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# *Public Hearing*

before

## ASSEMBLY HEALTH AND HUMAN SERVICES COMMITTEE

*“Women and Disability”*

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**LOCATION:** Marian Hall  
Holy Name Hospital  
Teaneck, New Jersey

**DATE:** May 10, 2002  
10:30 a.m.

**MEMBERS OF COMMITTEE PRESENT:**

Assemblywoman Loretta Weinberg, Chairwoman  
Assemblyman Matt Ahearn  
Assemblyman Willis Edwards, III  
Assemblywoman Nellie Pou  
Assemblywoman Joan M. Quigley  
Assemblywoman Rose Marie Heck  
Assemblywoman Charlotte Vandervalk



**ALSO PRESENT:**

David Price  
*Office of Legislative Services  
Committee Aide*

Wali Abdul-Salaam  
*Assembly Majority  
Committee Aide*

Tasha M. Kersey  
*Assembly Republican  
Committee Aide*

***Hearing Recorded and Transcribed by***  
The Office of Legislative Services, Public Information Office,  
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey

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**ASSEMBLYWOMAN LORETTA WEINBERG (Chairwoman):**

Good morning, everyone. I am Assemblywoman Loretta Weinberg and, very honorably, Chair of the Assembly Health and Human Services Committee, which is holding this hearing today. We do expect a couple of other members of our Committee to be here, but since the time is getting on, we are going to begin the hearing.

First of all, let me just tell you a little bit about the hearing. Anybody who wants to testify should please come forward to the microphone so that your remarks will be appropriately recorded, and then we will be getting a written transcript of everything that takes place today -- we members of the Committee -- which can be circulated to the General Assembly at large. So, please do take the time to come forth to the microphone.

I see another of our Committee members coming forth here, Assemblywoman Rose Heck.

We are honored to be at Holy Name Hospital. Before I introduce all the members of our Committee, I would like to introduce to you Catherine Yaxley from Holy Name Hospital, who is representing the administration here this morning, who's been very instrumental in helping us pull this together.

Catherine, if you would just wave back there.

Holy Name Hospital has been the scene of some other momentous events in our legislative history. This is the place where we held the first, I believe, and major hearing that resulted in the passage of legislation to require 48 hours of aftercare for new moms and their babies. The hearing was held here. Assemblywoman Rose Heck, at the time, chaired the Advisory Council on Women, and I, again, was privileged to be a member of that Committee.

That bill was actually signed by the governor right here at Holy Name Hospital in honor of what they did by extending this invitation to us. It went on, by the way, to become the model for federal legislation. The federal legislation was passed and is word-for-word the New Jersey legislation. So you are sitting in the hall that gave birth to the 48 hours for new moms and their babies, and it's something we're very proud of.

Here with us at that time was a great mover of Holy Name Hospital and of issues that affected women in all areas of their lives whether women becoming new moms or second- or third-time moms or women with disabilities, all kinds of events that shaped women's lives, and that was the very recent passage of Sister Patricia Lynch. She was the mainstay of Holy Name Hospital. She was a dear friend of many of us up here and a friend particularly to women in the State of New Jersey. I could not let this occasion go by without commenting on how much she did for all of us. I know how much she did for me personally. She was a role model. So every time you come in here, I hope you will think of Sister Patricia who moved issues of import to women ahead.

With that as an introduction, beside coming to the microphone, if you have any written testimony, you may give it to David Price, who is our staffer down here. He will see that we each get it.

I would like to take a moment now to introduce to you the members of our Committee. Assemblyman Ahearn, who is sitting down to my left, who represents neighboring District 38 and is sitting in for Assemblyman Conaway, who could not be here today. My colleague on the Health Committee, and he's been a great asset to all of us, Assemblyman Edwards,

who comes from neighboring Essex County, and we are really pleased that he made the trip to join us to hear you today. To my right, Assemblywoman Nellie Pou, who has really been involved for many years in social service delivery and issues of import to women and comes from Passaic County. And to her right, my colleague right here from Bergen County, also from neighboring District 38, is Assemblywoman Rose Heck. Our staffers, Wali, who staffs the Health Committee; David Price, whom I've mentioned; and my own legislative aide, Kevin Moore, who has done a lot of work on this. So I think we've introduced everybody. Oh, I'm sorry. Here comes somebody else who had a little bit of difficulty finding us -- another of our staffers from Trenton.

I'm also going to take just a few moments to tell you why we chose Holy Name Hospital. Besides the fact that I live and work in Teaneck and use the emergency room here over the years when my kids, both of whom were jocks, were growing up and went through the assorted sprained ankles and things that go on with raising children. I used to say, when I walked into the ER, they almost knew my Blue Cross/Blue Shield number by heart. Although this district has three major hospitals that I represent, this is kind of my hometown hospital.

It is a hospital that is devoted to women's issues. In particular, it is the home to the Multiple Sclerosis Center; a very, very high percentage of whose clients are women. This is a source of not only physical medicine, but of emotional support for MS patients, and they do a wonderful job. I'm sure we will be hearing a little bit about that this morning. They also host and do a wonderful job with the Womens Health Center. Many of you might have

passed the signage coming in here, pointing out where the Womens Health Center is. One of its unique attributes is that it has its own entrance. In order to use the Womens Health Center, you do not have to walk through the hospital. You come directly in. They provide services that are of particular import to women here, particularly women with disabilities, because it's well equipped to properly assist women with disabilities on a variety of issues that they face in terms of mammograms or just getting a physical exam.

They also have very recently opened -- and part of it was in honor of Sister Patricia -- their Cancer Center. They have an Adult Day Away Program here, which because we women live longer, the Adult Day Away Center is mostly peopled by women. It is a wonderful day care center for frail, elderly, for Alzheimer's folks. A great way for families who have decided to care for their loved one at home, but need a day center in which they can come while the family is either at work or just for a little respite, and their Department of Physical Medicine, which has much in the way of adaptive equipment to help women with physical disabilities. So we're proud of Holy Name Hospital, and we're proud to be here for this hearing.

We have been joined-- I'm sorry. I didn't see you slip by here -- by another of my colleagues, also a Bergen County resident, also a member of the Health Committee, Assemblywoman Charlotte Vandervalk.

So with that, we are here today to hear from you on issues of import on what we as a Legislature can do to make life easier, more productive, and most of all, healthier for women who have various kinds of disabilities. It is within those parameters that we would like to hear from you. We want to hear from all of you, and we do have a rather lengthy list here. So, if you have

written testimony, we would be happy to receive it. As I said, David Price will take that and make sure it's all sent to us. So summarize it. You don't have to read through your entire testimony.

I would also like to introduce, because somebody else is here from the administration, and that's Theresa Daniels, who is the legislative coordinator for the Division on Women in the State of New Jersey. You can clap for her. It's okay. (applause) So, she too will be submitting written testimony to us but will be listening to the kinds of things that are of particular import to women. So just before we open to testimony, if any of my colleagues have any points they'd like to cover, I'd be happy to hear from you.

Oh, and here is, from neighboring Hudson County, another of my colleagues on the Health Committee, Assemblywoman Joan Quigley, who works for a -- in her professional or daytime life -- works for a-- I won't give any kind of commercials to anybody else's hospital, but does work for a hospital system in Hudson County, so is a particularly good resource for us on the kinds of issues that we will be hearing about. So, welcome, Joan. Thank you.

ASSEMBLYWOMAN QUIGLEY: And I have to compliment Holy Name Hospital on its signage.

ASSEMBLYWOMAN WEINBERG: And I came in complaining that the signage was terrible. (laughter)

ASSEMBLYWOMAN QUIGLEY: They must have fixed it since you got here. (laughter)

ASSEMBLYWOMAN WEINBERG: Since I got here, that's right. How much did Catherine pay you to say that? (laughter)

Anyway, we do have, from the Health Care Summit Report on Women With Disabilities, we have four major issues that have been outlined in this report. I'm going to go over them really briefly. It talks about inadequate preparation of medical professionals to treat illnesses in women with disabilities; the inaccessibility of medical facilities and equipment, such as doctor's offices, clinics, mammography machines, and examination tables; the failure of medical professionals to treat women with disabilities as fully human, denying their sexuality and capacity to bear children and refusing to include them in important medical decisions affecting them; and the lack of adequate research on the impact of aging on women with different disabilities. So those are four areas that have already been outlined as problems that we hope we're going to be able to address, albeit slowly, but at some point in the future.

So, first of all, I would call Dr. Richard Bruno, who has asked to be on early. Dr. Bruno, are you here? Here you are. We had a wonderful phone conversation.

**RICHARD L. BRUNO, M.D.:** Yes, how is your water heater?

**ASSEMBLYWOMAN WEINBERG:** Thank you for joining us and would you please tell us about your association.

**DR. BRUNO:** Yes. My name is Dr. Richard Bruno. I'm the Director of the Post-Polio Institute at Englewood Hospital and Medical Center.

**ASSEMBLYWOMAN WEINBERG:** Catherine, you're going to move the microphone down so that the-- (referring to PA microphone)

**DR. BRUNO:** Okay.

ASSEMBLYWOMAN WEINBERG: It may be better for him to hold it.

DR. BRUNO: No, if I do that, I'll have a tendency to sing.  
(laughter)

Okay. Is that good? We're okay?

Madam Chairwoman, members of the Committee, thank you for allowing me to testify this morning on this most important topic. Unfortunately, women who have physical disabilities, especially those who have mobility impairments, are rapidly becoming New Jersey's silent majority. Merely, as you've mentioned, by virtue of living longer than men, women fall prey to conditions related to aging -- arthritis, stroke -- that cause mobility impairments, the effects of which they must live with for years longer than their male counterparts.

What's more, younger women find themselves more likely to develop a variety of disabling conditions, again as you mentioned, Madam Chairwoman, MS. Among New Jersey's 50,000 polio survivors, my patients at Englewood Hospital at the Post-Polio Institute, women are more affected by post-polio sequelae, the unexpected and often disabling symptoms that occur 35 years after the polio attack. So more women than men find themselves physically disabled and mobility-limited as they age.

Women are a majority of the population, a majority that increases with aging, but I call women with disabilities a silent majority because they cannot be heard by the medical community. Because women with disabilities often do not have physical access to doctor's offices. They cannot talk to doctors or be heard by doctors so as to receive the medical care they need.

This has become a bigger problem with the advent of HMOs, where the doctor choices are so limited.

A patient of ours this week needed to see an endocrinologist. She went through the HMO's book. There were 12 endocrinologists listed, 1 of them with wheelchair access. She called the doctor up. He was no longer a member of the HMO. Even if women with mobility impairments can gain access to doctor's offices, they are, more likely than not, unable to be examined because their doctor has a table that is too high for them to sit on. I can't tell you the numbers of my post-polio patients, who disabled early, have never in their lives had a gynecological examination because their doctor's examining tables are so high that a pole-vaulter would have trouble mounting them.

In order to allow the voices of women with mobility impairments to be heard and the needs of these women to be met, I asked this Committee to legislate physical access to medical care in New Jersey. The physical access to medical care bill would require the following: that by the year 2007, as a condition of license renewal, every health-care provider in New Jersey, including all types of physicians, psychologists, social workers, nurse practitioners, optometrists, would be required to provide proof that their offices are wheelchair accessible, as defined by New Jersey State Barrier-Free Construction Sub-code, access that will include parking lots, buildings, and bathrooms. It has been required since 1979 that all health-care providers who receive Medicare payment have offices that are wheelchair accessible. So this new State requirement will only reiterate to the Medicare providers what the federal government has required for over 20 years, requirements that are unfortunately not in force.

The Physical Access to Medical Care bill would require, by the year 2005, that as a condition of license renewal, all physicians will have in their offices at least one high low examining table. Such tables are adjustable in height down to 19 inches above the floor, allowing individuals with mobility impairments to transfer to these tables. They cost about \$2000. And as a requirement for licensure by the New Jersey State Department of Health, by the year 2005, all New Jersey hospitals would have at least two high low examining tables usable for gynecological examinations, one in the emergency room and one in a clinic area. The bill should also remind Department of Health examiners that to ensure that all hospitals meet the access requirements of the ADA, using the barrier-free subcode as the standard before they are licensed, including access to parking lots, buildings, elevators, and bathrooms. The physical access to medical care bill will help not only women with disabilities, but every man and woman in New Jersey who has a mobility impairment, due to disability or due to aging, receive the medical care that is available to non-disabled citizens of New Jersey.

Thanks so much for the opportunity to address the Committee.

ASSEMBLYWOMAN WEINBERG: Dr. Bruno, thank you very much for spending the time with us. Would you just tell the other members of the Committee, as well as the audience, about your program at Englewood Hospital, because it was very interesting when you and I had a conversation about that. Would you just briefly fill us in?

DR. BRUNO: Sure. There is the Post-Polio Institute which treats New Jersey's 50,000 polio survivors and the 20 million polio survivors around the world. There's also the International Center for Post-Polio Education and

Research, which is funded by a New Jersey trust, that is the research and education arm of the Post-Polio Institute. This year is the 50th anniversary of the largest polio epidemic in North America in 1952 where about 68,000 people were affected. The problem with post-polio sequela is that doctors don't know about them. Polio survivors often don't know about them, and it is vital that we get this information to both doctors and polio survivors because PPS are eminently treatable if polio survivors know what to do and doctors know what to do.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Does anybody have any questions of Dr. Bruno? (no response)

DR. BRUNO: Thank you all very much.

ASSEMBLYWOMAN WEINBERG: Thank you. We appreciate your being here.

Eileen Goff, who represents the program called HIP, Heightened Independence and Progress, which is located in Hackensack.

**E I L E E N G O F F:** Good morning.

ASSEMBLYWOMAN WEINBERG: And who is a very good friend.

MS. GOFF: A very good friend. Assemblywomen Loretta Weinberg is an outstanding representative of those of us in New Jersey.

Heightened Independence and Progress is a center for independent living which assists people with disabilities to achieve optimal lifestyles and, of course, that includes access to health care. I will keep my remarks brief because I suspect they're going to be echoed by many others.

As people, women with disabilities are living longer. There is an increased opportunity for occurrence of disability issues and for post-disability issues. There are a few serious problems that I would just like to touch on. One is that in some way we must address the problems that those who can only have Medicare as their medical coverage, because they're unable to afford secondary coverage, have serious problems with the acquisition of durable medical equipment. The equipment must be paid for at the time of purchase, and many of these folks do not have the funds for which to do that and reimbursement is only partial, as we all know. Therefore, acquiring the critical equipment that they need can become a terrible, terrible problem.

Issues of access is the other area, as my esteemed prior speaker spoke. Doctors' and dentists' offices frequently just do not have the ability for people with mobility impairments to have access to them in any way. The equipment that was discussed -- examining tables and X-ray machines and all of the other equipment used by women in medical situations, whether it be in doctor offices and hospitals, is a huge problem. I would suggest that all new equipment have to meet with specifications so that it can be affordable to all with universal design.

There's another area of access which very rarely is addressed. It is to those of us who are denied the use of standard print. When a person with vision goes to a hospital and has to sign consent and authorization forms, they're in a format that they can read. Very often, they are available, as in a county such as Bergen with a diverse population, in many languages. However, they are virtually not ever available in braille or in large print so that those people who require that accommodation can read the same forms, take

home the instructions, and so forth. HMO materials also are very rarely available in that kind of format.

As a broader look to access to health care, we critically, in New Jersey, need additional accessible housing. Because of the lack of accessible housing, there are many women who are confined to their home and can only access medical care when it's an emergency situation and the ambulance corps can transport them. We also need additional paratransit resources for the same reason, so that access to physicians and doctors is much more forthcoming.

The physicians specializing in disability care, specifically with HMO, is a major problem. That has already been touched on. But at our agency, we hear that a great deal. The physician who may be the one most knowledgeable in the area of a woman's disability is unavailable to them because the transportation system can't get them there, because the office isn't accessible, because the distance is too far.

I thank you very much for the opportunity to present these issues, and I commend Assemblywoman Weinberg and the entire Committee for bringing this issue to the forefront. Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you very much, Eileen. Any questions of Ms. Goff? (no response)

Thank you, Eileen.

Anita Clavering. Would you also tell us if you're representing anybody else besides yourself?

**ANITA CLAVERING:** Yes. Is the microphone on? (referring to PA microphone) Okay, thank you.

Good morning, Assemblywoman Weinberg, members of the General Assembly, members of the New Jersey Council-- Excuse me, first of all, my name is Anita Clavering and I represent--

ASSEMBLYWOMAN WEINBERG: Oh, I'm sorry--

MS. CLAVERING: That's okay. I get it all the time. Anyway, I represent the New Jersey Developmental Disabilities Council's Womens Health Care Steering Committee. First of all, I would like to say good morning, Assemblywoman Weinberg, members of the General Assembly, members of the New Jersey Developmental Disabilities Council's Womens Health Care Committee, and all citizens in attendance this morning.

My name is Anita Clavering. I live in Old Bridge, New Jersey. I am a woman living with mental, behavioral, and learning disabilities. I am a co-facilitator of the Monday Morning Advocacy Network of Middlesex County and a social recreation coordinator of the Alliance for Disabled in Action, which is a center, or independent living, representing consumers with disabilities in Middlesex, Union, and Somerset counties, and belong to many other community groups serving citizens both with and without disabilities. I am also a proud member of the New Jersey Developmental Disabilities Council's Womens Health Care Steering Committee, which had a groundbreaking summit last year that focused on the four major issues we will be addressing today in this hearing.

In my testimony, I will be addressing the great need for access to health care for women with all disabilities, focusing primarily on transportation as an important part. The reason for my interest in this issue comes from both my personal experiences and those of other citizens with disabilities. Many

consumers with disabilities rely and depend on one or more means of transportation to keep their medical appointments so they can tend to their health-care needs and stay well.

Many consumers with disabilities who live on fixed incomes and rely on Medicaid and/or Medicare as their primary insurance. I need to make a correction on the following statement which is much different from the copies that were distributed. Fortunately, I checked the correct information before the hearing this morning. I was very shocked and upset to hear that one of the members of our committee could not afford to pay a local taxi company when she was told that she had to pay \$75 each way, \$150 round-trip, without tips, to go to a doctor in Teaneck from her home in Fairlawn, which was just eight miles. Even at that, she was then told that the driver did not guarantee that she would have a ride or not.

Consumers with disabilities need more accessible, available, and affordable means of transportation and more flexible times, as well as in times when emergencies occur, to and from medical appointments so they can fully maintain their health and wellness.

One way is for medical professionals to work with transportation providers -- for example, livery medical transportation programs and the taxi companies assigned county paratransit systems, New Jersey Access Link, private ambulance companies -- and I need to also add senior citizen transportation buses -- in communicating with consumers on the times needed during waiting for their appointments or examinations and then consider their individual needs and make drop-off and pick-up times more flexible.

Since my Medicaid coverage provides transportation to and from appointments, I use the livery medical transportation program, which comprises of taxi services hired by the County Board of Human Services to drive consumers who have Medicaid to medical appointments. Many consumers who use the program call them Medicaid cabs because the taxi services are reimbursed by Medicaid to drive consumers to and from medical appointments. On many occasions since using the livery medical transportation, I either had to miss or cancel appointments altogether because the taxis were late to drive me to my scheduled appointments or had to wait long hours for them to drive me back home from examinations and/or therapy.

Last year, I had an appointment with my therapist to maintain my mental and behavioral health conditions, such as controlling my anger and dealing with stress and other difficult situations. I was told by my therapist at the time that if I wanted to cancel my appointment, I would have to do it well over a week or two in advance so there would be plenty of time to schedule another consumer for treatment. Unfortunately, I was all dressed and ready for my appointment with my therapist when I waited for the taxi to come. I was supposed to be at the therapist's office at approximately 10:30 a.m. When the time grew closer, the taxi still did not arrive. I called my therapist's office to let her know that I was going to be late for my appointment. I also called the taxi service to ask when will a taxi arrive to pick me up. By the time 10:30 rolled around, the taxi still never arrived. I then lost all hope when I had to contact my therapist's office to cancel the appointment. Worst of all, after I inconvenienced my therapist by canceling my appointment, a taxi did arrive.

I was so frustrated. I told the driver to cancel my ride and stated to him that I was supposed to be at the therapist about five minutes sooner.

If county boards of social services have livery medical transportation programs, advisory board councils, similar to county paratransit systems, should be seriously considered and formed so citizens with disabilities will have an opportunity to address county department of human services staff, county freeholders, and other public officials and representatives from agencies and organizations on how taxi services assigned should be also closely monitored in picking up, transporting and dropping off consumers to and from medical appointments in a more timely, as well as a safe manner. Also, taxis should be better maintained. Last week, I rode in a taxicab from a doctor's appointment where the roof was ripped up, and there were no seat belts. Also, the driver smoked without asking if I minded that he did.

Smoking should also be prohibited in the taxi cabs assigned by livery medical transportation programs, not only en route to and from appointments, but completely, at all times, if possible, for the vehicles reek of cigarette and cigar smoke when they are put out as consumers board them. If a consumer has asthma, bronchitis, and/or other respiratory ailments or not, he or she especially should not have to ride in the same taxicabs that reek of the smoke emanated from cigarettes and/or cigars. Smoking is completely prohibited on New Jersey Transit and by county paratransit systems. I strongly believe that if the livery medical transportation programs receive funding from Medicaid, smoking should be prohibited and discouraged in the taxi services assigned as well.

Consideration should also be made for consumers who only have Medicare coverage to take advantage of livery medical transportation programs if county paratransit Access Link or any other means of medical transportation are not readily available to transport them. Also, other consumers with physical disabilities who use wheelchairs, scooters, and other assistive equipment cannot use the livery medical transportation programs unless they are able to transfer to and from the taxis, which have no accessible lifts nor belts to tie them down.

Senior bus transportation from municipalities is also available for citizens with disabilities for medical appointments. Depending on the municipality, citizens with disabilities can register with the Office on Aging to use the senior buses. Unfortunately, also depending on the municipality, the senior bus transportation may be inflexibly scheduled because it can operate on a limited schedule on weekdays and may not be available to pick up consumers if their medical appointments are over. Also, some, if not all, municipalities may have senior buses which do not have fully accessible features to accommodate citizens with physical disabilities.

Consumers with physical disabilities, who cannot move nor transfer to and from wheelchairs, can use private ambulance companies as Able, Reliable, Maximum Care, Rural-Metro, Peoples Transport, and a whole array of others, which are covered by Medicaid and Medicare and have the mechanical lifts and belts needed to secure them while being transported to and from the medical facility. However, if a consumer with a disability does not have Medicaid, Medicare, and/or other private insurance nor any money

for private ambulance companies, they are out of luck because they cannot afford to pay for them in the event a medical emergency arises.

Although many county paratransit systems are assigned and devoted to transporting consumers to and from medical appointments free of charge and devote a lot of time serving consumers for kidney dialysis treatments, some if not all may require two weeks to a month in advance, which can be very inconvenient in case an unexpected medical emergency arises. Paratransit system schedules are filled two weeks to a month in advance and an opening on the day an emergency arises may be very rare and impossible to obtain. Also, if consumers who are using a county paratransit system have to wait long for the doctor for their appointments and then, when they are finally called, if the time of the examination exceeds the time they are picked up to return home, the driver may decide to leave after a period of up to five minutes.

Some consumers I know also use New Jersey Transit Access Link for transportation to and from medical appointments. Though transportation on Access Link can be arranged 24 hours in advance, there are many inconveniences because of its continuing policies of the 20-minute window, which many of its consumers have experienced and complained about. That window may include arriving either too early or too late for appointments. Then, like in county paratransit, the Access Link driver waits only five minutes while a consumer using a wheelchair may try to get out of the door after exhaustively rushing to get ready, or Access Link may arrive too early when a consumer is either still waiting for his or her appointment or in the examination room being treated. The driver may wait five minutes and then

leave. Also, not all consumers with disabilities qualify for Access Link service after an assessment, because they are determined not disabled enough and/or are capable of taking public bus and/or train service even though there are not enough direct routes.

The following arguments of opposition anticipated and expected are that transportation providers may not want to cooperate and work with medical professionals in discussing flexible times for consumers to be transported, dropped off, and picked up before and/or after appointments or examinations. Taxi companies assigned by boards of social services for their livery medical transportation programs may not cooperate with the proposed advisory boards on reducing waiting times nor make needed improvements in their vehicles such as fixing and adding seat belts. Money and funding needed for accommodations and maintenance of taxis may be considered too much for the companies, although Medicaid may require them to provide clean, well-maintained vehicles. Also, taxi companies may use their own discretion in allowing drivers and/or passengers who smoke in the vehicles.

Another argument of opposition is that the county paratransit systems and Access Link may not want to work with medical professionals in making drop-off and pick-up times more flexible for consumers to and from medical appointments and examinations. Also, money and funding are always an issue, especially since the State budget has been frozen. However, many counties have casino revenue hearings coming up, which I'm hoping that consumers will speak up and say that no funding should be allocated unless drivers are trained and learn how to work with medical professionals in scheduling more flexible times for pick-ups before and after the examinations.

I am hoping that the Legislature should look at the issues that citizens with disabilities face in obtaining direct transportation to and from appointments and examinations and consider the proposals and suggestions I've presented so that, hopefully, there is action in implementing more safe, clean, and most importantly, flexible transportation service to and from medical appointments and examinations.

Many consumers with disabilities, who are unable to drive, depend on different means of transportation to go places and participate in all aspects of the community. Everything we have to do in life, whether its going to and keeping medical appointments, going to work to support ourselves and our families, going to school to further our education, going shopping for food and other necessities, going to friends homes, recreational functions to socialize and participate in activities and other functions, and/or just going to a bank to take out and deposit money or sending letters and other mail to the post office, requires one or many means of transportation that is readily available and fully accessible both logistically as well as physically.

In conclusion, the road to good health and wellness for women with disabilities -- in fact, for all citizens with disabilities -- begins with safe, efficient, affordable, and available transportation both to and from medical facilities and appointments. Therefore, I hope this Committee will seriously consider the issues that I have stated in my testimony this morning regarding the vital need for more safe, available, efficient, and reliable transportation to all medical appointments for all women with disabilities, as well as present the suggestions I've proposed to all your colleagues in the Legislature.

If any of you have any questions and/or comments, please do not hesitate and feel free to let me know. I very deeply and gratefully thank you all so very much for all your time and consideration today.

ASSEMBLYWOMAN WEINBERG: Well, Ms. Clavering, I don't think there is much that you left unsaid about the problems in transportation. It almost could be put into a public administration graduate class, a dissertation. So well put together and well-outlined, and we appreciate it.

I don't know if anybody has any questions here?

ASSEMBLYWOMAN HECK: I just have a comment.

ASSEMBLYWOMAN WEINBERG: Sure.

ASSEMBLYWOMAN HECK: It is very thorough, Anita. I think a copy of her testimony should go to the new director of GDD and possibly he can take some action for you.

MS. CLAVERING: That would be great.

ASSEMBLYWOMAN WEINBERG: Thank you, Rose.

Anybody else have a comment? (no response)

Anita, would you leave your written testimony with David Price over there. If you need to, we can get it back. We'll get you a copy or--

MS. CLAVERING: I may need to send a corrected copy because I had to make a change in my testimony on the second statement.

ASSEMBLYWOMAN WEINBERG: Okay, thank you very much.

MS. CLAVERING: Thank you also very much.

ASSEMBLYWOMAN WEINBERG: Kate Blisard.

ASSEMBLYWOMAN HECK: Madam Chair, I think one of the things that--

ASSEMBLYWOMAN WEINBERG: Excuse me one minute.

ASSEMBLYWOMAN HECK: Oh, I'm sorry.

ASSEMBLYWOMAN WEINBERG: Anita, apparently we do have a copy of it up here. I'm sorry.

MS. CLAVERING: That's okay, but I will send a corrected copy.

ASSEMBLYWOMAN WEINBERG: A corrected copy.

Rose.

ASSEMBLYWOMAN HECK: Just as a point of information, the bond issue that we passed about eight or nine years ago is completed now, as of last year, and that is another consideration to do another bond issue to take care of the needs -- particularly housing that was brought up before.

ASSEMBLYWOMAN WEINBERG: And as we all know, the waiting list has grown exponentially over that length of time because money wasn't put in for staffing of the Homestead bills.

ASSEMBLYWOMAN HECK: Yes.

ASSEMBLYWOMAN WEINBERG: Ms. Blisard.

**K A T E B L I S A R D:** Good day. My name is Kate Blisard. I am a member of the Women's Health Care Steering Committee. I thank everyone here for convening this hearing. I'm going to speak today as a private citizen. I speak as a woman with a disability. I have a sister with Down's syndrome. Disability is part of my life. I was born with cerebral palsy in 1950. You can do the math. (laughter)

ASSEMBLYWOMAN WEINBERG: You didn't have to confess to that. (laughter)

MS. BLISARD: Okay. I am here today in support of the hearing with the hope that my story may help the cause of women with disabilities in New Jersey.

I didn't expect a music accompaniment. (laughter) (cell phone plays tune)

I was a young woman with a disability in the '70s, who could not attend the college of her choice because it was inaccessible. It was wrong. It changed my life. It still happens to women with disabilities. We need to enforce the laws that protect the right to equal, not separate, education.

I was an employed woman with a disability in the '70s, living on my own, raped at knifepoint, with no one to help or understand me. It was wrong. It changed my life. It shouldn't happen to any woman. Rape and domestic violence happens twice as often to women with disabilities. The lack of accessible medical and counseling services must be addressed.

I was a married woman, pregnant, and unable to find a knowledgeable physician to care for me and my unborn child. I was told to abort. I did not, and I have two grown children. It changed my life, though. It was wrong. Twenty years later, women with disabilities are still searching for that caring and knowledgeable physician. We can do this. We can educate the next generation of physicians to become caring and knowledgeable physicians.

I am here today as a mature, professional woman with cerebral palsy -- it doesn't go away -- dealing with the hard reality of aging faster than my non-disabled women friends and colleagues. Less than 25 percent of women with disabilities are employed full time. After mid-life, it drops to 8

percent. Once again, I find for the most part ignorance, discrimination, and lip service from the medical community. It was wrong, but there is light ahead. There is hope. There is progress. Women with disabilities are taking charge, choosing to live healthier and fuller lives. It is why I am a member of the Womens Health Care Steering Committee, and it is why we are all here, including all of you up there today.

I am here today because in my heart and mind I know there are answers and solutions. I believe that this hearing, convened by people of good will, can lead to a better life for women with disabilities and can make New Jersey a better state for realizing the skills and talents of these citizens for generations to come.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you.

Ms. Blisard, I would just like to comment, particularly about some of the things that we've talked about earlier and that you touched on in your testimony. The new president of the New Jersey Medical Society works right here in Holy Name Hospital. He heads up the Hemodialysis Unit here, Dr. Robert Rigolosi. I know that both Catherine and I, and I'm sure other members of this Committee, are going to be talking to Dr. Rigolosi about what needs to be done in the medical profession in terms of these kinds of issues. He's going to be hearing from us, Catherine.

Thank you very much.

MS. BLISARD: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Any questions? I'm sorry, does anybody have any questions? (no response)

Thank you very much.

MS. BLISARD: Thank you.

ASSEMBLYWOMAN WEINBERG: Janet Chiorello-Ellis.

**JANET CHIORELLO - ELLIS:** It's not really that long. It's just big type. (laughter) Okay. All right. Hi.

ASSEMBLYWOMAN WEINBERG: Hi.

MS. CHIORELLO-ELLIS: I'm Janet Chiorello-Ellis. I live in Piscataway. I wanted to thank you all for convening this meeting that's important to us. I'm a 36-year-old married woman with a disability. I am testifying today because of my own experiences, as well as those of many women with disabilities I know and have worked with as an advocate and a clinical social worker.

I'm a charter member of the Steering Committee that organized the Women with Disabilities Health Care Summit last year. While 66 of us came together then, we represented more than 850,000 other women with disabilities in New Jersey, about 10 percent of the total population.

My role at the summit was to facilitate the workshop on sexual and reproductive health. These are issues that effect us throughout our life cycle. It's no wonder that I began to worry about my health and wellness as a woman with a disability before I even reached puberty. I wondered if I would have a normal, healthy love life, sex life, family life. Would the doctors know how my disability would effect these things? The answer was, no, they didn't. I still don't think they do either.

My personal horror story is, so far, limited to finding a gynecologist who has experience providing basic preventative care to a woman

with cerebral palsy. But before the age of 22, I was to learn that this could be an issue of life and death. I heard the worst case scenario: a woman's symptoms of cancer could be mistaken for a secondary symptom of her disability, and because of that, the cancer was not detected and she died. This was an issue of someone with a spinal cord injury whose uterine cancer was not picked up.

At our health care summit, I learned that more than one woman with a disability has been denied a mammogram because she used a wheelchair. As a result, her cancer was not picked up, and she either had a mastectomy that could have been prevented, or she died of cancer that might have been treated effectively if detected earlier. These are the worst case scenarios. One of these is too many, and I'd like to avoid becoming one of those statistics.

I know that gynecologists, as well as general practitioners, are afraid of me and my sisters because they know so little about us. They often think of us as already sick, so their efforts to keep us well are not what they need to be. I know that I have great difficulty getting into a gynecologist's office. I know I had great difficulty getting on and fitting into the contraptions of an exam table. I know that my spasticity makes a complete pelvic exam nearly impossible for some doctors, and a Pap smear that identifies cancer is often not adequate to make a definitive screening possible because of my spasticity.

I eventually found and got to see the one gynecologist around with the experience I need. It's been many years -- it took a long time -- and I'm still not sure that I'm getting adequate screening for the illnesses I am at risk for. I recently found out that at 36 I am at risk for osteoporosis. I had a

screening that actually told me that I had a very severe level of it. Then I had another screening that said I was just within the normal range. But being just within the normal range at 36, it doesn't sound so good to me. So the research on women like me to inform the treatment and prevention doesn't exist, to my knowledge.

I'm not old enough to need a mammogram yet, but that is only a couple of years away. My older sisters with disabilities tell me that some facilities cannot screen them from their wheelchairs. Some say that they can be screened, but that screening is not considered to be adequate because of the curvature of the spine or whatever. So they can't really guarantee that they have actually have or do not have cancer. So, as far as preventing death from breast cancer, women with disabilities are at a distinct disadvantage.

These are just a few of the many health conditions that women with disabilities are more at risk of dying from. There are many other secondary conditions that might be prevented or better treated with improved attitudes, information, research, and treatment. I haven't touched on sexuality and childbearing, which Kate talked a little bit about. So what do we need? We need accessible facilities, informed and sensitive practitioners, cutting edge research, education, training for our new and old physicians and teachers in the medical profession.

We women at the summit realized that there was no place in New Jersey, maybe this is one of them -- where anywhere else in the country for that matter -- where women with disabilities can go with confidence to find a physician knowledgeable enough about our unique needs to effectively treat us and keep us well. But we do have a medical school in New Jersey. We were

thinking that a center, for lack of a better word, for the health of women with disabilities could be a place where the best doctors, researchers, teachers, could come to learn, teach, and provide the best treatment to women with disabilities in New Jersey.

That's our dream. More and more of us share it. We need your help to make it a reality. I'm not so sure how this can be done, but I hope you as legislators will help make our dreams a reality.

ASSEMBLYWOMAN WEINBERG: Thank you very much, and that's why we're here.

ASSEMBLYWOMAN VANDERVALK: Madam Chair?

ASSEMBLYWOMAN WEINBERG: Yes, Assemblywoman Vandervalk.

ASSEMBLYWOMAN VANDERVALK: Unfortunately-- Well, I'll start with the fortunately and then get to the unfortunately. A few years back, another woman legislator, Nilsa Cruz-Perez, and I had discussed the concept of having physicians and dentists appropriately trained to service the disabled population. A bill was passed and signed into law, and it was in conjunction with University of Medicine and Dentistry of New Jersey. The concept behind it was that if people were willing to-- They would get a scholarship grant if they were willing to devote a certain number of years after they've received their license to treating people with their knowledge, their specific knowledge.

The unfortunately part that I talked about -- I really don't know the outcome of that. I'm going to look into that to see if that took off, if there was a response to that. I know New York had also, at that same time, done a

program like that. It just seems to me, in light of what you're saying specifically, that there is a real-- I mean, we thought there was a need, but obviously there is a great need, and I'm going to look into that to see if we can-- Hopefully, it's working. And if not, maybe we can find out what will make it work.

MS. CHIORELLO-ELLIS: Thank you.

ASSEMBLYWOMAN WEINBERG: I also just want to point out, in terms of one of the issues you raised, that the Womens Center here at Holy Name Hospital can provide adequate mammogram screening for women with physical disabilities.

MS. CHIORELLO-ELLIS: That's good to know.

ASSEMBLYWOMAN WEINBERG: Assemblywoman Quigley.

ASSEMBLYWOMAN QUIGLEY: I know that the Robert Wood-Johnson Foundation gave grants to several New Jersey hospitals with teaching programs a few years ago to train residents to work with people with mental disabilities. As you can imagine, they don't have the physical problems, but they are a difficult population because sometimes they don't understand the treatment, sometimes they're non-compliant. If those grants are available for physicians who want to work with that population, there has to be something available for people with physical disabilities. I'm going to look into it with the Robert Wood-Johnson Foundation and see if they have money, since the State doesn't right at the moment. We hope they will soon. This may be an alternative route. So, while Loretta and the others are pursuing that, I'd like to go after the foundations with some of you and see what we can do, too.

MS. CHIORELLO-ELLIS: Sounds good. I know that Robert Wood University Hospital in New Brunswick has one accessible exam table, but that's the only one that I know about. I know my general practitioner does not have one.

ASSEMBLYWOMAN QUIGLEY: Well, I'm going back to check on Hudson County before the day is out. (laughter) I'll tell you that much. And e-mail is going to be burning up the wires today.

MS. CHIORELLO-ELLIS: Before I get up, because I'm sitting here, Holly Wetscher is right here.

ASSEMBLYWOMAN WEINBERG: Holly was the next on my list here.

MS. CHIORELLO-ELLIS: She's the Chairperson of the Steering Committee, and she asked me if I would read her testimony. Would that be okay?

ASSEMBLYWOMAN WEINBERG: Sure.

MS. CHIORELLO-ELLIS: I didn't do so well reading mine, but I'll try to do better with hers.

**H O L L Y   W E T S C H E R:** Thank you very much.

ASSEMBLYWOMAN WEINBERG: Thank you.

MS. CHIORELLO-ELLIS: Okay. (reading for Ms. Wetscher)  
"My name is Holly Wetscher. I am the Chairwoman of the Women With Disabilities Health Care Steering Committee of the New Jersey Developmental Disabilities Council. I am a resident of Westfield in Union County. You have heard much testimony relating to women with disabilities and aging. I would like to talk to you about my disability, which is cerebral palsy. This condition

is caused by brain damage, which is so nonspecific that affected areas can range from minimal to severe. Individuals can manifest severe physical impairments -- ambulation, visual, speech, hearing, and cognitive. There may also be related medical issues. An individual with cerebral palsy can present any of these impairments and they can vary in intensity.

When I was born, medical treatment for CP was in its infancy, and at that time and even now, it is considered a pediatric problem. I guess they thought that we would miraculously get better and live happily ever after. In the more severe cases, physicians recommended institutionalization because they were deemed hopeless. But we surprised them, we certainly did not get cured, and people are coming out of institutions. I'm wondering whether those physicians considered what would happen to us if we lived longer.

We seem to be seeking doctors who can explain our diminishing abilities, our pain, and our general deconditioning. Maybe we are aging. Why? They told my parents that I was a mild case and would be walking when I was 14. Well, needless to say, I just turned 52 and have not learned to walk yet. Yes, I probably sound cynical, but ladies and gentlemen, this is all true.

Yes, they were correct that cerebral palsy does not get worse, the brain damage remains the same. However, it seems as though the aging process has come to me before its time. Presently, I am experiencing various health problems which I did not have before such as neck and shoulder pain, greater difficulty in walking and speaking, fatigue, and digestive problems. It is noteworthy that these medical problems are often misconstrued and puzzling to my physicians. Each issue is treated separately, and they do not seem to

understand why they are occurring. These are secondary health problems which could and should have been prevented.

Up until recently, all information we had was anecdotal. A great deal of clinical research is needed to learn how these secondary health conditions can be treated and eventually prevented. We need legislation to support our efforts.

Our committee is working actively toward the goal establishing a center of excellence in health care for women with disabilities. The center would be a hub for women to obtain care from doctors who have been trained in best practices and experienced in relevant specialties related to specific disabilities. The center would also encourage medical researchers to explore significant research concerning developing criteria for appropriate and accessible health care and wellness for women with disabilities.

Thank you for your time and interest. Holly Wetscher.”

ASSEMBLYWOMAN WEINBERG: Thank you. Thank you very much. Thank you for being here and giving that written testimony, Holly.

All right. The next person we have written testimony from is Professor Ilise Feitshans.

**I L I S E L. F E I T S H A N S, E S Q .:** (speaking from audience) I’m Professor Ilise Feitshans. First Dottie Owens will speak, and then I’ll sort of answer a lot of questions.

ASSEMBLYWOMAN WEINBERG: Okay. Dottie Owens, will you come forward, please?

I’m just reminding you all that we are going to get a written transcript of this, that is what this recording is all about here.

**DOTTIE OWENS:** Hi, and I thank you for having me. This is now added testimony. The people before me and two people after me are all part of the Steering Committee. Our leader is over here is Pat. She started it with us, right here, and Holly is our leader. So, we're very, very lucky.

**ASSEMBLYWOMAN WEINBERG:** You all sound like leaders. I'm not sure that you need a mind-set. (laughter)

**MS. OWENS:** My name is Dottie Owens. I reside in Keasbey, Middlesex County. I am a woman with a disability. I've been diagnosed in September of '93 with multiple sclerosis. There is no cure yet for it. My multiple sclerosis is very complicated. My experience is that my eyes are going blind, optic neuritis. I have cognitive and speech problems and numbness all over my body. This shows up on my MRI as lesions on my brain and on my spine.

I have a registered nurse that comes in once a week to give me a inter-muscular shot of Avonex. This is to try to maintain what I have, but I still remit and relapse. I was in the hospital in March. My right arm never came back, even with the Prednisone.

Mammograms are hard for me to have because I cannot stand and balance unless I have support to hold me up. We need accessible equipment and more research for all women who have disabilities. I took three bad mammograms. I had to go back each time because they couldn't line me up right, sitting or standing.

Thank you for hearing me.

**ASSEMBLYWOMAN WEINBERG:** Thank you.

And now, Professor.

ASSEMBLYWOMAN QUIGLEY: It's nice to see you're still smiling.

MS. OWENS: Hey, we're going to win. (laughter)

MS. FEITSHANS: My name is Professor Ilise Feitshans, and I'm the last of the parade that you have to hear from the Steering Committee from the Women With Disabilities Committee from the New Jersey Developmental Disabilities Council.

Before I get to my portion, I have been asked by Betty Gill to read her testimony. All of the testimony that you've heard from our group is in this wonderful document, which Pat Krupka has gone to a lot of excess to make sure you have copies. It's the Strategies for Change from our summit from last year. We have attempted to address each of the four areas on Pages 12 through 19. There are more copies for people that are interested in it.

I would like to take a moment to summarize some of what Betty has to say before I speak.

ASSEMBLYWOMAN WEINBERG: Professor, I'm going to interrupt you for one minute, because it is getting late, and we have a lot more people who would like to speak.

MS. FEITSHANS: Yes.

ASSEMBLYWOMAN WEINBERG: So, in your testimony, since we have the written testimony, if you would just summarize that rather than reading all that. We would appreciate it.

MS. FEITSHANS: Yes. May I take a moment to read Ms. Gill's because I was requested to do so?

ASSEMBLYWOMAN WEINBERG: Yes. Sure.

MS. FEITSHANS: Ms. Gill says that she's unable to attend the hearing because, "My husband and I are both disabled. Ed is quadriplegic due to polio. I am quadriplegic due to a spinal cord injury. We both use wheelchairs. Ed was Postmaster in Dunellen for 20 years. We have managed to live in our home with the help of a personal care assistant and been able to drive our specially equipped van.

My testimony was written as a speech, and I would like one of the members from the Women With Disabilities Health Care Steering Committee to read it in my behalf."

I will read a very abbreviated version, and I please request of this Committee that you pay particular attention to her testimony because it could not be read in full.

"Good morning. My name is Elizabeth Gill. I am an active, voting resident of Piscataway Township, Middlesex County, New Jersey. I am submitting this testimony as a member of the Women With Disabilities Health Care Steering Committee of the New Jersey Developmental Disabilities Council. In 1963, I had a severe fall and broke my neck. At age 18, I suddenly became a woman with a disability, quadriplegia, and a permanent wheelchair user. If my injury had occurred in 1900, I would have died immediately. If it had occurred in 1940, before the discovery of the indwelling catheter, I would have died before age 20 with skin ulcers and an urinary tract infection.

A century ago, most women with major physical disabilities did not live to bear children, rear them, and grow old. Now, due to the miracles

of research, many do. I am 57 years old now and a member of a brand new and rapidly growing population of aging women with disabilities.”

I will now excerpt from there and leap to her recommendations. I apologize for the brevity, but she deserved the time.

“In our Women With Disabilities Strategies for Change Health Care Summit” -- the report I just showed you -- “our committee has agreed by consensus that the following facets of aging with disabilities should be given top priority. One, the initiation and/or support of legislation to mandate a comprehensive course in disability and aging as part of the curriculum for all medical and nursing students, with the requirement that the student serve one semester as a personal care attendant to a disabled person living at home. Two, the initiation of support legislation to mandate compulsory continuing education courses in disability and aging for doctors, nurses, and personal care attendants. Three, the funneling of more funds for attendant care through legislation. Four, the creation of a center for research on women with disabilities within the existing structures of public health research.

In conclusion, there is much talk about the graying of Americans. The longer a woman lives, the greater are her chances of joining the ranks of the disabled. In time, through illness or accident, you too could become disabled and find your doctor ill-prepared to deal with your special condition. If our recommendations are implemented, you will receive knowledgeable and compassionate medical care in the doctor’s office. We are all living longer. Shouldn’t we live our longer lives with good health and happiness?

I thank you for your consideration and time,” on behalf of Elizabeth Gill.

I will be as brief as I possibly can. You have our testimony. I will say, first of all, that in addition to teaching on the Web for Cornell University, I used to do legislative drafting, teaching it at Columbia University School of Law. So I feel confident that if there are legislative questions where I could be of assistance to this Committee, you're welcome to my expertise.

I have documented in my testimony my personal experience, and I will spare you the gory details, simply to say that without breakthrough genetic research from the national institutes of health, I would be a much sicker person today. That's a very important point because I cannot emphasize enough to this Committee the significance of research, and open-minded research that looks at disability in many dimensions and many different perspectives.

It's pretty obvious, I guess, by now that I'm speaking in conjunction with these other fine ladies. I would like to repeat for you that our four areas of concern are access to care, which Anita very clearly and really in a tour de force explained, the problems of transportation, which is without question the linchpin of access to care.

Janet and several others have outlined very carefully the cycle questions and the questions of accessible mammograms, which we would like to hasten to add that there is an understanding in our group that there is a breast cancer awareness bill pending. We would like to see the definition of education and awareness interpreted in such a manner that it could embrace education and awareness of accessible equipment.

ASSEMBLYWOMAN WEINBERG: Let me just interrupt for a moment because you just reminded me of something else which I think came

forth from your group. When we passed the legislation, which I sponsored, to create an Office on Womens Health, and it has an advisory council which is just now being implemented, we added a category on the advisory council for a woman with disabilities. I think that recommendation might have actually come from your group, that's how I knew about it.

MS. FEITSHANS: They say it did, so it did.

ASSEMBLYWOMAN WEINBERG: Yes.

MS. FEITSHANS: And we commend you on your wise action in response to our request. We hope that that will lead to a track record where you'll also look kindly upon our other requests. We only have two today.

The first is that somehow this concept of accessible mammograms in particular, but other accessible equipment be folded into this breast cancer awareness initiative. It's an enormous source of frustration for our members that one could be told how important it is to get an exam that they physically cannot get. There's even an economic argument here that actually the money is very well used for people to have access to equipment, otherwise there isn't much prevention really happening.

I should also point out that people who can stand up for mammograms would be perfectly willing once in a while to take a break and sit down, if it means that there's a difference in the kind of equipment that's available. (laughter)

ASSEMBLYWOMAN WEINBERG: That's true.

ASSEMBLYWOMAN QUIGLEY: We can attest to that.

MS. FEITSHANS: The third of our categories, about which you've heard several different perspectives, is health and aging. It's not yet a

crisis, but it's certainly foreseeable that as an unattended issue, it could become a crisis. That as disability goes on-- And we are lucky with medical technology and breakthroughs to extend the survival curve for people who were told when they were little they would live a year or two or experienced accidents that would have killed them a decade or a half century before. It's wonderful that they're alive, but we must seriously look at the interaction between prolonged life with disability and aging and try to parse out where that is a natural process of aging, and where that is a secondary effect of disability. There's an enormous need for research in this.

If you were to sort of tie that all together with a bow, then it would be our fourth area, which was staying well prevention and future research directions. There is a relatively page-long request in here explaining our reasoning why we would like to see a really good first-rate center for women's health and really a place that will look at research and that will really look at this longevity issue, which will doubtlessly also unravel many other medical riddles as these questions are looked at seriously and importantly. And it's very important that the population for that address the health-care community itself, the health-care providers, the continuing medical education programs. This is truly important. These are new issues that our society did not confront before because we didn't necessarily have enough people to demand it, but there's a very important and large constituency for it.

Lastly of equal importance, I'd like to point out that this research center really needs to look at the question of defining disability. That we have all our own personal definitions of disability and, of course, everyone in their own way has some deficit or disability of their own. But, in fact, if we don't

look at this definition candidly and forthrightly, there are three consequences. The first is that prejudice is around disability in myths of what disabled people can and can't do, some of which I hope my colleagues have debunked today just by their very actions and presence. I think that can rule our lives and discourage people from care, which is very important.

The second thing is that the definition has to be very flexible and open-ended. I like the way the Americans With Disabilities Act in particular has a nice, flexible definition. It does not look at categories, or in the old days, what used to be called a list format. If you're in that kind of disease, you're on, and if you're not in that problem, you're out. This can't work. It has to be something that looks at severity and that takes into account what we call invisible disabilities and other kinds of long-term conditions and may, in fact, embrace some of the health community that has mental health problems that you were talking about. Certainly cognitive disabilities cross the lines all the time. These are fluid concepts. People are healthy under one paradigm and sick under another.

The last thing is, of course, there are so many definitions under the statutes and criteria floating around this state that people can easily fall through the cracks because they may qualify for one set of services or one set of needs and then come upon an agency that, for whatever reason, doesn't have the same set of rules about how it's defined, and then the whole system breaks down and falls. This is an area of legal research that goes hand in glove with high-quality, cutting edge, frontier science research. As new things are discovered, there must be ways to legally fold them into the system so that the system flows smoothly.

For this reason, we therefore request a study to be authorized to consider developing this important center and to look at these components. We thank you for your gracious time, and I'll answer any questions, and then I'll be quiet the rest of the day.

ASSEMBLYWOMAN WEINBERG: Any questions? (no response)

Thank you very much, Professor. Thank your group.

MS. FEITSHANS: Thank you, and thank you to Pat.

ASSEMBLYWOMAN WEINBERG: Just before she leaves, I want to introduce Yvette Roland, who is representing my colleague, Assemblyman Gordon Johnson and has been here all morning listening. So you can carry the message back to him also. Thank you.

Okay. It's 12:00. We're going to have to end this at 1:00. We have a very long list here. The opening speakers did a wonderful job, and you've done so much research in this area. You certainly have given us all much to think about, so we appreciate that, but I hope that the next group of speakers can kind of summarize what it is they would like to say. I'm going to call you all in the order in which I was given this list, but first I would like to call on June Halper. Is June in the room? (no response) Okay. If she comes back -- because she represents the MS Center right here in Holy Name. And because of the issues surrounding mammograms, since Catherine has assured us that Holy Name is a hospital that can do that, perhaps at some point you can arrange some kind of an open house for--

Oh, I'm sorry, Catherine, you have to talk into the microphone in order to get your comments on the record here.

**CATHERINE A. V. YAXLEY:** If you don't mind, let me address the audience, too.

ASSEMBLYWOMAN WEINBERG: But you have to speak in this microphone, the little one here. (referring to recording microphone)

MS. YAXLEY: We do have, at Holy Name, mammogram capability, wheelchair sitting, standing, whatever need there is. We are able to accommodate that just fine. One of the speakers mentioned difficulty of getting up on an exam table. One of the projects that we approved last year was indeed to bring in a specialized exam table that does go up, down, every which way to accommodate any person's need to get on the exam table. So we do have that in the Womens Center. We are constantly striving to find other ways to help persons with disabilities.

I myself am the daughter of a father with polio, the niece of an uncle who is severely hearing and visually impaired, and I'm also the mother of an disabled son. So this has touched all our lives in many ways.

ASSEMBLYWOMAN WEINBERG: Thank you.

Christine Cripps-Barker.

**CHRISTINE CRIPPS - BARKER:** Good morning.

ASSEMBLYWOMAN WEINBERG: Good morning. Good afternoon now. (laughter)

MS. CRIPPS-BARKER: It flew by. (laughter)

Good afternoon, Chairperson Weinberg, Vice-Chairperson Conaway, and members of the Committee. Thank you for the opportunity to provide testimony to you today regarding health services for women with disabilities. My name is Christine Cripps-Barker, and I am an Information and

Referral Specialist at the New Jersey Division of Disability Services. Our Director, William Ditto, would like to have presented this testimony to you today, but an urgent appointment prevented him from doing so.

The Division of Disability Services serves as a central point of information and referral services for people of all ages with disabilities. We also administer a number of programs and services for people with disabilities. New Jersey was recently awarded a grant by the Federal Centers for Disease Control and Prevention, CDC, which we believe will be of interest to members of this Committee.

The New Jersey Capacity Building for Disability and Health is a three-year, \$420,000 grant which was awarded on April 1, 2002. We are very pleased that New Jersey was successful in obtaining this federal money. With this funding, we will be able to work toward improving the health of individuals with disabilities and preventing the development of secondary conditions.

In this time of limited State resources, we are gratified that we can bring additional federal dollars into New Jersey to accomplish this important work. A particular area of focus for this grant is health issues and concerns of women with disabilities. We already have a strong collaborative relationship with the New Jersey Coalition of Women with Disabilities and the many community-based organizations serving people with disabilities. With these partners and other State and county agencies, we will develop a state plan to address concerns.

Our plans include, among other things, ways to improve access to health-care services for women with disabilities; methods for encouraging and

supporting healthy lifestyles and awareness of risk factors for women with disabilities; strategies to prevent the development of secondary conditions in women with disabilities. We will be developing an inventory of the existing health and wellness programs and identifying gaps and barriers. Based on our findings, we will recommend a series of interventions and activities to improve the health status of women with disabilities.

We are excited to be working proactively to improve health outcomes for women with disabilities. As a woman with disabilities myself, I am acutely aware of the importance of addressing these concerns. I was born with a rare disorder. I originally came from Philadelphia where I had a wonderful orthopedist. When I moved to New Jersey, I asked this orthopedist for a recommendation of who I could see in New Jersey. I was referred to Robert Wood Johnson. There's a new surgery for my disability, which is a ceramic hip, which is very-- It's very new for a woman-- I am 31. This would prevent repetitive surgeries to correct the hip replacement. This doctor at Robert Wood Johnson said, "Oh, you don't need to worry about that. That's his thing." He completely dismissed the possibilities of me having some sort of corrective surgery and be able to function better every day. Again, these are some of the things that I think of.

My mother is hearing impaired. We go to a doctor. The doctor says, "I don't know what to do about an interpreter." So, if there is someone who is hearing impaired, the doctor doesn't feel it's his responsibility to communicate with this person. So this person doesn't always get the care that they need. These are some of the issues that affect me personally and in my role at the Division. It affects me professionally as well.

We appreciate the opportunity to present testimony today so that you can be aware of this statewide effort. We look forward to reporting to you in the future on our progress and achievement.

Thank you, and I will be happy to answer any questions that you have.

ASSEMBLYWOMAN WEINBERG: Thank you. And I would request, on behalf of the Committee, that as plans are more developed for the use of this grant, we would appreciate being informed of the ways in which it's being used and what you're specifically doing.

MS. CRIPPS-BARKER: Very good.

ASSEMBLYWOMAN WEINBERG: Thank you.

Any questions here? (no response)

Thank you very much.

MS. CRIPPS-BARKER: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Marilyn Gelman.

**MARILYN A. GELMAN:** Hello. I'm keeping my hat on, not out of disrespect, but because the glare from the light will make me sound like someone who is inebriated. It affects the injuries that I have. I'm going to eliminate three or four paragraphs of my two-paged, widely spaced comments because you all look so burdened by hearing all this information about disabilities that I feel compelled to give you some good news.

I wrote a letter to the Department of Justice, a simple letter, but the simple letter was based on civil rights training I had gotten from the Brain Injury Association and other training I had gotten from the New Jersey Developmental Disabilities Council's partner and policy-making. This simple

letter described how people with brain injuries, other cognitive impairments had trouble using the ADA information line because the voice menu, when the phone picks up, was so cognitively noisy and so difficult to manage that we were being denied our right to use the service the way other people would. I want you to know, based on that one letter, they changed their system.

So while you're sitting there, and you're hearing from us about the terrific struggles we have, know that we have the energy and good humor to be in a group. I've never met women as I have on the Health Care Steering Committee, and that change does happen.

Because it took me so much time this week to try to make arrangements to go 1.8 miles from my house down the highway for physical therapy, I could not coordinate with the Steering Committee or with the Brain Injury Association to see if I might speak on their behalf. So I'm speaking as a private citizen.

While driving home from work in Hackensack to where I vote in Fairlawn, New Jersey, a BMW crashed into my Chevrolet. I have written to my new people saying you don't know me yet, but there's legislation coming up. (laughter)

ASSEMBLYWOMAN WEINBERG: You've got them.

MS. GELMAN: I was so delighted with meeting them.

My Chevrolet was crashed into by a BMW. My injuries threw me into--

ASSEMBLYWOMAN WEINBERG: At least you picked a high-class car to crash into.

MS. GELMAN: No, he crashed into me.

ASSEMBLYWOMAN WEINBERG: No, I'm saying you picked a high-class car--

MS. GELMAN: To have been crashed into by.

ASSEMBLYWOMAN WEINBERG: --to have been crashed into by.

MS. GELMAN: And in the second crash, when I was a passenger in a car, I happened to be on an intersection where I had told the borough manager, when I saw it being built, I'm going to get killed at this intersection. He said, "Oh, no you won't." Well, I wasn't killed, but my injuries were made worse. Many aspects of this new environment that I have found myself into disables me almost as much as my injuries do. I am dealing with policies and programs in business and government that I have come to call cognitive staircases, when what I really need are cognitive ramps.

Brain injury does not inoculate you from other illnesses. A year after brain injury, I was close to death, and I was hospitalized with cancer. The reason I was close to death is that although I had seen symptoms every -- a lot -- my brain injury did not allow me to connect them to say, hey, danger, danger. I still have trouble if I have fever of 104 on Tuesday and 104 on Wednesday to put them together that this is two days of 104, you had better call the doctor, which won't do any good, because I can't get there anyhow.

When I was in the hospital, I had \$7 in my pocket. I was there for a month. The reason I only had \$7 to my name was that my auto insurer did not send me the benefits for income continuation to which I was entitled. I had no money, so I spent it. I was afraid to even buy a newspaper in the hospital because I thought I wouldn't have cab fare home.

ASSEMBLYWOMAN WEINBERG: Remember -- excuse me -- but we have to move ahead a little bit here, so--

MS. GELMAN: Sure. I also developed diabetes that I'm unable to manage because of the effects of brain injury. What I'd like this Committee to be aware of is places where public policy, applications for government programs places cognitive staircases in our way. I've tried to get a personal assistant. I couldn't do the telephone interview part. I can't answer four-part multiple choice questions over the phone. I forget the question before the answer. When I requested a reasonable accommodation such as please fax the questions to me, I was told they don't want us to do it that way. And by then, I'm sobbing too much. I'm too discombobulated to say it's against the law for you to not try to accommodate me, and I just have to let it go.

There's loads and loads of my testimony in your packet. So I'm not reading this piece, so I hope that you do.

Thank you.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Ms. Gelman, I think-- Assemblyman Edwards, did you want to ask something?

ASSEMBLYMAN EDWARDS: I think I just wanted to reiterate the Committee's commitment to addressing health-care concerns for the residents of the State of New Jersey. In addition to that, I'm the prime sponsor of the brain injury research act bill that recently passed out of committee, and co-sponsor, Assemblyman Matt Ahearn, is working diligently with us to move that piece of legislation forward so that we can look to actually finding some sort of a cure for brain injury research.

MS. GELMAN: And there's also a registry in there, too. I wrote your name down. And since you're working with brain injury stuff, I consider you to be my representative also. (laughter) The brain injury community has our own representatives, and now we've got one another.

Thank you for introducing yourself to me.

ASSEMBLYWOMAN WEINBERG: Thank you.

Heidi Gold.

**HEIDI GOLD:** Hi. Good afternoon. I do have--

ASSEMBLYWOMAN WEINBERG: Kevin, would you take it while we take the testimony, because David is--

MS. GOLD: My name is Heidi Gold, and I want to thank you for holding this hearing this afternoon, now, to address some of the unique health needs of women in New Jersey. My comments are abbreviated from my written testimony, and I will try and abbreviate a little bit more as I continue.

I'm a policy analyst and a social worker with the Poverty Research Institute of Legal Services of New Jersey. LSNJ coordinates the system of free legal representation and other assistance for low-income people with civil legal problems throughout the state.

The Poverty Research Institute was inaugurated in 1996 by LSNJ to focus on developing and updating information on the extent and effects of poverty in the state. Through original research, compilation of data from publicly available sources, and special projects like the Work, Poverty, and Welfare Evaluation Project, our Cost of Living Study, and the Budget Analysis Project, the PRI seeks to generate useful information that we like to share with our legislators.

There are many health issues that affect women in New Jersey, many of which you've heard about today. I would like to bring your attention to some mental health issues among poor women. As part of the Work, Poverty, and Welfare Evaluation Project, we did a study of long-term TANF recipients to look at the barriers that these women faced in leaving welfare. We were struck by the degree to which symptoms of depression were prevalent among women in this study.

As a social worker who did clinical work with homeless women prior to my work at LSNJ, I was continually reminded about the hidden effects of depression among my clients. Many of the women that I worked with have been victims of child abuse and/or domestic violence and were in deep pain that had lasted all of their lives. Many of them self-medicated this pain with drugs, and they had all be separated from their kids.

Major depression is a serious mental illness that affects one's thoughts, feelings, behavior, and physical health. Mental health, like physical health, has a tremendous impact on the lives of women and their families. It is well-documented that there is certain mental health conditions that disproportionately affect women living in poverty and particularly depression.

Here are a couple quick facts. Within a given year, about one-fifth of the U.S. adult population is affected by a diagnosable mental health condition. However, those in the lowest socioeconomic group are about two-and-a-half times more likely than those in the highest economic group to have a mental health disorder. Rates of depression among women are twice as high as they are among men.

In New Jersey, we have additional evidence. The study that LSNJ did of long-term TANF recipients, 98 percent of whom are female, found that 42 percent of respondents likely suffered from major depression in the preceding year. Another study done by Mathematica Policy Research found that among a group of former TANF recipients who were employed or recently employed, 11 percent, more than one in ten, reported that mental health made working difficult.

We know that people fall through the cracks, as many people who suffer with symptoms of depression never seek treatment despite the serious interference of these symptoms with daily life. In our study, only 30 percent of those who met the criteria for major depression had talked to a doctor about their feelings, and only 14 percent had taken prescribed medications.

A national survey released by the Kaiser Family Foundation earlier this week finds that a significant minority of women reported delaying or going without medical care in the past year or not filling a prescription due to costs. Women are more likely than men to face these problems. The Legislature must play a critical role in enhancing the safety net.

1) LSNJ worries from anecdotal experience about the availability of and access to a full range of mental health services particularly for women, many of whom have family and other issues, for low-income people in general, and for people who may have language barriers.

2) New Jersey should develop a system for social service case management that will be available for low-income people. At a minimum, people who leave welfare should have some follow-up to assure that they are progressing toward economic self-sufficiency and/or receiving all services and

benefits for which they are eligible. Such case management services would help assure that a minor crisis or problem gets addressed quickly, so that there is not a major disruption to a person or family's life.

3) To better assure that people do not fall through the cracks, New Jersey should mandate, then enforce coordination among all state agencies that serve family needs.

4) Because we must address welfare policy when talking about people living in poverty, I want to make two points specifically about Work First New Jersey. First, a full and comprehensive assessment, including issues of physical and mental health, should be made prior to sanction or termination from welfare to determine whether a person's physical or mental health was the barrier to participation in the Work First New Jersey Program. Two, welfare grant levels must be raised. New Jersey welfare grants have not increased since 1987. As a result, the value of a welfare grant in New Jersey has declined 68 percent since 1970 and represents the second largest decline in the country in the value of state welfare grants. New Jersey's 1970 public assistance payments of \$340 would have a purchasing power equivalent to over \$1300 in today's market. And yet a welfare grant for a family of three is just \$424 a month.

Finally, I must take this opportunity to address the threats of the family care program that I am sure you are aware of. The family care program has recently been restricted so that it provides health insurance coverage for low-income children, General Assistance, or GA recipients, and single adults or childless couples with incomes below 100 percent of the federal poverty level that enrolled prior to September 1 of last year. The general category for poor,

single adults making less than \$8860 a year and childless couples making less than \$11,940 per year is now closed, unless they receive General Assistance.

LSNJ recognizes that a substantial portion of the family care budget is due to mental health and substance abuse treatment. The preservation of the health-care coverage provided by the New Jersey Family Care Program is of the highest priority to LSNJ and to other organizations that we work with through the New Jersey Anti-Poverty Network. Coverage for all single adults should be returned to its original level. However, at this time of serious budget constraints, at a minimum, we urge to ensure that the current level of services and coverage continues, especially for those persons on General Assistance and single adults and childless couples. These are the people who are often most vulnerable to poor health.

We ask that the Legislature work with the governor and the Department of Human Services to do everything that you can to secure the amount of funds that are necessary to keep family care as the critical life link that it is. LSNJ and the Anti-Poverty Network have been communicating with Commissioner Harris and Governor McGreevey about our concerns of family care funding.

In conclusion, LSNJ recognizes that these are difficult times for New Jersey and that we do face a historic budget deficit. However, we know that New Jersey must enhance the safety net for the most vulnerable among us so that people do not fall through the cracks. We look forward to continuing our work with this Committee and the Legislature in general on all policy issues that affect people living in poverty.

Thank you again for your time this morning and this afternoon.

ASSEMBLYWOMAN WEINBERG: Thank you.

Any questions? Anybody? (no response)

Renee Krul, K-R-U-L? Renee, are you in the room? (no response)

Barbara Metz.

**BARBARA METZ:** Good afternoon, and thank you so very much for having us.

ASSEMBLYWOMAN WEINBERG: Good afternoon, and welcome after your little ride over here.

MS. METZ: We didn't hit anybody, so it wasn't so bad.  
(laughter)

ASSEMBLYWOMAN WEINBERG: You did very well.

ASSEMBLYWOMAN QUIGLEY: I'm only worried that somebody is going to steal your purse. Is that a dangerous place to hang it?

MS. METZ: It's safe in here, okay?

ASSEMBLYWOMAN QUIGLEY: In here, it's all right. Yes.

MS. METZ: I'll get it when I get outside.

I'm here on behalf of the Spina Bifida Association of the Tri-State Region. I'm going to cut this in half because much of it has been said.

Medicare and other insurances do not cover more complicated needs of people with disabilities. We need more extensive therapy, longer hospital stays, etc. Example: those manning phones in Medicare and other insurance offices do not appear to have the information that a fractured hip on an average woman in her 60s takes one segment of hospital time and a fractured hip on me would take something totally different. Page 22 says this condition gets this. There are no exceptions for extenuating circumstances.

Quality medical care saves money. I don't happen to have a lot of it because I have to buy things like this. It keeps people out of nursing homes. Most importantly, we, the disabled, need lower taxes just as do we all in the State of New Jersey, but never at the expense of lack of medical attention. Inadequate medical care does not in the long run save money for our citizens. It wastes money, bringing about further medical expenses.

Wheelchair access we have done. I'd add one other machine to that, and that's MRI and CAT scans -- try and get on one of them.

Team approach is necessary for the chronically disabled. There is no cohesive service for adults in New Jersey. Some are actually disappearing for our children. Adults are seeing pediatric specialists. Many hospitals, possibly all, do not allow pediatrics specialists to admit adults.

Secondary conditions are exacerbated due to lack of knowledge of health-care providers and endless rules that seem to make it impossible to deal with two issues simultaneously.

We need a committee to investigate ways to deal with extenuating circumstances affecting those with chronic disabilities, so Medicare and Medicaid, managed care, and commercial insurance carriers will provide appropriate coverage. Funding is needed for comprehensive, coordinated services for adults and children. Education of those determining what is eligible in governmental coverage -- Medicaid, Medicare and private carriers -- regarding complexities of those with primary and secondary disabilities. ADA must play a most vital role in medical care. Please enforce Medicare. Please enforce ADA in the State of New Jersey for all of us.

Thank you again so much. One out of every thousand live births in the State of New Jersey are affected by spina bifida.

ASSEMBLYWOMAN WEINBERG: Thank you very much, Barbara.

Jay Petillo.

**JOHN J. PETILLO III:** Good afternoon. My name is Jay Petillo. I am the Executive Director of the Chai Project, a comprehensive harm reduction organization in New Brunswick. Thank you, Chairman Weinberg and the Committee, for allowing me to speak. I'll be brief. I want to talk about women and HIV infection.

As written by Dawn Day (phonetic spelling) in *The Trenton Times*, "A rough measure of the effectiveness of HIV prevention among women is the percentage of all AIDS cases that involve women." New Jersey ranks last in the nation with the highest percentage of women among cumulative HIV/AIDS cases.

As of September 30, 1999, 35.5 percent of all New Jersey people living with HIV/AIDS were women. Minority women are disproportionately affected by HIV/AIDS. Black and Hispanic women account for nearly 90 percent of all New Jersey women living with HIV/AIDS. At 40 percent, HIV infection is the leading cause of death for women age 25 to 44 in Newark. Thirty-seven percent of HIV-infected women in New Jersey report injection drug use as the mode of transmission, includes sexual contact with an injection drug user, and half of all AIDS cases in women is attributable to injection drug use.

If New Jersey wants to reduce the spread of HIV, particularly among women, the action is to legalize syringe exchange programs and decriminalize syringe possession. The New Jersey HIV Prevention Community Planning Group ranks injection drug users and women at risk through sexual transmission as the number one and two priority populations to target for HIV prevention. The same group ranks syringe exchange programs and modifications of statutes which prohibit possession of injection equipment as the number one and two needed interventions to reduce the spread of HIV.

Studies using multiple methods to estimate injections per syringe by syringe exchange program participants in San Francisco, Chicago, Baltimore, and New Haven have found that syringe exchange program participants were significantly associated with increases in once-only use of syringes. The findings add to the weight of the evidence which shows that syringe exchange programs reduce the transmission of syringe-born infections such as HIV.

Thank you very much.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

I know that Governor McGreevey, and our new Health Commissioner, Clifton Lacy, have come out in support of a needle exchange program. We are looking at some of the ways on how this could be worked out as a hospital-based program, yet meeting local community needs. So I'm glad that you brought that other aspect or another aspect of women's health care to our attention.

Anybody have any questions? (no response)

Thank you very much, Jay.

Dr. Sandra Pinkerton. Not here any more, I guess. She is -- oh, I'm sorry. You were hidden behind the podium there.

**SANDRA RUTH PINKERTON, Ed.D.:** Hi. Many of you know me since this is my district and happy to have the hearing here. I'm used to traveling down the Turnpike, so it's great to have it in my backyard, from Fort Lee to here. I'm still late, but I make it easily. I wear many different hats, as most of you know. I've been actively involved in the Bergen County Status on Women, in addition to the various groups that are concerned with disability issues.

I was born with spina bifida, a disability that is referred to as womb to tomb, meaning from birth to death. It will not go away. Many years ago, to make this kind of light, the March of Dimes had a poster that used to say that disabilities last for a lifetime. So my parents applied for services, and it was for braces, and they were rejected. The reason they were rejected is they said that I was past 18 years of age and that I no longer qualified because I was past 18, and therefore I was not eligible for services. So my parents said, "But what about this flyer that says, 'It lasts a lifetime.'" They said, "Well, that's only up to 18." (laughter) So there's those kinds of things.

Another thing, and I'm making light of it, but it is a very serious issue, and I don't think too many people know about it is, I receive Medicare services in the morning. I have my doctorate from Teachers College, Columbia University, and am unable to work because of serious health problems. What happens is I get Medicare home health aide services in the morning. I get those services four hours, seven days a week. Those are services I basically cannot live without. The services say that I must be homebound. I must not

leave my house unless it's for medical reasons or for religious reasons in order to qualify for those services.

ASSEMBLYWOMAN QUIGLEY: So you're here illegally.

DR. PINKERTON: Yes. (laughter) I'm not finished yet. Yes, I definitely am here illegally.

ASSEMBLYWOMAN WEINBERG: None of us are going to squeal.

ASSEMBLYWOMAN QUIGLEY: We won't squeal. (laughter)

DR. PINKERTON: In the afternoon, I get services from Bergen County's personal assistance services program, and in order to qualify for that program, I must be a volunteer or work, get paid employment, so in the afternoon--

ASSEMBLYWOMAN WEINBERG: So, if you stay home in morning, you can go out in the afternoon. (laughter)

DR. PINKERTON: --I must leave my apartment. Because if I don't leave my apartment, I don't qualify for my afternoon and evening services, so that I lose that service. On one hand, I have to be very sick and be bedridden, and in the next one, I have to be well and walk out the door. So I just-- As I said, it has-- It's funny. It really is funny. But when you look at it, it's a very serious kind of vision.

ASSEMBLYWOMAN WEINBERG: I'm going to ask one of our staffers to please look into the problems between these two programs where the actual opposite requirements that are necessary in order to qualify for those eight hours of help.

DR. PINKERTON: Well, the Medicare has its ruling, and the Medicare also -- like if you pass 72, you can earn additional money.

ASSEMBLYWOMAN WEINBERG: Well, maybe they can change some of their rules, too.

DR. PINKERTON: I cannot earn additional money, because I'm on Social Security disability. So I'm not allowed. And because I get this home health aide services under Medicare, what happens is my salary, my Social Security disability, I'm right under the ceiling for it. If I make any money, I lose that four hours a day, seven days a week.

ASSEMBLYWOMAN WEINBERG: Which is why you need to be a volunteer in the afternoon, right?

DR. PINKERTON: No. It means that even in the morning, I cannot make any money whatsoever. Society has a person who has the ability to go out and contribute to society and generate money and not be totally on the roll for financially -- and yet because of the rules, I cannot make one penny, otherwise I lose my services totally. I missed the earlier presentations, and I don't know if that issue was raised, but it's been an issue that's been critical in disability.

ASSEMBLYWOMAN HECK: You're looking for commonsense rules and regulations.

DR. PINKERTON: Yes, and they don't exist. And they don't exist for someone who is highly educated and does not-- They're not set up-- I was told this summer, when I was reviewed for my Medicare Social Security disability, that the rules were not set up for someone who is as educated as myself and that if I was not as educated, that that would be better. I was also

told that I would have been better if I never went to college because then I would have been on Social Security, supplemental Social Security, instead of Social Security disability, and my wheelchair would have been paid for and services that I'm having trouble accessing now, I would have received. So 11 to 13 years of employment, full-time employment, people are telling me that that was wasted time. I'd just like to bring that forward to people so that they understand that not every person walking around with a disability doesn't want to work. Many of us do want to work, but there's a lot of hours involved in services that I would lose, and I cannot -- you could not afford to, to get those hours otherwise.

The other thing is just in terms of-- The Medicare is the one issue, and we're really running short, housing is-- I called up on a housing issue for some other reason, and it's unbelievable. As many of you know, the Section 8 housing that the government covers, there's no new Section 8 housing going up at all. I am living in a Section 8 housing complex in Fort Lee presently. There's no new Section 8 housing going up. I need to have like a roll-in shower. I am not in an apartment that has one. There's no new housing going up for me to move into an apartment that would have a roll-in shower. I cannot get that particular need in the housing that I'm living in now because it would create all kinds of problems to get the building owner -- because it's a privately owned Section 8 building that I'm in -- to give me the okay to do the massive changes to the building.

The other thing -- this has also a little lightness to it -- is I've been talking to several of the people who do the senior -- who's a head of the senior centers in Bergen County. I'm saying we're getting up there in age. We're

going to be coming into your yard. We're going to be asking for services and so forth. I think it was Janet that mentioned the graying community and so forth. And they said, "But what are we going to do with you?" I said, well, what do you think we are? They said, "Funding. Who's going to cover you, like how the money -- who's going to cover you for financially?" I said, well, what do we look like? They were like, "I don't know." I said, do you perceive that we're like a different animal or something, because--

ASSEMBLYWOMAN WEINBERG: Is this county people you--

DR. PINKERTON: These are the individual communities that run the senior centers. They're concerned that no money will come. The money will not cover those of us with disabilities. I said, but what do you think we are? We're human beings. We're like everyone else. Some of us may use wheelchairs, some of us may not read print, some of us may have hearing impairments. We'll be covered under existing funding. They claim that any funding they get for the senior programs that those of with disabilities -- we will not be covered. They're afraid that they're going to have to expend a great deal of money for specialized programs. I'm saying that that's not true. They're getting themselves upset about an incoming population that they're afraid they will not be able to service.

ASSEMBLYWOMAN HECK: Madam Chair?

ASSEMBLYWOMAN WEINBERG: Yes.

ASSEMBLYWOMAN HECK: May I add something?

ASSEMBLYWOMAN WEINBERG: Sure.

ASSEMBLYWOMAN HECK: Anne Ciavaglia, who is the head of the Senior Services in the county, is a muscular dystrophy patient since she

was a baby, and I know she would be shocked to hear this. We will bring it to her attention. This is unacceptable behavior, even if it is a local Senior Services chapter.

DR. PINKERTON: Right. The thing that's so critical about this is that we know that isolation leads to illness. Illness can lead to death, and that sounds so very -- it's strong. People say to me, "Don't you think that's exaggerating the situation?" I don't think so. Illness and lack of socialization and getting out with other people is critical.

ASSEMBLYWOMAN WEINBERG: Dr. Pinkerton, I know we've interrupted you several times, but we have just four more speakers and about 20 minutes left.

DR. PINKERTON: Well, that's fine. I'm finished anyhow. The only thing I wanted to say is that we're no longer satisfied with the crumbs thrown our way, and we want the change. We want the change now.

Thank you very much.

ASSEMBLYWOMAN HECK: I just want to add that a lot of services have come through the efforts of Dr. Pinkerton. She's, as you know, Loretta, she's been at our hearings oftentimes and brought very important matters to our attention.

Thank you again.

DR. PINKERTON: Thank you. Okay. Thank you.

ASSEMBLYWOMAN WEINBERG: Any questions? (no response)

Thank you very much, Dr. Pinkerton.

DR. PINKERTON: Thank you.

ASSEMBLYWOMAN WEINBERG: Janice Sangle.

**JANICE L. SANGLE:** Hello. My name is Janice Sangle. I'm from West Milford, New Jersey. I'm here on behalf of the Greater North Jersey Chapter of the National Multiple Sclerosis Society. I'm co-chair to the Government Relations Committee. I'm also their ADA consultant for their PAVE program which is Progress Through Accessibility, Visibility and Education. I serve on the Governor's Task Force concerning the Olmstead decision, and I am a member of the Passaic County Advisory Council on Disability. As a nurse, I am the Medical Representative to the West Milford ADA Compliance Committee. And finally, I am a woman with multiple sclerosis.

I'm going to cut this a little short also. Just a little bit about multiple sclerosis. It's a chronic and often progressive, disabling disease of the central nervous system that as we know affects women usually between the ages of 20 and 50 years of age.

ASSEMBLYWOMAN WEINBERG: Do you know what the percentages, by the way, of women with MS versus the male population?

MS. SANGLE: It's a very high percentage. I think it was -- I don't want to be misquoted--

ASSEMBLYWOMAN WEINBERG: Right.

MS. SANGLE: --until I have the facts. I can get those facts to you though.

ASSEMBLYWOMAN WEINBERG: Because I was told here at the MS Center here at Holy Name, 90 percent of their--

MS. SANGLE: That's my recollection.

ASSEMBLYWOMAN WEINBERG: --clients are women.

MS. SANGLE: I'm also a client. I feel like the advertisement for the hair club. (laughter)

ASSEMBLYWOMAN WEINBERG: Yes, that's the line actually. (laughter)

MS. SANGLE: With MS, the manifestations are highly individual. They can include abnormal fatigue, impaired vision, loss of balance, muscle coordinations, tremors, stiffness, bowel and bladder dysfunction, difficulties with speech, cognition, walking, and partial or complete paralysis. With these factors present, accessing quality health care is crucial for the well-being of women with MS.

It remains difficult for New Jersey women with disabilities to find transportation to medical facilities which are physically accessible, have the specialized medical equipment needed to treat the patient who is disabled, and which are covered as in-network medical providers and by their health-care insurance carriers.

These hardships result in a decreased choice of providers and consequential risks of inadequate care. Furthermore, they cause the patient to seek treatment from an out-of-network provider and increase both the patient's out of pocket medical expenses and time spent filling out complex, fatiguing, and tedious medical forms. As a result, women with disabilities are either less likely to receive all of their essential health care and preventative services or are required to pay an unwarranted premium for securing such treatment.

Frequently, providers of facilities which are accessible are unreachable due to the lack of adequate transportation of paratransit services.

This forces women with disabilities to find specially equipped medical facilities in order to receive care, often from providers which are out-of-network. Few providers or facilities invest in the specialized equipment needed to treat patients with disabilities. Those which do must bear the burden of increased hardware costs. Although having such equipment would allow health-care providers to increase the number of individuals with disabilities they treat, the reimbursement rate from insurance carriers will not be significant to offset the cost of specialized equipment, therefore, resulting in increased expenses on the part of the health-care providers.

As you can see, individuals with disabilities are compelled to seek out such providers even though they are out-of-network, and rather than receive exemptions from the insurance carriers, the patient is forced to pay financial penalties associated with utilization of an out-of-network provider. Insurance carriers treat the episode of care as if the provider had chosen randomly or for convenience, rather than that of medical necessity. Typically, the only time a carrier will grant an exemption and fully cover out-of-network services is when the patient is a victim of a life-threatening medical emergency.

Clearly, there is little point in traveling to a facility and gaining access to a provider if their equipment cannot be utilized to treat the patient with a disability. Examples of the hardware-related frustrations faced by women with disabilities abound. To be brief, I'm only going to touch quickly on these three issues, which have already been touched on. The issues of examination tables, except we haven't touched on dental chairs, which it is difficult to find a dentist--

ASSEMBLYWOMAN QUIGLEY: I wrote that down with a question mark, though, so I was thinking.

ASSEMBLYWOMAN POU: So did I. So we're listening.

MS. SANGLE: --which is difficult to find dentists whose chairs have articulated, removable, or swing-away arm rests. This presents awkward choices to the patients seeking dental care who cannot bring enough strong bodies into the procedure room and assist her in getting into the chair. It's quite a sight when they try to put me in that chair.

Mammograms, which we have already heard testimony on, which is a crucial procedure required by women. And finally, our research suggests that medical equipment manufacturers have no where to turn for guidelines on designing medical apparatus which is ergonomically accessible and usable by individuals with disabilities. While there are national, ANSI, A-N-S-I, and international, ISO, standards bodies, these organizations do not currently provide universal standards specifications for medical equipment.

Recommendations -- we would request that the American National Standards Institute, which is ANSI, the A-N-S-I, initiate a committee including individuals with disabilities as well as manufacturers who build, sell, and maintain medical equipment, to research and write medical equipment standards and provide recommendations for best practice guidelines to the State of New Jersey -- also, to establish a medical waiver requiring New Jersey health-care insurance carriers to recognize valid exemptions for unavoidable out-of-network services. This exemption would only be applicable when the out-of-network services were chosen by the patient with a disability out of necessity, such as transportation, accessibility, or equipment issues. When a

valid exemption occurs, the out-of-network provider's regular and customary fee for services would be covered by the carrier.

ASSEMBLYWOMAN WEINBERG: I just asked out staffer there to draft that piece of legislation, so--

ASSEMBLYWOMAN QUIGLEY: If it looked for a minute like she wasn't paying attention, she was fixing the problem. (laughter)

MS. SANGLE: Thank you.

The patient would be responsible for her own co-payment as it was in-network and provide a means for monitoring the success of these initiatives and ensuring compliance. The individuals with disabilities should be included in developing and monitoring this process.

I thank you for letting me speak here today.

ASSEMBLYWOMAN WEINBERG: Thank you very much. This has been an eye-opener. I know certainly for me, I would assume for you and other members of the Committee.

MS. SANGLE: I just also wanted to add to that. I'm in that same dilemma of having to be homebound and being able to get personal assistance services. I'm unfortunately not able to get my homebound services because of the volunteer work that I do.

ASSEMBLYWOMAN WEINBERG: Assemblyman Ahearn.

ASSEMBLYMAN AHEARN: On the request for the legislation, I would also like to request, with your permission, that we also do a resolution and try to get a joint resolution to the National Standards Boards.

ASSEMBLYWOMAN WEINBERG: That's an excellent idea.

ASSEMBLYMAN AHEARN: We can't tell the National Standards Boards what to do, but we can do a resolution as a Legislature. So we can deal with that, too.

MS. SANGLE: Thank you.

ASSEMBLYWOMAN WEINBERG: Pat Sayers.

**PATRICIA SAYERS:** You mean there's no way we can legislate common sense if we try? (laughter)

ASSEMBLYWOMAN HECK: Well, on the national level, it's a little different. (laughter)

MS. SAYERS: Okay. Well, we'll start here. We'll start here.

ASSEMBLYWOMAN WEINBERG: And if it were a prerequisite for public office. (laughter)

MS. SAYERS: You have to start somewhere. I'm going to be very brief. I'm here representing myself and other people who have brain injuries. I'd say for a few seconds being in the wrong place at the wrong time, you could be standing here, and I could be sitting there. So, for the last six years, my life is now upside down.

While I can deal with the brain injury and the physical ailments that I also have, the most difficult thing I have to deal with are the insurance companies and IMEs. Now, they'll tell you that it's an independent medical exam. For every one doctor that I go to, they're going to send me to an IME. They're not independent medical exams. They are insurance medical exams. I think what's really criminal here is that you have these doctors that make an easy living treating us in abusive ways, and they do.

Now, I've had two decent experiences out of about maybe ten to twelve. And because those doctors were familiar with the doctors that I treat with, because I care about the doctors that I treat with, care about being out of pain, and I care about living some sort of decent life. Okay.

So we go in. We are treated differently. I will tell you. I just want to say this. Not only do they affect whether or not we continue treatment, whether it's physical therapy or getting or seeing other doctors and getting it paid, as well as income continuance. Now, my insurance company-- I'm on Social Security disability, and they're telling me I can work. Okay. So, I'm out six months of income continuance. They just never paid me. All right.

They'll send me to one doctor who will say, "She can work." The following week they'll send me to another doctor, because they have a timeline. All right. And then they start putting the pressure on you. All right. If I saw four doctors, they're now going to be squeezing with their four doctors. Within a two-week period, I saw one doctor who hardly saw anything wrong, and I was able to go back to work, blah, blah, blah. They sent me to another one of their insurance doctors the following week. He said I can't work. Now, who do you think they believed. The first one that was giving them the report that I can work. This way they don't have to pay me money. All right. Then they'll go back to that second doctor and say, "Well, wait a second. Are you sure that she can't work?" He didn't see me again, and said, "Oh, yes, I think she can work by now." This is what you're dealing with.

You're in tremendous pain trying to get your life back on track, and this is what you're dealing with. You know what happens? We give up. We back away from doctors. Before this, I always paid my doctors, and I paid

my bills. I went to a doctor, he gave me service, I paid. Then when my doctors aren't being paid, and they still are kind enough to treat me, I start backing off because I'm embarrassed. All right. These are things that happen. They affect our economic situation. They affect physical therapy. I mean, you can really be doing well, and then they said, "Boom," just like that.

Then you have to have the energy to fight. Well, here you are fighting with the diagnosis of brain injury. No, I can't have a brain injury. You know, give me another six months, I'm going to be okay. I mean, there's real denial there. I can't read like I used to, can't write like I used to. All right. I can't do what I used to do, but I'm going to be okay. I'm going to be okay, as well as the physical injuries, the herniated discs, and what have you. All right. We're being denied this.

There's no oversight for these people. No oversight. Would you go to a compensation doctor if there's another doctor that you feel is better? I wouldn't go to a compensation doctor to treat me. They make easy money, and the only people they're responsible to are the insurance companies who pay them. There's no oversight, but they determine our lives. They make the struggle harder.

I will give you an example.

ASSEMBLYWOMAN WEINBERG: I think we have to sort of -- because I have two more speakers.

MS. SAYERS: Yes, this is it. This is it. I went to an IME. I'm there with my X-rays, and I'm there with my doctors reports, because he knows. He says, "You're not going to remember this, so bring this with you." So here I am. Because I couldn't give her all the information that she wanted

-- exactly everything that happened in the emergency room. I got hit by two cars, and I went into a wall. I got hit by two cars and went into a wall, but I'm supposed to remember everything. And because I couldn't, she said that I was uncooperative, because I couldn't provide her with all the information. She said, "I am the one--" She said this to me, "I am the one that's going to determine whether or not you continue treatment." I didn't realize it at the time, I had a brain injury. Because I had the audacity to say to her, "No, I'm the one that determines my treatment." She said, "No, you're not." I said, "Yes, I am." She leaves the room, comes back, tells me I can go. She called my insurance company.

This is considered a no-show because I was uncooperative, because I had the audacity to say I am the one, along with my doctors, that determine my treatment, and I was in the beginning of my treatment -- phenomenal pain, brain injury, concussion, the whole bit. But she's the one who is going to determine my treatment. I got a chastisement letter from the insurance company, but that's just one instance. And it's one on top of the other on top of the other on top of the other. So who speaks for us?

Two hours I can wait for another doctor, and I finally said, "I have to leave, because I have difficulty sitting and what have you." They call up and say, "She left." I went back to him again. They said, "Reschedule." Two hours again. I said, "I can't stay here." I think if I was a regular paying customer where you were responsible to me instead of this easy buck--

ASSEMBLYWOMAN WEINBERG: Where do you live, Ms. Sayers?

MS. SAYERS: I live in Bergen County.

ASSEMBLYWOMAN WEINBERG: What town?

MS. SAYERS: I live in Saddlebrook. This is what we go through all the time. There's no oversight for these compensation doctors. I'd like to know how many, out of 10 patients, how many of us they turned down? There's a blank form, just change the name, just change the name. No, they're fine. You've affected me. You've affected my life. You make my lawyer fight harder. I refuse to continue treatment. Oh, no. I'm not refusing to continue treatment, I'm embarrassed to continue. Or they'll say, "You know, Pat, they owe us \$5000."

ASSEMBLYWOMAN HECK: I think if she documents this matter, and I will look into it on the State level, because this sounds ludicrous.

MS. SAYERS: It is.

ASSEMBLYWOMAN HECK: You do have recourse. We have at times sent the appeals through the insurance and with a copy to the Attorney General. You do have recourse. Just give us--

MS. SAYERS: Yes, but you see, while we're waiting for that recourse, I'm not doing physical therapy.

ASSEMBLYWOMAN WEINBERG: You haven't had two Assembly people now who've offered to intervene.

MS. SAYERS: Fine. What do I do? What do you want me to do?

ASSEMBLYWOMAN WEINBERG: Put the documentation together.

MS. SAYERS: I know where you are. I know where you are. But anyway, I'm not alone. There's many, many of us facing this situation. They got us screwed.

ASSEMBLYWOMAN WEINBERG: Two more speakers, Laura Schwanger and then Jessica Cohen.

**L A U R A S C H W A N G E R:** Good afternoon. My name is Laura Schwanger, and I am representing the Eastern Paralyzed Veterans Association. EPVA is a veterans service organization dedicated to serving the needs of veterans with spinal cord injury and dysfunction by ensuring quality health care, promoting research, and advocating for civil rights and independence. On behalf of the EPVA, thank you Chairperson Weinberg and members of the Committee for this opportunity.

As you know, managed care has become the primary health-care delivery system in our country. Managed care stresses many positive features, such as preventive treatment, coordination of medical care, and cost containment. However, managed care was developed for healthier people. Women with disabilities may not fit into these plans and may experience problems because of their complex health-care needs, which includes susceptibility to heart disease, osteoporosis, and multiple sclerosis. Managed care aims to control the cost of health services and treatment for individuals with chronic health conditions which may be costly.

Provider choice is greatly limited in managed care, as most plans require a patient to see a provider in their plan network. Most plans also require patients to choose a PCP to coordinate all of their care. This obviously limits a patient's choice of doctors and presents many serious concerns for a woman with spinal cord dysfunction. Will she have a choice of PCPs whose offices are physically accessible, as we've heard here this morning? She may not. Will she have a choice of PCPs with experience in treating spinal cord

dysfunction? Will she have a choice in quality specialists? Will the plan pay for a new wheelchair if she needs one? Does her plan's provider network have a medical facility in her region with an accessible mammogram machine?

Our experience is that some plans are very good and work with patients with disabilities to understand and address their health-care needs. Others are not so good, especially concerning their treatment of women with disabilities. On numerous occasions when I have been sick, my physical symptoms have been ignored, and a doctor has told me that my problems are stress related. This type of treatment of women is common and also serves as an excuse for a plan not to spend the money, the necessary resources to fully examine a patient's physical symptoms.

Long-term care is a growing national crisis for women with disabilities, as well as for all Americans. Long-term care services address the needs of people with disabilities for assistance with basic activities of daily living such as bathing, eating, dressing, toileting, and mobility. When long-term care services are provided in a consumer's home, they promote independence, reduce the reliance on institutional services, and encourage productivity and self-reliance.

We recommend that the Committee initiate and support long-term care initiatives that promote the following principles: consumer choice, control, and independence. Services should be provided in the least restrictive setting, preferably in a community-based environment. Services should be available based on need, without income, disability, or age limitations, with reasonable sliding cost sharing by consumers. Programs should be adequately financed to meet the needs of all potential recipients.

The Personal Assistance Services Program incorporates all of these principles and is a great example of how personal assistance can help a person with a disability lead an independent and productive life. Approximately 500 New Jersey residents with disabilities participate in PASP, which allows them to receive up to 40 hours of service per week to maintain their independence, return to work or school, and to be active in the community. Moreover, participants develop the skills necessary to manage their daily activities and to supervise their assistants. Approximately 150 people remain on the waiting list. With increased funding, the State would integrate people with disabilities into the community and save the State health-care dollars in the long run, once these individuals become employed and begin paying taxes.

We recommend that the Committee advocate for an appropriation in the State budget that will allow PASP to serve all eligible consumers, including all of the individuals currently on the waiting list. In order to take advantage of programs like PASP, people with disabilities need to know about them. Last year, New Jersey established the Division of Disability Services to provide a one-stop service and information network for people with disabilities. While effective, this network could be even stronger if every county in New Jersey had a county office for the disabled. Such a network would enable counties to provide coordinated and comprehensive information and services to residents with disabilities.

In addition, these offices could work with the Division of Disability Services to improve and expand available services for this population. We recommend that the Committee supports Senate Bill No. 610 and Assembly Bill No. 780 legislation that provides statutory authority and

State aid for any county in New Jersey to establish a county office for the disabled.

Last, I want to mention that EPVA is a member of the New Jersey Disability Budget Coalition. Our mission is to give people with disabilities a voice in the budget process and to work together to achieve improvements in service systems that meet the needs of individuals with disabilities and their families.

On behalf of the Coalition and in addition to submitting the EPVA comments, I would like to submit our Coalition's inaugural disability budget agenda for the budget of the State of New Jersey. Over 20 advocates and organizations from across New Jersey are supporting this effort. We encourage you to carefully review the recommendation in EPVA's testimony and in our Coalition's budget agenda when developing policies for this population.

Thank you.

I'd just like to make one more personal comment.

ASSEMBLYWOMAN WEINBERG: Sure.

MS. SCHWANGER: I've sat here, and I've listened to all these women's problems. I really can't believe I'm about to say this, but I'm very happy that I'm a female veteran, and I receive care at the VA Hospital in Philadelphia. There's an accessible mammogram machine. The Women's Health Clinic has accessible lab tables. I haven't undergone these experiences personally, but I can't believe the VA provides this. I'm not saddled with going out into the public and private hospitals and not being served.

ASSEMBLYWOMAN QUIGLEY: Well, every once in a while the feds do something right. (laughter)

ASSEMBLYWOMAN WEINBERG: Thank you for giving us a positive comment about something that's working. Thank you for your patience. Did you come all the way from Philadelphia?

MS. SCHWANGER: Yes.

ASSEMBLYWOMAN WEINBERG: Well, thank you very much.

MS. CRIPPS-BARKER: (speaking from audience) I did, too. I live there, and I drove this morning.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Jessica Cohen.

**JESSICA COHEN:** Good afternoon. My name is Jessica Cohen. I'm here on behalf of The Arc of New Jersey. I am the Director of Governmental Affairs. I'm not going to touch on specific issues, because I don't think I could do it as articulately as anybody that has come before me. I think that everybody covered pretty much the broad range of what is going on with women and disabilities in New Jersey.

What I did want to mention very quickly were two things. One that Assemblywoman Vandervalk had brought up, which was the passage of the physician/dentist fellowship two years ago. To just kind of give you an update, I was lucky enough to catch her before she left. What it wound up happening is that after the legislation was passed, the process of developing the RP kind of got stymied in the Department of Human Services. The RP was just released in January.

ASSEMBLYWOMAN WEINBERG: Explain for the audience what that means -- the request for proposal.

MS. COHEN: The request for proposal, which would mean that the Department of Human Services would then go out and request that there would be proposals for people that wanted to do fellowships, specifically working on doing their residency focusing on people with developmental disabilities. Because the proposal was released in January of 2002, when Governor McGreevey came in, and there was this deficit, and he had to close the gap before the end of the year, this money had been sitting there for two years. And because he saw it as not being expendable by the end of the fiscal year, unfortunately was one of the things that had gotten frozen.

Although when Governor McGreevey did release his projected budget, we had talked with him about it, and he had put in his FY 2003 budget \$500,000 to kind of keep the process and the momentum going. But what I'm a little bit concerned about is just that as things spin out, if the \$500,000 is included in the budget and next year FY 2004 is just as bad fiscally and financially for us, what will happen then? If we get these requests for proposals, and we see that doctors really do want to focus on people with disabilities, and there is no money then to fund the fellowship. So just something to be aware of that will probably be coming down the pipeline.

It's funny because I just got a call from Assemblywoman Cruz-Perez, who, in southern Jersey -- it's not like north Jersey where there are a billion doctors everywhere. Although they might not be accessible in south Jersey, there are a very few physicians and fewer dentists. People from south Jersey, especially in Assemblywoman Cruz-Perez's district and Assemblyman Roberts's district, have to drive to north Jersey to be seen by a doctor, creating a problem with transportation -- all of those issues that you have heard

before. So that's just something for you to be aware of as you're going through the whole budget process now.

The second thing is that the Surgeon General, the former Surgeon General, had just released a report, before he left, talking about and identifying the disparities in health care for people with disabilities. I didn't bring a copy, but I will send you a copy so that you see it. We had talked with Assemblywoman Cruz-Perez again, and she had a bill. It's A-120. It's a medical care commissions act. And what we were going to use that commission to do is basically highlight the report and use that report as a springboard to kind of promote good health care and responsible health care and education for physicians in New Jersey and really focus on the disparities that we see for people with disabilities in New Jersey.

So I just wanted to bring those two things to your attention.

Thank you very much for letting me speak.

ASSEMBLYWOMAN WEINBERG: Thank you very much.

Does anybody on the Committee have any comment that they would like to end with at all?

Assemblyman Ahearn.

ASSEMBLYMAN AHEARN: I just want to say that I appreciated the opportunity to serve on this Committee and hear this testimony today. I learned a great deal. Some of it, in terms of the training in the profession, are issues that I will bring back to the Regulated Professions Committee and speak with the Chairman, Assemblyman Impreveduto, about what we might be able to do in terms of regulation of the medical profession and the training aspects

of it to solve some of these issues that were discussed today. So I appreciate the opportunity to be here today.

ASSEMBLYWOMAN WEINBERG: Assemblywoman Quigley.

ASSEMBLYWOMAN QUIGLEY: I think I will take the information that I've learned today, which was not only eye-opening but extraordinarily well presented. We must thank you for that. But probably my contacts, like Catherine's, are best through the New Jersey Hospital Association. So, in addition to helping the rest of the Committee members pursue legislation, I'll see what we can do about raising the consciousness of your hospital administrators across the state. And perhaps in spots here and there throughout New Jersey, we can get some voluntary compliance with some of your needs. I don't know how we'll get it reimbursed, but somehow we'll work it out, because you have demonstrated the needs more than adequately. Now that we're more sensitized to what you want, we'll do all we can to help you get it. (applause)

ASSEMBLYWOMAN WEINBERG: Assemblywoman Pou.

ASSEMBLYWOMAN POU: Thank you, Madam Chair.

And first, let me say that this indeed has been an extraordinary hearing and meeting, and I'm very happy to be here. The testimonies that were provided and all the eloquent speakers that came before us certainly gave us an opportunity of not only listening to what was really going on, but also getting educated on some very, very important and very serious issue. I have taken a lot of notes, even though I have copies of your testimonies on matters that perhaps every one of you have really touched upon or talked here today.

I'd like to go back and certainly followup on some of the things that was asked and was talked about, some of the legislations that are pending.

I'm especially interested in -- well not especially, but equally interested in some of things that were talked towards the end and on that fellowship grant and what has indeed happened with regards to those dollars that were made available very early on, long before we had knowledge that there was indeed this economic crisis that we are in today. Certainly, actions could have been taken very early on. We would have a different situation and a position where we would have been able to be acting upon not having to catch up on.

So I haven't been a member -- a former member of the Budget Committee and a current member of the Appropriations Committee. This is of interest to me and one that I would like to certainly follow up and look into. But I do appreciate the information and the incredible and intense knowledge that was shared here today.

I thank you all. Thank you.

ASSEMBLYWOMAN HECK: I just very quickly want to thank each and every one of you who have your own disabled community for sharing with us your personal stories, because it brings new life to the subject matter. We've done a lot in the past, the personal assistance, etc., but the incongruities between one group and another makes it so difficult to live a quality of life that all of you wish to live. So I'm sure that our chair will take that into consideration, and we'll all join together in working towards a solution to your problems.

ASSEMBLYWOMAN WEINBERG: I am going to ask the Committee to stay for another five minutes. Because although this is not directly on the subject, Victoria Carson, who is here from the CWA, Communication Workers of America. They want a few minutes to address us. So come forward.

And while you're doing that, I too would like to thank you all of you for the incredibly eye-opening testimony. Every time I think I've lived long enough to know almost everything, another day comes, and I find out that there is a whole lot of things I really didn't know. You have heard, because we have good liaisons here, people in the appropriations field, the folks that are actually in the hospital industry, as well as being legislators. Assemblyman Edwards is involved in the home health-care field and is well aware of many of the problems that you brought forth. And Assemblyman Ahearn who now is on the Regulated Professions Committee, so can talk about, bring to that Committee the issues of training of physicians. I know how much Assemblywoman Heck believes in these issues. As I've said earlier, she and I have been together in this very room--

ASSEMBLYWOMAN HECK: Many times.

ASSEMBLYWOMAN WEINBERG: --where new bills, new laws came that became national news. So maybe this is the beginning of that hopefully. So with that, thank you one and all, but stay for five more minutes.

ASSEMBLYWOMAN QUIGLEY: Thank you for arranging it. We owe you a round of applause, too, for doing it. (applause)

ASSEMBLYWOMAN WEINBERG: And Catherine, too.

(Conclusion of public hearing on women and disability)

I know both Assemblyman Ahearn and I have a 1:30 meeting that we're obviously not going to make by 1:30. (laughter)

So we do have to officially close this meeting so that the recording can go off.

**(HEARING CONCLUDED)**