Public Hearing

before

COMMISSION ON SEX DISCRIMINATION IN THE STATUTES

"Sex discrimination in the health field and in the delivery of women's health care"

LOCATION: Committee Room 9
Legislative Office Building
Trenton, New Jersey

DATE: February 1, 1994
10:00 a.m.

MEMBERS OF COMMISSION PRESENT:

Senator Wynona M. Lipman, Chair
Senator James S. Cafiero
Roberta W. Francis
Jeanne Fox, Esq.

ALSO PRESENT:

Melanie S. Griffin, Esq.
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in the Statutes

Caroline W. Jacobus, M.S.W.
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Commission on Sex Discrimination
in the Statutes

Hearing Recorded and Transcribed by
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State of New Jersey

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NOTICE OF PUBLIC HEARING

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

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

The hearings are expected to focus on the following areas:

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

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

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

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

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SENATOR WYNONA M. LIPMAN (Chair): Hello. We are going to begin this hearing now.

My name is Wynona Lipman. This is Senator James Cafiero, and this is Jeanne Fox. I am a member of the Senate -- we both are -- and for the past 16 years I have been intimately involved with the issues presented and studied by the Commission on Sex Discrimination in the Statutes. For 12 of the 16 years I have served as the Commission's Chairwoman. I brought many ideas to my colleagues in the Senate, which probably would not have occurred to them without the kind of interchange that I expect here today.

You will have noticed that these hearings coincide with the heated national debate on health care issues, but the issues are not only Federal. They affect the operation of State and local governments, private industry, individuals, and families. They affect the insurance industry and the hospital industry. They affect the professional responsibilities and opportunities of doctors, nurses, paraprofessionals, labor unionists, attorneys, and alternative health providers. They affect the blame that we place on the poor for our problems, the blame we place on the rich, and the feeling of being stuck in the middle paying bills. We have expressed that vocally at the polls in the last three elections.

On top of all of that, the concerns you will present to the Commission today will be presented and heard in the context of a growing concern about the present and future availability of health care to all of New Jersey's citizens.

We are honored to have many excellent speakers today. I want to express my sincere gratitude to all of the experts who have generously given of their time to come in person, to talk to staff on the phone, or who will submit written testimony to the Commission. With their work and their appearance here, many issues that have been buried and ignored for years because they only affect women will be explored.

Despite the excellent work we will hear about today, many of the health care issues of half of the State's population are not being addressed. Discrimination in the provision of health services, health-related workfare regulations, medical research, and in the very training of our physicians is resulting in poorer health, and even death, for many women, especially low-income and minority women.

For too long women's health needs have been ignored. The health consequences of the epidemic levels of violence in the home have a particularly serious impact, not only on the lives of thousands of women victims in our State, but also on our children, and ultimately on the economy of New Jersey. We have passed legislation to deal with criminal family violence, and we continue to look for new resources and new incentives to make criminals who operate in the family pay for their crimes and to stay away from their victims.

We also need to look for long-term social solutions to these problems. Our investment -- pitiful for most of this century -- in the family as an agent of social change must be renewed; must be revitalized. Our attention must focus on the reality of family life, not the fantasy. The reality is that women work at least two jobs, and the one they get paid for is often part-time or temporary, because that is all they can get. The reality is that divorce is a normal event in any given life, not an aberration. Given the reality, a health care plan that follows a permanent, full-time job or marriage is an anachronism for women. It is also rapidly becoming an anachronism for men and two-parent families. We must look to social institutional answers to these problems. We must look with our eyes open, and we must be willing to suggest radical ideas for change.

In this spirit, I welcome you to this hearing. I hope we can all come away with some radical ideas. Welcome, and thank you for coming.

The first witness this morning will be Dr. Martin Finkel, Chair of the Pediatrics Department, UMDNJ. Please have a seat, Dr. Finkel.

MARTIN FINKEL, M.D.: Good morning. Thank you for the opportunity to address your Commission.

I am Martin Finkel. I am the Founder and Director of the Center for Children's Support at the University of Medicine and Dentistry, School of Osteopathic Medicine, Acting Chairman of the Department of Pediatrics, and Cochairman of our Governor's Task Force on Child Abuse and Neglect.

Our Center is the sole diagnostic and therapeutic resource for the medical assessment and treatment of sexually abused children for the southern seven counties in the State of New Jersey, and a resource statewide.

Four of every five days I spend in my office listening to and examining children whose experiences each and every one of you might find so disturbing and foreign to your life experiences that your reaction might mirror society's; that is, its denial of the scope of the problem and the reduction of this problem to a statistic.

What's wrong with the statistics we hear from the Division of Youth and Family Services is that they do not, and cannot reflect the intensity of the maltreated children by someone they generally know, love, and trust, nor the societal cost of their maltreatment, nor the potentially devastating lifelong psychological impact of their victimization. If we listen to the details of what children experience during their maltreatment and feel their pain, we can then begin to sense the gravity of their needs.

When a child is brave enough to disclose their abuse, or their abuse is suspected, don't they deserve professionals knowledgeable enough to intervene with skill and sensitivity? For without validation of an allegation of abuse, there cannot be any intervention, and without intervention there cannot be therapy.

Today, I am going to restrict my comments to the state of the art of the medical validation of allegations of child abuse. I want you to keep in mind throughout my comments that what I am saying is not unique to New Jersey. In many ways we have been in the forefront in the provision of diagnostic services, but the unfortunate reality is that we provide a posity of adequate services statewide.

The Division of Youth and Family Services and law enforcement frequently look to the medical community to provide an opinion as to whether there is physical evidence of maltreatment. As you might imagine, the investigation and validation of an allegation of abuse is akin to putting together the pieces of a complex puzzle. Medicine has a very important role in that validation process. Medicine should be able to bring to the table one important piece of that puzzle. However, too few physicians possess the requisite skills necessary to do so. They too frequently fail to see the obvious, and lack the skills to elicit details of victimization from children in a facilitating, empathetic, and nonjudgmental manner. Their examinations and diagnostic impressions are too limited; the medical records are shamefully inadequate; and their ability to provide an opinion in court is also willfully inadequate.

Let me share with you a few examples of what I have been called upon to address after the fact:

* A six-year-old girl is taken to the emergency room because of vaginal bleeding due to inflicted trauma. The nurse tells the child's mother that for this kind of an examination it is hospital policy for parents to leave the room. The next thing the mother hears is her daughter screaming, as two nurses and a physician attempt to forcibly separate her legs to observe the injury. This child, already a victim of abuse

of power by her perpetrator, is again a victim of abuse of power and authority by a "helping professional." This is unconscionable.

* An 18-month-old is taken to an emergency room by her mother because she sees blood in her infant's diaper, and she is worried that the baby-sitter may have been messing with her child. The examining physician observes two lacerations to the anus, and informs the mom that if she thinks it is abuse, she needs to refer it to the Division. When mom returns home, she is upset by the arrogance and the inadequacy of the examination. She removes the diaper and sees two additional lacerations. She calls to speak to the doctor, and the nurse tells the doctor. The doctor tells the nurse to tell the mother, "If there are two additional lacerations, they occurred from the time she left the emergency room." The following morning I saw the child and collected semen from the anal rectal canal of this infant.

* A 14-year-old with 21 curvilinear whip marks covering her body was seen by two physicians prior to my examination for an opinion as to the cause of these marks. Neither physician would provide an opinion, in spite of the fact that the child vividly described how her father whipped her with an electrical cord as she stood naked in the bathroom.

* A 15-month-old male with four healed lacerations along the shaft of his penis is seen by an emergency room physician, a urologist, and a pediatrician, none of whom would provide an opinion that this was the residual to inflicted trauma.

The examples I have just provided, unfortunately, are not rare occurrences as to the inadequacies of the medical diagnostic services available in our State. In order for you to understand the reluctance of physicians to be involved in cases of maltreatment, I would like to read to you a letter written to me following a presentation I gave to a group of 300 family doctors on how to examine the sexually abused child.

The doctor's note is entitled: "Another Dilemma for the Family Doctor."

"The family doctor becomes concerned with the possibility of child abuse based on historical behavioral factors. Do I perform a genital exam? If I do, which I should, mom will become alarmed. What if she is aware of the abuse? What will my exam find? I probably won't know. There are too many variables. I have seen so few normal preadolescent genitalia. Besides, even abuse situations, by virtue of time delay, any trauma may have already completely healed. Mom will want to know what I found.

"If I say A-OK, I may give a false sense of security, and a false negative further hurts and frustrates the child emotionally. If I say a problem exists, I have created a whirlwind of problems. Mom will accuse someone as the perpetrator. The someone may come and challenge me. I must report alleged abuse to the authorities, attorneys, police, courts, depositions, a probable loss of the family as patients. If courts do not convict, countersuit to me; damage to reputation; and many sleepless nights.

"If my diagnosis and suspicion are not confirmed, but are true, a child continues to be ruined and wasted psychologically and emotionally. If my suspicions are false, I may be sued; I may be shot or beat up. My practice will suffer through whisper campaigns, yet if I am not vigilant and decisive, precious, innocent children will continue to be destroyed. Perhaps the only solution are specially trained community teams, including doctors, to whom suspected cases must be referred."

We are fortunate that we have a handful of skilled physicians throughout this State who are willing to see these children and who are skilled enough to provide a diagnostic opinion. These physicians are working at full steam, and they need support.

Although I have highlighted limitations in physicians' resources, in great part the same limitations apply with regard to the adequacy of the mental health professionals' experience with maltreated children and dysfunctional families. Medical and mental health professionals can be of enormous assistance to the Division and law enforcement. We must coalesce the limited resources we have into a network of regional diagnostic and treatment centers. Regionalization will improve access to services, provide a mechanism for quality assurance, serve as a training resource for professionals of all disciplines, and assure a multidisciplinary approach to the validation and treatment of maltreated children throughout our State. These centers will work hand in glove with the Division and law enforcement.

Seven years ago, I conceived the concept of diagnostic centers and testified to their need at the hearings for the Senate Subcommittee on Children's Services. The problems today are even more complex, and the solutions for our children and families even more elusive. Our most vulnerable citizens need your Commission to support the Governor's Task Force legislative initiative to develop these centers to help assure that children brave enough to disclose their abuse will have access to professionals skilled and sensitive enough to intervene.

Thank you.

SENATOR LIPMAN: Thank you very much. Do the Commissioners have any questions?

SENATOR CAFIERO: No questions, Doctor. Thank you.

MS. FOX: One question: I don't know a lot about this area. It is not my area of expertise, but some of the concerns I have heard expressed-- Do you think DYFS -- the Division -- is adequately staffed for this type of situation? Are they adequately trained, or are there additional things that need to be done with DYFS?

DR. FINKEL: As I said, understanding what has happened to a child is a puzzle. Each discipline has a very important part in terms of this validation process. The Division frequently relies on information provided to them by medical professionals. I could give you case after case scenarios of the Division acting appropriately based on information which on the surface appears to be good and valid information, but which, in fact, is totally incorrect.

It is clear that the Division needs bolstering. The Division does not have adequate caseworkers. I mean, you are all aware of the limitations of the Division. They need more resources. I think that the concept, the multidisciplinary intervention, shared decision making, and shared responsibility with professionals who have knowledge and skill focused in regional centers, will bolster the limited resources we have here in our State.

SENATOR LIPMAN: Roberta Francis?

MS. FRANCIS: Hi.

DR. FINKEL: Hi.

MS. FRANCIS: I'm sorry I missed the beginning. I was listening to some of the testimony from the back. I just want to go on record commending the work of Dr. Finkel. I represent the Department of Community Affairs on the Governor's Task Force on Child Abuse and Neglect. We certainly appreciate all the work that has been done out of that venue, as well as the rest of your professional venues. It is really important information.

DR. FINKEL: Thank you.

SENATOR LIPMAN: I expect you know Roberta Francis, don't you.

DR. FINKEL: Very nice. Thank you.

SENATOR LIPMAN: Commander Anita Batman, M.D., Regional Clinical Coordinator, U.S. Public Health Service, Region III. Did you bring someone?

ANITA W. BATMAN, M.D.: Yes, I did. I brought one of the cases I was going to cite. I brought the mother of the children in case you all had any further questions I could not answer, so that you could speak to her directly.

I have to state for the record, in accordance with Federal regulation, at the beginning, that my testimony represents my own views. Although I believe it agrees in all instances with the position of the U.S. Public Health Service, it does not necessarily represent the official position of the Department of Health and Human Services.

I am not speaking to you necessarily as the Regional Clinical Coordinator, Public Health Service, Region III, but as a family physician with 19 years of experience in treating victims of violence. I am a Family Practice physician whose practice has included emergency medicine, obstetrics, gynecology, and pediatrics. I thank you for letting me come today.

I want to say basically four things. First to speak to the magnitude of the problem: I see now that I am here that I may not have to say a lot to convince you all of that, but I find that in many places I go I am frustrated by good people sitting in front of me simply not believing how bad the problem is and how much of this problem exists.

The second thing I want to speak to you about is barrier number one, which Dr. Finkel has already spoken to. Barrier number one is the education of health care professionals to recognize and behave appropriately.

Barrier number two, which I want to speak to particularly to this group because you have the power to impact on it, is what happens when we health care professionals find, appropriately identify, and begin to treat someone who is a victim of domestic violence -- a beaten wife, an abused child -- and then we hit the wall. We hit barrier number two: the system -- the justice system, the social work system -- because they are not ready to hear the evidence we bring to them, and they are not ready to behave appropriately. And I want to speak to you about my bad experiences in the courts in several states -- I'm sorry, including New Jersey.

SENATOR LIPMAN: New Jersey?

DR. BATMAN: Yes, ma'am.

The final thing I want to do is to beg all of you for help, because I do have a suggestion that will greatly improve barrier number two -- hitting the system. We have some courts that are totally inappropriate. You can't improve if you don't know where your successes are and where your failures are, and you do not know what your record is. It is very parallel to what has gone on in medicine over the last 30 years.

When I first became a physician, we were very much under the thumb: Protect your brother. The next mistake made might be yours. Hide everything. You don't want to know. Keep the records closed. We are in a whole new age, and I find that I like it. I'm glad that every hospital and medical institution virtually has their quality assurance committee, their quality improvement systems. I am glad that HCFA comes and audits our records. I am glad that I am not asked to cover for colleagues who make mistakes, and I am very comfortable with the idea that now when I refer a patient to the next colleague, I can be more assured that the patient will receive good treatment.

Once someone is a judge, there are virtually no checks and balances. New Jersey has an unusually good record for enacting legislation, and I have been horrified to get into the courts and find out that these laws are not being implemented as they were intended by the Legislature. I don't think there can be any improvement until there is some sort of a vigilant system for the quality with which the laws are being implemented.

What I am going to close with is begging you all to help get a system of monitoring the courts' performance. In no hospital would a physician who did 60 percent of his births by cesarean section expect to keep his privileges unchallenged. You would be expected to have some mighty good reasons. Yet, there are courts where when custody is challenged, 80 percent of the time it happens exactly the way the male wants it to go, unless there is an allegation of abuse. I have a very good study with me that shows that 100 percent of the time, if the children allege that their father has abused them, he will be given sole custody. This is a North Carolina study.

I was curious when this happened, and because I live in Camden County and it is the nearest place, I commandeered two youngsters -- now I am digressing completely from what I had planned to say to you -- who were pre-law students. I sat them in the lobby of the Family Court of Camden County, and asked them to talk to each person who went in and out of the court. I am very convinced that we have an analogous situation; that in case after case after case, the children were not being heard, the women were not being heard, and no one was being protected.

If we wanted a pilot study to review someone's cases, I have a judge that I would suggest, and that would be Judge Grasso of Ocean County. Ms. Paivandy, who is with me, and I have a whole collection of cases that have just gone incredibly. There is just case after case. I would like to be found wrong. I would like someone to review these courts and tell me that the impression of my dozens and dozens of anecdotal cases is false. I would love to hear that. But I think that these anecdotes are so horrifying, that not to collect data would just be a sin.

Do you need for me to say anything about the magnitude of the problem? (no response) You know that 4000 women were beaten to death last year. You know that when I see women in the emergency room, one out of four is there because she has been assaulted. You know that the horrible statistics on child abuse represent massive underreporting; that retrospective studies show that many, many, many more children, when you take adults and question them about what happened long ago, and it doesn't matter whether you tell the truth or not -- many, many more children are being abused than we could even dream. So I do not have to speak to the magnitude of the problem, right?

SENATOR LIPMAN: Doctor, thank you.

SENATOR CAFIERO: You're singing to the choir.

DR. BATMAN: Thank you.

Dr. Finkel has spoken to the need for training, and I can say something good about that. With the Public Health Service physicians-- I will admit they are a special group, because those are the youngsters who want to serve the underserved and the high risk. They are an idealistic group. Since we -- in the short years -- have been providing professional training, the making of an appropriate diagnosis has been going up astronomically. I am already seeing a great improvement.

However, in one of the cases I was going to cite for you, one of the physicians who reported very adequately, and whose evidence was introduced into the court record, was Dr. Finkel, and he did a beautiful job of reporting it. There were twin boys named Esposito in the Camden County court of Judge Nardi. Having met the children myself in play, not as a physician, but "Let me play with you and these other children--" They abundantly verified their story of physical, emotional, and unspeakable sexual abuse by their father.

DYFS founded the case. Physician after physician after physician gave the evidence that these children were abused. The court's solution was to order the mother not to take the children to any more physicians. She is now afraid, and she has told me-- I said, "Do you know what your children just said to me?" She said, "Oh, God, please don't report it. The judge is going to put me in jail for contempt."

Now, even though DYFS has told the court that this man is sodomizing his sons and the evidence is abundant, Judge Nardi has ordered the mother to accept joint custody. So they spend half of their time in his presence, unsupervised. That is the case of Joann Esposito and her children. I would also state for the record -- and she did not ask me to say this -- I met the children because they played with my child. I am saying this, I am, so that Judge Nardi should not punish Ms. Esposito for any knowledge that I have shared with you.

One case that I wanted to speak to you about is Paivandy. I will skip through all the things I planned to say to convince you about how bad this is.

MS. JACOBUS: If you give us a copy of your testimony, it will all go into the record.

DR. BATMAN: Thank you. I brought three copies.

SENATOR CAFIERO: Would you have any objections to going before the Judiciary Committee?

DR. BATMAN: I would love to speak of this. This bothers me so terribly. Sir, I can't tell you how horrible it is to have patient after patient come before me. I am at the point where I am afraid to tell them to come to the system. It was brought home to me. In 1987, I had a little girl in my office. She had been raped by a neighbor. There was a time gap between when the school bus dropped her off and her working mother came home. It wasn't a big time gap, and she was not an irresponsible mother. The child was an adolescent who should have been able to stay home alone.

A neighbor came to the door. The neighbor raped her. She knew exactly who it was. She was badly hurt. The mother cried and begged me not to report her. That was the first time that I broke the law in reporting. I had never broken the law before that time, but you do not know what to say. I had been in court over and over and over. What the court does to the victim is so much worse than what the court does to the perpetrator.

The mother said to me, "My sister and I were raped when we were this age. I can't put my child through this nightmare. If you report it I will deny it, because I don't want my child to go through it." This has been for me a nightmare. Over the years it has become worse and worse. I was almost relieved when the Public Health Service pulled me from active practice to an administrative position, because it became a nightmare to go to court over and over, and to have a judge condescendingly lecture to me and say, "Well, I am surprised that a little lady like you, smart enough to be a doctor, is sitting here telling me that this child could not get trichomonas from a toilet seat. Everybody knows these are dirty children."

You go to court after court, and no amount of evidence is enough. Enough doesn't exist in some courts. I am not tarring everyone with the same brush. I don't even mean to say that there are not good judges. But there are courts where no evidence is enough; where they are going to attack the victim time after time. The only time I have ever had a rapist convicted was when the woman's father came to the court. He was doggone mad and he wanted justice. But I have never gone to court with a woman alone who said, "I have been raped," when the court didn't turn around and rape the woman.

SENATOR CAFIERO: Commander, I don't mean to interrupt you or to cut you short. A lot of what you are saying-- I don't want to usurp what they are doing--

DR. BATMAN: You know it.

SENATOR CAFIERO: --but it would be so much more appropriate for the things you are saying now to come before the Judiciary Committee, which, in turn, would give it to the courts, because we just went through this not too many weeks ago.

SENATOR LIPMAN: We sure did.

SENATOR CAFIERO: You know, we are sort of putting on the court that they have to patrol their own, and not leave it to every seven years when it comes before the Judiciary Committee to find out, and listen to a room twice as big as this and twice as filled at the time with all the people complaining about how they had been mistreated and demeaned. It seems from your information-- I am going to tell Senator Gormley, the Chairman, to arrange a time for you to come before that Committee to give us your input.

DR. BATMAN: I will give you the records of Ms. Paivandy and several other cases.

SENATOR LIPMAN: Yes, we would be glad to have those.

DR. BATMAN: Then you will have it in writing. I will just let it suffice to tell you that the evidence was abundant, and the children are with the perpetrator.

MS. FOX: I have a question: Do you know of any states which do something which you would think New Jersey might want to follow?

DR. BATMAN: No. One of the reasons I was happy to move to New Jersey was that on paper New Jersey looked so good.

MS. FOX: The laws are good, but--

DR. BATMAN: The laws are good. Really, I have been shocked by the audaciousness with which the courts do as they please, and then find excuses. It is almost like-- You know how they say, "You can prove anything by the Bible"? They will do what they want to do, and then they will find some little something. I have had to read so much of the law in the course of the cases, and I know that what is being done is not what the law says should be done. It also violates all natural law about tearing children out of the arms of their mothers. They teach us in psychiatry when we are medical students that the three things you should do when someone is a victim are: You strengthen their support systems. The first thing they do when you report a child as abused is put the child in a foster home. They do not take away the abuser; they separate the child from his support systems.

The second thing you do is empower the victim not to be injured any further. The protective orders, when violated-- The violations are not enforced, and the children who are abused-- They still give the abuser access to them, so number two is gone.

Then you come to number three, which is to help the patient heal. Well, you can help the patient heal from a past injury, but you can't help the patient heal from an ongoing injury. So I am filled with frustration.

What I was thinking there should be is, just as we keep statistics, like what percent of your deliveries are cesarean section-- There should be statistics parallel to this North Carolina study so that someone could say, "Eighty percent of the time, this court sides with the man," or, "Ninety percent of the time if abuse is involved, they find for the abuser." There should be statistics, and then I wouldn't be before you with anecdotes.

It would also work conversely, because if there are good judges who are doing things that work-- One of the characteristics of domestic violence-- It is very empowering for an abuser to go to court, because they go to court-- A lot of them are afraid before they go to court because they think they are going to be punished. Then they go to court and they find out that they are not going to be punished, and these good old boys are going to side with them. They are going to be allowed to do as much as they want of this. It is almost a bad thing to get someone like this into court, because it is so empowering to them. You can identify, because abused, beaten wives are beaten again, and they are beaten again, and they are beaten again. You go to court, and instead of punishing the perpetrator, they tell you, "Well, it wasn't really so bad." That is the first thing. They always minimize it.

Then the second thing is, they attack the victim. "She should have-- She should have this, she should have that. Well, is she this? Well, she got what was coming to her." It sickens your heart.

SENATOR LIPMAN: Bobbie, do you have any questions?

MS. FRANCIS: No. It is just very interesting testimony. It is an echo of what we heard in the spring. The Division on Women went to all 21 counties and held community forums for them. I would just say that we heard this in multiple places.

SENATOR LIPMAN: We heard this before.

DR. BATMAN: I know we need to educate ourselves. I know we need to help the young doctors so it shouldn't take them 19 years to get to where I am now. I know that I have my own conscience, because when I wake up at 2:00 a.m. with 20/20 hindsight and I remember the things that I saw in 1975, '76, and '77, I realize, "Oh my God, that is what this woman was trying to tell me. That is what this child was trying to tell me, and I didn't see it." I know that is barrier one. I know we have to address that; that we have to have education; and we have to have little groups of people who are knowledgeable, like Dr. Finkel, to teach the rest of the physicians and bring them all up to par.

But all of this is no good if we get to this point, where Dr. Finkel is and where I am, and we are seeing it, we are horrified by the amount we are seeing, and then you have a conscience problem with counseling the patient to approach the justice system, because you are almost putting them up for abuse again.

SENATOR CAFIERO: Melanie, do you know where to get in touch with the Commander?

MS. GRIFFIN: Yes.

SENATOR LIPMAN: Would you like to introduce us to the person you brought with you?

DR. BATMAN: I would be delighted. Margaret, would you-- This is Margaret Paivandy. She is a nurse. She is the mother of three little girls. She was an abused spouse. She has been beaten. She has had broken bones. It is a real common thing. It is a thing that I often see. They always say, "Well, she should have left him. She should have left him."

One of the reasons that you can't leave, besides the economic problems if you are not a nurse and cannot support your children, is that your children are held hostage. She left. First of all, she had protective orders that didn't protect her. Then she went home to her family, which is the right thing to do, where you have support and help with raising your children. Her husband secretly divorced her in her absence, and secretly got custody of the children. He then charged her with kidnapping of the children that she didn't know that she didn't have custody of. She was mistreated. She was jailed. New Jersey unlawfully extradited her children, tore them from her arms, put them into foster care, and they are now with the father. For all the years they were free they abundantly testified to horrible abuse by him.

Even now that the law has set it straight and it has been pointed out and the order has been set aside-- It was illegal, because her husband perjured himself when he said she didn't have custody when she left with the children. Judge Grasso, in Ocean County, has not returned her children to her, and they are still with him. She is being denied visitation.

Do you have any questions for Margaret?

SENATOR LIPMAN: Margaret, would you like to say something?

MARGARET PAIVANDY: Well, just thank you for having me here. I don't really know what to say. It has been a hard go. I did not expect for these things to happen.

DR. BATMAN: I think one of the horrifying things is, before I had ever been to court if anyone had tried to tell me how it goes, I would have said, "This can't happen." I had the same thing. I called Women Against Rape to try to get support for someone. The young girl I talked to, who was the telephone counselor, said, "Oh, but now she is in New Jersey, and this can't happen." I was kind of sitting there shaking my head, going-- (demonstrates)

It can happen, and it does happen. It happens abundantly. I guess along with educating physicians and putting some kind of a fact-finding feedback on the courts, because they really-- A court is like an emperor in his kingdom. There is no control. If there is a problem, you would not want it to be addressed on the basis of one case, because then the victim in the case would again be under attack. But if you could address a problem at over 100 cases, or 300 cases, and say, "This percent of the time this happens," then you would have the problem on trial instead of the victim.

That is why one of the things I came to do was to beg you all to see if we could get a system of reviewing the court's findings, just like we have morbidity and mortality reviews. Get the statistics. How often does it go? Which way? Is there gender bias? Answer the questions and see if the Legislature can find out if the laws they were good enough to enact are being carried out as they intended.

SENATOR LIPMAN: Thank you so much.

SENATOR CAFIERO: It is not only the Legislature, you know. When we had this hearing that Wynona sort of smiled at before-- The Administrative Office of the Courts should be interested in this. I told them when we were interviewing a judge, I said, "Maybe you fellows can open a charm school for some of these fellows who don't display the demeanor they should display." So I am going to put Dave Anderson in touch with you, too. Those folks ought to know. We see them in the Legislature, but when they are appointed you don't know what they are going to do. Then we see them after seven years and what they have done during those seven years, and all hell breaks loose on their seventh anniversary. You know, we are expected to decide right then and there whether they should go forward.

The court has heard for seven years, more often than not, these complaints, and I don't know what they do with them. But you know, we on the Judiciary Committee -- and you could be a big help with that; Anderson could, too -- could let the court periodically hear this stuff, and let them call their folks to task as they go along, not wait until the seven years have gone by and there have been so many victims who haven't had their needs addressed.

So I am going to put someone else in touch with you. You are going to be a busy person, Commander.

DR. BATMAN: Thank you. I appreciate it.

SENATOR LIPMAN: Thank you very much.

SENATOR CAFIERO: We'll elevate you to the rank of Captain.

DR. BATMAN: You know your ranks. You must have been in the Navy.

Here are some copies of what I had planned to say, but digressed from. This has chapter and verse, and some cases.

SENATOR LIPMAN: Ann Marie Hill, Executive Director, Commission on Cancer Research.

ANN MARIE HILL: Do you want copies of this statement of mine?

SENATOR LIPMAN: Yes, we do.

MS. HILL: We are going to shift direction a little bit. First of all, thank you for inviting me to be here to share some of my thoughts on cancer research in New Jersey, specifically how this research may affect women's health care.

I am Ann Marie Hill. I am Executive Director of the New Jersey State Commission on Cancer Research.

First, I want to applaud you as a Commission for actually recognizing that research belongs on this type of an agenda. Usually it is omitted. I think sometimes this is in error. If you look at diseases such as cancer, and all the other chronic diseases, the truth of the matter is that we cannot deal effectively with it. We are in that intermediary stage. People are not dying, but they are not being cured, and the diseases cannot be prevented. Therefore, we get these enormous expenses from these chronic diseases. The real way to solve the problems will be when we can prevent and cure cancer, and that is going to take research.

Actually, cancer is a very difficult problem to solve. We often hear about the war against cancer and that we have been losing it. That is because it really involves the very essence of living cells. So we have spent a great deal of time struggling with the problem of solving cancer and the enigma of cancer, but we have made some progress. Nonetheless, cancer takes a toll. It takes a toll on women in New Jersey.

I am not going to go through all of the statistics that I have provided in my testimony, but if you look you can see that in general New Jersey does have higher incidence rates and mortality rates for cancers and, in particular, for many of the cancers that are hormonally related, and that means cancers that women face -- breast, ovarian, dimetrial, and cervical cancers. Consistently you see that we have slightly higher rates, sometimes dramatically higher rates than SEER counterparts, and that is the comparison group that we look at at the national level.

So we do have a cancer problem. On top of that, cancer contributes about 10 percent to the cost of health care. I think we have to recognize that it will be contributing more and more with time. As we go into the next century, cancer is going to absorb more and more of the health care costs. So New Jersey definitely has a special interest in fostering cancer research, and that has been the job my Commission -- the New Jersey Commission on Cancer Research.

We were created in 1983 to actually fund original and significant research into the causes of cancer. We have tried to develop three major types of projects: The first one when we were created was the Seed Grant Project. We tried to get researchers established here in New Jersey working in laboratories and on the cancer problem.

The second was the Fellowship Program. Let's invest in young people with promise. The last was recognizing that New Jersey has some substantial and significant cancer problems. We wanted to address them, so what we decided to do was have a Cancer Research Development Program. We actually earmarked some of our budget for special problems: Cancer among the economically disadvantaged populations; cancer in radon; and a variety of others we have looked at. I have attached to your testimony some of the topics we have tried to take on.

One of my recommendations for this group is if we are going to be fair and equitable when we support research, we have to have scientific peer reviews, especially in medical and scientific research. If we do not, then we cannot be sure that we are funding those proposals that have the highest merit and the best chance of success. So I would ask you as you watch legislation to please make sure that research that is supported by the State has some system of scientific peer review. We will be happy to support any agency and help them to develop such a program. In point of fact, we have a pretty good program of scientific review. In fact, we were just happy to hear that the National Cancer Institute is going to allow some of our grants to receive matching funds, if they meet certain criteria that are rather narrow, because of the scientific review and the development of our grant program.

So please, keep your eye on that. It is, I think, a very important issue for New Jersey.

Now, I am going to discuss three general areas where I think research impacts on the health of women, in particular women in New Jersey.

The first is basic research. You may look at me and say, "Why are you funding so many researchers" -- gene jockeys, as they are sometimes called -- "in your basic laboratories?" The truth is, when it comes to cancer, this is where we are going to find the answers. This is the foundation upon which we build our research infrastructure. The Commission has been committed to this. It has supported other types of research, but it feels strongly that we have to make an investment in basic research, and it has successfully done so. For every $1 we spend in this area, we get about $3 back in Federal and national funding.

We have made a lot of progress; in fact, startling progress. We understand a lot more about cancer, but we are not seeing it down the line. We will be, I promise. Despite the discouraging words we hear about cancer, we are really gaining in our understanding of what is happening. As a result, you can expect, in the near future -- the not-too-distant future -- some diagnostic tools, some new early detection mechanisms, and hopefully new treatments that are going to have greater impact. We are, I hope, going to be able to do more in the prevention of cancer. Basic research is contributing to this. I think we need to make sure that we consider this an important area.

But as we get these new technologies, what we have to do is get a way to bring them to the women in New Jersey. I think this is one of the areas that I want to really spend a little time discussing.

The fact is, New Jersey is a wonderful laboratory for research, cancer research especially. Look at our population; look at our geography. They are ideal. Do you know what? We do not have an awful lot of cancer research -- clinical cancer research -- going on here. Historically, very few women have had access to clinical trials in New Jersey. I want to give you an example, because I think it sums up everything kind of nicely.

Taxol is a new chemotherapeutic product. You may have heard of it. It showed promise in ovarian cancer, breast cancer -- cancers that are important to women. Well, it's scarce. It was more scarce; it is now more available. A few years ago especially, it was very scarce. The fact of the matter is, it is made by Bristol-Myers Squibb, whoa, in Princeton, but women in New Jersey could not get access to taxol because it was distributed strictly through designated cancer centers from the NCI.

The fact is, New Jersey did not at that time, and still does not have a designated comprehensive cancer center. So our women have to go out-of-state to get taxol for their treatments.

Oh, well, you know, I go to New York all the time, and people go from Trenton to Philadelphia all the time. This should not be a problem. Well, I would like you to think about a woman who has just been diagnosed with ovarian or breast cancer. This is a sick patient. She is probably the caregiver in the family. She may not have an awful lot of money. She may have no insurance. She may be on her own. She may have an insurance that is saying, "Enough. We do not cover research." This is what we know happens all the time. She may not be able to get back and forth to New York or Philedalphia for these treatments. She may be from Camden, in which case-- Some 37 percent of Camden's residents are below the poverty level. And she may be one of the 52 percent who are women in Camden. We are not going to be able to see her cross the Delaware River so easily into the complexities of the research community. It is a very, very complex system, and we are expecting -- ha, ha -- these women to cross the river to get into the experimental protocol. It is very, very difficult.

So the Commission has strongly urged the cancer community in New Jersey to support all activities that will bring a designated cancer center to New Jersey. The main one going on right now is the Cancer Institute of New Jersey, and I think you are going to hear from someone from there.

I would also point out that that is not enough; that it is also difficult for someone to get from Camden to New Brunswick. So we need to develop clinical centers of excellence. These clinical centers of excellence have to network with community programs, so that we can get these types of new treatments and new experimental protocols -- the best medicine is now offering -- to our women.

Well, we are seeing some progress in this area. We are seeing the development of the Cancer Institute. We have seen some activities with the Garden State Cancer Center in Belleville, which is opening a new facility. We have three CCOPs -- Community Clinical Oncology Programs -- which are in NCI-funded community hospitals that offer clinical trials. We are seeing a lot of activity in our community hospitals, and a lot of interest. What we need to do is pull this together.

The Commission has been struggling with this, I've got to tell you, since 1985. It is not easy. There are lots and lots of problems. It is difficult to ask a community physician to become involved in clinical research. We have actually tried to get some requests for applications' research projects to look at models for this. I hope we will see-- Our vision is to see clinical centers outreaching into the community networks connected to New Jersey research bases such as the Cancer Institute. One hopes.

I need to carry on further and talk about prevention and early detection now, or I would be very remiss.

The truth of the matter is, we cannot really prevent breast and ovarian cancer. We have some ideas, but we still need to look at the basic research again. However, we are getting to the point where national intervention studies are coming across. You may have heard of the Tamoxifen Chemoprevention Study. The Women's Health Initiative is looking at very low-fat diets and trying to prevent reoccurrence.

When these are launched, again, New Jersey hospitals have to be in a position to offer an opportunity for women to enroll in them. Some of them do. I would hope, again, that the networking we are talking about might be able to develop that type of link in an even stronger fashion.

The truth of the matter is, cancer prevention and early detection takes epidemiologists, biostaticians, public health investigators, and data managers. New Jersey has very few of those. If you look at basic researchers, clinical researchers, and public health researchers, you are not going to see that they are at an equivalent level. We also have a Cancer Registry -- a State Cancer Registry -- that has been underfunded and short staffed for years, and has not been able to get as much research involvement as we would like to see. It needs to be supported more fully. We need to do more in screening. We need to do more in education models. We need to look at innovative projects.

You may hear again-- I looked at your testimony list. There may be someone talking about an innovative project that will involve a cell depository. The Coriell Institute and southern Jersey would like to do a breast cancer cell depository of women with histories of breast cancer. We would then look at those cells and do something called "molecular epidemiology." It is a very promising field, but we are nowhere near it right now in New Jersey.

Obviously, these things take resources far more than the million dollars that this Commission gets. As it is, we are stretched out to the hilt. But I have to make the statement that these are some things that New Jersey needs to seriously look at.

We have tried, with our little pile of studies, to make an impact on cancer prevention and early detection, but I think we, as a State, need to do a lot more. I would be shocked if I did not discuss for one minute the psychosocial needs of the cancer patient. It is often (indiscernible) research in all medical research, and it is one that should not be neglected. Fortunately, the Commission has about 100 or 150 volunteer scientist positions -- patients who work with us. Our Psychosocial and Nursing Advisory Group makes sure that we are very aware of the importance of the quality of life, support groups, and insurance and employment issues. All of these are serious problems for cancer patients. We need to find solutions to dealing with them. This Group has done an amazing thing.

I have included in your testimony a booklet in the back. Over there (witness points), it is the green booklet. It is called, "The Resource Book for Cancer Patients in New Jersey." That was actually part of a cancer project -- a research project that the Group did. It was really done at no cost. We had the Ortho Biotech Company publish and print it for us. We have distributed over 8000 copies. It is the hottest publication in New Jersey hospitals right now. Very little cost as far as research; big payback. I think that says an awful lot for this Advisory Group.

I guess I am going to end by saying, this Commission has worked very hard to try and move New Jersey through the cutting edge in cancer research. We recognize that we have special problems. We recognize that the women of New Jersey have serious impacts from these high cancer rates. We are certainly going to do all that we can to bring the best that science offers and medicine offers to the women of New Jersey. We hope you will also work to do that.

Thank you.

SENATOR LIPMAN: Thank you very much.

MS. HILL: Yes?

SENATOR CAFIERO: What is the stumbling block to getting money to NCI designations? Is it legislation?

MS. HILL: It is very difficult; very difficult.

SENATOR CAFIERO: Is it financial?

MS. HILL: Well, to a degree, but it is more than that. It is very competitive. Research funding nationally, statewide, everything, has been sort of-- They are not increasing the number of cancer centers. The NCI does not have the funding to increase the number of cancer centers, so what it is being forced to do is what we do. You cut the grants here, and you try to give a little less than you need over there. As a result, it is a very competitive situation. There will be many other states trying to get cancer center grants. The requirements are very, very difficult. We have a big job. The Cancer Institute has a big job ahead of us. It needs all the support we can give, and it does take an enormous amount of resources.

SENATOR CAFIERO: Are there facilities here that are contenders for it.

MS. HILL: Yes, the Cancer Institute of New Jersey.

SENATOR CAFIERO: Well, can they actually get it?

MS. HILL: Excuse me?

SENATOR CAFIERO: The facilities here that are anxious to get it--

MS. HILL: Oh, yes. In fact, the Cancer Institute has a planning grant, and it is trying to get one right now. It's tough. They have a lot of work to do. You have to have excellence in many, many areas of research, all the ones that I just talked about, some of which were not doing so well. You've got to be able to deal with all those things.

I would also point out: In and of itself, a cancer center is not going to reach out to all of the women, especially in the urban inner cities or the rural areas, where they cannot get to such centers. So we need to have a broad complex, I think, of treatment.

SENATOR CAFIERO: What do you think the Legislature can do to help you?

MS. HILL: I think we have to look at the fact that resources are limited. I think we have to be supportive of the Cancer Institute and other clinical centers. I think we have to do more in prevention and early detection to support them.

So, yes, there is a lot that can be done in cancer research, and we need to do it. We have been struggling. We have been limping along. I think we have done pretty well with what we've got. In fact, this Commission is a model for a lot of other states. But cancer is an expensive process; research is expensive. Actually, if you look at how much we spend on costs and how much we spend on researches--

We get $1 million in dedicated cigarette tax; $3.8 billion is the cost of cancer care in New Jersey every year. I think that gives you a little bit of a feel for where the problem is.

MS. FOX: Your funding comes from?

MS. HILL: The cigarette tax.

SENATOR LIPMAN: The cigarette tax?

MS. HILL: Yes.

MS. FOX: And that was established?

MS. HILL: In 1983.

MS. FOX: What is the rate? What is it?

MS. HILL: We get $1 million -- when we're lucky -- every year. It has been there.

We had, when we started the Fellowship Program-- We have gotten some really promising kids to stay in New Jersey to work, not only in our research institutions, but in our academics. We were up a little higher-- When we were able to do more in economically disadvantaged populations, we were up a little higher, but of course, it is tough times right now, and we are spread as thin as we can get.

Is there anything else?

SENATOR LIPMAN: Are there any more questions?

MS. FRANCIS: Yes. I'm sorry. I think it was the National Institute of Health's grant -- a major grant -- that came to the State to do several areas of research on women's health within the last year.

MS. HILL: Just on screenings.

MS. FRANCIS: Does any of that involve the cancer issues? I am trying to recollect what the--

MS. HILL: I believe they-- Someone will be speaking, I think, on the program you are talking about -- or the grants you are talking about. They are to develop the screening mechanisms to provide screenings and early detections for women. It is not just research. My understanding is that it will involve bringing screenings in. By the way, screenings are not the only answer. The fact of the matter is, it is the primary care physician who is the best person to screen us, and we do not have those in the inner cities either. So, you know, it is a complex issue.

MS. FOX: I have a question on the--

MS. HILL: Sure.

MS. FOX: --President's health care proposal.

MS. HILL: Yes, I would be happy to--

MS. FOX: Is there something specific in that that would help out with what you see the situation is in the State of New Jersey.

MS. HILL: No. I am going to be honest: I am a little concerned about what I am seeing. The good news is, they are looking at funding clinical cancer research. They say they are going to increase cancer research overall. I am not so sure. That is the good news.

The bad news is, if you look at things like bone marrow transplants for advanced breast cancer right now, you will see that they are saying, "You have to go to a designated cancer center to get that." That leaves New Jersey out of the loop.

MS. FOX: How many are there in the country, approximately?

MS. HILL: I can get that information exactly to you.

MS. FOX: I mean, are there five? Are there ten?

MS. HILL: No. There are at least 20.

MS. FOX: There is one in Philly, and there is one in New York?

MS. HILL: There are two in Philly, and four or five in New York. That makes it harder for New Jersey, by the way.

MS. FOX: Right.

MS. HILL: Because there are none in Iowa; there are none in Missouri, and there are powerful Senators from those states who also want to see them. Cancer center status is difficult. I am seeing that type of a trend, and that concerns me. I am seeing restrictions. As we go to managed care, we are going to find that expensive technologies -- they are coming down and they are going to be expensive -- are going to be limited. This is going to be reality. What we have to do in New Jersey is make sure we have access to them, especially for our women.

Our women are vulnerable. Our men are, too. I mean, I do not want to discriminate on the other side. But as I said, the statistics-- If you look at what a woman faces when she has breast cancer-- Now, okay, she may go through the traditional physician, but when you get into the research realm, it's hard. It really is. It is scary, and there are all sorts of pressures. You don't need to worry about all these other issues. But I am seeing some concerns.

I will be honest. I am also not happy-- I am going to go on record. I am not happy with NCI's latest decision to remove the guidelines for mammography, for women under 40 in particular. I debated whether I should include this, but I feel that when you make that kind of a statement -- and the studies are a little unsure-- I also question the studies and whether they are valid, but the truth of the matter is, cancer in premenopausal women -- breast cancer -- is very aggressive. We need to do everything we can. Maybe we just need to work on improving those equipments, not convincing women that, "You're under 40, so you do not need a mammogram."

That is another issue. There are plenty of them. I tried not to go too far, and I have already expanded my time. So I thank you for-- Anything you need, just let me know.

SENATOR CAFIERO: Time well-spent.

MS. HILL: Okay, thank you.

SENATOR LIPMAN: Thank you.

Ms. Courtney Esposito, Coordinator, Center for the Study of Violence. Is Courtney here? Oh, yes, there you are.

COURTNEY N. ESPOSITO, B.A.: Good morning.

SENATOR LIPMAN: Good morning.

MS. ESPOSITO: Some of this may sound a little familiar to you, because I have been to various public hearings discussing the same sort of issue.

I would like to go back to what Commander Batman was talking about. Here we have this morning a physician talking about problems in courts and with judges. Why would that be? Because essentially the same issues are operative -- avoidance, denial, neglect, and discrimination. They existed-- Some of you may know this in terms of all of the research done on heart attack victims over the years and years, and over the decades and decades. The researchers forgot about us, that we had heart; that we existed; and that we had heart attacks. So finally, they began to include another "Federal Regulations and Guidelines" requiring the inclusion of women in studies -- women subjects in studies.

There is an awful lot of data when we talk about it, and Dr. Finkel referred to it as well: Why don't physicians and health care professionals know that there is an issue that is of great import. It is a public health issue. It is a primary health care issue for women; that is, violence, abuse, and battering. Why don't they know that?

Well, they don't know that because no one told them for so many years. Then when we began to tell them, they didn't believe us, and there was something wrong with us. I myself am a survivor of abuse. I am a very strong advocate of survivors testifying, speaking for themselves, as opposed to -- not as opposed to, but in addition to their advocates speaking for them, because we can talk for ourselves. I believe that they do not know what they do not know.

I will submit my written testimony -- it will probably be somewhat familiar to some of you -- in which I, as usual, define what abuse is, and indicate that it is not just physical violence; it is also behavior which arouses fear in another human being. That leaves no bruises. It is also behavior which prevents someone from acting the way they wish; preventing a woman, for example, from taking her child for postnatal care, getting prenatal care for herself, speaking to relatives, having any friends, or leaving the house. It is also behavior which forces someone to act in ways they do not want to act, like overdisciplining children. Women, by the way, take the rap for that. The literature does not-- The child abuse literature does not indicate that in most of the cases -- in at least half the cases where a woman is being abused, the children are also being abused by the same person who is abusing the woman.

Child abuse literature always frames the woman as the abuser. In fact, in most cases of physical abuse, the abuser is male. In cases of neglect, there are more female cases. That would stand to reason, since women generally have been the caretakers. It also includes behavior which does not allow -- which forces someone to act in ways that they do not want to act.

It has been found-- There are some recent studies -- some recent findings that I would like to quickly share with you. One is, most health care providers, first of all, think as most human beings and other helping professionals tend to think of abuse as merely physical, and therefore it would leave injuries. If you screen for abuse and consider it only physical, you will miss a full 96 percent of all victims. They don't know that -- the health care providers don't -- so we need to keep training them and telling them that. We need to train them to train their colleagues, because their colleagues are going to hear it from them in concert with me, but they are not going to hear it from me so much, so well, alone. We know that now; we did not know that before.

The numbers show that victims of abuse are a cross section of the entire female population; that those of us who have college degrees get beaten up as well, and sexually molested as well; that that happens in the best of families -- in quotes, "the best of families." But look at some of the data. I now work at a health care institution where, believe me, they are in denial. When I talk about some of these issues and about how much psychiatrists, for example, need to know about sexual violence, and need to know about battering, they act as if-- I mean, they run in the other direction down the hall sometimes when they see me coming, because they are in denial.

About 64 percent of all psychiatric inpatients -- female psychiatric inpatiensts -- are abused women, and they are not being asked. Gynecologists are coming to me and saying, "Why are psychiatrists telling female patients that if their children are talking about abuse, they are probably making it up, and even if it did happen and they have been through court, don't-- It was too early. They won't remember the trauma, so forget about it"? This kind of ignorance and denial has been going on for decades. It is not unusual. You know the health care objectives we are all following come from a healthy, a healthy -- what is it called -- the year 2000 health care objectives?

UNIDENTIFIED MEMBER OF COMMISSION: Healthy People 2000.

MS. ESPOSITO: Yes. Promoting health/preventing disease -- the year 2000 objectives for the nation. You know, the first draft of that-- They talked about violence and abuse, but the four words were never mentioned -- battered women and domestic violence -- even though they knew that at least 30 percent, and more like 50 percent, of the women who were killed in this country were killed by partners or ex-partners.

There is a huge amount of denial about the fact, and ignorance of the fact that leaving can increase the chances that a violent incident will occur to someone. So generally what is asked, and what I try to get them over asking is, "Why do these women stay? Why don't they leave? Why do they put up with this kind of behavior?" It seems so simple from the outside. In fact, 65 percent to 75 percent of abused women who were murdered, were murdered after they left.

So we need to do some pretty intense training of helping professionals, medical and mental health included, so that they stop telling their patients to do things; stop giving orders -- you know, they are used to doing that, writing prescriptions and making it better -- that are, in fact, going to endanger their patients. We need to keep teaching them to consider the victim as the expert on what is the safest and best thing to do.

We need to teach them to increase safety and to decrease isolation. Generally, they do the exact opposite.

New Jersey, in the Division on Women, since 1984 -- maybe even earlier than that -- has been working hard on this issue and has given lots of money, resources, and staff to it. We have a history of making a very good start in this area. Then the money went away; then the money came back. I am here to say that you need to keep giving money, but I always say that. You know that.

I have four specific recommendations. We did protocols, training manuals, and audiovisuals on domestic violence, and we distributed them all around the State; in fact, to major health organizations around the country. We were in the vanguard; now we ain't no more. If you look at New York State, they did the same thing. They did manuals and protocols. They started looking at them in the mid-'80s. The difference was that they were able to fund-- Well, first of all, they were able to get their Health Department to say, "We need to have a protocol, and we need to have it in every hospital." And we do not have that in New Jersey.

Second of all, they teamed up their Department of Health with trainers from the Office on Domestic Violence -- on the Prevention of Domestic Violence -- that was within the Governor's Office, put them together, and started trainings.

Those trainings continue to this day. What we know that we did not know five years ago -- and now we know -- is that you can't just train them once and expect them to: 1) get it; 2) do it; and 3) do it properly. You need to provide technical assistance. We are talking about changing practice here, not just showing a video, doing some slides, giving them a book, because they will put them in a drawer, and there they will stay.

So you have to keep reminding them that it is an issue that really, truly can make a difference. Victims, survivors, tell us all the time what a difference health care providers make.

The reason I am testifying specifically on health care providers is because they see 10 times the number of victims that police officers see. Police officers see 10 times the number of victims than courts see. Judges get, in some cases thankfully, to see only a certain proportion, but health care providers can reach most victims, because everyone doesn't go to court and stand in front of a judge, and everyone doesn't call the police or get the police called on them. But everybody, pretty much, does see a doctor, a nurse, or someone during the course of their life, and therefore, during the course of their abuse. So we need to concentrate on health care again and refinance some of the efforts.

Now to my recommendations: We need to renew, expand, and intensify the training and technical assistance offered to all sectors of the health care community. Let's not forget mental health. These people do an awful lot of damage when they are misinformed, and they are mostly misinformed.

That is changing. It is changing slowly. So the governing bodies of this State can, and should holistically and in a coordinated fashion-- This is coordinated community response; otherwise, the health care people will get it, and then the judges will deep-six it; make it worse than if you had never said anything.

Formulate and create policies and programs around the issue of violence against women, and health care remedies to address it. This is a primary health care issue for women. So a coordinated response from health care, law enforcement, judicial, and direct service programs, with the inclusion of survivors of abuse who really know what is best for them and what works best for them, must be formulated.

This is happening in many states and it is happening on the national level. The American Bar Association and the American Medical Association are meeting this month, I believe, to discuss coordinated community responses. New Jersey must recommit its energies to innovative and viable activities that will assist battered women.

Two, ensure that protocol for health care intervention in domestic violence cases be adopted and disseminated by the New Jersey Department of Health. We can include the Hospital Association; we can include specialty societies, many of which have developed their own; and other appropriate health care agencies to their constituents. This could ideally be effected in one to two years, because we have had such a wonderful head start from the Division on Women, using the model developed in New York by that state's Department of Health and Office on Domestic Violence.

Three, increase media and public awareness efforts on the subject and on the training opportunities available, so that violence in the home can be loudly and clearly identified as that which it is -- did I say this before? -- a primary health care issue for women.

Four, I always say this at the end as well: Statistics from domestic violence programs indicate that they have gotten more customers than they have time or staff for.

We need to keep finding new ways -- which we have been in New Jersey -- to refund them and to increase their funding.

I appreciate the opportunity to talk to you today, and we will keep coming back.

SENATOR LIPMAN: We appreciate your coming, too.

Are there any questions? (no response) Okay, thank you very much.

SENATOR CAFIERO: Thank you.

SENATOR LIPMAN: You are going to send us your testimony? Oh, we have it already. Good. Very good.

Karen Spinner, New Jersey Association on Correction.

KAREN SPINNER: Good morning.

SENATOR LIPMAN: Good morning.

MS. SPINNER: Thank you for inviting me to testify today on the status of women's health care and incarceration.

My name is Karen Spinner. I am Director of Public Education and Policy for the New Jersey Association on Correction. The Association is a statewide citizen-based, not-for-profit that works for the improvement of the criminal justice and correction systems in New Jersey. Throughout the Association's 33-year existence, staff has maintained correspondence with inmates in State correctional facilities. In that time, complaints about medical care have been a staple of institutional life. Just a sampling of letters would give you an indication of how disappointed, or how unhappy both the men and the women are with the status of medical care in the State correctional institutions.

To be fair to the Department of Corrections, they do maintain medical units at each facility and medical emergencies are generally handled with dispatch. However, routine medical care is slow, and preventive medical care is almost nonexistent. All inmates receive a physical when they are first received into the institution. However, that is probably where the routine physicals end, although by standard, inmates over the age of 50 are to be offered a routine physical every two years. It is only if it is feasible.

Given the current status of overcrowding in the institutions and the cutbacks in all services except for custody, it is rather unlikely that anyone is receiving a routine physical on a fairly regular basis. For inmates under the age of 50, the routine physicals are offered every four years, if it is reasonably feasible. So it is definitely not a priority to provide preventive services to the men and women who are incarcerated in New Jersey.

The only time you get medical care is when you call attention to the fact. So if you think you have a problem, then you can get on the "sick call" list. If they can see you, if the limited time of the doctor or the nurse is available to you, then you will be seen.

One of the biggest problems, I think, when it comes to incarcerated women has to do with their routine physical and gynecological care. The Pap smears and gynecological exams are not provided on a yearly basis, as is available to most women in the community. Given that HIV infection in women often manifests itself through gynecological problems, it would seem important that the Department provide these types of screening services for female inmates, particularly for those who have been known to engage in high-risk behavior or have a history of IV drug usage, which is one of the major causes for the transmission of AIDS for women in this State.

While the Department does provide AIDS treatment to infected inmates, these services are problematic. Because of the stigma involved with having AIDS, many offenders choose not to be diagnosed until the later stages of the disease, thus complicating their treatment needs. Confidentiality of medical records is a serious problem in all correctional facilities in New Jersey, both for men and women. Unauthorized personnel have been able to access individual inmate records, and this kind of information spreads like wildfire in a closed institution. It causes fear among inmates, fear among custody staff who have to deal with these people. This works against having women seek medical care early, so that, especially in cases of HIV, they can receive adequate treatment.

The Department of Corrections has also not complied with certain sections of the consent decree they signed for dealing with AIDS inmates. One of the agreements was to permit inmates to participate in clinical trials of AIDS medications. Two years after the consent order was entered into, no inmates, male or female, have been participating in clinical trials. While we would agree that it is generally unacceptable to use inmates for experimentation purposes, the Department did agree to permit AIDS-infected inmates to participate in the clinical trials, because this is the only way they can get the most up-to-date AIDS treatment. They have been dragging their feet for the last two years in complying with this agreement, and we find that that is inexcusable.

The Department also provides a variety of prosthetic devices, which must be approved by a physician. These include: eye glasses, hearing aids, artificial limbs, and other devices deemed medically necessary by physicians and with the approval of the superintendent. There are, of course, many delays in providing these durable devices, particularly wheelchairs. There is a woman in Clinton who has been waiting, probably, two years for a wheelchair. She cannot go to meals. People have to bring meals to her. I think in cases like this we need to move the Department of Corrections to provide those necessary services to the inmates.

County jails are another issue. It is more difficult to get information from the county jails, because they each have their own staffs and they are funded individually by the counties. All the county jails have doctors on staff, basically on call. Sick call is required at least five days a week, based on the size of your institution. Since most of our institutions have over 200 inmates, they are required to have a sick call five times a week.

As you can imagine, women comprise only a very, very small proportion of all our correctional facilities. As an example, Clinton -- the Edna Mahan Correctional Facility for Women -- has about 800 to 900 inmates. The Department of Corrections has a total of almost 24,000 inmates, so the services are definitely skewed into providing services to men. That is even more so in the county jail system, because the women comprise a much smaller population. And of course, it is difficult because physicians are not on-site. You generally have nurses, but nurses cannot provide services unless there is a standing order from a physician, or they are able to get that physician in an emergent condition to give that permission. So it is extremely difficult to get adequate services in the institutions.

All female inmates, both in the State and in the county facilities, are tested for pregnancy upon arrival in the facility. Pregnant inmates -- most of whom end up in county facilities, although some of them do get into the State system -- are eligible to receive additional nutritional supplements. And they are eligible to receive services through WIC -- Women, Infants, and Children Services. I believe this is a very little known provision in the Federal law. It is not something that comes to you because you want it. It comes to you because it is just part of the law. Each county, each facility, must ask for the WIC services to be made available. It was permissive in the Federal legislation, and unless the county asks for it, or unless the State asks for it, you do not get WIC services. So I think it is an area where there is some work that needs to be done.

Mental health services are particularly in short supply in both county and State facilities, especially for women, who are under a great deal of stress when they are without their children. Most women who are incarcerated are mothers leaving their child behind either with a family member or under the care of the State, and this creates a great deal of stress for them. We are not providing a sufficient degree of mental health services anywhere in the State correctional facilities. Because of the cutbacks and treatment services in the last few years-- The people who have been leaving are social workers -- that is where the cuts came -- teachers, and counselors. While the institutions have grown, those services have not grown.

Drug treatment: When we look at the statistics for people coming into the system who are drug addicted or drug dependent, we note that almost 70 percent of all inmates have some involvement in drug treatment, and yet drug treatment is a service that is almost negligible throughout the entire system. The two programs the Department provides specifically in terms of drug treatment that are considered to be models are offered to the male inmates, here and down in South Jersey in, I believe, Bayside. There is a small program for women in Clinton, but it is hardly enough to provide the kinds of services to deal with the kinds of problems we have.

Without a doubt, there is a need for increased medical services for incarcerated women. The fact that women who are incarcerated receive more medical care than they would receive while they lived on the street is not something that we should be proud of. Often when we discuss this issue with the Department, they will remind me that women are getting more treatment than they would get if they lived on the streets. That does not mean that they should get lesser medical care. It does not mean that they should not get quality medical care. I think we need to move to a position where we provide services that are needed to the women who are incarcerated, so that in the end, when they are released -- and 95 percent of those who enter our correctional facilities will be released to the community -- they are not coming back with lesser health, less able to take care of their families, and creating larger problems for the community in general later in the process.

I would be happy to answer any questions you might have.

MS. SPINNER: Thank you.

MS. FRANCIS: Just one question: Clearly, a lot more dollars go into medical care for the male inmates because there are so many more -- what, 24,000 as opposed to 800 or 900? Is that what you said?

MS. SPINNER: It is 24,000 total inmates, but about 800 or 900 are women.

MS. FRANCIS: Okay.

MS. SPINNER: But it is still a significant difference.

MS. FRANCIS: But have you been able to compare proportionally; in other words, do you see -- to use our name -- sex discrimination in the application of the funds proportionally?

MS. FOX: Dollar per patient?

MS. SPINNER: Dollar per patient? I do not think you would necessarily find it dollar per patient, but you would-- When you look at the drug treatment, the fact that the drug treatment programs, the model programs, went to all the males, it raises questions in my mind as to whether the women are getting their fair share. Certainly, there is not enough to go around. There is no question.

I will provide my written testimony. However, our copy machine was down today.

SENATOR LIPMAN: Thank you so much for coming.

We have to go a little out of line now. Anne Weiss has to leave, so we are going to call her now. Anne Weiss is Executive Director of the Essential Health Services Commission, New Jersey Department of Health.

ANNE F. WEISS: Good morning.

SENATOR LIPMAN: Good morning.

SENATOR CAFIERO: Good morning.

MS. WEISS: Thank you for the opportunity to testify today before the Commission on behalf of the Essential Health Services Commission. I am the Commission's Executive Director. The Commission is chaired by Victoria Wicks.

The package that I have prepared for you today outlines the role of the Commission, which was created by the Health Care Reform Act of 1992. In the package I have tried to emphasize the items that I think would be of interest to the Commission. I would like to hand you some copies of that now. (copies distributed)

In its activities to date, the Commission has not explicitly identified practices or statutory provisions that encourage sex discrimination in the delivery of health care, or in the State's health care system. But many of the Commission's activities do touch directly on the health problems of women in the State, and that is what I wanted to have an opportunity to talk with you about today.

The first page of this outline basically tells you a little bit about the Commission, which has 11 members, including three Commissioners serving ex officio. The Commission was established by the 1992 Health Care Reform Act. What is really important is to understand how our role interacts with other insurance reforms that were created by that Act. There was legislation in the State at the end of 1992 which was designed to make it easier for individuals and small groups who are not affiliated with large employers to buy affordable health insurance with standard benefits.

On the second page, I have outlined the principal statutory responsibilities of the Commission. What I want to highlight for you is that the Commission is charged with developing, out of its Health Care Subsidy Fund, a program that provides subsidies to low-income individuals to purchase health insurance. That is what I am going to be talking to you about today. I also want to point out to you-- I want to preview something that I am going to come back to a little bit later. The Commission is told in its legislation that it should put an emphasis on encouraging preventive care, primary care, and managed care.

The third page basically outlines the funding of the Commission's principal programs. Here you see that the subsidized insurance program begins in 1994; is funded at a level of $50 million; and is slated to grow to $100 million in 1995. It is also, although it is not shown on this page, slated then to grow to $150 million in 1996. Funding is provided in the legislation through the end of 1995 via a transfer of surplus unemployment tax revenue.

I am now going to describe to you a little bit how it appears that this subsidized insurance program is shaping up. This is not a program where the Commission has formally taken a vote or action, or created regulations to be put into place, but it is pretty well-developed at a subcommittee level right now.

You may have read about this program. Actually, when the law created it, it was called Jersey Shield. It was a nice name, but it turned out to be a name that was copyrighted already by Blue Cross of New Jersey. So it is often referred to as the Subsidized Insurance Program, which is a little dull. We have just trademarked the name, "Access Program." So you can expect to be reading about the Access Program from here on in.

Here I want to emphasize to you that the Commission has made a tentative decision to run this Program by giving people subsidies to buy private insurance, not to create a new government program or a separate agency with its own insurance programs. The target population will be people who are:

unemployed, coming off of Medicaid, temporarily unemployed working, and working uninsured.

To be quite honest with you, the number of uninsured New Jerseyans with incomes low enough to qualify for this Program is much in excess of the available funding, certainly in 1994. So the Commission thinks it is very important to choose a target population. They will be targeting people who are unemployed or who are coming off of Medicaid.

The Commission is also very strongly committed to the notion that this Program should treat enrolled individuals like anyone else with private insurance; that a doctor or a hospital treating someone in this Program should not be able to tell the difference between this patient and any of us who are fortunate enough today to have private insurance.

Finally, you will see on this page that the Commission is most dedicated to a package of benefits in this Program that is not bare bones, but that is comprehensive; that emphasizes primary care, preventive care; makes it easier for people to get care where they need it; with low copayments and deductibles when you actually walk into the doctor's office or the hospital, so that you can afford to get the care you need.

The Commission notes that in this case, good medicine is also good economy. If you pay for good primary and preventive care up front, you will likely prevent a costly hospital admission.

On the next page I have outlined some of the tentative decisions about eligibility for the subsidies to buy insurance which the Commission has discussed. The law envisions that individuals would be eligible for a subsidy to buy insurance if their incomes are anywhere up to 300 percent of the Federal poverty line. Commission members envision that a subsidy would be available under that income level on a sliding scale basis, so the lower your income, the greater subsidy you would get to help you to buy insurance.

I noted before that the funding is limited, so when the Program is up and running -- which I expect to be in late spring or early summer -- the subsidies will be available on a first come/first serve basis.

The next page -- the last page -- is really, I think, where some of the decisions that the Commission has made about this Program touch directly on the health problems facing women. The Commission, again, has basically been interested in a comprehensive benefit package, and it is basically supporting a richer mental health benefit than that offered by insurers selling insurance in the individual market. They are interested, again, in making coverage affordable and in making individual visits to the physician or hospital affordable, and they are interested in covering all standard and necessary preventive care and screening tests as well.

Now, how does this benefit package address the health problems of -- the problems that women have traditionally had in our health care system? Well, clearly, the emphasis on preventive and primary care is important. Women are much more frequently at risk for health problems where prevention can make a difference, like cancer, like unanticipated problems of pregnancy. These are undetected problems very often, but they are treatable when good primary care is offered on an appropriate basis. The enriched mental health benefit is of great relevance in addressing women's health problems.

Finally, there is a basic economic fact of life here. Women in our society earn less money than men; are more often single parents; and are more often unemployed or less likely to be in the workforce. That is precisely the target population, in a sense, that this Program is looking at: folks who are unemployed; who are single parents and may not be able to afford health insurance; who are not in the workforce; or who are coming off of Medicaid and trying to get into the workforce.

In conclusion, while the Commission's activities have not focused directly on the health problems of women, with its principally financial focus I think you can see that the subsidized insurance program that the Commission hopes to make available later this year will have great relevance to some of the problems women in this State face in accessing the health care system.

I will be glad to answer any questions you may have.

SENATOR LIPMAN: Jeanne?

MS. FOX: Are you going to start publicizing it in the fall?

MS. WEISS: The tentative decision is to use a private insurance company to administer the Program. Some combination of this Commission and that insurance company would market the coverage publicly through appropriate marketing techniques when it is available. We are talking right now about a schedule late spring/early summer. I will be very honest with you, the principal thing that drives the timing of when this benefit will be available is the need to follow the rules of the State in writing regulations, in hiring someone -- an insurance company to process the benefits. That takes a certain amount of time. As soon as that process is through, then these benefits will be available.

MS. FOX: What is your estimate on how many families or how many people would be eligible, and how much that would cost? Obviously, you do not have enough money and you have your targets--

MS. WEISS: Right.

MS. FOX: --but what is your overall estimate?

MS. WEISS: The Commission hasn't developed a formal estimate of what it would cost to cover its entire target population. I will tell you a few interesting facts, though:

There are roughly 800,000 uninsured New Jerseyans. We estimate roughly that about 600,000 of those individuals live in families with incomes below the income level I mentioned earlier -- 300 percent of the Federal poverty line. Now, some of those 600,000 people may decide on their own that they are able to purchase insurance, because there have been reforms to the insurance market.

I will also tell you that in the first year that the individual insurance market reforms were in place -- since July of this year -- I believe about 20,000 individuals have been covered by individual policies who were not previously covered. That gives you a sense of how fast people can move into the Program.

Finally, one of the reasons it is so hard to talk about what universal coverage for this population would look like is exactly the issue you see today a lot in national reform, and I think one of great relevance, actually, to women's health problems; that is, insurance companies and analysts being a little tentative about what costs will be when people are allowed to sign up, but are not required to sign up. Will the most expensive individuals, the ones who have a lot of health problems, access the coverage, or will it truly be broad based and be a real pool of insurance risk?

I think, especially in this first year, when there is only $50 million-- Will that $50 million go quickly to a very few people who will have very high health care costs, or will it be a more representative population? We have devoted a fair amount of analytical work to examining that issue, but we have not reached any conclusions yet.

MS. JACOBUS: What would be the ongoing and increasing source of funding for the Program?

MS. WEISS: The law provides for three years of transfers from unemployment funds, and is silent about the source of funding for the Program after December 31, 1995.

MS. JACOBUS: Thank you.

MS. FRANCIS: Jeanne asked some version of the question I was going to ask, but just to ask a corollary: Clearly, you cannot predict the health care costs because of which segment of the population might go on this, but I was just wondering-- I liked your phrase, "Good medicine is good economy." I wonder if there isn't some way to come up with a good bit of data that would have at least a ballpark figure for the costs for someone on this Program relative to the costs for someone uninsured at this point?

MS. WEISS: I would be happy to go back and take a look at that. There is a figure, actually, in my statement which I did not mention. There is a concept in health care -- a financial analysis and a public health analysis of ambulatory care sensitive admissions -- which is the notion that you can look at hospital admissions for certain diagnoses and say if somebody had gotten appropriate primary care, that person would never have hit the hospital. A child ending up in the hospital with a severe middle ear infection is virtually always preventable, if there is appropriate primary care. You can bet when you see a kid in the hospital with that diagnosis there is no family physician and there is no insurance coverage.

There has been an estimate done by the Department of Health that there are about -- I have to refer to my statement here -- 130,000 of these admissions each year -- 130,000 of these hospital admissions a year, and that they cost the system about $650 million annually.

MS. FOX: This is just New Jersey or nationwide?

MS. WEISS: New Jersey. We also, of course, know that there is a lot of inappropriate emergency room use.

MS. JACOBUS: So that's six and a half times your annual 1995 budget.

MS. WEISS: Yes. The point is, though, I think some of those costs would be prevented, would never be incurred at all if there were primary care.

MS. JACOBUS: That's what I'm saying.

MS. WEISS: Right. So there is a tremendous trade-off. It is an investment. It is an investment. I think those issues are exactly the ones we have. Our actuarial staff and our financial staff are looking at that very closely, particularly because this Program is being built on the private insurance market, and we want private insurers-- We have had conversations with private insurers and we are pretty comfortable. We want them to feel confident that this is a good population to insure, and the Program has been carefully designed to make sure someone will want to offer this insurance.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you very much for coming.

Next we will have Ms. Jill Greenbaum, Executive Director, New Jersey Coalition Against Sexual Assault.

JILL GREENBAUM: Good morning.

SENATOR LIPMAN: Good morning.

MS. GREENBAUM: Here I am again to speak with you, and I am delighted to be here. Thank you for the opportunity to address the health care issues affecting survivors of sexual violence, their partners, and their families. As you will discover, in this testimony I have addressed various aspects of the interrelated areas of violence against women, adolescent health care, mental health services for women, and the need for research into the existing laws and policies.

The New Jersey Coalition Against Sexual Assault is comprised of agencies and individuals who work toward the elimination of sexual violence against all people. The mission of the Coalition is to effect attitudinal change in individuals, institutions, and the culture at large to meet the needs of survivors of sexual abuse. Our primary goals are the development, maintenance, and improvement of community-based services for all who have questions and concerns about sexual victimization. NJCASA has just recently opened its statewide office, with its function to serve as a conduit for information to survivors, pro-survivors, and professionals across the State.

In the past year, there have been many developments in the sociopolitical climate which have impacted upon the field of sexual violence. The persistent myths about who is sexually victimized, why the victimization occurred -- i.e., placing blame or responsibility -- and who commits sex offenses have faced some scrutiny in the courtroom and the media. In New Jersey, we have witnessed a refocusing of attention on the issues of consent and force, and what defines a person's capability to consent.

Well-publicized cases have afforded us the opportunities to address some of the issues we believe to be of import. Nonconsensual sexual interactions are being viewed by more and more people as violence and not sexual activity -- although there can be no question about the establishment of a backlash movement, whose members seek to deny all but the most stereotypical of cases of sexual violence.

In addition, attention is now being accorded to prevention efforts and the reality of sex offenders who leave prison -- with or without rehabilitation -- and reenter their communities of origin. While much of the pending legislation appears to have been created to satisfy the fears of the general public, it is a positive development that important questions are now being raised about community safety, probation, incarceration, parole, community notification, and supervision. Unfortunately, the new law created to require HIV testing of sex offenders is not a victims'-rights-oriented law, though it is perceived to be that by the general public. Laws which seek to maintain links between offenders and victims, and which do not adequately address medical questions and legal and ethical concerns of confidentiality, are not truly victims' rights laws.

However, in spite of the aforementioned, increasingly the needs of surviors are being served through the utilization of expert testimony regarding rape trauma syndrome, media attention to issues of consent, and identifying sexually abusive behaviors and offenders.

Perhaps one of the first areas which needs to be addressed is the fact that existing laws need to be monitored and enforced. Some of this work could be accomplished through the development of formal links between existing agencies and establishments. Research by NJCASA members revealed a lack of awareness of, and adherence to several recent laws, on the part of law enforcement and hospital personnel.

Public Law 1982, Chapter 9, delineates the use of doctor's discretion in the medical treatment of minors who are victims of sexual assaults. Specifically, a victim of a sexual assault may receive medical treatment without a parent's or guardian's consent. In six counties across the State, all the emergency departments were presented with the same scenario: If a 16-year-old girl, who was the victim of a recent sexual assault, went to the hospital in question, would she be treated without parental consent? In 26 of the 27 hospitals the answer was, "No."

Public Law 1987, Chapter 327, requires hospitals and local police departments to inform the victim of sexual assault about the local rape crisis center. Of the 129 respondents, 19 women went to the hospital and 4 of them were appropriately informed. Of 30 women who reported to law enforcement or criminal justice agencies, 16 were so informed. The most common source of referral was from mental health agencies. These are sobering statistics, and clearly the lack of adherence to laws which were designed -- and do work -- for the benefit of survivors impacts negatively upon the health, both physical and mental, of survivors and their families.

Thinking in terms of coordinating the delivery of services to reduce secondary trauma to victims and maximize efficiency, the development of standard operating procedures for law enforcement and medical personnel, the use of one standardized evidence collection kit across the State, and the creation of partnerships between agencies would be beneficial. Preceding all of the aforementioned would be the mandatory pre-service and in-service training of medical, law enforcement, and criminal justice personnel, from sex crimes unit investigators, to prosecutors, to judges, to probation and parole officers in the issues which face victims of sexual violence and the nature of sex offenders. Please refer to the attached article which offers empirical evidence regarding the need for training for all levels and types of professionals in contact with survivors.

In addition, we must address the fact that problems of sexual victimization do not affect only those clients with whom we work on a daily basis. These crimes affect women, children, and men, crossing all economic, racial, ethnic, and religious categories. Unfortunately, the majority of our social service systems are viewed -- and actually work with -- those who are in the majority. We must address our inattention to the needs of other than Caucasian and other than English-speaking populations, through training sessions for existing agency staff, the development of language and culturally appropriate materials, and outreach into underserved communities.

Our approach to the issues surrounding sexual violence must be proactive. We must create new avenues for coordinating services. The opening of the statewide office of the New Jersey Coalition Against Sexual Assault is a step toward addressing the needs of survivors at the State level, in concert with divisions, departments, agencies, and coalitions throughout the State.

Over the years, Coalition members have worked diligently to address the needs of clients and communities. This work has been impeded by the lack of adequate funding to agencies and programs throughout the State, lack of input into the funding process, and the fact that the Coalition's work -- until recently, with the hiring of one staff person -- must be carried out by those who are already overburdened with providing services to clients. Coalition members acknowledge the Legislature's support of rape crisis centers and the Office on the Prevention of Violence Against Women. These actions are a demonstration of the legislators' commitment to services for survivors of sexual violence and their families. It is our hope that the import of maintaining a statewide presence to voice the concerns and needs of survivors, and to participate in the projects outlined above, will be recognized in this year of changes across the State.

I have also included with the testimony an article which was based upon the research we did earlier -- well, not last year -- it was last year in 1983 (sic). I have one packet that includes some statistics, copies of the law, and the article I was referring to.

SENATOR LIPMAN: Thank you.

Are there any questions?

MS. FRANCIS: Just a little bit of follow-up to the resource. Thank you for the testimony.

When the Division's Office on Prevention of Violence Against Women was being formulated, we did a lot of talking about the fact that domestic violence response in the State has been fairly -- is progressive and has been fairly well-resourced. The Coalition for Battered Women has a certain level of staff support and, through DYFS, receives close to several hundred thousand dollars of support annually.

MS. GREENBAUM: Yes.

MS. FRANCIS: We talked about the fact that the support system on the issue of sexual assault, sexual violence, is just very, very far back in contrast to the way we are responding to domestic violence, per se. I just wonder if you would like to comment on ways you think -- again, because of our focus legislatively -- there might be some response to helping bring in a parity, which was one of our objectives -- response on sexual assault?

MS. GREENBAUM: Well, one of the areas which we are working on, and it does take time-- We started in July talking with the New Jersey State Department of Health, creating a memorandum of understanding, and then hopefully entering into a relationship with them. We are not sure that that is going to happen, because there were so many changes across the State.

One of the things I think we need to do is better coordinate the responses of the various systems and agencies or departments within the State, meaning medical personnel, law enforcement personnel, and rape crisis center/child sexual abuse program personnel. I think this office -- or me, really -- could help to facilitate that sort of thing. I have done police trainings down in Sea Girt, and I am well-versed in police and fire academies and their procedures. My background is as an educator.

I think, as Courtney was saying before, we need to do ongoing work. We can't just go in once and assume that things are going to neatly fall into place. We need to bring these departments together. I was just writing, actually, to Regina Potter and suggesting to her that we need to think across departments and divisions; we need to collaborate. That will also streamline some of the work that is already being done. Quite frankly, if you have a rape crisis center person or a child sexual abuse person going out to every police and fire academy from that particular county, you are getting differences in approach and information, and it is important to have consistency and to have a place where people can turn whenever they have questions.

That is what we hope to do in this office, but we obviously need more support to do it, because one person is not enough, in addition to the fact that none of our funding sources are stable.

MS. FOX: Your funding sources are mostly grants?

MS. GREENBAUM: Yes. At this point in time, we have had start-up moneys from the Victim and Witness Advocacy Fund. We have a start-up grant from VOCA -- Victims of Crime Act funding -- but that is a one-time happy event for us. Basically, we have money from the Office on the Prevention of Violence Against Women. We have received one grant; we hope to receive another. But it is not our intention to continue to rely on them. It is our hope to create relationships with existing departments and divisions to work on projects that will be ongoing over time.

But, yes. The only source we have past July 1 of next year is $7000 that comes from fines against violent offenders.

MS. FRANCIS: If I may just go on record, we are as generous as we can be, and we can only afford $15,000 to help to support -- to get them off the ground. The resources are very difficult to come by. The office is really hoping to do some of that coordinating across departments. I mean, we are set up with our Advisory Board, which you are aware of--

MS. GREENBAUM: Yes.

MS. FRANCIS: --to do that, but again, our resources are so minimal that we can't, without cooperation-- We are hoping the Department of Health and we can cooperate on that -- can do so.

SENATOR LIPMAN: Well, thank you so much for coming.

MS. GREENBAUM: You're welcome.

SENATOR LIPMAN: Next I will call Ms. Marsha Rosenthal, Pension and Health Finance Advisory Services. Here she is.

MARSHA ROSENTHAL: Good morning.

SENATOR LIPMAN: Good morning.

MS. ROSENTHAL: Maybe I should say, "Good afternoon." I am Marsha Rosenthal. I am a principal in a small consulting firm that specializes in elder care and long-term care. I consult with hospitals and other organizations on programs and grant writing. I have a special interest in the needs of older women, and recently published an article on the adverse impact that women's perceptions have on their ability to plan for their own long-term care.

I want to speak to you today about the health care needs of older women. Since much of my work is in financing long-term care programs, I will focus on that subject.

I also want to make a recommendation for enabling legislation that would set up a specific educational program to aid women as they grow older.

As I am sure you know, older women comprise a disproportionate number of those receiving long-term care. A disproportionate number of older women also live in poverty. It is a truism of this field that both the caregivers and the care recipients are most likely to be women. So when we talk about the difficulties of paying for long-term care, we are truly facing a women's issue.

One major facet of the problem is cultural. Americans value youth, not age, and women are especially subject to this insidious set of values. In addition, women are still brought up to believe that financial matters are a male domain. Taken together, these lead to an overwhelming reluctance by many women to think about growing older, about the possible need for long-term care, and about the financial needs they may face as a result. The same woman who willingly devotes years of her life to caring for an elderly mother or father, or a disabled spouse, will avoid thinking about the possibility that she might need the same care herself. This becomes a striking catch-22 for many women over age 65, many of whom are left widowed and with less financial means than they had when they were married. Because they are at greater risk for meeting long-term care, they are at risk for impoverishment and low quality of life.

The question is: How do we address women's negative perceptions and assist them in planning for themselves? We believe that knowledge would be a powerful tool to break this cycle, and this leads to my recommendation. The State should establish an information and education program on "lifetime health for women." This would cover health care for older women, and long-term care services and financing. The goal would be to develop an awareness and understanding of the ways a woman can safeguard her own health and her financial resources at several stages of life. The program should be targeted to specific at-risk audiences.

The targeted groups should include those who are at risk medically by virtue of their health backgrounds and lifestyles. It should also target those who are at risk financially. This would include most women at middle income and below. Despite some efforts by Wall Street firms to interest women clients, middle-income women are not usually reached by the financial industry. Yet, these are the women most at risk of becoming impoverished if they should become disabled later in life.

The program should include older women, midlife women, minority women, and even college women. One model would be the State's Senior Health Insurance Program, known as SHIP. The SHIP program is successful in providing information about Medicare, Medicare supplements, and other matters to a huge number of New Jersey seniors. SHIP uses trained, peer-level counselors and goes where the seniors are, such as senior centers and agencies on aging.

A woman's "lifetime health" program should be provided by trained women volunteers who speak the same language as the at-risk women. It should go where these women are -- to women's clubs and organizations, community centers, churches and synagogues, PTOs, YWCAs, and YWHAs. Such a program would be to provide different levels of information. Clearly, an 80-year-old woman living alone with income below the poverty level needs different information from a 50-year-old woman whose husband has an income of $50,000 a year. The key is to assure that the 50-year-old woman gains the information and the incentive to act on her own behalf, so that she does not find herself below the poverty level when she is 80.

It may appear that the State government has bigger fish to fry when it comes to devoting resources to older women's needs. Clearly, there are immediate health care needs of older women that are not being met. But a substantial educational program need not be a costly item, especially compared to paying out Medicaid dollars for nursing home care.

On an earlier project, we developed a three-year prototype for a public education program based on a budget of under $500,000. Medicare would pay out that much in three years for just six women who needed nursing home care. This is preventive medicine: reaching tomorrow's population that will be at risk for needing long-term care.

Today's oldest baby boomers are 48 years old. The estimates are that the population at risk for needing long-term care will triple by the time this cohort reaches age 80. At the same time, the working-age population -- the ratio to the disabled elderly is projected to drop from 21 to 1 down to 9 to 1. This imbalance will not allow those of us who are in this population group the luxury of expecting a younger generation to provide for our needs. It is essential that today's middle-income women, who are today's middle-aged and younger women, begin to plan for themselves. This is the best way to free up scarce Medicaid dollars to cover the long-term care needs of those who will really need them.

We also know that the State and Federal governments are perceived by the public as the most reliable source of information on these subjects. In a 1990 survey on long-term care and long-term care insurance, 54 percent of respondents felt that the provision of information was the single most important action the government should take. Since funding is always an issue, I will make a suggestion: One possible funding source for this would be contributions from the State-approved long-term care insurance carriers. The insurance companies are on record that public education on long-term care is in their best interest. In return, these entities should also be asked to serve, along with women's health care experts, on a steering committee for the education program.

In closing, I would like to offer to share with the Commission the results of a study we are planning to undertake this spring with Elder Men America, as part of a joint project. Together we are expecting to offer an educational and decision-making program for members of selected hospitals' senior groups. The program will focus on teaching members about long-term care and long-term care insurance. It will also offer members a set of long-term care insurance policies. As part of the pilot, we expect to conduct a study of those members who choose to participate and those who do not, as well as those who purchase long-term care insurance and those who do not. Among other variables, we will be examining the differences between male and female respondents and between older and younger respondents. I expect we will have the study results by next summer.

Thank you.

SENATOR LIPMAN: Thank you very much.

Do you have any questions, Senator?

SENATOR CAFIERO: You made one suggestion. You said you had some suggestions for some legislation?

MS. ROSENTHAL: Yes. I think that having an educational program of this type would require legislation. It would require an interdepartmental effort on the part of the administration. Since funding would have to be sought, it would require legislation to do that.

SENATOR CAFIERO: Would you mind dropping the Chairperson and me a note as to what your suggestions are--

SENATOR LIPMAN: Yes.

MS. ROSENTHAL: Sure. I would be glad to do that.

SENATOR CAFIERO: --and what the legislation would embody? Maybe we could team up.

MS. ROSENTHAL: I will also provide, if the Commission wants, written copies of my testimony, which I do not have with me today.

MS. JACOBUS: Yes, please. Thank you.

SENATOR LIPMAN: Thank you very much.

Next I will call Ms. Rosalind Thigpen-Rodd, who is from the Office of Minority Health, who will speak on policy issues for people of color.

MS. JACOBUS: Do you want me to take any of that from you? (speaking to approaching witness with regard to materials she is carrying)

SENATOR LIPMAN: Yes, she does.

SENATOR CAFIERO: Is that our homework assignment?

SENATOR LIPMAN: Yes.

ROSALIND THIGPEN-RODD, M.H.A.: (speaking off microphone) This is background information and copies of the testimony-- (remainder of sentence indiscernible to transcriber)

Good afternoon.

SENATOR LIPMAN: Good afternoon.

MS. THIGPEN-RODD: As Senator Lipman indicated, my name is Rosalind Thigpen-Rodd. I am the Executive Director of the New Jersey Department of Health's Office of Minority

Health. I was pleased to be invited to present testimony to discuss some of the critical issues that must be addressed if health care reform efforts are to effectively impact populations of color.

My testimony will:

1) Provide a brief historical perspective on the health status of populations of color, with some specific highlights on the health status of women of color; and

2) Discuss the core principles that are presented in a report that was released in April 1993 by the Office of Minority Health, in conjunction with the Commissioners' Advisory Committee on Minority Health.

Copies of my testimony have been submitted for your review and consideration. In addition, all Commission members and staff have been provided a copy of the final report on minority health, along with a short bibliography that lists a few of the major policy documents that have been developed to address the health needs of populations of color.

In New Jersey, not unlike the rest of the nation, populations of color experience a disproportionate rate of death and disabilities due to cardiovascular disease and stroke, cancer, diabetes, HIV/AIDS, infant mortalities, substance abuse, and homicides, suicides, and unintentional injuries.

New Jersey's four major race and ethnic minority populations constitute almost 21 percent of the total population. The race ethnic breakdown of the population is: 13.2 percent African-American; 9.5 percent Latino or Hispanic; 3.5 percent Asian/Pacific Islander; 0.2 percent American Indian; 79.6 percent white; and 3.5 percent other. Other race and ethnic populations that are known to reside in this State include, but are not limited to: Haitians, Africans, Middle Easterners, Portuguese, and East Indians.

From 1980 until 1990, nearly all of New Jersey's population growth occurred in the minority population. The Latino population, New Jersey's second largest minority population, experienced a 50 percent increase, based on the last census. The U.S. Bureau of the Census estimates that based on the growth rate, Latinos will be the largest minority group in the nation by the end of the century. Therefore, with continued growth and immigration, the overall proportion of populations of color is expected to increase significantly over the next decade.

Women in New Jersey comprise over 50 percent of the total population. The race and ethnic breakdown is: 14 percent African-American; 9.2 percent Latino; 3.5 percent Asian/Pacific Islander; 0.2 percent American Indian; and 82 percent white.

It is important to note that a major deficiency exists in the health database. As a result of this deficiency, there is an imbalance in the health data that is available on any particular race/ethnic group, regardless of gender. Another problem arises from the system often being driven by mortality or death data, rather than morbidity data.

While there is a lack of data, there are some striking statistics reflected in the Cancer Registry, which show disproportionate rates of cervical and uterine cancer; the maternal and child health database; the statistics that are maintained on infant mortality rates and prenatal care; and the AIDS database, where women of color comprise approximately 80 percent of all infected women.

The final report on minority health, entitled "Closing the Gap: Improving the Health of New Jersey's Minority Populations," presents a series of recommendations and strategic actions for resolving the health problems confronting minorities. If health care reform is going to be effective in assuring that populations of color are provided equal access, then five critical areas must be addressed in any plan of action:

1) We must increase accessibility to, and the availability of quality culturally and linguistically appropriate community-based health care services. The importance of culture and language and the role they both have in educating and treating women of color cannot be overemphasized.

2) There must be improvements in health care financing and reimbursement mechanisms. All people should have a basic health care insurance plan, and be fully educated on their benefits and rights. Insufficient reimbursement for basic heath care services and the unavailability of a provider can no longer be an obstacle for seeking and obtaining health care services.

3) A standardized race- and ethnic-specific health data collection and reporting methodology must be developed for the State. In addition, community-based organizations should receive grants to perform local community health needs assessments.

4) The number/proportion of race/ethnic minority health care professionals/providers, and senior-level policy and decision makers must be increased. In addition, all regulatory boards and councils should have racially and ethnically diverse representation.

5) Last, but certainly not least, there is the need for mobilizing and empowering communities of color with a voice in health care planning and policy development. This will ensure their representation in the design and implementation of an effective and responsive health care system that is intended to serve them.

As policy makers, we cannot pay lip service to communities. We must regain their trust, make room for them at the table, and involve them at all levels of the discussion.

In closing, I will reiterate the words of Dr. Martin Luther King, Jr. that: "We must not allow any force to make us feel like we don't count." Certainly as women we cannot allow this to happen, and particularly as women who are committed to our sisters who are, oftentimes, the most vulnerable.

Through our collective efforts, however, I am sure we can work together to improve the health and quality of life for all women in New Jersey. The Office of Minority Health looks forward to working with you.

Thank you.

SENATOR LIPMAN: Thank you.

Questions?

MS. FOX: In New Jersey, are there any specific diseases that are more prevalent with women of color, that stand out, that are really--

MS. THIGPEN-RODD: Well, first of all, you can look at life expectancy. Unfortunately, because of the inadequacies of the database, I cannot speak for all race and ethnic women's populations. But for the African-American woman you see a four-year disparity in life expectancy, which is, like, I think, on the average of 71 years for an African-American woman, and 74 years for--

MS. FOX: Is that nationwide, or for New Jersey?

MS. THIGPEN-RODD: That is for New Jersey, although you see various disparities across the nation in other states where it may be different. You know, for example, if you look at minority males -- just as an example -- you may see a greater disparity as the result of a study that was performed in Harlem by a Dr. Harold Freeman (phonetic spelling). They indicated the life expectancy of an African-American male as being worse than that of a man residing in Bangladesh.

Although I do not have the statistics handy, some of the things that we have observed clearly amongst the various cancer rates, when you look at cervical, breast, and uterine cancers-- I could not do anything but sit in the back and nod my head when former testimony was being presented about prevention, early intervention, and primary care as the basis for eliminating some of these disparities, because you do see a higher rate of incidents of various cancers. You also see lower survivability amongst women of color, because they are getting into care much later. Cardiovascular disease, cancer, and diabetes are the leading causes of death. You also see disproportionate rates amongst those categories.

We are just dealing with mortality data. When you start dealing with morbidity data and other types of areas of concern, such as how soon individuals are getting into prenatal care, you know, which is having a direct correlation to low-birth-weight babies and infant deaths-- That is just another area that we should be concentrating our attention on, looking at where the services need to be improved.

MS. FOX: Thank you.

MS. FRANCIS: When you mentioned the culturally, ethnically, racially sensitive treatment and, you know, all sorts of systems, and then you mentioned-- I thought immediately of encouraging more professionals, people of color, to go into that profession. You did mention that.

Do you have any strategies for that, or any ways the State could help to support getting more professionals?

MS. THIGPEN-RODD: Well, we work very closely with the University of Medicine and Dentistry, which is clearly one area where you could concentrate attention in terms of increasing your recruitment mission and retention of minority doctors, dentists, you know, nurses, and on down the line. You need folks at all levels. You even need a provider pool within the community of indigenous educators who may even get the message across better than the "professionals." If they are educating they are professional in my sense, whether they have the degree or not.

SENATOR LIPMAN: Thank you very much--

MS. THIGPEN-RODD: Thank you.

SENATOR LIPMAN: --for your testimony, and for the literature you brought.

MS. JACOBUS: Thank you for the reports, too.

SENATOR LIPMAN: I am going to call now Dr. Anne Slocum McEneaney. She is from Rutgers Counseling Services, Rutgers University.

ANNE SLOCUM McENEANEY, Ph.D.: Good afternoon.

SENATOR LIPMAN: Good afternoon.

DR. McENEANEY: I am Dr. Anne Slocum McEneaney. I am a Clinical Psychologist and Associate Director of the Rutgers College Counseling Center, which is part of Rutgers University in New Brunswick.

I am very pleased to have been asked to address the Commission on the adolescent health issue of eating disorders. I will talk some about the incidents, demographics, and consequences of these syndromes, and then address the issues of treatment and prevention, areas in which I think you, as legislators, can have a significant impact. I have kept this very brief so as to have as much time as possible for any questions you might have.

The two primary eating disorders are anorexia and bulimia. Both disorders involve managing psychological conflicts or feelings by means of intense focus on issues related to food and body image.

Anorexics do this by controlling what they eat to the point of self-starvation, while spending inordinate amounts of time thinking about food. Approximately one-half to 1 percent of the population of adolescent women have anorexia.

Bulimics begin every day determined to control their eating as rigidly. When they are unable to do so, they often respond by binge eating; eating up to 10,000 calories at a time, and then purging, or getting rid of the food by means of vomiting, laxatives, or excessive exercise. Approximately 5 percent of adolescent and young adult women have bulimia.

Symptoms of anorexia and bulimia without the full syndrome have been shown to affect as much as 35 percent to 50 percent of adolescent and young adult women.

I suspect it will surprise no one to hear that eating disorders disproportionately affect girls and women. More than 90 percent of bulimics are female, as are 95 percent of anorexics. Moreover, it is adolescent women who are at the very highest risk for developing an eating disorder. The two highest risk periods are ages 13 to 14, when the adolescent is beginning the process of forming her identity by finding her place within the group of her peers, and ages 18-19, when she is generally living away from home for the first time.

One thing that is important to point out is that the age of onset for these disorders has been steadily decreasing as young girls begin dieting at earlier and earlier ages. You will find nine- and ten-year-olds dieting now and developing eating disorders by the time they are 12-13.

Persons with anorexia and bulimia are found among all racial and ethnic groups. They are also found in all socioeconomic classes and among all religious groups. The consequences of eating disorders are significant. Anorexia generally results in amenorrhea, or the loss of menses, which can result in the permanent loss of bone density, such that a 20-year-old woman who has suffered from anorexia for five or eight years can have the kind of bones that an 80-year-old woman has. If she falls, she can break a hip.

Anorexia also results in a lowered body temperature and lower blood pressure, which can lead to fainting and fatique. Finally, untreated anorexia can lead to death. Five percent to 18 percent of anorexics will die, generally from the effects of starvation.

Bulimia also has very serious health consequences. These range from tearing the esophagus and destroying dental enamel to cardiac arrhythmias which can result in fatal heart attacks. Two percent to 6 percent of bulimics will die of complications or will commit suicide.

In addition, the personal and societal costs of eating disorders are very high. Bulimics and anorexics live lives of deep, but silent despair. Although they initially tend to be high achieving, well-educated, and highly productive, they may eventually become incapacitated in their job or schooling, become withdrawn from friends and family, and unable to contribute to society.

Treatment specialized to the needs of eating disordered women has been shown in the research literature and in my experience to be essential. This treatment recognizes the societal contacts, the immense pressure on women to be thin and look right, in which women struggle with their feelings about their bodies and, on a deeper level, their feelings about their very selves.

I am currently dealing with a very difficult situation in which a young woman needing hospitalization for bulimia has been told by her insurance company that they will pay for her to spend 30 days in an acute psychiatric unit, where the other patients would have been admitted primarily because they are psychotic and in need of medication management, but that the insurance company will not pay for her to spend those same 30 days in the eating disorders unit at the very same hospital. That makes absolutely no sense. I hope that is something you may be able to address sometime in your efforts, perhaps when New Jersey has universal health coverage, or at some other time.

I believe one of the reasons that insurance companies sometimes ignore effective treatment for eating disorders is precisely because it is a disorder affecting so predominantly women, especially young women who have no power base.

Another factor that contributes to effective treatment with eating disorders is early intervention. I would like to speak very strongly in favor of the school-based mental health programs in New Jersey, one of which, in particular, I am familiar with, but I believe they all do an excellent job. Many adolescents flirt with the symptoms of eating disorders; that is, dieting restrictively, binge eating, purging on occasion, or have subclinical eating concerns long before they develop full-fledged eating disorders.

School-based programs which educate students about the possible consequences of these behaviors or provide counseling to a student on the verge of an eating disorder are highly effective and, as everyone has said repeatedly today, very cost-efficient. It is much cheaper to prevent an eating disorder than it is to cure one. So they have been very cost-efficient as a means of reducing the incidents and also the personal and societal costs of eating disorders.

Thank you.

SENATOR LIPMAN: Thank you.

Questions?

MS. FOX: Yes, a quick question. In New Jersey, are there many high schools or colleges that have such school-based programs?

DR. McENEANEY: Yes. There is a program in New Jersey which-- I am familiar with one high school which is near-- Actually, I am not sure what school district it is, but I know someone who worked in the school-based program. It was a program primarily staffed by social workers, supervised by a psychologist. They do a lot of-- They are there all the time. I think that is part of a sort of crucial element, because the students know they are there. They can drop in kind of casually. Their setup is arranged so that there is sort of a lounge where students can come and sort of hang out. Women, in particular, will take advantage of that kind of a situation to seek out counseling, if it is readily available and they don't have to jump through a lot of hoops to get to it. I believe it has really been very effective. They do a lot of groups there. They will do groups specifically about things such as eating disorders, and they also do a lot of education. The simple fact that they are there educates people. They also go out to the classrooms and do a lot to--

MS. FOX: I would assume, then, that not many of the school systems have such a program.

DR. McENEANEY: Not many.

MS. JACOBUS: Jeanne, this may be part of the Department of Human Services' School-Based Youth Program, which is outlined in your report on that. There are 36 sites in the State. It may be one of those.

DR. McENEANEY: That sounds right.

MS. FOX: And that, I assume, is funded strictly by the--

MS. JACOBUS: It is funded through the State. That Program is seeking expanded funding from Federal sources at the moment. You will hear about that from some other witnesses.

SENATOR LIPMAN: How large is your program at Rutgers?

DR. McENEANEY: The program at Rutgers is not specific to eating disorders. Our Counseling Center has a staff of eight. We serve a population of about 16,000 students. We see about 800 students a year out of the 16,000. Those are both undergraduate and graduate students.

We do quite a bit of work with eating disorders. We try to do educational work as well, because the college population is very much at risk also.

Thank you.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you.

I would now like to call Ms. Sandra Hartnett, from the Mercer Medical Center Cancer Screening Clinic.

SANDRA HARTNETT, R.N., M.S.N.: Thank you for inviting us to share our experiences thus far.

I am Sandra Hartnett, Oncology Clinical Nurse Specialist. I am from the Mercer Medical Center in Trenton, New Jersey.

In 1993, the New Jersey State Department of Health received Federal funds to develop pilot programs aimed at providing breast and cervical cancer community outreach, education, and screening to socioeconomically disadvantaged and/or minority women over the age of 40. These funds were in turn awarded to five groups throughout the State which had submitted proposals for the program. The five currently include: a county board of health, a large hospital system, a community department of health, and another hospital similar in size to Mercer Medical Center.

Why fund such a program? The diagram I showed you is a graphic representation of statistics compiled by the State of New Jersey for the 1979-'85 period. They indicate, for example, that black women have a lower incidence of breast cancer than Caucasians, yet a very similar mortality rate. In regard to cervical cancer, both the incidence and the mortality of cervical cancer are higher in the black population.

In reaching out to the black community, it is tempting to lump all that is wrong under lack of access. Our brief experience so far indicates that lack of access is, in fact, a very big -- a crucial factor. Surprisingly, the women who have taken advantage of the program that we call "Brava," for taking care of yourself, are predominantly working women. They work as part-time or full-time home health aides, housekeepers in private homes, kitchen aides, waitresses, or are retired. In spite of working 40 or more hours a week, they have no health care coverage, and incomes that are generally between $10,000 and $15,000 a year.

They come to the screenings tired. They have worked all day, or the night before, or sometimes two shifts. They often have a grandchild in tow. It is very tempting for them just to skip the appointments.

I propose that no health insurance for the poor is not deliberate sex discrimination, but in actual practice it often plays out that way. They cannot recall where they had their last mammogram or Pap smear. There are three hospitals and various community services in this City. Some women have been to all of those hospitals within the last few years. Securing prior mammograms, if they exist, for comparison of an abnormality can take weeks. They got a Pap smear four years ago at Planned Parenthood; and the year before that at a federally funded neighborhood health center. They may see a local doctor for blood pressure medications, but he doesn't mention mammograms or Pap smears.

Such fragmentation of care means that no one takes any responsibility for the health of these women. Sometimes the people in the hospital say to me, "What is the matter with those people? They have such an attitude. Why don't they come to their appointments? Why do they cancel? Why don't they show up?" Transportation is a major obstacle. Promised rides never materialize; buses are late; it is cold and windy standing on the corner. There is no flexibility or assurance when you can't drive yourself to an appointment.

The last big factor, however, is awareness of, education about, and motivation to overcome attitudes and beliefs in this particular minority population regarding the irrelevance of preventative health care and fatalism about cancer.

Whatever programs are funded through legislation, they need to include provisions for health educators, and especially community outreach workers from within the peer group.

I included some recommendations, I think none of which are new to you. Obviously, the first one is universal health care. Second, community-based primary health care centers, which might be constructed along the lines of specific population densities or specific geographic areas. Third, State, local, and community-based culturally sensitive educational approaches. Fourth, community outreach workers from within the peer group.

Whatever programs are funded, whether through legislation or other means, I really cannot stress the importance of this role enough. I can go into inner-city churches and talk to women about mammograms. Do they listen? Sure, they listen to me. Church women are very polite. Do they go for mammograms? Not necessarily. I think the message needs to come from someone within the group who has shared their living experiences and who understands what their fears and hesitations might be.

So I think the role of health educator and community outreach worker is very important. It cannot be added on as a token or a volunteer role. That needs to be built into this type of legislation.

Last of all, I think some type of assistance for transportation is very important.

Thank you.

SENATOR LIPMAN: Is there -- as there is in Newark -- medical transport in the community? There is usually a van that carries people back and forth.

MS. HARTNETT: Yes. One of the things we are finding is that van transportation is very expensive. Someone has to coordinate who picks up the people, when and where. Someone has to pay the van driver, pay for gas, pay for insurance, and there is depreciation on the van. Not everybody really needs it, so we have diverted some of the funds that we had originally set aside for that. We just tell the people on the phone, "If you need transportation, take a taxi. When you get there I will reimburse you." Surprisingly enough, not everybody wants to do that. But for those who need it, it is a real godsend. I have total faith that when they arrive and tell me it cost $4.50, it did, and I can give them $4.50 to get back home. I suppose a lot depends on geographic area in Trenton. It is not a very big City. The largest fare I paid was $8.00. So I think that is more economical than paying a van driver who may not be busy for the total hours of the service.

SENATOR LIPMAN: Do you have a question?

MS. FRANCIS: You mentioned possibly a grandchild in tow. I mean, child care clearly is raised as another barrier to this in all of the hearings and forums we have had.

Do you see a way to build in some child care support as well? I mean, clearly there is--

MS. HARTNETT: That would really be nice. We talked about that, but things like that are not as easy to accomplish as one might think, because the hospital then incurs a liability for having these children in its care for a period of time. Who will be responsible for them? And then, what are the requirements for that job? But child care is important.

The other thing that comes up is also the hours that people do screenings like this. As I said, most people are working. These people don't have "sick days." If they don't go to work, they don't get paid. So having screenings and services of that sort in the late afternoon, perhaps on Saturday mornings, is also important.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you very much.

Ms. Nancy Fiorentino. Oh, there you are.

NANCY LEE FIORENTINO, M.S.W.: Hi.

SENATOR LIPMAN: Hi. Nancy is from the Office of Policy and Research, New Jersey Department of Health.

MS. FIORENTINO: Good afternoon. I want to take the time to do three things. Hi, Bobbie. (speaking to Ms. Francis)

I want to do a little bit of sort of the history of pregnancy and addiction as kind of a policy premier; then a little bit on some of the statistics and demographics; and then some policy options and recommendations.

I have worked in the addictions field in New Jersey since 1972 in various roles in the Department of Health.

First of all, it is important to acknowledge that the issue of pregnancy and addiction is both new and old. It is old because Benjamin Rush was saying pregnant women shouldn't drink as the first Surgeon General in Colonial days. It is new because the issue of prosecution of pregnant and addicted women only began, really, in 1987.

Prior to 1987, only two women had ever been prosecuted for using drugs while they were pregnant. Between 1987 and 1990, 19 states have taken action against 50 women. Florida, South Carolina, and Michigan have prosecuted women for delivery of drugs to a minor -- assault with a deadly weapon -- and if the infant died, manslaughter and homicide.

There have been bills which proposed to make drug use during pregnancy a felony per se. In Ohio, mandatory sterilization is being debated in the legislature for drug-addicted women. Many states mandate reporting drug test results. Some states mandate reporting drug test results to the health authorities, and others mandate reporting those results to the prosecutorial system. Two states have convicted women of harm to the fetus by their prenatal behavior. Florida takes custody of infants who have been drug exposed immediately at birth, regardless of an evaluation of the family situation or treatment for the mother.

In New Jersey, the history has been that we have generally taken a stand opposing the prosecutorial options, and have really promoted the perception of health care alternatives. The Division of Addiction Services, in 1993, spent $5 million on services for pregnant women and their children. All pregnant women received preference at all government-funded programs as a requirement of Federal funding.

In 1988, New Jersey started a very innovative program which became a national model, which was to screen pregnant and addicted women and provide them with risk reduction counseling and treatment. We have programs in 18 locations, with 25 full-time staff, who last year screened 15,000 people. To put this in a context, we have about 123,000 live births a year. So we are definitely not doing a large proportion of them, but we are doing a significant proportion, many more than most states and in a public health system.

One out of four of the 15,000 people screened were sent to the risk reduction specialist for addiction services. Four thousand were evaluated; 1500 were followed throughout their pregnancy; and about 750 were sent to treatment. About 24,000 health care professionals receive training in pregnancy and addiction, and in 1990, a set of perinatal addiction services were created which included prenatal care and addiction services in the same location. We have five of these in New Jersey, and that is another national model program that has been written up in a monograph.

In 1988, the State began purchasing treatment for pregnant addicted women. We are the only State that boasts of services on demand for pregnant addicted women. We have nine facilities that provide these services, and we have about 600 -- between 500 and 750 women a year who receive these services. We have had exceptionally good results. Everyone expected there would be preterm labors, high-risk babies, and low-birth-weight babies. In fact, of the first 1500 treated, there have been no doubts. There have only been preterm labors, both of them sent to the hospital and handled without difficulty. We have had some of those babies named after their head nurses, at least three that we know of.

We also have halfway house programs where mothers and babies can go, but we only have a dozen halfway house programs for women. Half of these take children. There are only 130 slots for women and 60 slots for children. That is shockingly small as a treatment capacity.

We have transportation services for people who go to those facilities. They are paid for by Medicaid; they are also paid for by Federal Block Grant funds. The women who go to these programs are unusually damaged women. We have estimates that 70 percent to 85 percent of these women were victims of sexual abuse, and as many as 85 percent came from addicted families; that is, they had a parent who was addicted to a substance. This sexual abuse doesn't even take into account the emotional abuse -- which no one even questions at the moment -- but emotional abuse is also very high in this population.

DYFS has also done some unusual things. They have established special foster homes for babies -- medically fragile foster home services. They train parents in these homes to particularly care for substance-exposed infants who need special care. They also have intervention programs in Mercer, Passaic, and Atlantic Counties. Their medically fragile program is a model program in the nation, featured in a monograph by the National Office of Child Abuse.

In New Jersey, we have an interdepartmental working group which tries to coordinate all the people who need to be involved when you are developing services for pregnant and addicted women. We have some particular treatment programs. We have a treatment campus in Meadowview that has 360 slots, which could be as many as 1600 slots annually for people, and that includes pregnant and addicted women. Seabrook House down in South Jersey got a grant for the treatment of pregnant and addicted women and their children. Trenton is developing an Addiction Science Center, which is intervention, in particular for pregnant and addicted women.

I think I am going to skip some of this data. I think you know about low birth weight, prematurity, and the relationship of alcohol and drug use to health outcomes. It is pretty self-evident. There is a good body of literature about that. The science is very detailed and specific. But there is a strong relationship between the absence of prenatal care and the use of alcohol and drugs. The majority of people who use alcohol and drugs who did not get prenatal care cite the use of alcohol and drugs as one of the reasons. There is a big fear factor. People are fearful that they will be tested with or without their knowledge and the test results will be used for prosecutorial purposes.

So people who are using illicit drugs are fearful of getting prenatal care. In fact, some states do that. You may have seen The New York Times. Just in the last two weeks, they had an article about North Carolina being sued by the Federal government for using those medical records for prosecutorial purposes on a routine basis.

We have a range of information about estimating prevalence, but New Jersey has completed its own labor and delivery prevalence survey. We are unable yet to release that data, but 3500 women were tested this year in a representative sample of locations. If we are going to be consistent with national results, we expect that somewhere between 5 percent and 11 percent of those women who were in labor and delivery will test positive for some chemical which has been harmful to their baby.

By the way, I should mention that everyone automatically assumes when we are talking about substance-exposed infants that we are talking about cocaine. Cocaine is a very critical issue, and between 1 percent and 3 percent of the population uses it. We can expect that at least that proportion of pregnant women are using. But alcohol is much more prevalent. Marijuana use is very prevalent, and nicotine use is also associated with low birth weight, which is associated with congenital anomalies and upper respiratory problems. So when we do programs for pregnant and addicted women, we deal with all of the addictions.

We want to have a deal, also, with HIV infection. You have probably heard about HIV infection, but we have more women -- a higher percentage of women than any other state, at 22 percent. We are third in the nation in children's cases. Among children with AIDS, we have 850 in New Jersey right now. Ninety-five percent of them contracted their infection from their mothers. Three-quarters of the women with AIDS are in their reproductive years and can be expected to experience a pregnancy. One in five is black or Hispanic. In New Jersey in the general population, you have four out of five AIDS cases that are women and children who are black and Hispanic. Two-thirds of HIV infection in New Jersey is transmitted by I.V. drug use, so there is a very close relationship, unlike some states where the majority of HIV infection is not I.V drug use related.

So we are really dealing with I.V. drug use, HIV infection, alcohol and drug dependence, a lack of prenatal care, and poor nutrition for many women, but that is not to say it is a socioeconomic status issue. It is not. In fact, there is very good data that the proportion of pregnant and addicted women is the same among all socioeconomic groups, and not disproportionately greater among low-income people, although the problems associated with addiction are greater among low-income people.

I am going to skip right through this (referring to her written statement) and talk about policy recommendations, because I have kind of used up my time.

There have been some really excellent reports. Rand did a report; the Governor's Task Force on Child Abuse and Neglect did a report; the Ad Hoc Drug Policy Group of the H&HS did a report. There are some very good recommendations about what is useful, but it is fairly obvious public health stuff, which is doing really good screening.

I am going to skip through all the policy recommendations and go to--

MS. JACOBUS: Nan, anything you would like to give us in full, we will include--

MS. FIORENTINO: Oh, write it up?

MS. JACOBUS: Or just Xerox your hand-written notes.

MS. FIORENTINO: Okay.

Basically, we should have mandatory testing for substances for pregnant women, but this should be medical testing. This should not be testing for prosecutorial purposes. This testing is not just required for pregnant women; it is also necessary for people who have experienced trauma, and for people who are in the hospital for addiction-related illnesses. All the medical associations have been recommending this for a long time. The trauma center directors recommend it; the American Society of Addiction Medicine recommends it. The general medical experts recommend mandatory testing for trauma patients, hospital admissions, and addiction-related diagnostic categories in pregnant women.

The testing, though, is very seductive. People often want to do testing, and then they say, "Oh, hurrah, we have done testing," and we wonder why. The testing is really a part of creating an overall clinical picture. Just as you would not determine somebody is suffering from an addictive illness because they had a high BAC, you would not do that with a pregnant and addicted woman who delivered a baby who was cocaine affected either. There has to be a comprehensive diagnosis. There is good diagnostic criteria in the DSM3R. We have excellent skilled people who conduct diagnostic workups for people. That is what is necessary -- a good diagnosis and a good treatment plan as a part of a confidential medical record. Then referral for addiction treatment. I mean, often we stop at testing; then sometimes we stop at diagnosis. We do that with special ed kids. We have this much stuff on diagnosis (demonstrates) and very little on implementing treatment plans. We need, then, to move to implementing the treatment plan.

In order to implement a plan for pregnant and addicted women, we have to have third-party reimbursement. It is not sufficient to say that a proportion of government money has to go for this, because government money only supports one in five of those live births. Four out of five live births are in the private sector. So we need general insurance coverage for addiction treatment; for pregnant women -- for all persons, but in particular for pregnant women.

We also need Medicaid coverage for treatment of addicted persons. Many states now provide Medicaid coverage. Some of them require a differential diagnosis first, but--
Then we need to tax the products which are harmful to people -- tobacco and alcohol -- and use those funds for prevention and treatment. There is very good evidence that increasing the price of alcohol and tobacco decreases use. Decreased use leads to decreased illnesses and injuries associated with use. So you can actually do econometrics formulas by which you derive the number of lives saved per percentage increase in price for both alcohol and tobacco. There is very good literature on that. The GAL has studied those models, and New Jersey demographics could be used to derive the same kinds of models.

Those are my summary and recommendations on pregnancy and addiction. I hope you will include some policy recommendations with respect to pregnancy and addiction, because there is a continuous interest in this area, an uninformed interest which tends to lead to inappropriate responses.

We have some very good policy. We have warning labels; we have signs posted. We have some very good policy, but we are missing the key pieces, which are the general health coverage, screening, diagnosis, and treatment.

So thanks very much.

SENATOR LIPMAN: Do you have an established time for mother and child to stay in one of the treatment centers after the birth?

MS. FIORENTINO: That is such a wonderful question. The addictions field has developed a thing called, "Patient Placement Criteria." The American Society of Addiction Medicine has adopted it; many states are using it; we are promoting it in New Jersey. I just taught it to 200 alcohol and drug counselors on Sunday in Ocean City.

What it says is: "We will assess each individual on six dimensions: withdrawal risk, medical complications, psychiatric complications, acceptance/denial, relapse potential, and then recovery environment. Based on their scores on those six things, we will decide whether they should get inpatient or outpatient, a week, a month, or a year." Whether their children should be with them or not is a part of that determination -- whether they should be separated. If they are in acute enough illness, they do need to be separated.

So, yes, there is a technology for doing that. It is not in widespread use. I have been promoting that we require it as a condition of licensure and contract renewal -- that kind of thing. We are bringing people up to speed. It is a new technology with new science. It takes time for people to learn it and apply it. But we have the ability to decide which people need which things pretty accurately now.

MS. JACOBUS: Nan, of the five indemnity plans that are outlined in the New Jersey Health Care Reform, there is an allowance for some maximum 30 days combined alcohol addiction and mental health services per year, per individual. Could you evaluate the sufficiency of that?

MS. FIORENTINO: That is really left over from our history of insurance's past practice of covering for that long. We have a history of having done that, so we can't let go of that history. There is no science to support it, whatever. We really need clinically determined variable lengths of stay in addiction care. There are some people who require a long, long time. It is a very small number of people. The majority who can be treated on an outpatient basis, those coverages-- Actually, HMO coverage does allow for more.

MS. JACOBUS: You can do a swap, a two for one swap if you do outpatient.

MS. FIORENTINO: You can flex, right, and you can trade.

We were glad to get coverage in those top couple of plans, but there is no question that there is no coverage whatever in the bottom plan, and the coverage is very poor in the middle plan. Some of the gatekeeping, even to the very, you know, sort of rich plans, is so prohibitive that it interferes with people who are in a teachable moment getting into care, because they have to get preapproval by sometimes three different levels of place: their primary care doc, their managed care company, their insurance company. There are a lot of hoops you have to go through.

So we definitely need to make things easier for pregnant and addicted women where the risk is so great. Really, pregnancy and addiction are diagnostic. You almost don't need to do a diagnostic, because if you continue to use when it is harmful to you and your baby, that is definitional for addiction. Nonaddicted people stop using when they are told it is medically necessary for them to stop using. So those women need treatment.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you.

MS. FRANCIS: I just want to pick up on one of the things. Nan and I have crossed paths several times on this issue -- one was on the Governor's Task Force on Child Abuse and Neglect -- but I think we jointly headed off New Jersey going down a more prosecutorial road.

Also, right now there is a Committee on Women and Addictions working out of the Governor's Council on Alcoholism and Drug Abuse. In all these cases, when we look at these things, we see some of the models you cited where New Jersey really is in the forefront. Yet, I also know from being a little bit up close in working on some of these things and chairing that Committee on Women and Addictions, that we still-- I mean, the number of locations that assure treatment for the indigent pregnant and addicted women, I know, has gone down from 10 to 9. We seem to be, at best, holding our own and giving resources to these clearly provably effective modes of treatment, intervention, and so on.

I just wonder what comments you might have relative to the level of-- Again, everyone is looking for more resources. It seems like we have some of the real answers, but we have not been able to expand them, let alone replicate them.

MS. FIORENTINO: Yes. That is a really great question, too, because, of course, the Federal government has been requiring that a percentage of their money go for services for pregnant women and their children. There is some advantage to those kinds of set-asides, because you spend no less than that. The disadvantage is, you also spend no more. And here you are. You are one-third of the patient population and you're all jumping for joy for getting an earmarked mandatory 10 percent of the money. I mean, there is something wrong with that.

I think there is a disadvantage to the earmarking, and yet, when you have nothing else, it is kind of like establishing a new office, like an Office on Women's Health. The advantage is you get attention to an underserved area. You have women's health needs that are not being met any other way, and you get the advocacy. You attract some new money. The disadvantage is you let everybody else off the hook now, and they don't have to all be doing their fair share. It is sort of the same thing with the money. You really want to-- If you have to do the earmark, you have to do the earmark, so you have at least no less than that. But you really need a more aggressive--

I think the policy thing of having mandatory testing part of a confidential medical record and access to treatment, for both the private-paying and government-paying people, makes it a level playing field and makes it a medical protocol -- the best practice standard for all medical care -- rather than a little separate categorical extra thing.

It's a tough question, though. It's a good question.

MS. FRANCIS: Thank you.

SENATOR LIPMAN: Jeanne, did you want to--

MS. FOX: I just want to make a comment. I work at DEPE, and everybody is smoking outside the building now.

MS. FIORENTINO: Yea.

MS. FOX: What is interesting is that there is a very pleasant woman -- and this happens every once in awhile -- who is outside smoking with people. Being the Commissioner, I don't want to go up and say anything to her, but--

MS. FIORENTINO: Oh, it would be powerful if you did, if you--

MS. FOX: Yes, but it would also probably get me in trouble.

Does Health have pamphlets and stuff that they give to other State departments so that, you know, they have them available so other people can--

MS. FIORENTINO: Yes. We have a lot of material on smoking cessation. We do a lot of training on smoking cessation. We have a large Federal grant called "Assist," to promote smoking cessation activities.

MS. FOX: Also with the addiction courses?

MS. FIORENTINO: The State also has courses to help people to stop smoking.

MS. FOX: I know that when I stopped the smoking at the building, we had people come in and do that for us.

MS. FIORENTINO: But it should be ongoing. I mean, this addiction is so deadly and so pervasive that you could have, during the lunch hour at every State department, you know, an addiction support group -- Nicotine Anonymous -- or an education and prevention presentation. I think that is what we really need.

I have a friend who works in addiction who is having a breast cancer test. She can't stop smoking, and her doctor told her, "You must stop before this breast cancer test." She cannot stop. She said, "Why doesn't the Health Department have a lunch hour support group for me?" We don't. You know, we are not doing enough to promote helping people. We have good data that people who smoke -- most of them do want to stop. So we need a lot more supports in the environment to help them to stop. That is why there is so little resistance to smoke-free areas, because even the smokers are glad to be told they are not allowed to smoke there.

MS. FOX: You know, we had hearings. Before I did it, we had hearings and things. While some people yelled, most people were pretty grateful for it.

MS. FIORENTINO: Also, it takes time to stop. It takes an average of 2.8 quits before you get the quit that takes. That works for smoking; it works for alcohol; it works for drugs. So that is the data, but only 30 percent get it the first time through. What that really means is that you need three relapses. It is an average of about three relapses before it works. But it does work; treatment does work.

SENATOR LIPMAN: Thank you very much.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Dr. Regina Kenen.

REGINA KENEN, Ph.D., M.P.H.: I was just trying to get a speaker for my classes, since I am here.

I am Professor Regina Kenen of Trenton State College. Thank you very much for inviting me here today. I have given you all the testimony, plus some additional material that I gathered, which I thought would be of interest. The only one part of my background that is not on the blurb today that I thought would be of interest to you, is that I am also the liaison between the Council for Responsible Genetics and the National Women's Health Network. I think genetics, which I am going to talk about just very briefly today, is going to be an issue in the future that you are going to have to address. I can provide you with material in this area further, if you need it.

In my testimony today, I want to focus on three related points concerning reproductive hazards in the workplace. In addition, I want to briefly address the issue of women and genetic testing, which needs to be thought about and discussed now. Future legislators will need to address this issue. I am attaching supplementary material to my testimony.

The three points concerning reproductive hazards in the workplace are:

1) Reproductive hazards in the workplace should not be considered in isolation from other workplace hazards, as

substances and agents suspected of causing reproductive damage are thought to cause other kinds of harm as well. So it really should not be just a reproductive health issue.

2) Reproductive hazards in the workplace are not just a woman's problem. Men are vulnerable, too. This is something that people tend to forget and comparatively little research goes on. But the woman is usually blamed for anything that has to do with reproduction.

3) We do not know whether or how companies are complying with the Supreme Court ruling in the Johnson Controls fetal protection policy case, determining that it violated the Federal Civil Rights Act of 1964 prohibiting sex discrimination in employment.

Those are the three points.

I want to mention the genetic testing point. I will go into a little more detail on each of the three points, and then the genetic testing point.

When widespread genetic testing becomes prevalent, women's rights need to be protected. In the United States today, when reproduction is involved, women tend to be targeted for responsibility, blame, and even curtailment of rights. There is no evidence to indicate that this attitude is changing, particularly with respect to poor, minority women. One of the things was said before by the previous speaker. She did not mention it, but in that North Carolina case, all the women were poor, minority blacks.

Point 1, that they should not be isolated reproductive hazards -- and I want to particularly make the link with cancer, since everybody is so worried about cancer.

On the basis of current understanding of human reproduction, birth defects are thought to occur in three ways: by gene mutation, by chromosomal mutation, or by acting as a teratogen, which is interfering with normal embryonic or fetal development. Therefore, if an agent is known as a mutagen, one that changes genetic material, or a carcinogen, an agent that causes cancer, it also may be a reproductive hazard. So if you get rid of some of these substances, you really give an knockout blow to a lot of different potential diseases.

Most carcinogens are mutagens, and some mutagens are also carcinogens. Because of this overlap, some scientists feel that until improved techniques are developed for detecting mutations directly, one way to eliminate them is by having a strong policy protecting individuals against carcinogens. So if you protect against cancer-causing agents, you may very well be protecting against reproductive hazards as well.

Cancer experts estimate that 80 percent to 90 percent of all human cancers might be linked to exposure to food additives, drugs, radiation, industrial chemicals, and smoking. Many food additives that can cause cancer have been taken off the market, and cigarettes have health warnings printed on the packages, but a large percentage of industrial chemicals has never been tested to determine if they are cancer causing. Others, like formaldehyde, which have caused cancer in laboratory animals and have been widely linked to illnesses in humans, are still being used widely. Cancer is also known to interfere with conception itself when it affects male and female reproductive organs.

We generally think that industrial chemicals are safe if they are out there, but most of the chemicals were out there before we put in the rules and regulations determining whether they were safe. So it is only those that are new, that came in since the laws were passed, that are being tested. Meanwhile, there are thousands out there that have never really been tested.

The second reproductive hazard is in terms of men's vulnerability. While the female has a finite amount of potential eggs, they are better protected than the sperm from toxic harm, as the eggs are embedded within the ovaries. So if a woman gets toxic harm and it is really severe, her eggs are hit, you know, with the one dose overall. She can't replace them. But if there is chronic, continuing low-grade toxics in the workplace, it may be the sperm that is affected, because they continue to regenerate and they take 70 days to 80 days to mature. Then a new batch starts. As a new batch starts, it can also be hit in the workplace. This process takes place near the surface of the body. So developing sperm are more exposed to toxic injury than the unreleased eggs.

It is interesting that the man leaves just when I am discussing the male parts, but-- (laughter)

Some scientists think that toxic substances absorbed by an exposed male may contaminate the seminal fluid and cross the placental barrier through intercourse. They then can be absorbed by the fertilized egg, causing miscarriages or birth defects. A few studies and case reports suggest that this may, indeed, happen. The association between reproductive harm and male toxic exposure also shows up in animal studies. These studies have identified more than 100 chemicals that produce spontaneous abortion or birth defects in offspring of exposed males.

In addition, the list of agents suspected of causing reproductive damage to human males through human male exposure keeps getting longer. Ionizing radiation, carbon disulfide, lead, estrogen, DBCB, vinyl chloride, anesthetic gases, ethylene dibromide, electromagnetic rays, and extreme heat are some of the villains requiring further investigation.

My last point is, we do not know what the companies are doing since the Johnson Controls case, and it is very hard to find out.

There are three logical possibilities:

1) Companies are not changing workplace conditions, leaving both women and men to be harmed.

2) They are allowing both women and men trying to conceive a child to be removed from the potentially hazardous condition and giving them another job. This has to be done before you conceive, because it is in the early stages that most of the harm is done, very often before you know you are pregnant. In men, it is before their sperm is affected.

Now, if they are removed, it can be: At the same pay, maintaining job security and seniority, or at lower wages, with no job security. It is more often the second one.

3) And this is the ideal, of course, cleaning up the workplace for everyone. But cleaning up the workplace for everyone is not likely.

New Jersey should require companies to report on their policies for workplaces that have the potential for causing reproductive harm. The State should review these policies, decide what safeguards are needed, and then legislate standards. Without such safeguards, a newspaper headline immediately after the Supreme Court decision, "Women Win the Right to be Harmed," will be all too true.

The last point I want to make is the one to do with genetic testing, which I think is going to be a big one for all legislative bodies in the State and in the Federal government in the future.

Biomedical technology offers a wealth of new diagnostic information, while raising complex social and ethical questions. With respect to genetic testing, a great deal of thought needs to go into social and ethical implications in order to arrive at a social consensus which is necessary before legislation is drafted. Sometimes this takes several years of back and forth between historians, lawyers, legislatures, and women, with all different kinds of religious attitudes and things.

The Human Genome Project, which is the one that is mapping all the genes and all the chromosomes, will increase the scope and magnitude of existing screening procedures, such as: newborn testing; newborn genetic screening testing; heterozygote carrier screening, which is to see if you are a carrier of a genetic defect; prenatal diagnosis; presymptomatic genetic disease screening, which is something like Huntington's disease, which starts in later life; and the new category, which is susceptibility genetic screening, which means, are you susceptible for Alzheimer's disease in the future, are you susceptible for cancer, all different kinds of things.

That is the one, probably, that is the most problematic, because susceptibility genetic screening just gives you a probability. There is no definite positive that you are going to get it. But the protection and privacy of this privileged information will be a nightmare, as well as the prevention of stigmatization and discrimination based on genetic makeup when qualifying for jobs, admissions to schools, and for medical and life insurance.

Scientists vary, but each one of us carries anywhere between four and eight -- is the usual guess -- of what they call "harmful, recessive genetic genes." It is just a matter of-- I think it is bad luck more than good luck if you are identified early, because if you are identified early then you can be stigmatized early before anybody knows anything about you. Once medical records have this on them, they seem to find their way into the insurance companies, into the workplace, into various things. Even though sometimes it is supposedly voluntary-- I mean, if you need the job and they say, "You voluntarily can submit this stuff," and you say, "No," the likelihood is that you are not going to get the job.

The Human Genome Project affects both men and women, but women are more likely to be discriminated against in two areas: reproduction and caretaking. That is the other onus on women. When reproduction is involved, women tend to be targeted for responsibility, blame, and even curtailment of rights, as can be seen in attempts at four cesarean sections; and arrests for drug use, which the previous speaker said, even when there are no available treatment programs for pregnant drug users available. There is no reason to believe the scenario will be any different regarding genetic testing.

In addition, women are more likely to be tested than men, because they go for prenatal care when pregnant; women can be carriers of X-linked genetic conditions; and women are more likely to be stigmatized when there is a genetic disease in the family. They are also more likely to bear the burden of being the caretakers of family members with genetic conditions.

That's it. Thank you very much.

Do you have any questions?

SENATOR LIPMAN: Thank you.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Questions, Bobbie?

MS. FRANCIS: Unfortunately, I always have questions.

One other thing I have been involved with, with the Johnson Controls decision, with Professor Nadine Taub at Rutgers--

DR. KENEN: Yes, I was involved with her, too.

MS. FRANCIS: Great, I was just going to ask and make sure that she got this, if you had not shared it with her. We had one or two meetings intragovernmentally to try to get a handle on who, where, might start ascertaining what companies are doing in terms of--

DR. KENEN: I did, I tried to call. I got no answer. I got the answer, "Yes, we would be delighted to give you this information when it becomes available. We are still working on it. We can get it to you as soon as I can get a release." I never got any of it.

MS. FRANCIS: Do you have, you know, a 25-word or less idea of how State government might best implement getting that information together and getting it out?

DR. KENEN: Do you have any power to command? (laughter)

MS. FRANCIS: Everybody is looking somewhere else.

DR. KENEN: Somewhere else, right. Well, Senator--

MS. FRANCIS: I think the Legislature is certainly--

DR. KENEN: I think the Legislature has to pass a bill saying that there has to be, you know, mandatory reporting of what is going on. I think that without mandatory reporting, you are not going to be able to get it.

MS. FRANCIS: Because there are hundreds and hundreds of--

MS. FOX: Or the Legislature could work with the Business and Industry Association, the Chamber of Commerce--

DR. KENEN: Right, they could. They could request it.

MS. FOX: --to basically say, "We are either going to do it voluntarily, or we can legislate it."

DR. KENEN: Right.

SENATOR LIPMAN: Yes.

MS. FRANCIS: Well, that's it. I guess I looked in that direction first thinking, you know, environmental protection, toxics, etc. To what degree are there already regulations in place that if the information were just gathered in the correct way, we could piece together some of this?

DR. KENEN: It is not just the information that is pieced. It is the fact, you know, what are they doing with this category of people? They could have all sorts of things in place, but this little piece of information you don't--

MS. FOX: It is not so much with the candidates. It is, what is their policy?

MS. FRANCIS: That's true. The response in terms of the employment, decisions made.

MS. FOX: It's not really regulatory, you know.

DR. KENEN: It sort of slides right in -- or it can slide into a crack. One of the companies -- and I do not know if this is typical -- seems to be working on my second point of removing them from the workplace; of doing free prepregnancy counseling. That is okay if you have alternatives for these people to do. It does not help people who become pregnant, you know, when they do not know about it; and it does not help the other people -- which is the point I was trying to make-- Usually, if there is a reproductive hazard, there are other hazards as well. So you are really not cleaning up the workplace. Or for the potential parents, you know, that may be 10 years, 5 years down the line wanting.

MS. FRANCIS: One last question I need to ask is: I was really disappointed to see the Bioethics Commission lose support and go out of business. Would a commission like the Bioethics Commission help to address your concern about the genetic issue?

DR. KENEN: I don't really think so. I mean, the topic has been discussed and there are plenty-- I could get you loads and loads of information. I think the consensus has to be made in the State, you know, make it available -- the material that has already gone onto the Legislature, or a legislative committee, to discuss it and to make the legislators aware of this kind of thing.

I think commissions become too, you know, sort of isolated. I mean, you appoint a commission, and then you do your job, because you have appointed a commission. Then the link between commission reports and actually getting it into legislation, I think, is where the weak link is.

I personally would like to see a legislative committee address these kinds of issues, because when they come up and you want to act on them, you do not want to act on them just, you know, sort of at a gut reaction. You really have to think about them in great detail.

MS. JACOBUS: Would you be leaning toward advocating legislation which would not permit hiring companies to ask potential employees for this information?

DR. KENEN: Definitely.

MS. JACOBUS: Would you also be advocating that insurance companies-- How could you prevent insurance companies from getting this information?

DR. KENEN: Well, what people basically feel is that you need the national health plan. If you get a national health plan in the country where there is universal coverage, that will solve this problem. So if a universal health care program comes through, that's fine -- which I hope, and I think it will eventually. If not, if New Jersey puts in -- and I know they are working at it, reworking the health care in New Jersey-- But if New Jersey does that in their Legislature, they cannot be discriminated against for that.

MS. FOX: That is the insurance problem.

DR. KENEN: That would be the insurance problem.

MS. FOX: You would still have the big problem about whether they are going to clean up or are they going to discriminate.

DR. KENEN: That's another-- I mean, there are a lot of problems here. There is not just one problem. It has a lot of ramifications.

MS. JACOBUS: Thank you.

SENATOR LIPMAN: Thank you very much.

DR. KENEN: Well, thank you. It was a pleasure.

SENATOR LIPMAN: I think we will have to break for lunch now.

(RECESS)

AFTER RECESS:

MS. FRANCIS: We are now going to convene the second portion of the February 1 public hearing on health issues for women being held by the Commission on Sex Discrimination in the

Statutes. My name is Roberta Francis, and I am the Director of the State Division on Women.

Our first testifier this afternoon will be Sharon Copeland, Executive Director, New Jersey Chapter-National Committee for Prevention of Child Abuse.

SHARON J. B. COPELAND, M.S.W., A.C.S.W.: Thank you for the opportunity to speak to health issues for women in New Jersey and their interrelatedness to the mission of my agency, which is the prevention of child abuse and neglect. I am also here on behalf of the Healthy Families New Jersey Consortium, which I will tell you about in a moment.

Currently, I sit on the Violence Subcommittee of the Medical Society of New Jersey, along with your representative, Melanie Griffin. This committee is working to educate the public and professionals about violence and its prevention, and to lend support to effective violence prevention efforts. We are most familiar with family violence, which is often a cycle of violence from cradle to grave, passed from one generation to another.

The child witness or victim grows to know violence as a way of communicating and controlling, is at risk of becoming an abuser, and, in old age, once again may become a victim of abuse within the home.

My agency, the New Jersey Chapter-National Committee for Prevention of Child Abuse focuses on the family and develops and promotes programs that build and support healthy families. In our programs that work with teenage parents, we have learned firsthand that sexually abused young women are at great risk of early pregnancies. Whereas, teenage parenting in itself does not need to be regarded as a dysfunction, the immaturity and lack of economic self-sufficiency, more often than not, create burdens that are difficult, if not impossible to overcome.

These teen parents are usually not emancipated, and may encounter difficulties accessing health care and social services that are more readily available to adult parents. Yet, I do not want to focus my comments today on teen parents or violence per se. Rather, I want to bring your attention to a model program, Healthy Families New Jersey, that is worthy of your consideration because of its effectiveness in three ways: in the increasing use of preventive health care; in preventing child abuse and neglect; and in linking family members with needed prevention and early intervention services.

The Healthy Families New Jersey initiative is being promoted by a Consortium of nearly 50 persons representing public and private sectors throughout the State. It is a program that may be able to play a major role in assisting new mothers and their infants who are now being discharged from hospitals within 24 hours of delivery.

For the past two years, the Healthy Families Consortium has been gathering information about intensive in-home visitation based on a model begun in Hawaii by the Hawaii Family Stress Center. Intensive, long-term in-home visitation to new at-risk parents immediately following the birth of the baby has had the following successes:

* 99 percent effective in reducing child abuse and neglect;

* 98 percent effective in obtaining immunizations;

* 95 percent effective in early identification of developmental delays.

The demonstration project began in 1985. In 1988, the Hawaii Department of Health developed the project into a statewide initiative. Their current Maternal/Child Health Director, Loretta Fuddy, recently stated: "While the principal purpose is the prevention of child abuse and neglect, the program provides an infrastructure to identify family and community needs, empowers families to access health and human services, and improves family functioning and health status.

Healthy Families New Jersey can serve as a mechanism for reaching families with multiple needs: new mothers who need help following an early discharge from the hospital after childbirth; children in need of lead poisoning screening; and improving access to health care for minority populations. Developmental delays can be picked up early, and the children enrolled in appropriate programs. Healthy Families links each family to a medical home. A medical home reduces overuse of the emergency facilities and increases the use of preventive health care, including prenatal care for repeat pregnancies.

In-home visitors also help family members access community resources and social services, such as domestic violence counseling and shelter.

The Healthy Families New Jersey Consortium has been providing information about this program to the seven regional maternal/child health consortia. Intensive in-home visitation has a place in the State's continuum of the health care plan that will be developed by the regional consortia. These consortia also have responsibility for tracking children and assessing the availability of health services in their region. Healthy Families utilizes universal screening prenatally or at the time of each birth, and it can provide real data about health services and their accessibility.

Further, as we work to define how pediatric home health care should be provided, these well-trained professional -- paraprofessional in-home visitors can be partners with health professionals using our limited resources as wisely as possible.

Dr. Terri Gallmeier, a psychologist from Colorado, noted that the public health sector demonstrates that any problem that has reached epidemic proportions will never be brought under control by treating affected individuals. You must go to the source of the epidemic and stop it. Where would we be today in trying to improve health care and control health care costs if we chose only to treat the patients who contracted polio and a host of other diseases, instead of creating vaccines, using sanitary practices, or cleaning up our water supply?

Child abuse and neglect in New Jersey and throughout the United States are of epidemic proportions. For the past six years, each year there have been over 50,000 reports of alleged child abuse and neglect in New Jersey. Nearly 20,000 of these reports are substantiated annually, yet only 4 percent of child protection service dollars is now spent on prevention.

The Healthy Families New Jersey initiative will put our resources into prevention, instead of trying to treat the symptoms.

On behalf of the Healthy Families New Jersey Consortium, I am advocating for establishing intensive in-home visitation programs. We hope that as you deliberate on how to improve health care for women, you will give serious consideration to supporting the Healthy Families New Jersey initiative as a means toward accomplishing your goals.

Thank you.

MS. JACOBUS: Thank you. Do you have any questions?

MS. FRANCIS: I always have questions. I will let you go first.

MS. JACOBUS: Sharon, do you have any rough idea of what percentage of the eligible population -- the eligible target population -- is being dealt with now through the Healthy Families New Jersey program?

MS. COPELAND: Well, right now we don't have a Healthy Families New Jersey program. We are advocating that these programs be established. We have some in-home visitation in New Jersey, but it varies greatly. None of it is as intense as the Hawaii model. In other words, we have some home health aide visitors. We have some programs that provide prenatal visitation, but then stop, like, within six months of the birth of the baby.

The model we are looking at actually provides weekly in-home visits for up to five years. Now, rarely does a family have that intensive, long-term service. They, in fact, would probably have intensive in-home visitation, and when the family stabilized, it would decrease and would maybe even be reduced to telephone contact, if the family had a telephone.

But then, because they want to keep in touch with these families for from three to five years until that child is enrolled in a Head Start nursery school school program, they continue to watch and work with that family as the family goes through transitions. You know, an infant, in terms of child development, is very different than your toddler going through the "terrible twos." Or what if the mom becomes pregnant again, or what if she goes back to work and then losses her job? There are lots of different stressers in the family that can contribute to a family losing its effectiveness in providing nurturing and care for the children.

So this program not only focuses on the child, but really focuses on the family in terms of how it can keep track of all the family members, to help the mom, the dad, siblings, if they are present, receive the kinds of services they might need.

MS. JACOBUS: Do you have estimates on, if you targeted specific populations, how many families you are talking about?

MS. COPELAND: In New Jersey? Yes. There are about 120,000 births in New Jersey annually. Now, based on the Hawaii model, they estimate that about 20 percent of the families they work with are at risk of being abusive, and then in need of a service like this.

They have developed a family stress checklist, which actually Dr. Henry Kemp originally devised. He is the one who came up with the term "battered child syndrome" over 20 years ago. He has since passed away.

But anyway, this program uses a couple of screening measures that in Hawaii they have found extremely effective in identifying what they consider to be the at-risk families -- by using these screening measures. Now, if we in New Jersey here replicated the program, we suspect that probably around 20 percent to 25 percent of all those screened would be at risk. So we're talking then, what--

MS. JACOBUS: Thirty thousand.

MS. COPELAND: --about 30,000 families a year.

MS. GRIFFIN: Do you sense that this would be a program in DYFS, or a program that would be a nonprofit service network supported by State funds?

MS. COPELAND: How are we looking at it right now?

MS. GRIFFIN: Our ultimate goal is to write legislation that will effectuate the recommendations of the Commission.

MS. COPELAND: Great.

MS. GRIFFIN: So give us an idea of an ideal setting.

MS. COPELAND: Well, here in New Jersey -- what you would see even by looking at the list of who serves on the consortium -- we have had a number of persons from the Department of Health, as well as DYFS representatives involved in the consortium. In Hawaii, it was the Department of Health that decided to take this on as an initiative because, you know, they were especially focusing on the prenatal or at-birth time of contacting the family and making it very universally acceptable. It is a voluntary program, even though they do the screening. So it has been very successful to offer it through the general health care model.

Here in New Jersey, we have been looking at a combined effort between the Department of Human Services, probably within DYFS, and the Department of Health. We have also been looking at what kind of third-party reimbursement might be available for this kind of a service.

We know that in one state they have been successful at getting Medicaid to pick up part of the initial costs after the birth. Frankly, I am just in the initial stages of a discussion with PruCare, because they are very interested in increasing their prevention programs for their managed care patients. So we are initiating discussions about where in-home visitation fits in this model. Because of the early discharge issue now, where a number of moms and their babies are being discharged within 24 hours-- Actually, I was at a hearing the other day where they were talking about going to the hospital for your birth may become a thing of the past. You know, if you just think a little more futuristically-- Moms used to have their babies at home, and we may be going more and more in that direction.

Then, in home visitation-- I mean, because you and I do not have extended families and all the natural support systems around that maybe they did 50 or 100 years ago, what kinds of community-based services could be there that would really help, not only the post-birth process, but that could cover a number of areas? I guess that is why we are so excited about this model. It was initially set up to deal with child abuse and neglect. When they looked at it, they said, "Gee, we are getting all sorts of health care kinds of positive results in terms of the immunizations."

So here in New Jersey, in particular, we are looking at, well, lead poisoning screening. We are having a terrible time identifying those families and getting to the families that need to have this screening done. I would bet that a large number of the at-risk families that would be served in this program would be the very families we want to do some lead poison screening on, also.

So it turns out that it could be a mechanism for dealing with just a lot of early identification, early intervention in both the social services and the health care areas.

MS. FRANCIS: What is the training of the people who go to the homes?

MS. COPELAND: Again, the model we are looking at, which has been in place now for almost 10 years-- They use paraprofessionals. They have three weeks of training before they begin. They are very particular about limiting the number of families per worker. The first year that you are an in-home visitor, you don't get to have more than 15 families on your caseload. Now, compare that to some of our DYFS workers where we have, like, 90 families sometimes. You can see that the emphasis is on providing, you know, a real base of care, of really getting to know that family, of developing a trusting, supportive relationship. This is not a therapist. This is not a nurse. This is someone who is going into the home, working with the family where the family is, in terms of looking at the family's strengths and trying to build on them, and then accessing other services in the community as they are needed.

MS. JACOBUS: That would be three visits per day.

MS. COPELAND: Probably. What they find after the first year, because some of the cases no longer need such intensive visitation, is that they do add on families. But I think after three years, they do not recommend more than 25 families. I don't think the caseload ever gets larger than about 25 families per full-time, in-home visitor.

MS. JACOBUS: Sort of halfway between that intensive family preservation-type program, where you have 24-hour availability for a number of weeks. This is less, but for longer.

MS. COPELAND: Less for longer, and it is much more prevention oriented. Family preservation, you know, is definitely a valuable service. But unfortunately, we access it at a point when the kids are already, you know, at risk of being removed from the home. Research shows us-- I mean, we have documented now that if we intervene with families before we see abusive patterns, we are far more successful. I mean, I am not talking about general populations. I am talking about control groups. We are far more successful at teaching the parents different ways to interact and understand their children, and successful at preventing child abuse and neglect, than if we wait until after they have trouble. If they are not in touch with DYFS, they are in touch with the court system or some other social body.

So that is why we are really trying to push. I guess sometimes when I think about it-- I have been in social services for a long time. We have been working so hard to try to fix things that I am feeling a bit frustrated and overwhelmed, because we never have enough resourses. So moving into this prevention arena--

Just to get back to how many families, right now we are spending $95 million a year just to investigate and adjudicate -- not treat, just to investigate and adjudicate these child abuse cases -- alleged cases. If we were to serve 15 percent of all families who are at risk, it would be $75 million. It is $20 million less that what we are just spending on adjudicating cases.

So it is a big amount of money, but I feel like it is all relative. You know, where do you want to end up really putting your dollars and your investment?

MS. JACOBUS: Good. Thank you.

MS. COPELAND: You're welcome.

MS. GRIFFIN: May I just ask something? Obviously, while the prevention system gets set up, we still have to do intervention. One of our witnesses this morning suggested that it was a mistake to remove a child from a home where there is only one abusive parent. We have been considering -- this Commission has been considering -- for some time drafting a law that would remove the abusive parent from the home, instead of the child.

Can you just give us your very professional thoughts on that?

MS. COPELAND: Okay. I feel like I always have to slip out of my hat of prevention and go back to some of the years I spent working with dysfunctional families.

I don't think New Jersey has nearly resolved its issues about permanency planning and, you know, what is in the best interest of the child. We are moving away from what used to be extended years of a child being in a foster care situation, but I don't-- It was possible for a child literally to be in foster care for five, eight, ten years. So we are trying to move away from that, but we still, in my opinion, have not resolved our issues about when do we say enough is enough and find a child one, or preferably two adults who are really caring, and there, and available for that child, because that seems to be the critical factor, whether it is foster care, an adoptive parent, or whatever, but that real connection with the child where they are watching out for the child and the child learns that there is that love, and that trust, and that secure relationship.

So I guess professionally I would say I don't think it is that black and white. What often happens is, it is the relationship between the mom and the dad, and unless that relationship is addressed, removing the abusive parent out of the home may not prove to be the best thing for the child. So just off the top of my head, I would say, yes, let's stop removing the child and start removing the abuser. If nothing else, it may force them into treatment to begin to change the dynamics in the family, so that you do not have one parent allowing the abuse and the other parent being the abuser, with the child as the victim. But it is not always that nice. It does not always work out that well. So I think, again, you are back to really looking at family issues, and who wants to be truly there for the child and is willing to put the child ahead of the relationship, sometimes.

MS. FRANCIS: Questions? (no response)

Thank you very much.

MS. COPELAND: Thank you.

MS. FRANCIS: We have a note that both of the next two speakers -- is that right, Sharon? -- Roberta Knowlton and Amy Robles-- They both canceled?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Didn't Roberta get in touch with you?

MS. FRANCIS: No. You had written her name there, too.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Oh, no. Amy was going to call Roberta.

MS. FRANCIS: Okay. Roberta is scheduled next, but is not here. That means that the next witness--

We will take a small break.

(RECESS)

AFTER RECESS:

MS. FRANCIS: The next person we will hear from will be Roberta Knowlton, who is with the New Jersey Department of Human Services. Roberta will talk about school-based health care education.

ROBERTA KNOWLTON, M.S.W.: After five years of development, the School Based Youth Services Program is now in a position to begin to make some statements about what we learned with young people out in the field, if you will.

Between 18,000 and 20,000 young people come to our various School Based Programs every year. There are 30 programs. They are in high schools, for the most part, although we now work in elementary and middle schools to some degree.

All of our programs provide health services in some way. All of them also provide mental health and family counseling, substance abuse services, job and employment training services, and--

MS. FRANCIS: Recreation.

MS. KNOWLTON: In a recreational setting. That is correct. The recreational setting is particularly important because it allows young people to come, check the place out, find out what the counselors are like, and to not be stigmatized. Nobody knows when you are going over to School Based whether you are going over to talk about the rape last week or to play Ping-Pong. Consequently, we get young people, for example, who--

Just for a very quick anecdote, there was the young person who came over and said to the recreation counselor, "You have counselors here, right?" He said, "Yes. Do you want to talk to one?" "Yes." So she stuck her head into the social worker's office and said, "There is a young woman here, she comes a lot. Would you like to talk to her? She probably won't be long."

The young woman went in and said to the counselor, "I have an obligation to terminate my stepfather." At that moment, you need a very good social worker, and you need someone who knows that schizophrenia is likely to appear in adolescent years; that substance abuse can, in fact, cause something like this; that sexual abuse at home can be causing this; that domestic violence at home can be causing this; that any number of different things can be symptomitized; and that various kinds of referrals or various kinds of help can be called for in this case. As a matter of fact, the stepfather is still alive. The young woman was seen very frequently by the counselor at the School Based Program, and it was worked out in a varying setting of family counseling, and so on. I don't know-- Because we work confidentially, I do not know the details. But it shows the fact that any number of health services could have been called upon in just that one very simple-seeming incident.

Likewise, a young woman who came said to one of the counselors, "That kid over there is going to run away from home." The counselor went over and said, "That kid over there says you are going to run away from home." "Well, so would you if your sister's boyfriend raped you last week." "Oh, so you are going to run away from home." Well, the mother came in. We found out that they were from another country. We found out that the mother had married the stepfather, but wasn't comfortable with him and had gone to stay with friends, but the girl was to stay at the stepfather's house.

We found out that in the end we ultimately needed the services of the legal authorities; we needed the services of health authorities; and we needed the services of the INS. We did, in fact, get a contract with the stepfather. They did, in fact, go home. The sexual harassing that he had been part of and hadn't realized, because he thought he was just being complimentary, was stopped. The young woman graduated from high school and we helped to find her a little scholarship to a nursing school in the South.

She called back collect three times every so often, and we discouraged it. The nursing school went bankrupt. We got her to another nursing school from New Jersey by telephone. This year she is at Howard University. What a different story if that young woman had run away, gotten involved with drugs, pregnant, etc., and so forth.

So we know that being available and accessible in a nonstigmatized way makes an enormous difference. We often, of course-- The health needs of young people are clearly related to behaviors. That makes them very difficult. It also makes the adolescent population the least served population we have, I would say. They are no longer appropriate for pediatricians. They are certainly not ready to sort out which kind of a specialist they need. They will not find their way to the psychological help they are likely to need, or to a gynecologist, as a general rule.

They do, however, need a lot of counseling that they can accept. Probably the best example we have of having come across, really, a way of working with young people is the coordinated work in the Pinelands Regional High School School Based Program, where we have seen the adolescent pregnancy rate go from about 20 per year, with its proportion of low-birth-weight babies, to 13 per year, with all babies full birth weight and all the mothers staying in school, to one or two per year. It has stayed that way for three years running, so we know we have something going.

I said to our Director, "How come we're getting all the credit for this as School Based?" because I did not see how we could really be responsible for such an unusual statistical change. She said, "We got in tight with the Family Life Education people and the comprehensive health educators.

Now, we have a person -- her name is Terry -- she works part-time at the local Family Planning office and part-time for the School Based Program. She would go to the classes once or twice a year, because Family Life Education is there for everybody. All students began to hear about Terry, and the teachers began to say, "Always remember, folks, if you have something personal someday, or your friends do, Terry is over there at School Based. It is confidential, and you don't need to have a crisis. You can go there when you are confused.

"The thing we adults never have time for is when a kid is confused. We will talk to them if they tell us they think they are pregnant, but we won't talk to them if they tell us they don't know what to do about their boyfriend or their girlfriend. But Terry has time to talk to you about your boyfriend or your girlfriend."

Not only that, but it turns out that Terry works on Tuesday nights at the Family Planning Clinic, so if a young person needs a STD exam, a pelvic exam, birth control, or some such thing as that, we make sure she gets there, if we have to transport her. We get them there on Tuesday nights when Terry is there. So now the young person doesn't have to go through her story again, and take a chance on somebody who is not appropriate helping her out. If at that point some kind of actual clinical help is needed that is beyond the Family Planning Clinic, we can then make sure that they get to the local hospital, even though it is 20 miles away, because that is also within our aegis.

We have a 24-hour hot line, and we are there for the sexually abused child; we are there for any kind of crisis if a family has details, questions, what have you.

So that is one kind of health need that we think requires as sophisticated an approach as we have, and yet as simple an approach as that really is, if we think about it. It is just adults working together in a way that is not stigmatized for kids.

Now, another interesting kind of health need that we have discovered needs to be met is the asthma situation, the upper respiratory illnesses that are seemingly statistically higher among Latin populations. I just read that somewhere; I am not sure about it. But in any case, we find a great deal of asthma. We are in schools where young people are from lower-income groups, and so on and so forth. We find that we have-- In Long Branch High School, there are 100 young people who are suffering from asthma. We have 40 who are actually getting treatment through our nurse practitioner there and are in support groups as well. All 100 have their medication dispensed sometimes through the nurse practitioner.

Another kind of thing we see is the kind of thing that you just don't know is going to come up. For example, the young person who came in because his father was beating him. His father was beating him because he wasn't on the Dean's List, and his father knew for sure he could be. The young boy was talking about pain. Well, the pain was not just from his father. The pain was in his feet. It turned out that he had the most terrible ingrown toenails that this particular nurse practitioner had ever seen, but the father did not feel he could take this young person to any-- There wasn't anyplace this father would take this kid. We took care of the ingrown toenails and got the kid involved with some social activities and what have you with other young people. His grades went up; he is on the Dean's List; his father isn't beating him anymore. So it goes like that.

Now, the way we do health services varies from one program to the next. The one I have just described to you has a full-time nurse practitioner as a part of the budget. They use part of their budget for that. The program that I described before, the kid who had been raped, and so on and so forth, that program is in Plainfield. The Plainfield Health Center is very close to the Plainfield High School, so we have a very close coordination with them. Rather than using money for practitioners, we use our money elsewhere, but we subcontract with the Plainfield Health Center.

Now, the Plainfield Health Center not only works with our young women on sexual and reproductive questions, and other kinds of things, but comes to the Child Care Center. Plainfield is one of two programs that has an actual Child Care Center on-site for the mothers who are in school, as a part of a much broader adolescent parenting program. The Health Center sends people over to work with the children; to help with the interaction between the mothers and the babies; to actually make sure the babies are okay; and to give them well-baby checkups, and that sort of thing. WIC comes to the school and works with the young mothers as well. We make sure that we have a pregnancy prevention program going along at the same time as we have such a program as that.

One of the most important things I like to talk to people about -- if I get a chance like this -- is, I saw such a program as that go down in New Brunswick years ago. It went down because people said, "All that money for those people is just encouraging them to have more babies." Okay? However, if you can make it clear to people that what you have is a program for all kids, to help them with jobs, to help them with their tutorial problems if they are failing, and help them with their substance abuse problems, their family problems, and so on -- all you are doing is making it possible for these young parents to stay in school and have the same services that other kids are getting, and that these services keep them in school and keep them out of the trap of poverty for generations to come-- We even have a baby who is deaf in the program. We are certainly making a difference in the next generation.

We had some research done. There is some evaluation on that program the Federal government helped to underwrite, because it is expensive to evaluate programs. It shows that 100 percent of the girls who stayed in that program for at least three months have graduated from high school, and have gone on to jobs or college afterward. That is 17 girls all told, in a couple of years. The repeat pregnancy rate is 1 percent, as opposed to the usual 20 percent for that amount of time.

MS. FRANCIS: You have 26 programs, do I recall, or how many?

MS. KNOWLTON: We started with 29. We now say 30, because Teaneck has created one for itself. It isn't quite the same funding mechanisms; they don't have quite as much money from the State, but they do have a program that we consider one of ours now.

MS. FRANCIS: This is a leading question, but--

MS. KNOWLTON: Go ahead.

MS. FRANCIS: --I am trying to point out that you have won a national award for this model.

MS. KNOWLTON: Thank you. Yes, we have. I think the most exciting one was the Innovations Prize, the Ford Foundation underwriting the Harvard School of Government. They came out and chose us out of 2000 possible programs as one of the 10 most important public service programs to replicate in the country.

We were also chosen by the APWA -- the American Public Welfare Association -- to be the program with the best management in a unique program in the country.

MS. FRANCIS: What is the budget?

MS. KNOWLTON: The budget we have now, which includes not only the original 29, but also about 15 elementary and middle schools, is approaching $8 million. We would run a program like this well on $200 per year per child. Out of the thousands we spend per year per child for education, if we could have $200 to bring this kind of program to wrap around the school, we could make a significant difference, I believe.

In the same school that has the pregnancy rate going down so low, the suspensions in that school for that year went from 179 to 88; the dropout rate went from 75 to 25, and 15 of those kids were in GED programs. There is another statistic there, but I forget.

We have recently become involved with the prevention of violence. One of the things that happens is, if you put a creative director under the aegis of a creative lead agency --

oh, yes, we do this by way of community-based organizations, for the most part -- and put them in a situation where they are working with young people and let them go and do whatever they can do, they love it. They work very hard. They work nights, they work weekends, and they do all kinds of things. They also keep track of what is happening with the kids. So when the violent stuff began to rise, our directors began to start to deal with it. We did not have to tell them to.

Two of our directors went out and got trained by way of a grant from Serve America through, you know, the Higher Ed people, from New Brunswick and South Brunswick. They came back and had already in their minds the idea of setting up something like Students Against Violence and the Victimization of Youth. They came back. They trained two people from each of the programs. Those people went back and created a big Saturday conference for at least 10 kids out of 22 programs, so we had 225 kids trained. They all left that conference with ideas about what they would do when they went back. They literally went back and created "savvies" in their schools.

The one in Newark created another conference, and then created a conference for 300 kids, run by kids, designed by kids, with workshops that were created and done by kids.

MS. FRANCIS: This is all prevention of violence?

MS. KNOWLTON: This is all prevention of violence.

In that particular school, they did something else which I think was very smart. They did a survey -- it's getting time, right?

MS. FRANCIS: I was just going to--

MS. KNOWLTON: I am going on and on.

MS. FRANCIS: No, it is very, very interesting, clearly, but I am the rookie Chair here, and I want to make sure I am keeping things on track.

MS. KNOWLTON: I'll just finish this thing about violence, then.

MS. FRANCIS: Yes, if you could do that.

MS. KNOWLTON: Because prevention of violence is prevention of health problems, as we know.

So anyway, they did a survey. They found out that the kids -- that 90 percent of the kids not only said they wanted their school to be violence free, but they would participate in helping to make it so if the School Based Program would tell them how and what to do. There were a lot of things they did, but the net result of this was, even in this year of trouble in Newark, there have been 15 fewer fights from Halloween to Thanksgiving than there were last year, and so on, and so on, and so on and so forth. Okay?

MS. FRANCIS: Excellent.

Are there any other questions?

MS. GRIFFIN: I just have a little question, I hope. I was looking at your Hackensack High School pamphlet, which is wonderful, and I would go. But it says, "Parental consent is required for all drop-in services."

MS. KNOWLTON: Yes.

MS. GRIFFIN: Have you found that -- not that I don't think you should say that if it is -- but have you found that to be a deterrent when you are talking about Family Planning services?

MS. KNOWLTON: Interestingly enough, we have not. Like the Family Life education people, where the mandate says you can write your child out and only 1 percent to 2 percent do, the same thing with us. What we do is, we get permission for kids to be part of the School Based Program at the beginning of the year.

MS. GRIFFIN: That's great.

MS. KNOWLTON: Hundreds of them.

MS. GRIFFIN: So the parents may not know exactly what services the child is asking for.

MS. KNOWLTON: No.

MS. GRIFFIN: So if there is an abused child, they will not withdraw consent necessarily?

MS. KNOWLTON: Exactly. Now, they do have on the consent form the possibility of checking off, "I don't want counseling for my child. I don't want health services for my child." Very few of them do. If we were to think that a child was abused and the parent had that on the consent form, we would do some checking ourselves, and so on and so forth.

MS. JACOBUS: You and the Department of Health are working together on a grant to get some Federal funding to expand your program?

MS. KNOWLTON: Oh, yes. The new thing we are thinking about, trying to get our minds around, because it is big, is that in the Clinton health proposal there is the idea of managed care being delivered through schools for adolescents, and it is connected up to where their families go, by computer at least, through managed care agencies. We are looking at other states that have done this, who are doing this, or who are beginning this. We are beginning to get this together.

We wrote a grant proposal to the Robert Wood Johnson Foundation to see if we could do that, but, in fact, that one did not go through. However, the Federal government picked up exactly, almost, what Robert Wood Johnson had proposed. In March, those rules and regs will come out and we will apply for that.

In Plainfield already, the Plainfield Health Center is trying to set up a mobile unit or a unit right within the school to bring a whole managed care program that would work in connection with School Based, into that school. That has not been accomplished yet, though.

MS. JACOBUS: The Medicaid funding would only apply to Medicaid eligible children.

MS. KNOWLTON: The complication is that if you bill for Medicaid, you must also bill everybody else. The School

Based Program provides everything free. When we have a nurse practitioner as part of our staff, those things I was telling you about did not cost anybody anything. But if the Plainfield Health Center comes in what will happen is, our people will refer to that program, as they always have. They will use their scale -- their sliding fee scale -- and they will figure out what to do about the provider agency or family, and that sort of thing. They will have their own particular parent permission forms as well.

MS. JACOBUS: As a last question: What would you recommend the New Jersey Legislature do to support this clearly successful model?

MS. KNOWLTON: I would say we need all the help we can get to expand this Program beyond 30 schools. We are only statewide in the sense that we have a Program at least in every county, but we are only really in 30 high schools and a few elementary schools. Schools are beating on our doors to get this kind of help. I believe the price is right. There needs to be some way to access those $200 per year per child. I believe the money needs to continue to come through the Department of Human Services, in order that all that huge body of people that cares about children in that area, and all that huge body of people that cares about children in the Department of Education area, have a carrot to work together.

It takes them awhile to learn how to work together for kids, but they can do it, especially around confidentiality, liability, and certification. But it can be done; it has been done. We ought to be able to do it in a structured way that maintains the kind of management we have had, and maintains the kind of energy that this Program has had.

MS. FRANCIS: So you're saying that $200 per student statewide would let you do this in every school?

MS. KNOWLTON: Absolutely.

MS. FRANCIS: Thanks very much.

MS. KNOWLTON: Okay. Thank you.

MS. FRANCIS: The next person on our list is Francine McLean. Is she here? (no response) Mary Todd? (no response) I know there is one person here who is on the list further down. Is there anyone else in the audience who has signed up and is on the list? May I have your name?

LINDA SHUTE: Linda Shute.

MS. FRANCIS: Linda Shute, okay.

May we have Howard Kipen?

HOWARD M. KIPEN, M.D.: Kipen. (corrects pronunciation)

MS. FRANCIS: I'm sorry. I should have just kept going. I would have called you right away. Dr. Kipen is from the Robert Wood Johnson Medical School.

DR. KIPEN: I am here today to speak about a very frustrating situation that arises in my clinical and teaching practice, which is the care of pregnant women who may be exposed to toxic substances in their workplaces, and the options that are available to someone trying to assist them.

My training is: I am a board-certified internist and a board-certified occupational health physician. For the last 10 years, I have been on the faculty of the UMDNJ Robert Wood Johnson Medical School. I am now an Associate Professor there, and I am the Medical Director of the Environmental and Occupational Health Clinical Center, which is housed within the Environmental and Occupational Health Sciences Institute, which is a joint program of the Medical School and Rutgers University, so that everyone has their due.

Back to my days in training as a student of occupational health when I was at Columbia University, I had the privilege of working with Dr. Gene Stelman (phonetic spelling) there and gaining quite a bit of insight into reproductive health in the workplace. In fact, Gene and I wrote a curriculum which I think is still used to train nurses in occupational health reproductive hazards. Since that time, I have come to the clinic and in my clinical practice there, which includes respiratory diseases, blood diseases, and all kinds of occupational things, we are on occasion asked by pregnant women, or by their physicians, or occasionally by their employers, to comment on the advisability of their working, continuing to work, or modifications or things.

Since that time, I have written a couple of review articles on the subject. In fact, two of them are waiting to be published now at various conferences, although I do not actively do research in the field. My research is in other fields.

The predicament we face is that if we make a determination that it is not in the best health interest of an embryo or fetus for a woman to continue working under the conditions that we believe she is working under, then the woman is left with a very difficult choice, because there is no protection for her in terms of being able to maintain income or health benefits or anything else. I am not aware of any remedy I have, as under the compensation system, to take that preventive -- to make that preventive recommendation and have it be viable for many people. It is obviously viable for women of upper socioeconomic status who have a lot of flexibility in their jobs. Maybe they are professors themselves, so they can go and write for a few months and stay out of the lab, or do whatever. But for people who are working in factories and service industries like dry cleaning and things like that, or maybe they are painters, or they may be artists even, there are not a lot of opportunities to deal with that.

The other frustrating thing, and perhaps more difficult to address legislatively, is that most women, the huge majority, do not end up at my door, and yet I know they have these concerns. They are talking to their private physicians, mostly obstetrician/gynecologists, who are not well-schooled in the nuances of toxic issues, and frequently, in my estimation, under- or overreact to a given situation.

Maybe part of the problem is-- You know, there is another issue, which is that it is not really clear when women come to see me and they have health insurance if there is anybody who is willing to pay me to offer my opinion. I don't really treat a pregnancy-related disease. It is preventive services again. There are a few obstetricians who refer to me, but not on a real regular basis. The State used to fund a teratology counselor through our Medical School at Camden, which was particularly interested in workplace-related issues. We even set up a little ongoing clinic for awhile, where she would come to my clinic on a regular basis. She would funnel women in who had these issues, and we would try to handle them. Her position is not funded any longer, so now we are kind of back to this "catch as catch can."

Teratology is covered for the State, meaning the prevention of birth defects through phone counseling, but the teratologists are mostly knowledgeable about drugs and radiation -- medical exposures, and perhaps food exposures. They are not knowledgeable about workplaces so they like to refer to me, but I am not really part of their network and it is not at all integrated. And of course, as you know, it is kind of funding and money that makes friends and integrates services in this kind of an atmosphere. Even though we are kind of willing, it just hasn't really fallen into place.

I could give you some details on some specific cases that have arisen, but I don't know that that would really serve our purpose here today.

MS. FRANCIS: Well, in the context of recommendations you might have, if any of those were related to how you think a remedy could be framed, then that would be appropriate.

DR. KIPEN: I am not well enough schooled in the ins and outs of the law; for instance, whether this would be framed under labor law and Workers' Comp, or whether it would be framed under some other kind of statute, I can't tell you.

I think what we need is protection of pay and benefits while appropriate preventive health actions are followed out by a woman. I think that is complex, because what is appropriate, as I implied -- and I may not be making friends when I say this-- I think a lot of physicians who might attempt to make these recommendations are not able to balance them as well as they might, because they do not regularly deal with them. So I think you would like to provide a mechanism where these things could kind of get reviewed or, you know, where knowledge could be gained about certain workplaces.

One of the big problems I have is, if a woman comes in and tells me, "I work with this. I am exposed to that," well-- Perhaps you people are familiar a little bit with a discipline called "industrial hygiene," where they can go in and measure how much of this or that a given person is exposed to. I rarely have access to that kind of data. When I have called up companies about a woman I was seeing and there was some issue-- I called up a printing company and I said I was concerned that based on what she was telling me there might be excessive exposure to solvents. Basically I got back, "Are you telling me that she has a compensable disease or not? What is her diagnosis? We don't want to talk to you about anything else, because we only see Workers' Comp. We don't see this broader issue you are talking to us about."

So it would kind of be to set up-- You need to protect the woman, and then you need to provide the woman or husband and the health care provider with useful tools and information, so that proper decisions can be made in this area of uncertainty. You know, it is not like I really can predict with a crystal ball what is going to happen to any given person, but so that the right information gets brought to bear.

Again, to kind of allow this to move a little more quickly, I am not at a point of making specific recommendations for legislation or regulations. I think perhaps a process that was directed toward solving this issue, with the right representatives from the legal profession, the Human Services people, medical people, toxicology people, and industry people -- who would probably bear some burden in this, if I am not mistaken -- to kind of reach some rational policy-- Larger corporations, we think, although we do not know yet -- we are going to try to do a little study of it -- have policies that are probably somewhat enlightened in this area and are protective. It is the smaller company or those with the lower value added kind of production that we think might be more of an issue with toxic exposures.

MS. JACOBUS: There is a third population. You delineated two populations that come to you, or are referred to you which you find troubling. There is the probably larger third population of women who don't know that they are at risk, who are not aware that they are working with substances which may put them at risk, or who may fear that they are, but do not have the slightest idea what materials they are actually working with.

DR. KIPEN: And may even fear that unnecessarily. You're right, but to do the outreach about who is at risk and who is not -- that is very important.

MS. JACOBUS: It would seem as if a small portion of the solution would be that every single obstetrician/gynecologist who deals with a woman who suspects she is pregnant should have a general protocol of asking this woman where she works, what chemicals she works with, what radiation she may work with -- just a general protocol that every single obstetrician/gynecologist would automatically ask about.

DR. KIPEN: That would be very useful, although as someone who sits on lots of national committees for how to educate medical students and practicing physicians about occupational and environmental issues, which are not well-dealt-with in medical school-- One of the big issues is, if you succeeded in doing that, you would need to create a place for that physician to go with the answer to that question, so that he or she doesn't either just get frustrated, you know-- Of course, it is kind of a cart and a horse thing, but one needs to be attentive to that, because otherwise-- I have this little theory that if you ask physicians to do things that they are not comfortable doing, to ask questions that if they get the answer they don't know what to do with it, like the rest of us, they are going to avoid those topics and go with the things they know.

It would be useful if we could do that and channel the responses effectively.

MS. JACOBUS: To a resource center where they could ask questions and get answers from experts.

DR. KIPEN: Yes.

MS. FRANCIS: Melanie?

MS. GRIFFIN: Yes. I would just like to know if you have any specific recommendations about the best-- We have come up with-- All day we have been hearing about how physicians need to be trained better in various areas. Do you have any insights about how that could best be accomplished? Is that a medical school thing? Is it a specialty training thing? Is it a licensing requirement thing?

DR. KIPEN: Those are all-- It is a big topic. On Monday and Tuesday of next week, I will be a member of a committee of the National Research Council of the National Academy of Sciences, which is going to address environmental education for medical school curricula. Now, that is not to say that there are not lots of other issues about educating physicians in practice post -- what is called post graduate training, or continuing education.

There are many, many different approaches. Some of it depends on which physicians you want to reach with which particular information. It is useful, I believe, to study things fairly specifically. A curriculum that you design for medical students is quite general, although we hope that if you teach students generally to appreciate environmental and occupational issues, that maybe they can carry that other places.

What Caroline just outlined is a very specific approach to the obstetrician/gynecologist or family physician managing a pregnancy, ideally even dealing with it just before pregnancy, prior to conception. That would certainly take a lot of the time pressures off of trying to make decisions.

I cannot make specific recommendations to that, but I think that a group of people who could be relatively easily assembled could make a recommendation for the State. I don't think it is clear which way is the right way. I think working with the societies-- I assume there is a New Jersey College of Obstetricians and Gynecologists. That might be a place to go and ask them, as the recipients of such education and who work on it, what would work best. I mean, maybe a flyer that they could put in their waiting rooms would stimulate the patients to ask them. I don't know how comfortable people would or would not be.

I think there are lots of options. I really didn't come here prepared to discuss all the different ones, but if we developed an overall strategy, then I think we could take particular tactics for certain goals within that strategy.

MS. GRIFFIN: Thank you.

MS. FRANCIS: Thank you, Dr. Kipen.

DR. KIPEN: Thank you.

MS. FRANCIS: Is Francine McLean here? (no response) Is Mary Todd ready, or would you like--

MARY B. TODD, M.D.: I'm fine.

MS. FRANCIS: We will now hear from Mary Todd, who is the Assistant Director of the Cancer Institute of New Jersey.

DR. TODD: I apologize for my tardiness. I got lost. I am still new to the State.

Thank you for inviting me to speak to the Commission on Sex Discrimination in the Statutes. There are three points I wish to make at this hearing.

First, I want to discuss the goals of the National Cancer Institute's Cancer Programs within the context of the Cancer Institute of New Jersey.

Second, I want to outline potential areas that may impact on women's cancer health care issues in the State of New Jersey.

And third, then, I want to discuss mechanisms by which the Cancer Institute of New Jersey can assist the State in addressing some of those issues.

The Cancer Center Programs were formally established in 1971 under the auspices of the National Cancer Institute -- NCI. The aim was the development of resources with which to conduct basic clinical prevention and control research, coupled with clinical research efforts in order to reduce cancer incidence, mortality, and morbidity, while simultaneously improving the quality of life.

Comprehensive Cancer Centers are those programs that engage in all aspects of cancer research, in addition to Outreach and Educational Programs. There are now 27 Comprehensive Cancer Centers in 18 states. Despite the fact that the incidence and mortality from cancer in New Jersey remains in the top 10 of all the states in the country, New Jersey does not have an NCI-designated Comprehensive Cancer Center Program. This lack, despite the excellent clinical cancer care in this State, has implications that impact negatively on all residents of New Jersey.

Fortunately, steps have been taken to establish an NCI-designated Cancer Center in New Jersey. The Cancer Institute of New Jersey received an NCI planning grant in 1992, providing designation as a planning site for the development of a Cancer Center. The goals of the Cancer Institute of New Jersey are the same as those of the NCI: to decrease morbidity and mortality of cancer within this region, which we define as the State of New Jersey.

In 1993, the appointment of the Director of the Cancer Institute of New Jersey, William Hait, M.D., Ph.D., was announced. Dr. Hait was Associate Director of the Yale Comprehensive Cancer Center, and is internationally recognized for his research in breast cancer. With his arrival, the Cancer Institute of New Jersey has grown in size and scope. Four basic research programs have been identified. These include the following: a Cancer Prevention Program; a program to develop new chemotherapeutic agents; a program to identify cells' signals which permit the growth of cancer cells and resistance to currently used chemotherapeutic agents; and a Gene Therapy Program to examine genes involving cancer development and application of this knowledge for detection, therapy, and for the prevention of cancers.

A mechanism for translation of these basic research initiatives into clinical arenas has been initiated. This mechanism includes methods to measure outcomes in terms of clinical outcomes such as survival, as well as quality of life outcomes, the psychological impact, and the cost analysis of therapeutic, diagnostic, preventive, or educational interventions. Identification of variables that impact upon these outcomes, such as lack of access to health care, or social or sexual bias, is necessary in order for us to measure the effect of any intervention. Thus, it is important that we know and understand potential areas of variables that may impact on women's cancer health care issues and clinical outcomes in the State of New Jersey.

Access to health care is known to affect clinical cancer outcomes. One example of this is a report published recently in the "New England Journal of Medicine," using data from the "New Jersey State Cancer Registry," which demonstrated that women who are uninsured and those covered by Medicaid presented with more advanced breast cancer disease than patients who are privately insured.[2] Survival is different in the uninsured and Medicaid population compared with the group of patients with private insurance.

Gender bias is another variable which can affect cancer outcomes. It is demonstrated, also, in a study published in 1993.[3] This study evaluated the relationship between physician gender and appropriate screenings of women for three gender-sensitive tests -- breast examination, mammography, and Pap smears -- and one gender-neutral test, the blood pressure test. Women cared for by female physicians were less likely to be deficient in the cancer screening tests, particularly Pap smears and mammograms, compared to women who were cared for by male physicians. There were no differences in blood pressure checks.

In addition, cultural acceptance can impact upon patient use of health care facilities and involvement in screening practices. Cultural differences may be particularly important in New Jersey, which has had relatively high numbers of racial minorities since its early settlement. At the time of the State's first census in 1790, African-Americans represented 8 percent of the total population. Hispanic immigration from Puerto Rico after World War II, from Cuba and Portugal in the 1960s, and from Latin America in the 1970s and 1980s, has continued to alter the population makeup of New Jersey.

More recently, Asians have been the fastest-growing minority, accounting for nearly half of New Jersey's total population growth during the last decade -- 1980 to 1990. While the white population has remained stable during that time, the African-American population increased by 12 percent, the Hispanic population by 50 percent, and the Asian population by 160 percent.[4] Thus, minorities are rapidly increasing as a percentage of the State's overall population mix.

This increased percentage of minorities impacts upon the survival of our population in New Jersey. For example, age-adjusted cancer mortality is 27 percent higher for African-Americans than for the general United States population. More specifically, the overall five-year survival for breast cancer is 80 percent for white women, compared to 63 percent for African-Americans. The overall survival for uterine cancer is 85 percent versus 55 percent,[1] white versus African-American.

Studies have also shown that Latinos have 7.3 times the incidence of cervical cancer when compared to Anglo women.[5] In addition, it has been observed that Latinos have lower rates of cervical and breast cancer screenings.[6,7] In a 1987 study, 20 percent of all Latinos over the age of 18 have never had a Pap smear, compared with 9 percent of African-Americans and 7 percent of white women.[6] This lack of utilization of screening, particularly with cancer by which death can be prevented by screening, may be due to a lack of culture in the appropriate primary care services; lack of awareness or knowledge regarding the positive benefits of screening; cultural bias about screening; or other variables that have not yet been identified.

The development of the Cancer Institute in New Jersey into an NCI Comprehensive Cancer Center will help to address these types of issues by providing a mechanism for core support for research initiatives. These research initiatives will include: outreach, prevention, type of social interventions, nutritional aspects, and screening and research protocols, with a special emphasis on women of color and other socioeconomic groups.

The Cancer Institute of New Jersey can assist projects of collaborators, partners, and affiliates to expand the scope of these research initiatives. Examples of such projects include: a recent collaboration for a proposal for an NCI cancer educational grant program to support cancer awareness and referral for Latino women in Perth Amboy, as well as numerous other research proposals. Another example is a conference which is being planned in conjunction with the Environmental and Occupational Health Sciences Institute to examine demographic trends in minority cancer and cancer prevention in New Jersey, and to identify research needs in this area.

Collaborations with the American Cancer Society, the New Jersey Division, for breast cancer screening initiatives, and with the New Jersey Breast Coalition and the previous Governor of the State to announce breast cancer awareness month, are additional examples.

Establishment of Cancer Center New Jersey will permit expansion of shared resources within the State, and an integration of the unique combination of resources already available in the region, including the universities, the American Cancer Society, New Jersey Division, the New Jersey Medical Society, the New Jersey Commission on Cancer Research, major pharmaceutical firms, and other health care institutions. These efforts will result in expansion of specific programs of prevention, research, and education, and importantly, under the direction of the Cancer Institute of New Jersey, coordination of efforts to integrate basic and clinical cancer research to make these available to New Jersey residents, and thus to decrease the incidents of mortality in this State.

Thank you. Are there any questions?

MS. FRANCIS: Is there a time line on which you are moving for the designation?

DR. TODD: Yes. We have the planning grant, and that implies, therefore, that we should go in sooner. We are planning to go in, in about a year or a year and a half for the Core grant. We have already established our basic research programs in the process of establishing our clinical research programs.

MS. FRANCIS: This is something that once you are in the process and you continue to perform, you will receive a designation, or is it still problematic?

DR. TODD: It is competitive. There are 27 comprehensive cancer centers. There were 10 planning grants given. The hope of the NCI is to fund all of those that do achieve all of the criteria necessary. We will achieve all of the criteria necessary. It is unclear that they have received increased appropriations, so it may be that we are competing against established cancer centers. Nonetheless, the Director and I are meeting regularly with the Director of the National Cancer Institute. I think we are coming along nicely, and I am confident we will be able to achieve the status.

MS. FRANCIS: Good. We heard testimony this morning that also made us very hopeful that things would work out, from Ann Marie Hill.

DR. TODD: Yes.

MS. JACOBUS: The designation of the Cancer Institute of New Jersey as an NCI site implies a certain financial commitment from NCI, I am assuming. What other mix of funding sources do you foresee?

DR. TODD: The designation-- Once we achieve the comprehensive cancer center-- We do have funding now from the NCI as a planning site. We have received a grant -- which you are probably aware of -- for our building, our facility, from the Department of Energy for $10 million. We originated with five partners, all of which put in significant funding initially. They are: the Robert Wood Johnson Medical School, the University Medical and Dental Schools of New Jersey, St. Peter's Medical Center, the Robert Wood Johnson University Hospital, and the New Brunswick Affiliated Hospitals. In addition, they were successful initially in getting some grants from the Robert Wood Johnson Foundation and from J&J.

The individuals whom we recruited thus far, which were recruited -- seven individuals, faculty -- all bring with them additional fundings that are peer-reviewed grants that they have.

MS. JACOBUS: Good. Thank you very much.

DR. TODD: Thank you for inviting me.

MS. FRANCIS: We will now hear from Alma Saravia. What kind of courtesy do we give to the former Director of the Commission on Sex Discrimination in the Statutes?

ALMA L. SARAVIA, J.D., M.S.W.: I don't know. You didn't let me come in the morning, so--

MS. FRANCIS: Alma is now the Director of Mental Health Advocacy, Department of the Public Advocate.

MS. SARAVIA: Thank you, Bobbie. Where do you want me to leave the copies?

MS. JACOBUS: Here, I will take them.

MS. FRANCIS: Caroline can take them.

The courtesy is that at least I bought you your Pepsi.

MS. SARAVIA: I am just going to summarize the comments, and ask that the full written text be submitted into the record.

The Division of Mental Health Advocacy in the Department of the Public Advocate provides legal representation to people who are involuntarily committed into the State, private, or county psychiatric system, and that means both adults and children. Last year we did 18,000 commitment-related hearings; about 3000 or 4000 of those were for children. When I went to look to see how many men and women we had handled in those cases, I found that we never collected that data. No one had ever thought about it or analyzed it, which was very interesting.

I also have a Federal mandate to provide protection and advocacy for individuals with mental illness. In looking at those numbers, we represented 1321 clients last year. Of those, 574 were women, and 747 were male. Thus, 43 percent of the clients served by the Federal program were females.

Looking at who is admitted to the State psychiatric hospitals, I looked at the Division of Mental Health and Hospitals' statistics in the Department of Human Services. According to their statistics, last year 37.4 percent of the people admitted were females, and 62.6 percent were males. According to information compiled by the New Jersey Community Health Board, outpatient is 50 percent female and 50 percent male in terms of treatment.

Other than this very basic statistical information, no data is collected in the State of New Jersey on the needs of women in the mental health system, and even reviewing the scholarly literature I found in looking at the "American Journal of Psychiatry," which is the premier journal in the psychiatric field, there were very few articles devoted to women. Interestingly enough, as I was preparing for this public hearing and going through my old files way back when, I found material published in 1978 that I must have gathered for some work with the Commission. First Lady Rosalind Carter, at that time, convened a panel of women as part of the President's Commission on Mental Health, and did a report. I would be happy later on to submit copies of this report or articles, if you would like.

Every recommendation that they called for in that report is still as relevant and timely as anything we would look at today. So nothing has changed since 1978.

In looking at some of the literature, we find that nearly half of all American adults have a significant broadly defined mental illness at least once in their lifetime, and nearly one-third of our citizens will have a mental illness in any one year. When we look at how that breaks down between men and women, it is interesting that women, for example, are twice as likely to be diagnosed as depressed than males, and suffer from other types of diagnoses that males do not get. When we look at who is treated for mental illness, it is, in fact, more women than men, yet interestingly enough, only seven out of ten cases will go untreated of people who have a serious mental illness -- seven out of ten untreated.

Another problem of great concern to me is looking at the plight of women who are dually diagnosed suffering both from substance abuse and a mental illness. We find with our clients that they have very serious needs that are not being addressed by the public psychiatric system: Family maintenance or reunification efforts are not established at the hospitals assuring appropriate contact with children; coordination with agencies servicing these children needs to occur; parenting skills training must be available; helping children deal with their mother's illness; and providing legal support for those facing loss of custody or termination of parental rights. Service systems in these areas have been very slow to respond to women and only recently began to address some of their needs.

According to a recent study on the gender differences in substance abuse disorders, women are significantly more likely to have another psychiatric diagnosis in addition to substance abuse. Women suffer more from anxiety disorders, and they have significantly more psychopathology than male alcoholics. There is a much higher prevalence of post-traumatic stress disorder than amongst the general population. Women with post-traumatic stress disorder are slightly more likely than women without post-traumatic stress disorder to develop drug dependence.

Another interesting finding is that female alcoholics are three times as likely as males to have panic disorder. In the general population, panic disorder is twice as common in females as in males. Having said all of that, there is no further research on how to provide adequate treatment if those numbers are, in fact, accurate.

Another form of discrimination against women results when clinicians treating hospitalized women fail to recognize the high percentage of women patients who have been sexually abused as adolescents or children. According to a recent study in the "Hospital and Community Psychiatry Journal," 51 percent of female State hospital patients were found to have been sexually abused as children or adolescents. Yet, only 20 percent of the abused patients believe they had been adequately treated for their sexual abuse. Interestingly enough, 66 percent of the abused patients met the diagnostic criteria for post-traumatic stress disorder, yet none had ever been treated for that diagnosis.

There is also a need for staff training in terms of women's unique needs within the system and in particular, again, for correct diagnoses. A recent article in the "American Journal of Psychiatry' analyzed psychiatrists' beliefs about gender-appropriate behavior. According to this article, what a psychiatrist believes about gender-appropriate behavior may -- I would say obviously -- influence the treatment of the patient. A survey found that female psychiatrists rated masculine traits as optimal for female patients and male psychiatrists believe traits characteristic of both masculine and feminine are optimal for both men and women patients. The study concluded that there have been significant changes in psychiatrists' attitudes toward gender in the past 20 years. Yet, despite this, it is my feeling that there have not been sufficient studies given to the gender differences in the types of diagnoses.

The first time any article was published on the treatment of sexual harassment victims was just this January 1994 in the "American Journal of Psychiatry." It was a very interesting article, where it concludes that sexual harassment produces an array of physical and substance abuse in over 90 percent of victims, and only 12 percent seek help from mental health professionals. Self-doubt is a central issue, regardless of gender, but in instances where the perpetrator is male and the victim is female, there are ramifications unique to the trauma of gender-based abuse.

According to this study, it is critical that therapists avoid contributing to the process of "second injury" and not imply that patients have brought their troubles on themselves. The article concludes by saying that few studies have focused on the victims of sexual harassment and that psychiatry can play an invaluable role in the assessment and treatment of victims.

Another very controversial area in terms of the psychiatric profession is whether or not any kind of premenstrual behavioral disturbances are psychiatric diagnoses. I imagine you have had some other testimony on that today.

MS. FRANCIS: As a matter of fact, we haven't, if you have anything.

MS. SARAVIA: Well, one interesting article I read is now linking it to a form of epilepsy and seizure disorders in the brain that produces some psychotic behavior in some women. Yet, on the whole it is a very unanswered question whether PMS should be a psychiatric diagnosis. There is really a scarcity of literature, although I am still searching to see what is out there in that area.

Another problem we have identified is the need for institutional abuse investigations for all psychiatric hospitals and units to deal with women who have been subject to abuse and neglect. While there is a Federal mandate to provide that, I don't think we have adequately sensitized staff and patients to what abuse is and that they may have been victimized within the hospital system.

Another issue that is very vital and very timely to me is the plight of women who are hospitalized in our State system, are pregnant, and who are suffering a complete lack of comprehensive health education, prenatal care, and education on the use of psychotropic medication during their pregnancy. We have had a number of women clients who have been pregnant, and we have a very difficult time getting them discharged from the hospital as their pregnancy comes to term, because the hospital is taking a parent's patria view that they know better and these women might not get appropriate medical care. We have had to threaten appeal up to the Appellate level to get them out.

As a matter of fact, today we had a case -- I couldn't believe it when I was talking to one of my managing attorneys -- a really incredible case of a woman who is black, Haitian, who went for some prenatal care. There was a cultural language barrier with the doctor, who wound up calling the Screening Center. She was committed to Marlboro Psychiatric Hospital, and lost custody of her other child, who is now in DYFS foster care. She never got the notice when she was in Marlboro about the DYFS foster care hearing that occurred. While the statute requires that you can't be committed unless you have both a mental illness and are dangerous to self or others, she has no diagnosable mental illness, yet the hospital does not want to discharge her, because she is so close to term and they are afraid that she won't get the right care because her hemoglobulin levels are off, and all of that.

I think we are going to prevail. I don't know what the outcome will be, but we took some steps to make sure we prevailed in that case by submitting a written brief, which is a little bit unusual in the kind of work we do.

We found a study looking at the plight of pregnant women in the psychiatric system, and found that of 35 pregnant women hospitalized for nonorganic psychotic symptoms-- The study showed that the majority of the women had been hospitalized five times or more and lacked social and economic supports. Almost two-thirds had had two or more pregnancies, but only 2 of the 35 women were living with their children. There has been a complete absence of custody issues being addressed by the hospital treatment programs.

In terms of outpatient care, there is a greater need for coordination between reproductive health services, rape counseling centers, domestic violence programs, legal service programs, substance abuse treatment programs, and parenting skills programs. We recommend that the Division of Mental Health and Hospitals' regulations require both institutions and community agencies to develop and implement programs for women.

Rehabilitation services such as education and vocational training offered both in the hospitals and at outpatient programs must be revised to eliminate stereotypical training for women. Women must also be included amongst "target populations" which must be served by community mental health centers.

I would say parenthetically that every other group now has gotten some special attention within the mental health system, such as the needs of the deaf children, or whatever groups, yet women have never been identified as a group that needs special attention.

In addition, both family systems clinicians and the growing family advocacy movement have slowly generated an awareness of the importance and efficacy of engaging families in treatment and rehabilitation, even of the seriously mentally ill. I suspect that these efforts have largely served to increase the involvement of female caretakers as the major providers of aftercare services, but they have not served to either ensure contact and communication between women and their children or focus efforts on motivating and helping men to stay with and support the mentally ill women in their family.

My final comment would go to the issue of health care reform. Whatever proposal is considered in Washington, we feel it is imperative that mental health be given the same consideration in terms of health insurance as physical illness. None of the legislation being discussed treats mental illnesses the same as physical illnesses. Without extensive lobbying, I fear that the limited benefits being proposed will be cut back even further.

At a recent conference I obtained information that the Clinton health plan now calls for a 30-day limit per year on inpatient hospitalization, with an additional 30 days only for individuals found dangerous to themselves or others or in need of drug treatment. I am concerned that this will result in the overcommitment of individuals who otherwise would not be involuntarily committed.

In addition, the Clinton administration plan calls for only 30 visits per year outpatient. In order to obtain additional visits, you must trade off one hospital day for four visits. Any legislation should provide coverage for prevention, early intervention, and follow-up care. With the current range of mental health treatments available today, many people are only incapacitated for a small amount of time and are very much able to go back to work and be productive members of society.

I would urge the Commission to look at the whole health insurance debate, not just for physical illness, but for mental health.

Those are my comments, and I would welcome any of your questions.

MS. FRANCIS: Thank you.

Comments or questions?

MS. JACOBUS: That was very comprehensive. Thank you.

MS. FRANCIS: I had a question about that article -- the January '94 article from the "Journal of Psychiatry," you said, on sexual harassment victims. Is that something you could submit to us?

MS. SARAVIA: Yes, absolutely.

MS. FRANCIS: I would be interested in seeing that.

MS. JACOBUS: I would also be interested if you could get Rosalind Carter's report from 1979.

MS. SARAVIA: I can actually put together a packet of all the articles I cited in my testimony, if that would be helpful.

MS. GRIFFIN: That would be great.

MS. FRANCIS: That would be wonderful.

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

MS. GRIFFIN: I did have one question: The woman you said Marlboro was hanging onto--

MS. SARAVIA: Yes?

MS. GRIFFIN: --in this parent's patria-- I know your particular responsibility probably ends there. Do you think there are sufficient community supports for her to get the kind of care she needs?

MS. SARAVIA: Actually, under my Federal mandate I retain jurisdiction when she is discharged for up to 90 days to do any kind of advocacy and outreach -- legal advocacy for her. I have directed that we immediately get in touch with DYFS if she wishes us to act as counsel, to find out how we can get her children back to her. I don't know. Part of the issue is that she has an apartment to go to, but they are saying that that might not be supervised enough for her, which, of course, is contrary to the statute. If you have a place to go, they have to discharge you within 48 hours if you are not commitable under the law.

So at the hospital they are supposed to be working through their social workers to establish all of those community supports. Obviously, that does not happen very well for most of our clients.

MS. GRIFFIN: Well, then, it can't be happening sufficient for their purposes if they think she has to stay in the hospital to receive the appropriate care.

MS. SARAVIA: Right, right.

MS. GRIFFIN: Thank you.

MS. FRANCIS: Okay, thank you.

Is Susan Silver here? (affirmative response from audience) Susan is also from the Department of the Public Advocate, the Inmate Advocacy section.

SUSAN REMIS SILVER, ESQ.: Yes. I see you have a full day of testimony before you.

MS. FRANCIS: Very good testimony.

MS. SILVER: Good.

As you mentioned, I am Susan Silver. I am the Director of the Office of Inmate Advocacy, which is part of the Public Defender's Office and within the Department of the Public Advocate. I am pleased to be here to address the medical needs of incarcerated women.

The Office of Inmate Advocacy has the statutory mandate to represent the 39,000 inmates, both male and female, who are incarcerated in our State's prisons, county jails, municipal lockups, and juvenile detention facilities. We seek constitutional and more humane living conditions for inmates.

The Office has three attorneys, including myself, and we bring litigation to benefit the interests of inmates as a class. We have four investigators who investigate systemic problems, as well as do individual advocacy. For example, we deal with mishandled medical emergencies, inmates' suicides and deaths, inmates in need of protective custody or mental health care -- every problem imaginable that could arise within daily life in an institution. We frequently receive complaints that inmates in both the State prisons and county jails are not receiving adequate medical care.

Incarcerated women are, and continue to be a forgotten population. This is due, in part, to the fact that historically, women have only been a very small percentage of the total inmate population. Unfortunately, women have been an afterthought in jail and prison planning. Our jails and prisons are simply not designed to hold women.

Today, there are many more women living behind bars, both in terms of the percentage of inmates and in terms of absolute numbers. In 1986, women were only 4 percent of the total inmate population in this country. In New Jersey, women are now 4.2 percent of the State prison population; 6.7 percent of the county jail population. We have approximately 2000 women incarcerated in New Jersey. Just to give the historical perspective, across the country, in 1980, there were only 13,000 women in state prisons and Federal penitentiaries. By the end of 1992, that number more than quadrupled to over 50,000.

Here in New Jersey, we have about 2000 inmates. We have slightly less than 1000 inmates in our State prison -- the Edna Mahan Correctional Facility for Women in Clinton -- and slightly more than 1000 women in each of our 21 county jails. With 2000 women incarcerated in New Jersey, we are talking about a sizable population, and they do have special needs that need to be addressed.

So who are these women? They are overwhelmingly poor, disproportionately women of color, and medically disenfranchised. They obviously have the stigma of being charged with breaking the law. They do not vote. They are essentially without any power, and very few groups are out there advocating on their behalf. They are mothers with small children, single heads of households, substance abusers, victims of violence, survivors of physical and sexual abuse.

Now, typically women in the community receive less medical care than men. This is also true in our jails and prisons. In fact, many women had received no primary health care before they were incarcerated, and the first time they are getting primary health care is when the criminal justice system becomes their primary health care provider.

Now, before I turn to the unique medical problems of incarcerated women, I first have to stress that overcrowding in our State prisons and county jails adversely impacts the quality of medical care that all inmates in our State receive. Across New Jersey, our county jails and State prisons are so overcrowded and understaffed that inmates frequently fail to get medical screenings and physical exams upon entering, and fail to get timely or adequate medical care once they are admitted to the facility.

Inmates throughout the State are subjected to delays in receiving even critically needed medical care. The first thing that happens when someone enters a jail is that all of their medications are taken away from them. Even if they have a life-sustaining need for those medications -- if they have asthma or a heart condition or AIDS -- the medications are stripped from them, and it can often take weeks, or even months for them to get those medications back. We have seen inmates with serious problems such as AIDS languish for months without appropriate assessment and care. There are also vast disparities from one State prison to another, and from one county jail to another. Because our county jails are significantly more overcrowded than our State prisons, inmates generally receive less comprehensive care when they are in a county jail.

Now, when you are sick and living behind bars, you are completely at the mercy of your jailers to get any sort of medical care. As a result of correction officer understaffing, many county jails will leave entire housing areas completely unstaffed by correctional officers for hours each day. Now, if you are an inmate, and if you are unlucky enough to have a medical emergency when there is no officer on your tier, your pleas for help and medical assistance will be unheard and unanswered. Unfortunately, this was partly the reason that an asthmatic inmate in the Essex County Jail Annex died on October 30 -- just this past October -- because she had a very serious asthmatic attack at a time when there was no officer on her tier, and no officer for the next hour and a half.

So as a result of inmate overcrowding and officer understaffing, inmates of both sexes are often subjected to extensive delays in the receipt of medical care. This can sometimes have even fatal results.

The Office of Inmate Advocacy recommends that this Commission formulate statutory guidelines to establish minimum standards of medical care and treatment, not only for women, which we believe is necessary, but also for all incarcerated individuals. Although there are State regulations now that govern the operation of county jails, these regulations are not routinely enforced. So we recommend the enactment of mandatory enforcement procedures which set forth the specific responsibility of the State Department of Corrections to ensure county compliance to these standards. We believe that more standards, clearer standards, and more comprehensive standards are needed, but we also believe there needs to be mandatory enforcement procedures to ensure that county jails are living up to their obligations.

I would like to now turn to the specific needs of incarcerated women. Now, to understand these needs, we first have to understand that although there are now many more women incarcerated, the almost exclusive focus on male inmates has not changed. As a result, the needs -- medical needs and other needs -- of women are not met. Facilities and staff available to inmates in both State and county institutions simply are not equivalent to the medical services available to men.

The male orientation of the jail design has a very direct impact on incarcerated women's health. To my knowledge -- and I have gone into many county jails and I have surveyed each one of my staff members -- not a single county jail in this State has a separate medical infirmary for incarcerated women. Many jails are so overcrowded that they house medically needy women in the same tiers as those who are placed in isolation for breaking institutional rules.

Alma Saravia mentioned the inadequacies with mental health care. That also is true when you look at the prison system. No county jail in our State has a separate mental health housing area for women, or even special cells for suicidal women. Unlike the male inmates in county jails who do have special housing areas if they have mental health needs, women with the same mental health needs are simply thrown in with the general population. As a result, it is difficult, if not impossible, for the correctional jail staff and medical and mental health staff to give these women the care and observation they may need for their mental health problems.

In addition, incarcerated women in every county jail in the State are placed directly in general population, rather than in new admission housing areas. No county jail in our State has a special admission housing area for women, despite the regulatory requirement that a woman and man first must get a medical screening, a physical examination, and a classification review before they are placed in general population. This happens by and large for our male inmates; it does not happen anywhere in the State for our female inmates.

As a result, a woman can be thrown into jail with a very serious contagious disease, such as active tuberculosis, and until her test results come back she will be housed along with other healthy women in general population areas. When you consider the fact that so many of our county jails have antiquated buildings with very poor ventilation, and that inmates are really overcrowded and breathing -- the same inmates breathing directly on one another, you can appreciate the danger of disease transmission in our correctional facilities.

Unfortunately, the housing areas for women are often more overcrowded than they are for men. The women are often segregated in a small section of a jail, without access to the facilities that are available to the majority male population. These facilities, such as gyms, libraries, classrooms, and vocational training space, are rarely duplicated in the women's housing sections of the jail. Even some of our newer facilities, like the Hunterdon and Middlesex County Jails, were designed to-- They were not designed to provide inadequate space, but upon opening they had inadequate space for their female inmates. For example, in Hunterdon, they had a double bunk in the women's section that was designed to only house one woman per cell, even before they opened, because they realized that they just did not design a large enough space for women. So the male inmates are living by and large one to a cell, and the women are crammed two to a cell. The same problem happened in Middlesex County, where they are double-bunking the women's housing area.

Now, just to visualize the space, the very limited and restricted living space that a woman will have, if you just put your arms out to either side, and add maybe four inches, that is the size of a cell that two women share. It is not even a woman's own. In some overcrowded facilities, such as Camden County Jail, there are dozens of women who are sleeping on these, like, one-inch thick mats on the floor of the dayrooms. They don't even have a cell they can call their own.

There is a book called "Prison Health Care: Guidelines for the Management of an Adequate Delivery System." In that book, Dr. Anno says that the literature on female offenders is replete with examples of inequality for female offenders in their housing arrangements, compared with their male counterparts.

So the question is: How do we begin to address this inequality? The first step is to realize--

MS. FRANCIS: Excuse me. Not to interrupt, but I wonder if you could perhaps sort of summarize some of it. This is very interesting, very good material, but we are trying to stay on track with the time. Obviously, it will all go on the record. It is intriguing and very, very thorough.

Thank you.

MS. SILVER: I will summarize. Okay.

As I mentioned, women do have the same health needs as men and, in some instances, have an even greater risk of diseases such as AIDS, sexually transmitted diseases, and drug abuse. Just last summer, there was a report that the Departments of Corrections and Health did looking at 2000 men and women entering our State prison system, where the women had a 15 percent positive HIV rate, the men only 9 percent. This was 30 times greater among the women in prison than their counterparts in the community. This is due, in part, to the fact that so many of the women who are incarcerated have substance abuse problems. Many of the women have turned to prostitution to support their drug addictions, which places them at particularly high risk for sexually transmitted diseases.

Incarcerated women also have higher rates of substance abuse. About 70 percent of all inmates are thought to have substance abuse problems, but it is estimated that it may be as high as 90 percent of the women who have substance abuse problems. We do not have enough drug treatment programs or counselors either in the community or in the correctional setting. We need to expand these programs both in the county and State facilities.

There is also a need to tailor protocols for the specific needs of incarcerated women, and again AIDS gives a very good example where women are not-- Well, first of all, the medical staff is not trained in recognizing the unique manifestations of HIV in women, and women are not given information about prenatal transmission of the virus or how their pregnancy may affect the HIV transmission. Neither men nor women throughout our correctional facilities have information on HIV transmission and treatment or prevention. Much more needs to be done in that area.

Women also have additional medical needs. A number of women who enter the facilities, State and county, are pregnant. For example, the Essex County Jail sees 10 pregnant women coming in their doors every month. Three or four of these women are also HIV positive. Because so many incarcerated women do not have good medical care prior to admission to the facility, they are high-risk pregnancies, and medical staffs in the jails are simply not equipped to give them the care they need. We get many complaints from pregnant women about inadequate care. Sometimes it stems from inadequate food. Women are not given nutritional supplements; they are not given the milk they need; and sometimes they are not given emergency medical care.

We recently got a complaint from a woman in the Camden County Jail who was four months pregnant, and was assigned to sleep on a mat on the floor. She could not get to a doctor. She finally saw a doctor and he said, "Well, we will see you next month." He gave her no care whatsoever. She began to vomit. She began to have severe abdominal cramps. Nothing was done for her. Fourteen hours later she aborted in her cell. That is not, unfortunately, atypical. We get complaints like that from time to time.

Incarcerated women also have a right to abortion services. Again, this is not always granted women as it should be. Just last month in the Essex County Jail Annex, a woman complained because once she made her request known to the jail that she did want an abortion, they delayed for two months her right to an abortion. By the time she finally got an abortion, after numerous phone calls and intervention attempts, she was already in the 20th week of her pregnancy. She had to have a saline abortion. She had 17 hours of labor, and then had a stillborn birth. I just visited this woman last week, and she is still visibly shaken by that experience.

Sometimes even things as basic as giving sanitary napkins to a woman who has her period are not done. In the Ocean County Jail, the correctional staff told a woman who had her period to use her socks instead. In the Essex County Jail, they routinely refused to give out sanitary napkins on weekends. Women are forced to share these items or to just use toilet paper.

There is also inadequate ob/gyn care, especially in the county facilities where the women are not provided with routine Pap smears or pelvic exams.

Confidentiality is also a statewide problem. Many women refuse to get tested for such things as HIV or sexually transmitted diseases, because they know that if they do test positive their medical condition will be announced to an entire housing tier, where they will be harassed, and they sometimes will face discrimination in their housing or access to programs and services.

The final issue I would like to raise is the fact that incarcerated women desperately need more time with their children. Approximately 80 percent of our incarcerated women are mothers, and 70 percent of those are single parents who frequently do not have any other care for their children. The stress of incarceration is very real with these women who are very concerned about the welfare of their children.

One of the very first county jails I went to when I first assumed my position as Director was the Middlesex County Jail. I was struck by the noncontact visit area, where there are just glass windows and telephones. A small boy had his hand up against one side of the glass and his mother her hand on the other side. They were trying to get close contact, but the jail was not making it very easy for them.

Many county jails don't have any kind of contact visitation areas, even though the State regulations recommend such programs. Many incarcerated women are extremely frustrated and in emotional pain over the loss of the daily contact with their children. They need to have counseling and treatment available to deal with the psychological pain they feel. But better yet, I would like to see more contact with women and their children. Visitation opportunities need to be drastically expanded. Most county jails only allow, even women with children, three, maybe four visits a week, 15 to 20 minutes in length. That is just not enough to maintain a good mother/child bond.

We also recommend that incarcerated women with infants or small children be allowed to live with their children, preferably in satellite housing areas outside of the main jail building. This is a program that is done in New York State. It is operating very successfully. I would like to see a similar program explored in New Jersey.

I also recommend that women who deliver children while they are incarcerated be given more time with their children. The current practice now is that a woman will go to a hospital and can spend the one or two days of her hospital stay with her child, but then must return to the jail childless. Her baby, her newborn, has to either be given to family or friends or placed in DYFS' care. From a developmental standpoint, this is not healthy for the mother or the child. It overburdens DYFS, and it overburdens our foster care system. When the very fragile mother/child bond is broken, it may be too late. When a woman comes out three months later, one year later, it may be too late to build that bond back.

We would also like to see halfway houses established for a woman maybe one year prior to her release date so she can resume contact with her family. We feel that this would also decrease recidivism rates, because if a woman appreciates the responsibility entrusted to her -- the responsibility of caring for her child -- she will work hard to get it right the second time around and be a law-abiding citizen.

In sum, we have an obligation as a society to provide necessary care, including medical care to inmates under our supervision. All inmates, regardless of whether they are State prisoners or county jail inmates, regardless of whether they are male or female, have a constitutional right to adequate health care. This right was recognized because inmates have no choice but to turn to their jailers to get adequate medical care, and unless we have statutory provisions in place to ensure the adequacy of their health care, those needs will not be met.

Thank you.

MS. FRANCIS: Thank you. That was excellent testimony. It was just so very rich that--

MS. SILVER: Oh, thank you.

MS. FRANCIS: --you needed some summarizing there. But it was very, very full of good information I hope we can work with.

Do you have any questions?

MS. GRIFFIN: No. Susan is available. We will be calling--

MS. SILVER: Yes, and I do have plenty of material that I can share with you if you want to explore different options.

MS. FRANCIS: I just need to observe that I felt you were sort of telling the plot of some awful movie as we were sitting here hearing this. It is the sort of thing that--

MS. SILVER: I feel like I deal with human tragedy every day in my work. There is so much that needs to be done. I am so glad that a Commission such as yours is looking into the problems.

MS. FRANCIS: Thanks very much.

MS. SILVER: Thank you.

MS. JACOBUS: Thank you.

MS. FRANCIS: Linda Shute, President, Local Independent Oilworkers Union, South Jersey, President, U.S. Oil and Chemical Workers Association--

MS. JACOBUS: And a litigant.

MS. FRANCIS: And a litigant. I didn't know how much time it would take Linda to get up here, so I didn't keep reading. I figured she would tell us that. Linda will be talking on an occupational reproductive hazards case.

MS. SHUTE: Right. Actually I am going to tell my personal story of what happened with me. November 1992 -- 1982, excuse me -- was when I first filed suit when I discovered that I was pregnant. I worked for Mobil Oil Corporation. I have been an employee there for 16 years. Out of the 16 years, 13 of those years I have been an officer of the Union, in one capacity or another. So I was aware of what I was up against.

I was the ninth woman hired in the refinery. I spent six months in the Labor Pool and I was the only female in the Labor Pool at that time. There was a lot of hard feelings between the men, and the women who felt, "You took my son's job." When I discovered I was pregnant, I wrote down the names of all the chemicals, and Dr. Kipen, who testified earlier, could appreciate this. I not only wrote down the name of the chemical, but I wrote down the chemical makeup of it.

I gave this to my doctor, who said she had no idea about industrial hazards. She forwarded all of this information to the New Jersey Department of Health. The New Jersey Department of Health told me that I had a 50/50 chance, with all the solvents and chemicals I work in, of having a healthy child. This was my first pregnancy.

When I demanded toxicology reports from all of these things, the company didn't particularly want to hand them over, but they did, since my attorney got after them about it. Everything I work in is considered a carcinogenic. My obstetrician had asked me if I was aware of fetal solvent syndrome, which I had never heard of. Under the Federal regulations, it says that if the company cannot, or will not clean up the workplace, the patient is considered to have a pregnancy-related disability. This is what I filed under.

I first went through the EEOC, which did absolutely nothing but take up a lot of time. I went through -- in 1991, in the later part of the year -- the final decision through the New Jersey Court of Appeals under Judge Rodriguez, who ruled in the company's favor.

In, I guess it was around December of 1992, when all of this first began, the company called me up and said, "We realize you're pregnant, but you have to come to work." I am a shift worker. I work all three shifts. They told me I was scheduled to be into work at midnight that night, and I could either show up, or I would be on a no-pay status. I have kind of gotten out of context in the way I am telling this. I'm sorry about that.

So I was out of work on a no-pay status. They called me in and forced me to sign papers to take a leave of absence, which I didn't particularly want to do, but I had no choice. I filed for unemployment. We had previously had one employee collect disability through the entire time of her pregnancy. We had had one employee collect unemployment through her entire pregnancy. I was the third pregnant employee. They told me they knew nothing of the two previous cases; I was pregnant, and I either worked or I was on a no-pay status.

I was denied unemployment, because they figured you are not unemployed. You are still employed, but you are on a no-pay status. Well, how am I supposed to live? I appealed the unemployment decision. I went in with my attorney the second time and I was again denied. I went through that process again and I was again denied.

MS. FRANCIS: I'm sorry, this was in 1982?

MS. SHUTE: Yes.

MS. FRANCIS: Okay. It was before the Johnson Controls decision?

MS. SHUTE: Right. In 1993 -- or '83, excuse me -- I was having a very stressful pregnancy with all the turmoil that was going on. When I would go back for my monthly checkups, I would go back and there were months where I had actually lost weight, rather than gained weight. During my entire pregnancy I had only gained 18 pounds. My son was born at 6 lbs., 4 ozs.

In order to live, I ended up having to sell some of my household furnishings. I had a show horse that I had always been very active with and I had to sell that in order to live.

I feel that the oil companies don't treat everyone equally. Even though there are Federal rules out there, they do not abide by them the way they should. I have contacted other colleagues of mine who are Union officials for the top four oil refineries in the country. I asked them how they handled this in their work facilities. They basically go on a case-by-case basis. They do not have any set procedure that they really follow. Some workers are given light duty and are transferred to other jobs. I had requested this and Mobil had denied it, although they had provided light duty for many years previous to this for a male employee. Now that I was pregnant and requested this, it was, "Well, we don't have light duty."

After I returned to work they reinstated light duty for any employee, which is infuriating. After I returned to work, we had other employees who again were able to collect long-term and short-term disability. You know, I felt I was--

MS. FRANCIS: Pregnancy related, do you mean?

MS. SHUTE: Yes. I felt it was very discriminatory for me, and I felt it was because I was a Union official trying to, you know, fight for workers' rights.

I think something needs to be done to make companies abide by the rulings that are out there. In the oil industry especially, it is apparent that they pretty much do as they please. That is the general consensus of the people I have spoken to through this.

I, at one point, attempted -- in 1986 -- through the OCAW, through a research department-- I had requested copies of any and all pregnancy clauses they had in any of their contracts. They sent me everything they had. I wrote up a proposal, presented this in the 1986 contract negotiations, and Ed Colacoski (phonetic spelling), the Employee Relations Manager for Mobil Oil Paulsboro Refinery at that time, told me that Mobil Oil is in business "to make oil, and not babies," and they did not give a damn about it. Those were his exact words. We have never been able to get any contract language for any type of maternity in our contract.

MS. FRANCIS: Do you know what-- The Johnson Controls decision was 1991, approximately, but the decision by the Supreme Court that occurred after your experience, my impression is, would address some of these issues, at least on paper. But what we are hearing clearly from you and others today is that--

MS. JACOBUS: Really, the Johnson Controls didn't deal so much with that issue. There was already legislation in place which outlawed the sort of discriminatory treatment that you received when it happened. The Johnson Controls speaks to some other aspects of pregnancy-related discrimination, I thought.

MS. FRANCIS: My impression would be that the company may not say, given that you are -- well, in this case, pregnant -- of child-bearing years, "We can move you into another job that is less." In that sense, I would think it would have said, "We can't make you go onto no-pay status." There might have been some bearing, but again, what we have heard today is that even what is on paper now, compared to 1982, does not get implemented in a way that protects against the kinds of things you are talking about.

MS. JACOBUS: The Pregnancy Discrimination Act-- What year was that?

MS. GRIFFIN: The year was 1978.

MS. JACOBUS: Oh, 1978, so in '82 there already was law on the books which said that a woman who is pregnant cannot be treated in any way that is different from similarly situated employees.

MS. SHUTE: I realize that, but they do it anyway.

MS. JACOBUS: They did it anyway, and apparently the courts were complicit in it, because they ruled in favor of Mobil Oil.

MS. SHUTE: Right.

The other issue that came up was the seniority issue. Everything I read about it said that you are not supposed to lose seniority due to maternity leave, and yet they did. Under my progression seniority where I would choose for vacation, it is my original date of August 22, 1977. Yet, when you look at my accrued seniority for pension reasons, all those months that

I was out due to maternity they have backed out. So it does affect your seniority issue.

Now, the first woman who was pregnant in the refinery, which was 13 years ago, she did not go through the Union when she was complaining about this. Instead, she had an outside attorney. She has a signed statement ruling by the court where she won her case, and she was reimbursed for all of her back wages and her benefits, which were the exact same thing that I was fighting for. In this ruling it states that her seniority will not be affected in any way by this ruling. She still has not been reimbursed with her seniority -- on the accrued part of it.

MS. FRANCIS: Do you have any specific way you would suggest that legislatively, or in terms of implementing what is already there, this can be better addressed?

MS. SHUTE: I don't know why these big companies are not made to abide by the rules. I mean, everybody else in the State is supposed to abide by the rules. Why aren't the major oil companies? You know, just because they have multibillion dollars, whatever they do to get away from it -- I mean, having to abide by these rules -- I don't think it is right.

MS. FRANCIS: Well, you have certainly raised it in a very well-focused context here. We have heard it elsewhere, too.

Are there any other questions at this point?

MS. JACOBUS: I am wondering if-- I mean, this sounds as if you could easily have grounds for a class action suit against the oil refinery by the women employees. I don't know. That would not be something that our office could deal with, but perhaps the Public Advocate. I don't know.

Well, thanks very much.

MS. SHUTE: Okay.

MS. FRANCIS: Thank you.

MS. GRIFFIN: We would appreciate getting from you any papers you would like to submit to us to just give us an idea about the dates and things. That would be helpful to us in terms of trying to figure out what laws applied when you were doing this, so we can look at what the State's responsibilities are. If you could do that--

MS. SHUTE: The chronological order of the pregnancies in the refinery, do you mean, or--

MS. GRIFFIN: What happened to you when, so that we can see what laws were in effect and kind of what was going on. If you have a copy of the Rodriguez decision, I would love to see it just to--

MS. SHUTE: It is about this thick. (demonstrates)

MS. GRIFFIN: Oh, well, whatever you feel like sending us, that would be great.

MS. SHUTE: I can look through it and send--

MS. GRIFFIN: Okay, great. Thanks.

MS. SHUTE: I guess your address would be on the information you sent me? Okay, I can do that.

MS. GRIFFIN: It is on that list you have in your hand, too.

MS. SHUTE: Okay. Thank you.

MS. FRANCIS: Thank you very much.

Regina Podhorin, Director, Office on -- of-- How can I get this wrong? It is the Office on the Prevention of Violence Against Women, New Jersey Division on Women.

REGINA PODHORIN: I'll give you, Caroline, copies for the record.

MS. FRANCIS: If we owed Alma some courtesy, I should owe you some, too. I should at least get the name of our Office right.

MS. PODHORIN: And my title.

MS. FRANCIS: What did I say?

MS. PODHORIN: You said Director.

MS. FRANCIS: Oh.

MS. PODHORIN: Thank you very much.

MS. FRANCIS: I read it on this list, that's why. I should have said "Supervisor." Excuse me.

MS. PODHORIN: Since you have seen this already, I will just highlight some of the points. I know Barbara Price is right behind me, so she will probably repeat some pieces of this and probably add some more. In terms of the issue of violence against women, I just want to make sure it is in the record and brought to people's attention -- although I also make some assumptions that Courtney may have brought it up this morning -- the fact that when we look-- When studies have been done of medical records in hospital emergency rooms, it is very disconcerting to see that in the records physicians may note that approximately -- of all the women coming into the hospital emergency rooms, somewhere between 5 percent and 7 percent of the cases have documented -- the doctor has documented that there has been violence of some sort. Yet, when you look at those very same people when they have done studies and done confidential questionnaires with them prior to them seeing the attending physician, more than 30 percent will readily say that they are victims of violence. So there is a great discrepancy between what is coming in the door and how it is being documented, and therefore, how it is being treated.

One of the hopes we have had for years is that the introduction of protocols in hospitals, especially in emergency rooms, would make a difference in helping physicians assess and identify victims of violence. What we have found in New Jersey and in other places is that that is true; that is happening; that when protocols are put into place which help people identify and ask the right questions in personal histories, the numbers identified in the medical records go up, but that there is slippage that occurs if there isn't follow-up to make sure that those protocols stay in place.

MS. GRIFFIN: May I just ask: How are you defining victims of violence? Is this family violence, male on female violence, all violence?

MS. PODHORIN: I am primarily talking about domestic violence and sexual assault. When the studies were done, these studies were around the issues of domestic violence and sexual assault.

MS. GRIFFIN: And this is 5 percent to 7 percent of all people, or 5 percent to 7 percent of women?

MS. PODHORIN: It's 5 percent to 7 percent of women entering hospital emergency rooms. I have the articles. There are three of them I can give you to support that.

One of the concerns we have, especially with what has happened in New Jersey, is that when there was an initiative that was specifically directed toward the medical field on the development and training on protocols, we saw the numbers going up of hospitals using and doctors using those protocols.

Recently, the Pennsylvania Coalition did some research into following up on those very same hospitals: How many were still using them, even remembered that they got them, or that they received the training? The numbers have changed somewhat. So what we are seeing is that only 46 percent of the doctors and nurses remembered that they had the training, and only 30 percent are still using the protocol that was suggested. So that emphasis, that momentum that was built, had dropped off somewhat and we must keep following up on it.

I will more specifically address that in my list of issues. I am breaking them down into two categories. One is treatment for victims, and the second is the issue of prevention. You have this outlined more specifically.

First, we need, for both the issues of domestic violence and sexual assault, some baseline standards in New Jersey for the collection of medical evidence, very specifically on the issue of sexual assault. Karen Pappas did not speak this morning, but I know Jill Greenbaum, and I think she brought it up also, the issue that to be sure there can be prosecution that will be successful, we need those standards from one hospital to another, from one medical practitioner to another, so that everyone is collecting the same kinds of information, even if the person says, "At this point, I don't want to pursue a legal remedy," because we find, over time, that they may choose to do so.

Added to the baseline of what is collected, is that there are provisions for the confidential safekeeping of that evidence, so that when the woman does want -- if she does change her mind, she can come back and it will be in her medical record in terms of what was there, the history, photographs, etc.

Secondly, the issue of statewide implementation of protocols, as I have said, to identify, protect, and treat victims is a major priority. There is a great fear when I talk to physicians and do speaking engagements about asking embarrassing questions. Their fear is that if I ask the question, what if I am wrong? What if there is no violence in that family? I have now embarrassed that person.

What we have found, both in practice working with victims of domestic violence as well as through research, is that when asking the direct question, "Have you been hurt by someone in your family, or someone you are close to?" people very readily will say, "Yes," and are not embarrassed by the question. For those who say, "No," they are also not embarrassed at having been asked. The embarrassment is on the part of the asker, not on the part of the person who is answering the question. So we do want to encourage that. I don't know how you could do that legislatively, except through the implementation of protocols throughout the State.

One of the ways that has been recommended is through the certifying, licensing, and State Board exams. They should include questions on treating victims of violence for professionals, as well as the licensing and monitoring of institutions, which should include questions on the use of the protocols, as well as the existence of ongoing in-service training. Currently, there are some questions in the monitoring of hospitals and institutions on whether people are receiving in-service training for sexual assault victims. If they say, "Yes, I watched the film," that's good enough. So the standards for what that protocol must be, and the standards for what that training must be should be on record and standardized, as well as some questions coming out of medical school: What did they learn? Do they have the basic information to go on?

Another issue: The legal system should routinely include the issue of coverage of related medical costs, restraining orders, judgments, and restitution awards. Although that is currently in place to some degree, the problem is that it is not routine. We are not asking victims to consider that some of the medical issues are longer term -- will last longer or will not show up for awhile. So sometimes we can get coverage for the immediate medical needs, but what about the longer term medical needs?

I was intrigued to hear Alma's statistics about the issue of psychiatric care, the numbers of women with panic disorders, and the numbers of women with a number of different disorders as being out of line with those of men. My claim here would be, from practical experience, that those women were misdiagnosed. It is not surprising to me that a great number of women are working under panic disorders. If I were living in a hostile situation, I would also be in a panic. It is situational; it is temporary. One of the problems we see in care is the issue that many of these women are then drugged; are then given medication to deal with this diagnosis of what is happening to them. Then they are less able to cope with what is happening. So now you have a woman who is sedated, who is going to go back into that situation of living in a violent home, and be less able to cope with the fact that someone is putting her in danger.

I am very much suggesting that we take great care in the psychiatric community both with the issue of diagnosis, as well as with the issue of giving sedatives, etc.; to be very careful about making sure there is a protocol for asking the questions about violence, so that someone does not become oversedated, overmedicated, thereby causing a risk of -- the issue of drug addiction.

Additionally, the field of obstetrics and gynecology must be made extra sensitive to the implications of violence against women. I think you have probably heard this before. Pregnant women are at serious risk of harm not only to themselves, but also to their unborn children. Sexually transmitted diseases through forced or unprotected sex are far more common than imagined. Asking an abuser or rapist to consider safe sex is impossible, if not dangerous. We must ensure that doctors in that field and health care practitioners are alerted to that fact, and that appropriate testing is done at the appropriate time.

Finally, on the issue of victim treatment, I don't think you can legislate this, but I will put it on the record anyway. The issue that I have seen over very many years is that the health care field must recognize victim advocates as partners in the management of cases. The health care field is highly professional and credentialed. Historically, there has been an element of distain -- that may be a strong word, but it is a true word -- for the uncredentialed victim advocate.

After spending 12 years myself in the field of domestic violence, I am still regularly asked to produce my credentials before speaking to doctors and nurses. There are constant questions about what are the letters after my name, to be sure I am appropriately speaking to that group of people. I am not making any judgments, except to say that victim advocacy is best learned through close, constant contact with the issue. New Jersey can be proud of the work of those in the field.

But a collaboration of the health care professionals and advocates would be a powerful force in the life of any victim. So whatever we can do to put together that collaboration without the credentials being part of the issue, would be helpful.

In summary, there is a lot that can be done on the issue of treatment of victims. I include domestic violence, sexual assault, and stalking also, especially with the psychiatric issue. Victims of stalking-- Part of the whole dynamic of stalking is to make the victim feel crazy, so we should not be surprised if they then go to the doctor saying they are feeling crazy because things that they cannot control are happening to them. So we have to be very careful of those procedures that psychiatrists use in asking questions to get to that.

I am going to switch quickly to the issue of prevention. We have not started talking about, although we are at the crossroads of talking about, using the health care field as a preventive measure. They have started doing that in the fields of alcoholism, drug addictions, and even smoking. Why not in the field of violence against women?

In "A Protocol for Health Care Providers: Identification and Prevention of Youth Violence' -- this was very specific to youth violence -- developed by the Violence Prevention Project of the Department of Health and Hospitals of the City of Boston, they stated: "Health care providers are in a position to establish confidential, supportive relationships with patients and can influence their attitudes and behaviors. By addressing violence in a fashion comparable to the way they address more traditional concerns" -- medical concerns -- "they can make the clinical setting more responsive to the needs of those at risk."

What their suggestions were are: When you are treating someone for the effects of violence, that you also then start asking questions about the violent behavior and what is happening to them, and also then start giving them remedies, or prescribing the cure for violence and talking about safe ways to take care of themselves; ways to assess danger in situations; ways to get out of violent situations. And for those who are being violent, ways to handle anger.

Health care professionals are in the unique position of being expected to prescribe a cure. The protocol mentioned above from Boston has a three-page guideline for the engaging of patients and the discussion of violence that includes assessing violence history, identifying availability of weapons -- and this is all done routinely -- and discussing anger management and strategies for keeping safe. Having doctors tell their patients that violence is wrong and unhealthy may seem simplistic, but it deserves attention. Teaching health care professionals to model peaceful behavior, as well as to prescribe changes in behavior the same way they prescribe a nicotine patch, is not as far-fetched as it may seem. We must all look for "teachable moments" and use them to offer alternates to destructive behavior.

I finished with -- and this part you can read -- what work the Office is doing in being part of that solution and hoping to capture those teachable moments. I would hope on any health care agenda that we don't only talk about the treatment of victims, although that is a high priority, but that we look at the issues of prevention and where they fit in.

MS. FRANCIS: Thank you very much.

Questions?

MS. JACOBUS: I have a question. Currently in New Jersey, and in many states -- I think most states-- In fact, all 50 states have a mandate that requires social work, medical, and education professionals, as well as other various professionals, to report suspected child abuse upon pain of liability. Many states now have a similar statute regarding the reporting of suspected elder abuse.

MS. PODHORIN: Correct.

MS. JACOBUS: Now, historically, there have not been mandates -- legislative mandates -- requiring the reporting of domestic abuse. The justification was that adult women are perfectly capable of reporting this themselves; that the professional community should not bear that responsibility. But certainly we have seen from all of our recent research that many adult women do not have full independence in reporting such instances.

Do you believe there should be legislative mandates for medical counseling and other professionals to report suspected domestic violence upon pain of liability?

MS. PODHORIN: I would prefer to look at that -- to mandate them to record, to put in the medical record, their suspicions, so that there is documentation of it, but not that it be a reporting to officials, because I still also believe that women have the right to not have that reported to officials until they are ready. One of the most critical things about following through and making sure that women are able to be empowered and freed-- It needs to be at their pace; it needs to be at their time. The danger level of doing it before that may help us feel better that we have done our part, but may put her in more danger. I don't know that that is a good place for all of us to be.

It almost feels like a salve. Instead of something that is helping the woman, it is something that is taking us off the hook by saying, "Well, we reported it." That is not necessarily helping her.

MS. FRANCIS: This isn't pleasant to say, but we have heard testimony more than once today about reluctance to engage women with the system, because the system does not then necessarily serve them well. Again, if you call it a salve or whatever, reporting it may, in fact, not only put a woman in more imminent danger because there is a sense -- I mean there is a knowledge that the most dangerous time in that sort of a relationship is when she is breaking away -- but also, it may be engaging her in a system that is going to put her in some of the situations we heard described earlier today.

What would you recommend to ameliorate the traditional system in its treatment of women who do make it into the court system in an effort to escape from domestic violence?

MS. PODHORIN: Be sure we--

MS. JACOBUS: There was testimony this morning about women who had finally made it into the court system, only to find that the judge did not have an open mind about what may have taken place, and she found herself in greater danger because the abuser discovered that the law was, in fact, going to protect him.

MS. FRANCIS: Custody issues were one of the things talked about.

MS. GRIFFIN: Plus the abuse of children.

MS. PODHORIN: I spent most of yesterday and most of Friday on the phone with a woman who feels very strongly that the entire judicial system has failed her; has forgotten its emphasis on not only protecting her, but also protecting her children. She said that dragging her children through the process around the issue of custody had now done irreparable harm to her children, because the case cannot get settled; the case cannot get finished. It is being dragged out, and it is being done through the developmental stages of her children.

One of her sons said to her -- and I know she would be happy for me to share this -- "I feel like I am doing the time for what Daddy did to you; that I am the one who is being punished."

It seems to me, if I were to put it in a nutshell-- I am separating it from health care, so that kind of puts me into another frame of mind. The speedier, the faster that we can put people through the system and have some resolution, the better. Right now, the system is very slow. It is faster than it has ever been before, but it is still very slow. So you're talking about something that has happened here which may not be heard for six or nine months to a year, even including contempt cases. We are separating the act from when it happened to where it is being heard, so all kinds of stuff can happen in the middle. So a speedy trial is a very important issue.

In addition to that, being sure that we are protecting the interests of the children and what is happening to them in custody cases, what is in the best interest of the children, not only what is in the best interest of the adults, is happening, and needs to be always in the forefront. People need to be reminded of that.

Then the issue of, "Do we mean what we say in accountability?" For years I have watched contempt orders of restraining orders just languish in terms of time, but also then come back and the message is, "All right, don't do it again," for all intents and purposes. We don't have a real clean way of saying, "You did it again. That's it." The meaning of arrest anymore, most people have figured out, means at worst a paper process, because there are not enough slots in the jail. It means someone goes in and gets booked on paper and then is released. Did they really get arrested?

MS. JACOBUS: Do you think monetary fines garnished out of paychecks for restraining orders which have been defied is a way to go since there are not enough slots in the jails?

MS. PODHORIN: There is not very much use right now in terms of fines. I think there is great capability there in terms of getting fines assessed, as well as being able to use that money for very productive causes. That is not currently being used. If jail is not going to be the option because there is not enough room, well, we are not going to fight that in a very big way right now, then we have to find an alternative. If it is the pocketbook, that can work, and we are not using it.

MS. FRANCIS: I thought your comment about in litigation making sure that medical costs are -- reimbursement of medical costs and those defined as broadly as necessary, including long term-- You know, that would be another way to come at it. It doesn't get at the direct contempt.

There are a lot of directions to go in the discussion. I think we need to keep moving, but I really appreciate that.

MS. PODHORIN: And the next person is going to have--

MS. FRANCIS: Well, I was going to say-- In fact, some of the questions -- the source of that had to do with custody issues, and I know the Coalition, last year, had a conference on "The Difficult Custody Case."

Thank you very much, Supervisor.

MS. PODHORIN: Now you've got it.

MS. FRANCIS: I only read what I saw in front of me.

Barbara Price, Executive Director, New Jersey Coalition for Battered Women. She will be speaking in general.

BARBARA M. PRICE: I do hope I get to answer those questions, too.

MS. FRANCIS: You are able to tell us whatever you want. Why don't you do whatever you would like?

MS. PRICE: Well, I am going to start out with some statistics and information. Some of it is a little bit more detailed than what Regina gave you, so I would like, you know, to discuss some of it.

I think the major issues we are talking about today that you see in the news media are health care reform and crime. That is all we hear about every day -- health care reform and crime.

Well, domestic violence is a crime, and it is also a major public health problem. Domestic violence affects three to four million women each year in this country. In 1992, there were 52,321 domestic violence offenses reported to the police. The domestic violence programs of the New Jersey Coalition for Battered Women sheltered 4527 women and children in 1992. In addition, we provided services to 15,649 women and children as nonresidents, and responded to 62,710 hot line calls from women victims.

Medical costs for domestic violence are estimated between $5 billion and $10 billion a year. One hospital in Chicago ran up one-year charges of $1,156,408 for acute care only for the 708 patients seen in its family violence program. These numbers do not begin to take into account the costs of therapy, counseling, child protective services, foster home placement, shelter for victims, criminal justice costs for victim response, the effect on children, or loss of productivity on the job. These are health care costs that are not necessary to incur. We could easily fund universal health care with the money we would save by eliminating the costs of treating these intentional injuries.

"Domestic violence is a cancer that gnaws at the body and soul of the American family," said former United States Surgeon General, Antonia Novello, M.D. Studies indicate that 25 percent to 33 percent of female trauma injuries are a result of battering. Stark and Flitcraft have found that domestic violence accounts for more injuries to women than rapes, muggings, and motor vehicle accidents combined.

Several studies also indicate that 25 percent of pregnant women are battered. Research by the March of Dimes indicates that battered women are four times more likely to deliver low-birth-weight babies than nonbattered women. Low-birth-weight babies are at 40 times more risk of dying and having more handicaps than average-weight babies. Also, miscarriages are double among battered women. The majority of battering injuries are to multiple sites, especially the head, neck, face, throat, chest -- especially breasts -- and abdomen. More than one million women per year seek medical treatment for injuries caused by battering. However, studies indicate that only one in ten is officially identified as a battered woman by health care professionals.

A battered woman seeking medical care for an injury is more likely than a nonbattered woman to exhibit signs of depression, anxiety, family, marital, and sexual problems, and vague medical complaints. As Regina said, she is often treated for her symptoms, not the domestic violence. That is not even mentioned. Then she begins to feel isolated because that hasn't even been recognized and no one has really addressed the problem at hand. That can result in all kinds of other psychosocial problems. Studies indicate that 53 percent of alcohol addicted women and 70 percent of women cocaine users are abused. Seventy-five percent to 80 percent of drug and alcohol abuse started after battering began. So they are using these drugs to medicate and kill the pain they have to go through. One in four women who have attempted suicide were battered within a few days of that incident, and usually attempted suicide with the drugs prescribed to calm her.

Why are health care professionals not responsive? The reasons are many, such as lack of training -- which you have heard about -- lack of knowledge, misinformation, and myths. Less than half of U.S. medical schools include domestic violence in the curriculum. Physicians and nurses need to universally screen for domestic violence and receive training on what to say if they get a yes answer. The American Medical Association has guidelines for such screening as part of their National Campaign Against Family Violence. Also, the Joint Commission on Accreditation of Health Care Organizations has set new domestic violence and elder abuse standards for hospital accreditation.

The survey that was previously referred to that the Pennsylvania Coalition and the people in California have done found that the hospitals are not really conforming to accreditation standards. It is going to be a long time before that accreditation kicks in and they are really following up on that.

In New Jersey we have protocols developed by both the Division on Women and by Dr. Howard Holtz of St. Barnabas Medical Center. However, a recent survey of hospital emergency rooms in New Jersey that the Coalition did with the National Health Initiative on Domestic Violence indicates that 65 percent to 68 percent of physicians and nurses do not use, or are unaware of these protocols. The good news is that the majority would attend trainings if they were offered. The New Jersey Coalition for Battered Women is working with the Medical Society of New Jersey to develop a series of programs for hospitals to use at grand rounds to train physicians and their office staff on how to identify and respond to victims of domestic violence, child abuse, and elder abuse. However, if such training was required for licensing, we would ensure that all health care providers would be informed.

I have included the results of the New Jersey specific questions on the survey at the back of my testimony.

While training for physicians and nurses is increasing, and doctors are asked to document injuries in medical records which might be used in criminal or civil domestic violence cases, insurance companies are evidencing a disturbing trend. In Pennsylvania, a battered woman has been turned down for medical insurance, life insurance, and mortgage disability insurance by two large insurance companies -- State Farm Insurance and First Colony Life Insurance Company -- because domestic violence was documented in her medical records. So here we are telling doctors to document it, and insurance companies are denying insurance to women. Another Pennsylvania woman has medical insurance through her employer, but with a disclaimer stipulating that if injuries are caused by domestic violence, they will not be covered by the policy.

We need to ensure that any proposed health care plans or other insurance in New Jersey are not permitted to deny coverage to battered women. That is an essential. This isn't just a preexisting condition thing that would be covered by the current law. I am talking about-- I think they still have the right to deny coverage on certain areas of health problems, and obviously they are doing it in some instances.

MS. FRANCIS: My instinct was, "They can't do that, can they?" but apparently--

MS. PRICE: They can do whatever they want, pretty much.

MS. GRIFFIN: Can they do less in New Jersey now, do you think? Is that your sense, or do you think this would be possible in New Jersey?

MS. PRICE: Well, the new benefits law says they must cover preexisting conditions, but that is when you are coming into a new health care plan. I imagine that if-- I don't know that they would look at that as a preexisting condition.

MS. GRIFFIN: Yes. I haven't seen the letter. I have heard about the issue, but I have not seen the letter to the woman that denied her coverage. Did they say it was a preexisting condition?

MS. PRICE: But it is more than health care. This other woman was denied, you know, disability insurance, mortgage insurance, life insurance, everything.

MS. FRANCIS: Does the Commission have, or can we get documents that--

MS. PRICE: Pennsylvania has the information, and it was State Farm Insurance and First Colony Life Insurance that did it. I believe State Farm is in New Jersey. I am not sure of that.

MS. FRANCIS: Is that something the Coalition might be able to get and pass along to the Commission so we would know specifically what to try to fend off here?

MS. PRICE: They are looking into it in Pennsylvania in terms of regulations through the Insurance Commissioner. It's a Secretary in Pennsylvania.

MS. FRANCIS: Anything that you could provide here would help to shore up how this is written here.

MS. PRICE: Right. I think that is a serious issue that we-- It has not happened here yet, and I hope it doesn't, but you never know, especially with all the changes that are coming down. Everybody is shuffling around trying to see what they can do to cut costs.

The Coalition is also concerned by recent proposed amendments to N.J.A.C. 10A:16-8.1, 8.2, and 8.3, the medical clemency piece in the Corrections Department. Current language which allows application for medical clemency when adequate treatment is not available would be deleted. The contention is that adequate treatment is arranged for women in prison when required, or anyone in prison when required.

The Coalition frequently works with battered women in prison, and a universal complaint is that adequate medical treatment is not available. I have had to intervene with prison superintendents many times, not just at Edna Mahan, but at local prisons, where women are not getting treatment; where they have broken wrists where they don't even respond; where they are not given ongoing medication that they may need for diabetes or whatever. That just doesn't happen.

This is especially also the case where a woman may exhibit mental health problems. Until she does something that causes harm to herself or others, she cannot get treatment. She is then removed to a mental health facility for 30 days. At the end of the 30 days, she is returned to prison with no further follow-up or medication until the same scenario occurs again. Wouldn't it be better to provide on-going treatment for such individuals? Support groups for battered women in prison and other counseling services are woefully inadequate.

According to a recent national survey -- and this is just out within the last month -- commissioned by the San Francisco-based Family Violence Prevention Fund, nine out of ten Americans say that women being beaten by their husbands or boyfriends is a serious problem facing families. The survey also found that almost twice as many people have witnessed incidents of domestic violence as have witnessed robberies and muggings combined. While we debate crime in the streets as a nation, there is an epidemic of crime going on in our homes. If we do not stand up and say that violence in our homes and families is unacceptable, we will continue to have crime in the streets and spend billions of dollars in health care to treat its victims.

MS. FRANCIS: Thank you.

I have, you know, 10 questions clearly that I would like to pursue.

MS. JACOBUS: You said there were some questions that you wanted to respond to that were originally posed to Regina Podhorin.

MS. FRANCIS: Right, but before that, your last sentence-- I am very frustrated by the -- not by the attention on violence right now, the crime in the streets, but by the fact that when it is talked about, so very seldom is it linked the way we know it is causally linked, to violence in the family. Maybe you have a few statistics at your fingertips as to the children who grow up in abusive home situations who are either acting out violence on the streets or in their own families later.

MS. PRICE: We know that children who grew up in violent homes, who witnessed domestic violence-- In 1992, 51 percent of the domestic violence cases' children were either present or involved; 9 percent were involved; 42 percent were present. Involved means they were also hit, as well as the mother being hit. We know that children who grow up in those homes, even just witnessing domestic violence, are more at risk for being adjudicated as juveniles or having problems with drug or alcohol abuse. There are all kinds of problems in school, etc., and mental health problems down the road. I am not talking about here today or tomorrow, but in the future.

Eighty percent of the women in prison were abused at some point in their lives, whether it was domestic violence, sexual assault, incest, whatever. We know how many criminals in jail were abused as children, and yet we continually ignore the fact that a lot of this comes from what is happening in our homes. If you can't get along with the people you supposedly love, how can we expect anyone to get along with their neighbors, or the people in the next town, or in the next country, or anywhere in the world? I really think-- This survey said that 34 percent of the people have witnessed domestic violence -- this national survey they did in California. Only 19 percent have witnessed crime in the street.

The fact of the matter is, we are talking about crime in the street at a time when all the crime rates are down. They are down across the country, not just in New Jersey. They are down everywhere. But this is, like, the politically correct, the in thing to talk about, but we are constantly ignoring women and children in this issue. We are talking mostly about males who are perpetrating crime in the streets, and that is what seems to be the major concern, instead of dealing with this whole issue.

MS. FRANCIS: I interrupted. You were given, Barbara, the open-ended opportunity to answer any of the other questions you would like, so--

MS. PRICE: I really wanted to talk about the custody issue--

MS. FRANCIS: I was going to ask specifically, if you didn't.

MS. PRICE: --because it is a real problem. What can we do, you know, with the judicial system? This is a particular issue with judges. We have tried for, I think, three or four years now to get the Supreme Court to appoint a subcommittee to look into the issue of child custody, especially when it involves child sexual assault. They insist that it can be dealt with through training. So far, we are only aware of one training that has been held with judges. The person who was brought in, we understand, is someone who supports the parent alienation syndrome, which is not something that we think is appropriate.

We are certainly aware of 19 cases in one county alone -- Ocean County -- where women have lost custody of their children, all through the same judge, all through the same psychologist, who was later exposed by the Asbury Park Press as not having any of the credentials he said he had on his resume. His license was lifted by the Board of Psychological Examiners. Unfortunately, those 19 women still do not have custody of their children.

It is happening all over. I mean, we have heard of Hillary Morgan in Washington who went to jail, who secreted her child away to New Zealand. That is not an unusual case. It is very common. It is happening all over New Jersey. Judges consistently think that if you stop the violence, if you get him out of the house and he stops hitting her, the children are fine. Everything is fine. The children are not influenced at all by what has happened or what they have seen. Yet, statistically we have all kinds of information that says how these children grow up and what the risks are for them.

We are still fighting that battle constantly, especially in the area of sexual assault. I saw that Marty Finkel was here this morning, and I'm sure he was quite eloquent about this. You know, even with physicians, who he says do not know and can't recognize when children have been sexually assaulted-- They don't study the children's genitals. They know they exist somewhere between the waist and the knees, but what exactly they look like they do not know.

So it is a major issue. We know that in 70 percent of the contested custody cases, fathers do get custody, contrary to what everybody thinks happens. So it is a real problem. This is another way for a batterer to control her, through the children. He says to her, "If you leave, I'll tell them what a bad mother you are, and I will get custody." And do you know what? He's right, he will. If it is contested, odds are he is going to wind up with those kids. We have seen it happen again and again.

Even in cases where the fathers kill the mothers and wind up in jail, the courts are reluctant to terminate parental rights.

MS. FRANCIS: There was testimony not only from Marty Finkel, but Commander Anita Batman this morning -- very good testimony -- that I think you would be pleased with the impact of.

MS. PRICE: She was part of a group that worked with us that began this group in the State that then-- The National Center for Protective Parents grew out of that whole issue. We are constantly having calls from battered women who are engaged in long-term custody battles. God forbid they should mention sexual assault or that that occurred. In any case, it is just awful.

MS. FRANCIS: May I ask just one quick follow-up? Would you endorse essentially what Regina responded to the mandatory reporting?

MS. PRICE: We do not approve of that. We know that women are most at risk of being killed when they leave their batterers. So they have the best ability to decide at what point it is safe for them to leave. For a doctor to report that-- I can just see all kinds of problems. A doctor could report it. What would happen then? The police would go out. At that point, she may not have any evidence of injuries, so then the police would not arrest. But that has aggravated him, because "What are the police doing here? What did you tell the doctor?" Then it is just going to be worse. So we really do not advocate that.

In fact, the laws in New Jersey do require, however, that doctors report any gunshot wounds. So anytime guns would be involved in a domestic violence case where he would be treating -- a doctor would be treating a gunshot wound, they would have to report that.

MS. FRANCIS: But they might not put it in the context of domestic violence.

MS. PRICE: But they might not put it in the context of domestic violence, unfortunately.

MS. GRIFFIN: The other thing on that is, I do not believe there has ever been a case brought to trial under the mandatory reporting of a professional who failed to report under the child abuse laws.

MS. PRICE: No.

MS. FRANCIS: In New Jersey?

MS. GRIFFIN: Right. So it means there are virtually no teeth even in that, where we think those people are unable to make the decision. So you are putting people at possible risk by irresponsible physicians with no stick to keep them in line, if you would want that.

MS. PRICE: And we are aware of physicians who have been threatened also by the batterer if she doesn't heal. I just don't think it is a good idea. We really do believe that the woman is the one who can best decide when it is safe for her to leave. We can be there; we can be supportive; and we can encourage her. Her doctor can listen, but I don't think it would be wise for the doctor to get involved in mandatory reporting.

MS. FRANCIS: Thanks very much. There is obviously much more to talk about on this issue, and we will continue to do so in other venues.

MS. PRICE: Thank you.

MS. FRANCIS: Bonnie Arkus, R.N., President and Executive Director of the Women's Heart Research Foundation. We were on time for the first stretch there. I apologize.

MS. GRIFFIN: I would like to apologize for Senator Lipman having to leave. She was very interested in your testimony, having been the victim of a heart attack.

BONNIE HARTMAN ARKUS, R.N.: I guess I am here today to talk about cardiovascular disease in women and why I started this new heart organization.

As you can see, I submitted this letter. It is just a synopsis. It breaks down an experience my mother had having a heart attack and ending up needing bypass surgery, and her very poor outcome.

She also, previous to having a heart attack, was a single parent, head of household, since my sister was five and my older sister was fifteen. She raised four children by herself. My father left us, and it was pretty stressful for her having to get a job, find out how she was going to make ends meet, and get the alimony and everything straightened out. It was a difficult time.

Years ago, she had been to her doctor and told him about different problems she was having with her aches and pains. He told her not to complain so much. "Everyone has aches and pains and you are just going to become a public nuisance." So she learned early on that you don't tell your doctor what is wrong with you. She had to just sort of bite the bullet. She didn't live near her family. She relocated to be with my father when they got married after World War II, and her family was in Boston. So she was without many support systems. When my father left her, she really lost all of her friends and contacts after that for quite some time, until they began to accept her again as a divorced woman. But it was a very difficult time for her.

She ended up developing heart disease at a young age. She was only two years post-menopausal and she had a heart attack. Previous to that, she had never been ordered any testing, because she always sabotaged her own care. From that point on, she called herself to the doctors, "I am just a nervous lady. Whatever is wrong with me is just in my head. Just tell me to take a pill and I will be all right," you know, that type of attitude, because she was told early on that there was nothing wrong with her.

When she had chest pain and would grab her chest, through the years that I remember-- When she would get upset about something, or if she had excessive nervousness within herself, she would say to us that she was having a panic attack. She was never diagnosed with any problems prior to her having the heart attack. Her cholesterol was 389. That is extremely high. She had extensive vessel disease. She never had cholesterol screenings done by her primary care doctor or her gyn, and no stress test.

She had what they call "white coat hypertension," where when you walk in the doctor's office you respond to that white coat. The blood pressure may have been high all the time, but they just didn't know because there was no follow-up with the personnel nurse with the government job she had, where they could have monitored this to see if, indeed, it was white coat hypertension or a problem with high blood pressure that was consistent.

She was a cigarette smoker. She tried to quit, but couldn't. A lot of women from her era were cigarette smokers, and still are. Unfortunately, more teenagers are taking up smoking, young girls, I understand, at alarming rates.

So she had her heart attack. That was on Mother's Day. She was unable to respond because of her fear. I was on the phone with her when she was having the heart attack. I couldn't convince her to go to the hospital, and I had to go there the next day to be with her. She was in a local hospital. I transferred her over to another institution, where my father had had bypass surgery four years earlier. We were very pleased with this world-famous, well-renown heart surgeon. We thought, "Well, we want the best for her, too."

She was accepted under the care of the cardiologist, but reluctantly. This cardiologist said, "I am going on vacation. I am really not anxious to accept another patient, but I know you do not know anyone, so I will take her on and do the best I can." With her being transferred in such an unstable state they were kind of concerned, but she managed to get through that okay. They diagnosed her the next day, after cardiac catherization, with "left main" disease, which is one of the worst conditions you can have. A large part of the myocardium is threatened and you have to decide whether or not you can go through bypass surgery immediately, because-- Well, immediately-- Hopefully, if you are having a heart attack, you can be operated on within the first six to eight hours. If you can't, they just do it as soon as possible because of the risk to the myocardium.

They decided that they would operate the next day. We said we wanted the same heart surgeon that my father had, and the cardiologist said, "Well, he's not available." I said, "What do you mean he's not available? That's why we came here, for that particular heart surgeon. We don't want her to have anyone else. She needs someone older and experienced, and we know she is a very sick person now." He just said, "He's not available. You'll have to take the young heart surgeon. He has the same survival rates as the older one. Besides, it is a very grueling operation and young doctors seem to do better physically, being able to withstand the endurance of such a procedure, hanging over the operating room table for so long."

We were very much against it, but he told my mother -- as every one of them on the cardiology team did -- that if she walked out the front door she would be dead; and that if she would have the surgery done, she would have a 95 percent chance to survive. She told them from the start, in no uncertain terms, that if she was even thought of as a surgical candidate, forget it. She was going to die. "Surgery is not for me. I know I can't take surgery. Don't even give it a thought." She knew that too many bypass surgeries are done, and she knew that women do not do well with bypass surgery, so "Stay away from me. I am doing just fine on this medication," which she was.

Eventually, they did talk her into meeting the heart surgeon -- the young one -- and he suggested to her that bypass surgery was the only way out; that he had a 99 percent chance of survival with his patients. He only lost one out of 100, so she was in good hands. Right away a connection was made, the bonding, "I am going to save your life," and that was that. Then he said, "By the way, have you had any medicines?" "Well, I had aspirin," she said. Of course, I told her to take aspirin. He said, "Well, I cannot operate for a week."

Ever since that time, everyone was kind of confused. Here it was an emergency surgery, and then it was delayed for one week. Everything was kind of topsy-turvy. I was by my mother's side and other doctors came in. "Oh, well now that the surgery has been postponed for a week, you can have the other heart surgeon." It was just very difficult to change horses in midstream after that bonding took place between the young heart surgeon and my mom. So we stuck with the young heart surgeon, because she had no real displeasure with him, or dislike for him. There was no reason to dislike him. We decided to proceed.

I spoke to this heart surgeon about what his success cases had been like. I didn't know who he was or anything. He was really up in arms that I would ask questions about where he went to school and the like. I said, "Well, my father was here four years earlier, and he had bypass surgery by the other doctor." He put his hands on his hips, took his glasses off, and said, "Look here now. We are all friends here. If you want the other surgeon--" So I said, "That's all right. My mother is the one to select the surgeon, not me. If she feels okay about this, then, you know, we will just keep you. I don't have anything against you, Doctor." His was just a very fragile ego.

Well, she was operated on a week later. When she was transferred from the basement OR to the sixth floor ICU, her blood pressure dropped, and she died on the way up, essentially. When she was in the Intensive Care Unit, we were walking in to see her at 3:30, because that was the time we were told we could see her, and we actually saw them trying to code her at that time. She was taken back downstairs after an hour of compressions. Then they reoperated using SVG procedure. They brought her back upstairs at 1:09 the next morning, so she was on machinery, bypass, essentially from the surgery, 8:00 a.m. the morning before until 1:00 a.m. the next day. She was still asleep, of course, when we saw her at that time.

She was on an artificial heart device that was experimental. She had 25 IV bottles, blood going in, a hypothermia blanket, a ventilator, a balloon assist pump for the heart, as well as the heart device. She had a completely open chest with a pool of blood and two huge cannulas protruding directly out of her chest. It was just an alarming sight. I have been an ICU nurse many, many times in many, many hospitals. I have never encountered such technology.

I said to the doctor right away, "Take her off of this. Let her die. This is awful." He said, "Well, we can't now. We are going to have to let her heart rest for three days. She is in heart shock. I could not get her heart to restart after I changed the procedure." My sisters, my brother, and I talked about it, and we decided we had to do something to not allow this to go on a moment longer. We tried to meet with the doctor to express our concerns. He was too busy to meet with us. He just wasn't willing to sit down and chat. We needed to have a heart-to-heart talk with him about quality-of-life issues.

We ended up meeting with the Sister who was head of the Medical Ethics Department for the hospital. She said, "Make him sit down and talk with you about what her quality of life is. Then you decide. Let him know that he is not to tell you that you are playing God, as he has. You need to tell him, on your mother's behalf, what she would want. Find out what her chances are of having a normal life again."

Finally, we did get him to sit down and talk to us, after waiting several hours. We learned the worst: that she would have brain damage, permanent kidney damage, a massive infection, and a heart so damaged that she would be incapacitated. Also, she would not be able to return to her job as an Administrative Secretary for the Army General at Walter Reed Army Hospital -- the Adjutant General.

She was a very bright woman. She had two homes and a mortgage on her beach home. She just had a very active life. In no way did she really think she could survive this procedure, and did she even want to, because she couldn't afford to? There would be a long rehabilitation period involved with this bypass surgery. She was very hungry for information about what her insurance was going to cover, just practical things like that. I tried to get on the phone when she was in CCU before the surgery to find out if Blue Cross would pay and what she would be responsible for in the way of doctors' and hospital bills. She set her mind straight that she could afford the $6000 out-of-pocket expenses.

Well, all that is for naught right now. What I found out afterward is most important, I think, and that was from the interviews with the doctor and the surgical team. A lot of it has to do with how women are different from men and how we are not being treated differently from men, and the timing of an operation. The anesthesiologist, for example, spoke with reservation. He said, "I would not testify and get on the witness stand, so don't even ask me to. But I will tell you this," because I asked very pointed questions. He looked at me, like-- He was so surprised. He said, "You asked every question that the doctors asked in the Surgical Review Board. How do you know all this?" I said, "Well, I have worked in a hospital for many years, and I know what's going on. I remembered that you don't mess with a healing heart. Why is it that she was doing so well on medication, looked 10 years younger, and was so full of color and feeling so well, and 10 days after a heart attack you operated on her and killed her? I need to know exactly what is going on here."

Sure enough, from the records I had xeroxed they did transfer her in a very unstable state, after being stable for only 10 minutes, and on a drug that was a very dangerous drug, levophed for causing spasm. The anesthesiologist was open with me. He said, "You know, I don't really know that we should even give this medicine to women. Perhaps we need to do pretests on women." There was just a lot of uncertainty about how to care for women with a cardiac diagnosis and facing bypass surgery. Perhaps the timing was a major factor, and that should not have been. He confided that all the doctors disagreed with the timing of the surgery.

He said, "Women don't do well at this hospital with this operation," and the surgeon admitted that he didn't operate on women usually and he didn't know they were so different. The IMA procedure, the artery procedure, was what he changed over to all veins, because that's what he saw went into spasm before he closed her chest up. He saw it spasm twice. When you have it go into spasm, there is competition for the blood entering into the myocardium. So all of a sudden you have the heart shock and cardiac arrest.

I asked, "Why is it the OR is in the basement and the ICU is on the sixth floor? Have you lost other women on the elevator ride because of the negative gravitational force? Women go into coronary spasm much easier than men because of our stress response, catecholamine response to stress. We are more likely to have panic attacks; we are more likely to have drug sensitivities, especially to vasopressors. Here we had an elevator ride to contend with on top of everything else.

Yes, they had lost two other women in the elevator ride there. That they admitted to me. You know, it makes you wonder if the institutional risk factors at certain hospitals are resulting in a higher death rate for women. The IMA procedure is one that is being talked about amongst cardiology circles today, whether or not it is wise to use it on women, and the issue of coronary spasm.

I went to Philadelphia and spoke to several heart surgeons last week. I learned that they are now doing a double bypass in that area, one artery and one vein, to the main part of the myocardial left ventrical. The vein allows for immediate transport of blood; whereas, the artery -- the IMA -- will eventually expand, and in two weeks' time supply more blood to that area and the vein will shut down. But all this is just, "We don't know if this is going to work. We are just trying it," because they have this problem they are dealing with, mostly with women. It happens with men, too, but more with women.

The quality of care: I don't know whether that was affected by a physician attitude, because the cardiologist told me about how "worse things have happened." They lost a man from bypass surgery who had a young child. He said that intelligent women don't seem to do as well with this operation. So I don't know if he does an IQ test on women, or what. I thought that was an interesting statement. I didn't know how he could back it up.

MS. FRANCIS: Read that one back -- about intelligent women.

MS. JACOBUS: Intelligent women don't do as well in this operation.

MS. ARKUS: It seemed to him.

I agree that she was not psychologically prepared. What they have in the heart surgeon community is a risk ratification system. I don't know if you have heard about that, but it all has to be filled out before a patient goes through an operation. The patient has to be told the truth about where they fall in risk factors. What is not included in any of the risk ratification systems is recent MI and patient attitude. But it is generally believed by the medical community that those are extremely important risk factors. They are just not quantitative, so they can't put them in there.

Unfortunately, my mother's attitude was that she was going to die, and she had had a recent MI.

MS. FRANCIS: This heart attack -- myocardial infarction?

MS. ARKUS: Oh, yes.

MS. FRANCIS: I can't imagine not having a risk factor being that you had a heart attack within the last week. Are you saying it's not?

MS. ARKUS: Well, it is not factored into the table, because when you actually had a heart attack is really hard to define. The testing really isn't that great -- the myocardial bands. It takes four days to get those back. It takes a long time to get real definitive proof that that person had an MI. So they can't really put that into-- At least--

I met with Dr. Parcinnet (phonetic spelling) who made up the Parcinnet Risk Ratification System. I told him, you know, "You really should put some sort of an addendum somewhere, because the doctors aren't paying much attention to this anymore." I think it is financially motivated to operate on anyone at anytime. They do these studies that show that, oh, if you wait past a certain point in time-- More people die if you wait the four to six weeks for the heart muscle to heal than if you just operate on them right away. All of a sudden, the whole idea about nature and healing the heart is sort of nonexistent anymore, because it is more important to do bypass surgery, and death is supposedly occurring more if you wait.

Well, there are a lot of other factors involved, such as if you have a fatal arrhythmia, which my mother did not have. The doctors I spoke with who are some of the best doctors in the country, the ones who are getting the best results are taking into account if you have had a recent MI. I met with Dr. Sinc (phonetic spelling) at the Philadelphia Heart Institute, because he was saving women's lives after bypass surgery at the same rate as men. His success rate is 2.3 percent mortality for both men and women; whereas, in the rest of the country they are having a death rate, supposedly, of two to three times that of men. So I said, "What are you doing--"

MS. FRANCIS: Post heart attack or post operation?

MS. ARKUS: Post operation -- bypass surgery. I said, "What are you doing differently? I want you to tell me." Well, it was very painful to get this information out of this heart surgeon. It was just like I was asking for the world.

He really paced back and forth for quite awhile, and it was just, you know, "Should I tell her or not?" Finally, he said, "It is not small hearts. It is not small vessels. It is not any of those things you are reading about." I said, "Well, then what is it?" He said, "It is quality of care." I said, "Oh, really?" He said, "Yes. I do the history and physical myself. I get to know my patients. I do the procedure myself. I don't let anyone else take over. I take my patients to their rooms." The layouts are next to each other, by the way -- the OR and the ICU -- as they are supposed to be. He has a wonderful surgical team of pre-op nurses who go in there and spend a great deal of time with each patient, painting a picture of survival, showing them the OR, the ICU, the videotape -- "This is what is going to happen to you" -- and introducing the patient who survived the procedure, whether it be male or female, hopefully female for female. All of these things -- and I have interviewed many bypass surgery patients -- are what contribute to survival.

My mother had none of them; none of them. She had no preparedness whatsoever, no pre-op teaching on coughing and deep breathing, no film, no tour, no nothing -- nothing. It disturbs me greatly that the surgeon transferred an unstable patient after 10 minutes of a normal blood pressure, or near normal.

I think there is a great deal of respect for life here with this particular heart surgeon in respecting women, and not passing judgment on who should live and who should die, for instance, about the statement, you know, a man's life being more important than a woman's. I don't think this particular heart surgeon feels that way. I think he spends as much time with his women patients as with his men patients, because he wants them to survive. He said, "I see them to the front door." That is commitment. He is one of the best heart surgeons in the country, and he has been written up. He is not going to let the rule of economics at the hospital tell him when to do bypass surgery. It is going to be done when it is clinically safe for the patient. I am very concerned--

MS. FRANCIS: You would hope that that would be the general approach.

MS. ARKUS: The norm.

MS. FRANCIS: Yes.

MS. ARKUS: But it is becoming not the norm. It is a very big concern of mine that more and more people are going to have bypass surgery at inopportune times, and the death rate may continue to climb. Bypass surgery can only be justified if the outcome is excellent. We are seeing outcomes all throughout the country that are not excellent.

MS. JACOBUS: And rates of preventive, well-prepared bypass surgery are much higher in men; whereas, rates of emergency, less than optimal situation bypass surgery are much higher in women.

MS. FRANCIS: My comment was going to be that a lot of what you shared clearly would be applicable to either males or females undergoing it, but some of the particulars-- We appreciate your sharing your personal experience, but some of those particulars lead us to draw conclusions in terms of the differential -- the gender differential.

MS. JACOBUS: There are studies that show that men have a much higher rate of prepared, preventive bypass surgery; whereas, women tend to get emergency surgery, because they were not given the preventive care.

MS. FRANCIS: Could you maybe just conclude briefly if you want to tell us about the Women's Heart Research Foundation which you set up as a result of this experience?

MS. ARKUS: Yes.

MS. FRANCIS: Is it primarily educational?

MS. ARKUS: Well, getting back to the diagnostic tests, the EKG is only 50 percent of diagnosing changes in women's hearts. If that is the case, they are less eligible to receive therapies and be diagnosed early on with heart disease and heart attacks. That is very unfortunate for thrombolytic therapy -- in receiving that.

They have the technology out there to improve it so that it is 85 percent effective, but they are not, like, charging ahead with it, even though they know it is out there.

MS. FRANCIS: How effective is it for males, do you know?

MS. ARKUS: I think it is better than 85 percent in males, but I do not have that statistic. But to get it up to that level for females would take the addition of a seismograph onto the probes.

MS. FRANCIS: What is the reason for that?

MS. ARKUS: They think it is with the additional fat tissue of the breasts.

MS. FRANCIS: The breasts, yes.

MS. JACOBUS: The tests were not designed for women. The tests were designed for men.

MS. ARKUS: Yes. As you can see also from my written material, my great-aunt died from bypass surgery, because she did not have the question asked of her, "Did you have a vein-stripping operation?" They should automatically ask that question, since women have it more than men because of child-bearing years and varicose veins.

There is also a problem with women not getting thromoblytics even though they are eligible. Some of the heart surgeons I am working with -- women heart surgeons -- are very upset about this. They gave joined, because of that, in asking: Why it is that women are not getting the thromoblytic therapy, even when eligible?

There is the other woman heart surgeon who said they have tried to have conferences on women and heart disease, and the men are not listening. The cardiologists who are male are just not showing up, or spending a lot of time on this issue. So they are very happy to know that we have now a new heart organization that is going to focus on women.

The heart organization I founded-- I feel the only way we can really get attention is to use our insurance dollars wisely, because that is the only equality that women have. The reimbursement for bypass surgery is the same for a woman as it is for a man. So we need to find doctors who are going to give us the best quality of care. That is what our programs are all about.

First of all, it is for getting better care through clear, objective, persistent communication. We have a button campaign coming up next week. We just received a proclamation from Governor Whitman to make next week Women's Heart Week, trying to draw attention to that problem.

We also have a new "Heart Attack Survival Guide" that has to do with making sure that if you don't feel you should be sent home and you still have chest pain in the ER, you should demand to see a cardiologist before being released, because that is your right -- patient rights.

Advance directives, I also did. That has to do with taking some of the fear away from people about what that law really means.

This particular "Queen of Hearts," my original "Heart Attack Survival Guide," is going to try to help people get the best heart surgeon for themselves. It promotes regionalization of bypass surgery, because that is really how you get lower death rates from bypass. The experience, like thousands of cases a year-- Each doctor will have enough skill and experience.

We have a new brochure, and I want to give you one of those, too.

I'm sure I am forgetting a lot, but I think that is about it.

MS. GRIFFIN: I would just like to commend you on these publications. I had a little chance to glance through them, and I know they are desperately needed out there. Thank you for forming this organization and distributing this.

MS. ARKUS: Thank you.

MS. FRANCIS: Absolutely. As with a number of other people who have spoken today, there is more important material than we can begin to take in, in one speaking or hearing. Obviously, anything else you would like to submit, we will be eager to get.

MS. ARKUS: Okay.

MS. FRANCIS: Are there any other--

MS. JACOBUS: No. Thank you very much, Bonnie, for coming.

MS. FRANCIS: Yes, absolutely.

We will have the second of the two hearings on women's health on February 9.

There being no other witnesses, this hearing is adjourned. Thank you very much.

(HEARING CONCLUDED)

APPENDIX

Statement of Dr. Anita W. Batman

The Role of the Health Care Provider in Cases Involving the Health of Women and Children as Endangered by Domestic Violence; The Challenges to Health Care Exacerbated by Inequities and Lack of Accountability in the Court System

Statement Pursuant to 45 CFR 73.735-704 and 708

For the record, I must state that my testimony represents my own views and does not necessarily represent the official position of the Department of Health and Human Services.

Text of Statement

I am pleased to be able to speak to this Committee today. I will give you the good news and the bad news. The good news is that the community of health care providers, including physical and mental health specialists, is becoming much more aware of how to recognize, and much more concerned about how to respond to, the greatest threat to the health of women and children in our society today: violence. The bad news is that although we can now recognize it, our ability to intervene is being denied to us by the court system and its adjunct social services system; thus, the bad news is canceling out the effect of the good news.

You, as legislators, have already passed laws and are now in fact passing more and better laws to deal with domestic violence. In fact, the New Jersey legislation is a model in this endeavor. These humane laws which you have enacted, however, are not being applied as you intended. They are being mediated by an interfacing system of judges and social services officials who lack accountability to you or anyone else, and as a result, your best intentions are being misused and your constituents are being deprived of the benefits you meant for them.

In my experience, the courts do not provide a level playing field for abusers on the one hand and their victims, usually women and children, on the other. What we need from you now is a legislated method to review the actions taken by our courts so that your laws are actually used for the purposes for which you have passed them. What we need is a form of judicial review that really works. Both doctors and judges hold the welfare of your constituents in their hands, judges even more so than doctors, because patients can change doctors if they are not being helped, but litigants cannot change judges if they are faced with uncaring, inappropriate or insensitive treatment. As physicians, we are all subject to quality assurance evaluations. Any M.D. who did 60 percent of his obstetrical deliveries by C-Section would automatically be reviewed. Mortality rates are carefully monitored. Yet there is no parallel system to regulate or even report on the quality of judicial performance. At the end of my presentation I will ask that, as a case in point, you investigate the record of Judge Vincent Grasso of Ocean County, and from that model, enact judicial review legislation aimed at bringing our courts, in practice, into compliance with your laws.

The greatest health challenge to Americans up to the age of 44 is violence. One out of every four women who appears in the emergency room in the United States is there because of violence perpetrated against her. Most of this is called domestic violence and is handled differently from other crimes. This is not a problem peculiar to New Jersey. According to the

FBI, roughly 4,000 women in the United States are killed each year in domestic violence cases. The Department of Justice reports that an estimated 6 million women are abused by their domestic partners each year. We see these casualties constantly. When I first began my career as a public health physician 19 years ago, I didn't have as much knowledge and experience as I do now to help me recognize the effects of violence in my clinic or in the emergency room. As the years went by, and I kept up to date in the field of family practice with an emphasis on women's and children's health issues, I became more adept at recognizing injuries and conditions associated with abuse. I am a mandated reporter of child abuse whenever I do suspect it. But this awareness is not common to every health care provider. I train my clinics and I encourage all providers with whom I come in contact to train all providers in recognizing and responding to the effects of violence. But many other providers do not yet have the expertise I have gained the hard way in this field. For example, a pediatrician in Union County who does investigations for DYFS has admitted under oath in court that he has NEVER, in 18 years of practice in New Jersey, made a single mandated report of child sexual abuse. It is frankly impossible that he has never seen or treated a child who has been molested -- he simply has not recognized, admitted, or reported these cases. I cannot offer a legislative solution to that problem, except mandated training for all health care providers licensed by New Jersey to teach them to recognize and REPORT suspected abuse.

The larger hurdle, unfortunately, is that once we, in the clinics, offices and hospitals, suspect or even diagnose the results of violence, we are mandated to report it to systems unprepared to deal with it effectively, and which hamper us from dealing with it appropriately. Social services and court officials take over these cases from us and do not follow through properly in the clients' best interests. The first interface in my clinic or office is my report to law enforcement personnel or DYFS. In my experience, the rule has been that once I report suspected abuse, the treatment the victims receive from the system is much worse than the treatment the alleged perpetrators receive from the same system.

I have had DYFS workers refuse to investigate a clear-cut case of SODOMY of a little boy because they reported that the family was about to move to Pennsylvania. I have had parents BEG me not to report the rape of a young adolescent by a known neighbor, because they had such negative experiences with the social services personnel when they, as children, were molested, that they wanted to spare their young daughter the abuse the system would heap on her after the trauma she already suffered. I could not help but sympathize with them because I have testified in court about raped children, and heard judges refuse to consider the evidence. I have heard judges who are presented with the evidence refuse to protect women and children from violence in spite of findings by me, other doctors, psychologists and social workers.

We are taught in medical psychiatry, how to help the patient who has been subjected to violence: (1) strengthen the support system of the victim; (2) protect and empower the victim; (3) heal the trauma. I have observed Social Services and the courts, however, do the opposite. They generally isolate the child from his or her support system, which is usually the non-offending or, as I say, protective parent. They usually empower the abuser by respecting his adversarial position so that he has continuing rights of access to the victims. And they continue the contact with the abuser by court order, so that the abuse itself either continues or so that the victim's outcry is chilled and inhibited. In addition, they punish the protective parent's resistance to exposure to the abuser, in the form of court-ordered visitation or even custody. Consequently, a health provider cannot treat the patient with emphasis on healing, because the prerequisites, one of which is removal from abuse, are not possible. When a judge orders a child into the care, custody and control of an abuser, a doctor cannot effectively treat the child to help the healing process from past abuse.

Case in point. Judge Grasso in Ocean County. The primary case I will describe today is that of the three Paivandy girls, now ages 15, 11 and 9. Their cases started in Ocean County in 1987, when they were 9, 6, and 4. Their mother, Margaret Paivandy, who is here with me today, had approached the Ocean County Family Court for an order of protection against her husband who had beaten her violently on several occasions and who was becoming more threatening as time went on. She was issued a temporary order of protection. When he violated it repeatedly, she was given a permanent restraining order, as if that, rather than punishing the perpetrator for disobeying the protective order, would keep her and her children safe.

Fearing that the order would protect her about as well as the temporary one had, and knowing that many women are dead with protective orders on file, Margaret Paivandy moved back to Oklahoma, where she had family, hoping to avoid her husband's wrath. In Margaret's absence, her husband divorced her without notifying her, but when he asked for custody, the first judge denied it for obvious reasons -- he was already ordered never to go near the children. Then he went to another judge and used a new docket number to apply for custody claiming that he could not notify the mother because she had left no forwarding address -- which was untrue since she was back with her family in Oklahoma and his minister was in contact with her minister, trying to reconcile the couple. He got a custody order from the new judge, but that may have been a fluke because the new judge was actually on his deathbed at the time; the order may have been fraudulent.

Nevertheless, his travels through the New Jersey courts had just begun to pay off in his attempt to punish his wife for escaping his abuse. He testified before a grand jury that he had the custody order a year BEFORE he really had it, and as a result of this perjury he got criminal process drawn against her for "interference with custody." As soon as she noticed his detectives in Duncan, Oklahoma, she fled with the children. Several months later the FBI arrested her and New Jersey unlawfully extradited her children to DYFS foster care without a hearing on the validity of the custody order. She was jailed and mistreated and her children were thrown into the care of strangers, although they had been disclosing sexual abuse by their father ever since they were out of his control after the issuance of the first restraining order.

The children disclosed sexual abuse to DYFS workers, mental health professionals, and physicians. Park Pediatrics of Ocean County documented their disclosures and physical signs of molestation. Dr. Katz, to whom DYFS took the girls, documented that two out of three of those girls did not have hymens -- definite signs of extreme sexual abuse. All of their disclosures, drawings, physical exams and behavioral indicators supported the conclusion that they had been molested. The caseworker from DYFS who originally handled the case found their disclosures credible and detailed. The Sheriff's office documented their descriptions of horrible abuse at the hands of their father.

On the legal front, while all this medical evidence piled up, the mother's lawyer pointed out that the criminal warrant was a result of perjured testimony at the grand jury hearing, because the custody order was made AFTER the mother and children left New Jersey, not BEFORE. Furthermore, he showed that the custody order itself was VOID because there had been no legal notice, as provided in the U.S. Constitution and New Jersey law. The New Jersey Superior Court vacated the custody order that the father had wrongfully obtained, so there was no foundation whatsoever for holding the children or the mother. The minute that custody order was vacated, those children should have been returned to their mother. Yet Judge Fall, and later Judge Grasso, held those children, without due process, trying to make the sexual abuse allegations "disappear."

It may occur to Your Honors that this is a very strange story and that if it really did happen, it only happened once. I assure you that this is commonplace in New Jersey, and elsewhere. Unfortunately common is the use of child custody suits to restrain a wife from escaping abuse. In fact, I have a study with me that says that in Orange County, North Carolina, it was discovered that every time allegations of paternal abuse were made, those fathers won sole custody of the children allegedly abused by them, if they sought it. Courts do not want to hear about child sexual abuse. I was actually informed by a lawyer in Mississippi, where I used to practice family medicine, that judges did not want to be told about child sexual abuse, so doctors had better not tell them about it. He also told me that mothers who discover that their children have been molested by fathers should shut up about it for fear of losing their children, because the judges would take the children from the mothers to prevent further disclosures.

As a physician, then, I am faced with the following moral and legal dilemma: if a mother like Margaret Paivandy were to come to me today with a child I felt in my medical judgment had been molested by her father, what would I do? Would I obey New Jersey state law and report the case, resulting in the mother being deprived of her child and the child being handed over to her alleged perpetrator? Or would I inform the mother of what the system and the lawyers have taught me: that these courts are so unwilling to protect women and children that the child's health is in more danger IF THE ALLEGATION IS MADE than if the abuse is accepted and limited to visitation periods, so the child may receive treatment and comfort during the rest of the week?

What would I have told Margaret Paivandy if I were a physician seeing her with her broken collar-bone after a beating or seeing her daughters with their disclosures, their fear and their torn hymens? Would I have told her the truth? Would this state's court system have allowed me to care about her health and her children's health as I have sworn to do in my Medical Oath? My oath also said that I should "DO NO HARM," and I would be afraid that if I advised Margaret Paivandy to go to court to try to protect her children, I would be doing her harm.

Margaret Paivandy's three children will suffer the effects of child sexual abuse all their lives, but they will suffer the effects of Judge Grasso's brutality far more. No amount of therapy as an adult can rebuild their faith in this system, even if they heal from the psychological sequelae of the abuse itself. I can count on this mother to help them recover from the abuse. I cannot turn to anyone but YOU to help them and the other women

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and children of New Jersey to recover from the abuses heaped on them by this court system, by judges like Judges Fall and Grasso.

Judge Grasso has had other victims. Apparently, DYFS knows how he operates and appeases him by making sure that allegations of abuse do not interfere with his "dispensing justice" as he sees fit. There is a mother named Patty Smith whose case in front of Judge Grasso was a horror story like this case. A mother named Arlene Willett met with the same kind of judicial tyranny at Judge Grasso's hands. I don't have time to give you the details, but I have fact sheets available for the Committee. There are, by word of mouth, hundreds of such cases in Ocean County. Colleen Adamczak is a mother who reportedly fears divulging the details of her case because of fear of judicial retaliation. Of course, all my information is anecdotal, but from the documentation I have seen and the fact that the stories told to me are internally consistent and credible, I am using the same kind of judgment I exercise when, as a physician, I assess a patient's history. I believe the anecdotal information I have heard is cause for concern about Judge Grasso, although he is not particularly unusual, although he may be particularly extreme.

What I ask of this Committee is the following: first, institute an investigation into Judge Grasso and the cases, including the Paivandy children's case, that have come before him in which the abuse of women and children is "disbelieved" and the women and children are deprived of protection and subjected to more risk. Second, if it is determined that there is some anomaly in the cases heard by Judge Grasso (such as a preponderance of custody cases with allegations of domestic violence or child abuse involved being decided in favor of the accused abuser rather than the protective parent), set up a model for judicial review based upon Judge Grasso's history. If, in fact, my anecdotal information about Judge Grasso does not lead to information about him that would provide a basis for such a solution, then I would invite this Committee to look into some of the other judges about whom we have heard these reports, such as Judge Nardi of Camden County. He has recently ordered joint custody of two twin boys whose mother, JoAnne Esposito, has faced years of abuse by her husband and the system, abuse that DYFS has documented over and over, abuse that medical professionals have tried to stop, abuse that will inevitably continue because these twins, who were molested by their father according to DYFS findings, will be living with him at least half the time in an unsupervised setting. This kind of outrage is not limited to Ocean County; it permeates the courts of this state.

Then, of course, the important thing is to pass enabling legislation to set up the judicial review board and keep it in operation so that all the other legislation you pass to deal with health issues for women and children and issues of domestic violence will have some TEETH in it. The review board should be composed of physicians, care providers, women's and children's lay advocates, and concerned citizens. It should not operate as a "court of appeals" that merely opines on whether a judge has made a legal error -- we have appellate courts for that. What we need to find out is whether or not a judge who has power to give or deny protection to persons at risk is making sound, humane, sensitive, informed decisions about RISK. Is he, on the other hand, making decisions motivated more by prejudice and outrage than by sound discretion? In the highly emotional and volatile circumstances surrounding allegations of domestic violence, it is always possible that a judge who would rule in a perfectly proper fashion when deciding a commercial case may not be as capable of good fact-finding and decision-making in a case involving allegations of wife-battering and child abuse.

In addition to the investigative function of the legislature, the subpoena power, and the enabling power, I would ask Your Honors to consider the very important function you can fill by making public policy for the State of New Jersey as follows: write law that says that domestic violence is as damaging to our society as public violence; write law that says that beating a wife is as serious as beating a bartender; write law that says molesting a child is as serious as sexually harassing a secretary; and write law that says a judge is accountable for his or her failure to use that law to protect victims of domestic violence, and persons at RISK of domestic violence, from harm.

Let's work toward three goals: ONE, a system where rapists and abusers are on trial, not their victims -- and assure ourselves of this by knowing the judges' track records on convictions of abusers; TWO, a system where abuse victims are protected -- and assure ourselves of this by comparing the judges' recidivist rates; and THREE, a system where child custody is decided on the child's right to be loved and nurtured, not possessive rights of adversarial adults in the child as property -- and assure ourselves of this by allowing no gender bias in contested custody cases, and especially, no bias toward custody for those accused of child abuse BY THEIR CHILDREN. Let's find the judges whose actions decrease the rates of repeated violence and reward and copy them. Conversely, let's find those judges who protect and enable perpetrators of domestic violence, and remove and replace them.

Thank you for hearing me out. I will be glad to provide referrals, documentation and any further assistance in this very important endeavor.

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Case Notes Paivandy

Margaret married her husband in March, 1977 in Oklahoma. She gave birth to three children, all girls. Early in December, 1984, after the birth of the third baby, and while the other two girls were 3 and 6 years old, Margaret's husband began to physically abuse her.

Her husband had just gotten citizenship in this country while Margaret was in the hospital having the baby. His friend had also come to Oklahoma and convinced him to move to New Jersey. When the baby was three weeks old, Margaret's husband ripped her clothes off, raped her, dragged her into the bathroom and beat her viciously. She still had the stitches from childbirth. After that beating, Margaret had a broken collarbone. She turned to her minister, not to the courts, at that time. Her minister advised her that had she been a good wife, she would not have been punished. She commented later, "I have found that this attitude is not confined to religious authorities." She recovered at her sister's house and then returned to her husband, hoping to avoid more "punishments."

Margaret was trying to save her marriage and to avoid further abuse, not realizing that such violence, unchecked and unpunished, increases. The Paivandys moved to New Jersey in July, 1986. In New Jersey, the violence continued. Margaret was not yet seeking the help of doctors or mental health professionals, but she was seeking the help of the WorldWide Church of God, the family's church. By December, 1987, however, her husband was so threatening and so violent that she feared for my life and the lives of my children. She went to the Family Court in Ocean County and Judge Pepe issued a temporary restraining order against Vahid Paivandy to stay away from the marital home and to avoid ALL CONTACT with Margaret and the children. On January 4, 1988, Judge Pepe turned that into a permanent restraining order because the husband had broken the TRO many times and had even entered the house illegally.[1] Two days later, fearing his reaction to this latest court action, and needing the support of her family, she returned to Oklahoma with the children. She was fully within her rights since she had custody and her husband, who had abused her and the children, had no visitation rights and was ordered to keep away from the family. Meanwhile, two ministers, one in New Jersey and the other in Oklahoma, seem to have communicated, and they were both in contact with Vahid Paivandy husband. They urged Margaret to return to him and not to object to his abuse.

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[1] Margaret was told later that DYFS was supposed to have contacted her within 48 hours of the first TRO issued by the Family Court. Since it did not do so, it is possible that DYFS later acted against her and her children's interests so that it would seem that there had been NO ABUSE in the past, so it would not be blamed for negligence.

In October, 1988, Vahid Paivandy filed for and obtained a New Jersey divorce against Margaret on default, pretending that he did not know where to locate her for service of process. By this time, since the children felt more comfortable and less afraid, they had begun to disclose various incidents of sexual abuse to their maternal grandmother.

One month later, Paivandy went to court in Ocean County, NJ and got custody of the children by default from Judge William J. Kearney -- in spite of the TRO that was still in effect. The reason this occurred was that Paivandy "changed" the docket numbers on the two proceedings -- domestic violence and divorce -- so that the courts were not coordinated, and of course, Paivandy was pretending not to know where Margaret was to notify her of proceedings. Judge Kearney was dying of cancer at this time, and is now deceased; it is possible that there was an actual fraud perpetrated on the court, for someone may have stamped Judge Kearney's order rather than actually informing him of the proceedings. There is no record of the hearing, if there ever was one. Shortly after obtaining custody by default and/or fraud, Paivandy hired detectives to go to Oklahoma. Margaret and her family noticed that, and began to fear that her husband was in Oklahoma to abuse her further and/or kidnap the children. She borrowed her parents' camper and fled with the children.

On January 6, 1989, Paivandy misused the court system again to file criminal charges against Margaret in N.J. for "interference with custody" for allegedly fleeing with the children when he allegedly had legal custody of them. None of that was factually true. Yet on January 18, 1989, the N.J. grand jury indicted Margaret for Interference with Custody because Paivandy lied under oath, claiming that he had gotten custody BEFORE she left for Oklahoma, not AFTER. He had simply lied and said he had a custody order from a date a year earlier than the date when he actually obtained custody. He later admitted that.

Meanwhile, Margaret had relocated with the children and they were feeling safer and more confident that their father couldn't find them to punish them for revealing abuse. All three Paivandy children told her that they were sexually molested, physically abused and threatened that if they told, they would be killed. None of them disbelieved that their father would be capable of carrying out his threats. He had been a very violent man and they had been terribly abused. Only when they were far away would they risk talking about what had been done to them. But Paivandy already had the law in New Jersey working to help him get those children back and punish them. Of course, he also wanted to punish Margaret for reporting his abuse and for trying to escape it. He had said to her, "Margaret, I married you until death do us part and you're not dead yet." Margaret reported, "my children would cling to me and say, 'when Daddy finds us, he's gonna kill us.'"

On May 4, 1989 the FBI arrested Margaret Paivandy in Salisbury, North Carolina. She was jailed without bond and the three children were thrown into foster care. Although she was arrested on a federal fugitive warrant, she informed the arresting officers that she had documentation proving that the NJ indictment was invalid, because it claimed that she had taken the children when they were in their father's custody, when that was shown to be false by the date on her custody order. The law enforcement officials then knowingly changed their charges to North Carolina criminal charges for interference with custody although that was bogus, because Margaret had not broken any NC law. Thus they were holding her without a valid warrant and they had the children illegally, all of which the FBI later admitted.

NJ and NC arranged an interstate transfer of the children which was illegal by both states' laws and by federal law. The children were physically fighting with the social worker even as she forced them onto the airplane to take them to NJ. When they were in NJ, Margaret and her parents rushed to that state to regain custody of them, but they found to their horror that New Jersey would not release the children to them.

On May 17, 1989, the children's statements were taken in NJ and they disclosed sexual and physical abuse. Later, it was discovered that the older two girls' hymens were missing, which is dramatic evidence of child sexual abuse.

The next day, however, Margaret was again arrested by the Ocean County prosecutor's office. Paivandy, in spite of the children's statements to the authorities, was never arrested nor did he even have a grand jury investigation on the charges of violent assault, battery, sexual abuse and harassment. Margaret pleaded NOT GUILTY to the charge of interference with custody in front of Judge Campbell on May 18, 1989.

Margaret's lawyer started proceedings to vacate the illegal custody order that had started the entire mess, and on June 15, 1989, the custody order of November 15, 1988 WAS ACTUALLY VACATED, nunc pro tunc (indicating that it was void on the day it was made as well as afterwards). In other words, the FBI had now admitted that this mother was illegally arrested; the underlying custody order that had given rise to all the bogus process in three states was then wiped out FROM THE BEGINNING. But Margaret was still facing criminal charges and her three children were still in the total control of the social services department and court system of Ocean County New Jersey, which did not have legal jurisdiction over any of them and which had in effect actually KIDNAPPED all four of them from another state, on paperwork that had been declared null and void.

Bob Peck of the prosecutor's office of Ocean County insisted on continuing the prosecution of Margaret Paivandy for "interference with custody" even though the custody order was vacated. Meanwhile,-those children were taken to their abuser for unsupervised overnight visitation while the mother was not even allowed to see them for over three months. The social services personnel forced them (with the help, of course, of their father) to "recant" their disclosures of sexual abuse. Still, the oldest girl would not recant and insisted that she had been molested as had the other two, whom she was trying to protect. After about three months, the mother was allowed to see the children in SUPERVISED VISITATION, but they were warned not to talk about the abuse or about what had happened to them. THIS WAS BEING DONE TO THE MOTHER AND CHILDREN BY THE DEPARTMENT OF SOCIAL SERVICES ITSELF, WHICH IS CHARGED WITH RESPONSIBILITY FOR PROTECTING CHILDREN FROM ABUSE AND WITH INVESTIGATING ABUSE CHARGES.

In late June, 1989, Judge Fall held a brief hearing in which it was decided that a psychologist would determine whether or not there had been sexual abuse of the children. That psychologist said he "could not tell" if the children were abused.

The Ocean County Sheriff's Department report 89AOONAKX003 reports on 5/25/89 that "The videotapes of each Paivandy child speaks of horrendous and terrifying allegations of Mr. Paivandy's ... brutal sexual abuse to his three daughters and many other female children. The Paivandy girls each give dramatic and SPECIFIC accounts of events occurring approximately 1-1/2 to 2-1/2 years ago." They say the police are investigating the allegations, but "Until the children are examined physically, as well as mentally, a decision at this point would be premature." Shortly thereafter, before the decisions to be made after the "physical and mental" examinations were concluded, the father was permitted to visit the children unsupervised.

That same Sheriff's report says that on 5/19/89, "[child] Paivandy (7 years old) was examined today by Dr. Barbara Katz. Inv. Bernabe was told that in examining [child] she found the HYMEN NOT TO BE INTACT."

The report says that on 5/23/89, "Mr. Paivandy [took] polygraph tests; with the results of each test conflicting."

Shortly thereafter, the Sheriff's notes reflect the fact that when the girls were taken to the doctor, a friend of Mr. Paivandy "happened" to be there and recognized the oldest daughter, talked to the foster mother to "dispel" the allegations of abuse, and apparently informed the father about this contact.

The further examinations of the girls' internal genitals revealed that "Dr. Katz reported that ... she found that [the middle daughter]'s hymen was broken; [the youngest daughter]'s hymen was not broken."

On May 24, 1989, Dr. Nagpal of Park Pediatrics in Bricktown, NJ wrote a letter to the Ocean County prosecutor's office reporting on the examination of the 7 year old girl: "diagnosis: possible sexual abuse. ... would recommend vaginal cultures and tests." On May 25, 1989, Park Pediatrics reported about the 10 year old girl, "Alleged sexual abuse by father and friends, alleged anal and vaginal penetration with fingers. Father's friend touched private parts with his penis, episode occurred 2 years back." The children were in the care of foster parents, not the mother, at the time of this particular disclosure. He described the child as "pleasant and appropriately verbal." On May 26, 1989, Park Pediatrics reported about the 4 year old child: "Foster mother has three siblings. Referred for evaluation by DYFS for sexual abuse. ... history of alleged abuse sexually by father and his friends. Father played with private parts with his fingers. Episode occurred 1-1/2 to 2 years back. ... Diagnosis: possible sexual abuse."

DYFS never filed abuse proceedings for these children so there never was a Title 9 case and they did not have a guardian ad litem. To this day they are unrepresented in New Jersey.

Margaret's husband had to re-sue her for custody because the custody order he had gotten was vacated. The children were in foster care although there was no abuse petition filed for them. DYFS kept the children in foster care while they allegedly checked out whether or not their father had really abused them, or whether the mother was "insane" and "paranoid," in spite of physical evidence that the girls were molested, reported by doctors to whom DYFS itself took the girls.

On October 18, 1989, the Domestic Violence Unit of the Superior Court of Ocean County ordered that after hearing a report of the Ocean County Child Placement Review Board, all three children and both parents were to be "evaluated by a therapist trained in Satanic cults." That order was never carried out because Judge Grasso, who had taken over the case, announced that he would not honor it, and it was made by another judge in another proceeding. Judge Grasso is still making decisions in abuse and custody cases in Ocean County.

Judge Vincent Grasso convened a custody trial, after Judge Fall had appointed Peter Friedman, a psychologist with no expertise in diagnosing or treating child sexual abuse, to be the children's therapist. Friedman was not asked to, nor did he, evaluate the children's disclosures of sexual abuse. No follow-up occurred after their physical medical findings were documented by Dr. Katz. At the custody trial, Judge Grasso did not order any further specialized testing to determine whether or not there was sexual abuse. Although Dr. Martin Finkel, a nationally-recognized expert in child sexual abuse, sought to testify by telephone about the physical findings (which, in his opinion, were 100 percent indicative of child sexual abuse) Judge Grasso refused to allow this testimony. At the same time, he said that he would not consider the children abused unless somebody "could absolutely prove it." At the end of the trial, which was conducted in such a way as to avoid rather than to adduce, the real evidence of the real abuse of the Paivandy children, Judge Grasso ordered custody to the father with no findings about whether or not those children were molested by him.

Judge Grasso became absolutely punitive toward Margaret and ordered that she could not visit her children until she had gone to therapy and had been CONVINCED THAT THE ABUSE DID NOT HAPPEN. Then he would only allow her the most stringent supervised visitation, all based on his decision that she would have to "recant" her own belief that my children were molested. Although Margaret reported that originally, Judge Grasso promised that the visitation would be normalized, this has not been allowed and Margaret is still only getting infrequent, supervised visitation -- which takes place in a room in the Judge's chambers, supervised by hostile supervisors who are court personnel and who regard Margaret's efforts to have her children protected as if that were in itself abuse. The children, in the total control of Paivandy and his new wife, have of course stopped revealing abuse. Now, since they no longer disclose, Margaret is being regarded by the court and DYFS personnel as "mentally unbalanced" to have believed in the abuse. Furthermore, Judge Grasso even tacitly admitted that Paivandy did something of a sexual nature to the children in the bathroom. He actually ordered that the STEP-MOTHER should be the only one to help the girls with their hygiene -- since the father was not to go into the bathroom with the children or undress them. Of course, without supervision, this order is meaningless. This father will do exactly as he pleases with those children because he has never been restrained and he has in fact been enabled by the court system.

Margaret has been forced to pay an enormous part of her income as child support and she cannot even afford legal assistance or transcripts for an appeal. When she went to court on her own to seek a reduction in child support (supporting herself as a registered nurse), Judge Grasso fined her $750 for trying to get legal relief. He also threatened her with jail within 30 days if she didn't pay all amounts he ordered. She had no visitation at all at the time these punitive orders were made.

Besides clear disclosures from all three children, corroboration from others, and internal genital damage from penetration, there is other evidence of the sexual abuse of these three children, some of it so graphic that it shocks the conscience. For instance: the six-year-old drew pictures of the abuse of a little girl by her father, with phallic symbols and weapons. She also drew a picture of many little girls waiting in line with tears pouring out of their eyes as another little girl was being

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knifed or actually beheaded by a grinning man. She also drew a picture of her father, sitting on what she called his "throne" while there was a child abuse ritual in progress. She also drew him in the bathroom with her -- with her in the bathtub and the father sitting on the toilet with his penis in full view, apparently masturbating. The genitals are very prominent in this picture and the depiction of the child in the tub has an alarmed look on her face, backed up against the corner of the tub. Another of this child's picture shows six men with their penises showing prominently, surrounding a baby in a jacuzzi. Five men are grinning and the sixth has his mouth wide open with the teeth showing. The details of their genitals and faces are very clear and gruesome. She made another drawing of a naked man labeled "Daddy" inserting a knife into the rectum of a child bent over a chair, who is saying "HELP ME." The 10 year old girl drew an extremely significant picture of a man ejaculating (or possibly urinating) on a little girl who is naked and has long dark hair. The picture is unmistakable. At the same age, this same child drew a picture of a child abuse ritual in a barn. Her picture is extremely detailed and accurate. The 6 year old drew a man with a knife poised over a prone baby girl who is crying, and the "balloon" at her mouth says "HELP ME!" She also drew a woman wearing an extremely sexy kind of "teddy" of black lace, with only bikini brief and pasties on under it, labeling it "All three bad women had the same suit" referring to women in the ritual in the barn. The 6-year old drew a picture of herself in a cage with snakes.

Marie Makar, of DYFS, was in charge of this case at one time. She believed these children when they disclosed abuse. She was removed from the case. Margaret has been unable to locate her, to try to find out why her children were treated as they were. From a simple reading of the facts recited here and supported in the written record, it is clear that both DYFS and the Ocean County court deliberately prevented the protection of these children from abuse, although the doctors involved acted correctly and responsibly.

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Notes of Ocean County Cases

Arlene Willett's son

DYFS reported to Judge Grasso shortly after an evaluation on or about September 19, 1992 saying "[the father] did strike [the child] on his genitals and buttocks as discipline ... when [the child] was approximately five years old. DYFS will substantiate physical abuse of [child] by [father]. ... Two ... referrals DID SUBSTANTIATE PHYSICAL ABUSE of [child] by [father]." [1]

This boy now suffers from mental and physical, even neurological problems that have their origins in early childhood trauma. Yet in spite of both the physicians involved and even DYFS, Judge Grasso had been ordering visitation between the child and his father when he was not psychologically or physically ready for this experience. As a result of the mother's attempts to explain to the court-appointed personnel that her son was very much negatively affected by this, Judge Grasso punished the mother by turning FULL CUSTODY over to the father, in spite of the DYFS findings of physical abuse against him. It is very clear in this case that the boy's medical difficulties were directly related to the abuse his father inflicted on him. Jersey Shore Neurology reported on August 12, 1989 as follows:

> "[The child has] a history of frequent physical abuse in the past by his father. ... Since that time he has developed headaches which have increased in frequency [this was during the time Judge Grasso was forcing him into visitation with his father]. ... The father had been physically abusing the family members frequently. ...
>
> "Past Medical History: (1) Physical abuse. (2) Hyperactivity. (3) Emotional instability." This medical report also observed that the boy had frequent enuresis and at times was unaware that he was urinating.

So this physician, Dr. Richard I. Sultan, did identify and respond appropriately to physical abuse. Judge Grasso prevented the medical treatment plan for this child from being implemented. By the time the boy was eight years old, he was diagnosed with post-traumatic stress syndrome. Dr. Peter Friedman, a favorite psychologist usually appointed by Judge Grasso to "undo" findings of abuse made by other professionals including medical doctors, was appointed in this case as well. (He was the very psychologist who helped lend credibility to Judge Grasso's decision to ignore the findings of sexual abuse in the Paivandy girls' case.)

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[1] According to a report by this child, the times when his father hit his genitals and buttocks, he approached the child "angry" and ordered him to "take off [his] clothes." In other words, the father beat the child's genitals and buttocks while the boy was naked.

Ocean Pediatric Group wrote a letter to WHOM IT MAY CONCERN in December, 1992, shortly before Judge Grasso gave this child to his father. Dr. DeGroote of that group observed that the boy had a long history of behavioral problems and Attention Deficit Disorder -- he was already on drugs for years. The doctor noted "paternal alcoholism and abuse." He noted that "it is apparent that [the child] fears these paternal visits for whatever his reasons. These stomach aches are accompanied by severe histrionics and vanish after any visitation is completed or not kept. For these reasons I recommend paternal visitation cease until a full, complete psychiatric evaluation of the child and father is completed, and then final psychiatric recommendations are made." That advice was ignored by Judge Grasso.

The child related other incidents when his father assaulted him and tore the phone out of the wall, choking him with the phone cord, when he smashed a flashlight into the wall breaking the door before administering a beating to the child, and other such terroristic attacks. He has drawn a very graphic picture with his father standing in a "KILLING ZONE" and with his face, dissociated, bearing the words DAD!! TIME TO DIE. The picture, drawn on December 26, 1992, shows the father is wearing a Santa Claus hat but his face is green and threatening. This was shortly before the boy was turned over to his father by Judge Grasso. Asked to draw pictures of his parents on January 11, 1993, he drew his father standing alone with a frown in a "KILLING ZONE" whereas his picture of his mom has a rainbow over it, shows her smiling, and has him standing beside her dressed as a happy cowboy. He labels the figures ME and MOM. Ten days later, Judge Grasso removed him from his mother's care and handed him over to his still-violent, still-dangerous father.

In or around January, 1993, this child was subject of a custody battle brought by his father, who relied upon Judge Grasso to punish the mother by handing over his son to him, in spite of the history of validated incidents of physical abuse. The boy had an "in camera" interview with the judge and apparently said that he was very much afraid of his father. This was a boy with multiple diagnoses already. On January 21, 1993, in spite of this history, Judge Grasso awarded full custody to the father. The boy's report card has shown that he went from A's, B's and C's to a present record of only two B's (band and drama, frequently the refuge of abused children who can only express themselves in music and dramatic persona) and one A (in physical education, where a hyperactive child will normally excel). He gets D's in reading and language arts, no grade at all in social studies, and C's in math and science. He is clearly deteriorating due to the medical neglect associated with Judge Grasso's refusal to allow proper treatment for the medical problems he sustained as a result of the violence to which he was, and probably is again, being subjected.

Patricia Smith's Son

This mother was subjected to a sort of "touch-tag" in the Ocean County Courts wherein Judge Grasso and Judge Fall (the same two judges in the Paivandy case) made orders back and forth and effectively prevented her from seeking outside help in protecting her son from abuse. She reported that the father was physically violent toward her during their marriage, but she did not receive court intervention or assistance. She was "gag ordered" not to reveal the details of her case and it is difficult for anyone who does not have subpoena power to ascertain all of the specifics, but the general history is as follows.

The child is just seven years old at the date of this writing, in February 1994. When his parents separated, he reported physical abuse by his father and paternal grandmother during visitation. He was taken to a Dr. Mendoza, who documented abuse and insisted on bringing DYFS into the case because of the mandated reporting law. A referral was also made to the prosecutor's office for child abuse, but never followed up because, apparently, DYFS and the prosecutor both knew that this case was not going to be supported by the judges in question. By April of 1992, the boy was having videotaped interviews about allegations he had made concerning sexual abuse by his father. He reported to Caseworker Bob Abrams that his father had put his "pee pee" into his "cookie," which the caseworker explained was his anus. The caseworker documented: "He said FA peed in his cookie. He said it hurt him and he told his FA to stop but he (FA) didn't." The report went on to add, "Child also stated that his father had put his pee pee in his ([child's]) mouth. [Child] said his father pee'd in his mouth. I asked what [child] did after that. He made a gesture of spitting out, turning his head to the side and said 'YUCK!'" Abrams did not found the case because, he said, the boy "reneged" when he told him about the incidents, in spite of the fact that the mother reported to him that her son had told her his father threatened to punish him for telling, so she considered it quite normal for the boy to renege when pressed by someone he might not yet trust.

Judge Grasso and Judge Fall have ordered that the mother not reveal the details of this case, and they have already forced the boy to visit his father unsupervised. Naturally, when that occurs, the child immediately recants all his prior disclosures, for fear of punishment or to comply with directions given by the abuser himself.

No physician can treat a child who is in the total control of the abuser. The Community Medical Center reported a diagnosis of "sexual abuse by history" on April 8, 1992, but the boy was never given treatment. Now the mother has been ordered ONLY to take the boy to medical personnel APPROVED BY THE COURT. Clearly, there is no chance of independent medical assistance to this child because of the conduct of the Ocean County Family Court personnel.

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Testimony to The New Jersey Commission on Sex Discrimination in the Statutes

Ann Marie Hill
Executive Director
New Jersey State Commission
on Cancer Research
February 1, 1994

On behalf of the New Jersey Commission on Cancer Research, I would like to thank the members of the Commission on Sex Discrimination in the Statutes for allowing me to speak today on cancer research in New Jersey and how such research affects women's health care.

I would like to start by commending the Commission for including research in its agenda on health care issues. All too often, research is missing from such discussions. In my opinion, this omission is a serious mistake. While all of the testimony given during these hearings will be very important, it is through research that serious diseases such as AIDs, diabetes, cardiovascular disease, Alzheimer's disease and cancer will be prevented and cured. When these medical problems are dealt with effectively, many pressing issues in the health care system will be reduced.

Cancer represents, perhaps, one of the most difficult medical enigmas. It is only when we unlock the very essence of living cells that we will truly overcome this disease. Yet, 30% of us will discover we have cancer during our life time, and two out of three of us will be touched by this disease. For women, cancer is now the leading overall cause of death in the United States.[1] The Cancer Registry program of the New Jersey State Department of Health in its 1986-88 report estimates that an average of 18,529 women are diagnosed annually in New Jersey with cancer.[2] According to the New Jersey Department of Health's report entitled, **Cancer in New Jersey 1986-1988**, the most current data presently available, incidence and mortality rates for cancer are higher in this state than the Surveillance, Epidemiology and End Results Program (SEER) of the National Cancer Institute's (NCI) comparison groups. For example, women in New Jersey have a 9% higher incidence rate than the SEER equivalents. The age-adjusted incidence for breast cancer in New

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Jersey women was 5% higher than its (SEER) counterparts. The death rates were 12% higher. In ovarian cancer, age adjusted incidence rates were 14% percent higher and mortality were 30% higher for New Jersey women than comparison groups. The story repeats itself for cervical and endometrial cancers for the women of New Jersey. There does not appear to be any reasons to believe that these trends have changed. In addition, it is estimated that cancer contributes about 10% to the total health care costs to this country. It has also been estimated that cancer costs to the State of New Jersey are $3.8 billion per year. More important, it is predicted that the economic burden of oncologic malignancies in the 1990s will increase significantly. Of course, no price can be put on the anguish faced by those who have suffered from cancer. So you see, New Jersey has a very special interest in fostering the development of strong cancer research so that it might better deal with the human tragedy that lies behind these alarming statistics.

During the last ten years, New Jersey has striven to enhance its capabilities in research. The New Jersey Commission on Cancer Research was established by the Cancer Research Act of 1983 to promote and fund significant, original research projects proposed and carried out by New Jersey scientists who are exploring the complexities of cancer. By law, the Commission receives one million dollars in dedicated money from the cigarette tax that fuels the Cancer Research Fund. To date, the Commission has provided funding of $10.15 million for 151 grants and $2.77 million for 75 summer, pre- and post-doctoral fellowships.

Typically the Commission provides seed grants of $40,000 per year for up to two years to new investigators attempting to become established in New Jersey and to senior scientists who are seeking new directions. In 1988, the Commission initiated The New Jersey Cancer Research Fellowship Program that attracts talented young scholars seeking to become cancer researchers to academic institutions in New Jersey. Finally, the Commission has designed a special New Jersey Development Program to focus the attention of New Jersey researchers on significant cancer problems of the state (List of Requests for Applications (RFAs) in Appendix).

The Commission uses a stringent system of scientific peer review, based upon standard National Institutes of Health/American Cancer Society practices, for all of its applications. Such a system assures the fair and equitable award of funding based upon merit and an application's potential for success. The Commission tracks its grantees over a period of years and has found that for every $1 it has invested using this system of review, nearly $3 in national research monies are returned to the state. The Commission on Cancer Research feels strongly that scientific peer review for all research is essential and urges the Commission on Sex Discrimination in the Statutes to monitor all potential legislation that funds research to include such a provision. The NJCCR would be happy to help any state agency or organization in the development of such a

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system and, in cancer funds, would be happy to provide such a review. We also follow NIH standards for inclusion of women on an equitable basis in clinical studies, thus assuring access to all NJCCR research sponsored projects.

We are very pleased to inform you that the NJCCR has negotiated matching funding from NCI for certain breast cancer grants that are being considered this year. Unfortunately, we have seen a 40% increase in applications during this cycle and a 30% increase in breast cancer proposals so that we expect to fund less than 15% of our applications. When the Commission began its seed grant program, we canned fund 50% of our proposals.

At this time, I would like to address three areas of research that have an impact on the health care of women in New Jersey. First, you will notice that the Commission supports a good deal of basic laboratory research. Originally, the mandate of the Commission called for support of research projects on the cellular and molecular causes of cancer, and the grant program was designed with this focus. While we later requested an amendment to our mandate to broaden the types of research we could fund, the Commission remains convinced that the real answers to cancer will be found through basic research and so, it has invested in this critical arena. The NJCCR has supported applications that have contributed to greater understanding of breast, ovarian, and other hormone related cancers. We funded an application by Dr. Laura Goldsmith of UMD - New Jersey Medical School last year that is exploring the role of the ras oncogene in ovarian cancer. Dr. M. Humayan of UMD-New Jersey Medical School is investigating the relationship between breast cancer and estrogen. New treatments involving gene therapy have been developed by Dr. Ralph Dornburg of UMD-Robert Wood Johnson Medical School. Dr. Arnold Dion of the Center for Molecular Medicine & Immunology (CMMI) in Newark is exploring new approaches that will mobilize the body's own defenses against breast cancer. This progress is leading to new diagnostic tools, better treatments, and a greater understanding of prevention. So, the Commission feels that basic research provides the foundation upon which real progress against cancer will be made.

With the emergence of new technologies, a means to bring such advances to women in New Jersey is critical. New Jersey is the most densely populated state in the country. Its citizens are a very diverse socioeconomic and ethnic population. For purposes of research, this is significant for the following reason: while the population of New Jersey has sufficiently large homogeneous groups, offering rich opportunities for research, it is also essentially a heterogeneous population. As such, it provides an excellent laboratory in which to evaluate access to clinical trials for women anywhere in the United States. In particular, New Jersey has a cancer problem that demands access to the most modern, safe and effective therapies. Major pharmaceutical firms reside within the State and the population provides exciting opportunities as a laboratory for studies with broad application for the rest of the country.

Despite these built in advantages, historically, very few women in New Jersey have had access to trials unless they traveled out of state to cancer centers. Taxol, a new chemotherapeutic agent that has shown positive results in breast, ovarian, head and neck cancers, provides a clear demonstration of this issue. Bristol Myers Squibb, its manufacturer, has a strong presence in New Jersey. Until this last year, the drug's availability was limited almost exclusively to NCI designated cancer centers. Since New Jersey did not have such a center then, women who wished to enroll in such trials had to leave the state. It has been suggested in certain proposed health reforms that similar restrictions be placed on other expensive, experimental therapies, eg. bone marrow transplantation for advanced breast cancer. Such a requirement can be a difficult burden on a very sick patient, especially women who have families to care for, who are widowed, alone, have limited income, no insurance or problems with insurance coverage for research activities, and no source of transportation. For example, we might easily assume that women in Camden have only to cross the Delaware to have access to a restricted drug such as taxol in Philadelphia. Unfortunately, the reality is very different. Almost 37 percent of Camden's residents are below the poverty level.[3] Women, representing almost 52 percent of Camden's population, face enormous obstacles when dealing with general health care problems. To expect poor women, who are already overwhelmed with the problems of daily survival, to cross the Delaware and maneuver through the complexities of the research establishment is completely unrealistic. It is for such reasons that the Commission has called upon the cancer community in New Jersey to support The Cancer Institute of New Jersey as it seeks to gain status as an NCI designated cancer center. We also urge the development of strong clinical centers throughout the state and the creation of networks that link such centers to community hospitals so that all women in New Jersey can have access to the most modern medical care available.

Happily, we have begun to see progress toward these goals. The Cancer Institute of New Jersey has begun to develop a strong clinical program as part of its effort to become a designated cancer center. The Garden State Cancer Center of New Jersey, affiliated with CMMI, is also completing plans to purchase and renovate a new facility in Belleville. It hopes to obtain status as a designated cancer center sometime in the future. New Jersey now has three CCOPs (Community Clinical Oncology Program): Hackensack Medical Center, Cooper Hospital/Medical Center in Camden and St. Joseph's/St Michaels Hospitals in Paterson/Newark. These programs receive funding from NCI and have access to many national clinical trials' groups including the Eastern Cooperative Oncology Group (ECOG), the National Surgical Adjuvant Breast and Bowel Project (NSABP), the Cancer and Acute Leukemia Group B(CALGB), and the Gynecological Oncology Group(GOG). In addition, we should also note that four New Jersey hospitals are affiliates of the Fox Chase Cancer Network, Philadelphia. Other

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hospitals are also offering access to some clinical trials. The NJCCR conducted a survey of hospitals in 1990 that indicated that approximately 40% of New Jersey hospitals are involved in some type of clinical trials. In addition, the Commission has almost 200 cancer physicians in New Jersey who have expressed serious interest in participating in clinical programs if the right support model can be designed. As a result, the Commission has just offered an RFA that is seeking new models of community networks that will link the CCOPs to community programs. Eventually, our vision is to see these networks linked to a New Jersey research base such as The Cancer Institute of New Jersey.

Needless to say, research activities on cancer prevention and early detection are essential. At this time, much of this work on the prevention of cancer, especially breast and ovarian cancers, is still being conducted at the basic laboratory level. Again, this is the reason the Commission has continued to focus on studies that look at the causes of cancer. Such studies have brought us to a point where large scale medical intervention studies eg. the Women's Health Initiative, have been launched nationally. Several New Jersey hospitals are involved in these chemoprevention studies including the Tamoxifen Chemoprevention Study that seeks to prevent breast cancers in high risk women through the use of anti-estrogens. The clinical networks suggested earlier could also play a critical role in making these trials available to more New Jersey women.

It must be recognized that in New Jersey the number of epidemiologists, biostaticians, public health investigators and data managers is small compared to basic and clinic researchers. Our state cancer registry has suffered from staff and funding shortages. We need to learn more about the barriers to screening and find new strategies to bring screening and education programs to those who are at greatest risk. The high cancer rates among disadvantaged populations demand action. Funding to expand these programs would require enormous support, far exceeding what is presently available.

Innovative projects such as a breast cell depository for women with a family history of breast cancer have great potential to unravel the genetics of cancer. Planned by the Coriell Institute for Medical Research and Cooper Hospital/University Medical Center, this program would help launch New Jersey into the realm of molecular epidemiology. However, the funds are simply not available to support a proposal of this scope.

The Commission has used it New Jersey Development Program to stimulate pilot studies that might attract federal monies. The largest portion of funding, earmarked by the Commission, has gone to studies that seek to reduce the high incidence and mortality rates among the socio-economically disadvantaged populations. We have a demonstration project presently looking at ways to improve the effectiveness of screenings for breast and cervical in high risk women in Newark. We are hoping that this project may obtain matching breast cancer monies from NCI. In addition, the Cancer Prevention and Control Advisory Group to the Commission is

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designing strategies that will promote interaction between researchers and community programs. In this way, networks can respond promptly to federal Requests for Proposals. However, the resources required to provide the depth and breadth needed for strong research on prevention and interventions are simply not available.

Finally, no discussion of cancer would be complete without mentioning the psychosocial needs of patients and their families. The Joint Psychosocial and Nursing Advisory Group to the Commission has provided strong leadership for this state. Because of its work, research on the quality of life, survivorship, employment/insurance issues and support activities are a part of our research effort. As evidence of just how valuable such work can be, I have enclosed a copy of THE RESOURCE BOOK FOR CANCER PATIENTS IN NEW JERSEY. This 70 page booklet was developed as part of a research project by the members of the group. Thanks to the generous support of Ortho Biotechnology, nearly 8000 copies have been provided to patients throughout New Jersey at no cost.

Since 1983, the Commission has sought to conduct a rigorous campaign to bring New Jersey to the cutting edge in the fight against cancer. It has mobilized the research community to bring its talents to bear against this tenacious disease. Investing its limited resources carefully, it has sought to bring the advantages of cancer research to the residents of New Jersey. The Commission has always recognized the particular problems that cancer represents for the State of New Jersey. Its citizens, especially its minorities, socio-economically disadvantaged, and women, deserve our very best scientific efforts towards the eradication of cancer.

FOOTNOTES

[1] Henderson, B, Ross, R., Pike, M., "Towards the Primary Prevention of Cancer, Science, Vol. 254, Nov. 22, 1991, Pg. 1131

[2] Cancer in New Jersey, Incidence & Mortality Rates by Race & Sex for Total Cancer in 11 Major Sties, 1986-1988, Cancer Registry Program, Division of Epidemiology, Environment and Occupational Health Services, New Jersey Department of Health, 1993, Pg. 9

[3] Office of Economic Research, . New Jersey State Department of Commerce, 1993

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TESTIMONY FOR THE PUBLIC HEARING ON ISSUES OF HEALTH CARE IN NEW JERSEY

VIOLENCE AGAINST WOMEN: The Health Care Response

Sponsored by the State of New Jersey Commission on Sex Discrimination in the Statutes

February 1, 1994
Trenton, New Jersey

Submitted by Courtney N. Esposito, BA
Coordinator, Center for the Study of Violence
Albert Einstein Medical Center
Philadelphia, PA

Senator Lipman, Assemblywoman Derman, Ms. Griffin, members and staff of the Commission, women and men:

Good morning. My name is Courtney Esposito. I have worked in the field of domestic violence prevention since 1978, and for the last nine years have provided training and technical assistance to the health care community on domestic violence awareness, assessment & intervention. I am also a Director on the Board of Womanspace, Inc., the Mercer County agency assisting victims of domestic violence, a member of the New Jersey Governor's Advisory Council on Domestic Violence, and serve on the Advisory/Experts Committee of the National Health Initiative on Domestic Violence. I am a survivor of abuse, & advocate strongly for the need & right of survivors to speak for themselves to public & private agencies which formulate laws and policies on their behalf.

I would like to begin with the words of two colleagues, Dr. Evan Stark, Ph. D. and Anne Flitcraft, M.D., who were 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."

A broad definition of violence, or abuse, would be any behavior which treats a person like a thing. More specifically, violent or abusive behavior is behavior which physically harms, like battering, rape or incest; behavior which arouses fear, like threats of physical harm, or threats to kidnap or kill the children; behavior which prevents a woman from doing what she wishes, like wearing a certain color, seeing family or friends, going to school or for pre - or post - natal care, properly feeding and adequately clothing her children or herself; or behavior which forces a woman to behave in ways she does not want to, like only wearing one color, forcing her to have sex with his friends every Friday night in front of a video camera, or returning to live with an abusive husband because he can afford a good lawyer but she cannot, or because there is no decent affordable housing available for her and her children to move in to.

The numbers I will refer to show battered women as a cross-section & substantial portion of the total female 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.

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 can actually increase the chance that a violent incident will occur:

65 - 75% of battered women killed were killed after they left the abuser.

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. Yet the scientific literature does not reflect this fact, just as it has ignored women as subjects in heart attack studies. 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 - 50% of all women presenting with injury to hospital emergency services, 25 - 37% of obstetrical patients, 40-50% of women with alcohol problems, up to 64% 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 practitioners see ten times the number of female victims of partner abuse that police see, & police see six times the number of victims that judges see. Educating health care personnel is therefore a crucial beginning step in the process of identifying and preventing abuse against women.

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 not so benign neglect happens for three primary reasons: 1ST 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: 2ND the lack of awareness of the community in general and health care personnel in particular about the prevalence and dynamics of abuse; and 3RD the feelings of frustration and helplessness many people, including helping professionals, experience when in the presence of a victim--they simply do not know what to do, or they 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 a history of making a very good start.

Beginning in 1985, 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, assessment and intervention. Most hospitals and major health care organizations in the state were personally addressed, and all received educational and training materials. New Jersey can be very proud of this work to help victims and the health care professionals who treat them on a daily basis. But it's not enough - we have data from studies to prove this - because training & support must be regular and ongoing in order to change practice.

Health care education on domestic violence 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 programs 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 wouldn't). "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 minute--to see that the real problem is the violence, the abusive behavior, and not the victim. We <u>must</u> go on teaching them, and encouraging them and giving them the tools to teach their colleagues. The beneficial effects in health care delivery to family violence victims will be 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 this 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 - and make no mistake: health care providers are the front-liners, 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.

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 to thousands of health care professionals, and have consistently been told that the information offered to them was new, convincing and useful. Two Surgeons General, the American Medical Association, the American Medical Women's Association, the American College of Obstetricians and Gynecologists, the Emergency Nurses and Physicians Associations, and dozens of specialty societies in health care have recognized the problem and funded initiatives to address it. 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.

I submit to you the following recommendations for reducing avoidance & denial in the health care field toward victims of family violence:

1. Renew, expand and intensify the training and technical assistance offered to all sectors of the health care community. The governing bodies of this state can and should, holistically and in a coordinated fashion, formulate and create policies and program around the issue of violence against women & health care remedies to address it. A coordinated response from health care, law enforcement, judicial & direct service programs must be formulated. This is happening on local & state levels elsewhere, & on the national level. New Jersey must re-commit its energies to innovative & viable activities that will assist battered women.
2. 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 could ideally be effected in one to two years, using the model developed in New York by that state's Department of Health & Office on Domestic Violence.

3. 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.
4. 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 can assure you that all of us who work to prevent violence against women will continue to bring opportunities to safeguard our clients to your attention. I appreciate the time to speak before you today, and I would be happy to answer any questions you may have. Thank you for your attention.

Lena Weiss

THE COMMITTEE ON SEX DISCRIMINATION

NEW JERSEY ESSENTIAL HEALTH SERVICES COMMISSION

o Eleven members appointed by the Governor

  - Eight with experience in hospital finance, health insurance or as consumers.

  - Commissioners of Health, Human Services and Insurance.

o Established by Health Care Reform Act of 1992 which also:

  - Two related bills reformed market for private insurance for individuals and small groups. Standard benefits, community rating = easier access to health insurance.

TASKS OF ESSENTIAL HEALTH SERVICES COMMISSION

- Administers Health Care Subsidy Fund.
  - Charity Care payments to hospitals.
  - Other uncompensated care (Medicare shortfalls).
  - Subsidized health benefits for low-income individuals.
- Charity Care Eligibility and Claims Processing System.
- Study hospital costs, charges and outcomes; compare to other States.
- Review Medicare and Medicaid payments.
- Help consumers make prudent choices.
- Encourage preventive and managed care.
- Develop health care initiatives and bond assistance program.

HEALTH CARE SUBSIDY PROGRAM

	1993	1994	1995
Charity Care	500	450	400
Other Uncompensated Care (Medicare)	100	67	33
Subsidized Insurance	-	50	100

o Funding

- Transfer of surplus unemployment tax revenue 1993-5.

ACCESS PROGRAM PRINCIPLES

- "Jersey SHIELD; Subsidized Insurance Program; The Access Program"
- Goals: reduce dependence on hospital charity care; maximize number of New Jerseyans with health insurance; improve quality and efficiency.
- Work with existing system.
    - Use individual insurance market as recently reformed; don't create another government program regulating insurance.
    - Give people subsidies to buy insurance. Target unemployed and those coming off Medicaid. Treat enrollees like privately insured.
- Emphasize primary and preventive care.
    - Comprehensive, community based services, not "bare bones."
    - Minimize financial barriers at point of service.
    - Good medicine = good economy; 130,000 hospital admissions cost $650 million annually; ERs often used inappropriately.

40X

THE ACCESS PROGRAM ELIGIBILITY

- Eligibility up to 300% of Federal poverty line:
  - Individual $20,910
  - Family of 4: $43,050
- Subsidies available on sliding scale below these income limits:
  - No assets test in first year.
  - Eligibility limited to New Jersey residents.
  - Only those without access to employer insurance.
- First come, first serve enrollment in spring/summer 1994 within available funds.

THE ACCESS PROGRAM: WHAT WILL IT COVER?

- Should be comprehensive, preventive, community based with minimal financial barriers at the point of service.
  - EHSC Subcommittee chose two of five standard plans available in individual market, plus HMO option.
  - Vary price by changing cost sharing and using managed care, not by limiting services.
- All cover - hospital, home health, skilled nursing, hospice, surgical services, rehabilitation, primary and preventive care, drugs, infusion, chemo- and radiation therapy, blood
- Plans chosen by EHSC also cover office visits, podiatry, substance abuse and mental health, dialysis, transplants, durable medical equipment, transport.
  - EHSC supports richer mental health benefit
  - First dollar coverage of prevention up to limit
  - Exclusions: preventive dental, pre-existing conditions
- Copayments for plans chosen by EHSC
  - If income is above 150% of poverty level, enrollee can choose a plan with $250 deductible, 20% with maximums of $2,000 for an individual and $4,000 for a family.
  - All enrollees can choose plan with $150 deductible, 10% with maximums of $1,500 for an individual and $3,000 for a family.
  - All enrollees can choose HMO plan: $10/visit
  - No balance billing

42X

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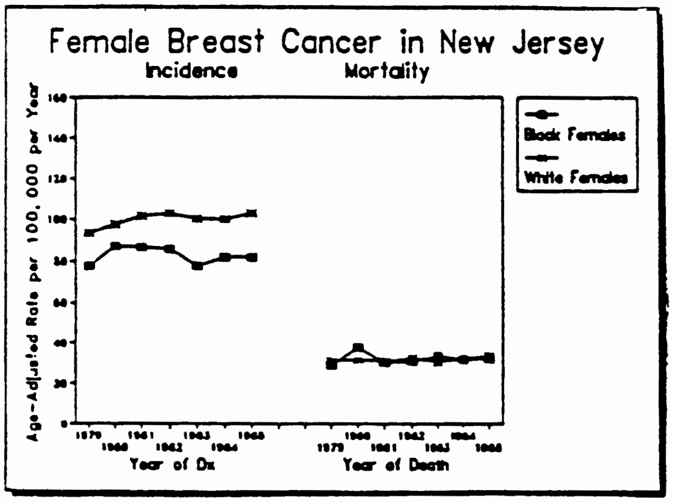
1994 Public Hearings on Issues of Health Care in New Jersey

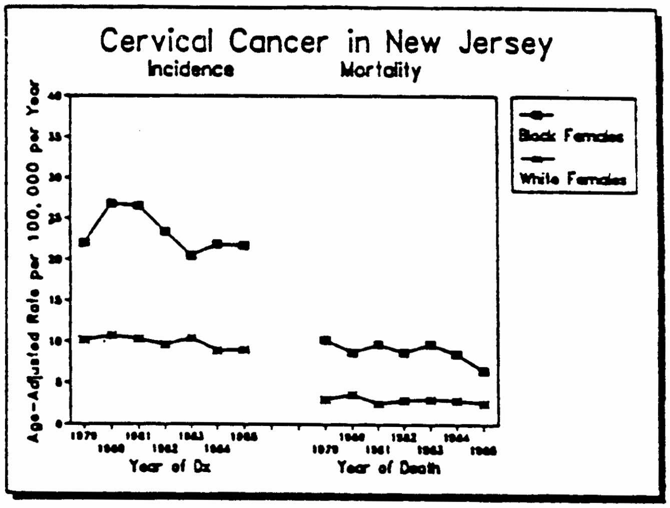
Sandra Hartnett, RN,MSN
Oncology Clinical Specialist
Mercer Medical Center
Trenton, NJ

Breast and cervical cancer in the African American community - observations from a breast and cervical screening project funded by the New Jersey State Department of Health for 1993-1994, currently in progress.

I. Statement of the Problem

A. Incidence, mortality





Note: Rates Adjusted to 1970 U.S. Standard Population
Source: Cancer Registry Program & Data Applications Program
New Jersey State Department of Health

II. Factors contributing to lack of access and/or under utilization of services that do exist.

A. Inadequate education, public awareness, of the benefits of preventative care, screening, early detection
B. Lack of motivation to overcome attitudes and belief regarding the irrelevance of preventative health care and fatalism about cancer.
C. Health care benefits tied to employment
D. Employment situation which do not promote personal health care behaviors
E. Fragmentation of care, frustration at negotiating systems
F. Transportation woes

III. Recommendations

A. Universal health care
B. Community-based primary health care centers
C. State, local and community-based culturally sensitive education approaches
D. Community outreach workers from within the peer group. Fund this role well, not as an afterthought.
E. Transportation assistance

Sure

I know I need
a mammogram
a pelvic exam
to take care of myself

But

I don't have health insurance
I can't leave the kids
I don't have the time

The BRaVa program can help

with breast care (exams, mammograms) and pelvic exams for women over 40, offered at **convenient times** and no prescription is needed.

There is no cost to women who meet income eligibility limits.

Call the **BRaVa program** (Breast & Cervical Cancer Screening) at Mercer Medical Center, **394-4045.**

Funded by a New Jersey Department of Health grant.

MERCER MEDICAL CENTER

BRaVa . . . . for taking care of yourself

Agents and Substances Reviewed for Reproductive Health Effects by the Congressional Office of Technology Assessment

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Chemicals:

- Agricultural chemicals:
  - carbaryl
  - dibromochloropropane (DBCP)
  - DDT
  - kepone (chlordecone)
  - 2,4,5-t, dioxin (TCDD), and agent orange 2,4-d
- Polyhalogenated biphenyls:
  - polybrominated biphenyls (PBBs)
  - polychlorinated biphenyls (PCBs)
- Organic solvents:
  - carbon disulfide
  - styrene
  - benzene
  - carbon tetrachloride
  - trichlorethylene
- Anesthetic agents:
  - epichlorohydrin
  - ethylene dibromide (EDB)
  - ethylene oxide (EtO)
  - formaldehyde
- Rubber manufacturing:
  - 1,3 butadiene
  - chloroprene
  - ethylene thiourea
- Vinyl halides:
  - vinyl chloride
- Hormones
- Undefined industrial exposures:
  - agricultural work
  - laboratory work
  - oil, chemical and atomic work
  - pulp and paper work
  - textile work

Physical Factors:

- Ionizing radiation:
  - x-rays
  - gamma rays
- Non-Ionizing radiation:
  - ultraviolet radiation
  - visible light
  - infrared radiation
  - radiofrequency/microwave
  - laser
  - ultrasound
  - video display terminals
  - magnetic field
- Hyperbaric/hypobaric environments:
- Hot environments
- Cold environments
- Noise
- Vibration

Stress

Metals:

- Lead
- Boron
- Manganese
- Mercury
- Cadmium
- Arsenic
- Antimony

Biological agents:

- Rubella
- Cytomegalovirus
- Hepatitis B
- Other infectious agents
- Recombinant DNA

Source: U.S. Congress, Office of Technology Assessment, Reproductive Health Hazards in the Workplace, U.S. Government Printing Office, Washington, December 1985. p.7.

Known and Suspected Reproductive Hazards by Industry

Artists and Jewelers

- boron and boric acid
- cadmium and compounds
- lead and lead compounds

Auto Manufacturing and repairs

- aromatic hydrocarbons (benzene,toluene,xylene)
- carbon monoxide
- chlorinated hydrocarbons (solvents)
- epichlorohydrin
- formaldehyde
- glycol ethers
- heat, extreme
- lead and lead compounds
- vinyl chloride (PVC)

Chemical workers

- anesthetic gases
- aromatic hydrocarbons
- arsenic and compounds
- boron and boric acid
- chlorinated hydrocarbons
- dimethyl sulfate
- epichlorohydrin
- ethylene dibromide (EDB)
- ethylene oxide
- mercury
- pesticides
- selenium

Clothing, textile and leather

- arsenic and compounds
- boron and boric acid
- carbon disulfide
- dimethyl sulfate
- dimethylformanide (DMF)
- epichlorohydrin
- ethylene dibromide (EDB)
- ethylene oxide (EtO)

Electrical workers

- boron and boric acid
- cadmium and compounds
- carbon disulfide
- PCB's and PBB's

Electronic and semiconductors

- aromatic hydrocarbons (benzene,toluene,xylene)
- arsenic and compounds
- cadmium and compounds
- chlorinated hydrocarbons
- glycol ethers

Food workers

- chlorinated hydrocarbons (solvents)
- ethylene oxide
- heat, extreme
- pesticides

General manufacturing

- aromatic hydrocarbons
- cadmium and compounds
- chlorinated hydrocarbons
- epichlorohydrin
- formaldehyde
- glycol ethers
- lead and compounds
- styrene, vinylchloride

Glass and pottery workers

- arsenic and compounds
- boron and boric acid
- heat, extreme
- lead
- manganese
- non-ionizing radiation

Hospital and healthcare

- anesthetic gases
- carbon disulfide
- ethylene oxide (EtO)

Known and Suspected Reproductive Hazards (continued)

ethyleneimine
formaldehyde
vinylchloride (PVC)

Office and other clerical

pesticides
video display terminals
stress
indoor air pollution

Painters

aromatic hydrocarbons
boron and boric acid
lead

Paper workers

chlorinated hydrocarbons
ethyleneimine
non-ionizing radiation
PCBs and PBBs

Pharmaceutical workers

chlorinated hydrocarbons
dimethyl sulfate
epichlorohydrin
estrogens
ethylene dibromide (EDB)
manganese and compounds
mercury and compounds

Plastics workers

cadmium and compounds
dimethylfomanide (DMF)
epichlorohydrin
styrene
vinylchloride (PVC)

formaldehyde
ionizing radiation
mercury

Refinery workers

aromatic hydrocarbons
carbon disulfide
ethyleneimine
lead

Rubber workers

carbon disulfide
chloroprene
lead
manganese

Steel workers

boron and compounds
carbon monoxide
heat, extreme
manganese

Wood processors

arsenic and compounds
boron and boric acid
ethylene dibromide (EDB)
formaldehyde
mercury and compounds

Source: Adapted from fact sheet, Philaposh, Philadelphia, PA.

VDU WORK AND REPRODUCTIVE HEALTH

In the fifteen years since reports of pregnancy problems among VDU workers first appeared, there has been an almost tenfold increase in the use of VDUs — as many as 10 million are now in use in UK workplaces.

The question of whether or not VDU work increases the risk of miscarriage, birth defects or other adverse reproductive effects remains undecided. This factsheet, which is based on a chapter in the London Hazard Centre's new book: *VDU Work and the Hazards to Health summarises some of the evidence, looks at possible causes and suggests action to reduce the risks.**

The official view, expressed in the *Display Screen Equipment Regulations*[1], discounts any link between VDU work and pregnancy problems. However, the London Hazards Centre believes that results from major experimental and epidemiological studies show that the following factors associated with VDU work *may* affect reproductive health under certain circumstances:

- **exposure to electromagnetic fields (EMFs)**
- **poor workstation ergonomics**
- **stress associated with work overload, lack of variety of and control over work by the worker**

One possibility rarely considered by those investigating possible VDU-related reproductive hazards is that more than one factor could be operating at the same time.

One of the largest studies on the reproductive effects of VDUs, involving more than 10,000 workers, is being conducted by the US Mount Sinai Medical Center and the research and campaign group 9to5. The results, due in 1994, may provide important information on the risks to health of VDU work. In the meantime, we must assume that VDU work may increase the risk of adverse reproductive outcome.

Reproductive risks

Although miscarriage and birth defects are the risks most commonly referred to, there are other possible reproductive effects:

- menstrual disorders
- sexual difficulties
- infertility (male and female)
- problems during pregnancy
- spontaneous abortion or miscarriage
- birth defects

Menstrual disorders

A 1990 study of 3,500 women working in the Inland Revenue showed a clear link between stress at work and menstrual disorders, with VDU workers being the worst sufferers.

Infertility

In the UK about 10 per cent of couples trying to conceive will not succeed. However, little is known about whether this is due to male infertility, female infertility, or other factors. A three year study of 2,340 women by the US National Institute for Occupational Safety and Health found that VDU operators were likely to have fewer subsequent live births after a miscarriage than those in the control group, indicating a possible effect on fertility or very early pregnancy loss.

Miscarriage

The suggestion that VDU work could increase the risk of miscarriage first appeared in the 1970's, with 'clusters' of miscarriages being reported in the UK, Canada, USA and Denmark.

The scientific community disagrees about the role of VDUs in miscarriage clusters, with many dismissing them as chance occurrences. If these clusters were unrelated to VDU use then we might expect to see a number of similar 'chance' clusters in offices where there are no VDUs, but as far as we know, none have been reported.

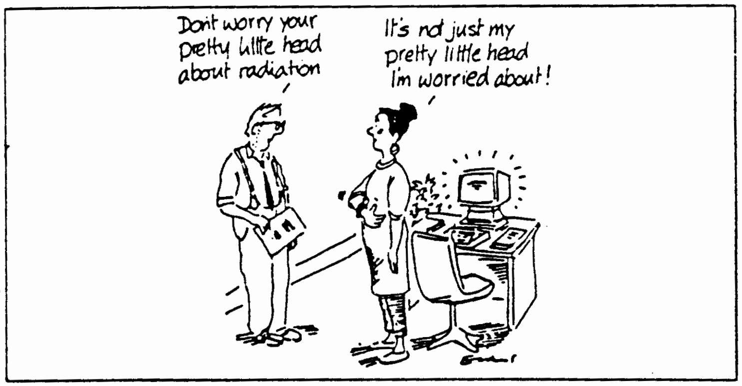
The reports that have caused continuing concern include both *experimental* (laboratory) studies — mainly on chick embryos, mice and rats, and *epidemiological* studies (of large groups of people).

Epidemiological studies

In 1988, researchers from the California-based Kaiser Permanente Medical Care Programme reported on a study of nearly 1,600 pregnant women over a two year period. They found that women who used VDUs for more than 20 hours a week during the first three months of their pregnancy were more than twice as likely to miscarry as those doing other types of office work.

A recent two year study of VDU workers at the California Department of Health Services of 1,900 women confirmed a 'consistent pattern of a possibly slightly increased risk' of miscarriage.

A 1992 study found that women exposed to VDUs which produce high magnetic fields averaging more than 0.3 micro Tesla (μT) had more than three times the miscarriage rate of those who were exposed to fields below this level. The researchers concluded that exposure to a high level of extremely low frequency (ELF) magnetic fields from VDUs in early pregnancy *is* related to an increased risk of miscarriage, for a small, but significant proportion of VDU users.



Experimental studies on spontaneous abortion

A 1991 Finnish review of experimental reports confirmed that the type of magnetic fields which are associated with VDUs may have an effect on the embryos of chicks, mice and rats. The range of effects include fetal loss (or abortion) and development of abnormalities or defects. In several of the studies reviewed, the effects of the magnetic fields were greatest during the *very early* stages of development.

Abnormalities and defects

Several reports have showed increased rates of underweight babies and of congenital malformations, especially of the heart, in children born to VDU workers.

Concern has been fuelled by a number of experimental studies which have shown that ELF magnetic fields of the type emitted by VDUs do affect the development of chick embryos. Researchers point out that any material or substance capable of a biological effect on embryo development in one species may also be capable of affecting embryo development in another species.

Protecting against VDU pregnancy hazards

The best protection for VDU workers who are pregnant, or wish to become pregnant is the *right* to transfer to non-VDU work when pregnant, or trying to become pregnant, *if they wish to do so.* Some unions have negotiated this right for their members including branches and chapels of the Inland Revenue Staff Federation, National Union of Journalists, National Association of Local Government Officers and the Council of Civil Service Unions. These agreements allow for transfer without loss of pay or status.

To minimise the risk of ill-health caused by VDU work, we make the following recommendations:

- ▲ Take regular breaks away from the screen — as least 10 minutes in every hour
- ▲ Where possible, avoid working for more than half the working day at the VDU — problems increase with increasing hours spent at the VDU
- ▲ Negotiate for VDUs that comply with Swedish guidelines for emissions[2] — or for liquid crystal display units which have very low levels of emissions
- ▲ Switch off the VDU when it is not in use
- ▲ Sit as far away from the screen as is compatible with visual and physical comfort — electromagnetic radiation emissions are reduced by distance
- ▲ Make sure that as a minimum, management implement the requirements of the *Display Screen Equipment Regulations.* These include the requirement to design jobs to reduce risk; assess workstations and remove risks.

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1. HSE *Display Screen Equipment Work.* HMSO, 1992. £5.
2. Swedish Board for Technical Accreditation (SWEDAC). *Users' handbook for evaluating visual display units,* 1990.

* ***VDU Work and the Hazards to Health*** £6.50. To be published by the London Hazards Centre in July 1993. ISBN 0 94897[illegible] 11 7

50X

WORKPLACE CHEMICALS AND REPRODUCTIVE HEALTH

Very little research on the reproductive hazards of chemicals was done before the mid-1970s and there is still intense debate about the reliability of available research techniques. However, there are at least 200 chemicals for which there is published evidence of reproductive hazards. This factsheet, the second in a series of three on reproductive hazards (see *Daily Hazards* 39 and 41) gives information on the main chemical hazards and how to avoid or reduce exposure.

Chemicals can affect the reproductive health of both men and women both before and after conception. There can be loss of libido, impotence, reduced sperm count and infertility in men. Women can suffer loss of libido, infertility and disturbances in ovulation, menstruation, implantation and placental development. Chemicals which can cause genetic damage in either men or women can lead to miscarriages, stillbirths, birth defects (low birth weights, deformities, chromosome abnormalities), genetic diseases and cancer in offspring, retarded physical and mental development in offspring and infant mortality. Some chemicals absorbed via breast milk may also result in infant mortality and retarded development. The following list of chemicals comprises those for which reproductive hazard is *proven* or highly likely. The list of *suspects* is non-exhaustive list of common pesticides with some evidence of reproductive hazard is:

Anaesthetics

Anaesthetic gases, mainly nitric oxide and, less conclusively, halothane, are suspected of causing spontaneous abortions; to a lesser extent they are also implicated in congenital malformations in offspring. There is evidence that the pregnancies of the partners of men exposed to anaesthetics are also more prone to end in spontaneous abortions. Those most at risk are operating room personnel including cleaners, dentists and their assistants, and veterinary workers.

Carbon monoxide

Exposure to carbon monoxide affects fertility in women. Exposure during pregnancy can lead to foetal death or brain damage in survivors. Carbon monoxide fumes are the by-product of a number of fuel-burning processes such as petrol and diesel engines and gas heaters. It is formed in small amounts by photocopiers and laser printers. It is a significant product of tobacco smoking.

Carbon disulphide

Carbon disulphide is a solvent which is used in the manufacture of plastics and also in a number of other manufacturing processes. It causes sexual dysfunction in both men and women. It is toxic to foetuses and can pass into mother's milk producing neurological disturbances in offspring.

Formaldehyde

Evidence is accumulating that exposure to formaldehyde can cause sterility in women. There is also evidence of menstrual effects and effects on pregnancy. There are a large number of reports of harmful effects in animals. Those particularly at risk are hospital personnel, furniture workers, construction workers and those involved in the manufacture of plastics, paints, foams and resins.

Glycol ethers

Despite strenuous efforts at denial by the electronics industry, some glycol ethers (also known as cellosolves) have been shown to cause miscarriages by both inhalation and skin contact. They are also and malformations. They also interfere with male reproductive capacity. Glycol ethers are used as degreasers in the manufacture of silicon chips. They are also used as solvents in a number of other manufacturing processes and as anti-freeze agents for petrol and other fuels.

Lead

Lead and its compounds are potent reproductive toxins for both men and women. They have been associated with sterility, menstrual disturbance, impotence, damage to sperm, miscarriages, stillbirths, increased infant mortality, low birthweight, slow infant development and infant retardation. Exposure before conception can result in reproductive failure and maldevelopment. Effects appear at low levels of exposure. In addition to workers involved in manufacturing processes, those at risk include welders, painters and people exposed to petrol fumes.

Metals

Many other metals in addition to lead are reproductive toxins. Particularly dangerous are cadmium and its compounds (kills or damages foetuses; affects postnatal development; causes testicular damage) and mercury and its compounds (menstrual disturbances and reduced ovulation; possible cause of spontaneous abortions through both paternal and maternal exposure; central nervous system defects in offspring; reduced libido and potency in men). Other metals suspected of reproductive effects are arsenic, beryllium, manganese, selenium, tellurium and thallium.

Pesticides

A variety of pesticides are non-exhaustive list of common pesticides with some evidence of reproductive hazard is: dibromochloropropane, DDT, dieldrin, aldrin, lindane, malathion, parathion, carbaryl, 2,4-D, 2,4,5-T, paraquat, simazine, atrazine, zineb, captan and pentachlorophenol. The list is only limited by the lack of research. At risk are chemical manufacturing workers, farmworkers, parks and gardens workers, construction workers (and a host of other people subject to non-occupational exposure).

Pharmaceuticals

A large number of medicinal drugs are now known to have adverse reproductive effects. This can pose a risk for the workers who manufacture or handle them. Particular hazards are known for the manufacture of oral contraceptives and the handling of anti-cancer drugs.

Polychlorinated biphenyls

Polychlorinated biphenyls are electrically non-conducting fluids with a variety of industrial applications. High levels are found in breast milk and this has been related to underdevelopment in children. There are also reports of menstrual problems.

Solvents

Organochlorine solvents (e.g. trichloroethylene) are associated with spontaneous abortions and the development of cancer in offspring. Aromatic hydrocarbons are also associated with reduced fertility, spontaneous abortions, malformations and low birthweight. There is evidence for cancer in offspring resulting from paternal exposure. The commonly used thinner methyl ethyl ketone can damage embryos and foetuses. Groups particularly at risk are dry cleaning workers, painters and laboratory workers.

Vinyl chloride

Paternal exposure to vinyl chloride monomer can cause central nervous system defects in offspring. There are conflicting reports on whether paternal exposure can cause spontaneous abortions. Vinyl chloride monomer is a cancer-causing agent which is known chemical is used in the production of plastics and process workers are most at risk but people living in the vicinity of plants may also be affected.

Protection in the workplace

The safe use of chemicals in the workplace is governed by the Control of Substances Hazardous to Health (COSHH) Regulations (see *Daily Hazard* 24) and by other legislation referring to particular chemicals (lead and vinyl chloride being examples of the latter). Employers are obliged to carry out an assessment of the risk of chemicals and processes and then either introduce safer materials and methods OR, if that is not possible, control the process OR, if that is not possible, provide protective equipment. In some cases health surveillance of exposed workers should be carried out. Union safety representatives should be consulted on assessments and on the safety procedures to be carried out. Try for substitution every time.

The key step in assessments is acquiring information on the hazards of chemicals. For reproductive hazards, never rely on the information in manufacturers' or suppliers' safety data sheets, always seek information from your union or other independent source. Try and obtain information about effects on women, men and offspring. Establish the safe conditions for a) pregnant women and b) both women and men planning to start a baby. Wherever possible, argue for the option of people in these categories to move off potentially hazardous processes onto safe work. Demand the management provides tests of exposure to known or suspected reproductive toxins.

Under the Workplace Health, Safety and Welfare Regulations and the Trade Union Reform and Employment Rights Act, there are general rights for pregnant women at work. These will be dealt with in the final factsheet in this series in *Daily Hazard* 41.

Key Information sources

S.M. Barlow and F.M. Sullivan, *Reproductive Hazards of Industrial Chemicals*, Academic Press (1982).
A.C. Fletcher, *Reproductive Hazards at Work*, ASTMS Equal Opportunities Commission

Occupational Conditions That May Affect Health During Pregnancy

Problems	Workplace Factors	Job Types
Backache	Standing, Lifting	Conveyer belt worker Supermarket shelf filler,checkout Waitress Teaching Nursing/HospitalWork Hairdressing Farm work
Expanding size	Use of protective clothing Work in confined areas	Food processing Cleaning Nursing/Hospital work Supermarket cashiers
Frequency of urination	Difficulty in leaving worksite	Telephonist Conveyer belt worker Nursing/Hospital work Driving
Morning sickness	Early shift work Nauseous smells	Office cleaning Food processing Nursing/hospital work Farm work
Possible miscarriage	Infectious agents Chemical toxics	Lab assistants Nursing/hospital work Manufacturing Teaching Agricultural/farm work
Tiredness	Overtime Evening work	Waitressing
Varicose veins Haemorrhoids	Standing/sitting Working in hot environment	Conveyer belt worker Waitress Hairdresser Dry Cleaner Food manufacturing Secretary

(continued)

Occupational Information to Obtain for Your Obstetrician, Midwife or Family Practitioner

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Provide specific information about your current job and past occupations. Include summer, temporary and part-time work.

A. Job titles

   (1) describe exactly what tasks you performed.
   (2) Describe a typical work shift in detail.
   (3) Describe the type of workplace and work station.
   (4) Describe any unusual or overtime tasks.

B. Give starting and finishing dates for each job.

C. Focus on new or changed processes at work.

D. List chemical, physical, biological and psychological stresses at work.

   (1) Use your rights of access to the employer's medical and exposure records (these rights are granted under the OSHA Medical Access Standard 1910.20).
   (2) Find out the chemical names of the substances you are exposed to at work. Ask for the MSDS (material safety data sheet) for those chemicals.

E. Try to estimate the extent of your exposure; e.g., My clothes are covered with a fine film of dust an hour after I start work.

F. Provide detailed information about eating, drinking, and smoking in the workplace; i.e., What you and others do, for how long you do them, where you do them, and what work processes are going on concurrently.

G. If you wash or shower at work, describe the facilities and what you do with your clothing.

H. If you wear any protective clothing or hearing protectors, describe the fit, how often you wear them and how comfortable they are.

I. Attempt to find out from your employer or union whether protective engineering systems and devices such as exhaust and ventilation systems are installed, whether they are functioning and whether they are adequate.

J. Monitor your symptoms and compare them with co-workers.

(1) How soon after you get to work do your symptoms start?
(2) How soon after you get home do your symptoms stop?
(3) Do your symptoms feel worse when a special process is being performed?
(4) Is there a pattern of symptoms among your co-workers?
(5) Are there other factors not connected to work that might solely or in combination with work-place exposures be causing your symptoms?

(a) Someone else in the household who may be bringing home a hazardous substance on work clothes.
(b) Some substance in the home such as art material, cleaning fluid, pesticide spray.
(c) Location of home near factory, incinerator, garbage dump, or contaminated source of water.
(d) Use of new cleaning products, soaps, cosmetics, clothing.
(e) A hobby that requires the use of hazardous material.
(f) Smoking cigarettes, cigars or pipes or heavy use of alcohol in the past or present.

(g) Previous change of residence because of a health problem.

Source: excerpted from Levy, Barry S., "Recognizing and Preventing Hazards in the Workplace," Consultant, Nov., 1983: 63-78, and "The Occupational History," Occupational Health Committee, Annals of Internal Medicine, Nov., 1983, Vol. 99, No. 8, 643-644.

Some Substances Known or Suspected of Harming Male Reproductive Health or the Health of Their Offspring

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1. Lead used in making storage batteries and paints: Fewer sperm, sperm that moved more slowly than normal (decreased sperm motility), and more funny shaped sperm (increased malformation of sperm).

2. DBCP (dibromochloropropane) a soil fumigant now banned: Mutagen, lowered sperm count, testicular dysfunction.

3. Ionizing and non-ionizing radiation, the former found in nuclear plants and medical facilities, the latter in high voltage switchyards and in communications facilities: Possible damage to germ cells and lowered fertility.

4. Anesthetic gases: Unexposed female partners are thought to have higher than normal number of miscarriages.

5. Vinyl chloride used in plastic manufacturing: Unexposed female partners are thought to have more miscarriages and stillbirths.

6. Kepone used as a pesticide: Possible loss of sex drive, lowered sperm count and slower movement of sperm.

7. Heat stress occurring in foundries, smelters, bakeries and farm work: Lower sperm counts and sterility.

8. Carbon disulfide used in the manufacture of viscose rayon and as a fumigant: Possible loss of sex drive, impotence and abnormal sperm.

9. Estrogen used in manufacturing of oral contraceptives: Possible loss of sex drive and enlarged and sore breasts.

10. Methylene chloride used as a solvent in paint strippers: Possible very low sperm counts and shrunken testicles.

11. EDB (ethylene bromide) used as an ingredient in leaded gasoline and as a fumigant on tropical fruit for export: Possible lower sperm count and decreased fertility in wives of workers.

Some Substances Thought to Cause Adverse Reproductive Health Effects in Animals or Humans Due to Occupational Exposure

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LEAD

Exposure	Female	Male
Prior to conception	- possible chromosome aberration (h) - menstrual disorders (h)	- possible chromosome aberration (h) - sperm abnormality (h) - degeneration of testes (h) - decreased sex drive (h)
At conception		- sperm abnormality (h)
During pregnancy	- miscarriages (h) - stillbirths (h) - malformations (a)	
On newborn	- lead in breast milk (h)	
On child (through clothing)	- lead poisoning (h)	- lead poisoning (h)
- hyperactive (h)	- hyperactive (h) - brain damage (h)	- brain damage (h)

ANESTHETIC GASSES

During pregnancy	- miscarriages and birth defects (h) (female exposure and male exposure)	

[continued]

Some Substances Thought to Cause Adverse Reproductive Health Effects [continued]

	VINYL AND POLYVINYL CHLORIDES	
Prior to conception	- chromosome aberrations (h)	- chromosome aberrations (h) - mutations in genetic material in sperm (a)
During pregnancy	- cancer in offspring	- miscarriages and stillbirths in partners (h)
	BENZENE, TOLUENE, XYLENE	
Prior to conception	- damaged chromosomes (h) - menstrual disorders (h)	- damaged chromosomes (h)
During pregnancy	aplastic anemia in woman (h) - birth defects (h)	
	CHLORINATED HYDROCARBONS	
Prior to conception	- chromosome aberrations (h)	- chromosome aberrations (h) - infertility (a)
During pregnancy	- liver damage to fetus (a) - in breast milk (h) - miscarriages (h) - cancer in offspring (a) - spinal birth defects (h) - stillbirths (a)	

[continued]

Some Substances Thought to Cause Adverse Reproductive Health Effects [continued]

CARBON MONOXIDE

During pregnancy	- smaller size of newborn and higher chance of dying soon after birth (a) - stillbirths, cerebral palsy, mental retardation in offspring (h)

CARBON DISULFIDE

Prior to conception	- irregular menstruation (h) - extreme bleeding (h)	- decreased sex drive (h) - sperm abnormalities(h) - impotence (h)
At conception	- decreased fertility (h)	
During pregnancy	- miscarriages (h)	

PCB's

At conception	- reduced ability to become pregnant (a)
During pregnancy	- small babies with PCB's in tissue (a) - stillbirths (h) - babies born with discolored skin which then fades (h)
On newborn	- PCB's in breast milk (h)

<u>KEY</u>: (h) At least one study on humans showed this effect.
(a) At least one study on animals showed this effect.

Some Substances Thought to Cause Adverse Reproductive Health Effects [continued]

ESTROGENS

Prior to conception	- effect on flow, frequency of menstrual cycle (h)	- sore and enlarged breasts (h) - impotence (h)
On child (through clothing)	- sore and enlarged breasts of prepubescent (h)	- sore and enlarged breasts of prepubescent (h)

IONIZING RADIATION

Prior to conception	- mutations in genetic material (a) - reduced fertility (h)	- mutations in genetic material (a) - reduced fertility (h)
During pregnancy	- leukemia and other cancers in offspring (h) - cataracts and eye defects in offspring (a) - small heads and brains in offspring (a) - mental retardation and retarded growth in offspring (h)	

PESTICIDES

At conception	- prevent conception (a)	
During pregnancy	- stillbirths (a) - miscarriages (a) - abnormal offspring (a) - leukemia in pregnant	

	mother and offspring (a)
On newborn	- pesticides in breast milk (h)

[continued]

Occupational Conditions That May Affect Health During Pregnancy

Problems	Workplace Factors	Job Types
Additional problems	Homeworking	Using machines and chemicals under unsafe conditions long hours
	(1) Exposure to ionising radiation	Radiographers Hospital workers Dentists/Vets Quality control
	(2) Exposure to lead	Lead battery workers Artists Metal reclamation Demolition work Potters

Protecting Women in the Workplace: What the U.S. Could Learn From the European Community

by Regina H. Kenen

March 1992 to March 1993 has been designated as the European Year of Safety, Hygiene and Health Protection at Work by the European Community. Although it may not sound exciting, its impact should be great because its aim is to publicize the importance of health and safety in the workplace. The target population includes the more than 52 million women employed in the 12 member nations.

While European Community (EC) legislation embraces workers of both sexes, several of the Workplace Directives (Eurospeak for legislation) especially affect women. The Protection at Work of Pregnant Women and Women Who Have Recently Given Birth Directive applies specifically to women. Two additional Directives, which were initiated in 1987 and are due to be completed and implemented by the end of 1992, affect women more than men simply because of the sex segregation of the labor market. These are The Display Screen Equipment (VDTs) Directive and The Part-time and Temporary Workers Directive.

The Part-time and Temporary Workers Directive

The Part-time and Temporary Workers Directive expands improvements in safety and health at work to temporary workers and to those permanently employed on a part-time basis. It also provides some restrictions on the use of temporary workers in particularly hazardous jobs. Women comprise most of this labor force. For example, in 1988 four-fifths of the more than five million employees who worked part-time in Great Britain were women. This represented forty-two percent of the British female workforce (usually in low-paid, low-status jobs with few benefits) but only eight percent of the male workforce. Unfortunately, the extension of other rights and benefits currently granted only to full-time permanent employees has bogged down in discussion among member countries.

The Display Screen Equipment (VDTs) Directive

The Display Screen Equipment (VDTs) Directive is more specific and fairly comprehensive. It sets the minimum safety and health requirements for work with display screen equipment, another predominantly female work arena. Employers who install new workstations need to meet the minimum requirements in the following areas: design of the display screen, keyboard and desk chair; environmental factors such as glare, lighting, noise, and humidity; task design; and software. The Directive also states that the design of daily VDT work schedules should include breaks or changes of activity. The majority of women working in offices will not benefit from all the changes immediately as workstations already in service are given a grace period of four years in which to be brought up to the new standards.

Under the Directive, workers are entitled to an eye and eyesight test before starting VDT work and reassessment at regular intervals. If workers experience visual difficulties attributable to their work, they are entitled to an ophthalmological examination and to special corrective lenses if necessary.

American workers have far less protection. Currently, there are no U.S. federal or comprehensive state protective statutes covering work using display screen equipment. The City of San Francisco has passed protective legislation, several other jurisdictions are considering legislation and the first VDT bill passed by Suffolk County, NY is still under appeal. These initiatives are a drop in the bucket. After 1992, protection of American VDT workers will still be light years behind VDT operators living in European Community countries.

The Protection at Work of Pregnant Women and Women Who Have Recently Given Birth Directive

The European Community has stated that one of its aims is to increase the number of working women while protecting their health and safety at work and supporting their *right* to maternity leave. The Protection at Work of Pregnant Women and Women at Work Directive goes further in protecting the rights and the health of pregnant workers than does American law. But this Directive has had a stormy history; its maternity leave provision has been particularly controversial, with the United Kingdom in the forefront of fighting this as well as other EC social legislation.

Details of the Directive are still being negotiated, but general agreement was reached subject to amendment by the European Parliament. Every EC country must finance 14 weeks statutory mater-

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Current Maternity Leave Provisions in the European Community

Country	*Maternity Leave*	*Pay*
Belgium	14 weeks (6 before birth)	100% for 1–4 weeks, thereafter 80%
Denmark	28 weeks (4 before birth)	90% of salary
FRG (Germany)	14 weeks (6 before birth)	100% of salary or fixed sum
Greece	15 weeks (6 before birth)	100% of salary
Spain	16 weeks	75% of salary
France	16 weeks (6 before birth)	84% of salary
Ireland	14 weeks (6 before birth)	70% of salary
Italy	20 weeks (8 before birth)	80% of salary
Luxembourg	16 weeks (8 before birth)	100% of salary
Netherlands	12 weeks (6 before birth)	100% of salary
Portugal	90 days (6 weeks before birth)	100% of salary
UK	40 weeks	6 weeks at 90% of salary and 12 weeks at a fixed reduced sum.

Source: Protection at Work of Pregnant Women and Women Who Have Recently Given Birth—A Proposal for a Directive from the European Commission, Annex 1 Maternity Leave.

A Model
(continued from page 7)

- The battered woman (who was referred to the legal system) obtains court intervention, which changes the balance of power in the battering relationship. The batterer is required to attend an appropriate counseling program, and, at least temporarily, stops the violence in the relationship. This allows the parties to remain together while the woman gathers strength to decide if and when she will leave the relationship.
- The battered woman goes back to her batterer and lives with continued violence, but later returns for assistance when she is ready to accept it. In many ways this "success" is the greatest, because the message is successfully conveyed that there is help, that violence is wrong, and that the door is always open to her.

When this message is conveyed, we are offering the battered woman a glimpse of a different life that she may create for herself and her children and showing her where she may turn when she is ready to leave her violent home.

For more information about domestic violence in immigrant communities or about Clinica's services, contact Clinica at 1736 Columbia Rd., NW, Washington, DC 20009 or call (202) 387-0434.

[1] In 1986, police in the District of Columbia received 19,526 calls for help from domestic violence victims. Forty-two (42) police reports were filed by officers. In 1988, police in the District received 18,264 domestic violence calls. Forty-four (44) police reports were filed.

[2] Of 5,600 total domestic violence cases reported in 1987 to the U.S. Attorney at the D.C. Citizens' Complaint Center (CCC), only 90 were prosecuted. Battered women are sent to the CCC when police arrive at the scene of a domestic violence incident and refuse to arrest their batterers.

[3] Hogeland C. and Rosen K: "A Needs Assessment of Undocumented Women" (March 1990). Unpublished study available from the Immigrant Women's Task Force of the Coalition for Immigrant and Refugee Rights and Services (CIRRS, 995 Market St., 11th floor, San Francisco, CA 94103).

Women's Voting Guide Available

If you are concerned with women's right to choose, equal pay, freedom from sexual harassment, safe and affordable child care, and access to good health care, this guide will help you make the right choices next fall. *The Women's 1992 Voting Guide*, by the Women's Political Action Group is now available for $3.95 from Earth Works Press. Contact Dayna Macy (510) 652-8533, ext. 11 for information on how to order.

Support the National Women's Health Network– Invite a Friend to Join Today!

Workplace *(continued from page 5)*

nity leave at a rate not less than sick pay. This package represents the minimum EC requirements and countries already offering better packages can not water down their provisions to the EC minimum. The legislation also protects a female employee from being fired because she is pregnant, but she may be dismissed for other reasons.

In general the compromise falls far short of the proposals the EC commission first presented in 1990, which dealt more extensively with parental leave, employment rights and working conditions. In the present watered-down version only women in Britain, Ireland and Portugal stand to gain from the maternity leave provisions as the other EC countries already provide pregnant workers with at least the new EC minimum.

EC member countries do not unanimously support all provisions in the Health and Safety Directives. Moreover, some are slow in implementing the Directives while others construe them very narrowly. In general, however, the European Community is steadily improving working conditions and protection for women. When American women learn about these advances, they can't help but wonder why their country is so backward on so many of these issues.

Regina H. Kenen is a co-chair of the Network's Environmental/Occupational Health Committee.

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THE NETWORK NEWS

NATIONAL WOMEN'S HEALTH NETWORK

September/October 1993

The Genetic Reproductive Technology Scene

This is the first of several articles to appear in The Network News *to inform members about current and future developments in reproductive genetic technology and to stimulate discussion about their impact on women's reproductive choices.*

by Regina Kenen

We live in the age of the Technological Imperative where existence of genetic diagnostic or screening tests seems to automatically translate into the expansion of these services for pregnant women. Although genetic services are presented as furthering women's choices, the pressures to use these tests may actually constrain their ability to choose. The new technologies are increasingly influencing reproductive decision-making in the United States and pose ethical questions for women/couples who are planning to have a child.

Concern about the overuse or misuse of reproductive genetic technology is widespread and has escalated in recent years as a result of the Human Genome Project (HGP), a 15-year, $3-billion research effort to map and sequence the estimated 50,000 to 100,000 genes that make up the Human Genome. The goal of the HGP is to locate all the genes in the hope of determining their functions. To do this, scientists need to construct two types of maps—genetic linkage and physical maps.

Genetic linkage maps show how frequently individual diseases and other traits are inherited together within families over several generations. Advances in molecular genetics allow scientists to use "markers" (unique segments of DNA) that can be followed in families as landmarks on a genetic map. If they lie close to the yet unidentified gene suspected of causing the disease, they are likely to be inherited together.

Physical maps give the actual distances between genes on a chromosome. It is not enough to know where the genes are located; it is also necessary to understand their precise functioning. Determining the order of the nucleotides in a gene's DNA is known as sequencing, and this order determines the genetic information the gene carries.

Although the HGP focuses mainly on mapping and sequencing genes, it is the application of this knowledge that invokes apprehension. In fact, Congress was so concerned about the social use of the information arising out of the Human Genome Project, that for the first time in history, it included a provision mandating that at least 3% of the money appropriated each year for the scientific project be spent on social, ethical and legal implications.

In addition, nationally known scientists, physicians, social scientists and women's health activists troubled by the possible social implications of genetic tests formed the Council for Responsible Genetics in 1983. The Council's purpose is to alert the public to the social issues raised by genetic technology and to promote discussion about these issues, many of which impact women. Two primary areas of concern are the overuse of genetic tests in the clinical setting and the erroneous interpretations and misuse of the test information by third parties.

The Carrier Label

As we all know, we inherit our genes from our biological parents and hand them down to our biological children. Some genetic diseases are carried on a dominant gene. This means that a child only has to inherit that gene from one parent in order to have the specific condition. Other diseases, such as Tay Sachs or cystic fibrosis, are carried on recessive genes, which means the harmful gene must be inherited from both parents in order for a child to develop the disease. In that case, if a child only inherits one gene, then he or she is a carrier of that disease, a person who can pass the gene on to another gener-

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Inside

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National Women's
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The only national public-interest
organization dedicated solely to
women and health.

Genetics *(continued from page 1)*

ation, but who will never actually develop the condition him or herself. Geneticists estimate that each one of us carries four to eight recessive genes that could cause conditions detrimental to our health. That makes it likely that as more genetic tests come on the market, all of us will be at risk of becoming identified as carriers of genetic conditions.

Most of us know that individuals with a genetic condition or disability experience discrimination in their everyday lives. Yet, few of us are aware that "carriers" of genetic conditions also experience discrimination. Sometimes people who are just at risk of being a carrier for a severe genetic disease are discriminated against if a member of the family is known to be affected. One woman had an uncle who had been diagnosed recently as having Huntington's disease (a dominant genetic defect which expresses itself in mid-life and leads to physical and mental deterioration and death), and was seeking medical information for her mother. She lost her own medical insurance and was unable to obtain life insurance when her insurance company found out about her uncle's conditions. This story gives us a glimpse into how vulnerable we are to invasion of our privacy by interested third parties.

Genes and the Environment

To complicate matters further, most diseases involve both genetic and environmental factors. Even though we constantly read and hear about how genetic discoveries will provide firm answers, the reality is different. Answers will not be clear cut. Human beings are not Mendelian peas. Cultural, social and environmental influences interact with genes, and genes interact with the rest of the cell. Thus, scientific and medical predictions of the future for individuals with certain genetic conditions may not be accurate. When large numbers of individuals are genetically diagnosed as being "at high risk" of developing specific diseases, but with no certainty that they will ever develop them, the stage is set for stigmatization and discrimination.

Despite academic discussions about how diverse people with the same genetic condition can be, a genetic diagnostic test is usually interpreted in terms of the worst possible outcome. For example, most people think of a child with cystic fibrosis (an inherited, chronic disease of the pancreas and the lungs) as being sick most of the time and dying before the age of thirty. Although this is true for many, the outlook is much better for others. It was this worst case scenario that obsessed one Health Maintenance Organization (HMO). The HMO was not very pleased when a patient decided not to abort her fetus when it tested positive for cystic fibrosis. Instead of offering her additional information about the disease and support services, the HMO informed her that her decision would limit her coverage for the pregnancy, any care of the new baby, and possibly even future care for herself, her husband and previous child. So much for our just and caring health care system!

Particular controversy surrounds genetic testing for diseases when environmental influences as well as genetic predispositions appear to play a role, such as in some forms of breast cancer. Rather than concentrating on the role of genes in breast cancer, many women's health activists believe that more emphasis should be placed on identifying cultural, social and environmental factors that might also play a role. A new study published in the *Journal of the American Medical Association* affirms that position (270(3): 331-337). The findings indicate that even when there is a family history of breast cancer, genes play a smaller part in the development of breast cancer than scientists previously thought.

Social decisions as well as scientific ones determine the areas on which we focus our scientific resources. Currently, we are riding a genetic bandwagon that overemphasizes the genetic components of health problems to the detriment of other areas of inquiry.

Addressing Women's Needs

New technologies must address women's needs. If used appropriately, they can be beneficial to many. Diagnostic tests can also cause anxiety, provoke conflicts among family members

(continued on page 4)

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New Network Officers

New officers were elected during the meeting of the Network Board held in Washington, DC, July 16-18. The new Chairperson is Jane Sprague Zones. Maxine Jo Grad was elected Action Vice Chairperson and Charon Asetoyer was elected Administrative Vice Chairperson. Susan Rennie was chosen as the new Secretary of the Board and Paulita Ortiz will be the new Treasurer. Together, they will form the new Executive Committee.

The Board congratulates the newly elected officers and expresses thanks to the outgoing Executive Committee for its service to the Board and membership of the Network. They include Olivia Cousins, Chairperson; Jane Sprague Zones, Action Vice Chairperson; Susan Rennie, Administrative Vice Chairperson; Katherine Sherif, Secretary; and Nancy Worcester, Treasurer.

Members who live in the area or who will attend the meeting of the American Public Health Association in San Francisco, Oct. 24-28, are invited to the program session of the Network Board meeting on Saturday, Oct. 23. Call the office for time and place.

Conferences

The **American Psychological Association's (APA) Committee on Women in Psychology** is planning a national conference on psychology and women's health entitled "Psychological and Behavioral Factors in Women's Health: Creating an Agenda for the 21st Century." The conference will be held May 12-14, 1994 in Washington, DC. Deadline for receipt of abstracts is Oct. 18. For more information contact: Gwendolyn Puryear Keita, Ph.D., APA, 750 First St., NE, Washington, DC 20002-4242, (202) 336-6044.

●

The **APA's Division on the Psychology of Women** will hold a one-day conference, January 21, 1994, in Madison, WI. To receive details, write Nancy Worcester, UW-Madison Women's Studies Outreach, 623 Lowell Hall, 610 Langdon St., Madison, WI 53703

Racism

(continued from page 3)

we have abandoned the health care needs of women who do not have access to ANY medical care, nevermind contraceptives or abortions. That is not a defensible position. We can't accept health care reform that includes abortion coverage for some women, but no coverage of any kind for others. The women's movement should raise a loud voice about health care reform and that voice should not be limited to the abortion issue. We applaud NOW's support of a single-payer system.

The women's movement must stand strong for ALL women. We can't do that if we don't talk with each other and break down the barriers between us. We must not fall prey to male-dominated forms of communication and organization. We must listen to each other with open hearts and minds and work through our differences. We don't pretend to believe that the struggle is easy. It is hard to step out of our own experience and see things from another perspective. But it is a skill that women have developed to a higher degree than have men. It is time to use it; we need the power it will bring us. Challenging the differences that drive us apart and growing stronger together as a result is the only way we will become strong enough to determine our own destiny in a world that still wishes we would just "stay in our place."

In the interests of sparking a dialogue, we have asked Patricia Ireland, president of NOW, and Elizabeth Martinez, author of the original article, to respond to this editorial. Their responses appear on page 5 and were edited for grammar only. We invite our members to join this discussion. Write to us and share your perspective. We can only grow from honestly sharing our feelings about these issues. Racism and classism, like sexism, never die of natural causes: they must be eliminated through hard and heartfelt work. Let's get to it; it's the only way to "get it."

P. Ellen Parsons, Ph.D., M.P.H., is editor of the Network News. *She has been involved in women's health issues for more than 20 years and is a health services researcher in the Washington, DC metropolitan area.*

Genetics

(continued from page 2)

and raise questions about the importance of the "perfect" biological child. In many cases it is society's attitude toward people with "disabilities" more than the "disability" itself that becomes the major handicap.

The number of genes responsible for genetic diseases that can be detected by screening tests and prenatal diagnosis in carriers continues to grow. In addition, the definition of what is considered a genetic flaw expands along with technological progress. This means that what previously may have been seen as a "difference" is now labelled a "defect." Improvements in effectively treating or preventing many disorders are increasing, although at a slower pace. Some scientists believe that for certain genetic conditions, there may be as long as a 50-year lag between carrier detection and prenatal diagnosis and a cure.

Yet, industry analysts estimate that over the next 10 years, as many as 18 million individuals will be screened for carrier status, chromosome abnormalities and common genetic predispositions (e.g., insulin-dependent diabetes, breast cancer). As people buy into the idea that genes are the most important cause of disease and disability, less energy, money and motivation will be spent on seeking answers in the cultural, social and environmental realms, and prevention will mean prevention of the birth of those considered genetically inferior. As reproductive issues are at stake, the pressure to use the new technology and the burden of decision-making will rest primarily on women.

For further information, or to receive a free copy of *geneWATCH*, the bulletin that raises social issues in genetics, contact: The Council for Responsible Genetics (CRG) 5 Upland Road, Suite 3, Cambridge, MA 02140, (617) 868-0870.

Further articles will focus on new genetic carrier and prenatal diagnostic tests and the possible stigmatization and discrimination by schools, employers and insurance companies.

Regina Kenen, Ph.D., M.P.H. is a Professor of Sociology at Trenton State College and serves as liason between the Council for Responsible Genetics and the Network.

CONTENTS

CHAPTER 4

The Human Genome Project: Creator of the Potentially Sick, Potentially Vulnerable and Potentially Stigmatized?

Regina Kenen

Introduction

A story going around Moscow in the late 1970s evokes an interesting aspect of the ethical and social debate surrounding the human genome initiative. Members of a visiting American dance troupe were very upset about a major problem they faced and sought help from the theatre manager. When he asked what the problem was, they pointed to a big hole in the stage floor. The manager shrugged and said 'That is no problem, that is a detail.'

While awareness of the social, ethical and legal implications of the Human Genome Project is high, some scientists supporting the project also seem to regard these concerns as being merely technical details of application. Furthermore, they complain that the 'undue' emphasis on them over complicates discussion about the project and thus prejudices the more important business of pursuing the science. Phrases such as 'scientifically illiterate,' 'misconception' and 'correct perspective' used in the following accounts are revealing and unsettling in their emphasis on the legitimacy and primacy of a particular view of the project.

> 'It would be a tragedy if 'slippery slope' arguments or misconceptions about what the genome project might tell us about how to manipulate human behaviour were to set back progress in a field which may have more to offer human well-being than almost any in the history of medical and biological research.'(Weatherall, August 1991 p. 30)

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of the individual in an era depicted by changing concepts of health and disease?

2. How will the advances accruing from the Human Genome Project (HGP) influence how individuals think about themselves and others, relate to one another, and perceive their responsibilities and obligations to significant others as well as to the community at large?

3. How will social norms regarding privacy and control over self-identity evolve, and will the concept of 'inner privacy' be eroded?

These issues may be profitably addressed in terms of the potentially sick, the potentially vulnerable and the potentially stigmatized. However, in order to put the discussion into perspective, debates surrounding the goals and scope of the Human Genome Initiative (HGI) and related social, ethical and legal issues need to be described.

What is the Human Genome Project?

The Human Genome Project is a plan to map and sequence all the human genes. So far ~~less~~ than 2,000 of the estimated 50,000 to 100,000 genes in the human genome have been mapped onto chromosomes and less than 1 percent of the entire length of human DNA has been sequenced (NCHGR pamphlet, no date). Scientists plan to develop two kinds of chromosome maps - genetic linkage maps and physical maps.

Genetic linkage maps involve studying how frequently individual diseases and other traits are inherited together within families over several generations. Advances in molecular genetics allow scientists to use "markers" (unique segments of DNA) that can be followed in families as landmarks on a genetic map. If they lie close to the yet unidentified gene suspected of causing the disease, they are likely to be inherited together. Physical maps give the actual distances between genes on a chromosome. It is not enough to know where the controversial possibilities. Funding for these activities will be provided by the Ethical, Legal and Social Implications (ELSI) program. HUGO also plans 'to encourage public debate and provide the information and advice on the scientific, ethical, social, legal and commercial implications of human genome projects.' (European Science Foundation. Report on Genome Research 1991 p. 11)

Social, Ethical and Legal Discourse

Much of the early interdisciplinary debate about the Human Genome Project focused on whether doing this project was a good idea, or not, and if it was a good idea, how bad applications could be prevented. Now that the project has been started, interest is focused on the more distant eugenic, evolutionary and 'designer genes' implications; on the more immediate ethical problems posed by future genetic screening tests and by possible clinical use of the new information and techniques, and on protection of the individual from abuses (Andrews and Jaeger 1991; Bobrow and Manners 1993; Gostin, 1991). This emphasis on more immediate problems is reflected in the NCHGR program on the ethical, legal and social implications (ELSI) of the Human Genome Project which identified three priority issues:

> I. Privacy of genetic information, including questions of clinical confidentiality and data management.
>
> II. Effective clinical integration of new genetic testing options, including questions of quality control and professional liability.
>
> III. Fairness in the use of genetic information, including questions of insurance availability and employment screening.
>
> (Executive Summary, The Ethical, Legal and Social Implications of Human Genome Research: Preparing for the Responsible Use of New Genetic Knowledge," (NCHGR report Jan. 1991 p. 1).

knowledge, he claims that the whole history of science and technology is full of examples of such suppression:

> 'In my opinion, the only reasonable way of thinking about the future in a scientifically and/or philosophically sound manner is to map the possibilities and to make a deliberate choice between them according to their relative feasibility and desirability, of course, by doing so, you inevitably suppress all the others. It is therefore unavoidable that one suppresses possible truths by merely trying to follow one of the possibilities which you regard as true, and which afterwards turns out to be one of the previously mentioned errors or failures.' (Zimmerly 1990 pp. 78-79).

While history may be full of such suppressions, it is also filled with examples of pressure to use those advances that had not been suppressed but were supported by vested interests. The impetus to develop new information and techniques is to be able to use them or apply them. Furthermore, '...the tendency of the fruits of technological invention to acquire a force of their own and, as it were, make themselves independent of their makers.' (Jonas 1985 p. 491). Much of the increased cost of health care in the United States today is due to the overuse of tests and procedures based both on the fear of malpractice suits and on the sometimes unsubstantiated faith in hi-tech medicine; examples include the regular use of the electronic fetal monitor, and of caesarian sections (Shy et al. 1990; Hurst and Summey 1984). What have been suppressed here are the non-technical options!

Many of the new biotechnologies have made the 'unknowable' knowable. Is this necessarily beneficial? Advances in genetic knowledge discovered by the Human Genome Project can lead to a substantial redefinition of the concepts of health, self-identity and privacy in a world consisting of the potentially sick, potentially vulnerable and potentially stigmatized. How can the use of probability as a predictor of future genetic diseases affect our lives and the kind fectious diseases and most of these are caused by multiple factors. There is no intervention on the horizon that is likely to eliminate non-infectious diseases by aiming at a single aetiological factor in the way that immunisations and antibiotics conquered infectious diseases (Holtzman 1989). To complicate matters further, different combinations of factors affect individuals differently. The expression or penetration of these factors can also vary widely - from full blown manifestations to the absence of clinical symptoms - depending upon whether still unknown factors are absent or present. Yet, despite this known variability, a test report is too often accepted at face value and acted upon, if a probability estimate is attached to it or a "positive or "negative" result is indicated (Nelkin and Tancredi 1989). The willingness to accept a test report as being more precise than it may be, seems to offer an almost mystical sense of reassurance when compared with the alternative of accepting a world of uncertainty.

The difficulty people have in understanding and dealing with probability combined with the uncertainties attached to prognosis pose problems for the medical profession and the larger society. Recombinant DNA technology will lead to the identification of susceptible-conferring or disease-causing genes for a large number of diseases, and ways to test whether healthy individuals possess these genes will be discovered. Problems with such testing involve the low sensitivity of available tests; counselling dilemmas due to currently *unresolvable* uncertainty over test results; high costs; confusion and social pressure leading to ill thought out reproductive decisions, and the lack of pilot studies carried out on the benefit of using carrier testing. Such difficulties have led to the recommendation <u>not</u> to undertake a population screening program for cystic fibrosis in the United States at the present time (Beaudet 1990).

Future health providers will test patients for genetic abnormalities and then try to socially and legally maintain the status of being healthy without question marks, caveats and limitations being placed on this status.'

2. Self/Other Interrelations: Changes in Social Construction

The "newly knowable" information about genetic makeup not only blurs the line between health and illness, but also blurs the line between normal variation and pathology. Thus, the new social norms arising from the clinical applications of recombinant DNA technology will affect how people see themselves, as well as how others see them. No longer will people be able to say, "What you see is what you get." People's identity will change over time as more genes are identified, genetic screening tests developed and treatments for defects provided.

> 'Perhaps much of what we are looking at, when defined as pathology (particularly for multifactorial diseases), will be due to the same genes that determine normal variation when present as other alleles or in single rather than double dose. If so, the distinction between human and medical genetics becomes even more blurred, because in medical genetics we are looking at extremes but, by definition, much of the time we are looking at the same genes that determine normal variation.' (Williamson 1990 p. 195).

A whole new vocabulary pertaining to individuals' genetic makeup is likely to enter the vernacular, just as ultra-sound and amniocentesis have become household words for those of reproductive age. We will be talking about 'alleles' (genes at a locus on a chromosome that differ in their DNA sequences), 'polymorphic alleles' (loci at which at least 2% of the population carry a variant allele), being 'homozygous' (having the same allele at a specific locus on both chromosomes), being 'heterozygous' (having a different allele at a specific locus on each chromosome), and 'degree of expressivity or penetration' (variations in age of onset and in severity of clinical manifestations, if any). Individuals will begin to ask whether

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The acceptance of an interdependent self as the norm for the sharing of private genetic information might lead to "genetic cheating", a new form of deviance in conjugal relationships. The Catholic church now grants annulments when prior to the marriage one prospective partner lies or withholds crucial information from the other that might have influenced the decision to marry. In the future, would one basis for annulments (or divorces, in the case of other religions) include hiding genetic information or refusing to be tested if one partner know that s/he might be at more than average risk?

Some of the same issues of responsibility - notifying partners and decisions to have children - arise in the case of an individual who tests HIV positive and are reflected in the laws relating to the spread of syphilis (Andrews and Jaeger 1991). When new medical technologies are available, categories of individuals often get transformed into new categories of potential clients. The medicalisation of normal processes of birth and death, where intervention is not always beneficial is an example, and segments of society are fighting back with the return to midwifery and the design of 'living wills'. It is possible that the new genetic information will create a new health care category and a new stigmatized social category. This is particularly likely if the United States continues to emphasize individual responsibility rather than the interaction between the individual and the social and physical environment in its public health promotion campaigns.

3. The Erosion of the Norm of Personal Privacy.

The norm of personal privacy is currently under attack. The norm is sanctified verbally, but its parameters are being redefined into a new entity not yet fully formed. When a long-standing norm is curtailed or circumscribed during period of rapid social change, the ensuing anomie frequently results in deleterious social consequences. The introduction of new technology is often the catalyst that sets off this cycle.

r health insurance (Gostin 1991). Furthermore, public health policy concerns itself with the community, rather than the individual, and tends to support norms emphasizing the rights of the group.

This social climate has been spawned by two powerful revolutions - the information systems revolution and the biomedical revolution. Their intersection has resulted in the development of parallel sets of norms, one set protecting privacy of personal information and another protecting the citizen's right of access to public information (Zimmerly 1990). The boundaries between the two will be increasingly difficult to define clearly.

In order to clarify the boundary between these two types of rights with respect to genetic information, Zimmerli (1990) distinguishes between 'strictly private personal genetic data' describing a particular person which nobody is entitled to reveal, and 'publicly accessible personal genetic data' information about the *generally valid principle* describing the relationship between genes and their expressions (nobody is entitled to withhold this). But Zimmerly gives himself an important exception that equally blurs the distinction.

> 'It is quite obvious that every human being has a *moral right* to preserve his/her *genetic* privacy, at least to the same extent as he/she has the right to preserve his/her *social* privacy. However, it is equally obvious that nobody should be entitled to claim genetic privacy if somebody else, and/or a higher value, would be seriously endangered by it. On the basis of this we already see that genetic privacy is not an unconditionally defendable 'categoric' good.' (Zimmerly 1990 p. 96)

If society accepts that individuals have the obligation to reveal genetic information when concealment could potentially harm others - knowing that they carry a susceptibility-conferring gene or disease-causing gene - what happens to the protection of 'strictly private genetic data'? While the international data bank for the scientific community is designed for can predict future diseases with less than perfect certainty. The potentially stigmatized are created when this information is distorted and misused. All three categories already exist, but a growing number of individuals will fall into the first two categories and, perhaps, the third. When a majority, or even a substantial minority, of individuals fall into these categories, there will be a change in the way society perceives its members, defines their role obligations and structures their rights. Why have these issues been neglected? When they have been raised, why have they been, more often than not, treated as 'details' to be worked out?

Control over nature has been a dominant theme in American culture. Outer space (space missions) and inner space (probing the secrets of DNA) provide new and fertile fields. Moreover, overconfidence in the power of technology to solve problems is still endemic, despite increased opposition and counter trends (e.g. natural childbirth, death with dignity). Too frequently, prediction outstrips performance whether we are referring to a 'smart bomb'' for a "clean war", a bionic man with an artificial heart or a reduction in genetic disease and parental distress by carrier screening and prenatal diagnosis (Frets <u>et al.</u> 1991; Hodgkinson 1990; Preston 1993). Limited performance is often transformed into a success story by political and professional rhetoric and amply portrayed in the media (Preston 1993). Nay sayers are portrayed as Luddites mired in a nostalgic longing for an earlier, better time that never really existed.

Economics also plays a role in the social construction of the Human Genome project. Gentech companies launched with venture capital have a vested interest in promoting the benign and optimistic image of applied human genetics, and employers, insurance companies and the government, all facing rapidly rising medical costs, grab at a "technological fix" to solve their fiscal difficulties.

Those most worried about the rapid incorporation of genetic technology are found

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LAST

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QUESTIONS FREQUENTLY ASKED ABOUT THE SCHOOL BASED YOUTH SERVICES PROGRAM

1. How are the collaborating agencies connected?

The schools and agencies in the community consortium are connected through the original grant application. When we issued the Request for Proposal (RFP), we required that both the schools and representatives of the community coalition sign the application giving us assurance that there would be integration of services and close cooperation. This application was then included as part of our contract with the School Based program managing agency at the local site. Beyond this connection, the schools and communities work together in a collegial fashion to accomplish the goals of the program.

2. How do the schools relate to the health and human services agencies?

As with any new venture when you are bringing different systems together, the schools and health and human services agencies had to adjust to one another. Both systems use similar words, but these words and phrases have various meanings within their respective disciplines. For the most part, this adjustment period was short. All of the schools and health and human services programs are very well integrated and work closely together to meet the needs of their teenagers. The School Based program and the schools have developed in-house teams that have established joint teams and feedback systems with teachers, guidance counselors, nurses, and other school personnel to assure close cooperation and follow-up with students.

3. What is the management structure?

The School Based program is overseen by the Department of Human Services under the direction of Edward Tetelman, Director, Office of Legal & Regulatory Affairs. Directly under Mr. Tetelman is Roberta Knowlton, who is the Director of the School Based Youth Services Program, and one other staff person. These individuals frequently visit the local sites and work closely with staff. In addition, they do trouble shooting as the need arises. At the local level the program is managed by public or nonprofit entities and schools. These entities follow their normal management structures. Each site has a project director who oversees the staff that delivers mental health and family counseling, health, employment, and substance abuse counseling, and a variety of other services to teenagers, including recreation and transportation. There is also a monthly meeting of the project directors with Department of Human Services' staff.

4. How is the program set up and integrated with schools?

On the local level, the School Based program project director works directly with school administrators, teachers, guidance counselors, nurses, parents, and teenagers. The program has space in the school and often has space near the school for various activities. The School Based project director and staff participate in school activities, including faculty meetings, and work one-to-one with various teachers and other school personnel. In addition, the

81K

School Based program sponsors various activities for teenagers and also provides prevention activities for teens. Furthermore, all School Based programs have a local advisory committee that has school, professional, parent, and community representation.

5. **How do service providers come into the program?**

When the School Based program was first organizing, the RFP asked local schools and nonprofit and public agencies to come together to respond to the RFP. Local nonprofit agencies and schools talked to one another and reached out to other agencies to meet the requirements of the RFP and to meet the needs of their local communities. So, at the beginning of the program, there was a core of nonprofit agencies and schools already working together. Since that time, other agencies have developed an interest in the School Based program and have come forward to see what they might provide for the program. They often become involved with the program after discussions with the local managing agency and school.

6. **Explain how the program is user driven? Why do kids volunteer to get in?**

First, the program is fun. It is not a pariah program directed only toward kids with specific problems. The program itself is open to all teens in the school, and there are a number of interesting activities that attract the students to the program. All local programs have a recreational component. Second, when we first organized the program, we asked the teens what they wanted to see in the program. The major item that these teens requested was caring adults who would be non-judgmental and help them with decision making. All of the School Based program sites have staff that reflect these qualities. Third, the teachers, guidance counselors, nurses, court system, and others refer students to the program. This program is less discipline-oriented and more aimed at helping the child, and therefore gets the teenager's attention and cooperation even in difficult situations.

If you make the program attractive to teenagers, they will use the program. You must build activities that will be interesting and attractive to the teens as well as provide hard core services if you expect to attract them.

7. **Explain the funding of the School Based Youth Services Program.**

The School Based budget is $6,661,000 for SFY'92. It is distributed among 29 sites based on negotiated contracts. There is a 25% local match requirement which can be met through in-kind services or contributions. Each program delivers a core set of services (mental health and family counseling, health, employment, and drug counseling) and a variety of other services, and their local budgets are allocated to different areas based on local need.

8. **Is it the intent to always have the above base? Will it be increased or phased out over time?**

At the present time, it is our intent to build off of the base of existing School Based programs. We do not intend to phase this money out. One of the major concerns presented by school boards at the outset of this program was that educational programs are always done on a pilot basis, and funding for these programs is then passed over to the schools. The school boards said that they simply could not afford to back up these pilot programs any longer. Indeed, we have seen cutbacks in core educational services which confirm the difficulty of the school in picking up such a program.

The School Based program does expect to expand in future years and is presently examining recent changes in our state education funding policy which provide for funds toward support services.

9. What is the number of students being served?

Annually the SBYSP provides individual services to approximately 16,000 students. Additionally, we serve thousands more in recreation and group activities.

SCHOOL BASED YOUTH SERVICES

NEW JERSEY'S "ONE-STOP SHOPPING" PROGRAM

American teenagers today, particularly in urban and rural communities, face many problems. They must cope with an increasingly stress-generating society--personal and family crises, financial stresses and welfare dependency, high teenage unemployment rates, peer pressures, and health care problems. These problems have been well documented, as in the Kids Count report published in 1991 by the Annie Casey Foundation.

How American Children Are Doing

KIDS COUNT Benchmark	National Trends Over the 1980s	State Trends
Percent low birth weight babies	3% worse	35 states worse*
Infant mortality rate (per 1,000 live births)	22% better	51 states better*
Child death rate ages 1-14 (per 100,000 children)	18% better	48 states better*
Teen violent death rate ages 15-19 (per 100,000 teens)	11% worse	34 states worse*
Percent all births that are to single teens	14% worse	42 states worse
Juvenile custody rate ages 10-15 (per 100,000 youths)	10% worse	32 states worse*
Percent graduating high school	0% no change	28 states better
Percent children in poverty	22% worse	40 states worse
Percent children in single-parent families	13% worse	44 states worse

*Includes the District of Columbia.

Center for the Study of Social Policy

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THE PROGRAM DESIGN

The School Based Program is designed to bring the services of the state Departments of Human Services, Health and Labor, as well as community programs, to schools so that young people and their families can have access to them, and to do this in a manner that unites these services with local initiatives and existing community resources.

The design provides state funding for each local program through the New Jersey Department of Human Services using a proposal and grant funding process. Grants were offered to communities that showed the support and participation of a broad coalition of local community groups, teachers and parents, businesses, public agencies, nonprofit organizations, students, and local school districts. Applications had to be jointly filed by a school district and one or more local nonprofit or public agencies. The applicants also designated a managing agency for the program which could be a nonprofit agency or school.

At the time of this writing, thirty-six schools in New Jersey have School Based Youth Services Programs. Twenty-nine of these serve 13-19 year olds through sites at public secondary schools, seven are located in elementary and middle schools. The programs serve young people out of school as well as those who attend.

their sexuality and the prevalence of alcohol and drugs, are commonly provided at local sites.

Managing agencies hire a director for the program and assist the director in hiring staff and/or subcontracting with local service providing agencies, and collaborative efforts with youth serving agencies throughout the area. Most of the 36 programs work with an average number of 12 community organizations or agencies.

From its inception, the design encouraged recreation services at all sites. These services assure that the programs are non-stigmatizing to those using the confidential counseling services by providing recreational reasons for program participation, as well as modeling safe and healthy ways to use non-school hours. It is a key element in making programs successful with children, youth and families.

The School Based Program has been well received. Educators and social service providers often say that they believe the program is on the cutting edge in addressing the needs of youth in our changing society. It is demonstrating that when schools and communities provide services in a convenient, sensitive and holistic manner, children, youth and families will use them. Department of Human Services' data found that over 19,000 youngsters participated in the and the Division of Youth & Family Services has noted a decided drop in cases of child abuse.

	1988-1989	1989-1990	1990-1991
Dropouts	--	73	24 (10GED)
Suspensions	--	322	78
Pregnancy	20	13	1

Additionally, the urban Hackensack High School program reported that student fighting decreased dramatically, from 148 in 1988 to 72 in 1990. This was accomplished through the establishment of anger control and dispute resolution program created by the SBYSP in concert with the school administration.

Originally, there were questions as to whether school personnel would welcome the social service personnel and SBYSP activities. So, in 1991, the Department of Human Services surveyed school personnel regarding the SBYSP in their school:

- Over 90% found the program to have a positive effect on students and the school's environment;

- Over 85% reported that the program allowed them to be more effective in their own jobs;

- Over 90% reported that the program allowed them to assist more students.

FACTORS CONTRIBUTING TO THE SUCCESS OF THE SCHOOL BASED YOUTH SERVICES PROGRAM

Several factors contribute to the success of the SBYSP, but none are more important that the fact that the SBYSP brings integrated resources to interrelated problems. When children and their families bounce like pinballs from problem to problem and from one agency to the next, and when we "legislate by symptom", as one educator puts it, we ignore the fact that the young person experiencing one problem is likely to experience several difficulties simultaneously. We end up with some families served by as many as forty agencies and others falling completely between the cracks and regulations. Two examples will suffice to illustrate both the need for one-stop services and the success this approach can provide.

A student at one SBYSP confided to project staff that her friend was about to run away. When the counselor approached the friend, problems emerged related to a rape and a home in disarray, with neglect, abuse and immigration difficulties. The young woman, overwhelmed with feelings of helplessness, hopelessness and confusion, was about to run away. The SBYSP was able to integrate the efforts of a family counselor, the local health agency, municipal authorities and school personnel. The family stabilized itself, the be funded by local boards of education or some other source, pending its success. It was created with a permanent funding base from the start. It also is able to expand by pulling in other funds from existing programs such as Medicaid and small grants. This is critically important to schools and educators who have seen too many fine initiatives come and go from their institutions, leaving a wake of unhappy families, educators, and children when the funding disappears. The thirty-six schools involved have been able to integrate the SBYSP into the school environment because they knew it would be a permanent addition to their programs.

SBYSP services are offered to all students and in a non-stigmatized setting. Each SBYSP has a recreational program and some space for just "hanging out." Because schools vary, these talking or playing spaces are unique to each school and locale, but in every case, the recreational setting makes it clear that the SBYSP is a program for all students, not just "those with problems." The program sees youth who are court involved as well as the best students and athletes in the school. The settings allow students to get to know and trust staff on an informal basis to build a base for confiding fears and problems. An example is provided by a high school nurse:

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It is also important to note that when the program was first organized the Department of Human Services met with, and conducted focus groups with statewide organizations, ranging from departments of state government, the teacher's unions, the New Jersey School Boards Association, the Parent Teacher Organization, child advocacy and community organizations, to private business and industry councils. Input was requested and utilized as the program design was finalized. The result was on-going support from those organizations.

The programs are community based and locally designed. It was known that many statewide initiatives have failed because they neither shared the power and responsibility for programs with local organizations nor were sensitive to the myriad of differences between one community and another. To avoid such problems, applicants for the New Jersey School Based Youth Services Program were required to document a united community approach. Representatives of community organizations, social agencies, school personnel, and parent groups selected the managing agency for the local program. As noted earlier, the managing agency could be any responsible, experienced public or nonprofit community-based organization. Its job is to receive and disburse the funds provided by the Department of Human Services in a manner that provides the required core services and additional optional services in ways that meet the particular needs of the local community. For example, all programs offer help them with decision making, and provide a safe haven" where they would not be labeled or stigmatized. At the local level, applicants for the program also obtained input from young people in the process of creating their proposals. Today, most SBYSPs have a youth advisory group to give direction to program activities. All programs adjust their services on the basis of sensitivity to youth concerns and suggestions. Students often rename their SBYSPs to suit their preferences. Teen Power House, The Imani Center, or the Drop-In Center can sound more inviting than the School Based Youth Services Program.

The school-community dimension is continually addressed. To provide the information students need today, educators must utilize every hour to its fullest extent but children who are hungry, grieving, or frightened can not make use of all that educators have to offer. It is the community that has the capacity to provide interventions that can make learning possible. What, then, is required to make an effective collaboration possible between schools and their communities?

In creating the collaboration, schools usually provide space, support and staff assistance. Communities supply social workers, youth workers, health practitioners, employment and job development counselors. Even this, however, is negotiated. Sometimes space must be adjusted, your friends experience personal problems related to any of these questions we've discussed today, remember that there's always someone at the SBYSP who has time to talk with you", and if they further suggest that students not wait for crisis but rather go to the SBYSP to talk while they're feeling confused, it often prevents negative actions. Unintended pregnancies, sexually transmitted diseases, and abuse of drugs and alcohol have all been reduced when this coordinated approach was put into effect.

In addition, when SBYSP and schools coordinate functions both groups benefit. In a key informant study and other interviews, school personnel often requested increased hours of orientation and in-service for faculty by SBYSP staff, while SBYSP staff consistently describe cooperative school functions with appreciation.

Referrals to the SBYSP counseling or health services are another school-community collaboration. Referrals come from community agencies, family courts, parents, and students themselves, but most often from teachers, guidance counselors, and school administrators. At the schools, a coordinated system of referral is developed in a series of meetings and revised when situations require additions or corrections.

young people. It was also agreed that non-educational services do not need a certificate.

The competence of site directors is key to each program. Site directors must have personal qualities consistent with the broad-based, unusual and demanding position they are assuming. They must be the type of person who will not be defeated in the face of multiple difficulties, who will visit the homes of children when appropriate, and who can communicate with all sectors of the community. When they also bring flexibility to their position, they are able to create programs that are remarkably successful.

These directors and their staffs work best when provided with continued training and forums in which they can learn from one another's experiences. An unusually low rate of staff turnover supports the observation that the support provided directors by the Department of Human Services is often critical to their success. The neutrality of the Department of Human Services as the funding agent often makes it possible to facilitate meetings and work through problems these programs face as they develop.

Collaborative Programs Are Developing Across the United States. Throughout the nation school districts are coming together with their community leaders to find ways to bring resources to families and children through schools. The

RESOURCE LIST

NEW JERSEY SCHOOL BASED YOUTH SERVICES PROGRAM

For more information, call Edward Tetelman, Director, Legal and Regulatory Affairs, New Jersey Department of Human Services, at (609)292-1617, or Roberta Knowlton, Director of the New Jersey School Based Youth Services Program at(609) 292-7816.

Bruner, Charles. Thinking Collaboratively: Ten Questions and Answers to Help Policy Makers Improve Children's Services. Washington, DC. Education and Human Services Consortium. 1991.

Mastny, Aleta and Robinson, Estelle: Linking Schools and Community Services: A Practical Guide and Resource Directory. 60 pages (each). Call or write Center for Community Education, Rutgers University, Building 4087, New Brunswick, NJ 08903

The Future of Children: School Linked Services. Vol. 1, Number 1, Spring 1992. 144 pages. Call or write Center for the Future of Children, 300 Second Street, Suite 102, Los Altos, California 94022. Attention: Dr. Richard Behrman.

Kids Count Data Book State Profiles of Child Well-Being. Kids Count. Center for the Study of Social Policy, Suite 503, 1250 Eye St., NH, Washington DC. 20005

New Jersey School Boards Association: Taming the Red Tape: Coordinating the Delivery of Government Agencies Services for Disadvantaged Children. Special Issue of the School Leader. Sept./Oct. 1991. 69 pages. Call or write NJSBA, 413 West State Street, Trenton, NJ 08605, (609) 695-7600, Attention: Peg Lawler.

Realizing America's Hope. South Carolina ETV, P.O. Drawer L Columbia, SC 29250. (8-800-277-0829). A set of 3 booklets.

What St Takes: Structuring Interagency Partnerships to Connect Children and Families with Comprehensive Services. Education and Human Services Consortium c/o IEL, 1001 Connecticut Avenue, NW, Suite 310, Washington, DC 20036-5541. Phone: 202-822-8405.

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DATA COLLECTION

AT THE NEW JERSEY SCHOOL BASED YOUTH SERVICES PROGRAM

> The data attached shows the aggregate use of services for one year. It is collected through the card/computer system exemplified at the back of the set.

The 29 sites serve more than 19,000 young people each year, with more than 75% working one-on-one with youth and family counselors, medical personnel or job and employment counselors. Data is carefully collected for all individual and family encounters.

Beyond individual and family services, the programs provide creative approaches to the prevention of violence, adolescent pregnancy and school drop-out and suspension problems through group discussions, workshops, conferences, trips and recreational activities. Data is not always collected on group activities or classroom visits by SBYSP personnel because it is usually impossible to ascertain characteristics of individuals when working with groups.

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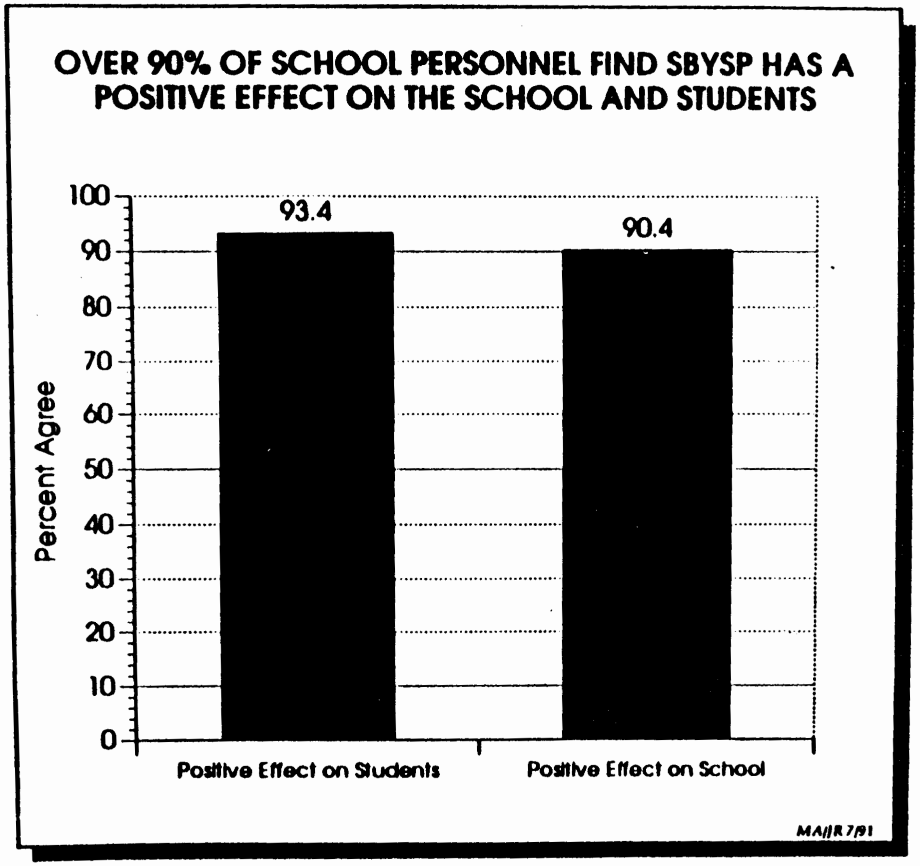
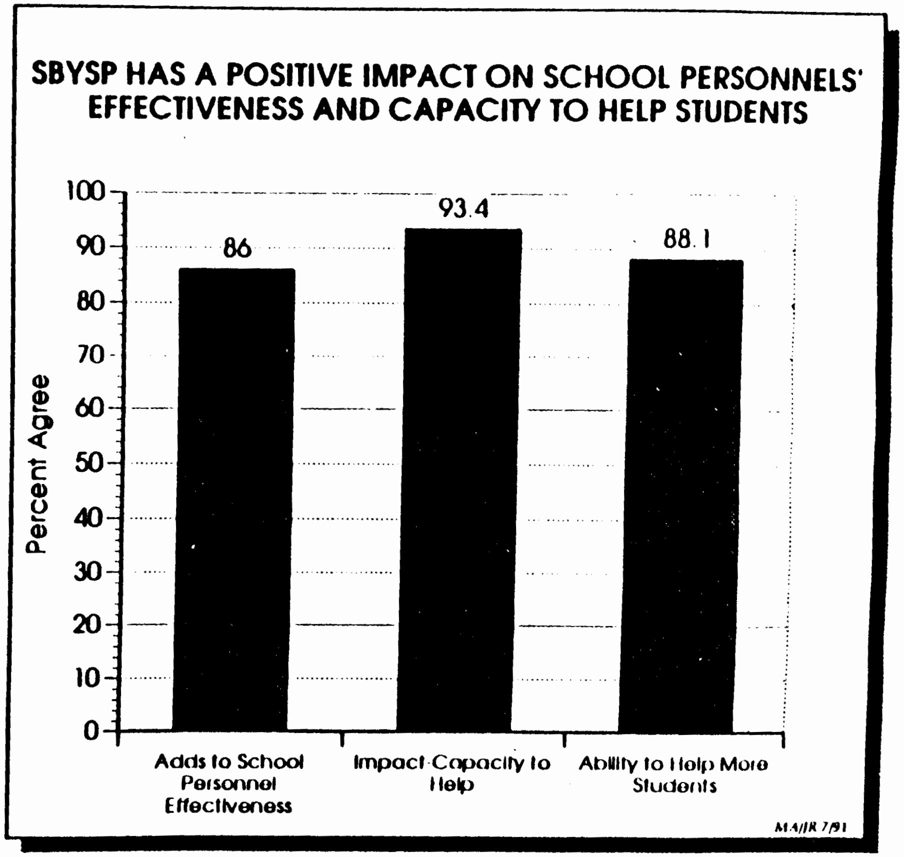
1991 SURVEY OF EDUCATORS' RESPONSES TO THE ESTABLISHMENT OF AN SBYSP AT THEIR SCHOOL

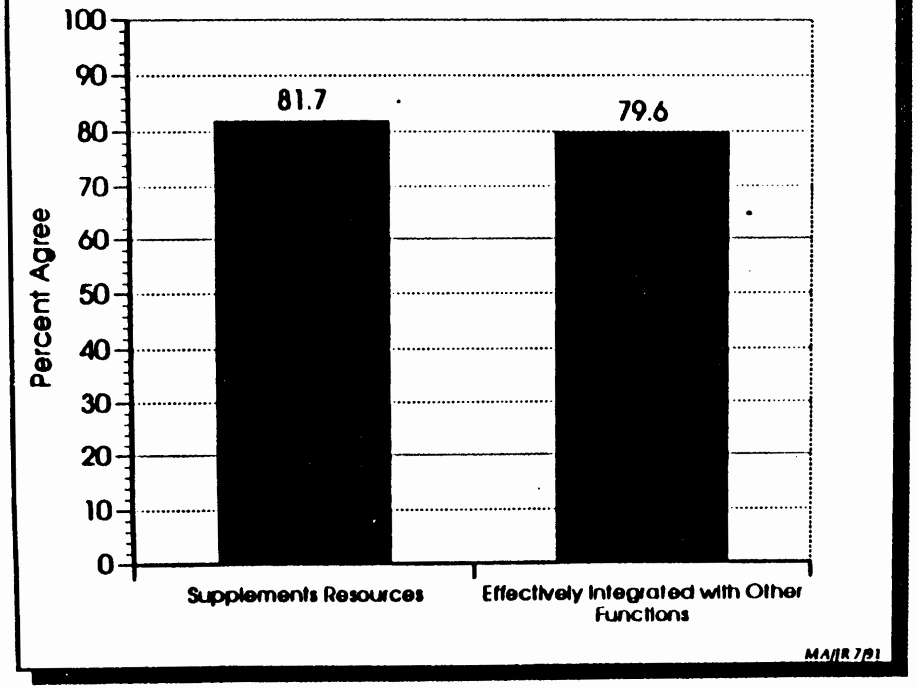


OVER 90% OF SCHOOL PERSONNEL FIND SBYSP HAS A POSITIVE EFFECT ON THE SCHOOL AND STUDENTS

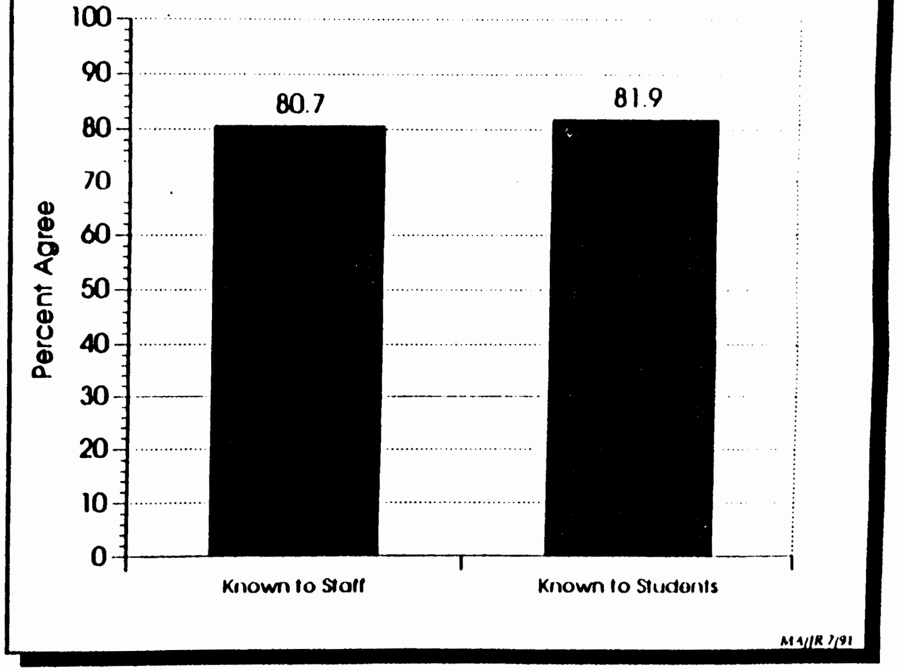


SBYSP HAS A POSITIVE IMPACT ON SCHOOL PERSONNELS' EFFECTIVENESS AND CAPACITY TO HELP STUDENTS

SCHOOL PERSONNEL FIND SBYSP SUPPLEMENTS RESOURCES THAT PREDATE THE PROGRAM AND HAS EFFECTIVELY BEEN INTEGRATED WITH SCHOOL FUNCTIONS

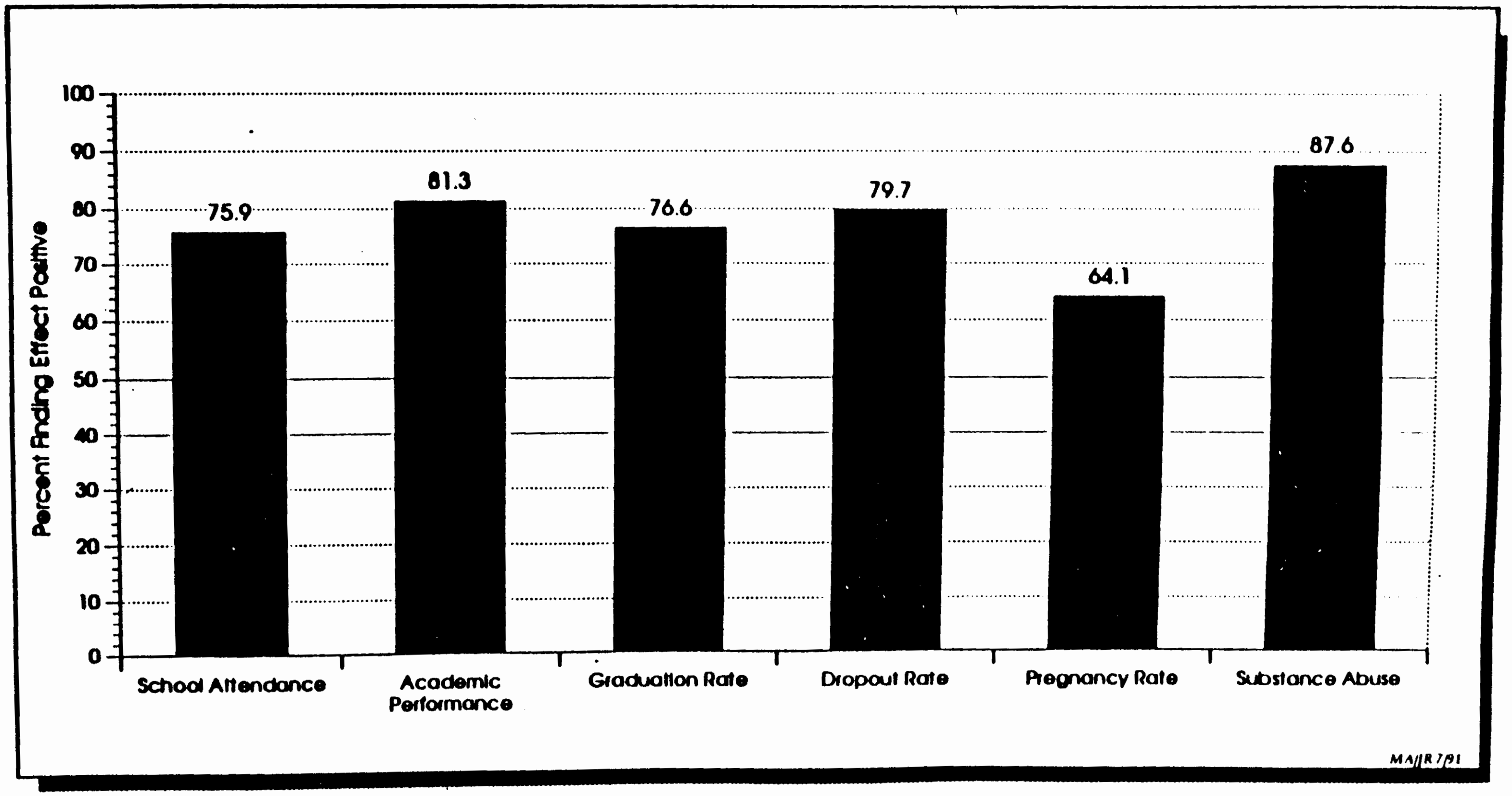


OVER 80% OF SCHOOL PERSONNEL FIND SBYSP IS WELL KNOWN TO BOTH STAFF AND STUDENTS



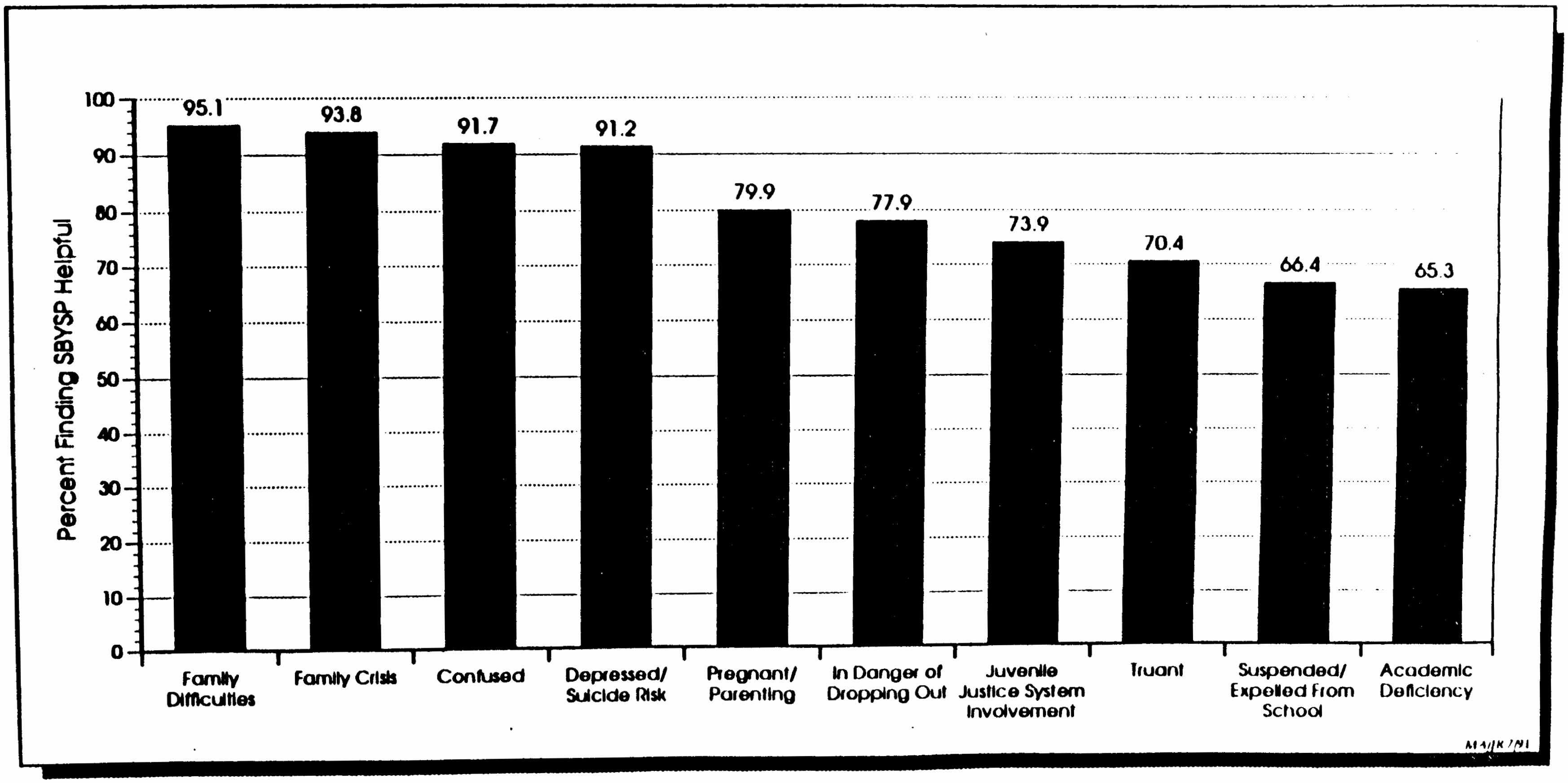
SCHOOL BASED IS MEETING OUR GOALS

SCHOOL PERSONNEL BELIEVE SBYSP HAS A POSITIVE EFFECT ON SOCIAL PROBLEMS



SCHOOL BASED FILLS A GAP

THE OVERWHELMING MAJORITY OF SCHOOL PERSONNEL FIND SCHOOL BASED HELPFUL WITH PROBLEMS FACING TEENAGERS



ALMOST 11,000 STUDENTS, OR 65% OF THOSE RECEIVING INDIVIDUAL SERVICES HAD ONE OR MORE 'SPECIAL CHARACTERISITIC'

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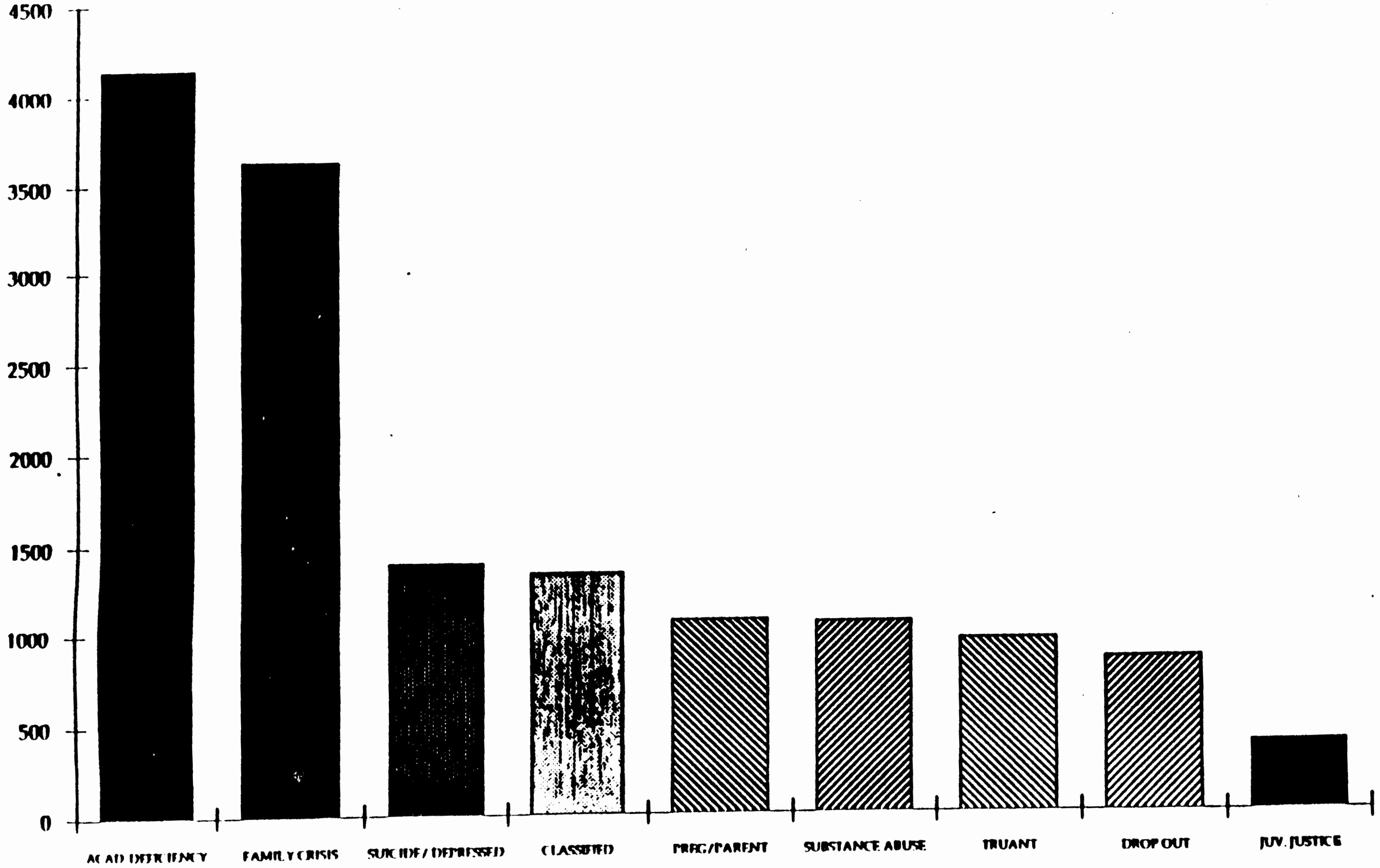
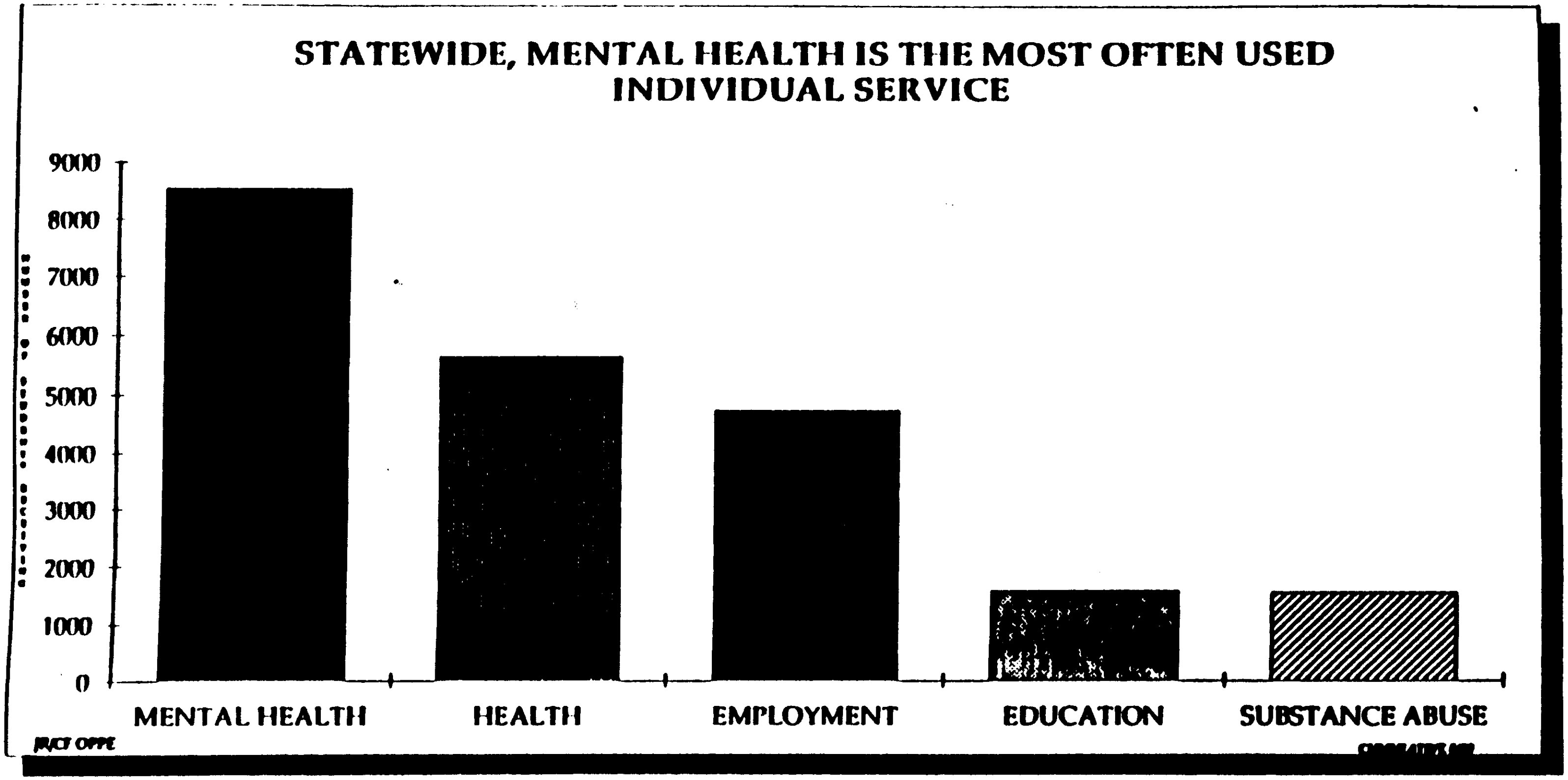


DATA FROM SFY'89



STATEWIDE, MENTAL HEALTH IS THE MOST OFTEN USED INDIVIDUAL SERVICE

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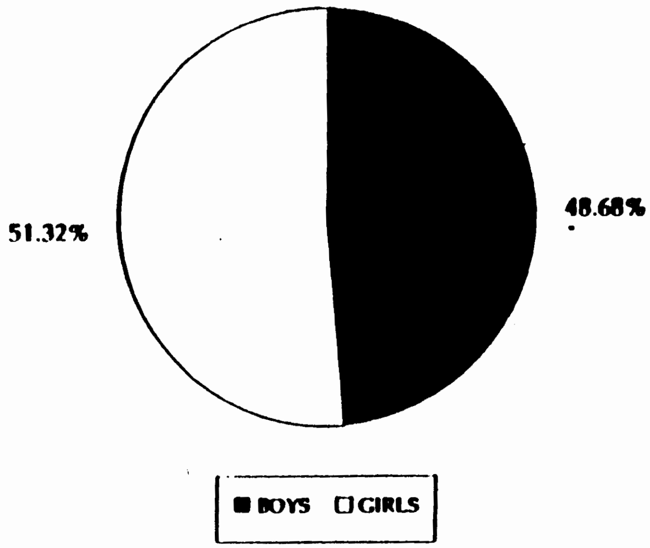
SBYSP IS EQUALLY EFFECTIVE AT REACHING BOYS AND GIRLS WITH INDIVIDUAL SERVICES



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The Cancer
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RESEARCH•TREATMENT
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Testimony to the Commission on Sex Discrimination in the Statutes
February 1, 1994
Dr. Mary B. Todd
Deputy Director, Cancer Institute of New Jersey

Thank you for inviting me to speak to the Commission on Sex Discrimination in the Statues.

There are three points I wish to make in this hearing: First is to discuss the goals of the National Cancer Institute's Cancer Programs within the context of the Cancer Institute of New Jersey; second is to outline potential areas that may impact on women's cancer health care issues in the state of New Jersey; and, third, is to discuss mechanisms by which the Cancer Institute of New Jersey can assist the state in addressing some of these issues.

The Cancer Center Programs was formally established in 1971 under the auspices of the National Cancer Institute (NCI). The aim was the development of resources with which to conduct basic, clinical, prevention and control research coupled with clinical research efforts in order to reduce cancer incidence, mortality, and morbidity, while simultaneously improving the quality of life. Comprehensive Cancer Centers are those programs that engage in all aspects of cancer research as well as Outreach and Educational Programs. There are now 27 Comprehensive Cancer Centers located in 18 states. Despite the fact that the incidence and mortality from cancer in New Jersey ranks within the top ten states in the country [1], New Jersey does not have an NCI designated Cancer Center Program and this lack, despite excellent cancer care in the state, has implications that impact negatively on all residents of New Jersey.

Fortunately, steps have been taken to establish an NCI designated cancer center in New Jersey. The Cancer Institute of New Jersey received an NCI planning grant in 1992, providing designation as a planning site for the development of a Cancer Center. The goals of the Cancer Institute of New Jersey are the same as that of the NCI: to decrease morbidity and mortality of cancer within this region, which we define as the state of New Jersey. In 1993 the appointment of the Director of the Cancer Institute of New Jersey, William Hait, M.D., Ph. D., was announced. Dr. Hait was Associate Director of the Yale Comprehensive Cancer Center and is internationally recognized for his research in breast cancer. With his arrival the Cancer Institute of New Jersey has grown in size and scope. Four basic research programs have been identified. These include the following: a Cancer Prevention Program to perform research in carcinogenesis and toxicity; a Developmental Therapeutics Program to develop new chemotherapeutic agents; a Growth Factor and Signal Transduction Program to identify cell signals which permit growth of cancer cells or the development of resistance to existing therapeutic agents; and a Gene

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Therapy Program to examine genes involved in cancer development and application of this knowledge for detection, for therapy, and for prevention of cancer. A mechanism for translation of these basic research initiatives into clinical arenas has been initiated. This mechanism includes methods to measure outcomes in terms of clinical outcomes, such as survival, as well as quality of life outcomes, the physiological impact, and cost analysis of therapeutic, diagnostic, preventive, or educational interventions. Identification of variables that impact upon these outcomes, such as lack of access to health care, or social or sexual bias, is necessary in order to measure the effect of any intervention.

Thus it is important that we know and understand potential areas or variables that may impact on women's cancer health care issues and clinical outcome in the state of New Jersey. Access to health care is known to effect clinical cancer outcomes. One example of this is a report published in the New England Journal of Medicine using data from the New Jersey State Cancer Registry of the New Jersey Department of Health, which demonstrated that women who are uninsured and those covered by Medicaid presented with more advanced breast cancer disease than patients who were privately insured [2]. Survival was different in the uninsured and Medicaid insured patient group compared to the group of patients with private insurance. Gender bias is another variable which can effect cancer outcomes, as demonstrated by a study published in 1993 [3]. This study evaluated the relationship between physician gender and appropriate screenings in women for three gender-sensitive tests (breast examination, Papanicolaou tests, and mammograms) and one gender-neutral test (blood pressure checks). Women cared for by female physicians were less likely to be deficient in the cancer screening tests, particularly Papanicolaou tests and mammograms, compared to women who were cared for by male physicians, while there was no difference in blood pressure checks. In addition, cultural acceptance can impact upon patient use of health care facilities and involvement in screening practices.

Cultural differences may be particularly important in New Jersey which has had relatively high number of racial minorities since its early settlement. At the time of the State's first census in 1790, African Americans represented eight percent of the total population. Hispanic immigration from Puerto Rico after World War II, from Cuba and Portugal in the 1960s and from Latin America in the 1970s and 1980s continued to alter the population make-up of New Jersey. More recently, Asians have been the fastest growing minority, accounting for nearly half of New Jersey's total population growth during the last decade (1980-1990). While the white population remained stable during that time, the African American population increased by 12 percent, the Hispanic population by 50 percent and the Asian population by 160 percent [4]. Thus minorities are rapidly increasing as a percentage of the State's overall population mix.

This increased percentage of minorities impacts upon the survival of our population in New Jersey. For example, age-adjusted cancer mortality is 27 percent higher for African Americans than for the general United States population. More specifically, the overall five year survival for breast cancer is 80 percent for white women, compared to 63 percent for African Americans; the overall five year survival for cervix uteri cancer is 69 percent versus 57 percent in white versus African American women, and for corpus uterine cancer, 85 percent versus 55 percent [1]. Studies have shown that Latinos have 7.3 times the incidence of cervical cancer when compared to Anglo women [5]. In addition, it has been observed that Latinos have lower rates of cervical and breast cancer screening [6, 7]. In a 1987 study, 20% of Latinos over 18 years of age had never had a Pap smear, compared with 9% of African American women and 7% white women [6]. This lack of utilization of screening, particularly in a cancer in which death can be prevented by screening, may be related to lack of culturally appropriate primary care services, lack of awareness or knowledge regarding the positive benefits of screening, cultural bias about screening, or other variables not yet identified.

The development of a the Cancer Institute of New Jersey into an NCI Comprehensive Cancer Center will help address these types of issues by providing a mechanism for core support for research initiatives. These research initiatives will include outreach, prevention, psychosocial interventions, nutritional aspects, and screening and research protocols with a special emphasis of women of color and lower socioeconomic groups. The Cancer Institute of New Jersey can assist projects of collaborators, partners and affiliates to expand the scope of these research initiatives. Examples of such projects include a recent collaboration for a proposal for an NCI Cancer Education Grant Program to support Latinas Unidas En Salud (LUS): Cancer Awareness and Referral for Latina women in Perth Amboy, as well as numerous other research proposals. Another example is a conference which is being planned in conjunction with the Environmental and Occupational Health Sciences Institute to examine demographic trends, minority cancer, and cancer prevention in New Jersey to identify research needs in this area. Collaborations with the American Cancer Society, New Jersey Division, Inc. for breast cancer screening initiatives, and with the New Jersey Breast Coalition and the previous governor of the state to announce Breast Cancer Awareness Month are additional examples. Establishment of a Cancer Center in New Jersey will permit expansion of shared resources within the state and integration of the unique combination of resources already available in the region, including Universities present in New Jersey, the American Cancer Society, New Jersey, Inc. the New Jersey Medical Society and the New Jersey Commission on Cancer Research, major pharmaceutical firms, and health care institutions. These efforts will result in expansion of specific programs of prevention, research and education and, importantly, under the direction of the Cancer Institute of New Jersey, coordination of efforts to integrate basic and clinical cancer research to make these available to New Jersey residents, and thus to decrease the incidence and mortality of cancers in New Jersey.

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TESTIMONY BEFORE THE
COMMISSION ON SEX DISCRIMINATION IN THE STATUTES
ON
WOMEN IN THE MENTAL HEALTH SYSTEM

Alma L. Saravia
Director
Division of Mental Health Advocacy
Department of the Public Advocate

February 1, 1994

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THANK YOU FOR INVITING ME TO TESTIFY BEFORE YOU TODAY. IT IS A PLEASURE TO BE BACK WITH MY COLLEAGUES FROM THE COMMISSION ON SEX DISCRIMINATION IN THE STATUTES. AS THE COMMISSION IS AWARE, HEALTH CARE IS ONE OF THE MOST CRITICAL ISSUES FACING THE STATE AND THE NATION TODAY. MY FOCUS WILL BE ON WOMEN IN THE MENTAL HEALTH SYSTEM. MY COMMENTS ARE DERIVED FROM MY EXPERIENCE AS THE DIRECTOR OF THE STATE'S DIVISION OF MENTAL HEALTH ADVOCACY IN THE DEPARTMENT OF THE PUBLIC ADVOCATE.

THE DIVISION PROVIDES LEGAL REPRESENTATION TO INDIVIDUALS WHO ARE INVOLUNTARILY COMMITTED TO PSYCHIATRIC FACILITIES. EACH YEAR, THE DIVISION PROVIDES REPRESENTATION AT APPROXIMATELY 18,000 HEARINGS. YET, UNTIL THIS HEARING WAS HELD, WE HAVE NEVER ASKED THE PROPORTION OF THE CLIENTS WHO ARE MALE AND FEMALE. UNFORTUNATELY, WE COLLECT NO STATE STATISTICS ON THE GENDER OF THE DIVISION'S CLIENTS. HOWEVER, WE ALSO IMPLEMENT A FEDERAL LAW PROVIDING PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS. LAST YEAR, WE PROVIDED ASSISTANCE TO 1,321 CLIENTS UNDER THE FEDERAL PROGRAM. OF THOSE, 574 WERE WOMEN, AND 747 WERE MALE. THUS, 43 PERCENT OF THE CLIENTS SERVED BY THE FEDERAL PROTECTION AND ADVOCACY PROGRAM ARE FEMALES.

THE STATE DIVISION OF MENTAL HEALTH AND HOSPITALS IN THE DEPARTMENT OF HUMAN SERVICES IS REQUIRED TO IMPLEMENT THE MENTAL HEALTH SYSTEM IN NEW JERSEY. ACCORDING TO THE LATEST STATISTICS OF THOSE INDIVIDUALS TREATED IN PUBLIC PSYCHIATRIC HOSPITALS, 37.4 PERCENT WERE FEMALES AND 62.6 PERCENT WERE MALES. ACCORDING TO INFORMATION COMPILED BY THE NEW JERSEY COMMUNITY MENTAL HEALTH

BOARD, 50 PERCENT OF THE OUTPATIENTS WERE FEMALE AND 50 PERCENT WERE MALE IN FISCAL YEAR 1992.

WOMEN HAVE SPECIAL NEEDS THAT DERIVE FROM THEIR ROLES WITHIN THE FAMILY, THE COMMUNITY AND SOCIETY. THEIR RELATIVE LACK OF POWER, THEIR POVERTY, THE HIGH INCIDENCE AND RISK OF SEXUAL AND PHYSICAL VIOLENCE IN THEIR LIVES, THEIR ABILITY TO BEAR CHILDREN, AND THEIR SPECIAL ROLE AS CARETAKERS OF ALL FAMILY MEMBERS (PARTICULARLY, CHILDREN AND THE ELDERLY) ARE ALL FACTORS AFFECTING THEIR MENTAL HEALTH. A MENTAL HEALTH SYSTEM WHICH PURPORTS TO BE GENDER-NEUTRAL AND FAILS TO PAY SPECIAL ATTENTION TO THESE FACTORS CANNOT PROVIDE APPROPRIATE INDIVIDUALIZED REHABILITATION SERVICES FOR WOMEN. FURTHERMORE, WHEN YOU EXAMINE GENDER BIAS IN HEALTH RESEARCH (E.G. THE USE OF ONLY MALE SUBJECTS), RESEARCH ON MENTAL HEALTH TREATMENT MUST BE CAREFULLY SCRUTINIZED FOR SIMILAR DEFICIENCIES.

OTHER THAN STATISTICAL INFORMATION, IT APPEARS THAT THERE IS VERY LITTLE EMPIRICAL DATA COLLECTED ON WOMEN IN THE MENTAL HEALTH SYSTEM. A REVIEW OF ALL THE ARTICLES PUBLISHED IN THE LAST THREE YEARS BY THE <u>AMERICAN JOURNAL OF PSYCHIATRY</u> REVEALS VERY, VERY FEW ARTICLES CONCERNING WOMEN.

INTERESTINGLY, DURING MY RESEARCH FOR THIS PUBLIC HEARING, I CAME ACROSS AN ARTICLE FROM MY GRADUATE SCHOOL DAYS WHICH IS AS RELEVANT TODAY AS WHEN IT WAS WRITTEN. FORMER FIRST LADY ROSALYN CARTER CONVENED A PANEL ON THE MENTAL HEALTH OF WOMEN AS PART OF THE PRESIDENT'S COMMISSION ON MENTAL HEALTH. THEY ISSUED A REPORT ON JANUARY 16, 1978 WHICH IS AS TIMELY AS IT WAS THEN. THE

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REPORT'S FIRST RECOMMENDATION CALLED FOR "THE ERADICATION OF SEX...BIAS IN...MENTAL HEALTH TRAINING RESEARCH AND SERVICE DELIVERY...." IN FACT, THIS RECOMMENDATION WILL BE THE FOCUS OF MY TESTIMONY.

ACCORDING TO A RECENT REPORT PUBLISHED IN THE <u>ARCHIVES OF GENERAL PSYCHIATRY</u>, NEARLY "HALF OF ALL AMERICAN ADULTS HAVE A SIGNIFICANTLY BROADLY DEFINED MENTAL ILLNESS AT LEAST ONCE DURING THEIR LIFETIME, AND NEARLY ONE-THIRD OF THEM HAVE ONE IN ANY GIVEN YEAR." ACCORDING TO THE AMERICAN PSYCHIATRIC ASSOCIATION'S PRIMARY REFERENCE TEXT, THE <u>DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDER</u>, VOLUME IIIR, MAJOR DEPRESSION IS TWICE AS COMMON IN FEMALES AS IN MALES. YET, MENTAL ILLNESS GOES UNTREATED IN SEVEN OF TEN CASES ACCORDING TO DR. FREDERICK GOODWIN, DIRECTOR OF THE NATIONAL INSTITUTE OF MENTAL HEALTH.

AN INCREASING PROPORTION OF THE INDIVIDUALS COMMITTED TO THE STATE'S MENTAL HEALTH SYSTEM SUFFER NOT ONLY FROM A MENTAL ILLNESS, BUT ARE DUALLY DIAGNOSED AS A SUBSTANCE ABUSER. THE PERCENTAGE OF INDIVIDUALS SUFFERING FROM HIV IS INCREASING, AND NOW MANY OF OUR CLIENTS SUFFER FROM AIDS DEMENTIA. WOMEN WHO ARE BOTH MENTALLY ILL AND SUBSTANCE ABUSERS HAVE UNIQUE PROBLEMS, PARTICULARLY AS PARENTS. FAMILY MAINTENANCE OR REUNIFICATION EFFORTS SHOULD BE ESTABLISHED AT THE HOSPITAL ASSURING APPROPRIATE CONTACT WITH THEIR CHILDREN, COORDINATION WITH AGENCIES SERVICING THESE CHILDREN SHOULD OCCUR AND PARENTING SKILLS TRAINING, HELPING CHILDREN DEAL WITH THEIR MOTHER'S ILLNESS, AND PROVIDING LEGAL SUPPORT FOR THOSE FACING LOSS OF CUSTODY OR TERMINATION OF PARENTS' RIGHTS SHOULD BE

PROVIDED. SERVICE SYSTEMS IN THESE AREAS HAVE BEEN SLOW TO RESPOND TO WOMEN AND HAVE ONLY RECENTLY BEGAN TO ADDRESS THEIR SPECIAL NEEDS.

ACCORDING TO A RECENT STUDY ON THE GENDER DIFFERENCES IN SUBSTANCE ABUSE DISORDERS, WOMEN ARE SIGNIFICANTLY MORE LIKELY TO HAVE ANOTHER AXIS I (WHICH IS A DIAGNOSTIC CATEGORY IN THE DSM-IIIR) DISORDER IN ADDITION TO SUBSTANCE ABUSE. WOMEN SUFFER MORE FROM ANXIETY DISORDERS, AND THEY HAVE SIGNIFICANTLY MORE PSYCHOPATHOLOGY THAN MALE ALCOHOLICS. THERE IS A MUCH HIGHER PREVALENCE OF POST-TRAUMATIC STRESS DISORDER THAN AMONGST THE GENERAL POPULATION. WOMEN WITH POST-TRAUMATIC STRESS DISORDER ARE SLIGHTLY MORE LIKELY THAN WOMEN WITHOUT POST-TRAUMATIC STRESS DISORDER TO DEVELOP DRUG DEPENDENCE. ANOTHER INTERESTING FINDING IS THAT FEMALE ALCOHOLICS ARE THREE TIMES AS LIKELY AS MALES TO HAVE PANIC DISORDER. IN THE GENERAL POPULATION, PANIC DISORDER IS TWICE AS COMMON IN FEMALES AS IN MALES. ALL OF THESE ISSUES NEED RESEARCH AND STUDY.

ANOTHER FORM OF DISCRIMINATION AGAINST WOMEN RESULTS WHEN CLINICIANS TREATING HOSPITALIZED WOMEN FAIL TO RECOGNIZE THE HIGH PERCENTAGE OF PATIENTS WHO HAVE BEEN SEXUALLY ABUSED AS ADOLESCENCE OR CHILDREN. ACCORDING TO A STUDY PUBLISHED IN THE HOSPITAL AND COMMUNITY PSYCHIATRY JOURNAL, 51 PERCENT OF FEMALE STATE HOSPITAL PATIENTS WERE FOUND TO HAVE BEEN SEXUALLY ABUSED AS CHILDREN OR ADOLESCENCE. YET, ONLY 20 PERCENT OF THE ABUSED PATIENTS BELIEVE THEY HAD BEEN ADEQUATELY TREATED FOR THEIR SEXUAL ABUSE. INTERESTINGLY, 66 PERCENT OF THE ABUSED PATIENTS MEET THE

DIAGNOSTIC CRITERIA FOR POST-TRAUMATIC STRESS DISORDER, BUT NONE HAD RECEIVED THAT DIAGNOSIS.

THERE IS ALSO A NEED FOR STAFF TRAINING IN TERMS OF WOMEN'S UNIQUE NEEDS WITHIN THE SYSTEM AND IN PARTICULAR ON CORRECT DIAGNOSES OF WOMEN. A RECENT ARTICLE IN THE AMERICAN JOURNAL OF PSYCHIATRY ANALYZED PSYCHIATRISTS' BELIEFS ABOUT GENDER APPROPRIATE BEHAVIOR. ACCORDING TO THIS ARTICLE, WHAT A PSYCHIATRIST BELIEVES ABOUT GENDER APPROPRIATE BEHAVIOR MAY INFLUENCE THE TREATMENT OF THE PATIENT. A SURVEY FOUND THAT FEMALE PSYCHIATRISTS RATED MASCULINE TRAITS AS OPTIMAL FOR FEMALE PATIENTS AND MALE PSYCHIATRISTS BELIEVE TRAITS CHARACTERISTIC OF BOTH MASCULINE AND FEMININE ARE OPTIMAL FOR BOTH MALE AND FEMALE PATIENTS. THE STUDY CONCLUDED THAT THERE HAVE BEEN SIGNIFICANT CHANGES IN PSYCHIATRISTS' ATTITUDES TOWARD GENDER IN THE PAST 20 YEARS.

YET, IT IS MY FEELING THAT DESPITE THESE CHANGES, THERE HAVE NOT BEEN SUFFICIENT STUDIES OF GENDER DIFFERENCES IN THE TYPES OF DIAGNOSES GIVEN MEN AND WOMEN. FOR EXAMPLE, IN THE JANUARY 1994 ISSUE OF THE AMERICAN JOURNAL OF PSYCHIATRY, THE FIRST ARTICLE WAS PUBLISHED ON SEXUAL HARASSMENT AND THE IMPACT OF SEXUAL HARASSMENT ON THE PSYCHOLOGY OF THE VICTIM. ACCORDING TO THE ARTICLE, SEXUAL HARASSMENT PRODUCES AN ARRAY OF PHYSICAL AND SUBSTANCE ABUSE IN OVER 90 PERCENT OF VICTIMS, AND ONLY 12 PERCENT SEEK HELP FROM MENTAL HEALTH CARE PROFESSIONALS. SELF-DOUBT IS A CENTRAL ISSUE REGARDLESS OF GENDER, BUT IN INSTANCES WHERE THE PERPETRATOR IS MALE AND THE VICTIM IS FEMALE, THERE ARE RAMIFICATIONS UNIQUE TO THE TRAUMA OF GENDER BASED ABUSE. ACCORDING TO THE AUTHORITIES, IT

IS CRITICAL THAT THERAPISTS AVOID CONTRIBUTING TO THE PROCESS OF "SECOND INJURY" AND NOT IMPLY THAT PATIENTS HAVE BROUGHT THEIR TROUBLES ON THEMSELVES. THE ARTICLE CONCLUDES BY SAYING THAT FEW STUDIES HAVE FOCUSED ON THE VICTIMS OF SEXUAL HARASSMENT AND THAT PSYCHIATRY CAN PLAY AN INVALUABLE ROLE IN THE ASSESSMENT AND TREATMENT OF VICTIMS.

THE OTHER CONTROVERSIAL AREA IN TERMS OF THE PSYCHIATRIC DIAGNOSIS OF WOMEN CONCERNS PSYCHIATRIC SYNDROMES LINKED TO THE REPRODUCTIVE FUNCTION IN WOMEN. NEW RESEARCH IS FOCUSING ON WHETHER PREMENSTRUAL BEHAVIORAL DISTURBANCES ARE RELATED TO EPILEPSY. IN GENERAL, THE QUESTION REMAINS UNANSWERED WHETHER PREMENSTRUAL BEHAVIORAL SYMPTOMS IS A PSYCHIATRIC DIAGNOSIS.

THERE IS ALSO A NEED FOR A MANDATED UNIFORM INSTITUTIONAL ABUSE INVESTIGATION SYSTEM FROM ALL PSYCHIATRIC HOSPITALS AND UNITS COMPARABLE TO THE CHILD ABUSE SYSTEM WITH MANDATORY REPORTING AND EXTERNAL INVESTIGATION COMPONENTS. WHILE THERE IS INVESTIGATIONS OF ABUSE AND NEGLECT ALLEGATIONS, I THINK IT HAS FAILED TO RECOGNIZE MANY OF THE ABUSE CASES AGAINST WOMEN. THERE MUST BE NEW DIAGNOSTIC AND SCREENING PROTOCOLS TO ENSURE THAT WOMEN THAT HAVE BEEN VICTIMIZED OR SUFFERED TRAUMA FROM PSYCHOLOGICAL OR SEXUAL ABUSE ARE IDENTIFIED AND PROVIDED WITH COMPREHENSIVE TREATMENT.

FOR WOMEN WHO ARE HOSPITALIZED, COMPREHENSIVE HEALTH EDUCATION, PRENATAL CARE AND CAREFUL USE OF PSYCHOTROPIC MEDICATIONS DURING PREGNANCY IS A CRITICAL ISSUE. A REVIEW IN THE <u>HOSPITAL AND COMMUNITY PSYCHIATRY JOURNAL</u> OF 35 PREGNANT WOMEN HOSPITALIZED FOR NONORGANIC, PSYCHOTIC SYMPTOMS SHOWED THAT THE

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MAJORITY OF THE WOMEN HAD BEEN HOSPITALIZED FIVE TIMES OR MORE AND LACKED SOCIAL AND ECONOMIC SUPPORTS. ALMOST TWO-THIRDS HAD HAD TWO OR MORE PREGNANCIES, BUT ONLY TWO WERE LIVING WITH THEIR CHILDREN. THERE HAS BEEN A COMPLETE ABSENCE OF CUSTODY ISSUES BEING ADDRESSED BY THE HOSPITAL TREATMENT PROGRAM.

THERE SHOULD BE A GREATER PROVISION OF MENTAL HEALTH SERVICES ON AN OUT-PATIENT BASIS AND NEEDS TO BE A CLOSER COORDINATION BETWEEN REPRODUCTIVE HEALTH SERVICES, RAPE COUNSELING CENTERS, DOMESTIC VIOLENCE PROGRAMS, LEGAL SERVICES, SUBSTANCE ABUSE TREATMENT PROGRAMS, AND PARENTING SKILLS PROGRAMS. THE DIVISION OF MENTAL HEALTH AND HOSPITALS' REGULATIONS SHOULD REQUIRE BOTH INSTITUTIONS AND COMMUNITY AGENCIES TO DEVELOP AND IMPLEMENT PROGRAMS FOR WOMEN. REHABILITATION SERVICES SUCH AS EDUCATION AND VOCATIONAL TRAINING OFFERED BOTH IN THE HOSPITALS AND AT OUT-PATIENT PROGRAMS MUST BE REVISED TO ELIMINATE STEREOTYPICAL TRAINING. WOMEN MUST BE INCLUDED AMONGST "TARGET POPULATIONS" WHO MUST BE SERVED BY COMMUNITY MENTAL HEALTH CENTERS. THERE IS A NEED FOR RESEARCH AND DATA COLLECTION ON THE ASPECTS OF WOMEN IN THE MENTAL HEALTH SYSTEM. THIS RESEARCH SHOULD ADDRESS WHETHER THERE IS DISPARATE TREATMENT OF WOMEN AND EXAMINE WHERE RESOURCES ARE ALLOCATED.

IN ADDITION, BOTH FAMILY SYSTEMS CLINICIANS AND THE GROWING FAMILY ADVOCACY MOVEMENT HAVE SLOWLY GENERATED AN AWARENESS OF THE IMPORTANCE AND EFFICACY OF ENGAGING FAMILIES IN TREATMENT AND REHABILITATION, EVEN OF THE SERIOUSLY MENTALLY ILL. I SUSPECT THAT THESE EFFORTS HAVE SERVED LARGELY TO INCREASE THE INVOLVEMENT OF

FEMALE CARETAKERS AS THE MAJOR PROVIDERS OF AFTERCARE SERVICES, BUT THEY HAVE NOT SERVED TO EITHER ENSURE CONTACT AND COMMUNICATION BETWEEN WOMEN AND THEIR CHILDREN OR FOCUSED EFFORTS ON MOTIVATING AND HELPING MEN TO STAY WITH AND SUPPORT THE MENTALLY ILL WOMEN IN HER FAMILY.

FINALLY, AT A TIME WHEN OUR COUNTRY IS EMBARKING ON A HISTORIC DISCUSSION OF HEALTH CARE REFORM, IT IS IMPERATIVE THAT THERE BE PARITY BETWEEN MENTAL HEALTH AND PHYSICAL ILLNESSES IN ANY HEALTH CARE REFORM LEGISLATION. NONE OF THE LEGISLATION BEING DISCUSSED TREATS MENTAL ILLNESSES THE SAME AS OTHER PHYSICAL ILLNESSES. WITHOUT EXTENSIVE LOBBYING, I FEAR THAT THE LIMITED BENEFITS BEING PROPOSED WILL BE CUT BACK EVEN FURTHER. AT A RECENT CONFERENCE I OBTAINED INFORMATION THAT THE CLINTON HEALTH PLAN NOW CALLS FOR A 30-DAY LIMIT PER YEAR ON IN-PATIENT HOSPITALIZATION WITH AN ADDITIONAL 30 DAYS ONLY FOR INDIVIDUALS FOUND DANGEROUS TO THEMSELVES OR OTHERS OR IN NEED OF DRUG TREATMENT. I AM CONCERNED THAT THIS WILL RESULT IN THE OVERCOMMITMENT OF INVOLUNTARILY COMMITTED INDIVIDUALS. IN ADDITION, THE CLINTON ADMINISTRATION PLAN CALLS FOR ONLY 30 VISITS PER YEAR. IN ORDER TO OBTAIN ADDITIONAL VISITS, YOU MUST TRADE OFF ONE HOSPITAL DAY FOR FOUR VISITS. ANY LEGISLATION SHOULD PROVIDE COVERAGE FOR PREVENTION, EARLY INTERVENTION AND FOLLOW-UP CARE. WITH THE CURRENT RANGE OF MENTAL HEALTH TREATMENTS AVAILABLE TODAY, MANY PEOPLE ARE ONLY INCAPACITATED FOR A SHORT TIME AND BECOME PRODUCTIVE MEMBERS OF SOCIETY. I WOULD URGE YOU TO FOLLOW THE HEALTH INSURANCE DEBATE AND ARGUE STRONGLY FOR THE INCLUSION OF COVERAGE FOR THE TREATMENT

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OF SUBSTANCE ABUSE AND MENTAL ILLNESS.

THANK YOU FOR THE OPPORTUNITY TO PROVIDE THIS TESTIMONY.

Presentation on the Health Needs of Incarcerated Women

By: Susan Remis Silver, Director of the Office of Inmate Advocacy
Department of the Public Advocate, CN 850, Trenton, N.J. 08625

Before the Commission on Sex Discrimination in the Statutes

February 1, 1994

I am pleased to be here to address the medical needs of female inmates. The Office of Inmate Advocacy has the statutory mandate to represent the interests of the more than 39,000 inmates, men and women, who are incarcerated in New Jersey state prisons, county jails, municipal lock-ups and juvenile detention facilities. We seek to foster constitutional and more humane living conditions for inmates.

The Office has three attorneys including me, and we bring litigation to benefit the interests of inmates as a class. For example, in our class action law suit <u>Roe v. Fauver</u>, we are representing all HIV positive inmates in New Jersey State prisons to ensure that they receive proper medical and mental health care as well as equal access to programs and services. We also have a number of law suits that address the totality of living conditions in county jails.

The four investigators in the Office investigate systemic problems and also advocate for individual inmates. For example, we deal with mishandled medical emergencies, inmates in need of protective custody or mental health care, reports of officers beating inmates, inmate suicides and deaths, and every imaginable problem relating to daily life in an institution. We frequently receive reports that inmates failed to receive necessary medical care.

Incarcerated women have been and continue to be a forgotten population. This is due, in part, to the fact that historically, only a small percentage of the inmates in our prisons and jails were women. As a result, women have traditionally been an afterthought in jail and prison planning. Our jails and prisons were never designed or built to hold women.

Numbers of Incarcerated Women

Today, many more women are behind bars both in terms of the percentage of female inmates and in terms of absolute numbers. In 1986, women were only 4% of the total inmate population in this country. By June 30, 1992, women prisoners accounted for 5.8% of all prisoners nationwide. In New Jersey, women are now 4.2% of the state prisoner population and 6.7% of the county jail population.

The absolute numbers of incarcerated women have also increased. In 1980, only 13,000 women were in federal and state prison in this country. By the end of 1992, that number almost quadrupled to 50,400. In New Jersey, we now incarcerate approximately 2,000 women. A little less than 1,000 of these women are state prisoners housed in New Jersey's only State prison for women, the Edna Mahan Correctional Facility for Women, and a little over 1,000 of the women are county inmates and housed in each of our county jails. With 2,000 women incarcerated in New Jersey, we are talking about a sizeable population of people who have special needs that have to be addressed.

Profile of Incarcerated Women

So who are these women? They are overwhelmingly poor, disproportionately women of color, and medically disenfranchised. They have the added stigma of having been charged with breaking the law. They do not vote, are essentially without power, and few groups are concerned with their welfare. They are mothers with small children, single heads of households, substance abusers, victims of violence, and survivors of physical and sexual abuse. Typically, women in the community receive less health care than men. This is true as well among the women in our jails and prisons. Many female offenders never received any primary health care before the criminal justice system became their primary health care provider.

Overcrowding Adversely Impacts the Quality of Medical Care

Before I address the unique medical needs of incarcerated women, I must first mention the serious and state-wide problem of overcrowding that adversely impacts the quality of medical care that all inmates receive. Across New Jersey, our county jails and state prisons are so overcrowded and understaffed that inmates frequently fail to receive timely physical exams upon entry or timely and adequate medical care once admitted to the facility.

Inmates throughout this State are subjected to delays in receiving even critically needed medical care, interruptions in receiving necessary medications, poor medical follow-up, and poor preventative care. We have seen some inmates with serious ailments such as AIDS languish for months without appropriate assessment or treatment. Vast disparities in medical treatment exist from one state prison to another and from one county jail to another. Our

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county jails are even more overcrowded than our state prisons, and inmates housed in county correctional facilities generally receive less comprehensive medical care than state prisoners.

When you are sick and living behind bars you are completely at the mercy of your jailers to receive any sort of medical care. As a result of correction officer understaffing, many county jails leave housing areas completely unstaffed by correctional officers for hours each day. If you are an inmate and unlucky enough to have a medical emergency when no officer is on your housing tier, your cries for medical help will go unheard and unanswered. This problem resulted in the tragic death of a woman at the Essex County Jail Annex who had a serious asthmatic attack while her tier was without any officer supervision for one and a half hours after her asthma attack began. As a result of inmate overcrowding and officer understaffing, inmates of both sexes often are subjected to extensive delays in the delivery of medical care, with sometimes fatal results.

The Office of Inmate Advocacy recommends that this Commission formulate statutory guidelines that establish minimum standards of medical care and treatment for <u>all</u> incarcerated individuals. Although state regulations exist that govern the operation of county jails, N.J.A.C. 10A:31-1.1 <u>et</u> <u>seq</u>, these regulations are not routinely enforced. We recommend enactment of mandatory enforcement procedures which set forth the specific responsibility of the New Jersey Department of Corrections to ensure county compliance with these standards.

Incarcerated Women Have Unequal Medical Facilities

To understand the health needs of incarcerated women in particular, we must first understand that although many more women are now incarcerated, the almost exclusive focus on male inmates has not changed. As a result, the needs of female inmates are often unmet. Facilities and staff available to incarcerated women in either state or county institutions simply are not equivalent to the medical services for men.

Lack of Infirmary Space for Women

The male orientation of our jail designs has a very real impact on incarcerated women's health. To my knowledge, not a single county jail in New Jersey has a separate medical infirmary for female inmates. Many jails are so overcrowded that they house medically needy inmates in the same tiers as those who are placed in isolation for breaking institutional rules.

Lack of Mental Health Areas for Women

Nor does any county jail in our state have separate mental health housing areas for women, or even special cells for suicidal women. Unlike male inmates in county jails who have special housing areas if they have mental health needs, women with the same mental health needs are simply placed in general population housing. As a result, it is difficult, if not impossible, for the jail's mental health staff to provide the close observation that women with mental health problems may need.

Lack of New Admissions Housing for Women

In addition, incarcerated women in every county jail are immediately placed in general population rather than in new admission housing areas. No county jail in New Jersey has a new admission housing area for women despite the regulatory requirement that all inmates first receive a medical screening and physical examination <u>before</u> placement in general population. N.J.A.C. 10A:31-13.9(b). In contrast, most county jails house new male admittees in separate new admission housing pending the results of their medical screening, physical exam, and classification review. As a result of the inadequate housing provided to female offenders, a woman with a very contagious disease such as tuberculosis can be thrown into jail, and until her test results come back, she is housed in general population, sharing small living space with other healthy inmates. When you consider the poor ventilation systems of many of our antiquated jail buildings together with the fact that the same inmates are breathing on each other in overcrowded facilities, you can appreciate the dangers of disease transmission in our correctional facilities.

<u>Jail Space Is Often More Overcrowded for Women than Men</u>

In the county jails, women are often segregated in a small area of the jail without access to the facilities available to the majority male population. These facilities, such as gyms, libraries, classrooms, and vocational training spaces, are rarely duplicated in the women's area of the jail. Even some of our newer jails, such as the jails in Hunterdon and Middlesex counties, were constructed without adequate facilities for women. In Hunterdon, even before the jail opened, the number of women inmates exceeded the planned bed space. To address this deficiency, the jail double-bunked its women's cells, which were designed to house only one inmate. Therefore, the female inmates are housed two to a cell, while male inmates are single-celled. In Middlesex, similar inadequate planning for women led to similar double-bunking of the women's housing area.

You can visualize the limited living space that a woman has in a double-bunked cell if you extend your arms and add maybe four inches on each side. Even this small cage is shared and is not her own. In some overcrowded facilities like Camden County Jail, dozens of women are forced to sleep on the floors of the dayrooms and do not even have cells they can call her own.

Dr. Jaye Anno states in her book Prison Health Care: Guidelines for the Management of an Adequate Delivery System, that "The literature on female offenders is replete with examples of inequality in their housing arrangements, the availability of programs and their access to services when compared with their male counterparts." So the question is, how do we begin to correct this inequality?

Incarcerated Women Are at Greater Risk of HIV, STDs, and Substance Abuse

The first step is to realize that women have many of the same health care needs as men and need the same financial resources to meet these needs. They are at risk for many of the same illnesses, such as drug abuse, AIDS, tuberculosis, and sexually transmitted diseases. In many instances, incarcerated women are at even greater risk of these diseases than their male counterparts.

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Incarcerated women have significantly higher rates of HIV infection. Last summer, the New Jersey Department of Health and Department of Corrections conducted a study of 2,000 men and women entering New Jersey prisons. This study revealed that an astonishing 15% of the female inmates tested HIV positive. This was significantly higher than the 9% positive rate among male inmates in New Jersey, and 30 times greater than the HIV infection rate among childbearing women in New Jersey. The federal Centers for Disease Control has also found that throughout the country, HIV prevalence rates are significantly higher for female inmates than for male inmates.

This is due, in part, to the fact that the majority of incarcerated women have substance abuse problems, and many turned to prostitution to support their drug addictions. This is a double whammy since IV drug use and prostitution are among the most risky of all activities that can spread the HIV virus.

The large number of prostitutes among incarcerated women also place these women at high risk of sexually transmitted diseases. However, our state regulations governing county jails do not require that medical screenings include pap tests, pelvic exams, or cultures for sexually transmitted diseases such as gonorrhea. N.J.A.C. 10A:31-13.9. Our state laws should be amended to mandate attention to these particular needs of women inmates.

Incarcerated women may also have a higher rate of substance abuse problems than incarcerated men. Roughly 43% of the inmates in New Jersey's prisons and jails are sentenced for drug offenses, and 70% reportedly have substance abuse problems. Among incarcerated women, however, it is estimated that as many as 90% have substance abuse problems. Unfortunately, drug treatment counselors and programs in the correctional system are being cut at an even greater rate than they are in the community, which is a disgrace in both cases.

We need more substance abuse programs in our correctional facilities. In fact, in our entire state prison system, we only have 180 beds for inmates who need drug treatment even though 70% of the 24,000 state prisoners have substance abuse problems. Some county jails in this State have virtually no drug treatment programs. The New Jersey Sentencing Policy Study Commission found that our prison system is moving backward in addressing the needs of inmates with drug addictions because the Department of Corrections has failed to fund drug treatment programs even though drug addiction often leads inmates into the criminal justice system in the first place. We need to expand substance abuse programs in our jails and prisons so every inmate who can benefit from such a program can enroll.

Incarcerated Women Need the Same Resources Tailored to Their Unique Medical Needs

Female Inmates Need Gender-Specific Information on AIDS

Incarcerated women need the same level of care and treatment that incarcerated men receive to address their medical concerns. However, treatment protocols must be modified to consider the specific needs of women. The issue of AIDS is a perfect example. Jail education programs need to discuss how HIV manifests itself differently in women. Female inmates who are pregnant or post-partum need information on prenatal transmission of the virus and on how their pregnancy affects the course of their own disease. Despite the significant population of HIV infected inmates in New Jersey, State prisons and county jails are not adequately providing these individuals -- male or female -- with information on HIV transmission, treatment or prevention.

<u>Incarcerated Women Need Adequate Prenatal Care</u>

Women also have additional medical needs which are too often overlooked in a jail setting. As many as 10% of female inmates enter the correctional system pregnant and require prenatal care and education. In Essex County, approximately 10 pregnant women are admitted each month to the county jail. Three or four of these pregnant women also are HIV positive. Since many of these women have not received proper medical care prior to their incarceration, many pregnant inmates have high risk pregnancies. Typically, the doctors in jails are general practitioners who may not have the necessary expertise to treat the complications of high risk pregnancies.

The Office of Inmate Advocacy receives numerous complaints from pregnant women concerning their medical care. Sometimes the complaints revolve around inadequate food. It is obviously important for a woman to have good nutrition during her pregnancy, but food portions in jail are small, and the food is often starchy, greasy, stale, and just tastes bad. In most jails, pregnant inmates are forced to eat the same food as other inmates without any allowance made for their additional nutritional needs. We recently received a complaint from one pregnant inmate who lost 15 pounds during her first three and a half months of pregnancy, and until our intervention, she was unable to receive additional food supplements and unable to receive more than one glass of milk a day from jail personnel. We also receive complaints from women who fail to receive necessary <u>emergency</u> medical care during their pregnancies. For example, in Camden County Jail, a woman was admitted to the jail who was four months pregnant, and she was assigned to sleep on a mattress on the floor. When she first saw a doctor three days later, the only "care" the doctor provided was to order that she be seen one month later in a prenatal clinic. The following day, she experienced severe abdominal pain. She was not examined by a doctor and was just given two Tylenol. Later that day, she began to vomit. Again, nothing was done. Some 14 hours later, she miscarried in her cell.

<u>Incarcerated Women Have a Right to Abortion Services</u>

Incarcerated women also have a constitutional right to receive abortion services, a right established in 1987 in litigation brought by the Office of Inmate Advocacy against Monmouth County Jail. In that case, the Third Circuit Court of Appeals held that a county jail cannot deny access to and funding for elective abortions. <u>Monmouth County Correctional Institute Inmates v. Lanzaro</u>, 834 F.2d 326, 337 (3d Cir. 1987). However, my office still receives complaints that county jails unduly delay abortion services for inmates. In Essex County, an inmate contacted us just last month because the jail delayed for close to two months her request for an abortion. When she first made her request to the appropriate jail official, the officer harassed her and sarcastically told her that the County should not pay for such medical services. It was only after her defense attorney made repeated requests to the jail that they finally provided an abortion to this woman, but by that time she was in her 20th week of her pregnancy. She was forced to undergo a saline abortion and had 17 hours of induced labor before she delivered a stillborn baby. When I met with this woman last week, she still looked frail and visibly shaken by this experience.

Women Inmates Need Adequate Personal Hygiene Items

Our jails also fail to provide women with necessary personal hygiene supplies. In Ocean County Jail, an inmate had her menstrual period and requested sanitary napkins. Correction officers in the jail refused to provide her with this personal hygiene item and told her that she should just use her socks instead. In Essex County Jail Annex, as well, the jail officials only provide sanitary napkins on weekdays, and women who need sanitary napkins or tampons on the weekend must either borrow these supplies from each other or use toilet paper.

Incarcerated Women Need Adequate Ob/Gyn Care

Jails in our state also do not provide incarcerated women with adequate information on ob/gyn care. Women in jail are not reminded to get a regular Pap smear. Women in jail need to know what medical follow-up care they need, and they have to be assertive and make sure they receive appropriate medical care.

Incarcerated Women Need Confidentiality in Medical Care

Incarcerated women also need more assurances that their medical care will be provided in a confidential setting. The lack of confidentiality is a serious and state-wide problem in both our county jails and state prisons. Many women refuse to get tested for HIV or sexually transmitted diseases, or to seek counselling for fear that their medical condition will be announced to correctional staff and other inmates. Once her medical condition is publicly announced, the inmate could suffer harassment, discrimination in housing and access to programs and services, or even physical harm from other inmates. The Office of Inmate Advocacy recommends that the legislature issue standards to protect the confidentiality of an inmate's medical condition.

Incarcerated Women Need More Time With Their Children

The final issue I would like to address concerns the large number of incarcerated women who are mothers. Approximately 80% of all women in our State prisons and county jails have children, and 70% of these women are single parents who frequently have no one to care for their children. The stress of incarceration is exacerbated by the separation from and concern for their children. I will never forget my visit to Middlesex County Jail where I witnessed a noncontact visit between a child and his parent. I watched the small child place his hand against the window of the noncontact visitation booth, and his mother place her hand against the glass from the other side. They were trying to maintain close physical contact, but the jail was not making their efforts easy. Many jails do not provide for any contact visitation despite state regulations that recommend such programs.

Many incarcerated women try to run their households from jail and try to be the primary caretaker of their children even as they live their life behind bars. Their attempts to maintain a close family unit can be frustrating and emotionally painful. Many incarcerated women grieve the loss of daily contact with their children. They have been forcibly separated from their children and need counseling and treatment to deal with the psychological pain that they feel.

We need to do more to nurture the family bonds between inmates and their children. Visitation opportunities between mothers and their children need to be drastically expanded. The current 15 to 20 minute visits that female inmates may have with their children several times a week is just insufficient to maintain good mother/child bonds.

The Office of Inmate Advocacy recommends that our statutes be clarified to allow incarcerated women with infants or small children to live with their babies in separate housing areas, preferably in satellite units outside the main institution. Currently, no county jail or state prison in New Jersey allows mothers to have their infant children live with them. However, in New York State, a similar program is now successfully operating where preschool children live with their incarcerated mothers.

The Office of Inmate Advocacy also recommends statutory changes that would allow those inmates who deliver a child while incarcerated to spend more time with their newborn babies. Under the current practice, an inmate is only allowed to be with her newborn during her short hospital stay. After the first two or three days in the hospital, the inmate must return childless to the jail, and her baby must be farmed out to a relative or to the Division of Youth and Family Services (DYFS). From a developmental standpoint, neither a mother's nor a child's interests are served by separating newborn children from their mothers. Once the mother/child bond is broken, it may never be repaired. When an incarcerated mother is released from jail and wishes to resume the care of her child, it may be too late. The current practice of separating mother from child can be devastating to the mother, damaging to the child, and overburdens DYFS staff and our foster care system. In addition, if an incarcerated woman cares for her own children and appreciates the responsibility that their care impose upon her, she will have the incentive to return to the community as a law abiding citizen and get things right the second time around.

We would also like to see halfway houses established to house incarcerated mothers and their small children for six months to a year before the woman's expected release date. We should offer women who participate in this program the opportunity for parenting skill classes, counseling and support to help deal with the difficulties of parenthood. Our goal should be to keep families intact. Unfortunately, our current prison and jail policies have the opposite effect, and the mothers and their children suffer as a result.

We, as a society, must accept our responsibility for providing necessary care, including medical care, to the inmates under our supervision. All inmates -- regardless of whether they are in state prison, county jail, or municipal lock-up, and regardless of whether they are male or female -- have a constitutional right to adequate health care. Estelle v. Gamble, 429 U.S. 97 (1976). The United States Supreme Court has recognized this constitutional obligation because an inmate has no choice but to rely on prison authorities to treat her medical needs. We need to put statutory safeguards in place to ensure the provision of adequate health care to incarcerated women in New Jersey. If correctional authorities fail to provide inmates with adequate health care, those needs will not be met.

Thank you for this opportunity to address this important subject.

State of New Jersey
DEPARTMENT OF COMMUNITY AFFAIRS

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TESTIMONY TO
1994 PUBLIC HEARINGS ON HEALTH CARE IN NEW JERSEY
COMMISSION ON SEX DISCRIMINATION IN THE STATUTES
BY
REGINA PODHORIN, SUPERVISOR
OFFICE ON THE PREVENTION OF VIOLENCE AGAINST WOMEN
NEW JERSEY DIVISION ON WOMEN

By this point in the hearings I hope that you have already heard the startling statistics regarding violence against women in New Jersey. You have also heard from my colleagues in the field that these cases of violence are woefully under-reported in the health care field. We all know for a fact that victims of violence use the health care system extensively but are misdiagnosed regularly. Studies done in emergency rooms throughout the United States in 1977,1981 and 1985 consistently reported that the percentage of female patients who had violence recorded in their medical file by the attending physician averaged 5-7.7%. When these same patients had been confidentially interviewed and directly asked how they had been hurt, 25-30% identified as victims of violence. Medical records clearly miss the majority of cases, or at the very least, fail to document the real cause of the pain and suffering.

Violence against women as a health care issue is only now starting to be recognized and treated. The good news is that the Center for Disease Control and Prevention has set a national health objective for the year 2000 that 90% of all hospital emergency departments would have institutionalized protocols for routinely identifying, treating, and referring victims of sexual assault and domestic violence. Also, the AMA's call to action initiated in 1991 has made the issue of violence against women move to the forefront of national discussion and problem solving among health care professionals. The bad news is that this type of system change will require years of

NEW JERSEY IS AN EQUAL OPPORTUNITY EMPLOYER

public education, massive changes in professional attitudes and constant follow up to ensure a permanent change in policies and practices.

For many years, the Division on Women had a special initiative for the training of health care providers on the identification, treatment and referral of domestic violence cases. 15,000 manuals were distributed, 6928 doctors, nurses and EMTs were trained between 1985 and 1991. A survey done by the Pennsylvania Coalition Against Domestic Violence showed that only 46% of doctors and nurses remember the training and only 30% are still using the protocol suggested. The loss of funding for this initiative created a serious gap in the momentum toward permanent change. The Office on the Prevention of Violence Against Women hopes to regain this lost ground in the future through a partnership with the Medical Society of New Jersey and providers in the field. The good news is that this time we have more partners working actively together to create and sustain the change. This time we will be approaching the issue from a broader base which includes not only our colleagues in the field of domestic violence but also in the fields of sexual assault, sexual harassment and education.

I would like to take a few moments to review the basic issues that will need attention in the near future. These issues can be categorized in two major ways - treatment for victims and prevention strategies.

TREATMENT FOR VICTIMS

The following list of concerns applies to victims of domestic violence, sexual assault and even stalking.

-We need baseline standards for the collection of medical evidence to assure that the prosecution of offenders will be successful. All medical personnel must be aware of the legal standards for evidence and should routinely collect the evidence even when the victim is uninterested in pursuing the case. For many victims the thought of filing charges immediately after the attack is too frightening. Confidential safekeeping of this evidence for the future possibility of legal action is essential.

-Statewide implementation of protocols to identify, protect and treat victims is a major priority. The fear of asking such "embarrassing" questions continues to prevent health care professionals from identifying potential victims. Our work in the field validates the fact that confidential, direct questioning through a medical history not only elicits the information easily, it gives the victim a sense of relief that she has permission to tell her story. For those patients that are not experiencing violence, the questions cause little, if any, pain or discomfort. The pain and discomfort is clearly on the part of the asker, not the victim.

The difficulty in pursuing the implementation of a protocol is that there is a critical need for follow up to ensure that it is being used. Without monitoring, protocols will sit in people's drawers. Certifying, licensing and State Board exams should include questions on treating victims of violence for professionals. Licensing and monitoring of institutions should include questions on the use of these protocols as well as the existence of ongoing in-service training.

-The legal system should routinely include the issue of coverage of related medical costs in restraining orders, judgements and restitution awards.

-Psychiatric care must be sensitive to the fact that many victims are prescribed drugs that have the effect of numbing protective responses. Diagnosis of schizophrenic disorders, borderline personalities and anxiety disorders are routine, though unwarranted for victims of violence. Careful monitoring for drug dependencies is critical. Post traumatic stress disorder is a far better diagnosis, if any diagnosis is even necessary. Victims of domestic violence and stalking are high risks for misdiagnosis. Without careful screening and assessment they may end up under a sedative that makes it even harder for them to cope with the very real dangers they face.

-The field of obstetrics/gynecology must be made extra sensitive to the implications of violence against women. Pregnant women are at serious risk of harm, not only to themselves but also to their unborn children. Sexually transmitted diseases through forced and unprotected sex are far more common than imagined. Asking an abuser or rapist to consider safe sex is impossible, if not dangerous.

-The health care field must recognize victim advocates as partners in the management of cases. The health care field is highly professional and credentialed. Historically there has been an element of disdain for the "uncredentialed" victim advocate. After spending twelve years in the field of domestic violence I am still routinely asked for my creditials before speaking to doctors, nurses, etc. Victim advocacy is best learned through close, constant contact with the issue and New Jersey can be proud of the work being done by those in the field. A collaboration of health care professionals and advocates would be a powerful force in the life of any victim.

PREVENTION

The saving grace for my sanity after twelve years in this field is that finally we are starting to talk about the prevention of violence. I now have the unique opportunity to create conversations about both treating and preventing the problems. The Division on Women's Office on the Prevention of Violence Against Women is gearing up to send positive start and stop messages to targeted groups, like health care professionals, as well as to the general public. As stated in **A Protocol for Health Care Providers:Identification and Prevention of Youth Violence**, developed by the Violence Prevention Project of the Department of Health and Hospitals of the City of Boston, "health care providers are in a position to establish confidential, supportive relationships with patients and can influence their attitudes and behaviors. By addressing violence in a fashion comparable to the way they address more traditional concerns they can make the clinical setting more responsive to the needs of those at risk."

Health care professionals are in the unique position of being expected to "prescribe" a cure. Treating victims is a critical issue, prescribing peace is a natural corollary. The protocol mentioned above has a three-page guideline for the engaging of patients in a discussion of violence that includes assessing violence history, identifying availability of weapons, and discussing anger management and strategies for keeping safe. Having doctors tell their patients that violence is wrong and unhealthy may seem a simplistic solution, but one that deserves attention. Teaching health care professionals to model peaceful behavior as well as to prescribe changes in behavior the same way they prescribe a nicotine patch is not as far-fetched as it may seem. We must all look for "teachable moments" and use them to offer alternates to destructive behavior. Violence is preventable, not inevitable.

The Office will play a part in the prevention of violence through the implementation of focus groups throughout the state discussing practical ways the public can create peace in their communities and relationships. A survey of male attitudes toward taking personal steps to reduce violence will give us the basis for a media campaign aimed at changing male behavior. A series of posters depicting culturally embedded messages toward children about violence will aim to alert parents to the subtle, yet pervasive way children learn that violence is an appropriate form of problem solving. Finally, a speaker's bureau will be developed to consistently send the message that modeling peaceful behavior is an easy task and an easy choice. Serving as the clearinghouse for materials about violence against women, the Office will provide many individuals and groups the opportunity to learn more about the problems and alternatives for solutions. We look forward to working closely with those in the health care field to create messages of peace.

2/1/94 RP

NATIONAL HEALTH INITIATIVE ON DOMESTIC VIOLENCE
EMERGENCY DEPARTMENT SURVEY

RESULTS OF NEW JERSEY SPECIFIC QUESTIONS

February 1, 1994

85 hospital emergency rooms were surveyed.
77% have responded to date
Physician Directors response 53%
Nurse Managers response 58%

1) Does your Emergency Department use "Domestic Violence: A Guide for Emergency Medical Treatment" published by the NJ Division on Women in 1986 for training staff?

Yes 29 No 42 DK 23* NA 1*

2.) Have your received the protocol recently sent to you from St. Barnabas Medical Center Continuing Education Program on Domestic Violence and Elder Abuse?

Yes 25 No 53 DK 15 NA 2

3.) Is any one person responsible for on-going education in the area of domestic violence?

Yes 37 No 54 DK 2 NA 2

4.) Does your Emergency Department work with the local domestic violence program in any way?

Yes 38 No 41 DK 13 NA 3

- If yes, what is the nature of your affiliation with the program?

5.) Have you attended a formal continuing education program?

Physicians	Yes 17	No 27	NA 1
Nurses	Yes 27	No 21	NA 1

If no, would you attend?

Physicians	Yes 20	No 4	NA 2	? 2
Nurses	Yes 21	No 0	NA 0	? 1

6.) How many annual emergency room visits has your hospital had in the most recent year for which you have statistics?

Less than 10,000	5	20,000 to 40,000	51		
10,000 to 20,000	23	Over 40,000	14	NA	1

*DK - don't know, NA - no answer

Public Hearing - Adolescent Health
February 1, 1994
Submitted by : Claire J. Warren

The Alliance for Teen Health is a vital source of information as well as support. With the problems facing our society today, there is and can be no question to the necessity of this program. With the health issues that are plaguing today's society such as cancer, hepatitis, AIDS and other STD'S, etc. people need to be made aware of the risks involved. Not only is it important that people be aware of the risk, they also need to understand how the diseases are transmitted and what they can do to protect themselves from them. This kind of education is necessary to eliminating the ignorance that can be deadly. This is what the goal of the Alliance for Teen Health is.

Health care is not only important to a student's physical self, but it also effects the student's academic work. When students are in pain, be it physical or emotional, their work suffers tremendously. Not only does their school work suffer, but the way they interact with others also suffers. I believe that many of the students that have been labeled as having learning disabilities simply have emotional problems that could be solved with counseling. With the cost of health insurance, it is not hard to conceive that a large percentage of students have never had a simple check up.

Although the Alliance for Teen Health is an excellent program, it would be even better and more cost efficient if the health services were offered right at the school. It would be easier to reach the students that desperately need this kind of support.

Public Hearing - Adolescent Health
February 1, 1994
Submitted by: Amy Bertelsen-Robles, M.S.W.

The Alliance for Teen Health Program (ATH) is a cooperative effort among three community based agencies located in the city of New Brunswick, New Jersey: the Eric B. Chandler Health Center (EBCHC), Planned Parenthood League of Middlesex County (PPLMC), and the School Based Youth Services Program (SBYSP) at New Brunswick High School (NBHS) (Attachment 1).

In 1990 New Brunswick was targeted by the N.J. Department of Health as an undeserved area, where access to comprehensive health care services among adolescents was limited. It was determined that there was a need for a centralized system of health service delivery, counseling, referral, and case management, with a strong health education component among high risk adolescents. Through a grant by the N.J. Department of Health, and the cooperation and commitment of the three agencies involved, the ATH has been able to provide easy access to comprehensive health care services at low or no cost, including reproductive health, prenatal and postpartum care, dental care, well child care, mental health and social services to approximately 300 adolescents in New Brunswick annually.

The program's target population is students at the NBHS and New Jersey Youth Corps of Middlesex County. Seven hundred thirty-seven (737) students are enrolled in NBHS, ranging from 13-21 years of age. Fifty-one percent (51%) of the students are male (376) and fourty-nine percent (49%) are female (361). The ethnicity breakdown is as follows: 50% African American, 45% Latino (many of which have recently immigrated from 15 countries in Latin America, South and Central America, Mexico, and the Caribbean Islands), 2.5% Asian, and 2.5% Caucasian. There were fourty-four (44) reported pregnancies in the high school during the 1992-

1993 school year. A day care center opened at the high school in January 1993 so that students who are parents can remain in school while caring for their children. Violence has also increased at NBHS. There was a total of 123 suspensions related to violent behavior between September and December 1993.

There were a total of one hundred eighteen (118) individuals serviced by the New Jersey Youth Corps during the 1992-1993 school year. The age breakdown is as follows: 53% were 16 - 17 years, 45% were 18 - 21 years, and 1% were 22 - 25 years. Seventy-four percent (74%) of the students were African American, 21% Latino, and 1% Caucasian. Seventeen percent (17%) of the total student population were single parents, and 10% of the total population were welfare recipients. Students at the Youth Corps have dropped out of school and receive educational training and work experience while enrolled there. One hundred percent (100%) of the student population is considered educationally disadvantaged since they were not attending school for a period of time. In addition, the circumstances which were involved at the time that they decided to drop out of school (dysfunctional families, etc.) put the students at a disadvantage. Many of these students are trying to live on their own, most have no health coverage and often do not have a steady place to live.

Most of the ATH staff is bilingual in Spanish and English. The staff works with teens one-on-one, communicates with their families, provides individual health assessment and treatment plans, facilitates appointments for services, and provides follow-up. In addition, there is a case management component.

Health education is an important component of the ATH. Through weekly presentations at NBHS on various health topics, health information packets, and educational field trips teens learn about different health topics in an enjoyable fashion. Presentation topics have included: Birth Control, AIDS/HIV, Peer Pressure, Self-Esteem, Rape, Relationships, Drug Addiction, Nutrition, Diabetes, Signs and Symptoms of Illness, and Child Abuse. All information is available in Spanish and

English.

There are several health issues that affect teens in New Brunswick. First, there has been a high rate of sexually transmitted diseases in the community. For example, in 1990 reported incidence of primary and secondary syphilis was 9.3 compared to a national rate of 2.0. In 1992, New Brunswick reported 23 cases of primary syphilis, 108 Gonorrhea, 51 Chlamydia, and 73 Trichonomas. In addition, drug use and HIV infection are growing problems in the community. Sixty percent (60%) of all known HIV positive individuals in New Brunswick list IV drug use or use of IV drugs by their partner as their risk factor. Although the figures for reported cases of AIDS among adolescents (13-19 years of age) for New Brunswick is zero, the city reported 37 cases in the 20-29 age category. Because the incubation time for AIDS to occur after the initial HIV infection is approximately 10 years, these figures demonstrate that people are becoming infected during their adolescent years and have full blown AIDS by the time they are in their twenty's. These statistics demonstrate the need for education about these health issues to prevent the spread of infection and disease as well as promote healthy, low-risk behaviors.

Out of the 155 new participants in the ATH in 1993 29% stated that they had no health coverage, 18% had Medicaid, 19% had private insurance, and 34% didn't know. Many had no regular dentist or doctor, and 19% of the teens and their families had utilized hospital emergency rooms for health care. Many teens were referred to the ATH with crisis situations due to lack of preventive care and immediate care when a problem is detected. Emergency dental care was and still continues to be the leading cause for referral (tooth pain, root canals, abscesses, cavities, etc.).

New Brunswick is a city that is very fortunate to have an abundance of health resources available. Most teens are dependent upon their parents or guardians to assist them through the health care system. Unfortunately, many parents and guardians are not familiar with the system themselves. In addition, many are often turned away due to lack of insurance. Entering this system can be confusing and frustrating. This experience is exasperated for someone from a different country, with a different culture, health care system, and language, as is the case with many of the ATH participants. The ATH has been successful in assisting adolescents in New Brunswick and their families to access the health care agencies in their community quickly and with ease.

The ATH program is important because it provides a user-friendly system of accessing health care for treatment and prevention. Rather than wondering where to go for health care and becoming frustrated, the ATH is like one-stop-shopping. The student can go to ATH staff and be given a referral for care, as well as a speedy appointment to various agencies in the community. Transportation is available for ATH participants who have health care appointments. All of the services provided by the program empower adolescents and their families. They are guided through the health care system and are taught how to utilize its services independently. This will increase the likelihood that they will access services at any time that they feel they need them. This access to preventive care and utilization of health resources can avoid major health crisis, which would also save money. In addition, it can help teens achieve what they strive for so that they can be productive adults.

The ATH is unique in that it was created by and operates in cooperation with three community agencies to provide comprehensive health care to adolescents. It integrates services at the cooperating agencies, with one central point of access. Representatives from the agencies are part of the Program Management Team which oversees the program's overall functioning, and Case Management Team which reviews ATH cases on a weekly basis. In addition, there is an Adolescent Advisory Council that the Project Director meets with on a weekly basis. These students serve as liaison between the ATH and its target population. They advise the ATH staff of effective ways to serve the teens, suggest topics for educational presentations, and assist with outreach to the target population and New Brunswick community.

The ATH is also unique in that it provides personal and individualized services, providing comprehensive health assessment, individualized treatment plans, transportation to appointments, accompaniment the teen to his/her appointment, and direct communication with the health care professionals.

As mentioned previously, the three cooperating agencies work together in different capacities to meet the program objectives. One advantage to this cooperation is the ability to accommodate the teen, which involves flexibility. The agencies give ATH participants speedy appointments and provide emergency appointments without any delay. Staff at the three agencies are familiar with the ATH. The Project Director attends staff meetings at EBCHC and SBYSP regularly. The ATH Nurse is present at the PPLMC staff meetings to represent the ATH.

The ATH is a respected program in the New Brunswick community. Various agencies in the city make referrals to the ATH. The program has potential to expand and become a huge program. Unfortunately, due to budget cuts, the ATH's funding has decreased drastically. However, even with the cuts the ATH administration and staff is determined to provide the teens in New Brunswick with the services that they need.

Although the cooperation of three community agencies and integration of services with one focal point is a unique and effective approach in the case of the ATH, it is often difficult to coordinate the facilitation of appointments, transportation to and from appointments, and parental accompaniment for those students under 18. It would be much easier for the students to access care if a health care facility was on site. This, of course, is the ATH's long term goal. The ATH enrollment and statistics for access to health care services are very good for a program with limited staff and with a five-step process to receive health care, which could be considered an obstacle for teenagers:

Step 1: Receive free health assessment
Step 2: Return registration form
Step 3: Make appointment(s)
Step 4: Arrange for transportation to appointment(s)
Step 5: Go to the appointment(s)

*For those who do not have insurance there would be a sixth step if they were to go to EBCHC for care:

Step 6: Receive financial screening to place on fee scale

This whole process could be shortened if all of the students were going to the same place, such as a health facility in the school. This would eliminate the need for transportation services, and would save time and money. Perhaps the ATH would be even more attractive to the students if it were closer to home, and be in a place that they are comfortable with and in a place where they could receive immediate care. For the young girl who fears that she is pregnant, she could receive a pregnancy test, counseling and education right there on the spot. Students could receive dental screenings without postponing it until an unscheduled check up manifests into the need for a root canal, and so much more. The possibilities are endless. The personal and individualized care would never subside, and the ATH would still be able to offer the same services; however, rather than bringing the teens to the services, the services would be brought directly to the teens. This would make it much easier for teens to get the services that they need, and with less obstacles.

ATTACHMENT I

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Eric B. Chandler Health Center

The Eric B. Chandler Health Center is a family oriented Community Health Center that provides comprehensive high quality ambulatory care. It is operated by the University of Medicine and Dentistry-Robert Wood Johnson Medical School (UMDNJ-RWJMS). The target population for the Health Center is the low income and medically indigent resident of New Brunswick and surrounding areas.

Primary care services provided by the Health Center are as follows: Preventive and restorative Dentistry, General Internal Medicine including services for preventive health, Pediatrics including well child care and EPSDT, and Obstetrics and Gynecology including family planning. Additional services include HIV counseling, testing, early intervention and treatment, Dermatology, Neurology, Laboratory, Clinical Social Services, Clinical Psychology, Community Outreach Case Coordination and Health Education. In addition, a Medicaid eligibility worker is housed at the Health Center full time through the County Welfare agency. Services are provided by a multi-disciplinary team of health care providers. These include physicians, nurse practitioners, certified nurse mid-wives, social workers, and health education. Eric B. Chandler primary care physicians are on call and available to take calls or see patients after Health Center hours at Robert Wood Johnson University Hospital (RWJUH) if care is needed.

As of January 1993, 56% of the Health Center's patient were between the ages of 0-19 years, 31% were between 20-44 years, 6% were 45-64, and 7% were 65 years or more. Seventy percent (70%) of the clients are African American, 20% are Latino, and 10% are Caucasian or other. The following is an ethnic breakdown of the new registered patients since October 1992. African-American 39%, Latinos 28%, Caucasian 28%, Asian 2%, and other 3%. Seventy-one percent (71%) of the patients at the Health Center have Medicaid, 7% have Medicare, 8% have partial insurance, and 14% have no health coverage at all. This last group is the fastest growing patient, going from 11% to 14% have no health coverage at all. This last group is the fastest growing patient, going from 11% to 14% in the past year.

The Health Center is open from 8:30 a.m. - 8:30 p.m. four days of the week, 8:30 a.m.-5:00 p.m. on Fridays, and from 9:00 a.m. - 2:00 p.m. on Saturdays. Services are provided at the Health Center by appointment and without regard to ability to pay. All kinds of health insurance is accepted. This includes Medicaid, Medicare, city welfare, and the Health Center participates in the Garden State Health Plan which is a prepaid capitate managed care program for Medicaid holders. In addition, a sliding fee scale is available for those without health insurance based on the Federal Poverty Guidelines.

SCHOOL BASED YOUTH SERVICES PROGRAM
1993

The School Based Youth Services Program (SBYSP) is a collaborative effort of the University of Medicine and Dentistry of New Jersey/Community Mental Health Center (UMDNJ/CMHC) at Piscataway, New Brunswick Tomorrow, and the New Brunswick Public Schools. The SBYSP was created in February 1988 as one of twenty nine such sites funded by the Department of Human Services of the State of New Jersey. In 1991, the program expanded from the high school into eight elementary schools. In January 1993, an on-site child care center was added at the high school.

The SBYSP is a centralized service delivery system which integrates existing school programs, creates new services within the schools, and links a network of youth service providers. It enables youth to complete their education and enhances the development of skills which lead to gainful employment and enriched mental and physical health. It is a dropout prevention initiative that focuses on services that specifically address "at risk factors" for dropping out.

The elementary component of the SBYSP has seven full-time and two part-time staff members. The high school component has one part-time and five full-time staff members. The Parent Infant Care Center (PIC-C) has four full-time and three part-time staff members. The staff represents a concentration in various specialty areas including: teen parenting, substance abuse, early childhood development, child psychology, and family therapy. These specialized counselors/consultants are full-time employees of UMDNJ/CMHC who bring years of experience to the SBYSP.

The program model is comprised of three core components of service delivery. Each is administratively and philosophically integrated with the others: direct service, prevention service, and outreach services. The direct service component allows adolescents to engage in structured and unstructured activities such as social skill development groups; individual, group, and family therapy; social problem solving, addiction counseling, cultural and recreational activities. A comfortable setting, much like a living room, is maintained in order to compliment and encourage participation in the direct service component. The prevention component offers information, referral and activities designed to promote social, medical, and mental health. Program areas include: tutoring, mentoring, parenting support, on-site child care, health assessment (in conjunction with Eric B. Chandler Health Center), social problem solving, substance abuse, and suicide prevention. The outreach component integrates the SBYSP staff into the school setting and the larger New Brunswick community through collaborative and cooperative relationships.

The staff develops relationships with students and faculty by attending and actively participating in school functions. In addition to outreach provided on site at the high school and elementary schools, program staff outreach into community agencies. Parents and students are requested to participate in activities sponsored by SBYSP as a way of highlighting and marketing the program.

The guiding philosophy behind the direct services component is a belief that a meaningful program must be structured in a way that is both appealing and pertinent to the needs of those it seeks to serve. Since it is difficult to engage youth in traditional outpatient counseling services, an integrated model has been developed which provides a variety of interrelated services. Social and cultural experiences as well as formal and informal counseling facilitate the engagement of youth and encourages participation in the overall program. Through exposure to this unique mix of structured and unstructured activities, youth can grow, develop and learn to effectively deal with problems while striving to attain their full potential.

sbysp93

PLANNED PARENTHOOD LEAGUE OF MIDDLESEX COUNTY

Background Information

In its 23 years of service, Planned Parenthood League of Middlesex County's mission has not changed; it is to provide high quality comprehensive reproductive health care services to the women and families of Middlesex County. In particular we target those women with the least access to traditional health care: low income women, minorities, teenagers, women with substance abuse problems, women with developmental disabilities and women who are incarcerated. Health care is interpreted in the broadest sense and includes education as well as medical care. We come to this mission from the belief that each and every child deserves to be wanted and loved.

We provide family planning services for close to 4000 women annually. In 1991 we added the new sub-dermal contraceptive NORPLANT and in 1993 the three month injectable contraceptive Depo-Provera to the those already available at PPLMC. Because, more often than not, we are the only health care provider that our patients see, outside of a trip to the emergency room, we include rubella immunization, cholesterol screening, cancer screening for breast and cervical cancer and nutritional assessments in our annual check-ups. We also provide testing and treatment for STD's and counseling and testing for HIV.

For pregnant women we provide options counseling where we stress <u>all</u> options: the option of continuing the pregnancy (and the importance of pre-natal care) and keeping the child or, if that is not possible, giving the child up for adoption; as well as the option of abortion. Our philosophy and our clinical practices support the right of each woman to control her own fertility.

Our counseling services enable our staff to provide support, assessments and referrals for problems including family problems, sexual issues, abusive relationships or date rape, which are identified in the course of a visit. Our center is viewed as a "safe and comfortable place" to go for services especially by our teen clients. Our counselors encourage teens to involve parents as well as partners in resolving crisis situations.

Because prevention is the cornerstone of PPLMC's mission, education and outreach are the key components of our community service. Our educational programs are tailored to meet specific community needs. In 1992 alone, health educators reached more than 4800 individuals in close to 350 programs.

Some outstanding educational programs of PPLMC include:

- reduction/prevention of teenage pregnancy; designed to focus on risk-taking behavior of young adolescents and addressing issues of decision making, parent/teen communication, future life options and HIV/AIDS.
- teaching social hygiene and reproductive health to women with developmental disabilities,
- group sessions for battered and incarcerated women focusing on reproductive health,
- identification and appropriate referrals for women with substance abuse problems, and
- teaching parents to teach their own children about issues surrounding sexuality.

Planned Parenthood League of Middlesex County has grown substantially in order to meet the needs of the community both medically and educationally. We have become known and respected in the community as a leader in our field.

"GENDER EQUITY IN ATHLETICS: IMPLICATIONS FOR HEALTH REFORM"

TESTIMONY FOR PUBLIC HEARING CONDUCTED BY NJ COMMISSION ON SEX DESCRIMINATION IN THE STATUE

Submitted by:	YWCA of Central Jersey Geraldine Harvey, Executive Director	Thelma Doby, President Board of Directors

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The report states females comprise approximately 50% of our high school and 53% of our college student population. Yet in college athletics only 34% of participants are women. These disporpotionate figure can be attributed to social and cultural norms as well as lack of interests and athletic abilities manifested by women in our society.

In response to arguments against women receiving equal access to athletics scholarship and media recognition. The Women's Sport Foundation Fact Sheet reports,"Men's sports participation has not suffered at the expense of providing participation opportunities for women -- there were 16,242 more male college athletics in 1991-92 than there were in 1981-82. For every two female participatio slots created in this ten year period 1.5 male participation slots were also added. Additionally, Football and other men's revenue producing sports will not be hurt by the achievement of gender equity. These sports will have to share their resources more equitably and remove excessive expenditures from their programs, but hey will not be hurt with regard to the quality of their sports or public interest in these programs".

The inequities in funding, promotion, and monitoring of athletics has led to the Gender Equity in Athletics Disclosure Act (H.R. 921). This legislation will raise public awarenes on the issue of gender equity in college athletics programs. The Women's Sports Foundation Fact Sheet cited the findings of the National Collegiate Athletic Association released on March 11,1992 revealed significant discrepencies in athletic opportunities at the collegiate level.

Female collegiate athletes are receiving less than 24% of the athletics operating dollar and less than 18% of the athletics recruiting dollar. Female athletes are receiving less than 33% of the college athletic scholarship dollar.

Male college athletes receive approximately $179 million dollars more per year in athletic scholarship grants than their female counterparts.

Medical Research findings consistently endorse the value of an active physcial fitness lifestyle. Participation in sports has been and will continue to be a popular and cost effective method of achieving fitness. Yet, women and girls continue to be denied equal access and participation in athletics at school and in the community.

Women and girls in New Jersey and Nationwide must join with health profesionals, educators, athletes, women organizations, and advocates in raising public awareness as to the negative social, psychological and health ramifications permeating gender inequities in athletics within our Community. State, Country and Worldwide

TESTIMONY: GENDER EQUITY: IMPLICATION FOR HEALTH

Health reform has been "touted" as assisting and improving the quality of life of all Americans irrespective of age, sex, education, socio-economic status, geographic location, religious or racial/ethnic background. Despite extensive media attention to increase public awareness of health promotion issues, there has not been substantial funding for medical research on women's health. Health officials have however, identified poor eating habits, lack of exercise and poor self-image as the most pervasive factors in obesity which contributes to chronic health problems in men and women.

The benefits of exercise as a part of a healthy lifestyle for women has been well documented. According to the Women's Sports Foundation report, two hours of exercise a week reduces a teenage girl's risk of breast cancer, a disease that will afflict one out of every eight Americann women. One out of every two women over the age of 60 suffer from osteoporosis, a $15 billion a year health problem. This is the result of generations of women who were not permitted to play sports or encourage to participate in weight-bearing exercise that are necessary to laying down bone mass when they were young.

Ongoing participation in sports is a prevalent way of maintaining fitness. Yet, traditionally sports has been perceived as a male dominated activity. Social mores and gender specific stereotypes have evolved around sports and the concept of competition. Boys early on are encouraged to join organized and competitive sports, ie. "Pop Warner", Community Soccer and Baseball whereas girls have traditionally enrolled in dance, and other non-competitive activities. Moreover, the value of organized sports extend beyond heightened physical prowess and the reduction in likelihood to be victims of in chronic diseases such as heart disease, cancer, etc.

Extensive research has shown that girls and women who participate in sports experience a higher quality of life. The 1990 Institute for Athletic and Educations Study revealed high school girls who play sports are 80% less likely to be involved in an unwanted pregnancy; 92% less likely to be involved with drugs and three times more likely to graduate from high school. 1985 Miller Lite Report concluded: Girls and women who play sports have higher levels of self esteem and confidence and lower levels of depression. An article published by New York Newsday in 1989 also reports that research suggests that girls and women who have low levels of self-confidence and self-esteem are more likely to get pregnant.

The Gender Equity in Athletics Educational Fact Sheet prepared by the Women's Sports Foundation contents sports is "where boys have traditionally learned about teamwork, goal-setting and the pursuit of excellence in performance -- critical skills necessary for success in the workplace. In an economic environment where the quality of our children's lives will be d ependent on two-income families. We cannot better prepare our sons than our daughters for success in a highly competitive workplace".

The document also advocates for the full enforcement of Title IX of the 1972 Education Amendment Act by the Office of Civil Rights in the Department of Education. Title IX prohibits discrimination on the basis of sex in any educational program or activity offered by secondary and postsecondary institutions that receive federal funds. According to the Women's Sports Foundation Educational Face Sheet on Gender Equity in Athletics, the Office of Civil Rights has never asked the Justice Dept. for assistance in gaining Title IX compliance at the high school or college level. Gender inequity in sports remains a critical issue as we apprroach the twenty-first century.

State of New Jersey

COMMISSION ON SEX DISCRIMINATION IN THE STATUTES

1994 Public Hearings on Issues of Health Care in New Jersey
February 1, 1994
February 9, 1994

THE HEALTH CARE NEEDS OF OLDER WOMEN: ELDERLY HISPANIC COMMUNITY NEEDS

TESTIMONY

EDNA I. ALEX M.S.W., A.C.S.W.
ELENA M. MARVEL M.S.N., M.A., R.N.

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We wish to thank the members of the Commission for the opportunity to submit testimony on issues affecting the Hispanic Elderly, more specifically, Hispanic elderly women.

Overview

Numbers of the Hispanic elderly are growing more rapidly than their white counterparts. The Census Bureau projects the rate of growth among elderly Hispanics will be 4.5 times as great as the entire aged population from 1987-2000. Along with the population growth will come an increased demand for services.

Unfortunately, the Census Bureau does not have a data base that accurately reflects the actual number of ethnic/racial minority older persons who have immigrated to the U.S. It estimates that 2.1% of U.S. population was missed in the 1990 Decennial Count,resulting in a disproportionate representation of elderly, minority, ethnic and poor populationswith resultant long term repercussions on services to this disenfranchised population.In the 1990 Census the proportion of Hispanics undercounted was estimated at 5.2%." We do not know how many Hispanics die each year in this country, let alone their health status,unmet health care needs or health care utilization rates (Trevino 1982)".

There has been a failureon the part of the State as well to collect specific Hispanic vital statistics and health related information. While much health related data is available on the elderly, data on the health status of the Hispanic elderly is, if available, limited and does not accurately reflect the

impact of social, political, and economic forces on their use of or under-utilization of health care resources. This lack of reliable statistical data on the Hispanic elderly makes it difficult for policy makers and service providers to address the needs of the Hispanic aging community.
It is imperative that planners and service providers have up-to-date and accurate numbers which will assist them with program planning and outreach plans for service.

Hispanic elderly although facing the same difficulties that the majority of our aging population is facing, have had the added disadvantage of a life time of discrimination, oppression, social, and economic inequities that has impacted their health status and utilization of available health resources.

Elderly Hispanic women are additionally disadvantaged. Due to types of employment, their limited or non-participation in the work force, plus cultural variables that reinforce the more traditional feminine role, the Hispanic elderly female is less financially prepared to deal with old age than her counterpart non-hispanic white female. (Sotomayor 1988)

Although generally people experience more health problems as they age, minority groups suffer from greater rates of illness and death than their non-minority counterparts. According to Dr. Thomas R. Ortiz, a Newark physician " The health status of Latinos, especially for Puerto Ricans is significantly lower than it is for blacks or whites" (1994)

Available data suggest that among Hispanics there are higher rates of cardiovascular disease, strokes, hypertension, diabetes, obesity, and cancer, with stomach and cervical cancers leading the list. (DHHS). Statistics reveal that although Hispanics suffer from more health problems than non-minorities, their use of medical services is substantially lower.

Under-utilization of available health resources by the Hispanic elderly can be related to the discrimination, that they have experienced over a life time.Therefore, it is imperative that policy planners and service providers recognize that, " Social services and programs based on cultural values different from those of the potential users, no matter how expertly designed and well -intentioned, and delivered by persons who seldom speak their language, are doomed to under-utilization."(1981 White House Conference on Aging) , and change current policies and programs to create new ones that are culturally sensitive and respond to the needs and concerns of the Hispanic elderly.

Lastly, although the Latinos in New Jersey represent 9.6% of the total 7,730,188 residents, they are:

* grossly underserved by governments at all levels (state, county, municipal)

*grossly under-represented in government from policy-making appointive positions on boards and commissions to all levels of government employment. This inequity is reflected in the number of Latinos, male and female, working in state government.

(N.J.Status Report on Hispanic Initiatives, 1993 - Refer to Appendix Table)

In conclusion, until the inequities faced by hispanics, and in particular, Hispanic elderly women, have been addressed by society and our policy makers, and until the under-representation and under-servicing of Hispanics in all levels of government (Federal, State, and County) has been remedied, it remains for our policy-makers to act as a shield against these inequities.It remains for them (policy-makers) to critically review and analyze existing policy to insure that culturally sensitive policy is developed and implemented to meet the needs of the disenfranchized Latino community; until such time that they themselves are empowered to become pro-active members of their community, more intimately involved with policy formulation and creation of effective legislation that addresses these inequities.

"Reducing poverty and inequality between Latinos and the rest of the State population is a social and political imperative." (State of Affairs of Latinos in New Jersey. 1993)

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2/20/94

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THE HEALTH CARE NEEDS OF THE LATINO OLDER WOMEN

The health care needs of the Latino older female are the following:

- Bilingual/Bicultural Medical personel at community health centers, clinics, emergency rooms, doctors office, laboratories and pharmacies.
- A pool of physicians and medical specialists who accept Medicare and Medicaid assignment.
- Community health programs to educate the old and the young and to monitor individuals who have become patients, such as diabetics.
- Education for caregivers as well as financial incentives in the form of tax deductions and/or stipend.
- Public announcements on Latino radio and television media as well as churches and schools.
- Latino hot-line manned by service informed bilingual/bicultural personnel.
- Training and work opportunities for elderly interested in the caregivers field such as homemakers home health aids and child caregivers.
- Research that will provide data regarding ethnic diversity within the Latino population; strengths and weaknesses of this community; their use of alternative medical care such as church counseling, folk medicine and hot/cold theory; compatability of cultural foods with American diet; intergenerational context; demographics outside of the Census.
- Latino representation in the Older American Act implementation structure to include the Area Offices on Aging Advisory Council of all the counties in New Jersey.
- Political Representation.

The Health Care Needs of The Latino Older Women are affected by the following factors:

I. AVAILABLE HEALTH DATA

While there exists volumes of data regarding the health status of the elderly in general, overall, data on the health status of the Latino women are limited, sparse, dated, unreliable and inconclusive. The few studies that have taken place within the last ten years relate to the Mexican-American community, the largest Latino population.

II. BARRIERS

- ETHNIC

The Latino community comprises of people from Puerto Rico, Cuba, Dominican Republic, South and Central America, Spain and Mexico. While all these groups have in common a Hispanic Cultural Heritage there are some variations based on the country of origin, ethnicity/race, level of education and social class. In reality the one common element among all these groups is a strong identification with the Spanish language.

- LANGUAGE

Language barriers keep the Latino elderly ignorant of services, benefits and entitlements preventing them from asking for help or participating in programs. Language barriers strip the individual from his right to confidentiality when his bidding depends on the efficiency of an interpretor most often times a third party. Anyone who has traveled in a non-English speaking country has experienced the discomfort of being unable to communicate. Language barriers compounds ordinary feelings of anxiety for an individual who is old, poor, perhaps frail and unaccustomed to negotiating any system.

Imagine that you are a diabetic. You experience a diabetic seizure. You are unconcious while they take you to the emergency room (E.R.). When you awake your surroundings are strange to you. You become frightened (raising your sugar level). You try to get your bearings. No one in the E.R. understands you. You become irrational, screeming. You are old. You are tied to the bed for fear that you will hurt yourself. At about 8:00 P.M. a cleaning person who speaks Spanish passes by. He understands you. He explains to the nurse your fear and concern. They untie you and contact a family member. Your seizure took place early in the A.M. This is one of many frightening episodes experienced by older Spanish speaking only adults.

- CULTURE

The Latino culture has definite expectations of the male and female. Men are seen as street smart with opportunity for outside recreation and socialization. Women are expected to be home bodies, docile with no need for recreation nor socialization other than what goes along with a caregivers role. Women are expected to safeguard her virginity. Any conduct that may have a sexual context is to be shared only with a husband or a common-law partner.

In a study which looked at the leisure preferences of the Latino elderly (Edna I. Alex & Irma Alicea, 1984) Latino elderly women did not recall "play" experiences in their childhood. Female subjects stated that they spent their childhood years as caregivers and mothers helpers, often times a stressful role.

Stress without opportunity for recreation and outside activity leads to depression. Depression leads to chronic ailments like ashtma, diabetes and emotional problems.

Latino women do not go for routine gynocological examinations. When they become pregnant most of them will seek medical care towards the end of the pregnancy. Consequently cancer diagnosis comes late to the Latino women.

The American Cancer Society has documented the fact that Latino women are more prone to cervical and breast cancer.

Religious observance is high priority on the Latino women's list. Her involvement in church functions is accepted and supported by the community.

Many Latino women suffer from nervous conditions, they depend on the church for counseling and mental health care. Only a lunatic goes to a mental health clinic according to many Latino elders. The outcome of such beliefs disallow for the treatment of depression or any other mental health problem. By the time counseling is sought many need institutionalization.

- CULTURE (CONTINUED)

Nutrition plays a significant part in the bodies maintenance and healing process. Nutrition is based on the American diet. The Latino woman prepares foods not found in the American diet. These foods have not been laboratorily tested for nutritional compatability. Latino women who are diabetic experience difficulty adhering to a diabetic diet.

Many of the Latino women use folk medicine. They believe in the hot/cold theory which most often times if not understood by western medicine, may impede medical care. Many Latino elderly depend on the "Botanica", a store that carries natural herbs, roots and folk medicine.

- EDUCATION AND INCOME

In a study conducted by United Way of Central Jersey (1991) focusing on the needs of the Latino community it was found that there is a corrolation between educational level and rate of income. The higher the grade the higher the income and the less need for services other than educational and recreational.

Most of the Latino elderly women have only completed five (5) years of school.

The Latino elderly female is documented as the most disenfranchized with twenty-two (22%) percent living on incomes below the poverty level, of whom 37% are at the 125th percentile level. (Bureau of the Census, 1983).

A lifetime of poverty, illiteracy, hard minial labor, unemployment, underemployment and limited support resources are known to lead to unsafe neighborhoods, less than desirable physical surroundings, sub-standard housing and generally poor physical and mental health.

III. POLITICAL REPRESENTATION

Although it is projected that the Latino older adult population 65 and older may quadruple by 2015 and may be seven times its present size (12% of total US population) in 2039 (US Department of Commerce, 1986), they do not have political representation. They continue to be an invisible group.

Factors that contribute to their lack of political representation are the following:

- RIGHT TO VOTE

Many of the Latino elderly are legal residents not citizens. They do not have the right to vote. Only the Puerto Rican older adult is a naturalized citizen. They are a very small percent of the total Latino population.

- LANGUAGE BARRIER

The language barrier impedes on the professional older adult's ability to seek political positions.

- OLDER AMERICAN ACT

The Latino elderly has very little representation within the Older Americans Act implementation structure.

- ECONOMICS

  The Latino community is a poor community lacking the financial resources nor the machinery to support a Latino candidate.

  On a positive note, politically speaking, even though many of the Latino older adult are not registered to vote, at the November 1988 election most of the Latinos who voted were Spanish - origin elderly 55 to 74 years; 47.8% voted as compared to 23.7% of Spanish - origin persons aged 25 to 34 years (US Department of Census, 1989).

SUMMARY

Health is usually rated as the greatest problem and fear facing the Latino older adult. This community perceives their health as being "poor". The Latino older female have higher rates of chronic illnesses including cardiovascular diseases, strokes, hypertension, diabetes, obesity, arthritis, depression, cervical and breast cancer.

Due to the factors previously mentioned, the Latino elderly women underutilize health care services. A 1980 study found that only 71% of eligible Latino older adults enrolled in Medicaid (NCLR, 1987). Those that have Medicaid experience difficulty in getting doctors who accept Medicaid assignment. Consequently many older adults turn to the emergency room when their health condition deteriorates. Available data indicates that poor people are hospitalized more frequently for longer periods of time and receive more care at emergency rooms and out-patient departments.

RECOMMENDATIONS

The general Latino population is the youngest in the United States with a Median age of 24 years, compared with the National Median age of 32 years (Williams, 1987).

Most Latino elderly retain traditional values, behaviors, and practices based on their countries of origin. These cultural features provide important bulwarks against the complex and rapid changes occurring in U.S. society. Language, strong self-image based on pride in ethnic group and common bonds with other elderly, promote social cohesion among this cohort of Latinos. Latino older adults also retain, to a large extent, important social roles, such as passing on their history to younger persons, acting as arbitrators and facilitators for their families and communities, and serving as role models (Becerra and Shaw, 1984).

The church often serves as the main social activity and a source for advocacy. The family continues to be intergenerational, although assimilation is occurring among young Latinos. The family remains the primary source of social interaction and emotional support for the elderly Latino.

Taking into consideration the demographics of the Latino population, their extended family, church involvement, culture and barriers, policy makers need to consider the following components when developing and implementing equitable and effective health care services.

- prevention
- intergeneration
- bilingual/bicultural
- community based
- Spanish media (T.V., Radio)
- research

RECOMMENDATIONS (CONTINUED)

Prevention must begin with education. Educating the present elderly through videos, public media, radio programs, church and the children through the schools. We must bring services into the schools and open the schools to the general Latino community.

Presently Robert Wood Johnson University Hospital in New Brunswick has sponsored community based health screening and health educational programs in Spanish which have proven to be of great resource to the Latino community.

Policy makers need to review such efforts in the pursuit of making such programs available state-wide.

Latino students who are bilingual and interested in a medical career should be provided with scholarships with the condition that they return to provide services to their Latino community.

Just like the court system is training their court interpreters the medical system should provide a pool of qualified medical interpreters.

The Latino woman is a natural caregiver. They are a great child care and home care service resource. We need to offer home health aid and day care certification classes in Spanish. These classes should be given in a church hall or a neighborhood school.

We need to facilitate for the development of alliances with organizations representing young and old Latinos. This action may help to dispel "Ageism" one of the jeopardies experienced by the Latino older adult.

Just like there exists sports scouts we need to scout for Latino leaders that exhibit political accumen, interest and commitment to the welfare of their community and then support them financially through the campaigning and election process.

We need to facilitate the process of applying for citizenship so that legal residents will become citizens and have the right to vote.

Although increasing numbers of Latinos are entering college and achieving professional success, a far larger percentage of Latino youths are facing poor education, illiteracy, unemployment and underemployment, and poor health augmented by drugs and aids. future generations will be considerably different, many more will speak English but we will continue to have an influx of immigrants from Latin America who may be similar to todays needy Latino elderly (Tores - Gill, 1986).

Edna I. Alex, MSW,ACSW
Middlesex County Board of Social Services
PO Box 509
New Beunswick, N.J. 08903

Edna I. Alex, MSW,
2/17/94

STATUS OF LATINO PERSONNEL EMPLOYED IN NEW JERSEY STATE DEPARTMENTS/AGENCIES

Department/Agency	Total Employees	Hispanic (Male)		Category	Hispanic(Female)		Category
Agriculture	194	1	(0.5%)	Professional	1	(0.5%)	Clerical
Banking	125	1	(0.8%)	Professional	1	(0.8%)	Clerical
Commerce/Development *	111	2	(1.8%)	Professional	3	(2.7%)	3-Clerical 1-Professional
Community Affairs *	986	19	(1.9%)	2- Administrative 12- Professional 5- Technicians	29	(2.9%)	4- Administrative 18- Professional 7-Clerical
Corrections *	9798	384	(3.9%)	Protective Services	105	(1.1%)	(Professional (Protective Services (Clerical
Envir.Prot.& Energy	3999	24	(0.6%)	Administrative Service	51	(1.3%)	(Administration (Professional (Clerical
Health	1543	13	(0.8%)	12-Professional 1 Clerical	37	(2.4%)	All Levels
Higher Education *	3339	114	(3.4%)		119	(3.6%)	
Human Services *	20,336	341	(1.7%)		680	(3.3%)	
Insurance	530	1	-	Professional	13	-	All Levels
Labor *	4092	55	(1.3%)		173	(4.2%)	
Law & Public Safety	8680	163	(1.9%)		147	(1.7%)	
Military/Vet.Affairs	1419 State 2193 Federal	66	(4.7%)		90	(6.3%)	
Personnel *	635	7	(1.1%)		10	(1.6%)	
Public Advocate	940	24	(2.6%)		61	(6.5%)	
State *	275	4	(1.5%)	3- Office Clerks 1- Professional	4	(1.5%)	Office Clerks
Office Ethnic Affairs	4620	67	(1.5%)		11	(0.2%)	
Treasury	4728	33	(0.7%)		69	(1.5%)	
Casino Control Commission	385	3	(0.8%)	Professional	3	(0.8%)	1- Professional 2- Office Clerks

SELECTED DEMOGRAPHICS

	White	African American	Hispanic	Asian/Pacific Islander	American Indian
% Population 65+ Years	11	8	5	6	5
Ratio Men to 100 Women					
ages 60-64 yrs	87	80	86	84	87
ages 85+	43	50	61	60	59
Marital Status 65+ yrs					
% Married					
Men	74	57	65	65	60
Women	36	25	31	30	31
% Widowed					
Men	14	22	16	13	21
Women	51	58	50	56	55
Living Arrangements					
% 85+ yrs in nursing home	23	12	10	10	13
Education					
% completed high school	41	17	19	26	22
Income Median 65+ Yrs					
Men ($)	7,408	5,551	4,592	4,257	4,113
Women ($)	3,894	3,476	2,873	3,033	2,825

Source: AARP Minority Affairs Initiative, *A Portrait of Older Minorities*, 1987. (discontinued)
Use on an overhead slide projector

165X

PREVENTABLE CAUSES OF DEATH

Cause of Death	Modifiable Risk Factors	Populations at Risk
Cancer	smoking diet alcohol	African Americans have highest cancer rates. Some Asian subgroups have lowest rates. American Indians have low rates, but low survival rates.
Cardiovascular Diseases	high blood pressure high cholesterol levels smoking diet obesity lack of exercise	A decline of 51 percent in stroke mortality and 42 percent in coronary heart disease (CHD) in African Americans has been observed, due to control of hypertension. CHD is twice as likely in African American women as in white women. Increases in death due to cardiovascular disease among Hispanics are due to: obesity, diabetes, and increased smoking. Asians appear to be at low risk. Except - Japanese men with higher rates of stroke mortality & Filipino women, for whom hypertension control is a problem.
Chemical Dependency	alcohol and drug use	Cirrhosis mortality rates for African Americans are two times as high as for whites. American Indians have a mortality rate for alcohol-related cause of death that is three times higher than other groups
Diabetes	diet obesity lack of exercise alcohol	Diabetes is higher among African Americans, Hispanics, American Indians, and Asian Pacific Islanders than among whites. Highly correlated with diabetes. 300,000 cases per year could be prevented with obesity control.
Homicide Suicide Injury	alcohol	American Indians have highest rate of deaths from injury. Risk for suicide among Chinese females 45 years + increases with age.

Sources: McGinnis, J.M. "The 1985 Mary E. Switzer Lecture: Reaching the Underserved." *Journal of Allied Health* , November 1986.
AARP, National Resource Center on Health Promotion and Aging, *Healthy Aging Model Health Promotion Programs for Minority Elders*, 1990.

BARRIERS TO SERVICE UTILIZATION

Physical Access to Services —

- Transportation
- Location of facilities and programs
- Rural access issues
- On-reservation access to services
- Lack of trained professionals

Economic Access to Services —

- Poverty among minorities
- Lack of insurance coverage

Cultural Access to Services —

- Inadequate outreach to minority elders
- Language barriers/lack of bilingual-bicultural staff
- Lack of culturally sensitive services
- Underrepresentation of minority health providers in community
- Lack of familiarity with bureaucracies
- Historically experienced discrimination and oppression
- Distrust of service providers
- Stigma associated with admitting a need or using public programs
- Knowledge of services

Source: Schoenrock, S.A. *Health Education and Promotion Among Multicultural Populations*. National Resource Center on Minority Aging Populations, 1990.

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WOMEN'S HEART RESEARCH FOUNDATION

P.O. BOX 7827, WEST TRENTON, NEW JERSEY 08628
TELEPHONE 609 771 8313

February 1, 1994

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

Dear Ms. Jacobus:

I am submitting to this Commission documentation of my mother's experience with coronary artery bypass surgery and resultant death in May of 1986. This was actually the second female death in my family from this operation, the first one being my 70 year old great aunt. She was not asked preoperatively if she had had a vein-stripping operation. The surgeon realized only during the procedure that there were no vessels to harvest from her legs and had to settle for inadequate vasculature. She died shortly thereafter as the vessels broke. The surgeon was angry that no one had screened her properly.

In my mother's case, there was inadequate preoperative screening and preparation, inadequate diagnostic testing for prognostic indicators, poor physician communication with the transferring facility and unsafe patient transfer by the surgeon.

I have founded this new consumer-based heart organization to address the highly controversial issue of timing of surgery status post M.I. (specifically as it relates to females), institutional risk factors (specifically as it relates to females), quality of care and patient rights as I could find no system that existed in our society to help me correct these serious deficits in our health care delivery system.

Sincerely,

Bonnie Hartman Arkus

Bonnie Hartman Arkus, RN
President &
Executive Director

advancing research and education for women's health

Case history: female patient with c-v disease and poor outcome from CABG

No previous cardiac diagnosis

- admonished years earlier for her c/o symptoms
- self-described "nervous lady", as labeled earlier
- had "white coat hypertension" but no follow-up
- history of panic attacks
- no cholesterol screenings Cholest. 359
- no stress testing
- history of cigarette smoking x 35 years
- single parent head of household x 20 years
- both parents died from heart disease

May 11, 1986

- M.I.
- delayed response x 12 hours with paralyzing fear
- only minor EKG changes...awaiting myocardial bands to confirm diagnosis
- Unstable Angina

May 12

- transferred to University Hospital by the family for care by the same experienced heart surgeon enlisted by father
- no communication with transferring hospital to confirm M.I. or check results of myocardial bands

May 13

- cardiac catherization: "left main" disease w/ 75-90% blockage
- CABG surgery deemed the <u>only</u> solution and an emergency. given a 95% chance to survive
- no fatal arrhythmia
- stabilized on medication
- patient refusing surgery ("I am going to die")
- family requests eval by experienced elder heart surgeon...request denied ("He is not available" cardiologist acting as gate keeper)
- eval by young heart surgeon -"You have a 99% chance to survive" "I only lost one of my last 100 patients"
- young surgeon delays surgery x 7 days since pt took aspirin and platelets need to regenerate (no longer an emergency?) " You'll ooze all over the table"
- pt continued to stabilize and improve. Repeatedly questioned the need to operate when feeling so well. Maintained that she would die.
- cardiologist visibly uncomfortable with delay of surgery by heart surgeon. <u>Asked family</u> if patient had had M.I.

May 19

- CABG surgery at 8 a.m. IMA procedure
- transferred at 3:30 p.m. No BP when entering I.C.U.
- surgical resident performed cardiac compressions as pt had cardiac arrest (this destroyed the heart muscle)
- reoperation @ 4:30 p.m. using SVG procedure. IMA removed
- heart shock. pt placed on an artificial heart
- returned to I.C.U at 1:30 a.m. w/ right and left ventricular assist device, balloon pump, ventilator, hypothermia blanket, 4 chest tubes, 25 I.V. bottles, blood, an open chest with 2 huge clear cannulas protruding from her heart and attached to the machine pump
- patient to remain sedated x 3 days. Heart to be resparked after this rest period
- cardiologist said mom now needed a heart transplant but that this hospital didn't perform them and she was not a candidate.

May 20

- awake in the afternoon
- cognizant of her surroundings. smiled. squeezed my hand. fluttered her eye lashes.

May 21

- exercising her arms and legs
- beginning to realize how sick she was
- family implored surgeon to remove her from the heinous machinery and allow her to die
- crying when dressings were ripped from her chest and when heart surgeon attempting to remove ventricular device

May 22

- family continued to pursue removal from machinery to end pain and suffering. meetings with nurses, chief surgeon, chief surgical resident, medical ethics department
- patient refusing anesthetic. angry and terrorized expression
- surgeon finally agreed to surgical euthanasia

May 23

- removed from device within guidelines of an operative procedure

Contributing factors to a poor outcome for this 60 y.o. female patient:

- inadequate family support systems
- not diagnosed earlier with cardiovascular disease
- not screened preoperatively for risk factors contributing to coronary spasm and possible pre-existing prinzmetal angina (CABG would have been contraindicated)
- not given echocardiogram to determine ischemia, ejection fraction or global dyskinesia
- not referred for psychiatric evaluation to determine why pt felt she was going to die if operated upon
- not referred for social work assessment
  (1) help patient financially plan to survive the operation (pt worked full time, lived alone and had two residences and a mortgage. She felt she could not afford to live)
  (2) mobilize family support systems. Assist with negotiations on ways each member can contribute to benefit patient during extended rehabilitation.
- not given pre-op teaching with coughing and deep breathing exercising, tour of O.R. and I.C.U., or a meeting with a CABG female survivor -- all important aspects to conjure mental imaging of survival in such an extraordinary operation
- denied her patient rights to choice of surgeon
- denied her patient rights to self determination (placed on the experimental artificial heart without consent of pt or family)
- denied her patient rights to self determination by being given false survival information. There was no informed consent. There were no outcome data available at that time regarding the IMA procedure and female survivial however, there is always a high death rate associated with emergency bypass surgery. We were not told of this.
- family given inaccurate information regarding survival after placement on a ventricular assist device
- not given all treatment options with survival statistics for her condition (diet & lifestyle changes vs. angioplasty vs. medication)

Results of interviews with the cardiology team 6/14/86 --

Anesthesiologist:

- Pt was transferred after being stable for only 10 minutes and on levophed -- known to cause coronary spasm. The surgeon was disciplined for knowingly transferring an unstable patient. No, we do not have an emergency access key for elevators to return patients to the O.R. We frequently keep patients in O.R. for more than 24 hours if deemed unstable
- Perhaps we should develop a pretest to determine sensitivities to vasopressors. Perhaps we should not use vasopressors on women due to their catecholamine response to stress (elevator ride is a stressor)
- The timing of the operation was poor. Everyone disagreed with the surgeon regarding the timing of CABG after having an M.I.

Nursing:

- women don't do well here with this operation

Surgeon:

- I don't usually operate on women. I didn't know they were so different
- The IMA procedure is an acceptable procedure. The problem is that they don't collect outcome data on women. I realize this is discriminatory, but that is just the way it is.
- The O.R. and I.C.U. is a problem here. I told administation that this is just not safe. I asked them to build a mini O.R. in I.C.U. for emergencies, but they refused.
- I didn't realize your mother was going to have coronary spasm after being transferred. I do not have a crystal ball.

Cardiologist:

- Your mother was not psychologically prepared to accept such an extremely invasive procedure
- She had a cholesterol of 389! She was only 2 years post-menopausal and had extensive disease. Her vasculature was like that of an 80 year old
- The stress of raising 4 children alone and working full time caught up with her at a young age. Cigarette smoking and diet could not have caused all that damage.
- It seems that very intelligent women don't survive this operation. ?
- Two other women have died on the elevator ride in this hospital
- Worse things have happened. We lost a man from bypass who had a young wife and child.