- and again, these are the only two trials in the country -- is concerned with the effect of the drug on the pregnant woman herself.

Research models have indicated that women comprise the fastest growing group of individuals now being infected with HIV. This is true on a national and international level. In New Jersey alone, in one year, we have seen a 36% increase in women diagnosed with AIDS, surpassing the increase for men in that same time period. So what we're seeing now in New Jersey,

and in fact in the United States, is the male/female ratio of infectivity becoming closer and closer to that which we've seen in Africa and the Caribbean. Up until this point we've insisted Africa was an aberration, the Caribbean was an aberration. We're the only ones who have it right with HIV infection, but we're seeing what's happening in the United States come much closer to that model. We have seen a 41% increase in the heterosexual transmission of HIV to women, again surpassing the increase for men.

Women have been made invisible throughout the epidemic as people who get sick and have been the focus of blame as "transmitters" of the virus. It is time to rectify this discrimination and to insure that women are given the medical services and the resources they require. It is time to make women visible.

Thanks.

MS. NEWMAN: In your studies, have you determined the percentage of births with HIV infected--

DR. PALLADINO: Right now all infants born of an HIV infected mother will be HIV infected -- will have HIV antibodies. I'm sorry, because of the transmission of the antibodies from the mother to the newborn. That's any antibodies. Within 9 to 15 months, they shed those antibodies, and now it's approximately 25% of children born to HIV infected mothers who actually are infected themselves.

MS. FOX: Do you have an idea of how many -- one out of how many births might be HIV infected?

DR. PALLADINO: Oh. I don't have the figures with me. Depending on where you look in the State-- I think in Newark it was-- I won't even give you the figure, but I can get you that information if you'd like me to do that.

MS. SAMPIERI: What specific recommendations would you make to include women in the testing of drugs -- in the receipt of care?

DR. PALLADINO: Certainly in the testing of drugs, and that should be very easy. I mean, we have protocols that are being tested. All you need to do is insure that the participants in those tests are women. Now, I don't mean are women in addition to men or including men. What we really need is clinical trials where the people -- the participants -- are only women, so we can look at that data and how the drug affects women, and then compare that group with a group of men who are getting the same protocol and see what kinds of effects the drugs do and do not have on women, and the differences. That's relatively easy to do.

We need, in terms of services-- First of all, we need more clinics. The clinic I referred to is Pat Kloser's clinic. She is servicing now about 500 women, mostly from Newark, in that clinic. The waiting time is about six hours. I was just talking to her on June 4 and she was real excited because she was getting two fellows as of July 1, so she would have two extra physicians to work with her.

Arlene Bardequez, who I noticed testified last week, also works with Pat Kloser, with women who are pregnant. They simply don't have the staff up there to deal with the women they see. They don't have the psychosocial support staff. New Jersey has no organized psychosocial support services for women. In other words, if you find out that you're HIV infected, if you find out you have AIDS, if you find out that your partner is infected, if you find that your child is infected, there's no specifically trained mental health center, or group of mental health clinicians who are dealing with that.

Again, I'll go back to Newark, because they're doing the most. Julia Aleman, who works at UMDNJ as a social worker, works closely with Pat Kloser and her clinic, but she's one social worker. She's the person who is doing the most consistent intervention with families affected with HIV, and she's one person. So, that needs to happen.

We need to have more mental health people trained. We need to have more people who come in contact specifically with HIV women. For instance, we have the TAP sites in New Jersey -- Treatment Assessment Program. You need to train that staff to do intake with women, to talk with women about their concerns, to do risk assessments that women will respond to. So, we need widespread staff training on the inpatient level, on the whole medical level.

We need that kind of training in drug treatment centers. One of the things that you always hear about is, well, addicted women are not represented in drug treatment centers. As far as I know, there is one drug treatment center in this State that takes into account a woman who has children. Now, you know, I'm not going to put my kids in foster care to go into a treatment center, and I don't think many other women are, either.

That's really one of the alternatives that women have. So if we look at transmission through drug use and linking that to HIV, we don't have a viable intervention. We need those kinds of centers.

We need housing for women and their children, again, infected women and/or infected children. No woman is going to separate-- Very few women are going to separate themselves from their children. One of the statistics that we see now is that women die three times faster than men. Women live-- After a diagnosis of AIDS, women live on the average of 14 weeks. Men live an average of two years.

MS. FOX: Can you guess why that is?

DR. PALLADINO: Yeah, I can give you several guesses. One is-- It's pretty complex. One is that most women who are infected are probably also part of a family structure where her partner is already infected, or may have died. She probably has children and probably at least one of her children is infected. So, it means that she is going to take care of

herself last. What medical services there are -- and I just described to you the medical services -- she's not going to put herself into. That's not unusual in women's health care. Women generally leave themselves last in terms of health care.

Look at the scenario: Let's say you live in New Brunswick, Middlesex County. You've got an infected child and you don't feel too good, okay? Where are you going to go with your child? Well, you can probably go to Robert Wood Johnson, or you can go up to Children's Hospital in Newark. But, then you've got to go someplace else -- if you can get into Pat Kloser's, which is up in Newark -- to treat yourself. Now, even if you live in Newark, you've got to wait six hours in Pat's clinic for services and then you've got to go to Children's Hospital for your child. Now, who are you going to go to first? Most women address their children. They have also been taking care of sick members, again, partners.

The other thing -- and I'll go back to the medical pieces -- is that what we see is that the physicians who are looking at, and who are working with, HIV infection, look for the signs of HIV infection in women, those of which have been now enshrined in the Centers for Disease Control's definition of AIDS. They don't look for the gynecological manifestations of HIV in women. They don't look for, for instance, if a woman has a sexually transmitted disease. One of the things that happens if they are HIV infected, is that disease is going to be much more potent, much more resistant to any drugs, probably resistant to all of the medical interventions, and she is going to keep coming back for three years getting her yeast infection treated, and it's not going to occur to anybody that this might be a case of HIV.

There's tremendous correlation between irregular PAP smears and human papilloma virus. Human papilloma virus has approximately 60 to 64 strains. Some are fairly benign; many of them lead to neoplasia. It's seen now that many of the

women who have HIV infection and have human papilloma virus wind up with the more virulent strains. They move quicker to cancer and they wind up with uterine cancer or ovarian cancer. Pelvic inflammatory disease usually winds up needing surgery, but physicians are not trained to examine women and look for these signs. So what happens is, a woman can be going -- even for health care, this is still answering your question -- going for health care and nobody picks up the fact that these are symptoms that should at least raise a red flag in terms of talking to that woman about her HIV status.

It goes the other way, too. Even women who are known to be HIV infected and have these other symptoms, they are very, very, rarely connected as to having anything to do with HIV. In other words, the course of the infection is not being tracked by the other kinds of medical manifestations, until she starts to get the more traditional manifestations, but at that point she may have been sick for three or four years. You can die.

Candidiasis is another thing. Once you get candidiasis in the mouth and the throat, that mirrors the state of your immune system. Once a person -- any person -- gets it in the throat or the mouth, their immune system is significantly impaired. Candidiasis first manifests itself vaginally in women. Now, that's a real important early intervention trigger. It's ignored over, and over, and over, again. Most of the time, physicians don't even pick it up, and if they do pick it up, they don't pick it up in terms of HIV infection.

MS. FOX: Do you know if medical schools train for that?

DR. PALLADINO: No.

MS. FOX: They don't?

DR. PALLADINO: No. We don't even have a protocol for anything. I mean, no, we don't have-- And the medical schools

are usually the last thing to happen, which means you don't have the manifestation I just talked about, even mentioned. I mean, our literature is the first mention of it in this country and in this State. That's pretty crazy, when you think about it.

MS. NEWMAN: So, basically, all they do is they treat that particular disease -- that manifestation -- without linking it with anything else?

DR. PALLADINO: Right, right.

MS. NEWMAN: Doesn't drug abuse also speed up the process of the HIV disease?

DR. PALLADINO: There are different theories about that. I mean, clearly drug abuse has already taken a toll on your body and on your immune system, if you're an IV drug user, so having HIV on top of that, obviously, is going to impact on the body differently. I'm not aware, but I'm not an expert in the drug abuse field. I know that someone is here from drug abuse. I'm not aware of any direct research linkages between -- you know, a cause and effect relationship, but clearly, once your immune system is impaired by any kind of abuse--

MS. NEWMAN: Because when they looked at addicts in Newark, for example, they found that the addicts died faster.

DR. PALLADINO: Addicts die at about the same rate as women, but again, I think it's such a complex situation, because I don't think addicts have wonderful access to health care in this country, and certainly not in this State. Most IV drug users that I'm aware of-- Not only don't they have access, they're hesitant to go for medical care because of their drug use. So, that plays another role in it as well. So when do they get diagnosed? When they have an opportunistic infection--

MS. NEWMAN: So then the ideal situation on your solution list is if we establish more drug treatment clinics and that we also work closely -- that the two work closely --

and not just be a drug treatment clinic or an AIDS treatment clinic, but that they work closely together.

DR. PALLADINO: And that they're trained to deal specifically with women and women's concerns and issues. You know, in this State we have this legislation, which is so boring already -- it's been introduced for the third year -- about testing newborns. You know, we thought we had put it to rest last year, but now it's testing the old newborns again, and really testing women. You know, you see this other piece, too. Not only aren't there those kinds of services, but there's this undertone of, "Let's get the women." You know, "Let's get women and let's stop them from having babies. Let's stop them from having sex. Let's criminalize what they're doing so we can stop this infection." So, we've got a two-level fight here.

MS. NEWMAN: You mentioned the criminalization. Do you know of any cases where women are being prosecuted for passing on HIV?

DR. PALLADINO: At the moment, I do not. However, I believe it's around the corner, because women are certainly being put in jail for passing on -- for having crack babies, and the whole drug scene. I think HIV is around the corner.

In this State, we have-- I don't have the new number with me of the legislation which criminalizes HIV transmission. It's an extension of the public law -- the venereal disease law, and if you look closely at that legislation-- I mean, it talks a lot about intercourse and passing on through intercourse, but there's a little paragraph in there that does not talk about intercourse. There is a statement in there that says, the passing -- the transmission of HIV infection -- the known transmission of HIV infection, is a crime of the third degree. That one section takes out reference to sexual transmission, and who does that apply to? It can only apply to women who become pregnant and have HIV infected children. I mean, that's the loophole.

That piece of legislation has not been passed in this State. It's been kicking around for three years, but it's still there; it keeps getting reintroduced. I'm very concerned that that kind of legislation will get passed and will dovetail very nicely with what's being done to women with crack babies and addicted children

MS. SAMPIERI: I hate to put another burden on your request for information, but do we have copies of what you did -- of your reports?

DR. PALLADINO: The literature? No, I didn't bring any today, but I will be happy to send a packet to all of you.

MS. SAMPIERI: We could even photocopy it if you can't get copies.

DR. PALLADINO: No. I just got delivery of 6000. Hoffmann-La Roche said they would print, hopefully, up to 25,000 for us, so I have some of them -- 6000 in the office now. I would be happy to make those available to you.

MS. SAMPIERI: Thank you.

MS. PERELMUTER: May I ask you how the medical community received your literature?

DR. PALLADINO: So far, well, the medical community-- Nurses have been responding wonderfully. The family planning groups have been responding. The OB/GYN Nursing Association has just asked one of the women who was on our work group to do a poster session at their regional conference. We have gotten an overwhelming response from them. I haven't heard a lot from physicians -- private physicians.

Physicians who are working in clinics in the public health sector, we've gotten a lot of positive response from. We've gotten requests from other states as well. For instance, the Ohio Department of Health has responded very positively. But the physicians in private practice, we haven't heard anything from.

MS. FOX: Any other questions? (no response)

Thank you, and we look forward to your literature.

DR. PALLADINO: Thanks.

MS. FOX: Could we take a five-minute break, and if you're scheduled to testify, please check in over at the table. Five minutes.

(RECESS)

AFTER RECESS:

MS. FOX: Why don't we get started? The next speaker will be Nancy Fiorentino, the Director of the Community Intervention and Referral Unit.

NANCY FIORENTINO: Hi. Should I talk into this or, is it good to just--

MS. PERELMUTER: This is just for the transcriber, so you need to speak out.

MS. FIORENTINO: Okay. Hi, I guess I feel first like I want to say that I'm so glad to have the Commission on Sex Discrimination in the Statutes existing. I was among the people who really believed it was important to retain and support and keep looking at.

I'm a middle manager in the Department of Health, Division of Alcoholism and Drug Abuse. In my section is the Office on Women, and the Office on Women has had several initiatives this year which have attracted considerable attention. The primary one which I'm going to speak about is the Pregnant Women's Treatment Project.

Also I prepared for you-- Let me just mention briefly the materials that I gave you. This topic has become so popularized in recent months that there's just a lot of material. "Nightline" this week was on the subject of pregnancy and addiction, so we had them fax us a transcript, and there's a copy for you. There's some very interesting material in there.

There are also two charts which tell drug effects on newborns, which are of public health a informational nature.

They're actually for posting in teaching. They're used in treatment centers for teaching and posting. Then there's an editorial and article from the most recent "Journal of the American Medical Association," which is on the subject of intervention, which I refer to in my testimony. I wanted to give you the original article.

Then there's a brief narrative description of our primary Pregnant Women's Treatment Project, and a list of the 10 providers who are presently providing treatment to pregnant addicted women.

With that I'll just go into-- Basically the estimates for how many drug exposed infants are born range from 300,000 to 375,000. In New Jersey there were 117,000 live births and using the national estimate of 11%, that's 12,870 drug exposed infants. Using the FAS rate of 1 per 500, there were 234 FAS babies. The total number of drug and alcohol exposed babies in New Jersey is at least 15,210. This is extrapolated from national figures; it's not original New Jersey reported data.

Many more babies were born with fetal alcohol effects which are not included in this estimate. There are large variations in rates due to geography and demography. We have been told that the rate in Atlantic City and Trenton is 35% to 50%, and still higher in Newark. In New Brunswick, the two local hospitals are conducting an original current survey to determine actual prevalence among all women admitted for delivery. They're doing drug screens and we will know what percent of all New Brunswick deliveries are drug -- have a positive toxicology. This data is not routinely collected and reported.

The societal response has been one of denial followed by mystification. People want to know: "Why don't pregnant women stop using alcohol or drugs?" This question misses the most essential fact about addiction. By definition it is characterized by loss of control and the inability to stop.

Addiction is not willful misconduct. It is a physiological and psychological urge like an instinct, a craving beyond human understanding. Lab animals take cocaine until death.

Treatment programs operate in many ways like traditional therapy, but in other ways they do a thing called a "brainwash" about addiction. Even with intensive work in this area, relapse is not uncommon and may serve as a part of the recovery process. Nonetheless, treatment does work, and we have scores of women whose lives were hopeless a year ago who now have clean and sober babies and lives.

The next societal reaction after, "Why don't they stop?" is, "If they can't stop, we should control them." Nationally, 50 women have been prosecuted for distributing drugs to a minor, their fetus. Between 18 and 25 states regard a positive toxicology or drug screen at childbirth as pro forma evidence of neglect. Children are removed from their mother's custody straight from the hospital.

In New Jersey, there has been at least one prosecutor who did ask the Health Department to join him in prosecuting a pregnant addicted woman, but when offered treatment, this woman consented. Originally she declined, because she thought the attitude was one of interest only in the baby, not her. When she was approached later, she changed her mind.

When a hospital or physician reports a drug exposed infant, a family investigation is undertaken by DYFS. The baby is not automatically placed. This year there will be funds for family interventions to teach the methodology of drug and alcohol intervention to DYFS workers. Drug and alcohol addicted families can be organized and empowered to move their addicted loved one into treatment, possibly, instead of the removal of children.

Pregnant addicted women cannot give their babies what they do not have themselves. The JAMA article tells the story of 935 mothers of low-birth-weight babies who were offered

intervention services. Ninety-six percent agreed, and they participated in these services for three years. These women want and need care and treatment, not censure and punishment. What if an arrest for driving while intoxicated were to constitute reckless endangerment of minor children? What if these drivers were subject to prosecution and loss of custody of their children because they drove while intoxicated? This is not likely to happen, in part because intoxicated drivers are mostly male, middle class, and white.

Some background on alcohol and drug problems, the good news: Consumption of alcoholic beverages is declining, and has been steadily. Cirrhosis, leading indicator of late stage chronic alcoholism, is declining, reflecting earlier treatment at young ages. Drug use in high schools is on a downward trend according to the most recent national survey. Drug related emergency room contacts in the last quarter of 1989 dropped 20% after many quarters of steady increases. The dopamine receptor gene has been located which may help explain addiction and would confirm the long held hypothesis that there is a genetic base. Self-help networks are available everywhere. They are free and demonstrate success for over a million people in the United States. There are 1500 meetings a week in New Jersey alone.

Obstacles: Of the government's \$10 billion effort in the war on drugs, only 30% is earmarked for treatment. Objective clinical drug and alcohol assessment and testing are still not routine in health care settings, in correctional facilities, in social service agencies, in employment or school settings. Treatment for addiction is not available to all those who request it, but particularly to underserved and high risk groups, the poor, and anyone with any complications, medical or psychiatric problems, hearing impairment, disability, acting out behavior, homelessness, and so forth.

Clients are seldom matched to treatment setting based on characteristics which predict outcome. For example, a person with an intact family, employment, and health has been demonstrated as being capable of recovery in intensive outpatient care, but these are just the ones who are sent to residential treatment, because they have good insurance coverage.

With all of the treatment available, we are only serving one in 15 or 20 addicted persons.

Alcohol and drug addiction: How is it different for women? The illness is telescoped. Women get sicker faster, using less of the substance. Women suffer more medical and social consequences from drinking and drugging, are more depressed. Addicted women are stigmatized and the thought of pregnant addicted women offends. Women are held to a higher standard of conduct.

Men with addicted women desert them. Women with addicted men and children stay, thereby developing the co-dependence syndrome, an illness in its own right characterized by medical and emotional symptoms and impaired functioning -- social and economic functioning.

Women are more likely to begin drinking in response to death, divorce, or disability, their own or a loved one.

Alcohol and drug addiction services for women: Women in treatment usually do have access to specialized women's treatment groups. This is essential. It allows a forum for dealing with incest and abuse, both of which are almost universal in an addicted population.

There are eight halfway houses for alcohol and drug addicted women in New Jersey. They are safe refuges to support recovery, but each one turns away up to two dozen women daily because the demand for services is so great. This morning, I left a group that wants to open a halfway house in Hunterdon County, and by the time we finished the meeting, we were all

sort of depressed because the obstacles to opening a halfway house are so grave in New Jersey. There is a terrible difficulty about getting capital construction money -- bricks and mortar money -- and you can't apply for operational grant money to the general grant makers until you've got that building.

And the local zoning problems are horrible. We have a halfway house for women and children in Monmouth County, which has been unable to provide counseling on the premises because of a zoning fight which continues in higher courts. We've had houses in other localities that were funded and ready to go, delayed for a year-and-a-half, and finally, never opened. We really need some kind of a way to supersede local zoning in order to site drug and alcohol facilities.

The local Councils on Alcoholism and Drug Abuse do advocacy and education on women and addiction. In Hunterdon, they were the genesis for this group that wants to open this house. Each staffs a county task force. Some have gotten alcohol removed from maternity wards in local hospitals. Some have gotten local ordinances to require posting warning signs, "A pregnant woman never drinks alone," and other health warnings.

In the eight perinatal care centers with the highest risk for infant mortality, risk reduction specialists screen pregnant women for drug and alcohol addiction. Five hundred addicted women were identified and counseled last year, which was the first year of the program. This is a national model program featured in a monograph by the Federal Office of Maternal and Child Health.

Ten residential treatment programs have developed a pregnant women's treatment initiative. Last year 356 women were treated; between 125 and 200 of them were pregnant. All records did not contain notes. This problem has been corrected for this year and the program has been expanded by one-third.

A comprehensive one-stop multiservice center has been established in New Brunswick, which offers support to pregnant addicted women. There is child care, transportation, addiction treatment, and parenting training all out of one site.

Several programs now offer simultaneous treatment to children of addicted families and their mothers on an outpatient basis.

Intervention with low-birth-weight mothers and babies has been shown in randomized clinical trials to improve both academic performance and behavior problems, raising IQs between 6 to 13 points.

Proper nutrition and regular perinatal care have been shown to produce healthier mothers and babies by raising low birth weight and early detection of potential problems.

The obstacles: The Women, Infant and Children Nutritional Supplementation Program has been cut at the Federal level due to an 8% increase in food prices. This means less cheese, less peanut butter, and less juice for pregnant women.

Perinatal care is also experiencing cutbacks. One center in Monmouth County which serves 600 pregnant women a year will this year be curtailing services due to cuts.

Low birth weight is of such seriousness, it persists across generations. Black mothers who are middle class continue to have twice as many low-birth-weight babies as their white counterparts.

Specialized care for children damaged by cocaine addicted mothers is estimated this year to have surpassed the \$2.5 billion level.

Recommendations: We need a statewide Commission or Office on Families, Health, and Addiction. Women and children require specialized programs. They require improved cooperation among all those agencies which serve them. New Jersey's own data should be gathered, cases documented, and advocacy offered. There should be a State plan which transfers

new knowledge from the empirical research world into programs in the community to strengthen families and prevent their deterioration. This State plan should incorporate education, health, and welfare objectives.

There are other public policy options deserving of consideration by such an office. These include:

- \* Pregnancy testing as routine in every drug and alcohol treatment program.

- \* Drug and alcohol assessment and testing as routine in all perinatal care programs.

- \* Potentially, a ban or limitations on alcohol and tobacco advertising, instead of a movement to fund counter-advertising.

- \* Drug and alcohol testing for all trauma cases in hospital emergency rooms.

- \* What about holding alcoholic beverage license holders responsible for serving pregnant women, the way we do for underage persons, instead of the current theme, which is blaming the victim?

- \* Posting warning signs in obstetric and gynecological service settings.

- \* A household survey of needs and public support, and efforts to combat racism, sexism, and classism.

There are other public policies which would be of immediate help and which would require much less debate:

- \* Establish a master plan for siting facilities for addicted women and children, thereby superseding local zoning requirements. This is done in mental health and developmental disabilities, and a consensus is building for the importance of this movement.

- \* Require interagency linkages among service providers as part of funding mechanisms. These would include: drug and alcohol treatment, perinatal care, Medicaid for the unborn, AFDC, DYFS, special education, WIC, and others.

\* Codify, for the purpose of promoting interagency cooperation, the methodology for exchange of information which should be used in order to still protect confidentiality and privacy of patient records.

\* Allow for a fast track administrative review and approval for Certificate of Need, licensure, and rate setting for any treatment facility which intends to serve pregnant addictive women and their infants.

The Federal funding which presently has a 10% women's setaside has been discussed for earmarking half of that for pregnant women. I would be bolder. I would recommend that it should be a 25% setaside; 10% earmarked for pregnant women.

One-third of the treatment population in the drug clinics are women, and one-fourth in the alcohol clinics are women, and in fact, it could be up to 40% if outreach were better and access were better.

There are special treatment needs of this population, pregnant addicted women. It is a very deprived group. As individuals, the women have been victimized. Every 15 seconds a woman in America is beaten. Some of these women display sexual acting out and prostitution. Usually they are incest survivors, and frequently they are in abusive relationships. Provocative behaviors are defenses that disappear with good treatment, however.

These women need support of the kind that has been demonstrated in the last JAMA article that is enclosed in the packet. They need long-term, in-home support for recovery from addiction. They need help in caring for their infants, often a difficult and damaged infants. Providing services to these women now could prevent the specter which The Trenton Times described this month, of one-third to one-half of all Trenton schoolchildren in the year 2000 being handicapped in their academic performance with behavior problems due to drug exposure during pregnancy.

Finally, after completing reviewing all of my materials and preparing all this, it dawned on me that I had been operating off a pattern of value statements which I decided to codify:

A pregnant addicted woman has a right to:

- \* be treated with dignity and respect;
- \* receive sufficient and healthful food;
- \* receive intervention and treatment for addiction;
- \* safety and security;
- \* freedom from physical harm;
- \* freedom from sexual abuse and sexual pressure;
- \* perinatal care and treatment;
- \* child care sufficient to participate in addiction treatment and perinatal treatment;
- \* transportation sufficient to support treatment for addiction and pregnancy;
- \* housing for herself and her family;
- \* education in the stages of development of her infant and child;
- \* education in the special needs of drug and alcohol affected infant and child;
- \* social and emotional support to recovery;
- \* confidentiality and privacy in the handling of her treatment needs;
- \* HIV counseling, testing, and treatment; and
- \* information about those benefits and services available to her and her family.

MS. FOX: Thank you. Any questions?

MS. FRANCIS: I would just like to say that was an excellent summary with a lot of very pertinent information that I wish a lot of people could hear and read.

MS. FIORENTINO: Thanks.

MS. FRANCIS: I always have a concern when we're dealing with issues related to pregnant women that we deal

carefully, so that we're not infringing on the autonomy of the woman in the interest of the fetus. But when I say that, I don't mean that we should not be concerned with the fetus; we certainly should. But it's sort of a general question: How do you recommend approaching this kind of an issue so that we insure the woman's autonomy as a person and not have an implication that you're dealing with two persons under the law, if you will?

MS. FIORENTINO: Well, I think you could tell from the tone of my testimony, I certainly am opposed to the kind of policy which those states which are prosecuting women who are addicted, are pursuing. I really believe in a policy of treatment and in a policy of promoting health -- the health of the mother first, and the health of the fetus secondly. I don't think that the interests are mutually exclusive, nor do I think that they are contradictory. I think that they are one and the same, and I think that approached properly, women will go to treatment.

Now, everybody says, "Don't you think you should have the option of punishment if the woman won't or can't?" I still want to see a woman who won't or can't being approached properly and with treatment access and availability available, and child care, and transportation, and all those obstacles that she has in the way of her participating. So, we've had, really-- The stories from the pregnant women who have been treated in our treatment programs have been just heartbreaking. I mean, these women are-- They're doing everything to turn their lives inside out to participate in this program, just like these women who were given the intervention program that is reported in JAMA. I mean, 96% of the population to participate for three years is unbelievable, in the research community. These are not women who want to damage themselves or others. I really believe that.

Now, I don't know how you put that out. I mean, you know, I don't know how you avoid this movement that people have toward wanting to punish. It goes at not understanding addiction, and it goes at wanting to take control. It's what, in the addictions field, we call society as co-dependent, when the society puts itself forth as if it were to control everything and everybody. I'm not sure.

I think if we improved services -- if we expanded services and improved cooperation among them-- I mean, it's been a nightmare to coordinate services on behalf of this little program for the two or three staff and the 10 programs that work on it. It is extremely difficult. We only recently discovered that there's a program called "Medicaid for the Unborn," which will pay for transportation for some of these women. We could have used this the last year, but we certainly will find a way to use it in the coming year.

So, I think, centralizing information about entitlements and benefits that these women have access to-- I mean, there's a lot of pregnant women not getting the food which is available to them.

MS. FRANCIS: I guess I look at it as a double-edged sword, though. When you say, "Medicaid for the Unborn," that has other implications, legally or constitutionally or whatever, that we always have to be wary of the fallout for other issues. I guess the one thing I picked up on in your recommendations was: Holding alcoholic beverage license holders responsible for serving pregnant women.

MS. FIORENTINO: Well, it's a little radical, but I'm just trying to shift the blame off of the woman. Not that I-- I shouldn't even use the term "blame," but I'm trying to have society participate. We have a societal acceptance of frequent heavy problem drinking which is extraordinarily high; it's abnormally high -- our acceptance of drinking.

MS. FRANCIS: My caveat, though, about that kind of approach, is that it makes the pregnant woman not only a unique entity there, but it's only because she's pregnant that you're saying this, and so you really are doing it in the interest of the fetus she's carrying, not her as a woman. I'd just be very cautious about recommendations like that, and I'm not sure I'd--

MS. FIORENTINO: Well, I use it in a way, the same way I use the DWI one. I don't really want to see us implement the DWI one, either. I really want us to just look at this whole situation a little more objectively. The woman is not to blame, solely. We have a network operating to hold the system--

MS. FRANCIS: You just have to watch both edges of the double-edged sword.

MS. FIORENTINO: You're right; you're right.

MS. SEHAM: I wanted to ask you for your card, because I'm involved with a women's center that has an alcoholism and drug abuse counselor, funded by the State Department of Health through the County Department of Health. I'm certainly going to turn this information over to her. I might want to call you and ask you some questions.

MS. FIORENTINO: Great, great. We are promoting program development all over. Yes, good. What county are you from?

MS. SEHAM: Bergen.

MS. FIORENTINO: Bergen? Oh, Bergen has had a very aggressive women's committee, and you're probably the leadership of it, or part of it.

MS. SEHAM: No, not I myself. Our women's center is multiservice. One advantage is that women can come in and they're not stigmatized for even coming in the door because they could be coming in for career counseling, or for any one of a number of things. Nobody points to them and says, "Ah hah, you're going in for alcoholism counseling."

MS. FIORENTINO: That's the advantage of the St. Peter's Little White House, too. It's a perinatal care center that happens to have everything available there in one place. Yes, that's true. That's a very important piece.

MS. FRANCIS: I just have one other quick question about the funding: You said the Federal funds that have the 10% set-aside now for women-- Is that the 30% of total drug directed funds that you mentioned before?

MS. FIORENTINO: That's the other thing which I gave you. Enclosed in your packet is a set of materials which is our progress report on the women's set-aside spending from last year, the 10% which was earmarked for women. It's the report on how that money was spent, and what services were provided. It starts on the bottom of the page with an Oxford House piece on top. Oxford House is the halfway house organization which is trying to get set up in New Jersey.

MS. FRANCIS: Is the implication though, then, that 90% is spent on males, or that--

MS. FIORENTINO: Well, it's general treatment and prevention, the 90% is. So, it's not--

MS. FRANCIS: Okay, it's not specifically male. Okay.

MS. FIORENTINO: --specifically and only males, but it is true that the earmark-- There would not be the women's initiatives that there have been in the last year or two without the women's earmark.

It's urgent to retain that earmark. Every year people try to eliminate it, and I think it must be retained and should be expanded, really, to a larger proportion, because all the states try to do as little as they can in that area. It's really important to have it named and pulled out separately.

MS. FRANCIS: So, you'd recommend that for any kind of initiative, probably, to make sure there's a specific--

MS. FIORENTINO: I don't think there's any other way to enforce the implementing agency agreeing with the intent of

the act. I received some calls this week and last week from Senator Bradley's office. Apparently they are trying to decide whether to reauthorize that 10%. Of course, there's a movement to not reauthorize it, and there's another movement to earmark some of the money -- the whole 10% -- for pregnant women's treatment. You know, there's such a thing about pregnant women's treatment, and of the 50 states last year, there were only four that did pregnant women's treatment out of their money. We were one of the four, so we faxed 25 pages of material for them to see what we did, because they may make the other states do like we did. However, they may equally eliminate the set-aside. They may equally mention pregnant women again, but not require a proportion of the money to go for pregnant women. So you can see of the 50 states that only four did pregnant women, when the law said that 10% is set aside for women, especially pregnant addicted women.

The law said that, but the states completely ignored it, and only four states bothered to do-- So, you've got to have those requirements. Otherwise, if the fiscal officers aren't tracking -- making the money go that way for you -- managers do whatever their system of operation is. They do more of what they always did before, whatever that was, which may be good stuff, but it's not stuff that will benefit pregnant addicted women.

MS. FRANCIS: Good point.

MS. SEHAM: But you also have to notify the women's organizations that that set-aside is there, because if they go in and demand it, and they say, "We know it's there, and we want some of it," it will make a difference. I think there has not been very good information on that.

MS. FIORENTINO: That's true. It's not widely known or understood, and in the past it was not implemented as a separate program. It really was-- All the existing treatment programs were kind of -- said, "Well, make 10% of whatever you

do be your women's effort for us, okay? Just tell us you're doing 10% of something out of what you already do." It was an awful way to do. It was how we did for several years, until it became impossible to keep defending-- The dollars became too big to keep saying we're going to be earmarking a percent of all existing contracts for women's services, so now there's a much-- Every time there is a new set-aside it goes for real women's programs. The old though, still goes the old way. It's very hard not to do that.

MS. FOX: In the old programs, is that mostly male, or is it-- What is the breakdown?

MS. FIORENTINO: Well, right now, one-third of the people in the drug treatment programs are female, and one-fourth of the people in treatment in the alcohol treatment programs are female, so it does go mostly for males, for lot's of reasons. I mean, there's lots of reasons.

MS. NEWMAN: Do the women who are in treatment programs-- Are their children removed from them when they are born, as well. I know that normally -- in many situations -- when a woman gives birth and she is addicted or is alcoholic, she faces losing her child. Do they have-- Is going into a treatment center a way of lessening that possibility? Is going into treatment--

MS. FIORENTINO: Oh, yes, definitely, but each situation is evaluated independently. That's what I said in here, I like about us in New Jersey. We don't have an automatic rule. We don't have--

Now, if we had an office on families and health and addiction, the first thing they should deal with is this, actually, because we should have reporting of drug exposed infants who are born. Those families should be investigated, and they should be offered a treatment alternative. Then there may be the placement possibility at the end of the treatment alternative process failing, but it should not be the first

wave response. It is the placement alternative, which is what it is in other states. It's not here, the first wave response. Usually-- I'm sure there are places in the State that are, you know, maybe still doing it that way, but we have a process for not having it take place that way.

MS. FOX: And in New Jersey there really isn't any kind of a movement at all which you've seen where criminal prosecution of women for--

MS. FIORENTINO: Besides this one, there is only one that I know of, that bubbled up to the point that the Commissioner was asked to take a position on it. There may have been others that were resolved at a lower level. I would expect there would have been others that were resolved at a lower level because this is a problem that people are noticing.

MS. FOX: Anyone else? (no response) Okay, thank you.

MS. FIORENTINO: Thank you.

MS. FOX: Our next speaker will be Deborah Ellis, from the New Jersey American Civil Liberties Union. She is their Legal Director.

**D E B O R A H A. E L L I S, ESQ.:** Thank you. We were told that we could testify about more than one subject, and I confined my testimony that you received a copy of to one subject. But, one of the virtues, or disadvantages of working in the ACLU, is that we're supposed to be a little bit expert about almost everything, especially because I just, prior to this job, was at the Women's Rights Project at the national office of the ACLU. I'm familiar with a lot of women's issues, and I just want to speak briefly to the last speaker's recommendation.

I thought her presentation was basically very good, but I was very, very disturbed at her recommendation, and I wanted, as a civil libertarian, to differ with it. We would, as people who are concerned about women and children, ever advocate that bar owners should be responsible for giving

drinks to pregnant women. I think the basic point about drug addiction and pregnancy is that we want, as a society, to encourage women to seek treatment. By punishing women, either by the threat of criminal prosecution or possibly by holding bar owners liable or by holding women liable for taking drinks, we would discourage what we all want, which is for women to seek prenatal care so that babies are not born addicted and that women themselves are not addicted.

There was an excellent article in "The Nation" magazine a few weeks ago -- I don't have a copy with me but I would be glad to send it to anyone -- and it was about this whole conundrum, this whole problem, and the business, the stations, and I think that the suggestion that we would hold bar owners liable for giving women a drink, or lots of drinks even, raises the specter to me of a pregnancy police. This article talks about that, about how people go up to women who are pregnant who are smoking, and say, "You shouldn't be doing that."

I think the basic point is that, women, given the resources that our society should provide for them -- which I think the last speaker detailed very well -- have a right to autonomy, and will make the best decisions for themselves and for their children.

I think her testimony was wonderful in most respects, but I thought that was a very disturbing suggestion and I just wanted to differ with it.

When I was at the ACLU Women's Rights Project in New York, one of the areas that I concentrated on was gender discrimination in insurance. Since coming to New Jersey I have continued that work, writing an amicus brief for the ACLU and other groups that challenges Blue Cross and Blue Shield's use of gender-based rates in its individual policies.

In my testimony today, I'm going to urge a simple amendment to the New Jersey statutes, since the directive that

I received said that we were supposed to think about ways to amend the statutes, since this is the Commission on Sex Discrimination in the Statutes.

I recommend that the unfair discrimination provision of the insurance law, which is New Jersey Statute Annotated, 17B:30-12, be amended to prohibit health insurance rates based on gender, as well as the prohibitions it now contains, which are discrimination based on race, creed, color, national origin, or ancestry.

My recommendation stems from the not only obvious fact that gender is missing from that list -- most of us think it should be included -- but that it is still not only possible, but common, for insurance companies to charge health insurance rates based on gender. Because women are generally charged higher rates than men for health insurance, this discrimination does severe economic harm to women. For women who are not provided health insurance by their employer -- an increasingly large segment of the population -- the resultant high premiums can put health insurance out of their reach.

Let me explain some background: Title VII of the Civil Rights Act of 1964, which prohibits all kinds of employment discrimination, also prohibits differential rates or benefits for insurance offered through employment, including pension and annuity plans. Thus, for those women and their children who are fortunate enough to have health insurance coverage through their employer, there really is no problem. However, in all other cases, insurance companies continue to charge women more for health insurance. The only exception is Blue Cross/Blue Shield, a company that is highly regulated in New Jersey and has been recently prohibited from basing rates on gender. It was actually-- Its demographic rating scheme was held to be unconstitutional, not because of the gender basis, but because it did not comport with the enabling statute, and then it submitted other rates to the Insurance Commissioner that were not demographically based.

I also want to depart from my written testimony here to mention that I think this problem is particularly acute because more and more women-- In fact, there was an article I read on the train coming down, in The Star-Ledger, about how more and more people do not have health insurance through their employers because it's so expensive.

In sum, the private insurance market is one of the only areas in American life where overt discrimination on the basis of gender is still tolerated. That this discriminatory practice is widespread does not, however, justify its perpetuation in the face of New Jersey's constitutional mandate of equality contained in Article I, paragraph 1, of the Constitution.

As I'll talk about in more detail below, other invidious classifications, such as religion and race, once widely used by insurance companies, are no longer used in recognition that such discrimination is unconstitutional and inherently unfair. For reasons both of civil rights and economic equity, the ACLU believes that gender can no more be a basis for insurance pricing than can other prohibited classifications.

When they are charged more for health insurance, women and children in the ever-growing number of female-headed households suffer adverse health consequences. Concentrated in low-wage, part-time, and small business jobs, women are less likely than men to receive insurance benefits as employees, and are left with purchasing health insurance on the individual insurance market. The higher health insurance rates women face lead them to purchase less comprehensive coverage or no insurance at all. This absence of affordable insurance coverage in turn reduces access to health care to the detriment of women and their children. These effects are particularly severe for women and children of color. For example, African-American women in employed families are far less likely than their white counterparts to be insured.

Although it is true that insurance companies group people for risk classification, it is also true that any individual can be grouped according to several characteristics for health insurance: religion, race, gender, ethnicity, age, residence, smoking, alcohol use, weight, hazardous work and hobbies, medical history, and diet and exercise, and that many, if not all of these groupings might be useful tools to predict accurately the risk of anticipated loss. However, when insurers classify by the prohibited classifications of race, religion, ethnicity, or gender, they run afoul of New Jersey's constitutional commitment to treat people as individuals, not as members of racial, religious, sexual, or ethnic groups.

The same justification that is now offered to explain gender classifications -- actuarial relationship of the classification to the risk of loss -- was once a rationale accepted for charging differential rates based on other prohibited characteristics, such as race and religion, even though risk classifications based on religion or race are now rejected as unconstitutional and contrary to public policy.

Moreover, the statistical arguments that are now advanced to justify gender-based rates are identical to those advanced in the past to validate rates based on religion or race, and are equally unconstitutional.

Although statistical differences between racial and religious groups still exist, especially in the area of health and life insurance, today insurance companies properly do not use race or religion as a classification characteristic. Thus, stripped of the aura of mystery surrounding statistics and actuarial tables, the industry's use of gender as a proxy for other characteristics is most aptly described as an administratively convenient generalization.

George Santayana said, "Those who do not learn from the past are condemned to repeat it." In that context, I think it is important to note that historically, the rating and

classification practices of the insurance industry have been in tension with the ideals of equality for which America strives.

In the 1870s the first insurance offered to freed African-American citizens was offered at the same rates as to white customers. By 1881, however, enterprising insurance companies found that mortality differences made it administratively convenient to charge higher rates for African-American customers. Some companies started to apply higher premium schedules for African-Americans than for white customers, charging African-American customers one-third more, or providing one-third less insurance for the same premium than for whites. Other companies stopped writing insurance on African-Americans entirely, or denied commissions to agents who sold policies to African-American customers.

Massachusetts was the first state to outlaw these practices. In 1884, led by an African-American legislator, it passed a law forbidding the charging of higher premiums to African-American citizens than to white citizens. Despite protests by insurance companies -- some companies entirely refused to do business with African-American customers, leading to the rise of insurance companies owned by African-Americans -- a few other states, including New Jersey in 1902, soon followed Massachusetts' lead, although most states continued to allow companies to charge higher rates to African-Americans.

I'd like to point out, too, that the statute that I'm recommending that we amend to include gender, is derived from that original 1902 statute.

As late as 1961, insurance texts justified race-based rates as rational discrimination contending that, "There is no more social discrimination involved in setting a different rate for a race which shows a higher average mortality than there is in setting a different rate for any other statistical reason."

Insurance companies have also used religious characterizations to set rates. As recently as 1954, Harry

Dingman, the Vice President of Continental Assurance Company, combined statistical knowledge with stereotypical assumptions to advise insurers:

"Jew tenacity of life is notorious-- Despite urban crowding, tuberculosis and other infections, disease has taken less toll of Jews than non-Jews. Now that urban living has proved superior to rural in longevity, the Jew is a better life risk than heretofore. He drinks less than the non-Jew. He has syphilis less often. He eats too much, with higher than average incidence of obesity and diabetes-- For life insurance, Jews are excellent risks-- For disability insurance, Jews are expensive."

When charged with discriminating on the basis of race and religion, insurance companies, as they do today to defend rates based on gender, argued that it would bankrupt the industry to prohibit such classifications. For example, in 1900, after the first antidiscrimination laws were passed, a statistician for the Prudential Insurance Company fulminated that race discrimination laws were motivated by "sentimental considerations" and "in defiance of the laws of mortality and ordinary business conduct."

Although, like gender-based rates, the industry defended the race-based rates as necessary for its financial well-being, in fact, no economic dislocations occurred in insurance markets following the introduction of nondiscriminatory rating practices.

The use of rates based on race and religion declined in the 1960s. In the wake of the civil rights movement, insurance companies realized that if they did not voluntarily desist from such practices, Congress inevitably would enact legislation prohibiting them from charging differential rates. Because the transition was voluntary, it was not monitored by any Federal agency or State commissioners. In fact, although it was widely believed that insurance companies had completely

stopped using race and religion in insurance rate making, a recent survey by the National Association of Insurance Commissioners in 1988 revealed that some companies continued to charge higher rates to African-Americans on whole life policies sold some years ago.

NAIC immediately condemned the practice as, "inherently unfair and unacceptable as a matter of public policy." I have to say that at that time, when NAIC issued that resolution, I wrote them a letter and sent them a copy of the resolution inserting "sex" everywhere where "race" was and suggesting they adopt a similar resolution, but I never received a response.

As with the history of race discrimination in insurance, today legislatures, insurance commissioners, and courts are gradually recognizing that gender-based insurance rates are also invidious in a nation committed to equality.

In 1985, Montana became the first state to bar gender in all forms of insurance. In 1987, Massachusetts became the first state to ban, administratively, gender discrimination in all forms of insurance. Following the decision in Bartholomew v. Foster, a case which I litigated, the Pennsylvania Insurance Commissioner proposed regulations banning gender discrimination in all forms of state-approved insurance. It's my understanding that those regulations have been vehemently opposed by the insurance industry, and have not yet been finally adopted.

The New Jersey Legislature expressed its disapproval of religious and racial classifications long ago, as I mentioned before, and the inherent unfairness of gender-based rates led a previous New Jersey Insurance Commissioner, in 1981, to recommend that they not be used for auto insurance.

In March, Judge Sylvia Pressler, of the Appellate Division, invalidated the demographic rating system used by Blue Cross. In that case, although she did not reach the issue

presented by the ACLU-NJ and other groups that gender-based rates violate the Constitution, she suggested that the Legislature might opt to delete gender rating in the future, either -- and here I quote from her opinion -- "as a matter of constitutional proscription or public policy."

When New Jersey adopted a new Constitution in 1947, the only change was that the word "persons" was substituted for "men," as Roberta Francis well knows. The legislative history demonstrates that this change was intended to guarantee full equality for women. For example, Governor Alfred Driscoll made specific references to the equality issue in his closing remarks to the Constitutional Convention:

"I, for one, do not presume to review the choices you have made in free and open convention. Who is to say that the law -- which (was) fixed by -- the Bill of Rights since 1844 is any more fundamental in character than the (new) law of taxation, or of labor relations, or than of equal rights for women?"

In the seminal case of Peper v. Princeton University Board of Trustees, the New Jersey Supreme Court affirmed that that change from "men" to "persons" in the 1947 Constitution granted women "rights of employment and property protection equal to those enjoyed by men."

Integrating New Jersey's strong commitment to gender equality with insurance case law and policy from other jurisdictions compels the conclusion that charging women more for health insurance cannot be reconciled with Article I, Paragraph 1 of the New Jersey Constitution, especially because, "New Jersey accords a high priority to the preservation of health," and there I quote from the Right to Choose v. Byrne case.

Although it may be administratively convenient for insurance companies to use gender-based classifications as a proxy for individual characteristics, administrative

convenience never justifies discrimination. Arguments from administrative convenience are nothing new and are not confined to insurance. Employers also once engaged in the same sort of invidious but convenient discrimination in selecting their work force; for example, hiring only men for jobs which required physical strength, despite the fact that many individual women could perform the work equally well.

In Peper, the Supreme Court of New Jersey held that "sex based presumptions," could not be used to deny women employment rights. Neither can such sex-based presumptions be used to "jeopardize the health of poor women."

It is time to demand equality in the insurance market so that gender stereotyping can be eliminated from insurance, together with the attendant economic harm to individual women and their children that it causes.

I urge the Commission to rectify the omission of gender in the New Jersey prohibition on insurance discrimination by adding "gender" to the list of prohibited discriminations in the statute.

Thank you for the opportunity to testify here today.

MS. SEHAM: Thank you very much for your testimony. It's very gratifying. I've been looking for a word other than "seminal" to use for an important case.

MS. ELLIS: That's a good idea. I'm sorry.

MS. SEHAM: If you come up with one, please tell me.

MS. ELLIS: Noteworthy?

MS. SEHAM: Ovarian doesn't quite do it.

MS. ELLIS: Good point.

MS. FRANCIS: Deb knows I could not resist commenting, because I was in contact with her when the ACLU filed the suit -- what, three or four months ago? -- with Blue Cross/Blue Shield, because my background has been an interest in affirming that New Jersey's Constitution actually does have an equal rights guarantee. We have it half affirmed, sort of, through

Peper v. Princeton, and the legislative history of adopting the Constitution in '47, but my sense would be that an issue like this, if it did get through the court process, would perhaps affirm, across-the-board, that we have that.

In the context of not then having to pass an equal rights amendment to the State Constitution because the Constitution itself affirms it, which leads to my question-- Do you-- I mean, we can't prove this 100%, but wouldn't you say that if, in fact, that equal rights guarantee does exist in our Constitution, that the law as it stands now is unconstitutional, because it does not say gender, and that we really would have extremely good leverage to convince the Legislature that they better put gender in, because the law is really unconstitutional without it? Could you just comment on that?

MS. ELLIS: I think you would. I have litigated-- I did the case of Bartolomew v. Foster in Pennsylvania, and basically in all the states that have either attempted to change through litigation or through introducing amendments to the statutes or regulations, there have been equal rights amendments. Unfortunately, the way the Federal Constitution has been interpreted, most people think it may not give enough protection to ban insurance discrimination, which has a statistical validity. But the higher level scrutiny under an equal rights amendment would, and I would agree with you, having done a lot of detailed analysis of the New Jersey cases, both before and after Peper, that I think we do have an equal rights amendment, and I think the provision is unconstitutional.

The reason that I think the equal rights amendment has not been more developed in New Jersey is really, from a lawyer's point of view, just that there's not been a need for it because we have good employment discrimination laws where most discrimination certainly does really occur. Boy, the ACLU certainly gets-- The majority of our calls are about

employment discrimination. There are both Federal and State laws about that, and New Jersey has a good law against discrimination which applies to public accommodations and other things, so that, I just think it hasn't really come up, and that this is one of the only instances where we actually may need to use that argument.

The court, as I said, in the Blue Cross/Blue Shield case, did not reach the constitutional argument about gender. However, Judge Pressler -- who I have to say is a wonderful judge for women-- It was really-- There was a wonderful interchange between her and the lawyer for Blue Cross/Blue Shield at the oral argument, where she said to him, "Well, wouldn't it be true, though, that you would just find it unthinkable to set rates based on race?" He said, "But, Your Honor, we have a statute in New Jersey that prohibits race discrimination." She said, "I don't care if you don't have a statute. Still, it would be just unthinkable, wouldn't it?" And he said, "Well, Your Honor, gender has never received the same constitutional protection as race." And she said, "Maybe not until now it hasn't."

I thought that was a good sign, and it certainly gave us a couple of good little suggestions in the opinion that they agreed with our argument, even though they didn't reach it.

MS. FRANCIS: Well, this is a kind of corollary question, but, are there states in which-- I know some years ago New Jersey's Insurance Commissioner -- outgoing, I guess, Sheeran -- had put forth an whatever you would call it, an edict, that auto insurance rates be gender neutral. That never got through before he was out, and it never was pursued. Could you picture pursuing this point through an insurance commissioner's dictum -- whatever you would call it -- as opposed to doing it-- Or is it more important to do it legislatively, to have it on the books that way?

MS. ELLIS: It think it really-- There are various considerations. I think it would be better to have it on the books, I guess, because I think that, as you said, the statute itself is, on its face, discriminatory, because it doesn't include sex. I mean, that's the basic list of prohibited classifications, and really, I think, gender should be in there.

I think that would be better from a public policy point of view, and then I guess it depends on tactical considerations. But I also think that when an insurance commissioner does something on his own, he is more subject to attack as that action being beyond his authority, than if it's done by the Legislature.

Both in Massachusetts, where they enacted a regulation, and in Pennsylvania, where the insurance commissioner, a woman, decided to just issue an edict, basically, they were subject to fierce challenge. In Massachusetts, ultimately, it was upheld, but I think it was more because the insurance companies didn't attack it as vociferously because they were worried about an AIDS regulation that had been passed at the same time and they concentrated their resources on that. I guess I think it would be better to do it through a statute.

I also want to mention that Governor Florio's plan for auto insurance that was recently enacted does ban gender discrimination in auto insurance, so that particular piece-- Of course, auto insurance is the one that benefits women in any case, but that's what's taken care of.

Although, I should say, we do believe that overall if auto insurance was priced, probably, the way it should be priced, which is based on mileage, women would benefit over the course of their entire lives, because really, the reason young women get a break is because they drive less miles than men. But women drive less miles, of course, across their entire lives than men do.

MS. NEWMAN: Unless they're commuters.

MS. ELLIS: A lot of men are commuters, too, though. But on the average, all this is generalization, so-- Of course, Allstate has attacked Governor Florio's plan for many reasons. They filed a lawsuit attacking it on many grounds. One of them is that ground, and I don't know the current status of that lawsuit.

MS. FOX: Anybody else? (no response) Thank you.

MS. ELLIS: Thank you very much. I appreciate your attention.

MS. FOX: Our next speaker is Linda Bowker, who is President of New Jersey National Organization for Women.

Nice to see you.

L I N D A B O W K E R: Nice to see all of you.

MS. FOX: You look chipper.

MS. BOWKER: Well, well rested. I want to make a disclaimer before my testimony. I do not know how to pronounce medical terms, have never claimed to be able to pronounce them, so as I fall all over them, you'll understand.

My name is Linda Bowker. I am the President of the New Jersey Chapter of the National Organization for Women. I am also testifying on behalf of The Fund for the Feminist Majority.

One of our highest priorities involving women's health is the availability of the French drug, RU486, which has a medical name that I don't know how to pronounce.

RU486 is manufactured by the French firm Roussel-Uclaf. The drug works as an anti-progestin. The hormone progesterone is essential for sustaining a pregnancy. By binding to receptors that normally accept progesterone, RU486 blocks the pregnancy-sustaining effects of that hormone.

RU486 is administered under medical supervision. A woman first takes a 600 mg dose of the drug in the form of three pills. Two days later she takes a prostaglandin, a drug

that facilitates uterine expulsion by inducing contractions. A final checkup occurs one week later to ensure complete termination of the pregnancy.

A March 1990 "New England Journal of Medicine" article concludes that RU486 is "an effective and safe method for early termination of pregnancy." Combined with prostaglandins, RU486 has a 96% success rate during the first 49 days of pregnancy. Unlike vacuum aspiration abortions, the procedure is noninvasive, eliminating the risk of infection, and does not require anesthesia.

Dr. Etienne Baulieu, a French scientist, developed the RU486 drug in 1982. This work has won him the 1989 Lasker Award, one of the most prestigious medical research prizes.

Over 40,000 Frenchwomen have taken RU486. In fact, RU486 accounts for at least one out of every four abortions in France today.

As an anti-progestin or as an anti-glucocorticoid, RU486 has been, or is being tested to treat the following:

Breast cancer: which strikes one out of every ten women. In clinical trials, RU486 has effectively slowed growth of certain types of tumors.

Meningioma: a benign but possibly fatal brain tumor. RU486 might be able to control or reduce the growth of these tumors.

Endometriosis: the abnormal growth of endometrial tissue. This extremely painful disease is one of the leading causes of infertility in women. Recent studies have been promising.

Cushing's syndrome: an adrenal cancer causing a dangerous overproduction of cortisol. Clinical tests have shown that RU486 can block the effects of the excessive cortisol.

Caesarian sections: RU486 may be effective in inducing labor in difficult pregnancies.

Burns and skin abrasions: applied topically, RU486 may expedite the healing process.

Today, we propose that New Jersey use its independent power to test and license drugs to begin clinical testing of RU486.

California took this step, very successfully, with AIDS drugs. Three years ago the FDA was frustrating the development of AIDS drugs. Legislation in California set up an independent, streamlined state program for testing and licensing AIDS drugs. As a result, seven experimental AIDS drugs are now being tested in California.

Virtually all new drugs approved for use in this country go through the FDA approval process. But that is not the only way. New Jersey can, and must follow California in exercising the independent legal right to test and license drugs for use within the State. The threat of competition may very well help convince the FDA to do its job.

This action is particularly fitting for New Jersey since Hoechst-Roussel, located in New Jersey, is an affiliate of Roussel-Uclaf, the French firm which developed RU486.

Abortion is a personal decision for each woman. RU486 is the moral property of women. No woman should have to run a gauntlet of obnoxious, harassing pickets in order to exercise her right to have an abortion or other medical treatment. RU486 can help remove abortion from the streets and the evening news and put the issue of abortion into the realm of a personal, private decision, where it belongs.

Thank you.

MS. FOX: Questions?

MS. FRANCIS: Let me clarify the recommendation, Linda, which is that: New Jersey, for the first time, declare that it is going to test and license drugs as a State, rather than simply permitting the sale of drugs that have been licensed by the Federal FDA?

MS. BOWKER: That's right.

MS. FRANCIS: And there's been no other recommendation before to do this with any other, like, AIDS drugs, in New Jersey, or anything?

MS. BOWKER: Not in New Jersey. The only -- and I have the legislation-- I didn't bring it, but, it would probably be helpful if-- I will forward the California legislation to you.

It could-- This is a first use, of course, and I believe a very important use, but the FDA is becoming more and more a political tool, and if more states did what California has done, it would help move the FDA, I believe, away from being used as a political tool.

MS. SAMPIERI: We heard earlier testimony about the minimal testing of AIDS drugs on women to see what the effect had been. Can you see that making a proposal like this might also open up testing of AIDS drugs on women?

MS. BOWKER: Absolutely, absolutely. AIDS drugs in general, and I would like to see it specifically for women.

And it's not only AIDS. Women are ignored in medical testing across-the-board, and if this country continues to ignore women, New Jersey could be a leader in medical research that does deal with women.

MS. FRANCIS: To come at it from the other direction: Is there any other history of another drug, the way there is with RU486, that has put limits on the development of it for nonmedical reasons? Did I ask that right?

MS. BOWKER: I know what you mean.

MS. FRANCIS: Is RU486 the only drug we know of that has had political decisions stopping the development of it?

MS. BOWKER: The AIDS drugs-- I mean, I believe that was political.

MS. FRANCIS: Okay, yeah. I shouldn't have even asked it like that, because of course, the AIDS drugs-- But, I mean, other ones that are specifically connected with the abortion issue, let's say.

MS. BOWKER: I'm not aware of any others, but there may be.

MS. NEWMAN: I take it these medical tests for breast cancer and endometriosis and etc., they're all being done in Europe?

MS. BOWKER: Yes.

MS. FOX: How long has this drug been available in France for normal use?

MS. BOWKER: Forever, I gather. I mean, it's very commonplace, one in four. There was a program on TV that actually showed -- I think it was "The Reporters" -- where a woman went with a woman who went through the whole process, and it makes it so much more civil. It really puts the entire process in focus, that it is a medical procedure. You know, you're going to a doctor's office; you're getting a medication; and then you're going home; the same as you would in many, many medical procedures. It takes it out of the emotional arena, where it doesn't belong.

MS. NEWMAN: So the types of complications that arise in other methods, you don't have with this?

MS. BOWKER: Actually there really aren't that-- Medical problems as a result of abortion are not the reason that there is objection to abortion. It's so safe.

MS. NEWMAN: But I'm just looking at the safety factor as another great selling point for RU486.

MS. BOWKER: Because you don't have to-- It's not invasive. You don't have the same worry of infection that you would with vacuum aspiration, or D&C, or any other methods.

MS. FRANCIS: I think I want to refine the question I asked about political decisions, because I guess my point basically was: This is a drug that has uses for treatments other than for abortion, and yet it's being stopped because of the one case in which it can be used that has political ramifications. Do you know of any other drugs that might be

abortifacient if used, but also are used for other diseases? You know, drugs that are primarily used for treatment of other things--

MS. BOWKER: Yeah, I know what you mean.

MS. FRANCIS: --but that would cause abortion if given to a pregnant woman -- that are now being used?

MS. BOWKER: I could see a scenario, where if our opponents were following this same strategy, we might not, at this point, have the low estrogen birth control pill, because that-- The birth control pill was actually developed to control women's menstruation, so they would have regular periods. So I can see, if people had been as fanatical at that point in history, we may not even have the birth control pill. As a matter of fact, we have far fewer methods of birth control in the United States than they have in Europe.

Our health is being seriously impaired by fanaticism, because an abortion is far safer than actually carrying a pregnancy to term. For many women -- maybe not many; many may be an exaggeration -- but for some women, carrying a pregnancy to term equates to death. And to deny women a safe, easy, method to terminate that pregnancy, I believe, is criminal.

MS. FOX: Actually, Linda, if you knew of some other drug that would act as abortively, you wouldn't tell us here in public, would you?

MS. FRANCIS: I realized after I asked that question-- If it existed, it would be in the headlines along with RU486.

MS. FOX: We keep these things secret.

Any other questions?

MS. SEHAM: I have something I still need that I forgot to ask Deborah.

MS. ELLIS: I'm still here.

MS. SEHAM: I know you are. Would you send us a copy of "The Nation" magazine article?

MS. ELLIS: Sure.

MS. SEHAM: Thank you. Just send us one copy, and we'll copy the copy.

MS. BOWKER: I wanted to make one comment on Deborah Ellis' testimony, where she said that women drive fewer miles: Except if you live in South Jersey, and then you drive many, many, many more miles, and the people here from South Jersey can understand that.

MS. NEWMAN: Not to mention those of us from North Jersey.

MS. FOX: Thanks Linda.

MS. BOWKER: Thank you very much.

MS. FOX: We'll have a break until 3:00.

(RECESS)

AFTER RECESS:

MS. FOX: The next speaker is Kay Pinneo, from the Family Planning Association.

KATHARINE S. PINNEO: Thank you. Good afternoon, friends. I'd like to ask a colleague of mine to join me, if I may?

MS. FOX: Could you introduce him, though, Kay?

MS. PINNEO: Oh, absolutely. Do you need anything special on the record of who I am and--

I'm Katharine Pinneo, the Executive Director of the Family Planning Association of New Jersey, and I'd like to introduce my colleague, Robert Quinn-O'Connor, who is the Director of the AIDS Services Expansion Program, which is a program of the Association which has been helping our agencies -- or the member agencies of the Association -- to enter into a testing and counseling process for women at risk of HIV.

Let me read from the prepared text, if I may:

I'm here this afternoon to present testimony on behalf of the Family Planning Association of New Jersey, a reproductive health organization.

The Association is a private, nonprofit, professional organization whose members are the 20 publicly subsidized programs in New Jersey providing family planning and prenatal care to low-income, at-risk women and teens. The seven Planned Parenthood agencies in the State are all members of the Association. In addition, we have a group of member agencies providing abortion services.

The goals of the Association are: To enable our member agencies to provide preventive reproductive health care -- blood pressure screening, early prenatal visits, breast exams, Pap tests, contraceptives, and reproductive health education -- and to ensure that these services are readily available to all low- and marginal-income women and men.

In addition, to ensure that all New Jerseyans continue to have the right to choose; continue to have access to safe and legal abortions; continue to have the right to contraception; and to continue to have the right and the responsibility to education about family life matters, including sex education.

And finally, to enable our members to deliver these services at reasonable cost.

Our areas of concern which we want to share with you are, first of all:

The need to protect New Jersey teenaged women from harmful parental notification. We're particularly sensitive about this today after the Supreme Court handed down its alarming and insensitive decision yesterday.

The need to protect New Jersey women's constitutional right to access to a facility to terminate a pregnancy.

The need to guarantee universal access for all New Jersey women to quality, community-based, cost-effective family

planning and reproductive health and education services, regardless of their location, race, age, income, marital status -- and of concern are:

- \* those women under- or unserved;
- \* those women in prison;
- \* those women with communicable diseases and women with the Human Immunodeficiency Virus; and
- \* women developmentally impaired.

Finally, the need to stop discrimination against HIV positive women, and women with AIDS.

Let me expand on these areas of concern: First of all, the need to protect New Jersey teenaged women from harmful parental notification required prior to pregnancy termination. Again, as I indicated in my table of contents, we're particularly sensitive to this one today.

Fortunately, New Jersey law does not discriminate between pregnant minors seeking abortion and those wishing to carry the pregnancy to term in our law giving pregnant minors the right to consent to their own medical treatment. We urge New Jersey legislators not to rush to change this law. The record in other states with such laws -- in other words, harmful requirements -- shows the real results are higher teen birth rates and more teens going out-of-state for abortions, not reduced teen sexual activity.

In addition, more high risk, late abortions to teens, not better protection for their health, and finally, despite desperate teens facing an intimidating, overburdened court system, not more teen-parent communication.

Let me, again, digress from my written testimony. It is estimated that under the Ohio decision -- the decision relating to the Ohio case that came before the Supreme Court -- that there is the possibility of at least a 22-day waiting period, in order to get a judge to come to a determination. This is irresponsible of us as a society to allow this to happen, and in New Jersey we don't have to. We are fortunate.

Then, let me go on to item number two: New Jersey women are being discriminated against because their access to abortion facilities is blocked by antiabortion extremists.

Last week, Dr. Kathleen Ruben and Lucile Pfleeger graphically testified before you describing the extremes to which antiabortion groups are going to prevent women in this State from exercising their constitutional right to choose an abortion. This problem in New Jersey is exacerbated by our wonderful patchwork of small municipalities -- they are wonderful in many ways, but also on the flip side, this has some problems -- few of which have the capacity to deal with clinic blockades on the scale we've seen them in New Jersey. A strong State role in law enforcement is needed.

A bill has been introduced in the Assembly by a member of this Commission, Assemblyman Neil Cohen. It is similar to that passed in Maryland last year making blocking access or leaving a health facility a state crime. Although we have not seen the wording of this particular bill, we believe that such a law would be of great help in New Jersey. Our trespassing laws do not seem to be adequate to deal with the situation.

We cannot continue to expose women at this very vulnerable time in their lives to the outrageous behavior of extremists because local police are overwhelmed, municipal budgets can't meet the expense of continually calling in other towns' police help, the local jail is overcrowded, or the health care facility can't afford the legal fees required to obtain an injunction or to assist in the prosecution of those who are out to shut the facilities down.

Our third issue: The need to guarantee universal access for all New Jersey women to quality, community-based, cost-effective, and confidential family planning, prenatal and reproductive health services, and education regardless of location of where they live, race, age, income, or marital status.

Two-thirds of New Jersey women at or below 150% of the poverty level. That's \$19,500 for a family of four -- poverty level being \$12,700 for a family of four. Two-thirds of New Jersey women below this level did not have access to publicly subsidized family planning services last year. I think if you're looking for an example of discrimination, that's a fairly significant one.

The member agencies of the Family Planning Association make available quality, affordable, and accessible reproductive health care primarily to low- and marginal-income women and men. Last year, this network of community-based, licensed ambulatory care clinics provided medical contraceptive services to well over 109,000 citizens. We estimate, however, that approximately 180,000 women, teens, and families are, and were, still without services. An expanded and more secure funding system would enable the providers to reach the large and ever-increasing number of citizens without access.

Let me say that a number of studies have been done in our agencies, and for many a woman -- and this study was done, for instance, in Newark -- this is her only access into the health care system. She is above Medicaid eligibility and has no insurance, if you will. In addition, she sees this as her primary health care provider. In addition to reproductive health we deal with blood tests, sickle-cell anemia, obviously the whole matter of HIV, general health, high blood pressure, etc., and women with identified problems are then sent on for specialized care.

Let me go back again. By focusing reproductive health care on preventive measures, two interests are served: First, publicly subsidized family planning providers help people take control of their lives; second, the taxpayers save money. I call your attention to the cost of an unintended pregnancy versus the average annual cost of providing medical contraceptive services. The former is \$38,700, versus \$135.

Another major issue, again here in the area of access, is health care for pregnant inmates. Our agencies are sometimes called in by the prison system to provide counseling for women in jail who are pregnant. At such a time, prompt access to counseling and medical care about pregnancy options is essential. Whether the woman's choice be to continue the pregnancy, or have an abortion, there is the vital need to protect the woman's health and that of any child subsequently born.

A 1988 rule by the U.S. Third Circuit Court, subsequently upheld by the U.S. Supreme Court, found that local, county, or state prisons had to allow a pregnant inmate to obtain an abortion if she chose, even an elective, nontherapeutic one, and that the local, county, or state administering the prison had to pay if alternative means were not available. Despite this ruling, there is reason to believe that prompt access to such care is not as available as we would like.

Recently, one of our member agencies was called in by the State prison system to counsel a pregnant inmate so advanced in pregnancy that she was nearly past the time when any physician or health facility in the State would provide the abortion she thought she wanted. This was entirely due to the fact that although she had been sentenced to serve time in State prison, she had been held in a county facility until space opened up in the State facility. No counseling was offered her in the county facility, even though she knew herself to be pregnant.

Several years ago, a bill prepared by this Commission which would have insured prompt medical care for women in prison, particularly those found to be pregnant-- Sorry, a bill was prepared. Although we could not support it in its entirety as it was originally drafted, amendments were prepared that would insure this sort of situation not happening. I

think it's time we take a look at that bill again. This was a bill co-sponsored by Senators DiFrancesco and Lipman.

We would like to tell you about the discrimination that women experience as consumers of health care services when they have, or are perceived to have Human Immunodeficiency Virus -- HIV -- and Acquired Immune Deficiency Syndrome -- AIDS. Some of this discrimination occurs just in women's attempts to be acknowledged as people who can get this disease.

Since 1981, when AIDS was first named, it has been perceived as a disease of men, initially gay men, and later intravenous drug-using men. Our outreach and education programs, our prevention and technological components, our medical and social responses have all been geared towards stopping the spread of the disease among men, and later babies.

Until recently the only times women have been discussed in this disease has been as vectors of infection; as mothers giving HIV to their fetuses and babies; and as sex industry workers giving it to their clients, and hence introducing it into the mainstream heterosexual population. These designations of women as transmission routes rather than people experiencing HIV disease and AIDS, have left women who do experience the disease feeling incredibly isolated, self-blaming, worthless, angry, and skeptical of the health care and social service systems.

Women are discriminated against:

- \* by the Centers for Disease Control -- CDC -- classification of opportunistic infections for HIV and AIDS that do not include some of the early manifestations of HIV in women and the gynecologic infections that women get with AIDS;

- \* by the lack of funding for education and prevention programs that target women -- there has been some money that was earmarked in this area, but it is being continually cut back -- that are sensitive to their needs, and that circumvent the problems women have in accessing information for their own health care;

\* by the small number of studies that have been done to gauge the epidemic in women. We have studies of neonates, men in emergency rooms, intravenous drug users in treatment -- which are mostly male -- men in bathhouses, military recruits, and the list goes on and on, but few studies of women;

\* by a lack of funding for, and education of all health care practitioners in the presenting symptoms of HIV infection in women. These symptoms, subtly different from those in men, are early markers of infection in women, and their detection can make the difference in diagnosis, treatment, and hence, life enhancement;

\* by a lack of access to drug trials and protocols for experimental lifesaving or life-extending treatments simply because they are women, or more likely, because they are women in their childbearing years. This obsession with women's childbearing capacity being more important than their own lives has continued. Women are delayed in getting access to treatment because drug trials are first okayed by men and then the results must be adapted to women;

\* by the even more restrictive rules for the entry into protocols if a woman is pregnant. She is often denied access to all drugs and medication, even those already available and proven effective. The fetus is considered more important than the living woman.

\* finally, by the small number of HIV testing and counseling sites with counselors who are knowledgeable of, and sensitive to women's histories, needs, and concerns, and places where women feel safe and protected.

We would like to take just a few minutes more and recount some specific examples, but let me go on and say, as well, we have also been told by women of specific examples of gynecologists, obstetricians, and dentists who refused to see them because they were HIV positive or had AIDS. In some cases

the women were tested for HIV without giving their permission and were given the results without being counseled or getting referrals.

We would like to give you a case example: Karen is a 32-year-old white woman living in northern New Jersey. She has a 10-year-old son and had worked for 10 years as a senior chemical operator for a major firm in New Jersey. She was laid off from her job, and after going back to school, took another job as a computer operator. Karen discovered by accident that she was HIV positive several years ago after she heard that a former partner had died of AIDS.

Karen immediately felt that she had to know her own status. Once she knew she was HIV positive, Karen felt no need to lie or hide her condition. She was unaware of the strong stigma attached to being HIV positive, much as she had been unaware she was at risk of contracting the disease. There were no education programs in the mid 1980s warning women that they should protect themselves.

After telling her employer of her status, she was demoted several times, finally ending up as a low-paying correspondence clerk. She was in no way unable to do the job she was originally hired for. Her employer told three co-workers who told others that she had AIDS. This was not only illegal, unethical, and immoral, it was also incorrect; she was HIV positive. One co-worker quit, others became over solicitous. It became unbearable for Karen to continue to work there because everyone knew her status and treated her differently. She went out on disability and had to move from a beautiful home to a one-bedroom apartment.

Karen can now no longer work because of the medical complication of HIV disease, yet she has been denied Supplemental Social Security because she isn't totally disabled. She is a single parent trying to survive on \$232 a month plus food stamps.

Karen had been going to the same gynecologist for years. She told her friends how caring, gentle, and sensitive he was. Yet when she told him she was HIV positive, he refused to see her anymore. He made it seem that this was so because she was late with a \$40 bill. Karen was confused and angry. Wasn't she supposed to tell him that she was HIV positive? Karen was sure she was.

Later Karen went to see her dentist, and once in the dental chair she told her dentist she was HIV positive. Her dentist put on two pair of gloves before he came near her again. Then he just touched the tooth that was already loose and ready to come out, and said, "Yes, it has to come out, but we don't do that here. You'll have to go to a clinic that pulls teeth or sees HIV positive people."

Karen had never heard of a dentist that didn't pull teeth. She called other dentists for appointments and again told them she was HIV positive. Dentist after dentist discriminated against Karen by: 1) not calling back; 2) offering excuses of being booked ahead for months; 3) simply telling her they had all the patients they could handle, or telling her they didn't see HIV positive patients.

The same was also true of general practitioners. One doctor called Karen a liar when she told him she was infected. He insisted she must be one of those drug addicts, because women don't get AIDS from sex. The feeling of rejection that accompanied these attempts at basic health care made Karen hold off on seeking further care. She reports feeling worthless, dirty, angry, but impotent and ashamed.

Karen finally received gynecological care at the HIV clinic at UMDNJ, but it was a year later and some complications had now set in because of the delay. When she again tried to obtain dental care she ended up needing four teeth removed and gum work because of the delay. One dentist finally agreed to see her and Karen entered a hospital for dental surgery. While

her surgery went okay, Karen had a lot of bleeding afterwards and was repeatedly sick. She was left for long periods of time without attention in the recovery room, bleeding all over herself and throwing up into pails that were already full. She repeatedly called for assistance but only twice did someone come and help her. One nurse who came to check on Karen put a rubber glove on the end of her stethoscope before putting it on Karen's arm to check her blood pressure.

Throughout all of this Karen has had to live with the realization that unless there is a cure found for the virus, she will never again be able to have a child. Since she was a young girl Karen had dreamed of having a large family.

Karen is still living with HIV and plans to go on living. She has created a warm, loving, honest home for her son and herself where her diagnosis is talked about openly, and where her son has chosen to become a 10-year-old advocate for the rights of HIV positive people.

He has had to endure the subtle insults and outright anger that comes from others' inability to accept his mother's refusal to live secretly with HIV. He has also found friends who understand and support him.

Karen has also spoken out about her infection in hopes of protecting and warning other women. She is a buddy to someone with AIDS. When her strength allows, Karen plans to visit a home for HIV positive babies, and currently represents HIV positive women on a statewide committee trying to educate professionals and women to the issues around women and AIDS. She has not been silenced. Karen is a woman living with the HIV disease.

Let me just conclude on this and say this is a long laundry list. I think what you are doing and the task that you have undertaken is momentous. You are to be congratulated for it. Women are discriminated against in the delivery of health

care because of lack of funds, because of over legislation, and because of ignorance. We needn't let that continue in the State of New Jersey.

We also, particularly related to yesterday's activities, are fortunate, and we need to insure for our youth, that we will not set up a system which will discriminate with them and worsen their situations and their lives.

I would like to thank my colleague, Robert Quinn-O'Connor, who put together the last part of our testimony. I think it is extremely good, and I appreciate his working with me on this.

We would be delighted to answer any questions you may have. I notice that Ann Levine, also a colleague many of you know, is here, and the three of us would be delighted to answer, or attempt to answer any questions, or comment on anything that you have.

Thank you very much. I appreciate this opportunity, on behalf of the providers and all the women of New Jersey.

MS. FOX: I have a question: When you say that 150% of the women below poverty level did not have access, is that saying that it wasn't accessible, or is that saying that they didn't know about it and didn't show up?

MS. PINNEO: It's a mix of things. Part of it has to do with the fact that services need to be delivered in readily accessible locations, for instance, or that there need to be more clinics. Down in Gloucester County, I believe, where we have the highest teen pregnancy rate of the State, there is a six-week waiting period for new patients. So that--

There are dramatic kinds of things, so we're talking about the number of hours that services are delivered, the number of sites that services are delivered at, and the number of people who are able to deliver these services.

It also has to do with-- You talked about not knowing about these services. It has to do with outreach. There are

not that many people available in the individual agencies to go out and do the outreach that is critical, whether we're talking to the Latino community, the black community, any of the individually discreet communities, or this, the community at large.

In addition, the whole matter of networking that our agencies do in terms of their ability to refer has constantly to be worked on, and that's part of it, too. So, it's a long, long answer.

MS. FOX: Anybody else? I've got two questions--

A N N L E V I N E: Could I just add something here? The reason I'm late coming to this hearing -- I apologize -- is that I've been covering the meeting of the Governor's Health Care Cost Commission, which is a very important body, which I think is really going to be making some major recommendations that will vastly improve the access of everyone, not just women, but those who don't have access to care now. I would hope that this Commission would share the concerns that are being raised at these hearings with that body.

MS. PINNEO: Unfortunately, I don't think that--

MS. FOX: The transcriber didn't get that, Ann. If you want it for the record, come--

MS. PINNEO: Yes, why don't you pull up a--

MS. LEVINE: My name is Ann Levine. I'm Executive Director of Family Planning Advocates. I'm also the spokesperson for Choice, New Jersey, and the Senior Policy Analyst for the Association.

I just want to say that the reason I'm late for these hearings is because I've been covering the meetings of the Governor's Commission on Health Care Costs, which was meeting up on the fourth floor today, and just adjourned. I think it looks to me that they are going to be making some very significant recommendations to State government about vastly expanding access by the poor and the uninsured to the health

care system in New Jersey, as well as approving that system. I would certainly hope that the concerns that are being raised at these hearings are being shared with that group.

MS. FOX: Thank you.

MS. FRANCIS: I had two questions, Kay, or Ann, or-- One was to clarify: You said that under health care for pregnant inmates that there have been court rulings that a woman in prison has the right to have an abortion, even an elective one, and that if she is unable to pay, the jurisdiction of that prison must pay.

MS. PINNEO: I'd like Ann to--

MS. LEVINE: Yeah, I had the citation of that case in my original draft of this part of the testimony, but it's not here.

MS. FRANCIS: I don't even need that so much, as to just clarify. I mean, it seems like a paradox, almost. This was upheld by the U.S. Supreme Court, so it's nationwide. A woman in a state which does not have Medicaid funding of abortion could get arrested and go to prison and have her abortion paid for?

MS. LEVINE: That would be a rather clever way to deal with it. I'm not sure what--

MS. FRANCIS: I mean, is that the implication of this? Is that the--

MS. LEVINE: Actually, this decision only covers states in the Third Circuit, which, I believe, are Pennsylvania, New Jersey-- Phoebe, you'd probably know better what the Third--

MS. SEHAM: I don't know it by heart, but we can find out.

MS. FRANCIS: That's okay. I thought the implication was-- I thought when it was a U.S. Supreme Court decision it had implications for--

MS. LEVINE: No, the Court did not decide, it merely affirmed the Third Circuit without comment.

MS. FRANCIS: Okay. It was just a twist that I wanted to clarify in my own mind.

MS. LEVINE: Yeah, and I believe the case is Lanzanno v. Monmouth County Correctional Institutional Inmates. It was brought by the Public Advocate, and the decision came down in 1988 -- the Supreme Court affirmation.

MS. FRANCIS: Okay. My other question was about parental notification, and the decision that was just made. I'm interested in your comments about the implications for New Jersey. We, in dealing with this issue before, said that New Jersey's State Supreme Court decisions -- I guess particularly in the decision in Right to Choose v. Byrne -- gave a stronger underpinning for opposing parental notification than the Federal Court rulings. I'm wondering if you could comment on the fact that the U.S. Supreme Court has come down with this ruling. Does that make New Jersey any less vulnerable than the other states, or do we still have a stronger State constitutional basis for opposing those laws, because in Right to Choose v. Byrne, it was said that our State must be neutral when it comes to childbirth, or when it comes to pregnancy? I'm just interested in your comments on that.

MS. LEVINE: I am--

MS. PINNEO: Excuse me. Let me just say that I think that as far as New Jersey is concerned, we are fortunate in the fact that we had this past history. I think that the Supreme Court decision that was handed down yesterday opens it up wide to any and all comers who want to present proposed, or submit proposed legislation. I would hope, because of our particular uniqueness, that this-- It would make it tougher. I don't know, and I am not a lawyer, unfortunately, but let me go on and say, I think that we need to know that New Jersey is a pro-choice State. There was almost, I believe, a referendum last November on the issue.

I think it is crucial, and I think in New Jersey we need to point out the fact that -- or at least the figures indicate -- that over 50% of those minors who do want to go for abortions, do so with the knowledge and understanding of their parents, and it is the parentless or the single parentless, the nameless, who are without any real family connection, or in our meaning, our traditional meaning of a family, who are the ones who are going to be at risk.

Maybe Anne-- I know you'd like to comment on that.

MS. LEVINE: Yeah, more specifically, one of the whole bases of the Right to Choose v. Byrne case was the discrimination between pregnant women seeking abortions as opposed to pregnant women who wanted to carry to term. It seems to me precisely that argument can be made, if we change our present law which allows pregnant minors to consent for their own medical care to make an exception requiring notification or consent for pregnant minors seeking abortions.

MS. FRANCIS: Thanks.

MS. FOX: Anybody else? (no response) Thank you.

MS. PINNEO: Thank you very much.

MS. FOX: Our next speaker will be Courtney Esposito, who is a consultant with the Division on Woman.

C O U R T N E Y N. E S P O S I T O: Good afternoon. I brought handouts. I always bring handouts.

My name is Courtney Esposito, and until the end of this fiscal year I am serving as a consultant with the Domestic Violence Prevention Program of the New Jersey Division on Women. I am responsible there for providing training and technical assistance to the health care community. I am also a Director on the Boards of Womanspace, which is the local Mercer County shelter for abused women and children, and the National Woman Abuse Prevention Program in Washington, D.C. I am also a member of the Governor's Advisory Council on Domestic Violence, and I chair the Committee on Public Awareness, Education, and Training.

I would like to begin with the words of some colleagues of mine. Dr. Evan Stark, and his partner Dr. Anne Flitcraft, are responsible for most of the early and substantive research on domestic violence done in the medical setting, and I quote:

"Five cases of leukemia in a single high school make national headlines. A single recorded death from 'swine flu' stimulates a campaign costing hundreds of millions to identify and control the virus. The typhus victim and carrier are identified. But the battered woman and her attacker are not, although battering accounts for up to half the serious injuries women bring to the emergency room."

My history of working in this field began a long time ago, as the great niece of two battered women and the granddaughter of a third. When I was a little girl and I first began to understand domestic violence as a common fact of life for women, there were no shelters and there were no programs; there were no protecting laws, there were no hot lines; there was no place to run, and there was no place to hide.

I really do not believe that there was anything unusual about my family members in terms of the violence that they experienced in their lives, and the statistics that I brought to share with you today support that conviction. I didn't know it then, but I've come to realize it with all of the wonderful research and talking about this that has occurred in the last 10 years or so.

I, then, in the early '70s, myself became a victim, and I got what I prefer to refer to as hands-on experience for my current responsibilities. I believe that my knowing abused women as a child and growing up and then becoming one myself were unrelated, serendipitous circumstances. Even though I knew abused women in my home and several on my street, I never thought that I would become one. I never thought that I caused or deserved being beaten.

The numbers that I would like to share with you refer to battered women as a cross section of the total population, so we are not this odd minority somewhere that has some personality quirks that make us get into these situations or make people want to beat up on us. There are too many of us. We come from all walks of life, all races, and all religions, also socioeconomic strata, and for that reason we can't be classified as a personality type.

About half of all women murdered in the United States each year -- and that's about almost 2000 women a year, or about 38 women each week -- are killed by a male partner. In this country, women are more at risk of homicide at the hands of a male partner than from all other categories of persons combined. Each year, two million to six million women are beaten by their husbands or boyfriends, or by their ex husbands or ex boyfriends. It has been determined that leaving an abusive partner actually increases the chance that a violent incident will occur, which makes us have to think twice before we ask people why they don't leave, and assume that that is going to be a wonderful solution to their problem, as if they never thought of it themselves.

Battering is the major single cause of injury to women. It is more common as a cause of injury to women than rapes, muggings, and automobile accidents all combined. Almost half of all incidents of child abuse occur in the context of battering, and men who are abusing women are also abusing the children as well.

The literature, interestingly enough, does not reflect this. I am referring to not neglect, not emotional deprivation -- I'm sorry, economic deprivation -- I'm referring to physical abuse. The vast majority of physical abusers are male, and yet the literature almost exclusively refers to the mother as the abusive parent or the responsible parent for the abuse, whether she committed it or not.

Battering has been identified as the single strongest risk factor for becoming a batterer in adulthood. We used to think it was also a risk factor for becoming an abused person in adulthood, but we have found in most recent studies that that is not the case. Battering accounts for 25% of all female suicide attempts. It is not, however, found on most assessment forms for intakes where suicide cases or attempted suicide cases would be taken. There is some preliminary evidence that that number of 25%, is 50% for black female suicide attempts. And abused women comprise approximately 20% of all women presenting to emergency rooms with injuries, 25% of obstetrical patients, 40% to 50% of women with alcohol problems, 30% to 50% of female psychiatric inpatients. Battering is one of the most common and yet least identified health problems women present to health care professionals.

Clearly we can see that violence in the family is a primary health care issue for women. Often I find with lecture audiences as I do the statistics -- which I do in the beginning when I'm certain that they're awake -- is that they seem surprised and taken aback, and express dismay at those large numbers. Interestingly enough, if I have an hour or so with them, by the end of the presentation when it's time for questions and answers and if people feel free enough to do this, a number of them: 1) begin to identify patients that they didn't identify before as abuse victims, and sometimes ask for case conferencing after the lecture to determine whether it is someone that they've missed; and 2) some of them self-identify as either current or former victims of abuse. One nurse said to me, "I didn't know I was a battered woman until half-an-hour ago, after listening to you. I always thought that when he drank he was nasty," but she did identify as having gone through five or six years of abuse before he died of alcoholism.

The first person outside the family that a battered woman or other victim of domestic violence often will turn to besides a law enforcement officer, will be a member of the health care community. Health care facilities are therefore a very crucial step in this process of identifying and preventing abuse.

Preventing abuse is a very important term here, because in this area, as a health care issue, I think it's not only possible but likely that we can prevent an awful lot of abuse if certain steps are taken.

And now, a piece of health care trivia for all of you: The original draft that was issued for public comment of the U.S. Department of Health and Human Services document "Promoting Health/Preventing Disease: Year 2000 Health Care Objectives for the Nation," virtually omitted domestic violence and battered as named categories anywhere. Although violent and abusive behavior is discussed, women as primary victims are not mentioned. This neglect on a governmental level is sadly often duplicated in the examining rooms.

I believe that this happens for three primary reasons: The first is the relegation of violence within a family unit to the private matter realm, to the stuff we don't talk about, to the stuff that goes on behind closed doors as not our business, and certainly not a criminal act. I will date myself, and see if anyone will have the courage to join me, and ask if you remember Kitty Genovese? I have been in audiences of physicians, none of whom had ever heard of her because they were all too young. After Kitty Genovese was beaten to death on a New York City street, and I think it was '68 -- '65, '68 -- the police did an investigation. There were a lot of witnesses, because it was near an apartment complex. They were all asked -- all of the people who heard or saw but did not call anyone, did not shout out, did not pick up a phone, did not intervene in any way -- were asked why they

didn't. The major response to that from the majority of the people investigated was that they thought that the couple were married. Kitty Genovese did not know her attacker, which is an interesting comment on what the marriage license -- a marriage license -- means to some people.

I think this is cultural and it's something that has developed over thousands of years, and our expectation of it changing with a few training sessions is a naive one. It will take a long time.

The second is the lack of awareness of the community in general; that means all of us, and health care personnel in particular, about the prevalence of abuse and the dynamics of abuse: What it feels like to be a victim? What options do you have? How is it a different life, to try and navigate through the day, through the next hour, and stay alive? Most people, thankfully, have not had to face that and have a very difficult time -- and this is understandable -- putting themselves in that kind of a position and thinking like a hostage.

And the third is the feelings of frustration and helplessness that many people experience when in the presence of a victim they simply do not know what to do, or they feel powerless to help.

That is the bad news. The good news is twofold: 1) that we can change all of this, and 2) that in New Jersey we really have made a very good start at this.

Since about five years ago, the Division on Women's Domestic Violence Prevention Program developed and distributed protocols, training manuals, videos, and slide and lecture presentations for the health care community on domestic violence awareness and intervention, and I brought for you today the health care manual. Most hospitals and major health care organizations have been personally addressed, and all have received copies of the educational and training materials.

The model program aired nationally on Lifetime Medical Television the first four months of this year, and the videos are being gobbled up by health care facilities and domestic violence programs across the country.

We can, I believe, be very proud of the work that we have done, and I always hate to come kvetching about how nothing has happened, and we need to not lose sight of that.

All of the education that I do really comes down to some very basic concepts. We increase the victim's safety level while we decrease her level of isolation. It sounds very simple, but that doesn't necessarily mean that it's easy. It is nice, however, to say to people, "You can change this. There's a simple and straightforward intervention you can do. You can do it in two minutes on the-- You can do it in 20 seconds, the busiest night in the emergency room, and I will show you how."

If a victim has been given the phone number of a local program or received help in exploring even one of her options, then she is safer. If she is made to feel, whether by the practitioner's statements, body language, nonverbal communication, or attitude that she is stupid, sick, crazy, a bimbo, or to blame for the mess she's gotten herself in and now inflicted upon you, then she is more isolated. If the practitioner is kind, nonjudgmental, and supportive, then she becomes less isolated.

The most common question directed to victims, or varieties of these questions are -- by all of us, really, by nurses and physicians and the general public -- are: "Why don't you leave him?" Always implied there, is, "I would." Or, "Why do you put up with it, why do you take it?" Again, victims know, we're not stupid, we know that you're saying, "I wouldn't put up with anything like that." Which makes me okay, and you very odd. "How can you stand for it, this kind of behavior?"

These questions isolate. What you're saying when you say that to a victim is that she is the problem; that her behavior is clearly put into focus as the problem. What happens then is that a very insidious alliance is formed between the helping professional and the abuser, because there is somebody else who has been telling her that there's something wrong with her, that it is her fault, and that she is the reason why she is getting beaten.

That alliance works very brutally and dangerously against the health care interests and the safety of victims. When health care practitioners are showed how this dynamic works they are appalled, they feel guilty. Then we talk about care for the caregiver and relieving them of the fact that they didn't know any better before, but that now they do and they don't have a lot of excuses. They learn to see that the real problem, even though they don't go for its jugular, is the violence, and the abusive behavior, and that the real problem is not the victim, and that they are only hurting by making it look as if she is.

I believe very strongly that we must go on teaching them. If I thought that they really didn't get it, then I wouldn't suggest this, but the good effects in terms of health care delivery to family violence victims are practically instantaneous.

Recovery from abuse, from living with abuse, is a process; it is not a one-time event. "Why don't you leave?" "Oh, my God, what a great idea. I don't know why I didn't think of that? Thank you for helping me," and it's done. If you need to be home at 5:00 to cook dinner or you're going to get hurt, then you're going to go home at 5:00 and cook dinner, for today.

Most problems, whether they be situational or diseases, the recovery from them is also a process, not an event. There is nothing different about this, and I believe

that with consistent and ongoing training the quality of health care for victims, most of whom are women and children, will improve considerably. If we discontinue this work, then victims will not be helped and families in crisis will receive a very bitter message that the system, overall, doesn't care, that their doctors and nurses think that they are to blame, and that seeking help will become the same thing as hazarding a humiliating experience.

Health care people are frontliners on this issue and I believe that they need to be sensitized. They need to be taught to ask the questions, to be kind, to refer people to the experts on this, and to do what they all learn to do in nursing school and medical school; which is, do no further harm. Otherwise we end up being punitive agents to our clients and our patients and add to the entrapment that they are already enduring. Their isolation then becomes validated by those who are entrusted with their care and safety, and that would, indeed, be a shame.

I am certain from my experience that people in the health care community are ready to hear what survivors of abuse need, and they are ready to listen to those of us who are trying to help survivors. I have consistently been told that the information that we have offered to them was new and useful and convincing.

In January of 1989, former U.S. Surgeon General C. Everett Koop did a press conference with the American College of OB/GYNs and the National Coalition Against Domestic Violence, and came out urging routine assessment of all female patients for signs of family violence. That does not mean that it automatically began to happen, however. The AMA did the same thing last fall in a conference on the prevention of family violence and victimization. I think it would be a fine idea for us to capitalize on the examples set by these leaders

in the health care field. I realize it will take an investment of time and money, but meeting health care objectives in any kind of an equitable way always does.

I would like to make the five following recommendations for reducing and eventually eliminating this not so benign neglect in the health care field toward victims of family violence:

1) That we continue to expand and intensify the training and technical assistance offered to all sectors of the health care community.

2) That we increase media and public awareness efforts on this subject and on the training opportunities available so that violence in the home can be loudly and clearly identified as that which it is, a primary health care issue for women.

3) Insure that a protocol for health care intervention in domestic violence cases be adopted and disseminated by the Department of Health, the New Jersey Hospital Association, and other appropriate health care agencies to their constituents. This would ideally be able to take place in a year or two. New York has just been the first state to do that. I don't see anything wrong with us being second, for a change.

4) Require certain health care providers -- staffs in hospitals, clinics, and mental health services, as an example -- to record the numbers of suspected and confirmed domestic violence cases treated so that data on the nature and extent of violence in this State can be collected. I have included a copy of how Connecticut does that for your consideration.

5) Statistics from domestic violence programs throughout our State indicate that demand far exceeds the supply. Indeed, many services are in the unfortunate position of annually denying immediate shelter to more clients than they house, and abuser counseling programs, too, commonly maintain

waiting lists for treatment of offenders. More shelters and services are needed to house, counsel, and otherwise assist both victims and abusers. Hopefully, additional funds will continue to be made available to these programs so that they can endure in their business of saving lives.

I appreciate the opportunity to have spoken in front of you today, and I'd be happy to answer any questions you might have.

MS. FRANCIS: I've always got a question. I have two, in fact, on different points. One is that -- this needs a couple-sentence set up -- but I have read about the Stockholm syndrome, so-called, which happens with hostages. This is not based on domestic violence, but it's when people are taken hostage by terrorists, basically. After a day or two they develop some kind of a strange bonding, some kind of a strange accommodation to the hostage-taker that is a kind of self-preservation. It's been analyzed psychologically as a survival technique.

I've not seen that analysis of that syndrome applied to the domestic violence situation, but it seems to me that there might be a component there of staying there, you know, taking it, being a survival technique that psychologically is similar to what happens with the Stockholm syndrome. Has that been looked into?

MS. ESPOSITO: There's been some connection, some writing on the connection. Sometimes it's referred to as becoming like a hostage or Stockholm syndrome. Sometimes it's talked about as co-dependency. I think there's value in all of that. I'm just careful about the victim blaming that people tend to take and run away with, "Oh, so in other words, she could leave, but she stays."

What happens is that -- and this is when the emotional abuse goes on for weeks, months, years, before the physical begins, and you are cut off from everyone and you are more and

more isolated, and begin to think of yourself as someone who has something vitally wrong with you, because everyone seems to tell you that with their faces--

Battered women develop a whole set of coping mechanisms and survival tactics that work in the short run, and then scapegoat them in the long run. You have to do a case-by-case basis, so that one battered woman that I can think of said, about being in front of a therapist in marriage counseling, "I would agree to anything he said as long as he was sitting in the room, because I was never safe if he was there."

Sometimes that's referred to as learned helplessness, what you talk about; that the only way to get by is to do everything your captor says and identify-- And do some women lose themselves in that and do they become mentally ill? Yes, but I don't believe that they are the majority. I think that the majority are doing things that look very bizarre to everyone else, like if you know he is getting drunk and the kids will be home at 1:00 from early dismissal, you put yourself in his face after two beers and provoke him so that: 1) it's not as bad as after two six-packs, and 2) the kids don't see it.

That's a survival tactic; I think that's a smart move. It's a hideous move, but it's a smart one, and if you are not prepared to disappear yourself from the kids that day, it's a pretty wise thing to do, if he said, "Leave, I'll find you. I'll kill the kids," or, "Fine, go, take the kids, I'll kill your sister." And the problem is, we never know which ones who say that -- and many of them say it -- are actually going to carry it out, and neither does the victim. So what looks like insane behavior is playing it safe.

MS. FRANCIS: I guess my sense is, I don't picture people blaming the hostages, blaming the victims, when it's a case of the Stockholm syndrome. They analyze it and say, "Well, that was a smart survival technique."

MS. ESPOSITO: That was scientific, yeah.

MS. FRANCIS: So, if we could carry that sense over to the victims of domestic violence, there might be less blaming of the victims there.

MS. ESPOSITO: We didn't with Hedda Nussbaum.

MS. FRANCIS: My other question-- Again, this cannot be answered in 25 words or less. But I just want to raise the issue here in this context: Right now we see both federally and on a number of State levels, attempts to pass hate crime bills that would identify victims of violence based on race, religion, national origin, ethnic, all of the categories. It sounds like health insurance, too. All of the categories are there except gender. We don't see any conceptualizing of hate crimes based on simply the fact that a person is female.

Could you comment on whether you believe domestic violence might be one dimension of what we could call a hate crime based on gender?

MS. ESPOSITO: Hate -- the hate is hard, because once you talk about it within the family-- Because it doesn't fit in the category, I don't think that means you throw it out.

MS. FRANCIS: As I say, there's no 25-word-or-less answer.

MS. ESPOSITO: The single strongest identifiable risk factor for becoming a victim of physical abuse is sex. Period. Should we do something about that on a national and local level? Absolutely.

I read in the paper -- I think last week -- that, in fact, there were hearings and that there's talk of setting up an Office on Violence in Washington. Women were mentioned, not preliminarily, but later, as hearings went on, and domestic violence victims, in fact, were also mentioned as possible recipients of services from that Office.

MS. FRANCIS: I think the conversations are just beginning, but I wanted to raise the issue, to have it on the

record here. I believe that it is a new conceptualization for policymakers and for society in general, and I think it will be built on in the future, so I just wanted to raise the question.

MS. ESPOSITO: Well, if you think about violence in the family as power and control -- an issue of power and control -- which it is-- It's not a loss of power; it's not a loss of control by the abuser. It's a means of achieving it over another person. It's an inside out issue. And then you think of Nazi Germany and power and control and then hate crimes. I think we could move our words around to say that it certainly should apply.

MS. SEHAM: Along those lines, and taking off from a statistic that you mentioned earlier: You said something about more domestic violence than other crimes of violence against women combined. The Bergen County Commission on Women did a study on crimes of violence against women in 1977. It was one of the first in writing, and we found that there were no statistics. We had to circularize the Medical Society to create a data base, which we knew was going to be conservative, but at least we got some data. We found that there were more crimes of violence against women than all other crimes of violence combined against women or men; not just against women, but against women or men.

MS. ESPOSITO: Countywide?

MS. SEHAM: In our county, which I don't think is atypical-- I don't think it is atypical, even though on Channel 4 they said there is an epidemic of wife beating in Bergen County. It's just that nobody else is talking about it.

MS. ESPOSITO: And in every other county.

MS. SEHAM: Right. And the other thing we found-- I mean, what you're saying is all studies come up with the same results. It's just you have to do it in your county; otherwise they think this happens elsewhere.

But one of the things we found, even in going through the information before we put things down in black and white, was that the more extreme cases were so horrible that even those of us who were working on the study had a reaction of incredulity. That of the danger-- You have to tell about the less extreme cases, or your audience simply will not be able to believe what you are saying, which is strange, but it's true.

MS. ESPOSITO: Yes, you lose them.

MS. SEHAM: I had a similar experience making a presentation to the trustees of the Bar Association on another subject, on the subject of collection of child support, which is equally abusive. Their reaction was, "We just don't believe your statistics."

MS. ESPOSITO: I've heard that reaction.

MS. SEHAM: "We just don't believe it. It's too horrible. It can't be true." So, we soft-pedaled it.

MS. FOX: Thank you very much.

MS. ESPOSITO: You're very welcome. Thank you.

MS. FOX: Our next speaker will be Lynn Miller, who is the Editor in Chief of the Rutgers Women's Law Reporter.

L Y N N F. M I L L E R, ESQ: I just graduated, so I'm the former Editor in Chief.

I want to talk to you today about breast cancer, still a very important subject in the area of women's health. I know you heard earlier today about the incidence rate. I'm going to speak to you rather personally because I'm not an expert, I'm a patient.

I guess that makes me an expert in my case, but what I went through, I think, is somewhat typical, and I want to emphasize that one in 10 women get breast cancer. That means it's a 10% incidence rate. That affects a lot of people who live in New Jersey.

The research money to find out what causes breast cancer and how to prevent breast cancer has not been generous.

The National Institutes of Health have underfunded this area of research, and if there is anything that this Commission can do to encourage the State of New Jersey to do any research whatsoever into the causes and prevention of breast cancer, that would be excellent. I don't know if the State of New Jersey funds medical research, but if they do, this would be an area to insist on.

As you know about priorities in medical research, the male diseases have been featured, and they even use white male rats to do their research on, so we need to push our agenda. One in 10 is a lot of people. We don't know enough about causes, although personal habits have been highlighted. They always try -- the medical profession -- to make sure that you are responsible. They want you to stop smoking; that's good. They want you to eat right; that's all good. They want you to exercise; that's good. But how come Japanese women who live in Japan have -- I don't remember the incidence rate -- but as soon as those very same women come to live in the United States, the incidence rate becomes one in 10? Is there something in our environment? Could it possibly be that it isn't your personal fault that you get breast cancer, or some personal habit of yours, or even only genetics, but something is really going on in our country? It would be good if they would look a little bit into the environmental causes.

I want to talk to you about the importance of early diagnosis. I was very lucky in that in my very first-- It sounds funny to hear someone say I was lucky that they told me I had breast cancer, but in my very first mammogram, at the age of 47, an irregularity was detected. It was recommended that I get a biopsy, and much to everyone's surprise, because I was extremely healthy -- had wonderful blood, had great cells, I was in extremely good shape -- this thing was malignant. It was at the earliest possible stage, and I was able to have a minimal kind of -- minimally intrusive surgery, and radiation.

So I didn't lose my breast, but-- I have a very good chance of licking it. I have, like, a 90% chance and up survival possibility, but a lot of people don't get mammograms for a lot of reasons.

A tremendously important reason that they don't get them is, insurance generally does not cover screening devices or preventative health care devices. I want to emphasize that mammography is different from other preventative health care in that it is almost part of the treatment, and insurance companies just have to change the way they look at screening mammographies. If there is one thing that this Commission can do, it is to push those bills that are now, I believe, being introduced. I don't have any information on these bills, I'm sorry, but there are bills being introduced that require insurance companies to cover screening mammographies.

Self-examination is a very important technique, but by the time you can feel a lump it is often too late; it has spread.

My paper, that I handed you, is something I did as an independent study in law school on informed consent legislation. That's another area I'd like to focus on.

Once you get the diagnosis -- and it's the most shocking diagnosis that you probably get in your life-- I know people-- AIDS seems to have obscured the underlying horror of cancer. It's still a horrible disease, and breast cancer is especially horrible for women. You have to make a decision once you get the diagnosis. No one can really take that away from you. You have to decide what kind of treatment you have to get. Very often, women are rushed into going with radical mastectomy, when they have other options.

The importance of informed consent, with the emphasis on the "informed," has to be stressed. I don't think our laws about informed consent are strong enough about the kind of information that women have to get before they make their decisions.

In my paper there are several other states' laws outlined, and I just recommend that you look at Florida, where the physician is required to inform the woman, either in writing or orally, or both, about every treatment option appropriate for her cancer, and not, as with me, having to go to four physicians hearing everything from, "Leave it alone and we'll wait and see what happens in six months," to, "Off with the breast, with everything," and everything in between. "Just radiation, well, maybe a little surgery plus a little radiation," I mean--

Luckily, I was a librarian in my former life, and was able to go to the medical school library and do my own research and come to some conclusion of my own. There was no one, and no piece of paper, and no information handed to me about my options, other than Rose Kushner's book, "Alternatives," which is an excellent book, but slightly out of date. She recently died of breast cancer. I think that the informed consent law in New Jersey should be strengthened to require better information.

Just to summarize very briefly: This is my own experience. Fear, ignorance, terror, and denial are the greatest enemies to early diagnosis and adequate treatment, and cause more problems. If women just had more and better information and better counseling, they'd be able to make better decisions about this awful disease.

MS. FOX: Okay. Questions?

MS. SAMPIERI: Thank you.

MS. FOX: And study hard for the bar.

Our next speaker will be, actually two, from the New Jersey State Nursing Association, Jane Adams. No, Dorothy Fleming is speaking for Jane Adams.

D O R O T H Y D. F L E M M I N G, R.N.: Good afternoon. I was sitting in the audience, and you have an awesome task. If you asked me to vote on priorities for any of the former

speakers, you know, I'd want to vote for all of them, because they're all just major, major things.

I am Dorothy Flemming, Executive Director of the New Jersey State Nurses Association.

I thank you for this opportunity to present the views of the health care in New Jersey. Nursing is the largest group of health care professionals and is essential to any discussion on decent, cost-effective health care.

Professional nurses are not invested in the present system of health care delivery. We are actively seeking a change in emphasis from tertiary care of the acutely ill to preventive primary care of the well.

We are actively seeking a change in the gatekeeper mentality that allows all the control of health care delivery to be put into the hands of the physician. Specifically, we seek to obtain prescriptive privileges for a small group, a very qualified specialist in nursing practice; Nurse Practitioners, Clinical Nurse Specialists, and Nurse Midwives. Prescription of drugs is an act integral to the assessment, diagnosis and treatment cycle in the provision of primary care. To provide primary care, primary care nursing practitioners are seeking prescriptive authority.

I want to give you a brief history of prescriptive authority in this country specifically to debunk some of the common assumptions that only an M.D. is qualified to keep us safe from dangerous drugs.

I credit Gene Harkless with the information from the article published in the "Nurse Practitioner," which is attached, August 1989.

Prior to 1900, consumers could obtain any available drug through pharmacists without a prescription. Three factors resulted in the shift of control from the consumer to the physician.

First, patent medicines were the target of progressives who were attempting to deter deceptive business practices. Second, the American Medical Association mounted a campaign to cease advertising of medicines to the general public. And third, drugmakers recognized that doctors' opinions were increasingly important in the patients' use of medication.

These events, in conjunction with the relatively new licensing laws for medicine, helped place physicians in the new role of drug experts. Authority moved from the consumer to the physicians.

The Federal laws of 1904 and 1938 were designed to protect that public from false labeling and improper and dangerous manufacturers. Regulations that were developed in 1938 designated drugs as prescriptive and nonprescriptive, with the intention that very few would be designated as prescriptive. However, just the opposite happened, and the regulations took control from the consumer and embedded prescriptive practice more firmly in medical practice. The 1957 Federal Drug Law placed almost all new drugs in the prescription-only class.

Nursing did not keep pace with these changes. The original Nurse Practice Acts were legislated prior to the passing of the 19th Amendment, so depended on the support of male-dominated legislatures and physician groups for passage. This helped set the stage for the perception of nursing as a physician-controlled occupation.

Finally, to the benefit of organized nursing, a court case in 1965, the case of Darling v. Charleston Community Memorial Hospital clearly established that the duty of the nurse was to be knowledgeable about diagnosis and prescribing, so as to monitor the care of patients and to take action if the case was negligent.

From that time on, Nursing Practice Acts have included diagnosis and treatment through the nursing regime as part of their practice act. The New Jersey Legislature amended its Nursing Practice Act in 1974 to accommodate that language.

Nursings' struggle to obtain autonomy in prescriptive authority translates to a social inequality issue. We ask your support of legislative language that affords nurses the greatest degree of structural autonomy for the safe practice.

Our Practice Act should include a definition of nursing that includes, or at least does not prohibit, the performing of diagnosis and prescribing.

Senator Wynona Lipman's bill, S-2100, is the legislation we think will accomplish that. Primary health care services are essential to a reformed health care system. Nurses have been educated to assume the role of primary health care provider.

NJSNA is asking the New Jersey Legislature to correct the inequities of the past system which invests prescriptive privilege only in the medical field.

We are asking for legislative relief from a very restrictive practice atmosphere for nursing in New Jersey.

Additionally to the reference that is attached, I do have another reference for your information. It is by Elizabeth H. Hadley, JN, MPH, and it's, "Nurses and Prescriptive Authority, A Legal and Economic Analysis," which was published in the "American Journal of Law and Medicine," 1989-1990, volume 15, pages 245 to 266.

What is not in my testimony, however, is also when one speaks in the testimony of nurse practitioners-- Nurse practitioners have been educated in New Jersey for the past 20 years. They are working in some health care settings. In my other life, before I assumed this life, I was a Certified Pediatric Nurse Practitioner.

Some of the practitioners are working in very limited constraining areas. We do see that practitioners would be extremely valuable, especially in the primary health care, not only in pediatrics, but moving into gerontology, and the OBRA '89 law now has it that states that recognize nurse practitioners, that nurse practitioners can be reimbursed under Medicare. This would enable geriatric nurse practitioners to work as a team with the physician to do visits in nursing homes and also to work in clinics that are Medicare/Medicaid certified. This is one area where we have felt very much constrained by the Medical Society in New Jersey for full utilization of nurse practitioners.

I can take any questions.

MS. SEHAM: I have one: When we discussed this in Commission, before that bill was introduced by Senator Lipman, there was disagreement on one particular issue. Our Commission, although maybe individually we may feel strongly about a situation, can only act on it -- make recommendations on it -- if it affects one sex more than the other. No matter how egregious the situation, we can't study it, or make a report on it, or recommend anything about it, unless that is true. We need to get more of a linkage from you. I have made the argument that there are more women nurses and more male doctors, and I think that's still very true.

MS. FLEMMING: That's very true.

MS. SEHAM: Would you say that, I mean for example, a possibility would be that there are more women who need to depend on the services of nurse practitioners in order to maintain their health, because women tend to be poor as a group? I don't know whether that's true or not.

You mentioned pediatrics and gerontology. That would not answer what I'm saying to you. If you can give us more linkage between what you want done -- which I certainly agree with -- and an impact more on one sex than the other, it will,

you know-- Women's health-- Would it have more of an impact on women's health, to allow nurse practitioners to prescribe?

MS. FLEMMING: Okay. Yeah, I can understand. I'll try to get--

MS. FOX: Also, I'd like to know the percentage, or the numbers of women nurses and male nurses in this State. Also doctors, although I think that's changing, probably quicker than the nursing profession.

MS. FLEMMING: As a matter of fact, the number of women attending medical school, as you probably know, has increased -- I want to say it's 50-50 now, it might even be 60-40 -- but there is a large group of women going into medicine.

I just came back from our national convention, and our House of Delegates had-- They did a poll -- an electronic poll -- and I think in the House of Delegates we had, I want to say 6% to 8% male. The normal staffs, if you were asking me-- I would say it has gone up to probably about 4% male, so obviously it is still, very much a women's profession. We do have on our Board-- We have two male nurses on our Board of Nursing.

MS. SEHAM: So they are overrepresented in the governing body?

MS. FOX: Surprise, surprise.

MS. SEHAM: Yes.

MS. FLEMMING: But, I think what you said is true, and we-- I'm sure that we can get that information, especially working with Kay Pinneo. And when I say children, children have mothers, and we know that the poverty level for single mothers-- I have also worked with pregnant teens, and again you have a very vulnerable population. It has a very limited access in families where they don't have any health insurance at all.

So, very much, we would like to see that we could utilize what the Federal government has said for reimbursement to bring primary health care to these populations that are underserved at this time.

MS. SEHAM: Of course, there are more elderly women than elderly men, too.

MS. FLEMMING: Yes, and I found that out when I was trying to get placement in a nursing home for my father, who has since died. There are a limited number of male beds in nursing homes, so if you have a male relative who you are trying to place, sometimes your wait is longer because the beds assigned-- This was in Massachusetts, but I would imagine that it could be carried over to Jersey, to the nation, that they had set more beds aside for women. And most of the rooms were two-bedded rooms, unless you were very wealthy and you went into a single room -- we weren't in that category -- then you had to wait for somebody to die so that the bed would free up. But the percentage was very low for male beds in nursing homes.

MS. FRANCIS: That sounds like an issue of sex discrimination in something.

MS. SEHAM: Well, they're doing it statistically.

MS. FLEMMING: Well, I think it's a reality of life: Some things are discrimination, and some things just evolve that way.

MS. FOX: Anybody else? (no response) Thank you.

MS. FLEMMING: Thank you.

MS. FOX: We're going to jump down to our 5:30 people. Marta Stretton and Carol Watchler for the Women's Agenda of New Jersey.

Thanks for coming early.

C A R O L W A T C H L E R: It's valuable information all the way around.

M A R T A S T R E T T O N: Hi, I'm Marta Stretton, and I'm a member of the Women's Agenda of New Jersey.

Most of what we are saying here today has already been said, so this is somewhat of a sum-up.

In the following testimony, we will present a number of issues in which the availability of health care for women is different from that for a comparable situation for men in such a way that public policy initiatives should be developed to guarantee greater equity in the system. We will also describe areas where discrepancy in the provision of health care arises because of the invisibility of women's health needs, and the standards for healthiness and pathology are frequently male.

According to many sources, including the National Women's Health Network -- hereafter better known as NWHN -- women use the health care system more frequently than men. They make a greater number of personal physician visits, have greater amounts of medication prescribed, undergo greater numbers of surgeries, and make more doctor visits with their dependents.

Women's high amount of use of the health care system comes partly from the need for reproductive health care. Public policy needs to support a women-centered environment accessible to all women. This means respect for each woman's ability to make her own decisions and to be an active participant in her own health care.

Such phenomena as a prenatal care physician's refusal to renew a prescription for birth control because he believes a woman should be bearing children by a certain age, are clearly examples of sex bias. Likewise, a law enforcement system which fails to deal with persons who harass patients and attempt to prevent access to health care facilities needs the pressure of clear State policy, to ensure that women can obtain health care where they choose. This type of harassment and intimidation occurred at nine out of ten freestanding facilities in New Jersey which provide abortion services.

Women find their way into the health care services often as victims of rape and domestic violence. It is estimated that as many as half of the adult female population has suffered some physical violence from a partner in their lifetime, and one in five suffer chronic severe abuse. In 1986 police responded to 43,548 domestic violence calls in New Jersey. These victims encounter many hurdles on their road to recovery. One such hurdle is the treatment by the emergency staff at the hospital. It depends on the knowledge, understanding, and sensitivity of the doctor on duty, whether the traumas of the brutal assaults will be decreased or increased. No added burden should be placed on the victims, such as unnecessary questions by the physician or long waiting periods in rooms with other patients.

Our society still places much fault with the woman who is the victim of rape, and doctors still cling to the assumption that women ask for it. But the FBI has placed the crime of rape on the same list as murder and kidnapping, and they have done this-- As far as I know, they did this in the late '70s already, when I was involved with rape crisis centers.

It is important that doctors learn to be sensitive to the needs of both the rape victim and the battered woman. Standards of certification and accreditation should be developed to promote quality and to encourage innovation in the health care services that deal with abuse against women.

A conflicting societal view of women is that of a perennially dependent person. Unfortunately, this view of women often follows them into office visits with a private physician. According to NWHN, when women and men present the same symptoms, women are more likely to be prescribed drugs, and men are more likely to be given a physical exam. Women exceed men in the consumption of prescription mind-altering drugs in a ratio of two to one.

With this as a factor in addition problems for women, treatment models that center on regaining self-esteem are called for, rather than standard male-centered models of rehabilitation.

In testing for HIV, the AIDS causing virus, doctors need to recognize the fact that the virus behaves differently in women than in men. The existence of previous gynecological conditions such as herpes or genital warts or the use of oral contraceptives in women may be factors in the susceptibility to the AIDS virus. Early gynecological detection gives women the advantage of treatment.

The following guidelines for testing passed by the National Women's Health Network Board of Directors should be considered. Testing should be readily available, quality controlled, voluntary, and in a setting which guarantees informed consent, including a clear explanation of the risks and benefits of knowing test results. It should not be used for employment or nonmedical reasons.

The purpose of testing is to detect the disease so that those who have it can take appropriate measures to avoid spreading it. Testing should be made available to anyone, and doctors should not exclude the testing of middle-class women. Says Dr. Iris Davis at Woodhull Hospital in Brooklyn, "We've seen some very sick middle-class women, who had been given every diagnostic test in the book except the HIV test. Many doctors don't even consider AIDS a possibility in middle-class women, and they are wrong." Doctors should not take it upon themselves to decide who is or who is not at risk, but rather make testing immediately available upon request without intimidations or unrelated assumptions.

I mention unrelated assumptions because this is something that happened to me when I visited my gynecologist and asked him to give me the HIV test. He sort of immediately assumed that I could not be at risk.

Costs for health care are a problem for women. A gap exists between those eligible for Medicaid and those with sufficient income to purchase insurance. Often, even for those with individual subscriber insurance, the spiraling costs of health insurance create questions about the future of using our present system of reimbursement. Low-paying and part-time jobs do not provide health benefits, and this affects far too many women and their families. Added to this is the fact that health care delivery often focuses on high-tech solutions which are generally the most costly, rather than on preventive health care.

Public policy is needed to support and encourage preventive health services, health education, and the widespread uses of factors such as diet and exercise that enable people to have long-term positive effects on their health.

Women are present in health care to a greater extent than men as workers, not just as clients. Far greater than half of health care workers are women, though women's positions tend to be less powerful than men's. While this may be changing with the increasing visibility of women as physicians or administrators, public bodies which make policies regarding health care need to reach out and look into all of the health care fields to identify women for such leadership positions and to achieve a stronger women's voice in policy-making bodies.

According to NWHN, women as physicians are more likely to work in primary care facilities, see more new patients and spend more time with each patient. This suggests that the woman physician is more likely to deal with the patient as a whole person. Public policy should support and encourage health care systems with this style of patient/physician interaction.

The area of research is a final one with an example of bias against women. This may come in the choice of project for

funding, as well as in the choice of subjects used in any research project.

The need for funding for breast cancer research is such a case. With up to 150,000 new cases of breast cancer each year, it is remarkable that only 26% of the National Cancer Institute's request for grant funds have been met. "All in all," says an Ellen Goodman column, "13% of the National Institute of Health's \$5.7 billion budget goes to study the health risks of the half of the population that is female."

In addition, the writer points out that major health studies on such topics as cholesterol, smoking, and the use of aspirin were all carried out with male subjects.

Thus the health care system finds women as its most prominent users in terms of numbers, but women's needs are seldom the focus of health care initiatives.

As I said before, this was somewhat of a summary of what you've already heard last Tuesday and today, I'm sure.

MS. FRANCIS: The executive summary. Thank you.

MS. FOX: Any questions? (no response)

MS. STRETTON: I think Carol wanted to-- Did you want to add anything or not?

MS. FOX: Oh, okay, go ahead.

MS. WATCHLER: No.

MS. FOX: We do have time, Carol, if you want to.

MS. WATCHLER: Well, I simply would add that you have heard many more details from some of the organizations, in fact, that are part of our Women's Agenda as a whole, regarding some of the things which we simply tried to provide an overview of. Overall, I think that the message, cumulatively, is pretty powerful that not -- that the bias may not be in someone doing this or doing that, or not, but in the overlooking of the importance of seeing women as having specific needs in health care and seeing women as having possibly the same needs in some cases, but that our whole bodies need to be viewed and studied to know what happens to ourselves.

MS. FOX: Thank you.

MS. FRANCIS: Just one quick question, of course, but I want to pick up on something I haven't heard elsewhere, I don't think; which is the need for a stronger women's voice in policy making-bodies. I mean, it was certainly implicit in a lot of things, but I would ask specifically because I know the Women's Agenda is-- One of its missions is to increase the hearing of women's voices in policy making. Would you have any specific recommendations to carry that out?

MS. WATCHLER: At the moment I don't have a specific recommendation to make, but as we look at the issue of health care in our whole study, we certainly would want to bring back the question of insuring that there are greater numbers of women on policy bodies. As we wrote this, one of the things we said was, is sex equity what you look for in policy-making bodies? And you know, being aware that in some areas health care is provided by all women practitioners, there's an area that women perhaps need to direct -- women practitioners for women clients -- sometimes women may need to direct-- I wouldn't look for that, but certainly our voice needs to be heard at a higher level to a greater extent.

I can see that there are areas that we weren't able to touch here that -- the questions of mental health, the treatment of women and mental health, access to-- One of the things we mentioned was in reproductive health care, that women's centered environment, the emphasis on-- I'm not sure what the Commission does related to that, except for our awareness of things like birthing centers, where any legal realities or regulatory realities enable those to exist as far as for women who are seeking their services.

MS. FOX: Thank you.

I think we have one more person who is scheduled for 5:00, from the NJEA, so we will wait for her.

MS. SEHAM: Feel free to wait with us. We'll wait till 5:00 for her.

UNIDENTIFIED MEMBER OF COMMISSION: She's on her way.  
We called the NJEA.

(RECESS)

AFTER RECESS:

MS. SEHAM: Thanks for coming a little early, we appreciate it.

B E T T Y H I C K E Y: Thank you. I'm sorry I was a little late. We were still racing around seeing if anyone else was going to come over with me.

MS. SEHAM: This is Betty Hickey, Associate Director of the Instruction and Training Division of the New Jersey Education Association.

MS. HICKEY: Correct.

MS. SEHAM: Okay. Go ahead.

MS. HICKEY: I'm not going to read you all of the testimony we submitted.

MS. SEHAM: Thank you.

MS. HICKEY: It's late. I'd like to tell you that we talked about two issues. We talked about-- There are many issues that you are soliciting testimony on that are really important issues. We zeroed in on teenage pregnancy and the needs of teenage pregnant students, who by the way, all happen to be female. So, what we're really talking about here are the needs of women.

I think if you read through our testimony on that -- probably you've heard this already -- but in 1988 there were over 7000 pregnant teens in New Jersey -- over 7000. The current data that's coming in show a high increase in the number of pregnancies between the ages of 10 and 14. So, it's a really, really serious area that needs to be addressed in New Jersey.

We're talking about several things that you need to look at. Providing health care: Many of these young woman do

not get health care until the third trimester of their pregnancy. It's not readily accessible. If you go back to even before that, counseling choices that somebody might have during pregnancy, they're often-- They don't even know where to go. You know, many of these things are done through Planned Parenthood or through family health clinics, and they don't even associate that with something they can pick up on. They're very lost and frightened and they need a lot of support, which they're not getting.

Currently there's a program that's being piloted in the State of New Jersey. It's being piloted in 29 school districts and it talks-- It's a youth-based clinic and it's a drop-in clinic where teenagers receive, you know, information. They also have minimal, as I understand it, screening for dental and eye. But this is a referral system, so they at least would have a place where they could go and know where to get information on medical services or counseling that's available. It's being piloted only in 29 schools. That, coupled with--

MS. SEHAM: Where are they?

MS. HICKEY: They're throughout the State. We can get that information. It's being funded by the Division of Human Resources, so we could get that information for you. It's not something that is directly under the auspices of the Department of Ed., is it?

TRUDI THORNTON: (speaking from audience) It's the Department of Human Services.

MS. HICKEY: Okay. This is Trudi Thornton. She also works in Instruction and Training.

MS. THORNTON: I have a list of the districts. There is at least one in each county. (next sentence indiscernible to transcriber; no microphone) They work with the community hospital, and some of the schools.

MS. FOX: Would you come up--

MS. HICKEY: Yeah, come up.

MS. FOX: --and repeat what you just said for the transcriber. (Ms. Thornton complies)

MS. HICKEY: Trudy works with our Youth Services Committee, so we sort of talk about these topics jointly, between the Women In Education Committee, which I work with, and the Youth Services Committee.

MS. THORNTON: We're currently studying some of the programs that are available to youth who are in our schools. Right now we've been working rather closely with the Department of Human Services, in studying their pilot program.

There are 29 school based youth service programs in the State. There is at least one in each county, and I do have a list of the schools that are participating at this time.

We did a survey this year to find out whether or not they are finding the programs to be a success. For the most part they reported back that they just need more. They need more funding. They need more programs. They did indicate there should be more interplay between these different agencies and the school, and that the feedback was inadequate. That was the only real criticism, but they are now saying, "Move them up and start them with middle school. Don't wait until high school; it's too late."

MS. SEHAM: Well, if they're getting pregnant at 10?

MS. HICKEY: That's right. This was like absolutely frightening to me. My daughter is going to be 10 in July, and I looked at her when I was going over this testimony and I thought, you know, we're talking about a child here who very soon could be pregnant. The other problem that we see is that it is a referral system, so the kids come in, they get information, but then they have to be able to get help from whatever community resource you send them to. And then, depending on that community resource, the help they get varies from location to location, so we really need to look at not

just expanding that program, but coming up with a way to coordinate it to make sure that if they do have the courage to go, then the information they get puts them in contact with a system that helps them right away. Because what happens with teenagers is, if they don't get that help immediately, they just don't follow through on it as well as they should.

The other thing that we need to seriously think about is, there seems to be more of a need to start early on in health programs teaching the need-- We teach about human sexuality, but I think we need to reinforce that with the need for pre- and postnatal care. We don't always talk about, you know, how, you know, what the needs are as far as the health goes, and so maybe the only information these teenage girls are getting is from a limited health program, and that needs to be expanded.

The other thing is that, they're-- Once the teenage mother has the baby, all right, there is little support system. As far as we can determine, there are several schools in the State that provide day-care in the school. We can think of-- The ones that we know of are: Newark, Elizabeth, the Heller School in Burlington County in Mount Holly, and there may be one or two others.

Let's take Newark, for example: About 300 girls get pregnant a year, in Newark. Their day-care program provides slots for 20 babies, -- 20. So, you've got a need of 300. One school, only, provides day-care. So, first of all the teenage mother has to get the child to that day-care center; it's on a waiting list. If she happens to get pregnant early on, then she has a better chance of getting her baby into day-care. So you're talking about, even where there is a system in place, the need simply is not being met, of the girls who are getting pregnant.

The other thing that we need to talk a little bit about is: In addition to better education and more complete

education for boys and girls, we need to talk about having readily accessible health care for these girls. The reality is that in many places there's no readily available health care. Many of the family planning clinics which provide free or low-cost health care are located in 16 places in the State of New Jersey. Currently the State funds them at about 24% funding, so all the rest of it comes from private sources.

Now, it doesn't take any genius to figure out the 16 centers. They are primarily in urban areas. I did talk to them. For instance, there is one center in Cumberland County, Vineland, that takes care of all of those South Jersey counties, and those rural areas are places that often get overlooked. What's provided is often provided minimally, minimally in urban centers, but when you get into South Jersey and rural areas, you know, these kids would have to travel an awfully long distance.

So there's not the health care available to them. It's that simple. It isn't readily accessible for them and for their babies, and they don't, perhaps, even understand the need for it. If they do, how are they going to get it? It's just not available, and I think, unfortunately, places like family planning clinics and Planned Parenthood-- They really take a bum rap, all right, in my opinion. They're often linked solely with the issue of abortion, and everybody ignores all of the other services that they are providing, where often they are the only centers that provide those services. Coupled with the bad rap that they get and the limited resources available, there just aren't enough health centers to go around.

Many people tell me that even though hospitals say they provide services, it's a very cumbersome procedure. Even though you may be able to get procedures through welfare, that is also a cumbersome procedure, and the procedure often scares off a pregnant teen. You're talking about a 14-year-old girl. I mean, they really have to have a lot of moxie to persevere and get the services that they need, and it just doesn't happen.

Many times hospitals have a lot of cumbersome forms that need to be filled out, and they need to verify that they can't get Blue Cross and Blue Shield coverage. And from what I understand, there are even some things that need to be looked at in making sure that Blue Cross and Blue Shield are providing the services to the pregnant daughter from the parents' coverage. That needs to be looked at real closely by this Commission to make sure that those services are being provided, without riders, all right, without other attachments that the employer might have to purchase.

The other area that we zeroed in on was the area of battered and abused women, which is an area of high concern to the Women in Education Committee. It's our feeling that-- We mention several things. We need a really accurate system of recording the number of cases that are occurring in the State of New Jersey. It's not a very good system for reporting. Women are often reluctant to admit that they have been battered, abused, or raped.

We have what might be considered a real radical theory on this, but a lot of us feel that part of the problem is that low status is given to those types of crimes. Oftentimes these are crimes against women based on gender; I mean, you happen to be a woman. It isn't that all of these men go out and commit these crimes because of their mothers, all right? They happen to be, you know, crimes against women, based on gender, and in New Jersey you have a law for reporting different kinds of biased crimes, but not on gender. The Federal government is in the process now, I think, of passing a similar law, but not on gender, so there is no basis of reporting gender crimes. They're simply lobbed as domestic violence often, or crimes of rape, and we all know all of the war stories about what happens when someone reports a crime of rape, and often the crimes of reporting battered -- of being battered and abused by a spouse. Little protection is offered; it's low status. All

the stereotypes exist: she deserved it, you know; it's in their culture, you know; this is the way these women are used to being treated, etc., etc., which is simply a bunch of bunk. The reality is that these women are scared and they need to be assured of some protection. And they really need some system of counseling right away, and that often is not in place.

We offered several suggestions: One is that some hospitals now have these Women Health Networks. Some programs -- whether it's those or other programs -- need to be expanded so that women, 24 hours a day, can be assured with one phone call that they are going to be able to talk to somebody who is supportive of their problem; who is going to put them in touch with whatever health services are available and whatever counseling services are available, because without that support system, they often don't follow through, and that is really sad.

And also, we need to start talking about educating our children. We need to reemphasize the need for starting early on to teach boys and girls about stereotypes, and what they mean. Rape is a word we seldom hear in health classes. We may talk about sexuality, health, sex education, but we don't talk about rape. Rape is like the biggest thing in the world and we just say, "Oh, it's something." It was really brought home to me, again with my daughter, when she was asking me what I was getting ready for, and I told her one of the things I was going to talk about was battered women and rape. She said to me, "What is rape?" She's going to be 10, and going into the fifth grade, and I realized as a parent that I've even been remiss by not really sitting down and talking to her seriously about what this meant. Certainly, she had no concept of it from education.

I think when we talk about family domestic violence-- That's another topic that we don't talk about, and I think when you couple that with what kids learn from an early-on age as stereotypical views, that's just reenforced.

The last thing that we want to talk about that's of an educational nature is: You need to look at the kind of education that -- which we should have mentioned earlier -- that pregnant teens are receiving. Our members tell us that many times there are very few school programs for these girls, and so a lot of these girls are put on homebound instruction. It's like, send them back to Aunt Millie; we'll send them to homebound, and they're not getting the same educational program. It's that simple.

If a girl is in Voc Ed, she's not getting beauty culture, being on homebound. If she goes somewhere else, to another school, is she getting the basic reading and writing, or is she getting comparable education? Title VI clearly says that they should be receiving the same education. It should be the student who decides whether they're uncomfortable being in that educational environment, and our members tell us that many times this is not happening, and that these girls are just put off somewhere or afraid to come to school, or embarrassed to come to school, and it's not something, again, that we talk about.

Again, for the boy, suddenly, like the girl disappears off the face of the earth, so there's no reminder, no responsibility that it takes two to get pregnant.

And so I think you need to look at some of those educational areas. Maybe you don't need new legislation, but you need to see what your old legislation is doing and see how it's being monitored and how it's being enforced, because I don't think it's happening out there, and that's something you need to look at. Thank you.

MS. FOX: I have a question: How does Blue Cross and Blue Shield and health services for the pregnant daughter -- whoever is covered-- Does it occur, or is it because the daughter doesn't tell the parent, or--

MS. HICKEY: I'm not-- This is an area that I was remiss in starting to get data on until really late. It's my understanding that Blue Cross and Blue Shield does cover the care for a pregnant daughter, as long as she has been designated as someone that's currently being covered on the parents' plan.

First of all, the parent has to have parental coverage, so that may limit it right there, whether the child is available for coverage.

The second part of that is-- I understand that I'm not clear on this and I will get more data on it, but I think you need to look at it also. Some places are saying that there needs to be a rider. I don't know whether that's really true or not, but there has to be--

MS. FOX: In New Jersey?

MS. HICKEY: In New Jersey there has to be this pregnant dependent child rider. I don't know whether that--

MS. SEHAM: It's pretty much a guarantee that they'll never have to pay it, because most people wouldn't put that on.

MS. HICKEY: Right, and it has to be asked for by the employer. Now that's not-- I'm getting mixed information on that. One person who spoke to Blue Cross and Blue Shield said that there was a need for this rider. Someone else in our Research Division said, "No, that's not true. You don't need this rider, as long as they have family coverage. As long as it's a minor, they are covered." So, that's my understanding of how it should be. That was the most current data I got about 15 minutes before coming here, that, "No, this rider is not something that's needed. It should be covered as long as it's family coverage and as long as it's a dependent child."

But again, the child has to go to her parents and explain that she's pregnant and then be able to get the coverage that way. And of course, once the delivery occurs, there is no coverage for the child of the child, all right? So the child of the child--

MS. SEHAM: The parent would have to go to the employer, too.

MS. HICKEY: The parent would have to-- Now the parent, who is often a teenaged girl, has to go and get coverage for the child.

MS. SEHAM: No, but I'm saying the teenager's parent would have to go to the employer--

MS. HICKEY: Right.

MS. SEHAM: --to get that coverage applied, which would be another embarrassing thing, and another possible obstacle.

MS. HICKEY: Right, right. And sometimes that just doesn't happen because the parents, unfortunately, may be the last to know, so that that early on health care is not there because the teenager just doesn't go for it. They just don't go to their parents.

MS. THORNTON: May I just add something? As I'm sitting here and listening, only because this is so current in what I'm working on with the Committee-- One of our primary studies right now in dealing with especially, teenage pregnancy, is the whole area of drug and substance abuse and the concern about lack of education in health services to assist any adolescents who may be abusing substances, who get pregnant, and then have no place to turn. What we're seeing is just a skyrocketing number of children being born today -- infants who are addicted to substances -- which is going to impact so heavily on our society. I just emphasize the need, more and more, for health services for young women -- for all women.

Substance abusing women need help immediately.

MS. HICKEY: Absolutely.

MS. THORNTON: The services just aren't there.

MS. NEWMAN: The Division on Women has a Domestic Violence Prevention Program that has an educators' training

component which works with the educators and teaches them how to recognize the symptoms of domestic violence as exhibited by the children. Would some similar type program -- because I'm thinking, I'm in Newark, and the number 300 sounds awfully low to me, considering the number of births to teenagers--

MS. HICKEY: That's reported.

MS. NEWMAN: --in UMDNJ alone. It sounds like it's higher than that. But, would a similar type program of teaching the educators on how to teach teenagers and middle school and even, I guess, in places like Newark, the elementary school-- Would something like that be helpful to the teachers?

MS. HICKEY: Oh, yes. Absolutely. Because I think the information is so current that unless you can get the current information out there-- You know, you have people who may have gotten their education 10 or 15 years ago, they need to have access to the most current information so that that can help them in what they do in the classroom. It's really important.

MS. NEWMAN: Because as I was listening to you speak, I was thinking, how important is the role of the teacher in this educating? You've got the children for most of the day, and many teachers don't want to admit that there's a possibility -- because they have the old ideas, that this just doesn't happen. There are, unfortunately, too many people in New Jersey who don't believe that teenage pregnancy is a problem.

Perhaps the teachers in Newark might know it a little better because they see it more often, but I was just wondering, how much of an active role do you see the teachers playing in trying to combat this problem?

MS. HICKEY: I think that if you don't have the educational system on board, and they don't start to educate those children from elementary school on, it's a very difficult proposition, because where are they getting the information from if they're not going to get it from the school system?

You have to then rely on them either getting the information from their parents or getting their information from some other institution -- churches perhaps, okay? -- but there's no other source of information. That's why we were so pleased with that new youth-based clinic idea, because, at least it seems to us, the school was going to be the center of where the child is going to look to get information. If the school can't provide the information, then the child often is at a loss to know where to turn to get that information, and they do have rapport, perhaps, with their nurse, with their counselor, with their classroom teacher, and they have to have-- The teacher and the school have to have that information available so that when the child comes, they've got the information to provide to the child. Then there's got to be a system in place where the information means something, that there is somewhere you can go for help, but it's critical--

MS. NEWMAN: We've had horror stories of -- and fortunately there are some very good social workers out there who can recognize it-- There was the case of a teenager who after she had the child, didn't know what to do with it; didn't know how to feed it and didn't realize that the baby could not hold the bottle itself, but that she would have to hold it. If there were a program as you describe in the school to teach them not only about caring for themselves -- perhaps in life skills courses -- but also how to care for the children--

MS. HICKEY: Right. If you could have more school-based child care for these women who have the babies, then they could get the information from the schools. That's one of the things I mentioned. It seems to me it's absolutely a hand-and-glove relationship. If you could get more of those day-care centers in the schools, then they could provide the information. Then the pregnant teen -- excuse me, the mother who is now a teenager -- would have a source of information right there to get all the information she needs about how to

care for the baby, now that she has it. Right now, that information is just not available. It's critical, and if the school, through that youth-based clinic, could provide information, here's where you go to get information on prenatal care, even have those little pamphlets there, have the information there, have a resource there that would tell them, you know, some of the things they need to start doing, I think it would make a big difference, because right now they're not getting that information anywhere, that I can determine.

MS. THORNTON: I think in Elizabeth, where they have the day-care, they rotate the teenage mothers through that day-care center, and it's part of their family life. Don't quote me, because I may not be accurate on location, but there are some sites where they are, in fact, providing day-care, and it is the teenage mothers who are actually there caring for these infants and learning how to care for them at the same time. So, they have found a way to meet a social need with an educational component, which-- But, we just don't have enough of that.

MS. FRANCIS: Well, you used the magic words that I was going to ask about, which are "family life education." The mandate that exists in New Jersey for that is up for renewal, I understand, within some months in the fall. It was a five-year mandate, which is going to be looked at again, and I would be interested -- I mean, I think I know what your answer would be, but my question is: Would you recommend renewing it?

MS. THORNTON: Absolutely.

MS. FRANCIS: Would you also-- In line with your third recommendation, where you say, "There should be educational health programs to provide information on gender stereotyping, domestic violence, rape," and so on, it seems to me that that is part of what the intention of family life education was, but I also know that when it was set up, it was carefully framed so that local-- The curriculum planning was

left to the local districts, probably rightly so given the home rule mentality in this State. It may not have gone through otherwise. But could you see recommending any part of curriculum to be mandated to include some of these topics along with the renewal?

MS. HICKEY: Well, I think it's a good idea to at least recommend what you think topics should be, and then it seems that you can still allow the local school district to best then fashion how those topics might be covered in their school district. But it would seem to be logical to at least have a list of topics that you feel are important areas that need to be addressed. You can still bring in that concept of home rule by saying, "Okay, you need to discuss rape. You may decide here in this particular district whether you should discuss it in the fourth grade or in the fifth grade, and how you are going to handle it," or whatever, which still allows for local flexibility. Without a list of things that need to be addressed, I think that, unfortunately, there may not be enough consistency from district to district to ensure that family life education really covers a lot of critical topics.

MS. FRANCIS: Is NJEA concentrating on that renewal issue? I mean, are you prepared to address that?

MS. HICKEY: We're aware of it, and I believe that we have a program, you know, a system in place where we're going to be addressing that, but we were in favor of that the last time. We offered testimony on that, and we believe it's something that really needs to be looked at.

MS. FRANCIS: If it's as controversial this time as last time, it will be interesting.

MS. HICKEY: It's going to be controversial. I think that part of the problem-- The reason for that is that you often find parents who feel that, you know, here we have schools, and perhaps government, interfering in things that are strictly family issues. But I think that we have such a need

in this State and that if you look at those statistics for pregnant teenagers, it's not something that we can ignore. I think we can't just say that this is a family matter to be discussed. It's something that's critical. We have to start educating, and educating early on, because there are those horror stories. I mean, I have been out of the classroom for five years, and I was an eighth grade teacher. The last year I was there I had a girl come back in the ninth grade -- and I taught in Toms River, okay, not Newark -- with her baby in hand. That was five years ago, and she was pregnant almost as soon as she graduated from eighth grade, and was not continuing her education. It was a very depressing situation. As you say, many of these cases are not reported, so I think that 7022, which was from 1988, really represents only a portion of the number of pregnant teens in the State of New Jersey. So, they're not getting education at home, and they've got to get the information somewhere.

MS. FRANCIS: One last question about, again, a controversial issue, but there was a bill proposed that didn't get too far in the Legislature, to say that school-based clinics should not be allowed to dispense any information on birth control, or pregnancy-related issues, especially abortion referrals, etc. Does NJEA have a position on that bill, and how would you say that issue should be addressed?

MS. HICKEY: I'm not an NJEA lobbyist. We work in the Instruction Division, so I'm not sure what our position is. I can tell you that we have strong policy that says that we are in favor of reproductive freedom for women, and that included in that policy there is information that says we believe that information should be provided on all methods of birth control to men and women. If that means through clinics or whatever, we strongly advocate that position. This I know about, since I was instrumental in our passing that policy. I know we have strong policy on that.

MS. FRANCIS: Thank you.

MS. FOX: Does anybody else have a question? (no response) Thank you.

MS. HICKEY: Thank you.

MS. FOX: This concludes our hearing. We'll be using this information for our own discussions, and will also hopefully be providing it to the Governor for his study of health care in New Jersey. Thank you.

**(HEARING CONCLUDED)**



**APPENDIX**



Testimony  
Commission on Sex Discrimination in the Statutes  
Nancy Florentino  
June 26, 1990

Alcohol and Drug Addiction Among Pregnant Women

The estimated number of births in the United States affected by alcohol and drug use is 300,000-375,000. There were 117,000 live births in New Jersey in 1989. Using the national estimate of 11%, there were 12,870 drug exposed infants born in New Jersey last year. Using the FAS rate of 1/500 births, there were 234 FAS babies born. The total number of drug and alcohol exposed babies in New Jersey is at least 15,210. Many more babies were born with fetal alcohol effects, which are not included in this estimate. There are large variations in rates due to geographic and demographic differences. We have been told the rate is 35-50% in Atlantic City and Trenton and higher in Newark. In New Brunswick both local hospitals are conducting a survey to determine actual prevalence there among all women admitted for delivery. This data is not routinely collected and reported.

The societal response has been one of denial followed by mystification. "Why don't they stop?", Ted Koppel asks for the American people. This question misses the most essential fact about addiction: that it is, by definition, characterized by loss of control, the inability to stop. Addiction is not willful misconduct. It is a physiological and psychological urge like an instinct. The craving is so beyond human understanding that laboratory animals take cocaine until death. Treatment programs operate like traditional therapy but in part they do what has been called a "brainwash" about addiction. Even with intensive work in this area, relapse is not uncommon and may serve as part of the recovery process. Nonetheless treatment does work. We have scores of women, whose lives were hopeless a year ago, who now have clean and sober babies and lives.

The next societal reaction is: "If they can't control themselves, we should control them." Nationally, fifty women have been prosecuted for distributing drugs to a minor, their fetus. Between 18 and 25 states regard a positive toxicology or drug screen at childbirth pro forma as evidence of neglect. Children are removed from their mother's custody straight from the hospital.

In New Jersey, there has been at least one prosecutor, who asked the Health Department to join him in prosecuting a pregnant addicted woman. When offered treatment, the woman consented. When a hospital or physician reports a drug exposed infant to DYFS, a family investigation is undertaken, the baby is not automatically placed. This year there will be funds for family interventions to teach the methodology to DYFS drug and alcohol workers. Drug and alcohol addicted families can be organized and empowered to move their addicted loved one into treatment, possibly instead of removal of children.

Pregnant addicted women cannot give their babies what they do not have themselves. When 935 mothers of low birth weight babies were offered intervention, 96% agreed and complied for three years. These women want and need care and treatment, not censure and punishment. What if an arrest for DWI were to constitute reckless endangerment of minor children? What if these drivers were subject to prosecution and loss of custody because they drove while intoxicated? This is not likely to happen, in part, because intoxicated drivers are mostly men, middle class, and white.

### Alcohol and Drug Problems

#### Progress

- Consumption of alcoholic beverages is declining and has been during the last decade or so.
- Cirrhosis of the liver, a leading indicator of late stage chronic alcoholism, is down, reflecting intervention and treatment at younger ages.
- Drug use in high schools is also on a downward trend according to the most recent national survey.
- Drug related emergency room contacts in the last quarter of 1989 dropped 20% after a long period of steady increases.
- A dopamine receptor gene has been located which may help explain addiction. This would confirm a long held hypothesis that there is a genetic base.
- Self help networks are available everywhere. They are free and demonstrate success for over a million people in the United States. There are 1,500 meetings a week in New Jersey.

#### Obstacles

- Only 30% of the Government's 10 billion dollar effort is earmarked for treatment.
- Objective clinical drug and alcohol assessment and testing are still not routine in health settings, correctional facilities, social service agencies, work and school settings.
- Treatment for addiction is not available to all who request it, especially underserved high risk groups, the poor, and anyone with any complications such as medical or psychiatric problems, hearing impairment, disability, acting out behavior, homelessness, etc.
- Clients are seldom matched to treatment setting based on characteristics which predict outcome. For example persons with intact family, employment and health can recover with intensive outpatient, but they are the ones who are sent to residential treatment because they have good insurance coverage.

- With all of the treatment available, we are only serving one in fifteen or twenty addicted persons.

Alcohol and Drug Addiction: Its Impact on Women

- The illness is telescoped. Women get sicker faster, using less of the substance.
- Women suffer more medical and social consequences from drinking and drugging.
- Addicted women are stigmatized and the thought of pregnant addicted women offends. Women are held to a higher standard of conduct.
- Men with addicted women desert them. Women with addicted men and children stay, thereby developing the co-dependence syndrome, an illness in its own right, characterized by medical and emotional symptoms and impaired functioning.
- Women are more likely to begin drinking in response to death, divorce or disability, their own or a loved one's.

Alcohol and Drug Addiction Services for Women

- Women in treatment usually do have access to separate women's treatment groups. This is essential to allow a forum for dealing with incest and abuse, both of which are almost universal in an addicted population.
- There are eight halfway houses for alcohol and drug addicted women in New Jersey. They are safe refuges to support the recovery process. Each one has to turn away up to two dozen women in need of such placement daily.
- The local Councils on Alcoholism and Drug Abuse do advocacy and education on women and addiction. Each staffs county task force. Some have removed alcohol from maternity wards. Others have gotten local ordinances to require posting warning signs "A pregnant women never drinks alone." and other health warnings.
- In the eight perinatal care centers with the highest risk for infant mortality, risk reduction specialists screen pregnant women for drug and alcohol use and addiction. Five hundred addicted women were identified and counseled last year.
- Ten residential treatment programs have developed a pregnant women's treatment initiative. Last year 356 women were treated. Between 125 and 200 of them were pregnant. All records did not contain notes on the pregnancy. This problem has been corrected for this year and the program has been expanded by one third.
- A comprehensive one stop multi-service center has been established in New Brunswick to offer support to pregnant addicted women. Treatment for addiction, child care, transportation, parenting training are all accessible from one little white house.

JX

- Several programs are now offering simultaneous treatment to the children of addicted families while the mothers are in a group of their own on an outpatient basis.
- Intervention with low birth weight mothers and babies has been shown in randomized clinical trials to improve both academic performance and behavior problems, raising I.Q.'s 6 to 13 points.
- Proper nutrition and regular perinatal care have been shown to produce healthier mothers and babies by raising low birth weight and early detection of potential problems.

#### Obstacles

- The Women, Infant and Children Nutritional Supplementation Program has been cut at the federal level due to an 8% increase in food prices. This means less cheese, peanut butter and juice for pregnant women.
- Perinatal care is also experiencing cutbacks. In Monmouth County, one center, which serves 600 pregnant women a year, will be curtailing services.
- Low birth weight is of such seriousness, it persists across generations. Black mothers who are middle class still have twice as many low birth weight babies as their white counterparts.
- Specialized care for children damaged by cocaine addicted mothers is estimated to have surpassed the 2.5 billion dollar level this year.

#### Recommendations

We need a statewide Commission or Office on Families, Health and Addiction. Women and children need specialized programs and they need improved cooperation among agencies which serve them. New Jersey data should be gathered, cases documented, advocacy offered. There should be a state plan transferring new knowledge from empirical research into programs to strengthen families and to prevent their deterioration. The state plan should incorporate education, health and welfare objectives.

There are other public policy options deserving of consideration by such an office.

They include:

- Pregnancy testing in all drug and alcohol treatment programs.
- Drug and alcohol assessments and testing in all perinatal care programs.
- Ban on alcohol and tobacco advertising.
- Drug and alcohol testing for all trauma cases in hospital emergency rooms.

- Holding alcoholic beverage license holders responsible for serving pregnant women the way we do for underage persons.
- Posting warning signs in all obstetric and gynecological service settings.
- A household survey of needs and public support.
- Efforts to combat racism, sexism and classism.

There are other public policies which would be of immediate help and which require little debate:

- Establish a master plan for siting facilities for addicted women and children, superseding local zoning requirements.
- Require interagency linkages among service providers. as part of funding. These include drug and alcohol treatment, perinatal care, medicaid for the unborn, AFDC, DYFS, special education, WIC and others.
- Codify for interagency cooperation the methodology for exchange of information while protecting confidentiality and privacy.
- Allow for fast track administrative reviews and approvals for Certificate of Need, licensure and rate setting mechanisms for treatment facilities to serve pregnant addicted women and their children.
- The federal funds should have 25% women setaside, 10% of which is earmarked for pregnant addicted women.

There are special treatment needs of this population. It is a very deprived group. As individuals these women have been victimized. Every fifteen seconds a woman in America is beaten. Some of these women display sexual acting out, even prostitution. Usually they are incest survivors and frequently they are in abusive relationships. (These provocative behaviors are defenses that disappear with good treatment.)

These women need support of the kind that is demonstrated to be effective. They need long term, in home support for recovery from addiction and help in caring for the infant, (often a difficult and damaged infant). Providing services to these women now will prevent the specter the Trenton Times described of one third to one half of all Trenton school children in the year 2000, handicapped in academic performance and behavior problems due to drug exposure in pregnancy.

A pregnant addicted women has the right to:

- be treated with dignity and respect.
- sufficient and healthful food.
- intervention and treatment for addiction.
- safety and security.
- freedom from physical harm.
- freedom from sexual abuse and sexual pressure.
- perinatal care and treatment.
- child care sufficient to participate in addiction and perinatal treatment.
- transportation sufficient to support treatment for addiction and pregnancy.
- housing for herself and her family.
- education in the stages of development of the infant and child.
- education in the special needs of drug and alcohol affected infant and child.
- social and emotional support to ongoing recovery.
- confidentiality and privacy in the handling of her treatment needs.
- HIV counseling, testing and treatment.
- Information about benefits and services available to her and her family.

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Division of Alcoholism and Drug Abuse Funds Treatment  
for Pregnant Alcoholics and Addicts

Since September 1989, the Division of Alcoholism and Drug Abuse has funded 10 centers to treat pregnant and indigent women. The original grant, \$1,000,000, has been increased to 1.35 million in 1990-1991.

Female alcoholics and addicts face more than their share of roadblocks in recovery. Many have children, and no safe place to leave them. Few agencies are equipped to house a recovering woman and her children for extended aftercare. A pregnant woman is often under greater stress. Social disapproval of her behavior, from peers and some well-intentioned helpers, may blame her even further into her addiction. Personnel in therapy and agencies may be leery of detoxification's effect on the fetus, and unsure of their liability. Many are not licensed to work with addicts on birthdays. The Division looked to destigmatize this experience, and establish a national model for treating pregnant addicted women, and for PAS prevention.

The eight risk reduction specialists in their first year have identified 500 pregnant addicted women. The pregnant women's treatment project, during its first year, is expected to treat about 350 women, of whom 125 are expected to have been pregnant.

The agencies have reported many success stories. One client named her child for the head nurse at the facility. A grant "alumna" addressed a meeting held by the division for the 10 agencies, thanking them for their interest, and asking them to continue their efforts. Another place found that none of its pregnant clients had relapsed, six months after completing treatment. One director reported that "Without the grant, we wouldn't even have tried to treat pregnant women. Now we know it's possible. They calmed the place down."

Currently, one agency, the Center for Addictive Illness in Morristown, accepts pregnant clients on methadone. The Division is working to increase this number, and towards an agreement to work with pregnant adolescents at another center.

Prepared by:

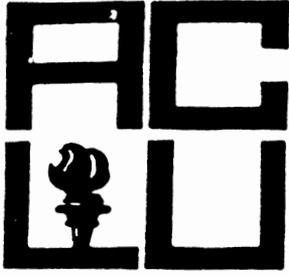
Christine Deaton,  
NY Department of Health  
Division of Alcoholism & Drug Abuse

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Pregnant Women's Treatment Programs

1. Center for Addictive Illness  
95 Mount Kemble Avenue  
Morristown, New Jersey 07962-1978  
  
Contact Person: Claire Bogan  
(201) 285-4700
2. Century House  
Riverview Medical Center  
35 Union Street  
Red Bank, New Jersey 07701  
  
Contact Person: Mary Anne Ruane  
(201) 530-2415
3. Harbor, The  
1405 Clinton Street  
Hoboken, New Jersey 07030  
  
Contact Person: Dennis E. Bosco  
(201) 656-4040
4. John E. Runnels, Hospital of Union  
County  
Bonnie Burns Road  
Berkeley Heights, New Jersey 07922  
  
Contact Person: Jeff Firsichbaum  
(201) 322-7242
5. New Hope Foundation, Inc., The  
P.O. Box 66  
Marlboro, New Jersey 07746-0066  
  
Contact Person: George J. Mattie  
(201) 946-3030
6. Parkside Lodge of New Jersey  
East 2nd Street and Pancoast Road  
Moorestown, New Jersey 08057  
  
Contact Person: Jane Rinkin  
(609) 235-7900
7. Seabrook House  
705 Polk Lane  
Seabrook, New Jersey 08302  
  
Contact Person: Ed Diehl  
(609) 455-7575
8. Sunrise House  
P.O. Box 600  
Lafayette, New Jersey 07848  
  
Contact Person: Beth Nathan  
(201) 383-6300
9. Turning Point, Inc.  
P.O. Box 111  
Hilltop-Sanitarium Road  
Verona, New Jersey 07044  
  
Contact Person: Jim Piero  
(201) 239 9400
10. West Jersey Hospital  
Residential Alcoholism Treatment  
Program  
Northern Division  
Mt. Ephraim and Atlantic Avenues  
Camden, New Jersey 08109  
  
Contact Person: Ted Millard  
(609) 342-4505

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# American Civil Liberties Union of New Jersey

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**TESTIMONY OF DEBORAH A. ELLIS, LEGAL DIRECTOR  
AMERICAN CIVIL LIBERTIES UNION OF NEW JERSEY**

**BEFORE THE COMMISSION ON SEX DISCRIMINATION IN THE STATUTES  
PUBLIC HEARING ON HEALTH  
JUNE 26, 1990**

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I'm Deborah Ellis, the Legal Director of the ACLU of New Jersey, and I'm pleased to have the opportunity to testify here today. Before coming to New Jersey, I was a staff attorney at the Women's Rights Project of the national ACLU office in New York. One of the areas I concentrated on there was gender discrimination in insurance and since coming to New Jersey I have continued that work, writing an amicus brief for the ACLU and other groups challenging Blue Cross/Blue Shield's use of gender based rates in its individual policies.

In my testimony I urge a simple amendment to New Jersey's statutes: that the "Unfair Discrimination" provision of the insurance law, N.J.S.A. 17B:30-12 be amended to prohibit health insurance rates based on gender as well as the prohibitions it now contains: "discrimination based on race, creed, color, national origin or ancestry."/1 My recommendation stems from the fact that it is still not only possible, but common, for insurance companies to charge health insurance rates based on gender. Because women are generally charged higher rates than men for health insurance, this discrimination has severe economic harm. For women who are not provided health insurance by their

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1/ Section 17B:30-12 provides:  
No person shall discriminate against any person or group of persons because of race, creed, color, national origin or ancestry of such person or group of persons in the issuance, withholding, extension or renewal of any policy of life or health insurance or annuity or in the fixing of the rates, terms or conditions therefor, or in the issuance or acceptance of any application therefor.  
See also N.J.S.A. 17:29B-4(7)(c).

employer, an increasingly large segment of the population, the resultant high premiums can put health insurance out of their reach.

Let me explain some background. Title VII of the Civil Rights Act of 1964, 42 U.S.C. Section 2000e et seq., prohibits differential rates or benefits for insurance offered through employment, including pension and annuity plans. Thus, for those women and their children who are fortunate enough to have health insurance coverage through their employer, there is no problem. However, in all other cases insurance companies continue to charge women more for health insurance. The only exception is Blue Cross/Blue Shield, a company that is highly regulated in New Jersey and has been prohibited from basing rates on gender. In sum, the private insurance market is one of the only areas in American life where overt discrimination on the basis of gender is still tolerated. That this discriminatory practice is widespread does not, however, justify its perpetuation in the face of New Jersey's constitutional mandate of equality contained in Article I, paragraph 1. As I'll talk about in more detail below, other invidious classifications, such as religion and race, once widely used by insurance companies, are no longer used in recognition that such discrimination is unconstitutional and inherently unfair. For reasons both of civil rights and economic equity, the ACLU believes that gender can no more be a basis for insurance pricing than can other prohibited classifications.

When they are charged more for health insurance, women and

children in the ever-growing number of female-headed households suffer adverse health consequences. Concentrated in low-wage, part-time and small business jobs, women are less likely than men to receive insurance benefits as employees, and are left with purchasing health insurance on the individual insurance market. The higher health insurance rates women face lead them to purchase less comprehensive coverage or no insurance at all. This absence of affordable insurance coverage in turn reduces access to health care to the detriment of women and their children./2 These effects are particularly severe for women and children of color. For example, African American children in employed families are far less likely than their white counterparts to be insured./3

Although it is true that insurance companies group people for risk classification, it is also true that any individual can be grouped according to several characteristics for health insurance: religion, race, gender, ethnicity, age, residence, smoking, alcohol use, weight, hazardous work and hobbies, medical history, diet and exercise, and that many, if not all, of these groupings might be useful tools to predict accurately the risk of anticipated loss. However, when insurers classify by the

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2/ Babies born to women without insurance are 30% more likely to die or be seriously ill at birth. See "Babies of Uninsured Parents Found to Be at Risk," N.Y. Times, Aug. 24, 1989, at B13.

3/ More than 30% of African American children in moderate-income families had no employer coverage in 1986, as compared to less than 20% of similarly situated white children. Children's Defense Fund, "A Vision For American's Future," at 7-9 (1989).

prohibited classifications of race, religion, ethnicity, or gender, they run afoul of New Jersey's constitutional commitment to treat people as individuals, not as members of racial, religious, sexual, or ethnic groups.

The same justification that is now offered to explain gender classifications -- actuarial relationship of the classification to the risk of loss -- was once a rationale accepted for charging differential rates based on other prohibited characteristics, such as race and religion, even though risk classifications based on religion or race are now rejected as unconstitutional and contrary to public policy. See Lange v. Rancher, 262 Wis. 625, 56 N.W.2d 542 (1953) (state insurance commissioner may not bar African Americans from state insurance program simply because statistics show that African Americans as a group have a lower life expectancy)/4; J. Greenberg, Race Relations And American Law 87 (1959) (discussion of state statutes prohibiting race discrimination by insurance companies).

The statistical arguments that are now advanced to justify gender based rates are identical to those advanced in the past to validate rates based on religion or race and are equally

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4/ In Lange the insurance commissioner defended the discrimination and the trial court approved it for a reason analogous to that of Commissioner Merin here, i.e., that it was generally accepted in the insurance business. "[I]t is the practice of life insurance companies generally, that insure both white and Negro lives, to differentiate between them, either by charging a higher premium for insuring Negroes, or allowing a lesser commission to agents for selling insurance to Negroes, and limiting the solicitation of Negroes." 262 Wis. at 635-36 (Fritz, C.J., dissenting).

unconstitutional. Although statistical differences between racial and religious groups still exist, especially in the area of health and life insurance, see e.g., Los Angeles Dep't of Water & Power v. Manhart, 435 U.S. 702, 709 n.15 (1978), today insurance companies properly do not use race or religion as a classification characteristic./5 Thus, stripped of the aura of mystery surrounding statistics and actuarial tables, the industry's use of gender as a proxy for other characteristics is most aptly described as an administratively convenient generalization.

George Santayana said that those who do not learn from the past are condemned to repeat it. In that context, I think it is important to note that historically, the rating and classification practices of the insurance industry have been in tension with the ideals of equality for which America strives. In the 1870's the first insurance offered to freed African American citizens was offered at the same rates as to white customers./6 By 1881, however, insurance companies found that mortality differences made it administratively convenient to

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5/ However, there are still those who support discrimination against racial and religious minorities. See Benston, The Economics of Gender Discrimination in Employee Fringe Benefits: Manhart Revisited, 49 U. of Chi. L. Rev. 489, 511-12 (1982) (arguing that the additional risk of sickle cell anemia in African Americans or Tay-Sachs disease in Jews should be accounted for by charging higher life insurance rates for African Americans and Jews).

6/ M. James, The Metropolitan Life: A Study in Business Growth 338 (1947).

charge higher rates for African American customers./7 Some companies started to apply higher premium schedules for African Americans than for white customers, charging African American customers one-third more, or providing one-third less insurance for the same premium than for whites. Other companies stopped writing insurance on African Americans entirely or denied commissions to agents who sold policies to African American customers./8

Massachusetts was the first state to outlaw these practices; in 1884, led by a African American legislator, it passed a law forbidding the charging of higher premiums to African American citizens than to white citizens./9 Despite protests by insurance companies (some companies entirely refused to do business with African American customers, leading to the rise of insurance companies owned by African Americans)/10, a few other states, including New Jersey in 1902, soon followed Massachusetts'

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7/ F. Hoffman, History of the Prudential Insurance Co. of America 137 (1900).

8/ Id. at 137-38; M. James, supra note 6, at 338. See generally, G. Myrdal, An American Dilemma: The Negro Problem and Modern Democracy 316-17, 955, 1262-63 (1944) (history of differential treatment accorded blacks by white insurance companies); M.S. Stuart, An Economic Detour: A History of Insurance In The Lives Of American Negroes (1940); G. Stephenson, Race Distinctions In American Law 138-140 (1910); Note, The Constitutionality of Racial Classifications in Mortality Tables, 11 Rutgers L. Rev. 757 (1956).

9/ F. Hoffman, supra note 7, at 153; Mass. Gen. Law Ann. ch. 175, section 122.

10/ G. Myrdal, supra note 8, at 316-17.

lead/11 although most states continued to allow companies to charge higher rates to African Americans. As late as 1961, insurance texts justified race-based rates as "rational discrimination" contending that "[t]here is no more social discrimination involved in setting a different rate for a race which shows a higher average mortality than there is in setting a different rate for any other statistical reason." R. Mehr & R. Osler, Modern Life Insurance 471 n.8 (3d ed. 1961).

Insurance companies have also used religious characterizations to set rates. As recently as 1954, Harry Dingman, the Vice President of Continental Assurance Company, combined statistical knowledge with stereotypical assumptions to advise insurers:

Jew tenacity of life is notorious .... Despite urban crowding, tuberculosis and other infections, disease has taken less toll of Jews than non-Jews. Now that urban living has proved superior to rural in longevity the Jew is a better life risk than heretofore. He drinks less than non-Jews. He has syphilis less often. He eats too much, with higher than average incidence of obesity and diabetes .... For life insurance, Jews are excellent risks .... For disability insurance, Jews are expensive./12

When charged with discriminating on the basis of race and religion, insurance companies, as they do today to defend rates based on gender, argued that it would bankrupt the industry to prohibit such classifications. For example, in 1900, after the

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11/ Connecticut outlawed race discrimination in insurance in 1887, Ohio in 1889, New York in 1891, Michigan in 1893, Minnesota in 1895, and New Jersey in 1902. M. James, supra note 6, at 448 n.70.

12/ H. Dingman, Risk Appraisal 116 (1954).

first anti-discrimination laws were passed, a statistician for the Prudential Insurance Company fulminated that race discrimination laws were motivated by "sentimental considerations" and "in defiance of the laws of mortality and ordinary business conduct."/13 Although, like gender based rates, the industry defended the race based rates as necessary for its financial well-being, in fact, no economic dislocations occurred in insurance markets following the introduction of non-discriminatory rating practices.14

The use of rates based on race and religion declined in the 1960's. In the wake of the civil rights movement, insurance companies realized that if they did not voluntarily desist from such practices Congress inevitably would enact legislation prohibiting them from charging differential rates./15 Because the transition was voluntary, it was not monitored by any federal agency or state commissioners./16 In fact, although it was widely believed that insurance companies had completely stopped using race and religion in insurance ratemaking, a recent survey

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13/ F. Hoffman, supra note 7, at 153, 138.

14/ See, e.g., M. Gray and S. Shtasel, Insurers are Surviving Without Sex, 71 A.B.A.J. 89, 91 (1985).

15/ Although rates based on race and religion have always been constitutionally suspect, the Supreme Court's decision in Jones v. Alfred Mayer Co., 392 U.S. 409 (1968), that 42 U.S.C. Section 1982 applies to private as well as public entities, made explicit the illegality of rates based on race. See also Patterson v. McLean Credit Union, 109 S. Ct. 2363, 2369-72 (1989)(Section 1981).

16/ See Justifying Unisex Insurance: Another Perspective, 34 Am. U.L. Rev. 329, 352 n.139 (1985).

by the National Association of Insurance Commissioners ("NAIC") revealed that some companies continued to charge higher rates to African Americans on whole life policies sold years ago. NAIC immediately condemned the practice as "inherently unfair and unacceptable as a matter of public policy." NAIC Resolution Regarding Race Differential Premium Rates, Adopted June 1988.

As with the history of race discrimination in insurance, today legislatures, insurance commissioners and courts are gradually recognizing that gender based insurance rates are also invidious in a nation committed to equality. In 1985, Montana became the first state to bar gender in all forms of insurance. Mont. Code Ann. 49-2-309./17 In 1987 Massachusetts became the first state to ban administratively gender discrimination in all forms of insurance. See 211 C.M.R. 35.00 et seq. Following the decision in Bartholomew v. Foster, 541 A.2d 393 (Pa. Commw. Ct. 1988), aff'd mem., 563 A.2d 1390 (Pa. 1989), the Pennsylvania Insurance Commissioner proposed regulations banning gender discrimination in all forms of state approved insurance.

The New Jersey legislature expressed its disapproval of religious and racial classifications long ago, see N.J. Stat. Ann. 17:29B-4(7)(c), and the "inherent unfairness" of gender based rates led a previous New Jersey Insurance Commissioner to recommend that they not be used for auto insurance. He found:

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17/ Three other states, Hawaii, Michigan, and North Carolina, bar gender rating in auto insurance only. Hawaii Rev. Stat., tit. 17, sections 294-33; Mich. Comp. Laws 500.2027(c); Gen. Stat. N.C., sections 58-30.3 and 30.4.

Sex-based classifications are of the highest order of concern. Price classifications based on sex-related stereotypes amount to the type of discrimination which has been targeted for elimination of all phases of commercial life by New Jersey's courts and legislature. Sex discrimination is no less offensive to the public policy of this State than discrimination based on race or religion./18

In March, Judge Sylvia Pressler of the Appellate Division invalidated the demographic rating system used by Blue Cross. In the Matter of the November 14, 1989, Non-Group Rate Filing by Blue Cross and Blue Shield, 239 N.J. Super. 434 (App. Div. 1990). Although she did not reach the issue presented by ACLU-NJ and other groups as amici curiae that gender-based rates violate the constitution, she suggested that the Legislature might opt to delete gender rating in the future, either "as a matter of constitutional <sup>§</sup>pro~~s~~cription or public policy." 239 N.J. Super. at 453 n.6.

When New Jersey adopted a new constitution in 1947, the only change was that the word "persons" was substituted for "men." The legislative history demonstrates that this change was intended to guarantee full equality for women. For example, Governor Alfred E. Driscoll made specific reference to the equality issue in his closing remarks to the Constitutional Convention:

I, for one, do not presume to review the choices you have made in free and open Convention. Who is to say

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18/ In re Hearing on Automobile Insurance Classifications and Related Methodologies, Final Determination, at 41, para. 127 (N.J. Dep't of Ins. Apr. 1981), rev'd & remanded on other grounds, No. A-3909-80T2 (App. Div. May 23, 1985).

that the law . . . which [was] fixed by . . . the Bill of Rights since 1844 is any more fundamental in character than the [new] law of taxation, or of labor relations, or than of equal rights for women.

I Proceedings of The New Jersey Constitutional Convention at 929 (1947)(emphasis added). See also Note, Rediscovering the New Jersey E.R.A.: The Key to Successful Gender Discrimination Litigation, 17 Rut. L. J. 253, 270-75 (1986)(discussion of 1947 Constitutional Convention); Comment, Sex Discrimination and the New Jersey Constitution After Peper v. Princeton, 6 Women's Rights L. Rep. 133, 135 n.27-30 (1980)(same). In Peper v. Princeton University Board of Trustees, 77 N.J. 55, 78 (1978), the Supreme Court affirmed that the change from "men" to "persons" in the 1947 Constitution granted women "rights of employment and property protection equal to those enjoyed by men."

Integrating New Jersey's strong commitment to gender equality with insurance case law and policy from other jurisdictions compels the conclusion that charging women more for health insurance cannot be reconciled with Article I, Paragraph 1 of the New Jersey Constitution. Application of New Jersey's constitutional balancing test reveals that there is no showing of public need that could be made here to justify the infringement of an important personal right, especially because "New Jersey accords a high priority to the preservation of health." See Right to Choose v. Byrne, 91 N.J. 287, 308-09; 304 (1982).

Although it may be administratively convenient for insurance companies to use gender based classifications as a proxy for

individual characteristics, Tomarchio v. Township of Greenwich, 75 N.J. 62, 72 (1977), teaches that administrative convenience never justifies discrimination. Arguments from administrative convenience are nothing new and are not confined to insurance. Employers also once engaged in the same sort of invidious but convenient discrimination in selecting their workforce; for example, hiring only men for jobs which required physical strength, despite the fact that many individual women could perform the work equally well. See, e.g., Dothard v. Rawlinson, 433 U.S. 321 (1977). In Peper v. Princeton, supra, the Court held that "sex based presumptions," 77 N.J. at 79, could not be used to deny women employment rights. Neither can such sex based presumptions be used to "jeopardize the health ... of poor women." Right to Choose, 91 N.J. at 310. It is time to demand equality in the insurance market so that gender stereotyping can be eliminated from insurance, together with the attendant economic harm to individual women and their children that it causes. I urge the Commission to rectify the omission of gender in the New Jersey prohibition on insurance discrimination by adding "gender" to the list of prohibited discriminations in N.J.S.A. 17B:30-12(a). Thank you for the opportunity to testify here today.

*This transcript has not yet been proofread against video tape and cannot, for that reason, be guaranteed as to accuracy of speakers and spelling. -JPM-*

ABC NEWS NIGHTLINE Show #2367  
Air Date: June 19, 1990

## Jailing Pregnant Drug Users: Does It Help or Hurt?

**TED KOPPEL:** *[voice-over]* It's a national tragedy. More than 300,000 babies born every year to mothers who use illegal drugs; many of the infants born crippled by the drugs, others die. One controversial deterrent: criminal prosecution of the mothers.

**DAVID HAGERMAN, Prosecutor:** When she caused injury to an innocent person, in this case an infant, it fits the elements of the criminal abuse statute, and I'm constitutionally obligated to prosecute that conduct.

**KOPPEL:** *[voice-over]* But not everyone agrees.

**ALAN RAPOPORT, Attorney:** I think that the "war on drugs" has degenerated into a war on women.

**KOPPEL:** The controversy tonight.

**ANNOUNCER:** This is ABC News Nightline. Reporting from New York, Ted Koppel.

**KOPPEL:** This is a program about how the law is struggling to adapt to social change. In this case the social change involves the dramatic increase in the use of illegal drugs, especially crack cocaine. Not just in general, but specifically by pregnant women. The babies born to these women are more likely to be malformed, hyperactive, irritable and suffering from neurological problems. Not unreasonably, then, lawmakers are trying to find ways of discouraging pregnant women from using drugs. But whether these ways are causing more good than harm, whether indeed they are even constitutional, is still somewhat up in the air.

The motives may be of the highest order, but the end result is still the subject of a fierce legal debate. We begin our examination of this story with Nightline correspondent James Walker.

**JAMES WALKER, ABC News:** *[voice-over]* They are the smallest, most vulnerable, most innocent victims of the nation's drug crisis. Their plight is leading more and more prosecutors to treat their mothers, pregnant addicts, as criminals.

California, 1987. Pamela Rae Stuart, a drug addict, is one of the first women in the nation criminally charged with neglecting her fetus, which dies four weeks after birth. Florida, 1989. Jennifer Johnson is the first woman convicted in the U.S. of transferring drugs to her newborn through the umbilical cord. She's sentenced to 15 years probation.

In just the last three years, 13 states have launched prosecutions of women for drug use during pregnancy. The most recent conviction was in Kentucky. In late May, jurors convicted Connie O'Neill of criminal abuse of her son, Steven Tyler O'Neill, who suffered drug withdrawal hours after his birth last December. Connie

O'Neill is 34 years old, mother of three, who for the past 17 years has been addicted to drugs, most recently painkillers Percodan and Dilaudid. Her addiction is no secret.

*[interviewing]* During the course of your pregnancy, you did shoot up?

**CONNIE O'REILLY:** Yes.

**WALKER:** How often did you shoot up?

**Ms. O'REILLY:** Usually every day.

**WALKER:** Every day. You knew that this would have an effect on the baby that you were carrying.

**Ms. O'REILLY:** Yes, I did.

**WALKER:** *[voice-over]* O'Neill's trial focused on a mother's responsibility for the health of the fetus.

**GARY BRANHAM, Juror:** She did admit at the hospital that she had taken drugs the night before she gave birth.

**TOM REYNOLDS, Juror:** The testimony was that the baby was in pain, suffered several symptoms that required it to be treated for withdrawal symptoms.

**WALKER:** And you felt that it was the mother's responsibility?

**Mr. REYNOLDS:** Absolutely. Her drug addiction was not on trial. What was on trial was whether or not she abused her child.

**WALKER:** *[voice-over]* After deliberating for only 35 minutes, the jury found O'Neill guilty, and recommended she be given the maximum sentence on the abuse charge, five years in prison.

**SHARON STEWART, Juror:** Most women would take especially good care of themselves during a pregnancy. I mean, what you want to do to your own body is one thing, but what you're going to do to an unborn child is something else.

**WALKER:** *[voice-over]* Judge Charles Sennette agreed.

**Judge CHARLES SENNETTE:** I must weigh your rights against the rights of the child. That child has a constitutional right to come into this world free of any drugs.

**WALKER:** *[voice-over]* Faced with the prospect of imprisonment, O'Neill began to consider therapy as an alternative.

*[interviewing]* Connie, what would you say to the jury members who convicted you?

**Ms. O'NEILL:** I don't think jail is the right answer for this. I think that I should have had professional help counseling.

**WALKER:** While Connie O'Neill's jury felt her conviction and sentence was appropriate, there are others who believe that drug abuse should be handled as an illness, not a crime, and that the focus should be on treatment, not punishment.

*[voice-over]* In Muskegan County, Michigan, the use of prosecution to encourage drug treatment has come to a head for Kimberly Hardy, the first woman in the state charged with child abuse and with delivering cocaine to her baby through the umbilical cord. Hardy sought treatment before her arrest, but according to prosecutor Tony Tagg, that wasn't early enough.

**TONY TAGG, Michigan Prosecutor:** We're trying to send a strong message that mothers, if they learn they're pregnant, should immediately seek some type of treatment if they're using cocaine at the time.

**WALKER:** *[voice-over]* Carrie Moss is a lawyer with the American Civil Liberties Union, which has taken on Kimberly Hardy's case.

**CARRIE MOSS, ACLU Attorney:** She successfully completed treatment, and then she was arrested nonetheless. So what's really going on here, seems to me to be the real question. Are we really trying to promote the best interests, best health interests of her and her child, or are we really trying to punish her?

**WALKER:** *[voice-over]* Hardy has already lost custody, temporarily, of her three children. If tried and convicted, she could get 20 years in prison.

**KIMBERLY HARDY:** It's not fair. It's— I think, to me, it's not justified. I mean, to put a woman in prison for abuse of drugs is just insane. And I've gotten my life together, I've been through treatment, I'm staying clean.

**WALKER:** *[voice-over]* But while Hardy may be recovering, what about the pregnant women who still need to find help? Is prosecution the only way to steer them towards treatment, or will it discourage mothers from seeking prenatal care?

**Dr. WENDY CHAVKIN, Beth Israel Hospital:** I'm afraid that a pregnant addicted woman must experience herself as caught between a rock and a hard place. On the one hand, everybody is furious with her for taking illegal drugs while she's pregnant. On the other hand, there's no treatment available. If she provides honest information to her doctor, she may end up losing her baby. And if she lives in the wrong state, she may end up in jail.

**WALKER:** *[voice-over]* Three years ago, Dr. Wendy Chavkin surveyed 78 New York City drug treatment programs and found that over one-half refused to treat pregnant addicts. Sixty-eight of them, or 87 percent, denied treatment to pregnant women on Medicaid who were addicted specifically to crack.

Several states are considering new laws ranging from expanding treatment programs to making drug use during pregnancy a felony. Others have passed legislation making a positive drug test at the time of birth evidence of neglect.

**Ms. MOSS:** Insofar as we are telling pregnant women how they can and cannot behave while they're pregnant, these prosecutions violate the right to privacy and the right to bodily integrity, which means that doctors and others can't tell a pregnant woman how to behave while she's pregnant.

**WALKER:** *[voice-over]* Connie O'Neill's behavior has put her behind bars, where she expects only more temptation and no rehabilitation.

**Ms. O'NEILL:** And there's going to be people coming up to you and—

**WALKER:** In prison, offering you drugs.

**Ms. O'NEILL:** —right. And you can't walk away from

it that easy, unless you know how to deal with it, and don't know how to deal with it.

**WALKER:** This is James Walker for Nightline in Catlettsburg, Kentucky.

**KOPPEL:** Later in our broadcast, we'll talk with a district attorney who has prosecuted pregnant women who failed to get off drugs, and we'll be talking with a lawyer who defended drug-addicted mothers. But first, when we come back, we'll be joined live by a woman who used illegal drugs while she was pregnant with each of her two children.

*[Commercial break]*

**KOPPEL:** Gina, who is with us now in our Washington bureau, has asked us not to use her last name. She has two children, one eight and one five. Gina used heroin for the full nine months of her first pregnancy and cocaine during the last four months of her second. She says she is now drug-free.

Where are the children, Gina?

**GINA, former Drug Addict:** My older son is now with my mother and father, and my younger son is with his father's family.

**KOPPEL:** You hope one day to get your children back?

**GINA:** If that's what's foreseen for me in the future, that's what will be. Right now what I'm doing is building relationship with my older son. My younger son, unfortunately, at this time in my life, I have no contact with.

**KOPPEL:** Let me ask you a very strange question. If your children were back with you now, would you even dream of giving either one of them drugs?

**GINA:** Never.

**KOPPEL:** Did you ever think about it when you were pregnant, that in a sense, that's what you were doing?

**GINA:** I never looked at it as though I was actually feeding them drugs, no.

**KOPPEL:** And yet, you know, I'm sure that some people have explained to you, whether doctors or lawyers, that in the eyes of certainly some courts, that's what you were doing.

**GINA:** Exactly.

**KOPPEL:** How do you think— I mean, rationalize that for me, if you will. Why do you think, you know, what is so clear once you're a child is born is so unclear when you're dealing with an unborn child.

**GINA:** Well, I guess the reality of actually seeing the child when he's born and going through withdrawal, then you realize what you had been doing all along. At the time that I was using, when I was pregnant with my first child, the last thing that I thought about was I was actually feeding my child, you know, drugs purposely. It wasn't something that I thought, "This is what I'm doing."

**KOPPEL:** Look, I mean, even to the degree that, you know, you go to some bars and there'll be signs up there warning you that alcohol can be harmful to an unborn child, there are some suggestions that smoking cigarettes can be harmful to an unborn child, so I mean, you're not alone. I'm sure there are an awful lot of pregnant mothers who are out there drinking and smoking. But did you ever think about the welfare of the child at all? Usually a pre

nant mother, you know, may even modify her diet, do all kinds of things, for the welfare of the child. Or did the drug addiction so take over that it just never occurred to you?

**GINA:** You know, Ted, I just really believe that the disease of addiction is something that is so unknown by people, society, so to say, I think the actual— my addiction took over my entire well-being. It took over my entire life.

**KOPPEL:** If you had known at the time, if someone had come to you and said, "Gina, you know, we're going to test you, and if we find that you're on drugs, you're going to end up spending time in jail," what difference would that have made to you?

**GINA:** Well, I can't answer that question as of— you know, not knowing what jail was like, but now have gone through actually having a child addicted, going through certain treatment and gone through prison, I can tell you today that prison is not the answer for a woman who is addicted and has a child.

**KOPPEL:** Well, it may not be the answer. I guess what I'm asking, though, is whether the fear of going back to prison would have been enough to cause you to go and seek out help, to cause you to say to someone, "Look, I am an addict, I need help, I don't want to go to prison, I want to help my child"? I mean, that's the logic that's being put forward by some of these folks, right?

**GINA:** Well, I believe that if a woman is told, "You're going to go to prison unless you go seek some type of help," that woman will do that. I don't think she'll have really, basically, a choice. The choice comes once she goes through treatment and decides that she wants to go back out and use, then that's her choice, and jail is a option, it's a consequence behind the choice of going back out. But—

**KOPPEL:** So— no, go ahead and finish your thought.

**GINA:** —I just think that, you know, knowing, "Hey, you're going to go to jail or go seek treatment," that the woman, nine times out of 10, is going to go seek treatment before they say, "Okay, we'll send her to jail."

**KOPPEL:** All right. Let's take a break. When we come back, we'll hear opposing sides in the legal debate over whether to prosecute drug-addicted mothers or expectant mothers, as we talk with Charles Condon, a South Carolina district attorney and Lynn Paltrow, a lawyer for the American Civil Liberties Union.

*[Babies whose mothers use cocaine during pregnancy are up to 10 times more likely to die in infancy.]*

*[Commercial break]*

**KOPPEL:** Charles Condon is district attorney for Charleston and Berkeley counties in South Carolina. He's been engaged in a program aimed at getting pregnant women off illegal drugs by using the threat of arrest and prosecution. Lynn Paltrow is an attorney with the American Civil Liberties Union. She took part in the defense of two of the women mentioned in James Walker's report, Pamela Rae Stewart and Jennifer Johnson.

Let me begin, Lynn Paltrow, with you, and let's pick up where Gina left off. At the very end, when I asked her what would have happened if she had known that she was facing prosecution, she said she probably would have gone for treatment at that time. In other words, her response is,

in a sense, the idea worked.

**LYNN PALTROW, ACLU Staff Counsel:** Well, what Gina actually said is she thinks it would work. I think you might want to go back and talk to her again, because I think in terms of her own life and what's really going on out there, is that Gina never had that choice. She never had the choice to go into treatment.

**KOPPEL:** Well, what's wrong with the choice? Let us say that it is— that the choice is put just that way. "We have a program" — and of course, it's important to be able to say that — "we have a program, ma'am, you are on drugs, if you don't get off drugs, we're going to prosecute you, possibly even send you to jail. If you go through the program no problem."

**Ms. PALTROW:** Well, this jumps ahead of all the things we need to look at. Why are we ready to look at this as a criminal problem when we haven't even begun to address it as a public health problem? We live in a country where there are virtually no drug abuse treatment programs for pregnant women. The people watching the show, everybody knows somebody's who's been addicted to something illegal or legal, alcohol, nicotine, caffeine. They know that you don't just stop using that drug, that addiction is a problem that you need help with, that takes a long period of time. And to pretend that it's just a problem of getting these women into treatment that's available is misleading because the real problem is these women desperately want to get help, these women don't take drugs because they want to hurt their babies, they want to get treatment.

And then the next question is, is there treatment that's appropriate for women? Because what's out there isn't appropriate for women, and so they go through failure after failure after failure.

**KOPPEL:** Let's hold on for a moment on the first part of that, and Mr. Condon, let me just ask you. If there are no adequate facilities available— in other words, let's say you've got 200 beds and you've got 201 addicted pregnant mothers—

**Ms. PALTROW:** Most states have 10 or just 20.

**KOPPEL:** —I understand, but let me just pursue my question with Mr. Condon, if you don't mind. What happens to that 201st mother?

**CHARLES CONDON, Charleston, SC District Attorney:** That's not been our experience here in Charleston. First of all, to answer Lynn's question of why treat this as a criminal law problem, I don't know how the situation is in New York City, but it's against the law in South Carolina to use cocaine, so it is against our criminal laws. And what our experience has been is this. When the women have been coming into the hospital and have been told simply and educated simply that cocaine use is bad, it can hurt your fetus and can cause great damage, many women continue to use cocaine without a sanction being in place. We developed a program where this happened to them. If you're identified as using drugs in Charleston while you're pregnant, we do not prosecute you or arrest you immediately. We tell you that you have to go to drug treatment, which is available here free of charge, and if you go to this treatment program and finish the program

and remain drug-free, you will in fact not be prosecuted.

The flip side of that, though, is if you fail to go to drug treatment or if you continue to use drugs, cocaine in particular, which causes tremendous damage to innocent, innocent children, yes, you will be prosecuted. And what has happened here locally is that these women have stopped using the cocaine.

**KOPPEL:** Now, Ms. Paltrow, you were sort of— well, I don't want to describe your facial expression, but you clearly were not pleased with what Mr. Condon was saying when he made reference to the "innocent, innocent children," and yet, I'm sure there are a great many people watching tonight who feel precisely that way. It's one thing, what a human being does to himself or herself; it's something else again if you extend that damage to another living being. Why is that such a difficult concept?

**Ms. PALTROW:** I think what makes me sad, and I think what people to look at, is why we're so ready to give up on the women themselves. Everybody's ready to call these women selfish women, to see them as selfish, when in fact the real problem is that they're not selfish enough. The women who are taking drugs, who are drinking, who are not eating adequately, all the things that can harm fetal development and the babies they want, is first and foremost harm to themselves, and we have to enable these women to get the help they need.

Now, what Mr. Condon said about using drugs is illegal, that's true. And we're not arguing that Mr. Condon shouldn't arrest pregnant women for what they would arrest anybody else for in terms of illegal drug use. But what these prosecutions are doing is making it a crime for a woman who has an addiction problem to become pregnant, and they are sending the message that if you can't get off the drug today, immediately, and you continue your pregnancy, then you are a child abuser and you may end up in jail. In fact, in South Carolina, women have been taken out of their hospital beds right after delivery and dragged to jail cells where, in some cases, they're still bleeding from the delivery, and told to sit on a towel.

What health care workers in the community are saying, it's not that women stop using drugs, because people don't, can't, without help just stop using drugs, that women are no longer going to those hospitals in Charleston because the word is out that if you do, you could end up in a jail or a treatment program that isn't designed for women or provide the services that are really necessary to get a woman off drugs.

**KOPPEL:** Okay. You've said a lot of things that I'm sure Mr. Condon wants to respond to. We're going to take a break, and then he can when we continue our conversation in a moment.

*[An estimated 11 percent of the children born in the U.S. last year were exposed to illicit drugs during pregnancy.]*

*[Commercial break]*

**KOPPEL:** And we're back with Mr. Condon again. I'm sure you'll be happy to confirm that you are glad that New York's problems are not Charleston's problems, but here in New York, as you probably heard in James Walker's report, 87 percent of the drug clinics, the drug rehab cen-

ters in this town, will not accept a pregnant woman who is an addict and who is also on Medicaid. Now, what is that poor woman supposed to do?

**Mr. CONDON:** Well, absolutely, there has to be made available treatment for people who want to undergo it. But our experience here locally is not— that's not the problem. The problem has been when the medical community/legal community people such as the ACLU want to treat the use of cocaine as something casual, or something that ought not to be held contemptuous. And what we do, and we're vitally interested and concerned about the women who use the cocaine, we're also very concerned about the children, what we do simply is this. If you're using the substance and we identify you, we will offer you this free treatment. Please go to that, and please simply stop using the cocaine. I think as you saw from the addict that you had earlier on the program, she herself admitted that if such a program were in effect at the time that she went through her problems with cocaine use and heroin use, that she would have stopped using them. That's been our experience here locally. We have been able to demonstrate quite clearly that with an effective prosecution program available as a last resort, and the women knowing that something will in fact happen to them eventually, they have simply stopped using the cocaine. And there's absolutely no evidence here locally that the women are not seeking prenatal care.

**KOPPEL:** We are—

**Mr. CONDON:** They *[crosstalk]* same hospitals as before.

**KOPPEL:** —we are down to our 30 or 40 seconds, and Gina, I've been watching you in the monitor there, you desperately want to jump back in again. Go ahead and take it, respond any way you like.

**GINA:** I just wanted to say, Ted, that I think, from my personal experiences, I've been in treatment before, and I think the quality of treatment. I wouldn't suggest for— there are not enough treatment facilities for women, and for women only. Going into treatment with men, for me, was a hinder. It did not allow me to get honest with what had happened in my past. When you go into treatment as a woman, and a woman addict, you've been abused, used, there's incest in the family, women don't feel comfortable going into treatment with men, talking about these past experiences.

**KOPPEL:** Gina, I've got to stop you at that point. We are almost totally out of time. But I thank all of you very much for being with us tonight.

That's our report for tonight. I'm Ted Koppel in New York. For all of us here at ABC News, good night.

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Group Home Revolving Fund (Section 1916A)

The AFMS requirement to establish a \$100,000 revolving loan fund for recovering substance abusers has been established through a purchase order with Oxford House, Inc. to implement the fund. In addition, DADA executed a grant with Oxford House, Inc. of Great Falls, Virginia for them to provide for technical assistance in the establishment of the initial four to seven residences, and management of disbursements and collections from the \$100,000 revolving loan fund.

Several representatives of Oxford House, Inc. attended a meeting in Trenton, New Jersey on September 27, 1989 to present the group recovery home concept to a number of the New Jersey County Alcoholism and Drug Abuse Coordinators. Presentations at the meeting covered: the history of Oxford Houses; current operational guidelines; the personal experiences of several residents and the services available through the central office in Virginia. During Fiscal Year 1990, additional meetings will be scheduled with the County A/D Coordinators on a regional basis to facilitate implementation of this project.

The initial Oxford House efforts have been directed towards the development of the first several New Jersey homes, targeting diverse geographic regions statewide. This effort has been organized through the local offices of the County Alcoholism and Drug Abuse Coordinators. Subsequent homes are projected to be created, in part, as a result of demand emanating from these initial homes.

The \$100,000 revolving loan fund will provide loans of not more than \$4,000 to groups of four or more recovering individuals to cover the first month's rent and security deposit on a rented property in order to start democratically self-run, self-supported recovery houses. The loans are available only to "non-profit" entities, and are available through the Oxford House standard simplified loan request procedure. Loans must be repaid within two years. Repayments from recipients will be without interest, but with a reasonable penalty assessed for late payment. The loans will be repaid through a loan management and collection system managed by the Oxford House central office. Oxford House will provide DADA with a detailed monthly financial statement of all outstanding loans, by geographic area. DADA will monitor these monthly reports, and conduct quarterly monitoring activities with the Oxford House representative on location in New Jersey.

As of December 1989, none of the targeted group recovery homes had been implemented in New Jersey. All the fiscal and program development mechanisms are in place, and it is anticipated that implementation activities will result in new Oxford Houses in early 1990.

5. 1989 Women and Children's Set-Aside (WOSA) [Section 1916 (c) 14]:  
Alcoholism Performance and Expenditure Report

Thirty-five percent (35%) (\$2,394,353) of the 1989 AFMS BG funds allocated for alcoholism services were designated for implementation of the ten percent (10%) Women and Children's Set Aside (WOSA). This initiative was clarified under the Drug Abuse Treatment Technical Amendments Act of 1989 (P.L. 101-93).

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The cornerstone of the WCSA initiative has been the renewal of the New Jersey Alcoholism Awareness Project comprised of the sixteen (16) county based councils on alcoholism. It represents \$592,500 in State contracted services. Beginning September 1, 1989, these services were again targetted at the special needs of both alcoholic and at-risk women who constitute a minority underserved population. Specific services provided through this network of councils include the provision of: alcoholism public awareness activities; public information and referral services; client outreach and advocacy services; and media presentations and events aimed at increasing public attention to alcoholism related women's issues. Each of these activities will specifically focus on aspects of women and alcohol use, and each council will participate in, or coordinate, a county task force on women and alcohol.

The rationale for the renewal of this activity was based on two (2) major concerns. First, women represented only 23.2 percent of the population served in formalized treatment programs in New Jersey during CY 1988. Secondly, the effort to provide outreach and awareness activities to increase the percentage of women in treatment was perceived as a statewide need, which the network of alcoholism councils could address in a coordinated manner.

Additionally, two full-time professionals within the TEPU, with clerical support, were assigned to implement programmatic elements of the WCSA. They performed program planning and development functions. A description of their major activities provided during FFY 1989 follows.

The DOA Office on Women has been responsible for coordinating activities relevant to the issue of Fetal Alcohol Syndrome (FAS), and for coordinating and promoting statewide activities concerning women and alcohol. Assigned responsibilities included: providing staff support to the New Jersey Task Force on FAS, provision of staff support to the twenty-one (21) County Plan Review Committee on Women and Alcohol; serving as the FAS liaison to the Governor's Council on the Prevention of Mental Retardation; serving as a resource liaison to the New Jersey Task Force on Women and Alcohol; formulating recommendations for county alcoholism coordinators on pertinent issues regarding the need for specialized women's alcoholism services; and designing, coordinating, and implementing training and education programs addressing women and alcohol use.

Activity highlights from October 1988 through September 1989 included the provision of technical assistance consistent with these primary tasks. It also included coordination of, or participation in, the following activities and events:

- Provided coordination for the quarterly meetings of the 21 County Plan Committee on Women and Alcohol. The committee's goals for 1989 are as follows: (1) support and promote establishment of halfway houses for women and children; (2) aid and enhance identification and treatment for co-dependency; (3) establish more women in leadership positions at all levels; (4) confront declining numbers of women in treatment in four of nine treatment modalities; (5) develop five goals to be

incorporated for women and alcoholism in all 21 county plans in the section on "Special Populations."

Served as liaison from the DOA to the Executive Board of the New Jersey Task Force on Women and Alcohol, and participated in the planning of a statewide three day conference held during November 1989, which 500 professionals attended; assisted in processing eighty scholarship applications for this conference for which thirty-five (35) individuals received full scholarships valued at \$200 each and 10 persons received partial scholarships valued at \$90 each.

Provided evaluation for the Training and Education Unit of the curriculum entitled, Preventing FAS and Other Alcohol Related Birth Defects, developed by the Association for Retarded Citizens of the United States; the material gives comprehensive and appropriate information regarding FAS in a manner that is interesting, relevant and convincing.

Provided evaluation of the curriculum materials developed by the Coalition on Battered Women to be used in the shelters for drug and alcohol treatment for women and their children

Participated in monthly meetings for the N.J. Coalition on Women and Disabilities, which provides education and advocacy related to the needs of women with disabilities. A conference on alcoholism and drug abuse is being developed for May of 1990.

Attended an all day workshop at Honesham Clinic in Pennsylvania on "Women and Co-Dependency." Under DADA leadership, county agencies are developing similar training programs for women in New Jersey. A training session in Ocean County to professionals on this issue was presented.

Attended regular monthly meetings of County Task Forces on Women, Alcohol and Drug Abuse in Hudson, Mercer, Morris, Somerset, Warren, Cape May, Atlantic, Ocean, Bergen, Cumberland and Camden Counties; each task force has developed a mission statement, goals and objectives for the year and has planned several activities for local professionals, and each county sends a representative to the 21 County Plan Review Committee Meeting.

Attended meetings at St. Peter's Hospital in New Brunswick and St. Joseph's Hospital in Paterson regarding the development of the demonstration grants for two substance abuse treatment programs for pregnant women and their infants.

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- . Provision of technical assistance and the coordination of the six applications from agencies for the WCSA money from the 1989 ADMS Block Grant funds for the development of programs to treat women and their children, described below.
- . Development of an all day training program on the Obstetrical Management of Pregnant Women for the ten (10) agencies receiving monies to treat indigent pregnant women for 28 days in residential treatment, described below.
- . Attendance at the Third National Conference in Oklahoma on Women's Issues, entitled "Beyond the Barriers" from May 7-10, sponsored by Alcohol and Drug Problems Association of North America.

**New and Expanded Initiatives Under the WCSA**

Consistent with the 1989 ADMS BG application, the DOA (and later DADA) implemented new treatment and prevention initiatives focusing on alcoholic and drug abusing women, especially women with children. These initiatives were defined in partnership with the New Jersey Women's Resource Panel on Substance Abuse, and the New Jersey Task Force on Women and Alcohol. They were designed to increase the number of women in treatment for alcoholism and drug abuse and to assist addicted women in overcoming barriers to treatment. A summary of these community based grants which began on 9/1/89 follows.

Eva's Halfway House for women in Passaic County (\$100,000) and Epiphany House, Inc. (\$100,000), a halfway house for women and children in Monmouth County, were implemented with start-up grants. One hundred thousand dollars (\$100,000) in BG funds was awarded to Choices, Inc. in Essex County, a halfway house for women and children, in order to expand their services.

Holy Name Hospital (\$55,000) in Bergen County, and the Center for Industrial Human Resources (\$55,000) in Middlesex County, two outpatient treatment programs, expanded their specialized treatment services for women and children from two days to four days per week. Safe House (\$50,000), a new treatment program for victims of domestic violence, who are also alcohol and/or drug addicted, was implemented for women and their children in Cape May County. One family per month is provided with comprehensive care services.

In cooperation with the Division of Community Health Services (DCHS) within the Department of Health, the Division of Alcoholism and Drug Abuse made available \$50,000 to augment funding for the Fetal Alcohol Syndrome (FAS) Prevention Project. This effort was accomplished through a memorandum of understanding between the two Divisions, which facilitates grants to seven (7) perinatal centers statewide. Each of the seven grantees was funded with awards ranging from \$5,000 to \$10,000. The purpose of these grants is to identify and refer additional pregnant women for treatment of their addiction, and to provide followup services, in

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order to reduce the likelihood of birth defects due to substance abuse. A listing of these grantees is included as agencies 34 and 47 through 53 in Appendix III.

Demonstration grants of \$100,000 each were also awarded to St. Joseph's Hospital in Paterson and St. Peter's Hospital in New Brunswick through a memorandum of agreement between DADA and CHS. The purpose is to provide services to drug and alcohol addicted women during pregnancy. St. Joseph's provides drug or alcohol abusing women with prenatal care within the existing treatment facility, whereas the St. Peter's program provides additional alcohol and drug treatment within an established perinatal center. In each case, the provision of program services will occur through a cooperative effort with other community agencies.

DADA implemented a purchase of service initiative with ten licensed Residential Alcoholism Treatment Facilities (RATF), statewide. Executed through Letters of Agreement, each of the RATFs was targetted to receive \$100,000 for the provision of treatment stays averaging 28 days to medically indigent women, with pregnant women targetted for first priority admission. Payment has been based on the cost based per diem rate established by the Department of Health's rate setting initiative, which averages \$125 per day. Up to 275 women are targetted for treatment. Each of these providers is listed in Appendix III (agencies 53 through 62).

In sum, the early indication is that the implementation of these initiatives under the WOSA are effective in targetting the needs of A/D dependent pregnant women and women with dependent children. However, they can neither address the volume of need nor all of the gaps in service delivery for this population.

Eight (8) of the RATFs were providing treatment services well beyond the projection of the Letter of Agreement, five (5) of whom have drawn down their twelve (12) month allotment within six (6) months. The programs in the project have demonstrated a commitment to pregnant women and have accumulated experience and expertise in providing services to this population.

Women with dependent children are receiving services in the three (3) halfway house/shelter services and at the three (3) specialized outpatient services described above. The slots in these shelter programs are filled, and there are waiting lists for admission. The three (3) outpatient services are also filled to funded capacity.

In addition to the need for expansion of these important initiatives, other needs for these specialized WOSA populations are evident. Education of health care professionals is needed to emphasize the hazards of alcohol consumption and drug abuse during pregnancy. Medical services need to be matched to the needs of addicted pregnant women, especially, methadone maintained pregnant women, whose high risk pregnancies sometimes limit to appropriate care. Transportation and child care problems also limit access to care for addicted women.

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# Enhancing the Outcomes of Low-Birth-Weight, Premature Infants

## A Multisite, Randomized Trial

The Infant Health and Development Program

Members of the Infant Health and Development Program include the following.

**National Study Office:** Ruth T. Gross, MD, director; Donna Spiker, PhD, deputy director; Norman A. Constantine, PhD, director of data analysis; Wendy L. Kreitman, director of field operations; Christine W. Haynes, codirector of field operations (The Department of Pediatrics and the Center for the Study of Families, Children and Youth, Stanford University, Stanford, Calif.)

**Program Development Office:** Craig T. Ramey, PhD, director; Donna Bryant, PhD, associate director; Joseph Sparling, PhD, and Barbara H. Wasik, PhD, codirectors of curriculum development; Isabelle Lewis and Claudia Lyons, curriculum development specialists; Kaye H. Fendt, MSPH, director of data management and statistical computing (The Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill)

**Participating Universities:** University of Arkansas for Medical Sciences (Little Rock); Albert Einstein College of Medicine (Bronx, NY); Harvard Medical School (Boston, Mass); University of Miami School of Medicine (Miami, Fla); University of Pennsylvania School of Medicine (Philadelphia); University of Texas Health Science Center at Dallas; University of Washington School of Medicine (Seattle); Yale University School of Medicine (New Haven, Conn.)

**Site Directors:** Patrick H. Casey, MD, Arkansas; Cecilia M. McCarton, MD, Einstein; Michael W. Yogman, MD, and Daniel Kindon, PhD, Harvard; Charles R. Bauer, MD, and Keith G. Scott, PhD, Miami; Judith Bernbaum, MD, Pennsylvania; John E. Tyson, MD, and Mark Swanson, MD, Texas; Clifford J. Sells, MD, and Forrest C. Bennett, MD, Washington; David T. Scott, PhD, Yale.

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The Infant Health and Development Program is an eight-site clinical trial designed to evaluate the efficacy of a comprehensive early intervention in reducing the developmental and health problems of low-birth-weight ( $\leq 2500$  g) premature ( $\leq 37$  weeks) infants. Nine hundred eighty-five infants, stratified by site and weight ( $\leq 2000$  g or 2001 to 2500 g), were randomly assigned to receive an educational curriculum focused on child development, as well as family support and pediatric follow-up, or only pediatric follow-up. At corrected age 36 months, the intervention group had significantly higher mean IQ scores than the follow-up group (mean difference in the heavier group was 13.2 and in the lighter group 6.6), significantly fewer maternally reported behavior problems, and a small, but statistically significant, increase in maternally reported minor illnesses for the lighter-birth-weight group only, with no difference in serious health conditions.

(JAMA. 1990;263:3085-3042)

OVER THE last decade, the survival rate for low-birth-weight (LBW) infants has increased markedly,<sup>1,2</sup> raising questions about their subsequent health and development. A number of studies have found that LBW infants are at increased risk for developmental delay<sup>3</sup> and for a variety of medical complica-

For editorial comment see p 3089.

tions<sup>4,5</sup> in infancy compared with their normal-birth-weight counterparts. At later ages, LBW children tend to have lower scores on tests of cognitive functioning,<sup>6,7</sup> are more prone to difficulties in behavioral adjustment,<sup>8,9,10</sup> and are at risk for having learning problems and poor academic achievement,<sup>11</sup> even when cognitive test scores are normal.<sup>12,13</sup> The risk for cognitive deficits is present throughout the full spectrum of birth weights less than or equal to 2500 g, although the risk increases as birth weight decreases.<sup>14,15</sup> The likelihood of adverse developmental and scholastic

outcomes also is greater in the face of socioeconomic disadvantage<sup>3,16,17</sup>—itself a risk factor for low birth weight and prematurity<sup>18</sup>—and places many LBW premature infants at dual risk from both biologic and environmental factors.<sup>19,21</sup>

A number of intervention studies have shown improved outcomes for LBW infants.<sup>22,27</sup> However, most have been conducted at single sites with a small number of subjects and have assessed short-term benefits. The most persuasive evidence of the efficacy of early intervention comes from single site studies of normal-birth-weight infants and preschoolers from socially disadvantaged families.<sup>28,29</sup> The applicability of interventions designed for normal-birth-weight children, however, has not been tested for LBW premature children, a population that may have biologic constraints that limit their responsiveness to such interventions. Furthermore, many such programs include a group care component that might result in increased exposure to acute infectious conditions,<sup>30,31</sup> the effect of which is unknown on this vulnerable population. Current legislation, Public Law 99-457,<sup>32</sup> focusing on provision of interventions for handicapped and at-risk children, heightens the relevance and the immediacy of this issue.

From the Infant Health and Development Program, Stanford, Calif.

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Table 1 — Targeted and Actual Enrollment for Primary Analysis Group

Study and Weight Group*	Targeted No. of Patients (Per Site)	Actual No. of Patients†								
		Arkansas	Einstein	Harvard	Miami	Pennsylvania	Texas	Washington	Yale	Total
Follow-up	90	80	92	93	56	53	68	90	66	608
Heavier	30	30	32	31	20	23	30	31	23	220
Lighter	60	50	60	62	36	30	58	49	43	388
Intervention	45	48	48	45	44	48	49	51	48	377
Heavier	15	21	15	14	15	22	17	16	22	142
Lighter	30	27	31	31	29	26	32	35	24	235
Total	138	128	138	138	100	101	137	131	112	985
Heavier	45	51	47	45	35	45	47	47	45	362
Lighter	90	77	91	93	65	56	90	84	67	623

\*Follow-up indicates the group receiving the pediatric follow-up services but not the intervention services; intervention, the group receiving the pediatric follow-up and the intervention services; heavier, infants weighing 2001 to 2500 g at birth, and lighter, infants weighing less than or equal to 2000 g at birth.  
†For full names of sites, see list of participating universities.

The Infant Health and Development Program is the first multisite, randomized clinical trial designed to evaluate the efficacy of combining early child development and family support services with pediatric follow-up in reducing developmental, behavioral, and other health problems among LBW premature infants (birth weight,  $\leq 2500$  g; gestational age,  $\leq 37$  weeks). The intervention protocol and the specific curricula used in the Infant Health and Development Program were adapted for LBW infants from two longitudinal studies of successful early intervention with socially disadvantaged normal-birth-weight children.<sup>11,12</sup>

#### PATIENTS AND METHODS

Eight medical institutions that serve diverse demographic populations in different geographical locations were selected through a national competitive review.

#### The Sample

**Enrollment Criteria.**—A total of 4751 inborn infants who would reach 40 weeks' postconceptional age between January 7, 1985, and October 9, 1985, and whose birth weights were less than or equal to 2500 g were screened at birth for eligibility. Of these, 3249 infants were excluded before randomization by protocol criteria related primarily to (1) residence; (2) gestational age greater than 37 weeks, as assessed by a modification of the Ballard Examination<sup>13,14</sup>; or (3) hospital discharge before or after the designated recruitment period. (Details are in appendix 1, which is deposited in National Auxiliary Publication Service [NAPS] document 04773.) Unhealthy infants were included unless they had an illness or neurological deficit so severe as to preclude participation in the intervention program; only 61 such infants were excluded. Thus, the sample includes the majority of LBW premature infants who survived the neonatal hos-

pitalization and lived in the catchment area, ie, within 45 minutes transportation time of each center. Of the 1302 who met the eligibility criteria, the parents of 274 (21%) refused consent to be randomized. Among the 1028 infants who had the consent of their parents and were randomized, 43 were withdrawn before participating in the study. The remaining 985 infants constituted the primary analysis group on which the findings of this report are based.

**The Target Sample Size.**—The research design included stratification by eight sites and two birth-weight groups (infants weighing 2001 to 2500 g, designated *heavier*, and those weighing  $\leq 2000$  g, designated *lighter*). One third of the sample came from the heavier and two thirds from the lighter group. To minimize the cost of the study, subjects within each weight group were allocated such that one third were randomized to the intervention group and two thirds to the follow-up group. The targeted overall sample size was based on an estimated effect size (ES = difference between treatment group means, expressed in SDs) of 0.5. For a single outcome, a power of 99% ( $P = .05$ , two tailed) was required in the total group and the lighter group alone.

Based on our research design, the targeted number of patients at each of the eight sites was 135. The targeted and actual numbers of enrolled patients are shown in Table 1. The differences between these numbers reflect the effects of randomization allocation and the shortfall of subjects at some sites. The actual enrollment remained adequate for a power of at least 99%.

#### Recruitment and Randomization

Immediately after hospital discharge, patients were randomized by the National Study Office using an adaptive randomization method<sup>15,16</sup> that monitored for a 2:1 balance and for absence

of bias between the two study groups in each site and birth-weight stratum. In the randomization, balance was monitored for birth weight, gender, maternal education (less than high school graduate; high school graduate; some college, or more), maternal race (black, Hispanic, and white/other), primary language in the home, and infant participation in another study. Further details of the randomization process will be presented in a separate article.

#### Program Description

The program was initiated on discharge from the neonatal nursery and continued until 36 months of age, corrected for prematurity. Infants in the intervention and the follow-up groups participated in the same pediatric follow-up, which comprised medical, developmental, and social assessments, with referral for pediatric care and other services as indicated. The services exclusively for the intervention group consisted of three components: home visits,<sup>17</sup> child attendance at a child development center, and parent group meetings. All services were provided free to the families.

**Home Visits.**—The protocol specified weekly home visits for the first year, and biweekly visits thereafter. The home visitor provided health and developmental information and family support and implemented two specific curricula. One curriculum emphasized cognitive, linguistic, and social development via a program of games and activities for the parent to use with the child.<sup>18</sup> The second curriculum involved a systematic approach to help parents manage self-identified problems.<sup>19</sup>

**Child Development Centers.**—Beginning at 12 months and continuing until corrected age 36 months, the intervention children attended the center 5 days a week. The teaching staff continued to implement the curriculum of

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Table 2.—Baseline Characteristics (Before Randomization) of the Primary Analysis Group

Baseline Characteristic	Site*							
	Arkansas	Einstein	Harvard	Miami	Pennsylvania	Texas	Washington	Yale
Birth weight, g (mean ± SD)								
Intervention group	1661.0 ± 429.1	1785.3 ± 427.6	1741.2 ± 455.0	1727.1 ± 492.7	1920.9 ± 422.3	1754.3 ± 395.4	1810.6 ± 432.5	1947.8 ± 434.2
Follow-up group	1817.0 ± 437.1	1837.9 ± 420.9	1781.7 ± 466.0	1682.4 ± 566.3	1810.4 ± 466.8	1746.3 ± 440.9	1842.6 ± 455.8	1719.9 ± 504.3
Gestational age, wk (mean ± SD)								
Intervention group	33.1 ± 2.3	32.6 ± 2.5	33.1 ± 2.8	32.6 ± 2.3	33.6 ± 2.7	32.8 ± 2.8	33.1 ± 2.5	33.3 ± 2.2
Follow-up group	33.0 ± 2.5	32.8 ± 2.5	32.7 ± 2.9	32.7 ± 2.6	33.7 ± 2.7	33.2 ± 2.6	33.5 ± 3.1	32.7 ± 3.0
Neonatal Health Index† (mean ± SD)								
Intervention group	100.5 ± 16.4	104.2 ± 14.1	100.9 ± 14.2	103.0 ± 15.0	99.8 ± 15.6	96.4 ± 19.2	101.4 ± 15.9	97.3 ± 16.4
Follow-up group	99.7 ± 15.7	97.8 ± 16.5	99.6 ± 16.7	97.7 ± 16.3	100.1 ± 16.1	100.9 ± 13.9	99.2 ± 19.1	101.8 ± 15.4
Maternal age, y (mean ± SD)								
Intervention group	23.3 ± 4.5	24.8 ± 6.1	26.4 ± 5.9	22.7 ± 6.1	24.3 ± 5.6	22.0 ± 6.0	26.3 ± 5.4	26.9 ± 5.9
Follow-up group	24.5 ± 5.9	25.7 ± 6.5	27.7 ± 5.7	22.7 ± 5.2	22.8 ± 5.7	21.4 ± 5.0	27.3 ± 5.7	25.7 ± 5.8
Maternal education‡ (mean ± SD)								
Intervention group	1.8 ± 0.8	1.7 ± 0.9	2.2 ± 0.8	1.5 ± 0.7	1.7 ± 0.8	1.6 ± 0.8	2.1 ± 0.9	2.3 ± 0.8
Follow-up group	2.0 ± 0.8	1.8 ± 0.9	2.5 ± 0.7	1.5 ± 0.7	1.9 ± 0.8	1.4 ± 0.6	2.2 ± 0.6	2.3 ± 0.8
Gender, % M								
Intervention group	47.9	50.0	46.9	52.3	47.9	49.0	48.0	54.3
Follow-up group	47.5	50.0	48.4	50.0	41.5	40.9	50.0	62.1
Maternal race, %								
Black								
Intervention group	54.2	41.3	40.0	77.3	95.8	69.4	23.6	26.1
Follow-up group	52.5	47.8	31.2	80.4	94.3	71.6	16.3	45.5
Hispanic								
Intervention group	2.1	39.1	6.7	11.4	0.0	14.3	2.0	4.3
Follow-up group	0.0	40.2	6.5	14.3	1.9	14.8	2.5	1.5
White/other								
Intervention group	43.7	19.6	53.3	11.4	4.2	16.3	74.6	69.6
Follow-up group	47.5	12.0	62.4	6.4	3.8	13.6	81.3	53.0

\*For full names of sites, see the list of participating universities.

†Neonatal Health Index is a score standardized to a mean of 100, with high scores signifying better health.<sup>44</sup>

‡Maternal education is measured on a three-point scale, where 1 indicates less than high school graduate; 2, high school graduate; and 3, some college or more.

learning activities used by the home visitors<sup>45</sup> and tailored the program to each child's needs and developmental level. Teacher-child ratios were 1:3 for children aged from 12 to 23 months and 1:4 for those aged from 24 to 36 months; class sizes were six and eight children, respectively. Each site provided transportation in Infant Health and Development Program-operated vans to any child who needed it.

**Parent Groups.**—Beginning at 12 months, bimonthly parent group meetings provided information on child rearing, health and safety, and other parenting concerns, as well as some degree of social support.

A further description of the intervention program will be presented in a separate article.

#### Assessment Schedule

Each child in the two study groups was assessed by the clinical staff at eight clinic visits occurring at 40 weeks' conceptional age and at 4, 8, 12, 18, 24, 30, and 36 months, corrected age. Ninety-two percent of the 36-month assessments occurred within a specified time window of ± 2 weeks.

At each clinic visit, data were collected from the mother about the child's

health and developmental functioning and about social and demographic characteristics of the family. Growth measurements of the child were gathered at all visits. Cognitive assessments were performed at 12, 24, and 36 months. Behavioral data were obtained at 24 and 36 months. Additionally, at 12 and 36 months, home visits were made to assess the quality of the home environment.

Specially trained assessors were used for cognitive, behavioral, and growth assessments. They were monitored to ensure consistency across sites, and they were "blinded" to study group status. All assessments in the study were administered in English.

#### Primary Outcome Measures

This report is restricted to eight primary outcome measures that were chosen to answer three main research questions: at 36 months corrected age, do children in the intervention group differ from those in the follow-up group in (1) cognitive development, (2) behavioral competence, and (3) health status?

**Cognitive Development.**—The Stanford-Binet Intelligence Scale, form L-M, 3rd edition (1972 norms),<sup>46</sup> was selected as the measure of cognitive development at 36 months.

**Behavioral Competence.**—The mother's report of behavior problems was selected as the measure of behavioral competence at 36 months, using the Child Behavior Checklist for Ages 2 to 8 years.<sup>47,48</sup> Employing the authors' "Total Problem Raw Score," higher scores indicate more reported behavior problems.

**Health Status.**—Health status was regarded as multidimensional.<sup>47,49</sup> The dimensions evaluated in this study were (1) *morbidity*, defined as the presence or absence of health conditions; (2) *functional status*, defined by limitations in activities of daily living due to health problems and by alterations in physical growth; and (3) *maternal perception of the child's health*. As no single comprehensive measure existed, six different measures were selected to assess these three health areas.

**Morbidity.**—Two measures were developed by the Infant Health and Development Program to ascertain (1) the overall morbidity experienced by the child and (2) the seriousness of the reported health problems. At each assessment, mothers were asked to recall and report the incidence of each illness and condition that occurred since the last assessment. Their verbatim reports were assigned *International Classifi-*

cation of Diseases ICD-Ninth Revision codes<sup>21</sup> at the National Study Office, and all reports corresponding to the same code (using the first three digits) were counted as one illness or condition per assessment period.

● **Mother's Report: Morbidity Index.** This index is a summation over the three years of the number of hospitalizations, outpatient surgeries, injuries not resulting in hospitalization or outpatient surgery, and different (code) illnesses and conditions.

● **Mother's Report: Serious Morbidity Index.** This index consists of the number of years (0 to 3) in which there was one or more of the following: hospitalizations, outpatient surgeries, prolonged or recurrent illnesses totaling 30 days or longer in a given year, and injuries and briefer illnesses that were pre-defined as serious by a panel of pediatricians.

**Functional Status.**—The Functional Status II(R) Scale<sup>22,23</sup> used at 36 months, gauged the mother's view of the limitations in the child's basic daily activities as a result of health problems. Higher scores indicate a more favorable functional status. Growth was assessed by length and body mass index at 36 months.

**Maternal Perception or Rating of Child Health Status.**—The General Health Ratings Index from the Rand Corporation Health Insurance Study<sup>24</sup> was used at 36 months. Higher scores indicate better perceived health.

All health data were collected by the clinic staff, except the 36-month growth measures.

#### Analytic Strategies

**Primary Analysis.**—To accommodate the possibility that the effect of the intervention would differ among sites, a procedure developed by Fleiss<sup>25</sup> was adopted. In brief, the procedure first tests for heterogeneity of ESs across the 16 subgroups (eight sites and two birth-weight groups) and then estimates and tests either an averaged ES if there is significant heterogeneity or a pooled ES if not. (Details are in appendix 2, which is deposited in NAPS document 04773.)

To protect against false-positive results in testing efficacy with eight primary outcome measures, a Bonferroni correction was applied, and the .006 (.05/8) significance level was used for each outcome.

**Secondary Analysis.**—When a significant effect of the intervention was found in the primary analysis, a secondary analysis using multiple linear regression was employed to test whether certain initial status variables had an

Table 3.—Primary Outcome Measures, by Study Group

Measure	Study Group						Effect Size* (P)
	Follow-up			Intervention			
	No.	Mean	SD	No.	Mean	SD	
Stanford-Binet Scale, form L-M							
Heavier group†	203	84.8	19.0	125	98.0	18.5	.83 (<.001)
Lighter group†	358	84.4	20.5	222	91.0	19.0	.41 (<.001)
Child Behavior Checklist for Ages 2-3 y	547	47.2	20.5	338	43.7	19.1	-.18 (.006)
Mother's Report: Morbidity Index							
Heavier group	200	6.8	3.0	126	7.3	3.2	.17 (NS)
Lighter group	351	7.0	3.2	219	7.9	3.4	.29 (<.001)
Mother's Report: Serious Morbidity Index	551	1.21	0.95	345	1.19	1.00	-.001 (NS)
Functional Status II (R) Scale	561	0.96	0.08	346	0.97	0.07	.03 (NS)
Length, cm	535	94.7	3.9	341	95.0	4.1	.09 (NS)
Body mass index, kg/m <sup>2</sup>							
Heavier group	196	15.4	1.3	124	15.6	1.2	.08 (NS)
Lighter group	338	15.1	1.3	217	16.2	1.2	.10 (NS)
General Health Ratings Index	559	27.1	5.1	344	27.5	5.4	.07 (NS)

\*The effect size for an outcome measure is the difference between intervention and follow-up group means, expressed in SDs. In those cases in which there was a differential effect by site and weight groups, results are presented separately for the heavier and lighter birth-weight groups. NS indicates not significant.

†The heavier group comprises infants with a birth weight of 2001 to 2500 g and the lighter group comprises infants weighing less than or equal to 2000 g.

effect on outcome. Included among these variables were site; birth weight (as a continuous variable); gender; a Neonatal Health Index<sup>26</sup> based on length of stay in the newborn nursery, adjusted for birth weight and standardized to a mean of 100, with higher scores indicating better health; and the following sociodemographic variables: maternal education level, maternal age, and maternal race. The main effect of each initial status variable (irrespective of study group), and of the intervention, was tested to ascertain whether overall each variable was independently predictive of the outcome. Further, the interaction of each initial status variable with the intervention was tested, again controlling for all other variables, to ascertain whether the effectiveness of the intervention was related to that initial status variable. Because the regression analysis was employed only when a significant outcome was found in the primary analysis, a .05 significance level was used for these tests.

#### RESULTS

##### Sample Description and Retention

Although the baseline characteristics of the study sample varied greatly among the eight sites (Table 2), overall the randomization procedure resulted in comparable intervention and follow-up groups at study entry. Retention was high, with 913 of the 985 children in

the primary analysis group participating in the 36-month assessment for at least one of the primary outcome measures (98% of each study group). This small level of attrition did not affect the comparability of the two study groups at 36 months.

##### Primary Outcomes

The results for each of the eight primary outcome measures by study group are presented in Table 3. Where there are significant differences in ESs between the two weight groups, results are presented separately for the heavier and lighter groups.

**Cognitive Development.**—**Primary Analysis.**—Overall, the mean IQ scores on the Stanford-Binet Intelligence Scale were significantly higher for the intervention children than for the follow-up children. Because the effect of the intervention varied significantly between birth-weight groups, separate ESs were estimated for each weight group. The effect in the heavier intervention vs the heavier follow-up groups was 13.2 IQ points (ES = .83,  $P < .001$ ), and in the lighter intervention vs lighter follow-up groups, 6.6 IQ points (ES = .41,  $P < .001$ ) (Table 3).

Controlling for site and initial status variables, the adjusted odds for having IQ scores less than 70, ie, in the mental retardation range, were 2.7 times greater in the follow-up group (95% con-

34x

Table 4. —Cumulative Stanford-Binet Scale IQ Scores, by Birth Weight and Study Group

Cumulative Stanford-Binet Scale IQ Scores at 36 mo*	No. (%) of Patients in Birth-Weight Group		
	≤1500 g	1501-2000 g	2001-2500 g
<70			
Intervention group	22 (26.8)	11 (7.9)	6 (4.6)
Follow-up group	43 (28.7)	39 (18.6)	37 (18.2)
<85			
Intervention group	39 (47.6)	44 (31.4)	32 (25.0)
Follow-up group	95 (63.3)	97 (46.6)	111 (54.7)
<90			
Intervention group	48 (58.5)	58 (41.4)	43 (34.4)
Follow-up group	104 (69.3)	119 (57.2)	124 (61.1)
<100			
Intervention group	64 (78.0)	87 (62.1)	69 (55.2)
Follow-up group	123 (82.0)	152 (73.1)	158 (77.8)
Total sample			
Intervention group	82 (100.0)	140 (100.0)	125 (100.0)
Follow-up group	150 (100.0)	208 (100.0)	203 (100.0)

\*The cutoff point of 70 is the IQ level below which the scores fall into the mental retardation range, according to the Stanford-Binet manual.† The groups with scores less than 85 also include children with scores that are 1 SD below the mean, which we refer to as subaverage. The groups with scores less than 90 include 23.2% of the distribution, which approximates the lowest quartile. The groups with scores less than 100 include those below the mean.

Table 5. —Multiple Regression Analyses: Relationship of Initial Status Variables to Three Major Outcome Measures\*

Initial status variable	Stanford-Binet Scale		Child Behavior Checklist for Ages 2-3 y		Mother's Report: Morbidity Index	
	Standardized Estimate†	P	Standardized Estimate	P	Standardized Estimate	P
<b>Main Effects‡</b>						
Site		<.001		.028		<.001
Race		<.001		.044		<.001
Birth weight	.100	<.001	-.025	NS§	-.111	<.001
Sex	.050	NS	-.072	.029	-.079	.010
Maternal age	-.008	NS	-.006	.013	-.024	NS
Maternal education	.242	<.001	-.165	<.001	.075	.040
Neonatal Health Index	.090	.001	.007	NS	-.125	<.001
Intervention effect	.225	<.001	-.095	.003	.118	<.001
<b>Interaction Effects</b>						
Site x intervention		NS		NS		NS
Race x intervention		NS		NS		NS
Birth weight x intervention	.087	.014	-.019	NS	-.010	NS
Sex x intervention	.040	NS	.045	NS	.003	NS
Maternal age x intervention	.024	NS	-.069	NS	-.105	.003
Maternal education x intervention	-.024	NS	.102	.009	.003	NS
Neonatal Health Index x intervention	.005	NS	-.002	NS	.001	NS

\*These are the three outcome measures that showed significant effects of the intervention.  
 †Standardized estimate is the regression coefficient multiplied by the SD of the outcome measure divided by the SD of the independent variables. They are presented only for the quantitative independent variables to indicate the direction and magnitude of their effects on the outcome measures.  
 ‡The main effect of each initial status variable (irrespective of study group) and of the intervention was tested to ascertain whether overall each variable was independently predictive of the outcome. Further, the interaction of each initial status variable with the intervention was tested, again controlling for all other variables, to ascertain whether the effectiveness of the intervention was related to that initial status variable.  
 §NS indicates not significant.

confidence interval, 1.6 to 4.8).

Table 4 shows the proportion of children in three birth-weight groups with IQ scores below several cut points of clinical relevance. In each of the three birth-weight groups there was a larger proportion of follow-up group children

than intervention group children with low IQ scores. In one subgroup only, the infants who weighed less than or equal to 1500 g and had IQ scores in the range less than 70, this difference was negligible.

**Secondary Analysis.**—As previous

research has found, and as seen in Table 5, the multiple regression analysis indicated a significant main effect of several of the initial status variables on the Stanford-Binet Scale IQ scores. Higher scores were associated with some sites and also with being white, with higher birth weight, higher Neonatal Health Index, and higher maternal education. Controlling for these variables, there was a significant effect of the intervention (adjusted ES = .59,  $P < .001$ ). Finally, there was an interaction between birth weight and the intervention such that the intervention was more effective for infants of higher birth weight ( $P = .014$ ).

**Behavioral Competence.**—**Primary Analysis.**—The average score on the Child Behavior Checklist was significantly lower for the intervention group than the follow-up group, with higher scores indicating more reported behavior problems (ES = -.18,  $P = .006$ ) (Table 3). Although the difference between study groups was small, the adjusted odds for having a score above 68, the cut point above which scores are correlated with clinically evident behavior problems,<sup>44</sup> were 1.8 times greater in the follow-up group (95% confidence interval, 1.2 to 2.9). The actual percentages were 18.8% for the follow-up group and 18.9% for the intervention group.

**Secondary Analysis.**—The multiple regression analysis indicated significant main effects of several initial status variables. Higher scores (suggestive of more behavior problems) were associated with some sites, with being black or Hispanic, with being male, and with lower maternal age and education level (Table 5). Controlling for these variables, there was a significant effect of the intervention (adjusted ES = -.20,  $P = .003$ ). The only variable that had a significant interaction with the intervention was maternal education ( $P = .009$ ). With college-educated mothers there seemed to be little difference between the follow-up and intervention groups, whereas with mothers with less education, those in the intervention group reported fewer behavior problems.

**Health Status.**—**Primary Analysis.**—Among the six health status measures, the only measure with a significant treatment effect was the Mother's Report: Morbidity Index. Higher morbidity scores were reported for the lighter-born children in the intervention group than for the lighter-born children in the follow-up group (ES = .29,  $P < .001$ ); no significant difference was found in the heavier groups (Table 3).

**Secondary Analysis.**—The multiple regression analysis indicated significant

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Table 6.—Site Variations in Three Primary Outcome Measures\*

Site and Study Group	Outcome Measure								
	Stanford-Binet Scale			Child Behavior Checklist for Ages 2-3 y			Mother's Report: Morbidity Index		
	No.	Mean	SD	No.	Mean	SD	No.	Mean	SD
<b>Arkansas</b>									
Follow-up	77	85.2	16.8	76	47.8	22.7	77	7.0	3.2
Intervention	42	99.5	18.0	42	39.3	16.7	41	6.9	2.7
<b>Einstein</b>									
Follow-up	78	74.2	15.7	77	47.1	20.5	77	6.2	2.6
Intervention	43	84.7	16.4	43	49.0	22.6	43	6.5	3.3
<b>Harvard</b>									
Follow-up	88	96.7	22.4	87	44.6	20.2	88	6.8	3.5
Intervention	43	97.1	21.5	40	41.1	16.4	43	9.1	4.1
<b>Miami</b>									
Follow-up	51	68.0	14.2	49	63.8	21.3	49	5.5	2.4
Intervention	40	81.0	12.0	39	49.1	16.0	40	6.1	2.6
<b>Pennsylvania</b>									
Follow-up	51	82.5	16.2	51	45.6	19.9	51	6.6	3.0
Intervention	43	95.1	12.6	43	43.9	24.2	43	6.9	2.4
<b>Texas</b>									
Follow-up	79	80.4	12.9	75	48.1	20.6	77	5.7	2.4
Intervention	47	87.1	17.6	47	42.7	17.2	47	7.8	3.5
<b>Washington</b>									
Follow-up	78	92.0	21.6	73	49.1	18.7	76	7.8	3.1
Intervention	47	100.5	21.3	46	45.7	17.9	47	3.6	3.6
<b>Yale</b>									
Follow-up	81	91.1	20.0	59	42.6	18.0	57	7.1	3.2
Intervention	42	102.5	17.3	38	38.7	16.6	41	6.7	3.0
<b>Total</b>									
Follow-up	561	84.5	19.9	547	47.2	20.5	551	6.9	3.1
Intervention	347	93.5	19.1	338	43.7	19.1	346	7.6	3.3
Follow-up and Intervention	908			885			896		

\*These are the three outcome measures that showed significant treatment effects.  
†For full names of sites, see list of participating universities.

main effects of several initial status variables. Higher values of the Morbidity Index (suggestive of more morbidity) were associated with some sites, with lower birth weight, with lower Neonatal Health Index, with being male, with being white, and with higher maternal education level. Controlling for these variables, there was a significant effect of the intervention (adjusted ES = .27,  $P < .001$ ). The only variable that had a significant interaction with the intervention was maternal age, with younger mothers in the intervention group reporting higher scores than younger mothers in the follow-up group (Table 5).

**Site Differences**

There was a wide variation in the primary outcomes among the eight sites. This variation is demonstrated in the scores of the follow-up groups and in the differing magnitudes of the treatment effects (Table 6). With the IQ test, for example, the follow-up group scores ranged from a mean of 68.0 at the University of Miami (Fla) School of Medicine to a mean of 96.7 at Harvard Medical School, Boston, Mass. Similarly, the magnitude of the treatment effects var-

ied from an IQ difference of 0.4 at Harvard to 14.3 at the University of Arkansas for Medical Sciences, Little Rock. The multiple regression analyses suggest, however, that the site differences are associated predominantly with variations in the initial status characteristics. Specifically, in Table 5 it can be seen that after controlling for the initial status variables, no significant site-by-intervention interactions are detected, and the effect of the intervention overall is statistically significant for the three measures.

**COMMENT**

This study is the largest reported multisite, randomized clinical trial of an intensive early childhood intervention. It is also the first home- and center-based educational intervention for LBW premature infants from birth to age 3 years. The results of this study indicate the effectiveness of a comprehensive intervention, even for biologically vulnerable infants. Our findings show that the children who received the intervention experienced: (1) significantly higher IQ scores; (2) significantly fewer maternally reported behavior problems; and (3) a small, but signifi-

cant, increase in maternally reported minor morbidity, with no evidence of an increase in reported serious health problems. The magnitude of these effects and also the levels of the three outcome measures in the follow-up groups (Table 6) were influenced by the variation in the initial status characteristics at the sites (Table 2).

**Cognitive Outcome**

The largest treatment effect was the significantly higher cognitive scores achieved by the intervention group compared with the follow-up group at corrected age 36 months. The overall results are consistent with the magnitude of cognitive gains reported previously in single-site intervention studies with normal-birth-weight disadvantaged children.<sup>28,29</sup> Further, the low scores in the follow-up group parallel those reported in other samples of LBW socially disadvantaged children.<sup>7,30,31</sup>

Birth weight had a main effect on the level of the IQ scores as well as an influence on the efficacy of the intervention, with a greater effect on heavier-born children. Two important observations regarding birth weight warrant emphasis. First, as shown in Table 4, low and subaverage scores are not limited to the smallest infants. In the follow-up group, more than 18% of those weighing 1501 to 2000 g and 2001 to 2500 g have IQ scores below 70, and almost 50% are below 85. Second, Table 4 also suggests that there is one group in which the effectiveness of the intervention is questionable—those with birth weights less than or equal to 1500 g and with IQ scores less than 70. In this lowest-weight group, there is little difference in the proportion of intervention vs follow-up children who have IQ scores less than 70. In all other weight-by-IQ groups, the results favored the children in the intervention group.

The improvement in cognitive development in the intervention group was statistically significant at seven of the eight individual sites ( $P < .05$ ). We speculate that the nonsignificant result at the one site, Harvard, may be related to the sociodemographic characteristics of the site, such as the large proportion of college-educated mothers, as well as the relative abundance of community resources compared with the other sites.

Other issues warrant consideration in the interpretation of the cognitive findings. The first is the potential effect of bilingualism. Bilingual children are reported to perform less well on tests administered in English<sup>32,33</sup>; here the Stanford-Binet test was administered only in English. Although prerecruitment screening ensured that all mothers

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could communicate in English sufficiently to participate in the program, 23% of the children were regularly exposed to another language. We therefore repeated the primary analysis, excluding all children in bilingual environments. Among the remaining monolingual children, the overall advantage for the intervention group remained large and highly significant (heavier group:  $ES = .81$ ,  $P < .001$ ; lighter group:  $ES = .28$ ,  $P = .006$ ). Thus, the effect of the intervention is not solely a consequence of English-language facilitation in the subgroup of children in bilingual environments.

Another issue to consider is whether exposure to the test items or to similar materials during the study influenced the magnitude of IQ scores in the intervention group. The intervention curriculum and the cognitive instruments were selected independently, and as a further precaution, the protocol denied specific feedback to the education staff on any child's cognitive test performance.

Finally, although all assessments in this study were based on age corrected for prematurity, repetition of the primary analysis using uncorrected chronological age yielded similar significant results for cognitive outcome and the same mean differences between the two study groups.

#### Behavioral Outcome

Compared with the follow-up group, the intervention group at 36 months experienced a small, yet significant, advantage in behavioral competence, as indicated by lower behavior problem scores on the Child Behavior Checklist. In secondary analysis, the treatment group difference was seen largely in reports from the less-educated mothers. Thus, the intervention may have helped these mothers to become better informed about age appropriate behaviors and consequently to report fewer behavior problems; it may have taught them more effective techniques for behavior management; or it may have altered the children's behavior. Although the data were collected through maternal report, other studies involving maternally reported behavior problems at this age indicate that such reports correspond to clinically detected problems and may be predictive of longer-term adverse outcomes.<sup>44</sup>

#### Health Status Outcomes

Given the positive effects of this program in cognitive development and behavioral competence, it is important to ask whether group participation in the child development centers led to an in-

crease in serious health problems within the intervention group. The only health measure with a significant intervention effect was Mother's Report: Morbidity Index, where the lighter intervention group had higher reported morbidity scores than the lighter follow-up group. Further analysis of the components of the Morbidity Index indicated that the difference was accounted for primarily by an increase in the number of reported brief illnesses and conditions. No significant differences were reported by the mothers in the two groups in the Serious Morbidity Index.

At face value these findings suggest that the intervention led to a slight, but significant, increase in morbidity. However, other factors may well have contributed to these findings. First is the issue of reporting bias. Other studies indicate that maternal report may understate children's health conditions,<sup>45</sup> particularly in disadvantaged groups.<sup>46</sup> A second issue is the more intense health surveillance and health education in the intervention group compared with the follow-up group.

It is unclear whether the higher Morbidity Index score in the intervention group reflects more complete and accurate reporting or a real increase in acute conditions (that may well occur with children in group care). Nevertheless, during a 2-year period at eight different rigorously controlled child development centers there was not a single serious infectious epidemic or a single major accident. It is also possible that the pediatric follow-up program extended to all the children, regardless of group assignment, improved the health of both study groups relative to LBW children in most communities.

#### Retention and Compliance

In this randomized clinical trial we largely avoided the concern of differential attrition in the two groups by achieving a 93% retention rate in the intervention and the follow-up groups, with good comparability in the initial characteristics of the subjects at entry and of those retained at 36 months. The level of participation in the intervention was generally high and similar across sites; further detailed analyses are forthcoming in a separate article.

The issue of "crossover" between the intervention and follow-up groups also might be a matter of concern. In the follow-up group, 80% had entered a community day-care center by 36 months corrected age; conversely, 14% of the intervention group never attended the child development center. Because subjects were retained and analyzed in the group to which they were

randomly assigned, the effect of such crossovers would be to reduce the apparent magnitude of the effect of the intervention, ie, the actual treatment effects might be somewhat larger than those we have documented.

#### Conclusions

We conclude that this comprehensive and intensive early intervention program shows substantive promise of decreasing the number of LBW premature infants at risk for later developmental disability. We also document its apparent safety in a biologically vulnerable population. Additional exploratory studies are under way to examine the variations in ESs across different subgroups of children.

The long-term significance of these findings is being addressed in the continued follow-up of the study cohort. From follow-up studies of normal-birth-weight disadvantaged children in preschool programs, it seems that IQ effects attenuate when such children enter the usual inner-city schools but that subsequent advantages of the interventions may accrue in the primary grades. Such advantages include higher academic achievement, fewer placements in remedial classes, and lowered risk of grade retention and school dropout; later, there may be reduced juvenile delinquency and increased employment.<sup>44</sup>

Improving the status of young children is the subject of policy debate currently and in the foreseeable future. The results of this study are especially timely and relevant to the concerns at the federal and state levels for providing appropriate interventions for children at risk for developmental delay.

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#### References

1. *Neonatal Intensive Care for Low Birthweight Infants: Costs and Effectiveness*. Washington, DC: Office of Technology Assessment; 1987. Health technology case study 38 (OTA-HCS-38).
2. McCormick MC. The contribution of low birth weight to infant mortality and childhood morbidity. *N Engl J Med*. 1985;312:82-90.
3. Shapiro S, McCormick MC, Starfield BH, Kriecher JP, Bross D. Relevance of correlates of infant deaths for significant morbidity at 1 year of age. *Am J Obstet Gynecol*. 1980;136:363-373.
4. Hack M, Blanche C, Rivara A, Fanaroff AA. The very low birth weight infant: the broader spectrum of morbidity during infancy and early childhood. *J Dev Behav Pediatr*. 1983;4:243-249.
5. Drillien CM. *The Growth and Development of the Prematurely Born Infant*. Edinburgh, Scotland: E & S Livingstone; 1964.
6. McBurney AK, Eaves LC. Evolution of developmental and psychological test scores. In: Dunn HG, ed. *Sequelae of Low Birthweight: The Vancouver Study*. Philadelphia, Pa: JB Lippincott; 1986:54-67.
7. Broman SH, Nichols PL, Kennedy WA. *Preschool IQ: Prenatal and Early Developmental Correlates*. Hilldale, NJ: Lawrence Erlbaum Associates Inc; 1976.
8. Escalona SK. Babies at double hazard: early development of infants at biologic and social risk. *Pediatrics*. 1982;70:870-876.
9. Field TM, Dempsey JR, Shuman HH. Developmental assessments of infants surviving the respiratory distress syndrome. In: Field TM, Sostek AM, Goldberg S, Shuman HH, eds. *Infants Born at Risk: Behavior and Development*. New York, NY: Spectrum Publications Inc; 1979:261-280.
10. Neilan GA, Kolvin I, Scott DMcl, Garside RF. *Born Too Soon or Born Too Small: A Follow-up Study to Seven Years of Age*. Philadelphia, Pa: JB Lippincott; 1976.
11. Scott DT. Premature infants in later childhood: some recent follow-up results. *Semin Perinatol*. 1987;11:191-199.
12. Klein NK, Hack M, Breslau N. Children who were very low birth weight: development and academic achievement at nine years of age. *J Dev Behav Pediatr*. 1988;10:32-37.
13. Hunt JV, Cooper BAE, Tooley WH. Very low birth weight infants at 8 and 11 years of age: role of neonatal illness and family status. *Pediatrics*. 1988;82:596-603.
14. Nobel-Jamieson CM, Lukeman D, Silverman M, Davies PA. Low birth weight children at school age: neurological, psychological and pulmonary function. *Semin Perinatol*. 1982;6:266-273.
15. Dunn HG. Neurological, psychological and ophthalmological sequelae of low birthweight. In: Dunn HG, ed. *Sequelae of Low Birthweight: The Vancouver Study*. Philadelphia, Pa: JB Lippincott; 1986:1-22.
16. Francia-Williams J, Davies PA. Very low birthweight and later intelligence. *Dev Med Child Neurol*. 1974;16:709-728.
17. Hoy EA, Bill JM, Sykes DH. Very low birthweight: a long-term developmental impairment? *Int J Behav Dev*. 1988;11:37-47.
18. Committee to Study the Prevention of Low Birthweight. *Preventing Low Birthweight*. Washington, DC: National Academy Press; 1985.
19. Sameroff AJ, Chandler MJ. Reproductive risk and the continuum of caretaking causality. In: Fomon FD, Hetherington EM, Scarr-Salapatek S, Siegel GM, eds. *Review of Child Development Research*. Chicago, Ill: The University of Chicago Press; 1975;4:187-244.
20. Werner EE, Smith RS. *Vulnerable But Invincible: A Longitudinal Study of Resilient Children and Youth*. New York, NY: McGraw-Hill International Book Co; 1982.
21. Parker S, Greer S, Zuckerman B. Double jeopardy: the impact of poverty on early child development. *Pediatr Clin North Am*. 1988;35:1227-1240.
22. Ramey CT, Bryant DM, Sparling JJ, Wasik BH. A biosocial systems perspective on environmental interventions for low birth weight infants. *Chin Obstet Gynecol*. 1984;27:872-892.
23. Bennett FC. The effectiveness of early intervention for infants at increased biologic risk. In: Guralnick MJ, Bennett FC, eds. *The Effectiveness of Early Intervention for At-Risk and Handicapped Children*. Orlando, Fla: Academic Press Inc; 1987.
24. Scarr-Salapatek S, Williams ML. The effects of early stimulation on low-birth-weight infants. *Child Dev*. 1978;49:94-101.
25. Ross GS. Home intervention for premature infants of low-income families. *Am J Orthopsychiatry*. 1984;54:263-270.
26. Resnick MB, Eyster FD, Nelson RM, Eitzman DV, Bucciarelli RL. Developmental intervention for low birth weight infants: improved early developmental outcome. *Pediatrics*. 1987;80:68-74.
27. Bromwich RM, Parmelee AH. An intervention program for pre-term infants. In: Field TM, Sostek AM, Goldberg S, Shuman HH, eds. *Infants Born at Risk: Behavior and Development*. New York, NY: Spectrum Publications Inc; 1979:389-411.
28. Ramey CT, Bryant DM, Sparling JJ, Wasik BH. Educational interventions to enhance intellectual development: comprehensive daycare versus family education. In: Harel S, Anastasiou N, eds. *The 'At-Risk' Infant: Psycho/Social/Medical Aspects*. Baltimore, Md: PH Brookes Publishing Co; 1985:75-85.
29. Clarke-Stewart KA, Fein GG. Early childhood programs. In: Museen PH, ed. *Handbook of Child Psychology*. 4th ed. New York, NY: John Wiley & Sons Inc; 1983:918-999.
30. Zigler E, Abelson WD, Trickett PK, Seitz V. Is an intervention program necessary in order to improve economically disadvantaged children's IQ scores? *Child Dev*. 1982;53:340-348.
31. Fleming DW, Cochi SL, Hightower AW, Broome CV. Childhood upper respiratory tract infections: to what degree is incidence affected by day-care attendance? *Pediatrics*. 1987;79:55-60.
32. Haskins R, Kotch J. Day care and illness: evidence, costs and public policy. *Pediatrics*. 1986;77(part 2):951-952.
33. The Child Day Care Infectious Disease Study Group, Centers for Disease Control. Public health considerations of infectious diseases in child day care centers. *J Pediatr*. 1984;105:683-701.
34. Education of the Handicapped Act amendments of 1986. Public Law 99-457, October 8, 1986.
35. Ramey CT, Campbell FA. The Carolina Abecedarian Project: an educational experiment concerning human malleability. In: Gallagher JJ, Ramey CT, eds. *The Malleability of Children*. Baltimore, Md: PH Brookes Publishing Co; 1987:127-139.
36. Ballard JL, Novak KK, Driver M. A simplified score for assessment of fetal maturation of newly born infants. *J Pediatr*. 1979;95:769-774.
37. Constantine NA, Kraemer HC, Kendall-Tackett KA, Bennett FC, Tyson JE, Gross RT. Use of physical and neurologic observations in assessment of gestational age in low birth weight infants. *J Pediatr*. 1987;110:921-928.
38. Efron B. Forcing a sequential experiment to be balanced. *Biometrika*. 1971;58:403-417.
39. Pocock SJ, Simon R. Sequential treatment assignment with balancing for prognostic factors in the controlled clinical trial. *Biometrics*. 1975;31:103-115.
40. Wasik BH, Bryant DM, Lyons C. *Home Visiting*. Newbury Park, Calif: Sage Publications Inc. In press.
41. Sparling J, Lewis I, Neuwirth, S. *Early Partners*. Lewisville, NC: Kaplan Press. In press.
42. Sparling J, Lewis I. *Partners for Learning*. Lewisville, NC: Kaplan Press; 1984.
43. Wasik BH. *Coping With Parenting Through Effective Problem Solving: A Handbook for Professionals*. Chapel Hill, NC: Frank Porter Graham Child Development Center; 1984.
44. Terman LM, Merrill MA. *Stanford-Binet Intelligence Scale: Manual for the Third Revision, Form L-M*. Boston, Mass: Houghton Mifflin Co; 1973.
45. Achenbach TM, Edelbrock CS, Howell CT. Empirically based assessment of the behavioral/emotional problems of 2- and 3-year-old children. *J Abnorm Child Psychol*. 1981;15:629-650.
46. McConaughy SH, Achenbach TM. *Practical Guide for the Child Behavior Checklist and Related Materials*. Burlington, Vt: University of Vermont, Department of Psychiatry; 1988.
47. *Constitution, in Basic Documents*. Geneva, Switzerland: World Health Organization; 1978.
48. Eisen M, Donald CA, Ware JE, Brook RH. *Conceptualization and Measurement of Health for Children in the Health Insurance Study*. Santa Monica, Calif: The RAND Corp; 1980. RAND publication series R-2313-HEW.
49. Starfield B. Measurement of outcome: a proposed scheme. *Milbank Mem Fund Q*. 1974;52:39-50.
50. Haggerty RJ, Roghmann KJ, Pless IB. *Child Health and the Community*. New York, NY: John Wiley & Sons Co; 1975.
51. *International Classification of Diseases, Ninth Revision, Clinical Modification*. Washington, DC: US Dept of Health and Human Services; 1980. Publication (PHS) 80-1280.
52. Stein REK, Jessop DJ. A noncategorical approach to chronic childhood illness. *Public Health Rep*. 1982;16:354-362.
53. Stein REK, Jessop DJ. *PACTS Papers/AE-COM Tables Documenting the Psychometric Properties of the Functional Status III(R) Measure*. Bronx, NY: Albert Einstein College of Medicine, Department of Pediatrics; 1986.
54. Fleiss JL. Analysis of data from multicentric trials. *Controlled Clin Trials*. 1986;7:267-275.
55. Scott DT, Bauer CR, Kraemer HC, Tyson J. A neonatal health index for preterm infants. *Pediatr Res*. 1989;25(part 2):263A. Abstract.
56. Collaborative Group on Antenatal Steroid Therapy, National Institutes of Health. Effects of antenatal dexamethasone administration in the infant: long-term follow-up. *J Pediatr*. 1984;104:259-267.
57. Dunn LM. *Bilingual Hispanic Children on the U.S. Mainland: A Review of Research on Their Cognitive, Linguistic and Scholastic Development*. Circle Pines, Minn: American Guidance Service; 1966.
58. Hakuta K. *Mirror of Language: The Debate on Bilingualism*. New York, NY: Basic Books Inc; 1986.
59. Richman N, Stevenson J, Graham P. *Preschool to School: A Behavioral Study*. London, England: Academic Press Inc; 1982.
60. Wright AL, Tauszig LM, Ray CG, Harrison HR, Holberg CJ, GHMA Pediatricians. The Tucson children's respiratory study. II: lower respiratory tract illness in the first year of life. *Am J Epidemiol*. 1989;129:1232-1246.
61. Andersen RM, Mullner RM, Corneliu LJ. Black-white differences in health status: methods or substance? *Milbank Q*. 1987;65(suppl 1):72-99.
62. Lazar I, Darlington RB, Murray H, Royce J, Snipper A. *Lasting Effects of Early Education: A Report From the Consortium for Longitudinal Studies*. Chicago, Ill: The University of Chicago Press; 1982. Monograph series 195:47:2-3.
63. Berrueta-Clement JR, Schweinhart LJ, Barnett WS, Epstein AS, Weikart DP. *Changed Lives: The Effects of the Perry Preschool Program on Youths Through Age 19*. Ypsilanti, Mich: High Scope Press; 1984. Monographs of the High Scope Educational Research Foundation, No. 8.
64. Lally JR, Mangione PL, Honig AS, Wittner DS. More pride, less delinquency: findings from the ten-year follow-up study of the Syracuse University Family Development Research Program. *Zero to Three*. 1988;8:13-18.
65. Seitz V, Rosenbaum LK, Apfel NH. Effects of family support intervention: a ten-year follow-up. *Child Dev*. 1985;56:376-391.

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# Low-Birth-Weight Infants

## Can We Enhance Their Development?

The remarkable advances of the past two decades in neonatology have resulted in saving the lives of many low-birth-weight infants. As birth-weight-specific mortality declines, concern about developmental disabilities among the survivors becomes appropriate. Attention properly has focused on efforts to enhance the developmental potentialities of these infants.

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See also p 3035.

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A pioneering study reported in this issue of THE JOURNAL sheds considerable light on this matter.<sup>1</sup> The study is pioneering in several respects: (1) The prospective, sound design, formulated at the outset, gave reasonable assurance of providing answers to an important clinical and public policy issue. (2) It demonstrated that the well-accepted multicenter design of clinical trials is applicable to research in human development. (3) It demonstrated that it is feasible to apply a comprehensive intervention in a variety of communities. (4) It illustrates that private foundations can play an important role in identifying important policy issues and supporting the acquisition of the knowledge base for enlightened public policy.

The study included 985 premature and low-birth-weight children, one third of whom were randomly assigned to the intervention group, which received a comprehensive program with home visits in the first year and, in years 1 through 3, attendance at a child development center, continued home visits, and parent group meetings. Both the intervention and the follow-up groups received pediatric surveillance and community referral services, but the follow-up group did not receive the other components of the intervention. Quite striking was the low attrition rate in both groups: 913 children (93%) completed the study at 36 months. This probably reflects the many efforts and careful attention of the staff at all sites to the provision of services and the bonding of the families to the program.

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The results have considerable clinical and potential public policy significance. The premature low-birth-weight study sample was divided into heavier (birth weight 2001 to 2500 g) and lighter (birth weight  $\leq$ 2000 g) groups, with twice as many infants in the lighter group, which was considered to be at greater risk. For the heavier group, the intervention resulted in a mean effect of IQ scores 13.2 points higher in the intervention group than in the follow-up group. For the lighter group, the intervention effect was not as great but still significant—IQ scores were 6.6 points higher in the intervention group. For the overall group, the odds of having an IQ score below 70 (the mental retardation range) were 2.7 times greater in the follow-up group, which did not receive the intervention. It is important to note that in one subgroup only, infants with birth weights below 1500 g with IQ scores below 70, the difference was negligible. Among these smallest infants, however, there was a definite effect of the intervention in the group with cumulative IQ scores below 85. It is of considerable importance that the larger infants were also at risk; 18% had IQ scores less than 70, and almost 50% had scores less than 85.

In the evaluation of behavioral competence, the study indicates that children in the intervention group fared better than those in the follow-up group. With college-educated mothers there appeared to be little difference between the intervention and follow-up groups.

Among the health status variables, for the children in the lighter birth-weight group, mothers of infants in the intervention group reported more morbidity than mothers of infants in the follow-up group. This may reflect the more frequent health surveillance and greater number of contacts in the intervention group and may be the result of group care. It is reassuring, however, to note that there was no evidence of an increase in serious health problems in spite of more reports of minor illness. The fact that pediatric care was provided to all of the children regardless of group assignment may have minimized significant health risks for both groups.

This largest study of a comprehensively enriched program for premature low-birth-weight infants has demonstrated significant improvement in cognitive and behavioral function over the first 3 years of life. The implications of this finding for public policy are considerable at a time when day care and

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early-intervention programs are expanding. Any efforts to enhance the cognitive and behavioral development of these children who are at greater developmental risk because of low birth weight are potentially important for their functioning in school. Thus, there might be an additional, longer-term benefit in the reduction of later expenditures for developmental disabilities.

Any good study raises questions for additional inquiry. We hope that the improved performance at age 3 years will be sustained; however, it is important to know how enduring these gains will be, suggesting the need for continuing observation of these children. We trust the investigators will find additional support for assessing the performance of these children as they grow older, particularly as they move into the school years.

It is important to identify the groups that may benefit the most from such programs. A particularly intriguing problem is the lack of effect on one group of infants, those with very low birth weight (<1500 g) and IQ scores (<70). Since this is the group most vulnerable to developmental disabilities, this lack of effect is disappointing. Although simple explanations might attribute this result to a fixed biological deficit, the data suggest that behavioral explanations offer more promising avenues for future research. Further inquiry may reveal that, for this group, a "standardized intervention" adapted from work with full-term infants may not be fully adequate, and more-tailored, individual intervention efforts may be indicated. Certainly, this finding needs a good deal of further exploration.

The data suggest that family circumstances—such as levels of parental education and economic status—are important indicators of which children are most in need of intervention. For example, at one site in which the parents had a higher educational level and in which community resources were favorable, both the treatment and comparison groups did well. The differences between the groups were not significant.

The report of this study comes at a very important time, when there is great interest in the prevention, early detec-

tion, and management of children with developmental disabilities. Since the study was initiated, the Education for All Handicapped Children Act (PL94-142) has been extended by the passage of PL99-457, which lowers the entry age from 5 to 8 years and encourages states to implement the program for children under 8 years and to include children at risk for handicapping conditions.

It is reasonable to expect that the states will attempt to minimize the untoward developmental outcomes among low-birth-weight infants, and this study indicates some important directions for undertaking such efforts. At a time when the costs of programs receive much attention, it is important to emphasize that comprehensive intervention programs for low-birth-weight infants need not be financially prohibitive. The number of low-birth-weight infants in any given year is relatively finite, approximately 6.9% of all births; hence, no significant escalation in demand for such programs will occur. Based on our new knowledge, it should be possible to target those infants in greatest need. Although many of these children may attend community-based day-care programs that are currently available (as did 30% of the follow-up group in the present study), the quality and content of these programs will need to be upgraded to produce the results reported herein. We should recognize the potential for long-term savings through the prevention of disabilities and their consequent costs.

We can look forward to additional analyses stemming from the data that have been collected. The results provide those responsible for policy with a more rational basis for developing programs. Further refinements in tailoring programs will emerge from subsequent analyses. The foundations that funded this work are to be commended for supporting a model that enhances our ability to establish sound public policy that will result in improved outcomes for a vulnerable group of children.

Julius Richmond, MD

1. The Infant Health and Development Program. Enhancing the outcomes of low-birth-weight, premature infants: a multisite, randomized trial. *JAMA*. 1990;263:3086-3042.

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## Drug Effects

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	Fertility	Obstetrics	Fetus	Other
Alcohol	Males-lower testosterone levels, lower sperm counts Females- Disruption of menstrual function	Vaginal bleeding, early placental separation, fetal distress, spontaneous abortion Severe withdrawal can induce labor	Mental deficiency IGUR FAS/FAE	Lactation - decreased breast milk, alcohol in breast milk.
Tobacco/ Nicotine	Males-spermatogenesis, sperm morphology and motility, androgen secretion may be altered Females-may effect fertility if smoke > 1 pack/day	Premature placental separation, vaginal bleeding, abnormal placental implantation, ruptured membranes, premature birth	Low birthweight, decreased length, reduced head circumference, interactive effects with alcohol	Smoking cessation programs recommended Nicotine gum contraindicated in pregnancy
Marijuana	Males-lowered sperm counts Females-irregular menstrual cycles, ovulation abnormalities	Research results are unclear, possible complications	Low birth weight, postpartum=tremulousness, altered visual response, "withdrawal-like" crying	THC appears in breast milk
Opiates	Males - lowered testosterone levels, diminished sex drive Females- amenorrhea menstrual irregularity	Pre-eclampsia, anemia, merconium-stained amniotic fluid, premature rupture of the membranes, abruptio placentae, placenta previa, multiple births	Small for gestational age, small head circumference, lower apgar scores, 3x higher rate of perinatal mortality, metabolic disturbances, risk for hyaline-membrane disease	Maternal withdraweal during pregnancy may result in fetal death

## RANGE OF RISKS FOR DEVELOPING FETUS

Subtle neuromaturational deficits

Significant neurological effects including lowered I.Q.

Low birthweight

Premature delivery

Physical malformations

Postnatal withdrawal syndromes

Fetal death

42x

TESTIMONY FOR THE PUBLIC HEARING ON SEX DISCRIMINATION IN THE HEALTH CARE FIELD

Sponsored by the State of New Jersey Commission on Sex Discrimination in the Statutes

June 26, 1990

Submitted by Courtney N. Esposito, BA  
Domestic Violence Prevention Program  
Division on Women  
New Jersey Department of Community Affairs

Senator Lipman, Assemblyman Cohen, Ms. Griffin, members and staff of the Commission, ladies and gentlemen:

Good afternoon. My name is Courtney Esposito, and until the 30th of this month, I serve as a consultant with the Domestic Violence Prevention Program of the New Jersey Division on Women, responsible for providing training and technical assistance to the health care community. I am also a Director on the Boards of Womanspace, Inc., the Mercer County agency assisting victims of domestic violence, and the National Woman Abuse Prevention Program in Washington, DC. In addition, I am a member of the Governor's Advisory Council on Domestic Violence, chairing the Committee on Public Awareness, Education and Training.

I would like to begin with the words of a colleague of mine, Dr. Evan Stark. Dr. Stark and his wife Anne Flitcraft, MD are responsible for the earliest and most substantive research on domestic violence in the medical setting.

"Five cases of leukemia in a single high school make national headlines. A single recorded death from 'swine flu' stimulates a campaign costing hundreds of millions to identify and control the virus. The typhus victim and carrier are identified. But the battered woman and her attacker are not, although battering accounts for up to half the serious injuries women bring to the emergency room."

My history in this field began as the great niece of two battered women and the granddaughter of a third. When I was a girl and I first began to understand domestic violence as a common fact in the lives of women, there were no shelters or counseling programs or hotlines, no special laws, there was nowhere to run or to hide. I do not believe that there was anything unusual about my family members in terms of the violence in their lives, and the statistics I will share with you support this conviction. In the early '70's, I myself became a victim, which provided further training--"hands-on" experience if you will--for my current responsibilities.

The numbers I refer to show battered women as a cross-section of the total population, and there are far too many of us, from all walks of life, races, religions and socioeconomic strata, for us to comprise a certain "personality type" which makes us want to, enjoy or deserve being beaten.

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About half of all women murdered in the United States each year--almost 2,000 women a year or about 38 women a week--are killed by a male partner. In this country, women are more at risk of homicide at the hands of a male partner than from all other categories of persons combined. Each year, 2 to 6 million women are beaten by their husbands or boyfriends. Leaving a partner actually increases the chance that a violent incident will occur.

Battering is the single major cause of injury to women, more common than rapes, muggings and automobile accidents combined. Almost half of all incidents of child abuse occur in the context of a battering. Men who are abusing women are often abusing the children as well. Battering has been identified as the single strongest risk factor for a witnessing child to become a batterer in adulthood. Battering accounts for 25% of all female suicide attempts, and abused women comprise approximately 20% of all women presenting with injury to hospital emergency services, 25% of obstetrical patients, 40-50% of women with alcohol problems, 30-50% of female psychiatric in-patients. Battering is one of the most common, yet least identified health problems women present to health care professionals.

Clearly we can see that violence in the family is a primary health care issue for women. The first person outside the family a battered woman or other victim of domestic violence often turns to is a member of the health care community. Health care facilities are therefore a crucial step in the process of identifying and preventing abuse.

And yet, the original draft for public comment of "Promoting Health/ Preventing Disease: Year 2000 Objectives for the Nation", formulated by the U.S. Department of Health and Human Services, virtually omitted domestic violence and battered women as categories. Although violent and abusive behavior is discussed, women as primary victims are not. This neglect on a governmental/institutional level is sadly often duplicated in the examining room.

I believe this happens for three primary reasons: the relegation of violence within a family unit to the "private matter" realm--what occurs behind closed doors is not our business and certainly cannot be considered a crime; the lack of awareness of the community in general and health care personnel in particular about the prevalence and dynamics of abuse; and the feelings of frustration and helplessness many people experience when in the presence of a victim--they simply do not know what to do or feel powerless to help.

That's the bad news. The good news is two-fold: we can change all this, and in New Jersey we have made a very good start.

Since 1985, the Division on Women's Domestic Violence Prevention Program has developed and promulgated protocols, training manuals, videos and slide and lecture presentations for the health care community on domestic violence awareness, assessment and intervention. Most hospitals and major health care organizations in the state have been personally addressed, and all have received the educational and training materials. Our model program has been the subject of a Lifetime Medical Television segment on domestic violence aired nationally the first 4 months of this year, and our videos are being purchased by health care facilities and domestic violence programs throughout the country. We can be very proud of the work we have done to help victims and the health care professionals who treat them on a daily basis.

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All of the health care education I conduct comes down to two basic concepts: we must increase the victim's safety level while decreasing her sense of isolation. The intervention is simple, although it may not always be easy. If a victim has been given the phone number of the local domestic violence program, or received help in exploring her options, then she is safer. If she is made to feel, whether by the practitioner's statements, body language, non-verbal communication or attitude that she is stupid, sick, crazy or to blame for her dilemma, then she is more isolated. If the practitioner is kind, non-judgmental and supportive, then she is less isolated.

The questions most often directed to victims--by nurses, physicians and all of us--are "Why don't you just leave him?" (I would) "How can you put up with this?" (I couldn't) "Why do you take it?" (I wouldn't). These questions isolate the victim's behavior as the problem, and each time they are asked, an alliance is insidiously formed between the "helping" professional and the abuser--an alliance which works brutally against the interests, safety and well-being of the victim. When health care practitioners are shown how this frightful dynamic occurs, they no longer practice it. Instead, they learn--in the frame of a few minutes--to see that the real problem is the violence, the abusive behavior, and not the victim. We must go on teaching them. The beneficial effects in health care delivery to family violence victims are instantaneous.

Recovery from living with abuse is a process, not an event. I strongly believe that with ongoing training and appropriate intervention techniques and programs to identify, treat and refer abuse victims, the quality of physical and mental health, and hope for the future of many thousands of individuals will be vastly improved. If we discontinue our work, then victims will not be helped and families in crises of violence will receive the bitter message that the system overall does not care, and that to seek help may be to hazard humiliation. Without consistent training and sensitization for the "front-liners" on this issue, teaching them to ask, to be kind, to refer, to do no further harm, we risk becoming punitive agents, capable of adding to the very real sense of entrapment that victims endure. Their isolation becomes validated by those of us who are entrusted with their care and safety. And that indeed would be a shame.

I am certain that the health care community is ready to hear what survivors of abuse need and what the advocates who represent and assist them have to say. I have spoken in a variety of formal and informal settings to over 3,000 health care professionals, and have consistently been told that the information offered to them was new, convincing and useful. Just last year, former U.S. Surgeon General C. Everett Koop joined with the American College of Obstetricians and Gynecologists (ACOG) and the National Coalition Against Domestic Violence to recommend routine assessment of all female patients for signs of family violence. The American Medical Association's (AMA) Fall 1989 Conference on the Prevention of Family Violence and Victimization was an encouraging sign that the issue has indeed become mainstream. Both the AMA and ACOG have also announced a national training initiative for their membership on domestic violence awareness and intervention. These years are crucial ones for those of us working with victims of abuse to network and educate within the state of New Jersey on the subject, and to capitalize on and go beyond the recommendations set by national health care leaders. It will take an investment of time and money, but meeting health care objectives in an equitable way always does.

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I submit to you the five following recommendations for reducing and eventually eliminating the not-so-benign neglect in the health care field toward victims of family violence:

- \* Continue, expand and intensify the training and technical assistance offered to all sectors of the health care community
- \* Increase media and public awareness efforts on this subject and on the training opportunities available so that violence in the home can be loudly and clearly identified as that which it is---a primary health care issue for women
- \* Ensure that a protocol for health care intervention in domestic violence cases be adopted and disseminated by the New Jersey Department of Health, the New Jersey Hospital Association and other appropriate health care agencies to their constituents. This would ideally be effected in one to two years.
- \* Require certain health care providers (e.g., hospital, clinic and mental health services) to record the numbers of suspected and confirmed domestic violence cases treated, so that statistical data as to the nature and extent of domestic violence incidents occurring in our state can be collected. Several other states mandate such record-keeping, and I submit a copy of the Medical Data Collection Report Form from the state of Connecticut for your information and consideration.
- \* Statistics from domestic violence programs throughout our state indicate that demand far exceeds supply--indeed many services are in the unfortunate position of annually denying immediate shelter to more clients than they house, and abuser counseling programs too commonly maintain waiting lists for treatment of offenders. More shelters and services are needed to house, counsel and otherwise assist both victims and abusers. Hopefully, additional funds will continue to be made available to these programs so that they can endure in their business of saving lives.

I appreciate the opportunity to speak before you today, and I would be happy to answer any questions you may have. Thank you for your time and attention.

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## GENERAL INFORMATION

This report is required to provide statistical data to the Governor and the General Assembly as to the extent and nature of family violence incidents occurring in Connecticut. At present, legislation requiring this reporting is effective from October 1, 1986 requiring data compilation for a period of five years. Please complete this form consistent with the examples and explanations provided below. In general, all DATES requested should be entered in the form of "10/01/86" instead of October 1, 1986. In MULTIPLE CHOICE areas choose the most appropriate response and circle the letter which precedes it. The examples and explanations applicable to the response areas are noted below. Direct any questions or comments to the State Police Crimes Analysis Unit (203) 238-6575.

Item

1. Treatment Facility Name & Location  
Example: "Hartford Hospital - Hartford," or "Norwalk O/P Clinic-Norwalk"
2. City/Town of Offense  
Enter town or city in which assault occurred.
3. Incident Date & Time  
Enter date and time of assault, i.e., "10/01/86" & "10.00 p.m."
4. Victim Date of Birth & Sex.  
Indicate victim date of birth in the form of MM/DD/YY  
Circle "a" or "b" choice indicating appropriate sex designation.
- 4a. Assailant Date of Birth & Sex  
Similar procedure for assailant information as in Item 4. If DOB is not known for assailant, write in approximate age as known or estimated by victim, i.e., "age 32".
5. Does Victim Verify Incident as One of Family Violence?  
Circle "a" for yes if victim's recitation of incident circumstances indicates the assailant was one within the family relationship.
6. Does Victim Claim Prior Injury as a Result of Family Violence?  
Circle "a" if victim claims injury at another time which was inflicted during a prior incident of family violence.
7. Character of Relationship Victim/Assailant  
Circle letter which best describes familial relationship between victim and offender. If "e" is best response indicate why in space or Remarks
8. Is Victim Being Referred?  
Circle appropriate choice. If "c" give name of agency to which referred
9. Injuries Sustained by Victim.  
Circle appropriate response. Clarify if necessary in Comments/Remarks.
10. Medical Treatment Given  
Circle appropriate choice. Use "T" when victim is DOA or expires. Furnish name of medical facility to which victim is transferred
11. Provider Comments/Remarks  
Self explanatory
12. Name of Medical Care Provider  
Name of treating physician, printed or typed. No signature is required
13. Date of Service  
Enter date on which victim was examined and/or treated.
14. Signature of Reporter  
Signature should be that of whomever is making the report.
15. Date of Report  
Enter date on which report is completed.
16. Title of Reporting Person  
When either the examining physician or a medical records clerk completes this form, then circle the appropriate designation. Others, such as Administrator, Director, Secretary, make the appropriate entry to designate title or job description of person making the report.

47 X

CONNECTICUT DEPARTMENT OF PUBLIC SAFETY  
 DIVISION OF STATE POLICE  
 CRIMES ANALYSIS UNIT  
 SP-231-C (Rev. 7/86)

MEDICAL DATA COLLECTION REPORT  
 FAMILY VIOLENCE PREVENTION AND RESPONSE ACT  
 (P.A. 86-337)

Public Act 86-337, Sec. 5b provides: "A medical data collection report shall be completed for any victim being treated for injuries for which the victim states resulted from family violence or which the mandated medical provider has reasonable cause to believe resulted from family violence."

Public Act 86-337, Sec. 5d provides: "Any person required to report under the provisions of this section who fails to make such report shall be fined not more than FIVE HUNDRED DOLLARS." (emphasis added)

1. Treatment facility name & location CD: _____		2. City/Town of offense CD: _____		3. Incident (MM/DD/YY) Date: _____ Time: _____ am/pm	
4. Victim DOB/Sex Date of Birth: _____ Sex: a. female b. male		4a. Assailant DOB/Sex Date of Birth: _____ Sex: a. female b. male		5. Does victim verify incident as one of family violence? a. yes b. no	
6. Does victim claim prior injury as a result of family violence? a. yes b. no		7. Character of relationship victim/assailant a. spouse or ex-spouse b. other family at home c. live-in or companion d. other relative not residing in home e. other _____			
8. Is victim being referred? a. to police b. to DCYS c. to other agency d. no referral contemplated		9. Injuries sustained by victim a. none observed by examination b. minor injuries: treated & released (pain, swelling, scratches, contusions) c. moderate injuries: short stay admit (laceration, fracture, head trauma) d. severe injuries: characterized as incapacitating or life threatening e. fatal or probably fatal injuries			
10. Medical treatment given a. none required or treatment was refused b. treated and released c. admitted for observation d. admitted for extended care e. transferred to other medical facility: _____ f. admitted to pathology service					
11. Provider Comments/Remarks _____					
12. Name of Medical Care Provider		13. Date of Service		14. Signature of Reporting Person	
15. Date of Report		16. Title Reporting Person (physician, medical records clerk, etc.)			

REPORT SUBMISSION REQUIREMENT

Public Act 86-337, Sec. 5c provides: "The medical data collection report shall be submitted to the Department of Public Safety on a QUARTERLY basis for quarters ending on SEPTEMBER THIRTIETH, DECEMBER THIRTY-FIRST, MARCH THIRTY-FIRST, and JUNE THIRTIETH. The Department of Public Safety shall tabulate and compile data from the medical data collection reports and report such compilation annually for the five years following the effective date of this act to the Governor and the General Assembly." Please mail this report to:

CONNECTICUT STATE POLICE  
 CRIMES ANALYSIS UNIT  
 294 Colony Street  
 Meriden, CT 06460  
 Tel.: (203) 238-6675

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**DOMESTIC VIOLENCE  
IDENTIFICATION, TREATMENT AND REFERRAL OF ADULT VICTIMS  
A PRESENTATION FOR HEALTH CARE PROFESSIONALS**

Designed to:

- increase understanding of the dynamics of domestic violence
- cite statistics concerning the incidence of domestic violence
- address myths and biases which impede appropriate treatment of victims
- review signs and symptoms of abuse
- provide assessment questions to help identify victims
- introduce a specially designed domestic violence protocol for health care facilities and tools for its implementation
- review resources and referrals available to assist victims and their families
- consider issues of documentation, liability and care for the caregiver

**Sponsored by the New Jersey Department of Community Affairs  
Division on Women  
Domestic Violence Prevention Program**

**Developed and conducted by  
Courtney N. Esposito B.A.  
Box 193B Blackwell Road  
Pennington, New Jersey 08534  
(609) 737-2982**

The Domestic Violence Prevention Program has three major goals:

- the development and implementation of domestic violence prevention training programs for professionals in the health care, law enforcement, clergy and educational systems
- provision of public information and community outreach to enhance and support the efforts of current programs dealing with domestic violence throughout the state
- to evaluate, coordinate and promote legal protections and the provision of services to assist victims of domestic violence

**Continuing Education Units Available**

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## INFORMED CONSENT AND BREAST CANCER

by Lynn F. Miller, JD Rutgers Law School, June 3, 1990.

### I. Introduction.

An analysis of the public policy about breast cancer in the United States reveals a shocking lack of official concern about this disease that affects many Americans.

According to the American Cancer Society's 1987 Cancer Facts and Figures, there were approximately 130,000 new cases of breast cancer diagnosed in American women, and approximately 41,000 women died of breast cancer in 1987. The 1987 statistics represent the first time that breast cancer deaths have climbed into the 40,000 deaths per year range, having remained in the mid-30,000 for many years. In 1987 also for the first time, the percentage of incidence rate rose; one out of every ten women will develop breast cancer in their lifetimes. By 1988, the American Cancer Society's estimate of new cases per year rose to 135,000, with 42,000 women dying from the disease. By comparison, in 1984 Cancer Facts and Figures, the American Cancer Society reported approximately 115,000 diagnosed cases (still more than ever before until that time). Breast cancer is the most common cancer to strike American women, accounting for more than one-fourth of all women's cancers.<sup>1</sup> In the 1970's "only"

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<sup>1</sup>John L. Young, Jr., Constance L. Percy, and Ardyce J. Asire (eds.), Surveillance, Epidemiology, End Results: Incidence and Mortality Data, 1973-1977. U. S. Department of Health and Human Services, NIH Publication No. 81-2330, June 1981.

one out of every 11 women developed breast cancer, about 9% of all the women in America. Now, about 10% of all the women in America will develop breast cancer. Many "famous" women, such as Nancy Reagan, Betty Ford, Happy Rockefeller, Susan Sontag, and Sandra Day O'Connor have had breast cancer, and so have many "ordinary women." Given the one in ten incidence rate, almost every person in the United States has been or will be affected by breast cancer, either directly or because someone they know--family, friend, business associate--has it or has had it. By any method of assessment, breast cancer represents a serious threat to the health and welfare of the people of the United States.

What has been the response of the federal and state legislatures, those responsible for formulating policy with regard to public health and welfare? Unfortunately, in the area of research, very little has been done. "Male influence has . . . affected the search for treatments and cures of breast cancer."<sup>2</sup>

II. What the states have done: a survey.

State "informed consent" laws serve the purpose of requiring that patients receive all information about various treatments available for their particular ailments, prior to the initiation of treatment. There are both general "patients' rights" laws, requiring doctors to discuss alternative treatments available for all medical problems, including but not limited to cancer, and specific "breast cancer patients' consent" laws, requiring doctors to inform about alternative treatments

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<sup>2</sup>Kushner, Alternatives 378 (1984).

available for breast cancer. The core of all the consent laws is the stipulation that physicians and surgeons treating breast cancer patients must inform patients being treated for breast illness or disease, usually by means of a standardized written summary, of the alternative methods of treatment. This note will discuss only those states that have specific breast cancer informed consent laws, rather than all the states having general informed consent laws.

A. CALIFORNIA

A California 1980 law<sup>3</sup> states:

"The failure of a physician and surgeon to inform a patient by means of a standardized written summary, . . . in layman's language and in a language understood by the patient alternative efficacious methods of treatment which may be medically viable, including surgical, radiological, or chemotherapeutic treatments or combinations thereof, when the patient is being treated for any form of breast cancer constitutes unprofessional conduct. . . ."

The statute goes on to state that it is the responsibility of the State Department of Health Services, on the recommendation of its Cancer Advisory Council, to develop a standardized written summary in layman's language and in a language understood by the patient. The summary was to be printed and made available to physicians and surgeons by the Board of Medical Quality Assurance. The pamphlet was to inform

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<sup>3</sup>Cal. Health & Safety Code §1704.5 (West 1980)

the patient of the advantages, disadvantages, risks, and descriptions of the procedures, with regard to medically viable and efficacious alternative methods of treatment. A physician or surgeon who gave this pamphlet to her patient would comply with the law. The law became effective on January 1, 1981. A pamphlet was produced and mailed to California physicians in March 1983. According to a pamphlet distributed by The American Cancer Society, this law produced "a protracted debate."<sup>4</sup> According to the same pamphlet, it took thirty rewrites to produce a brochure acceptable to physicians, patients' groups, state officials and legislators.<sup>5</sup>

It is interesting to note that the California law specifies that the information must be provided "in a language understood by the patient." [emphasis supplied] This seems to mean that pamphlets in languages other than English must be supplied to those who do not read English. It is also interesting that, although it took slightly more than two years to produce and mail the pamphlet, that amount of time is not surprisingly excessive, given the process of consensus mandated by the advice requirement from the Cancer Advisory Council, constituted of laypeople and health professionals, along with the difficulties of bringing any printing project to fruition.

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<sup>4</sup>American Cancer Society, Division Involvement in State "Informed Consent--Breast Cancer Treatment" Laws/Legislation. (May 1983)

<sup>5</sup>Id.

B. **FLORIDA**

A 1984 Florida statute<sup>6</sup> directs the Florida Cancer Control and Research Advisory Board, by January 1, 1985, to prepare a standardized written summary, in layman's terms and in language easily understood by the average adult patient, informing actual and high risk breast cancer patients of the medically viable treatment alternatives available to them in the effective management of breast cancer, describing such treatment alternatives, and explaining the relative advantages, disadvantages and risks associated with them. Upon its completion, the summary is to be printed in the form of a pamphlet or booklet and made available to physicians and surgeons (M.D.s) and to osteopathic physicians (D.O.s) in the state. The Board is also required to develop and implement an educational program, including distribution of the pamphlet or booklet developed under the statute, to inform citizen groups, associations, and voluntary organizations about early detection and treatment of breast cancer.

The law obligates every physician treating a patient who is, or is the judgment of the physician is at high risk of being, diagnosed as having breast cancer to inform such a patient of the medically viable treatment alternatives available, to describe the treatment alternatives, and to explain the relative advantages, disadvantages, and risks associated with them, to the extent deemed necessary to allow the patient to make

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<sup>6</sup>Fla. Stat. §§381.3712(4)(m), 485.324, 459.0125 (1984)

a prudent decision regarding the treatment options.

In order to comply with the statute, the physician may, in her discretion, either orally communicate the information directly to the patient or her legal representative, give the patient or her legal representative a copy of the written summary and express willingness to discuss the summary, or both directly communicate the information and provide a copy of the written summary for further consideration and possible later discussion.

When the physician provides the information, the patient's ability to understand the information, as well as the patient's physical and emotional state, must be considered. The physician may, in her discretion and without restriction, recommend any mode of treatment which is, in the physician's judgment, the best treatment for the patient.

Every physician treating a patient who is, or in the judgment of the physician is at high risk of being, diagnosed as having breast cancer must indicate on the patient's medical record compliance or noncompliance with the statutory provisions outlined supra regarding communication of treatment alternatives.

The law defines "medically viable" as applied to treatment alternatives to mean modes of treatment generally considered by the medical profession to be within the scope of current, acceptable standards, including treatment alternatives described in the written summary prepared by the Florida Cancer Control and Research Advisory Board.

Note the deference throughout to the physician's

discretion, which probably resulted from a compromise with the state chapter of the American Medical Association. Also note that there seems to be no specific language requirement, although the patient's understanding is emphasized.

C. **GEORGIA**

Georgia enacted a law<sup>7</sup> directing the Composite State Board of Medical Examiners to publish an informational booklet on breast cancer and the treatment of breast cancer. The statute requires the booklet to contain a summary of the latest information on breast cancer and in brief form to discuss the generally accepted and widely prevailing medical and surgical treatments for breast cancer. The booklet must include a valid assessment of the relative risks and benefits of the accepted and widely prevailing methods of treatment.

A copy of the booklet must be made available by the Board to "every appropriate physician" in the state. A letter by the Board is to accompany the booklet stating that the Board urges the physician to distribute a copy of the booklet to each and every patient whose disease or course of treatment is covered by the material in the booklet. Copies must be made available to any person upon request at a fee sufficient to cover the cost of printing and distribution. The booklet will be updated and redistributed at such times as the Board deems necessary. This law places all the onus on the Board, which must "urge" physicians to distribute the pamphlet. Only the Board's

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<sup>7</sup>Ga. Code Ann. §43-34-21(g) (1984)

actions are mandated or constrained by the statute. The fee may be a deterrent to the widest distribution; a free booklet would be preferable.

D. **HAWAII**

The Hawaii Legislature adopted a resolution<sup>8</sup> requesting the Hawaii Medical Association and the Hawaii Chapter of the American Cancer Society to cooperate in preparing a Breast Cancer Treatment Alternatives (BCTA) information sheet, which would describe, in a manner easily understandable by the patient, the risks and procedures involved in alternative methods of breast cancer treatment. The resolution further requested the Hawaii Medical Association to develop a model consent form which could be used to verify that a patient for whom breast cancer surgery is prescribed has seen, read, and understood the BCTA information sheet. The state medical association was also requested to prepare a plan to ensure the timely distribution of the information sheet and consent form to persons with breast cancer.

Pursuant to the above resolution, the Hawaii Medical Association and the American Cancer Society, Hawaii Division, developed a pamphlet entitled Breast Cancer Treatment Alternatives: A Woman's Choice.

Two days after the above resolution was adopted, the Legislature passed another resolution<sup>9</sup> requesting that the

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<sup>8</sup>H. Res. 321, 1983

<sup>9</sup>S. Res. 148 (1983)

Board of Medical Examiners and the Department of Commerce and Consumer Affairs provide for the effective distribution of the standards on informed consent for breast cancer treatment to Hawaii physicians. Additional copies are to be distributed or readily available for the use of their patients.

Hawaii enacted a law<sup>10</sup> requiring the Board of Medical Examiners to establish standards for health care providers to follow in giving information to a patient, or to a patient's guardian, to ensure that the patient's consent to the performance of a mastectomy is an informed consent. The law requires the standards to include the substantive content of the information to be given, the manner in which the information is to be given by the health care provider, and the manner in which consent is to be given by the patient or the patient's guardian. The substantive content of the information to be given must include information on the recognized alternative forms of treatment.

Note that the initial resolutions simply requested the Board of Medical Examiners to take certain actions, whereas the law passed subsequently required, that is imposed an affirmative duty on, the same Board to establish standards for health care providers. With a request, presumably, the Board is urged to comply, but no sanctions can be imposed if it fails to do so, other than perhaps public disapproval. However, with a statutorily imposed legal requirement, presumably sanctions would

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<sup>10</sup>Haw. Rev. State §671-3(c) (1983)

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<sup>10</sup>Haw. Rev. State §671-3(c) (1983)

result from a breach. Furthermore, a request results in a discretionary duty for a Board, whereas a requirement results in a mandatory duty for a Board. This distinction implicates the level of review a court can give Board action or inaction; discretionary duties of an administrative body are not usually subjected to the same level of judicial scrutiny as are mandatory ones court, under normal administrative law procedures.

The Hawaii Board of Medical Examiners has adopted "Guidelines for Methods of Treatment for Breast Cancer." The Guidelines define biopsy, mastectomy, local excision plus radiation, chemotherapy and other procedures including radiation, reconstructive clinical trials and protocols.

E. **KANSAS**

Kansas expanded the grounds for revocation, suspension or limitation of a medical license to include "failure to inform a patient suffering from any form of abnormality of the breast tissue for which surgery is a recommended form of treatment, of alternative methods of treatment specified in the standardized summary supplied by the Board."<sup>11</sup> The State Board of the Healing Arts is statutorily designated as the agency to develop and distribute the summary to licensed physicians. The summary shall outline alternative modes of treatment, including surgical, radiological or chemotherapeutic treatments and the attendant risks. The provision will not be construed to "empower or authorize the Board to restrict in any manner the right of a

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<sup>11</sup>Kan. Stat. Ann. §65-2836 (o) (1984)

person licensed to practice medicine and surgery to recommend a method of treatment or to restrict in any manner a patient's right to select a method of treatment."

Even though framed in the negative, as grounds for imposing a penalty, this statute seems to impose an affirmative duty on physicians to inform patients. However, there is no specific provision for informed consent prior to treatment explicit or implied.

G. ~~KENTUCKY~~

Kentucky enacted a law<sup>12</sup> requiring the McDowell Cancer Network, Inc. and the James Graham Brown Cancer Center to develop and submit to the Cabinet for Human Resources "a standardized written summary, in layman's language and in language understood by the patient, of the advantages, disadvantages, risks and descriptions of all medically efficacious and viable alternatives for the treatment of breast cancer." Any physician who treats a patient for any form of breast cancer must provide the patient with the summary, informing the patient of alternative modes of treatment "which may include surgical, radiological or chemotherapeutic or combinations thereof."

G. ~~LOUISIANA~~

Louisiana adopted a Resolution<sup>13</sup> urging and requesting all physicians in the state to advise their patients

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<sup>12</sup>check this cite H.B. 609 (1984)

<sup>13</sup>check this cite H. Con. Res. 125 (1983)

orally and in writing of the alternatives to a radical mastectomy prior to performing such a procedure. The Resolution also urges and requests that prior to performing a radical mastectomy on any woman, each physician obtain the signature of the woman on a copy of the written advisement in which she acknowledges that she has been informed of the alternatives to a radical mastectomy. The Resolution further urges and requests each attending physician performing a radical mastectomy to provide the woman with a copy of the written advisement signed by her and to make a copy of this written advisement a part of the medical record of each woman upon whom she/he has performed a radical mastectomy.

This Resolution seems, more openly than most examined, to be designed at least as much to protect physicians from malpractice suits as to protect women from overeager or unscrupulous surgeons and physicians, or from those whose medical education dates from the early part of the century. The emphasis on making a copy of the physician's written advisement signed by her a part of the medical record of each patient on whom the physician has performed a radical mastectomy seems to help doctors build into the record their defense against medical malpractice suits based on failure to inform adequately. The statute, in this regard, seems designed to advise doctors of the best methods to protect themselves against such suits. It does not seem designed with the patients' welfare as primary. Also, this is a mere resolution, which "urges and requests." There seem to be no legal or medical-ethical consequences built into the statute, as

also is the case in Kentucky, Hawaii, Georgia, and some other states, for a physician who fails to comply with the urgings and requests. Urgings and requests can be read as describing a discretionary act, not a mandatory one.

#### H. **MASSACHUSETTS**

Massachusetts enacted a patient's rights law<sup>14</sup> which states that: "Every patient or resident of a facility shall have the right: . . . (h) in the case of a patient suffering from any form of breast cancer, to complete information on all alternative treatments which are medically viable." The law does not make clear when the complete information must be given to the patient, nor whether the information is part of the consent procedure prior to surgery. The Massachusetts Division of the American Cancer Society was involved in drafting the brochure available to all breast cancer patients in the state.<sup>15</sup> The involvement of a private voluntary organization in carrying out what has been seen as a state responsibility in other states is of interest.

#### I. **MINNESOTA**

The Minnesota patients' bill of rights statute<sup>16</sup> states that every patient or resident suffering from any form of breast cancer must be fully informed, prior to or at the time of

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<sup>14</sup>Mass. Gen. Laws Ann. ch. 111, §70E (Law. Co-op. 1983)

<sup>15</sup>American Cancer Society, National Office, Government Relations, Division Involvement in State "Informed Consent--Breast Cancer Treatment" Laws/Legislation (May 1983)

<sup>16</sup>Minn. Stat. §144.651, Subd. 9 (1984)

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admission and during her hospital stay, of all alternative effective methods of treatment of which the treating physician is knowledgeable, including surgical, radiological, or chemotherapeutic treatments or combinations of treatments and the risks associated with each of these methods.

J. **NEW JERSEY**

New Jersey law<sup>17</sup> requires that before a physician operates on a patient for a breast tumor, the physician must obtain written consent from the patient, or the patient's authorized representative, on a form which allows the patient to (1) give consent for a biopsy only; (2) give consent to perform any necessary operation or procedure including breast removal if it is determined that the patient has a malignant tumor in her or his breast or other breast abnormality; or (3) give consent for both a biopsy and an additional operation or procedure if necessary. A physician who fails to comply with this act is subject to disciplinary action by the State Board of Medical Examiners pursuant to the New Jersey Medical Practice Act.

K. **PENNSYLVANIA**

Pennsylvania law<sup>18</sup> provides that before a physician operates on a patient for a breast tumor, a consent form must be executed which contains two options. The patient may consent to either or both options. The first options gives consent for a breast biopsy only. The second option states that:

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<sup>17</sup>N.J. Rev. Stat. title 45, ch. 9 (1984)

<sup>18</sup>H.B. 1972 (1984) check this cite

"If it is determined that I have a malignant tumor in my breast or other breast abnormality requiring surgery, then I authorized Dr. \_\_\_\_\_ to perform such operations or procedures, including breast removal, which are deemed necessary. I have been informed of the current medically accepted alternatives to radical mastectomy." There is no stated requirement for any standard, prescribed information. Failure to comply with the above statutory provisions subjects the physician to disciplinary action under the state's Medical Practice Act or Osteopathic Medical Practice Act.

L. VIRGINIA

The Virginia statute<sup>19</sup> is similar to the Pennsylvania law. Virginia law spells out the paragraphs required in the form "Consent for Treatment of Breast Tumor." Before a physician operates on a patient for a tumor of the breast, a consent form must be executed on which the patient must consent to either of two options or to both. The two options are essentially the same as the ones spelled out in the Pennsylvania statute.

The "blanket," or one-stage, consent in the Pennsylvania and Virginia statutes gives a great deal of discretion to the physician and does not allow women to participate in a fully informed way in decisions about their treatment.

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<sup>19</sup>Va. Code Ann. §54-325.2:2 (1985)

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There is no consistency among the states as to how informed consent to breast cancer treatment is to operate in that state. There seems to be no principled definition of what informed consent in the treatment of breast cancer is or should be. There are many states that have no laws dealing with this area of medical practice. As a result, many women are ill-informed about treatment options and make a very difficult decision too often based on panic and ignorance.



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New Jersey State Nurses Association

Jane A. Adams, M.S., R.N.  
*President*

Dorothy D. Flemming, M.S.N., R.N.  
*Executive Director*

Testimony: June 26, 1990

I am Dorothy Flemming, Executive Director of the New Jersey State Nurses Association.

Thank you for this opportunity to present NJSNA's views on health care in New Jersey. Nursing is the largest group of health care professionals and is essential to any discussions of decent cost effective health care.

Professional nurses are not invested in the present system of health care delivery. We are actively seeking a change in emphasis from tertiary care of the acutely ill to preventive primary care of the well.

We are actively seeking a change in the gatekeeper mentality that allows all control of health care delivery to be put into the hands of the physician. Specifically we seek to obtain prescriptive privilege for a small number of very qualified specialists in nursing practice; Nurse Practitioners, Clinical Nurse Specialists, and Nurse Midwives. Prescription of drugs is an act integral to the assessment, diagnosis and treatment cycle in the provision of primary care. To provide primary care, primary care nursing practitioners are seeking prescriptive authority.

I want to give you a very brief history of prescriptive authority in this country specifically to debunk common assumptions that only an MD is qualified to keep us safe from dangerous drugs.

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Darling vs Charleston Community Memorial Hospital clearly established that the duty of the nurse was to be knowledgeable about diagnosis and prescribing so as to monitor the care of patients and take action if the case is negligent. From that time on Nursing Practice Acts have included diagnosis and treatment through the nursing regimen as part of their practice act. The New Jersey Legislature amended its Nursing Practice Act in 1974 to accommodate that language. Nursings' struggle to obtain autonomy in prescriptive authority translates to a social inequality issue. We are asking for support of legislative language that affords nurses the greatest degree of structural autonomy for safe practice. Our Practice Act should include a definition of nursing that includes or at least does not prohibit the performing of diagnosis and prescribing. Senator Wynona Lipman's bill S-2100 is the legislation we think will accomplish that. Primary Health Care Services are essential to a reformed health care system. Nurses have been educated to assume the role of primary health care provider. NSJNA is asking the New Jersey Legislature to correct the inequities of the past system which invests prescriptive privilege only in the medical field.

We are asking for legislative relief from a very restrictive practice atmosphere for nursing in New Jersey.

AWA:DF/k

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# Prescriptive Authority: Debunking Common Assumptions

Gene E. Harkless, R.N., C., M.S.N.

## Abstract

*Prescription of drugs is an act integral to the assessment, diagnosis and treatment cycle in the provision of primary care. To provide primary care and specialty services, advanced practice nurses are seeking prescriptive authority. This article examines the historical development of medical prescriptive authority, challenges four commonly held assumptions regarding prescriptive authority for nurses, and discusses how medicine's dominance in prescriptive authority relates to nursing's struggle for power and autonomy. Nurses must direct their political and educational activities toward developing true structural and attitudinal autonomy in all aspects of nursing practice.*

Prescription of drugs has become an act integral to the assessment, diagnosis and treatment cycle in the provision of primary care. The role of the nurse in primary care has expanded over the course of the more than 20 years since the founding of the first nurse practitioner training program to claim competency in providing the full range of primary care services.

In spite of the increased knowledge and skill professional nurses attain, many nurses in this country cannot legally prescribe medications or other items requiring a prescription. It is commonly accepted by both nurses and the public that only physicians (MDs) have this authority. Patterns of authority tend to take on the status of objective social fact. Patterns of authority are perpetuated because people come to believe that this is how

things always were, always will be and always should be.<sup>1</sup> After all, the MD has considerable education, years of experience, and with drugs being so dangerous it only makes sense for this system to continue. Or does it? The question arises as a growing number of nurses are seeking prescriptive authority to provide specialty services and primary care.

## Historical Context of Prescriptive Authority

Prior to 1900, consumers could obtain any available drug through their pharmacists without a prescription. Some sought the advice of their physicians about drugs, but this was neither a mandatory nor frequent practice. At the turn of the century, a major transition began as control of drug information and purchasing was shifted away from the consumer and placed under the authority of the physician. The start of this transition was largely the result of three factors. First, muckraking journalists and other Progressives joined physicians in a crusade for regulation of patent medicines as part of a more general assault on deceptive business practices. Second, the American Medical Association (AMA) acquired, through its growing membership, the financial resources to mount a major campaign in favor of requiring that patent medicine manufacturers disclose the contents of their products and cease advertising to the general public. In conjunction with this campaign, the AMA also established its Seal of Approval for drugs. Third, drug makers recognized that they were increasingly

dependent on doctors to market their products because of the public's increased dependency on professional opinion in making decisions about medication. These events, in conjunction with the relatively new licensing laws for medicine, helped place physicians in the new role of drug experts. Authority was moving from being granted by the consumer based on functional role perception to authority being embedded in the institution of medicine.

The first federal legislation to place controls on the dispensing of drugs was the Pure Food Act of 1906. This law made it illegal to misrepresent drug contents by false and misleading labeling. Its intent was to protect the consumer from widespread fraud and to help ensure that fair value was received for the money spent. The law improved the functioning of the market by making consumer information more accurate.<sup>2</sup> Although the law did give physicians prescriptive authority for drugs containing narcotics, all non-narcotic drugs were still available to the consumer without a prescription. The limited prescriptive authority of physicians is illustrated by the fact that in 1929, less than one-third of all medicines bought were prescribed by physicians.

In 1938, the Federal Food, Drug and Cosmetic Act was passed following a tragedy in which a pharmaceutical company released a toxic preparation that killed more than 100 people. This act extended the mandate of the Food and Drug Administration (FDA) to include

regulation distinguishing over-the-counter drugs from prescription drugs. Drugs were defined as any product, including medical devices,

medicine's control of drug prescription farther from the marketplace. In 1951, the Humphrey-Durham Amendment provided for an expert

authority for prescribing.

Even more restrictive to nursing practice was the disclaimer in the 1955 model nurse practice act developed by the ANA that explicitly excluded the acts of diagnosis and prescription as nursing functions. Nurses had never stopped providing a wide variety of services, including diagnosis and treatment; however, this disclaimer, which was incorporated in the nurse practice acts in a number of states, widened the gap between actual nursing practice and the statutory definition of nursing.<sup>4</sup> In 1965, the case of *Darling v. Charleston Community Memorial Hospital* clearly stated that the duty of the nurse was to be knowledgeable about diagnosis and prescribing so as to monitor the care of patients and take action if the care is negligent.<sup>5</sup> It was not until 1970 that the ANA amended its model definition to recognize the responsibility professional nurses had and continue to have for diagnosing and prescribing.

**As consumer influence declined ... medicine was turning authority into social privilege and economic power. Nursing did not keep pace with these changes.**

that affected bodily structures or functions even in the absence of disease. Physicians, by virtue of their position in the health care field, were given the authority to control access to these prescription items.

Upon passage of the 1938 act, the FDA stated clearly that the legislation would not usurp any control from the consumer. However, the regulation that the agency developed six months later ended up doing exactly the opposite. The designation of prescriptive vs. non-prescriptive drugs was delegated to the manufacturer, and those drugs requiring prescription had to be labeled in such medical terms so as to not be easily understood by the ordinary individual. According to Temin, it is not clear why this approach was introduced at this time.<sup>3</sup> He speculates that the FDA probably thought there would be only a small number of prescription drugs designated. However, this resolution of the question of who — consumers, pharmacists, doctors or the FDA — should choose which medicine people take has had enormous impact on health care and been of great benefit to the position of physicians within this system. These regulations took control from the consumer and embedded the prescription of medications more firmly into the existing medical hierarchy and increased consumer dependence on the physician. This increased prescriptive authority in combination with licensure requirements helped further move medicine out of the market economy and into an insulated hierarchical ar-

review board to decide whether a drug was safe for use.<sup>3</sup> Following the 1951 law, almost all new drugs were placed in the prescription-only class. The Drug Amendment in 1962 took even more decision-making away from the consumer. This amendment gave the FDA authority to regulate which drugs could be used for which illnesses. Both manufacturers and practicing physicians were placed in subordinate position to the experts appointed by the government.

As consumer influence declined, the physicians' growing authority to prescribe drugs increasingly obliged pharmaceutical companies to court medicine's good will, finance its journals, and subsidize its professional associations and political activities. Medicine was turning authority into social privilege and economic power.<sup>2</sup>

Nursing did not keep pace with these changes. The original nurse practice acts were legislated prior to the passage of the 19th Amendment and so depended on the support of male-dominated legislator and physician groups for passage. This helped set the stage for the perception of nursing as a physician-controlled occupation. The original licensing boards of nursing contained physicians and required letters of supports from MDs for licensure.<sup>4</sup> However, nurses in a variety of situations, such as private nursing and public health, continued to work independently of physicians and make recommendations regarding drug therapy as a matter of course. The FDA legislation of 1938 forced this accepted practice by many

Nurses have been unofficially performing prescriptive activities over time. Historically, the RN has assumed a great deal of unofficial critical client management, including drug-related decisions without formal recognition. The move toward accountability and autonomy in nursing is an attempt to make official these functions. Along with increased regulation of specialty nursing, there has been a gradual acknowledgment of the expanding scope of practice in nursing-related legislation. Bigbee supports prescriptive authority as a tool necessary for the growth of the practice of nursing.<sup>6</sup>

Twenty-eight states have passed legislation or rules granting prescription authority to certain nurses, usually advanced practice nurses (NPs) in primary care specialties.<sup>7</sup> However, nurses have not been accorded a great deal of structural autonomy in the decision-making that surrounds prescribing functions.<sup>8</sup> Prescribing authority is limited in two ways in most states. First, only certain nurses can prescribe. Second, the drugs or devices are limited by formulary and/or protocols/practice agreements.<sup>9</sup> In some states, prescriptive authority is a delegated

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not the nurse's status as an independently licensed professional. This has limited value in recognizing the scope of advanced nursing practice.

physicians' and the public's perceptions of autonomy, control, responsibility and competence. History is clear that the authority for prescribing

numerous drugs, including common antibiotics, analgesics and other items such as contraceptives, that do not require the mandatory supervision of a physician.<sup>3</sup> However, medicine believes that drug treatment is central in medical care and has guarded this privilege as its exclusive domain.

**History is clear that the authority for prescribing treatment 1) has not always rested with the MD, 2) developed with little challenge and examination, and 3) may be competently carried out by others.**

Requiring physician supervision through protocols or practice agreements is considered the most restrictive since it affects both the choice of drugs and the autonomy of action on the part of the nurse. It presumes approval of and consistency of a nurse's decisions with those of a supervisor's. In contrast, the formulary is considered the least restrictive. It limits the choice of drugs but grants autonomy in decisions about drug use.<sup>10</sup>

#### Assumptions and Challenges Regarding Prescriptive Authority

The assumptions that sustain the belief in the preeminent authority of the physician to prescribe include the following: 1) Medicine has always had the sole authority to prescribe; 2) MD knowledge and education lead to a scientific and instrumental approach to decision-making; 3) the vast increase in the number of therapeutics and the risky nature of prescribing make it appropriate only for physicians; and 4) the nurse is the assistant to the MD and less competent to provide prescriptive services. The issue of public safety and the complexity of the treatment decisions that are made continue to be the main arguments for maintaining physician control.

The first assumption is based in the historical review supporting the strong sense of ownership of prescriptive authority by physicians. This sense of ownership developed

treatment 1) has not always rested with the MD, 2) developed with little challenge and examination, and 3) may be competently carried out by others.

The second assumption concerns the superiority of MD knowledge and approach to prescribing activities. Temin reviewed research concerning behavior involved in making drug choices.<sup>3</sup> The research shows that there is very little data on comparative benefits of drugs and that few physicians know about comparative costs. Instead, choice of drugs and evaluation of prescribing activities is based on customary behavior, i.e., the choice is based on usual medical practice.

The third assumption argues that the vast increase in the number of therapeutics and the risky nature of prescribing make it appropriate only for physicians. It is commonly believed that with the vast increase of medications on the market, a need was created for physicians to be in charge. However, this is historically inaccurate since physician control happened prior to the development of the modern drug era. Most drugs developed after 1938 were identified as prescription items. What is evident is that drugs vary in their level of risk. There do exist well-known and frequently used drugs that are relatively risk-free. An example of the recent loosening of the traditionally tight control of the drug market was the movement of ibuprofen from prescriptive to non-prescriptive status. This drug was relatively safe as a

Physician dominance over prescriptive authority has not assured high-quality prescriptive practices. The study by Morris et al. revealed some disturbing information regarding the prescriptive practices of physicians.<sup>11</sup> In a telephone survey of more than 1,000 people who had recently obtained new prescriptions, only 60 percent stated that the physician provided information or directions for use. Only 32 percent were informed about precautions, and even fewer (26 percent) were informed about side effects. The majority of those interviewed stated they were more likely to use a non-MD for advice regarding their drug therapy.

The fourth assumption identifies the nurse as the physician's assistant and less competent to provide the services of primary care where prescriptive authority is necessary. However, research has shown nurses to be competent primary care providers and safe medication providers. LaPlante and O'Bannon reviewed numerous studies that clearly document the effectiveness, safety and client acceptance of NPs.<sup>12</sup> They found in their research of NP prescription practices that of 2,081 NP-initiated prescriptions reviewed, only 2 percent of the prescriptions were changed after consultation with the supervising physician and only two drugs (0.1 percent of all recommended) were changed to different drug categories. Batey and Holland examined the prescribing practices of NPs and found drug utilization similar to MD data and the intensity of prescribing of prescribing less than that of physicians.<sup>10</sup> Consultation with physicians occurred with highest incidence for health problems treated with the least frequently prescribed drugs. Physician consultation or referral occurred in only 14 percent of all prescriptions.

In another study, Ramsey et al. compared care given by NPs with care given by physicians for a group of hypertensive patients and found some health outcomes superior for the NP and others equivalent.<sup>13</sup> This supports other studies that estimate that 67 to 90 percent of people seeking primary care can be managed by NPs.<sup>12</sup>

### Analysis: The Issue of Power and Autonomy

The stability of the medical hierarchy, MDs' perceived role as experts, the rise in technological development, and the support of government agencies have created a value-generating system that has served to strengthen the hierarchical structure of medicine. Historically, a climate of conformity was fostered that viewed differences of values and opinions as curious heresies or irrelevant eccentricities to be dismissed as of no consequence.<sup>14</sup> Over time, the reality of the physician as the only medical authority was constructed and embedded in the medical and lay culture through texts, references, scientific works and law.<sup>2</sup> This facilitated the legitimation of medicine's power and influence by making accepted fact the profession's authority, activities and outcomes. This construction of reality was held by most of the nursing profession until recently.

The scientific advances in medicine reinforced the perceived need for government assistance and involvement while supportive government regulations helped protect medicine's control of the health care hierarchy. The rewards of cooperation between regulatory bodies and the organizations they controlled outweighed the conflicts, to the great benefit of medicine.<sup>15</sup> If an individual or subunit is assumed to be irreplaceable, that individual or subunit can control this position of monopoly by ensuring that no other similar unit is brought into the organization or even to the attention of those in control.<sup>1</sup> Medicine clearly has controlled access into the medical hierarchy at any level that could be seen as competitive with physicians. The success of this control has been to make unthinkable the possibility of alternatives.<sup>14</sup> Medicine's ability to control prescriptive authority until the recent challenges

by NPs attests to the power and influence it wields. Through authority sanctioned by laws and regulations and by its power in the health care hierarchy, medicine has set itself up as the judge of its potential

the autonomy and influence it wields. Nurses are breaking old traditions and setting precedents on which to base new traditions.<sup>6</sup> History will show how successful these new traditions will be.

**Nursing's struggle to obtain autonomy in prescriptive authority translates to a social inequality issue. In order to transform the perception of their role as physician-dominated, nurses must direct their political and educational activities toward developing true structural and attitudinal autonomy in all aspects of nursing practice.**

competitors (e.g., nursing). Power originates in dependence and, historically, nursing was very dependent on medicine.

Nursing's struggle to obtain autonomy in prescriptive authority translates to a social inequality issue. In order to transform the perception of their role as physician-dominated, nurses must direct their political and educational activities toward developing true structural and attitudinal autonomy in all aspects of nursing practice. Suggested strategies include working toward the elimination of restrictive legislation in nursing and other laws. Also, support should be given to legislative language that affords nurses the greatest degree of structural autonomy for safe practice.<sup>8</sup> Practice acts should include a definition of nursing that includes or at least does not prohibit the performing of diagnosing and prescribing. Nursing should promote itself to the public and government as providing high-quality, independent nursing care including the provision of primary health care services. This should help set the stage for increased autonomy in all aspects of nursing's practice.

Greenlaw predicts that competing societal, professional and economic forces will continue to positively affect nursing practice.<sup>4</sup> Future legislation will reflect this growth in technical skill as well as

### REFERENCES

1. Pfeffer, J.: *Power in Organizations*, Marshfield, Mass., Pitman Publishing Inc., 1981, pp. 114, 298-9.
2. Star, P.: *The Social Transformation of American Medicine*, New York, Basic Books Inc., 1982, pp. 5-24, 132-3.
3. Temin, P.: *Taking Your Medicine: Drug Regulation in the United States*, Cambridge, Mass., Harvard University Press, 1980.
4. Greenlaw, J.: "Definition and Regulation of Nursing Practice: An Historical Survey," *Law, Medicine & Health Care*, June 1985, pp. 117-21.
5. Cazalas, M.W.: *Nursing & the Law*, 3rd Ed., Germantown, Md., Aspen Systems Corp., 1978.
6. Bigbee, J.L.: "Territorial and Prescriptive Authority for Nurse Practitioners," *Nursing and Health Care*, 1984, 5:2, pp. 106-10.
7. "How Each State Stands on Legislative Issues Affecting Advanced Nursing Practice," *The Nurse Practitioner: The American Journal of Primary Health Care*, January 1989, 14:1, p. 27.
8. American Nurses' Association: *Prescribing Privileges for Nurses: A Review of Current Law*, 1984.
9. Bullough, B.: "Prescription Privileges in Nurse Practice Laws and Regulation," *Pediatric Nursing*, 1983, pp. 462-4.
10. Batey, M.V. and Holland, J.M.: "Prescribing Practices Among Nurse Practitioners in Adult and Family Medicine," *American Journal of Public Health*, 1985, 75:3, pp. 258-62.
11. Morris, L.A. et al.: "A Survey of Patient Sources of Prescription Drug Information," *American Journal of Public Health*, 1984, 74:10, pp. 1161-2.
12. LaPlante, L.J. and O'Bannon, F.V.: "NP Prescribing Recommendations," *The Nurse Practitioner: The American Journal of Primary Health Care*, 1987, 12:4, pp. 52-8.
13. Ramsey, J.A. et al.: "Physicians and Nurse Practitioners: Do They Provide Equivalent Health Care?" *American Journal of Public Health*, 1982, 72:1, pp. 55-7.
14. Navarro, V.: *Medicine Under Capitalism*, New York, Neale Watson, 1977, pp. 153-4.
15. Galbraith, J.K.: *Economics and the Public Purpose*, Boston, Houghton & Mifflin, 1973, p. 160. ○

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SENATE, No. 2100  
STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel  
PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Senator LIPMAN

1 AN ACT concerning prescriptive powers for specialists in nursing  
2 practice, amending R.S.45:14-13, R.S.45:14-14, and  
3 R.S.45:14-15, and amending and supplementing P.L.1947, c.262.

4  
5 BE IT ENACTED by the Senate and General Assembly of the  
6 State of New Jersey:

7 1. (New section) The Legislature recognizes that nursing is a  
8 dynamic field, the practice of which is continually evolving to  
9 include more sophisticated patient care activities. It is the  
10 intent of the Legislature through this act to provide clear legal  
11 authority for functions and procedures which have common  
12 acceptance and authority; to recognize the existence of  
13 overlapping functions between physicians and registered  
14 professional nurses; and to recognize that certain professional  
15 services can be provided to consumers at greatly reduced cost  
16 without affecting the high professional quality with which these  
17 services are currently provided

18 2. Section 1 of P.L.1947, c.262 (C.45:11-23) is amended to  
19 read as follows:

20 1. Definitions. As used in this act[.]:

21 a. The words "the board" mean the New Jersey Board of  
22 Nursing created by this act.

23 b. The practice of nursing as a registered professional nurse is  
24 defined as diagnosing and treating human responses to actual or  
25 potential physical and emotional health problems, through such  
26 services as casefinding, health teaching, health counseling and  
27 provision of care supportive to or restorative of life and  
28 well-being, and executing medical regimen as prescribed by a  
29 licensed or otherwise legally authorized physician or dentists.  
30 Diagnosing in the context of nursing practice means that  
31 identification of and discrimination between physical and  
32 psychosocial signs and symptoms essential to effective execution  
33 and management of the nursing regimen. [Such diagnostic  
34 privilege is distinct from a medical diagnosis.] Treating means  
35 selection and performance of those therapeutic measures  
36 essential to the effective management and execution of the  
37 nursing regimen. Human responses means those signs, symptoms,  
38 and processes which denote the individual's health need or  
39 reaction to an actual or potential health problem.

EXPLANATION—Matter enclosed in bold-faced brackets [thus] in the  
above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

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1 The practice of nursing as a licensed practical nurse is defined  
2 as performing tasks and responsibilities within the framework of  
3 casefinding; reinforcing the patient and family teaching program  
4 through health teaching, health counseling and provision of  
5 supportive and restorative care, under the direction of a  
6 registered nurse or licensed or otherwise legally authorized  
7 physician or dentist.

8 The terms "nursing," "professional nursing," and "practical  
9 nursing" as used in this act shall not be construed to include  
10 nursing by students enrolled in a school of nursing accredited or  
11 approved by the board performed in the prescribed course of  
12 study and training, nor nursing performed in hospitals, institutions  
13 and agencies approved by the board for this purpose by graduates  
14 of such schools pending the results of the first licensing  
15 examination scheduled by the board following completion of a  
16 course of study and training and the attaining of age qualification  
17 for examination, or thereafter with the approval of the board in  
18 the case of each individual pending results of subsequent  
19 examinations; nor shall any of [said] these terms be construed to  
20 include nursing performed for a period not exceeding 12 months  
21 unless the board shall approve a longer period, in hospitals,  
22 institutions or agencies by a nurse legally qualified under the laws  
23 of another state or country, pending results of an application for  
24 licensing under this act, if such nurse does not represent or hold  
25 himself or herself out as a nurse licensed to practice under this  
26 act; nor shall any of [said] these terms be construed to include  
27 the practice of nursing in this State by any legally qualified nurse  
28 of another state whose engagement made outside of this State  
29 requires such nurse to accompany and care for the patient while  
30 in this State during the period of such engagement, not to exceed  
31 six months in this State, if such nurse does not represent or hold  
32 himself or herself out as a nurse licensed to practice in this  
33 State; nor shall any of said terms be construed to include nursing  
34 performed by employees or officers of the United States  
35 Government or any agency or service thereof while in the  
36 discharge of his or her official duties; nor shall any of [said] these  
37 terms be construed to include services performed by nurses aides,  
38 attendants, orderlies and ward helpers in hospitals, institutions  
39 and agencies or by technicians, physiotherapists, or medical  
40 secretaries, and such duties performed by [said] the persons  
41 aforementioned shall not be subject to rules or regulations which  
42 the board may prescribe concerning nursing; nor shall any of  
43 [said] these terms be construed to include first aid nursing  
44 assistance, or gratuitous care by friends or members of the  
45 family of a sick or infirm person, or incidental care of the sick by  
46 a person employed primarily as a domestic or housekeeper, not  
47 withstanding that the occasion for such employment may be  
48 sickness, if such incidental care does not constitute professional  
49 nursing and such person does not claim or purport to be a

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1 licensed nurse; nor shall any of [said] these terms be construed to  
2 include services rendered in accordance with the practice of the  
3 religious tenets of any well-recognized church or denomination  
4 which subscribes to the art of healing by prayer. A person who is  
5 otherwise qualified shall not be denied licensure as a professional  
6 nurse or practical nurse by reason of the circumstances that such  
7 person is in religious life and has taken a vow of poverty.

8 [Nothing in this act confer the authority to a person licensed to  
9 practice nursing to practice another health profession as  
10 currently defined in Title 45 of the Revised Statutes.]

11 c. "Specialist in nursing practice" means a registered  
12 professional nurse who through study and supervised practice at  
13 the post-graduate level has become an expert in a selected  
14 clinical area of nursing knowledge and practice. A registered  
15 professional nurse who is a specialist in nursing practice, who  
16 meets qualifications approved by the board and who is authorized  
17 through the board's rules and regulations, may prescribe drugs,  
18 medicine and devices, excluding controlled dangerous substances  
19 except for those listed in Schedule V pursuant to P.L.1970, c.226  
20 (C.24:21-1 et seq.), as part of the execution and management of  
21 the nursing regimen, and delegate to other registered professional  
22 nurses the appropriate execution of said regimen.

23 3. Section 2 of P.L.1947, c.262 (C.45:11-24) is amended to  
24 read as follows:

25 2. The board; appointment of members; terms; oath of office.

26 a. The board; appointment; terms. In addition to the members  
27 appointed to represent the interests of the public pursuant to  
28 P.L.1971, c.60 as amended by P.L.1977, c.285 (C.45:1-2.2) the  
29 New Jersey Board of Nursing shall consist of 10 members, [seven]  
30 six of whom shall be registered professional nurses, two of whom  
31 shall be licensed practical nurses, one of whom shall be a  
32 registered professional nurse who is a professor of pharmacology,  
33 and one of whom shall be an additional public member, all to be  
34 appointed by the Governor. Appointments to the board shall be  
35 for terms of five years or for the unexpired portion of a term in  
36 the case of a vacancy for any cause within a term, and until a  
37 successor shall be appointed and qualified. In making  
38 appointments the Governor shall give due consideration to, but  
39 shall not be bound by, recommendations submitted by the various  
40 nurses' professional associations of this State. Upon notice and  
41 hearing, the Governor may remove from office any member of  
42 the board for neglect of duty, incompetency, unprofessional or  
43 dishonorable conduct.

44 b. Qualifications for appointment. Each registered  
45 professional nurse member of the board shall be a citizen of the  
46 United States and a resident of this State; shall be a graduate of  
47 an accredited school of nursing within the United States; shall be  
48 a registered nurse in this State; shall have had at least five

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1 years' experience in professional nursing following graduation  
2 from an accredited school of nursing; and shall at the time of  
3 appointment be actively engaged in nursing or work relating  
4 thereto. The licensed practical nurse members of the board shall  
5 be citizens of the United States and residents of this State; shall  
6 hold a valid license to practice practical nursing in this State;  
7 shall have had at least three years' experience in practical  
8 nursing; and shall at the time of appointment be actively engaged  
9 in practical nursing or work related thereto.

10 c. Oath or affirmation of office. Within 30 days after receipt  
11 of the commission, each appointee shall take, subscribe and file  
12 in the office of the Secretary of State the oath or affirmation  
13 prescribed by law.

14 d. Duties and powers. The board shall have the following  
15 duties and powers: (1) It shall hold annual meetings and such  
16 other meetings as it may deem necessary at such times and  
17 places as the board shall prescribe and a majority of the board  
18 including one officer shall constitute a quorum. (2) It shall elect  
19 from its members and prescribe the duties of a president and  
20 secretary-treasurer, each of whom shall serve for one year and  
21 until a successor is elected. (3) It shall appoint and prescribe the  
22 duties of an executive secretary to the board who need not be a  
23 member thereof by who shall be a citizen of the United States, a  
24 graduate of a college or university with a major in nursing  
25 education, a registered nurse of this State with at least five  
26 years' experience in teaching or administration or both in an  
27 accredited school of professional nursing, or have equivalent  
28 qualifications as determined by the board. The executive  
29 secretary shall hold office during the will and pleasure of the  
30 board. (4) It shall employ and prescribe the duties of such persons  
31 as in its judgment shall be necessary, for the proper performance  
32 and execution of the duties and powers of the board. (5) It shall  
33 determine and pay reasonable compensation and necessary  
34 expenses of the executive secretary and all employees of the  
35 board. (6) It shall pay to each member of the board the  
36 compensation hereinafter provided. (7) It shall have a common  
37 seal, keep an official record of all its meetings, and through its  
38 secretary-treasurer report annually to the Governor the work of  
39 the board. (8) It shall examine applicants for a license or  
40 renewals thereof, issue, renew, revoke and suspend licenses, as  
41 hereinafter provided. (9) It shall in its discretion investigate and  
42 prosecute all violations of provisions of this act. (10) It shall  
43 keep an official record which shall show the name, age, nativity  
44 and permanent place of residence of each applicant and licensee  
45 and such further information concerning each applicant and  
46 licensee as the board shall deem advisable. The record shall show  
47 also whether the applicant was examined, licensed or rejected  
48 under this and any prior act. Copies of any of the entries of the  
49 record or of any certificate issued by the board may be

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1 authenticated by any member of the board under its seal and  
2 when so authenticated shall be evidence in all courts of this State  
3 of the same weight and force as the original thereof. For  
4 authenticating a copy of any entry or entries obtained in its  
5 record the board shall be paid a fee of \$3.00, but such  
6 authentication, if made at the request of any public agency of  
7 this or any other jurisdiction, may be without fee. (11) In its  
8 discretion it may publish at such times as it shall determine a list  
9 of nurses licensed under this act, a list of schools of nursing  
10 accredited or approved under this act, and such other information  
11 as it shall deem advisable. (12) It shall prescribe standards and  
12 curricula for schools of nursing and evaluate and approve courses  
13 for affiliation. (13) It shall hear and determine applications for  
14 accreditation of schools of professional nursing, conduct  
15 investigations before and after accreditation of such schools and  
16 institutions with which they are affiliated, and issue, suspend or  
17 revoke certificates of accreditation as hereinafter provided. (14)  
18 It shall approve schools of practical nursing which shall conform  
19 to the standards, curricula, and requirements prescribed by the  
20 board, and suspend or revoke approval for violations thereof;  
21 provided, that this power shall not extend to schools operated by  
22 any board of education in this State. (15) It may consult with the  
23 Medical Society of New Jersey and the New Jersey Hospital  
24 Association with respect to any matter relating to the  
25 administration of this act and shall consult with those  
26 associations with respect to standards and curricula and any  
27 challenge thereof for schools of nursing. (16) It shall issue  
28 [subpenas] subpoenas for the attendance of witnesses and  
29 production of documents at any hearing before the board  
30 authorized by this act and any member of the board shall  
31 administer an oath or affirmation to persons appearing to give  
32 testimony at such hearings. (17) It may conduct any  
33 investigations, studies of nursing and nursing education and  
34 related matters, and prepare and issue such publications as in the  
35 judgment of the board will advance the profession of nursing and  
36 its service to the public. (18) It shall perform all other functions  
37 which are provided in this act to be performed by it or which in  
38 the judgment of the board are necessary or proper for the  
39 administration of this act. (19) It shall from time to time  
40 prescribe rules and regulations not inconsistent with this act.

41 e. Compensation. Each member of the board shall receive  
42 \$15.00 per day for each day in which such member is actually  
43 engaged in the discharge of duties and traveling and other  
44 expenses necessarily incurred in the discharge of duties.

45 4. R.S.45:14-13 is amended to read as follows:

46 45:14-13. Prescriptions filled only by pharmacist or  
47 apprentices duly supervised. No person who is not a registered  
48 pharmacist of this State, or an apprentice employed in a  
49 pharmacy under the immediate personal supervision of a

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1 registered pharmacist, shall compound, dispense, fill or sell  
2 prescriptions of physicians, dentists, veterinarians [or], any other  
3 medical practitioners or specialists in nursing practice licensed to  
4 write prescriptions for drugs and medicines.

5 5. R.S.45:14-14 is amended to read as follows:

6 45:14-14. The term "prescription" as used in [section]  
7 R.S.45:14-13, R.S.45:14-15 to R.S.45:14-17 [of this Title] means  
8 an order for drugs or medicines or combinations or mixtures  
9 thereof, written or signed by a duly licensed physician, dentist,  
10 veterinarian [or], other medical practitioner or a specialist in  
11 nursing practice licensed to write prescriptions intended for the  
12 treatment or prevention of disease in man or animals, and  
13 includes orders for drugs or medicines or combinations or  
14 mixtures thereof transmitted to pharmacists through word of  
15 mouth, telephone, telegraph or other means of communication by  
16 a duly licensed physician, dentist, veterinarian [or], other medical  
17 practitioner or a specialist in nursing practice licensed to write  
18 prescriptions intended for the treatment or prevention of disease  
19 in man or animals, and such prescriptions received by word of  
20 mouth, telephone, telegraph or other means of communication  
21 shall be recorded in writing by the pharmacist and the record so  
22 made by the pharmacist shall constitute the original prescription  
23 to be filed by the pharmacist, as provided for in [section]  
24 R.S.45:14-15 [of this Title], but no prescription, for any narcotic  
25 drug, except as provided in [section] R.S.24:18-7 [of the Revised  
26 Statutes], shall be given or transmitted to pharmacists, in any  
27 other manner, than in writing signed by the physician, dentist,  
28 veterinarian, specialist in nursing practice or other medical  
29 practitioner giving or transmitting the same, nor shall such  
30 prescription be renewed or refilled.

31 6. R.S.45:14-15 is amended to read as follows:

32 45:14-15. The registered pharmacist compounding, dispensing,  
33 filling or selling a prescription shall place the original written  
34 prescription in a file kept for that purpose for a period of not less  
35 than five years if such period is not less than two years after the  
36 last refilling, and affix to the container in which the prescription  
37 is dispensed, a label bearing the name and complete address of  
38 the pharmacy or drug store in which dispensed, the brand name or  
39 generic name of the product dispensed unless the prescriber  
40 states otherwise on the original written prescription, the date on  
41 which the prescription was compounded and an identifying  
42 number under which the prescription is recorded in his files,  
43 together with the name of the physician, dentist, veterinarian  
44 [or], other medical practitioner or specialist in nursing practice  
45 prescribing it and the directions for the use of the prescription by  
46 the patient, as directed on the prescription of the physician,  
47 dentist, veterinarian, [or], other medical practitioner or specialist  
48 in nursing practice licensed to write prescriptions. Every  
49 registered pharmacist who fills or compounds a prescription, or

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1 who supervises the filling or compounding of a prescription by a  
2 person other than a pharmacist registered in this State, shall  
3 place his name or initials on the original prescription or on the  
4 label affixed to the container in which the prescription is  
5 dispensed or in a book kept for the purpose of recording  
6 prescriptions. The [board of pharmacy] Board of Pharmacy or any  
7 of its agents is hereby empowered to inspect the prescription  
8 files and other prescription records of a pharmacy and to remove  
9 from said files and take possession of any original prescription;  
10 providing, that the authorized agent removing or taking  
11 possession of an original prescription shall place in the file from  
12 which it was removed a copy certified by said person to be a true  
13 copy of the original prescription thus removed; provided further,  
14 that the original copy shall be returned by the [board of  
15 pharmacy] Board of Pharmacy to the file from which it was  
16 removed after it has served the purpose for which it was  
17 removed.

18 7. This act shall take effect immediately.  
19

20  
21 STATEMENT

22  
23 This bill defines a "specialist in nursing practice." It provides  
24 that registered professional nurses who are specialists in nursing  
25 practice, who meet qualifications approved by the New Jersey  
26 Board of Nursing and who are authorized by the board's rules and  
27 regulations may prescribe certain drugs and devices. It also  
28 provides pharmacists with the authority to fill prescriptions  
29 signed by specialists in nursing practice.  
30

31  
32 REGULATED PROFESSIONS

33 Provides specialists in nursing practice with prescriptive powers.  
34

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## PROPOSED AMENDMENTS TO S-2100

1. p.1. In explanatory statement, delete specialist in nursing practice and substitute Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist
2. p.3. Delete line 79-90, as written; substitute the following:
  - 2c. Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist means a registered professional nurse who through completion of a formal postgraduate nursing education program and national certification in a specialty has demonstrated expertise in a selected clinical area of nursing knowledge and practice. A Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist who meets qualifications approved by the Board\* and who is authorized by the Board's rules and regulations may prescribe drugs, devices and immunizing agents appropriate to her specialty area in accordance with a Board approved formulary. Drugs may not be sold for profit by a self employed registered nurse.
3. p.4. Change italics in line 9 to read: One of whom shall be a Nurse Practitioner, Nurse Midwife or Clinical Nurse Specialist in active practice.
4. p.6. 45:14-13, lines 7 and 8: change specialist in nursing practice to Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist.
  - p.6. 45:14-14, line 6 and lines 12, 13: change specialist in nursing practice to Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist.
  - p.7. line 23 (top of page): change specialist in nursing practice to Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist.
  - p.7. line 17 (middle of page): change specialist in nursing practice to Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist.
5. p.8. Change statement to read: This bill defines a Nurse Practitioner/Nurse Midwife/Clinical Nurse Specialist. It provides that registered professional nurses who are Nurse Practitioners/Nurse Midwives/Clinical Nurse

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New Jersey State Nurses Association

Jane A. Adams, M.S., R.N.  
*President*

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*Executive Director*

Specialist who meet qualifications approved through rules and regulations established by the New Jersey Board of Nursing may, in accordance with a Board approved formulary, prescribe drugs, devices and immunizing agents appropriate to their specialty areas. It also provides pharmacists with the authority to fill prescriptions signed by Nurse Practitioners/ Nurse Midwives/Clinical Nurse Specialists.

- p.8. Under Regulated Professions, change to read: Provides Nurse Practitioners/Nurse Midwives/Clinical Specialists with prescriptive powers appropriate to their specialty area in accordance with a Board approved formulary.

\*Board means New Jersey Board of Nursing

NJSNA-PHCNP Forum  
Revised 11/89

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TESTIMONY FOR THE COMMISSION ON  
SEX DISCRIMINATION IN THE STATUTES  
JUNE 26, 1990

Thank you for the opportunity to speak on the issue of sex discrimination in the health field and in the delivery of health care. Many of the areas on which you have decided to focus are of importance to NJEA and its membership; however, we have decided to offer testimony on two critical issues.

One area of major concern facing New Jersey is teenage pregnancy. The current statistics report that 7,022 teenagers, between the ages of 10 and 18 became pregnant during 1988. In addition, the most recent data shows an increase in the number of teens between the ages of 10 and 14 becoming pregnant. These statistics are indeed alarming, especially when one considers that many more cases go unreported! The total spectrum of health care and other services available to these young women is woefully lacking. This is often a very traumatic time which interrupts the teenager's family life and education, and a very thorough counseling system is needed to lessen the impact of being young, often unmarried, and pregnant.

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Parents and churches may provide the necessary support system, but all too often these systems may not be enough. These young women need the following; (1) a network of support clinics which explain all of the options for dealing with pregnancy that are currently available; (2) fully funded health/family planning clinics in all areas of the state; (3) an educational program which provide accessibility to all of the options available to non-pregnant students, and; (4) school based child care so that they may return to school and finish their education.

Presently, New Jersey is piloting 29 school based Youth Service Clinics, which service teenagers on a "drop-in" basis. Many of the services provided by these clinics is of referral nature. So pregnant teenagers will be sent to other community resources which actually provide medical or other services. These school based clinics seem to be very successful and need to be expanded once this last year of the pilot program is completed. Teenagers need to have easy access to getting the help they need and schools are able to provide this accessibility.

Currently, many teenagers do not receive medical attention until the third trimester of their pregnancies, which often has adverse effects on both the health of the mother and the baby.

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Many young women do not know where to go for proper health care during pregnancy -- some do not even know that they should go for prenatal care! Supplying information is not enough. Health care must be both accessible and supportive. A young woman's first visit often determines if she will return for continuing check-ups. Presently, Family Planning Clinics provide the majority of these health services and only 24% of the cost of running these clinics is covered by state funding. These clinics need to be fully funded and we need to increase the number of clinics. (Currently, there are only 16 in New Jersey.)

A pregnant student needs to be assured of receiving the same educational opportunities that she would have had available had she not become pregnant. New Jersey Title VI, Equality in Educational Programs, states that "there shall be no discrimination against students because of pregnancy, childbirth, pregnancy-related disabilities, actual or potential parenthood, or family or marital status. A student shall not be excluded from any educational program or activity because of pregnancy or related conditions unless she so requests or a physician certifies that such exclusion is necessary for her physical, mental, or emotional well-being. If she is excluded for these reasons, she must be provided with adequate and timely opportunity for instruction to continue or make up her schoolwork without prejudice or penalty."

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All too often, pregnant teenagers drop out of school and, if they do remain in school, they do not continue their current educational program. Sometimes students are placed on home bound instruction until after the birth has occurred. Education "out of the mainstream" may provide the basics, but is often not equipped to provide the specialized programs available in vocational or comprehensive high schools. Elizabeth, Newark, and the Heller School in Mt. Holly are some of the very few schools which provide special educational systems for pregnant students. School districts must re-examine the educational programs provided for pregnant teenagers and must expand their role as a source of health and health care information.

Teenage mothers need to have continued support after the birth of the baby. Information on postnatal health care must be made available and these health services must be provided throughout the state. These young women also need to have access to school based child care. Continuing their education must be made much easier and providing day care in schools would assure both the availability of good day care programs and dissemination of information on postnatal health care.

The second issue we would like to address is an issue of the detection and treatment of domestic violence and rape. This is an area of grave concern to the members of the NJEA Women in Education Committee. It is our contention many of these crimes are committed as acts of violence against women, based solely on

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gender. These crimes are often not reported and, when they are reported, are treated as minor offenses. There are still stereotypic beliefs that: (1) these women "asked for it;" (2) this is a private "family matter," or; (3) these violent acts are "a part of certain cultures." The treatment and prevention of violent crimes against women must become a priority in both New Jersey and the nation as a whole.

The following are suggestions for improving the treatment of women who are victims of domestic crimes and rape:

1. The concept of Women's Health Networks, which some hospitals have started, could be expanded to provide 24 hour "hotline" number services so that abused women or rape victims would be provided with both immediate health services and support counseling system information.

2. We need to develop a thorough system for reporting incidents of both domestic violence and rape, complete statistical data would help demonstrate the need for expanded programs of prevention and treatment.

3. Educational health programs need to provide information to both boys and girls on overcoming gender stereotyping, understanding domestic violence, and dealing with rape. These programs would help provide students the opportunity to discuss topics which are often avoided and can only be overcome by a thorough understanding of their nature.

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