
Meeting

of

GENERAL ASSEMBLY TASK FORCE ON GRANDPARENTING

“To discuss problems facing grandparents who are raising their grandchildren for economic reasons or due to the absence or inability of the parents to care for their children, and possible solutions to these problems”

LOCATION: Auditorium
Herman Pogachefsky Senior
Services Pavilion
Atlantic City, New Jersey

DATE: September 9, 1999
11:00 a.m.

MEMBERS OF TASK FORCE PRESENT:

Assemblyman Kenneth C. LeFevre, Chair
Assemblyman Samuel D. Thompson, Vice-Chair
Assemblyman Peter J. Barnes Jr.
Assemblyman Alfred E. Steele
Howard Berger
David Dorn
Anne-Michelle Marsden



ALSO PRESENT:

David Price
*Office of Legislative Services
Task Force Aide*

Tasha M. Kersey
*Assembly Majority
Task Force Aide*

Dana Burley
*Assembly Democratic
Task Force Aide*

***Meeting Recorded and Transcribed by
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ASSEMBLYMAN KENNETH C. LeFEVRE (Chair): Good morning and welcome. Hopefully, everyone can hear me clearly. If not, we can make some adjustments and be happy to do that in case someone doesn't hear us in the back of the room.

My name is Ken LeFevre. I'm a State Assemblyman that actually represents this district that we're sitting in here in Atlantic County, and also Chairman of the Task Force on Grandparenting. This Task Force was the result of a resolution that I sponsored in the State Assembly, that was passed by the State Assembly, to call for the creation of a Task Force on Grandparenting that was done earlier in this year. And today represents the third public hearing that we've had by the Task Force. The first that we had was in Paterson, New Jersey. The second was in Old Bridge Township, and the third being here this morning, in Atlantic City.

I'm joined with a very distinguished membership on this Task Force, and I'd really like them to be able to introduce themselves individually. We do have one member who is not here presently. I'm expecting him to be here, Assemblyman Barnes, from Middlesex County. So I'm sure he'll be walking in just after we get started. So if I could, I'll begin at my far right. Our first member, if he can introduce himself?

MR. DORN: My name is David Dorn. I'm from Pennsville, New Jersey, Salem County.

MR. BERGER: I'm Howard Berger, from Atlantic County.

MS. MARSDEN: I'm Anne-Michelle Marsden, from Rutgers Cooperative Extension of Atlantic County, Rutgers University.

ASSEMBLYMAN THOMPSON: Assemblyman Sam Thompson, from the 13th District of Middlesex and Monmouth counties.

ASSEMBLYMAN STEELE: Assemblyman Steele, from the 35th District, Paterson.

ASSEMBLYMAN LeFEVRE: And again, the seventh member is Assemblyman Barnes, from Middlesex County, and he should be joining us shortly. There are seven members.

And again, what we plan to do after today is to then regroup and try to come to some consensus as to what are those issues that we have learned and heard about in our public hearing process that we need to include in a final report to the full General Assembly. And we would hope to do that before the end of the year.

But again, your input today here is very important. We've heard some very interesting stories and advice with the first two hearings, and again, we anticipate that that will be the case today.

Having said that, I'd like to begin. Our first individual to testify today will be Richard Squires, who is the County Executive of Atlantic County. I know -- oh, here he is -- he was here a little while ago and he disappeared, but he's standing behind me.

So, Mr. Squires.

RICHARD E. SQUIRES: Well, thank you very much. First, let me officially welcome you to Atlantic County and thank you for bringing this public hearing actually to Atlantic County, and the audience that's in attendance certainly supplies the necessary ingredients to what will be a very informative, I'm sure, hearing.

As you know, we in Atlantic County did participate, a couple of years ago, with six counties in doing some fact finding, shall we say, on grandparenting, and we did put a report together which was made up of public and private information. And that information has been very helpful, I think, and I know the State of New Jersey has already executed some of the thoughts pertaining to the areas in which it was at that time addressed. We in Atlantic County -- we have 2.4 million families in 1997 in the United States headed by grandparents. And I think, more importantly here in Atlantic County, we have experienced maybe more than what a lot of people think is our share of grandparents raising grandchildren. And it's increasing. The numbers are increasing every day. I think it's great that this Task Force has come together to recognize those needs and to also try and figure out programs that are going to benefit the grandparents.

I'm also pleased that Assemblyman LeFevre's bill, A-2125, for the establishment of Kinship Foster Care Program, is in place. We really feel that this is a step in the right direction, and we in Atlantic County fully support that. And we feel that Atlantic County, through our Division of Intergenerational Services, has been very helpful in fact-finding and will continue to do that. For all those of you who are participating on this panel, you will note that we have an ongoing, I think, fact-finding ability to keep all this information right at our fingertips so that it can be transmitted to both the State and any other government that wishes to hear it. On behalf of Atlantic County Government, I would say that if there was additional information after today's hearing, feel free to call us.

ASSEMBLYMAN LeFEVRE: Thank you, Mr. Squires. We thank you for coming here today. For those who might not know, Mr. Squires is leaving office at the end of this year. We want to commend you for what you've done for Atlantic County over these last 16 years and appreciate you being here today, too.

MR. SQUIRES: Thank you very much.

ASSEMBLYMAN LeFEVRE: Thank you.

Again, the next individual-- And for those who would like to testify this morning, there's just a slight, little process that we have. If you could sign-- On the side table there's a little form that you could sign, give your name and who you're affiliated with and bring it up. We'll make sure that you're called upon, and your testimony is made part of the record.

The next individual that would like to speak is Professor David Burdick. Professor Burdick is the Associate Professor and Coordinator of Gerontology and Psychology at Richard Stockton State College.

DAVID C. BURDICK, Ph.D.: Good morning.

My comments have been distributed to the front table, if you wish to follow along.

Mr. Chairperson and members of the Assembly Task Force on Grandparenting, it is a great pleasure to join you here today to discuss ways and means by which our State can better meet the growing needs of grandparents who are the primary caregivers to their grandchildren. As one of the first presenters in your last hearing today, I would like to welcome you to South Jersey.

As a product of Northwest Bergen County, I used to have the impression that some of the best that South Jersey had to offer were its beaches, but after living here for 15 years, I've come to recognize that South Jersey is home to quite a few gerontologically oriented public servants, advocates, and educators who have exhibited significant leadership at improving the lives of our older citizens. Like the grandparents and grandchildren we discuss today, they have spanned a number of generations.

One of the first that I encountered -- a caring person for older adults -- was the late John Gaffney, who represented Atlantic County in the Assembly. And of course, Mr. LeFevre is one of John's successors in this area, carrying on a fine tradition of supporting older adults and their needs.

In addition, the honorable Senator Bill Gormley, State Senator Bill Gormley, has been supportive of the elderly, and the honorable William Hughes, former Chairperson of U.S. House Select Committee on Aging, was also a very important South Jersey product in meeting the needs of our growing number of older adults, as well as his successor, Frank Lobiondo, who from the opposite side of the aisle in the U.S. Congress has really become a surprising advocate on behalf of older adults at the national level.

The South has also blessed New Jersey with the leadership of two other important members of your Task Force, who I count as colleagues and friends: Mr. Howard Berger, a noted Atlantic City radio and news man -- and you noticed, he was the best with the microphone this morning -- has a new career as an advocate for older adults; and my friend Anne-Michelle Marsden, arguably among the most dynamic and important gerontological educators of any age in the State of New Jersey.

In this context, I humbly present to you my credentials as someone who might have something important to say to you on this topic. I've been at Stockton for 15 years, having studied Gerontological Psychology at the University of Notre Dame, where I earned my doctoral degree. I've done a number of things with and for older adults that I hope make me someone who has something important to say today.

In the area of grandparents raising their grandchildren, I've worked with a number of people to try to assist the Atlantic County Grandparents Raising Grandchildren Coalition and Support Group. We took six students and a number of members of that coalition to Washington, D.C. for a conference. I've assisted one of your committee members, as well as some other local folks, in bringing the first Brookdale Foundation's Relatives as Parents Grant to Atlantic County.

I really would be remiss, as we are speaking of what Atlantic County is trying to do, to not mention both Jerry Del Rosso (phonetic spelling) and Mr. Squires as leaders in the intergenerational movement. Our county has a Division of Intergenerational Services which still is rather unique, and it does offer wonderful opportunities for serving the needs of grandparents and their grandchildren without services being compartmentalized, and makes things less difficult.

So what I'm suggesting to you, and I'm abbreviating what I've written, is that I think I've been a good student in the study of grandparents raising their grandchildren. And as you finish up your work, you remind me of students, because you, after all, have been students over the last several months and you're ready for your final exam.

My students have embarked on a new semester today, and I see a great number of analogies between your task today and the task at hand for my students, who have just embarked on another semester. They're in a quest for knowledge, enlightenment, and the grade. And I'd like to submit to you that your task is a little bit more important than theirs, because what you choose to recommend to the Assembly will have an impact on all the generations today, but also future generations in the state.

I'm wondering if this makes you nervous. You've got more than just a final exam to take. And as a psychologist, I'd like to suggest that it's probably good to be a little bit nervous about what it is you're trying to do, because some discomfort and some nerves are a good thing for students and for the student politician. It can energize us and motivate us. But please take heart, those of you on the Task Force, for it's not your job to completely shoulder the burden of grandparent caregivers. In fact, no amount of government funding nor legions of government workers or servants can possibly replace all of the wonderful care provided by family members for other family members. In fact, you would do great harm if you were to create a system which supplants their efforts. So rather, what you must do is remove some barriers to their effective caregiving for their grandchildren.

So what I really hope you do, as you put together your report and your recommendations to the General Assembly, is for you to have a paradigm shift and focus upon the strengths model. We're not talking about weak, older adults. We're not talking about people with major vulnerabilities worse than others. We're talking about folks with incredible strength. By this, I mean that, while understanding that grandparents and the situations of caring for

grandchildren are quite diverse and difficult, we're basically dealing with strong individuals, willing and able to unexpectedly step in and raise the youngest generation. We're most likely to be of help to them if we capitalize on their strengths and capacities.

Next, I'd like to suggest that you listen and work with both your intellect and your emotions, your mind and your heart. Hearing percentages from demographers, theoretical positions from sociologists, and the many individual predicaments of the caregivers themselves, and then carefully integrating and synthesizing these inputs will allow you to capture the true spirit of this contemporary American phenomena that we refer to as families headed by grandparents.

Next, good students constantly ask themselves, "Where have I been? What have I learned? What have I yet to learn? How can I accomplish this? What are my strengths, and what are my weaknesses?" So in New Jersey, we might ask where do we stand vis-à-vis support for grandparent caregivers? I've heard some say that we're very backwards in New Jersey. The group of students that my grant sent to Washington to NCOA, and the group of grandparents, and the members of the coalition came back and reported their impression. "The conference, informative and timely, also served to impress our attendees with a fact worth noting: New Jersey lags behind most states in addressing the needs and concerns of grandparents raising their grandchildren." That was a quote. I don't necessarily totally agree. I would suggest that we do lag behind, but we lag behind our potential. We don't necessarily lag behind most states, but we certainly lag behind many. We could and certainly should learn from the model programs which were

presented at NCOA, which are presented by the Brookdale Relatives as Parents Program, in which I'm sure you've had a chance to learn about in your quest for the best information on this topic.

But are we really worse off in New Jersey than most other states? Are the needs substantially different from one county to another in New Jersey? The answer, I would suggest, is generally not, probably not. I compared the county reports from three different counties. I reviewed an excellent report prepared in Illinois. I consulted information from several other good sources, the American Association of Retired Persons Grandparents Support Center, Brookdale Center on Aging of Hunter College, Grandparent Caregiver Law Center, several others.

It seems to me in reviewing the literature and listening to some of the folks that you will hear from today that the mechanisms leading to the need for caregiving, for grandparent caregiving, are remarkably similar: parent drug abuse, incarceration, mental health issues, immaturity of the parent, and so on, are rather consistent and, as well, the resultant problems encountered by grandparents and grandchild are rather consistent. They suffer from emotional problems; they suffer financial hardships; difficulty navigating a complicated system of programs and services; and most importantly, the ineligibility for several services which are extended to all children raised by their biological parents, but yet to none of the children being raised by their grandparents.

This last point bears your important attention, because we're not here talking about another special interest group seeking special privilege.

Rather, we seek to extend to them and to the children in their care the rights that have been extended to parents and children in traditional nuclear families.

As I complete my comments to you today, I'd like to make liberal use of the testimony of my friend and colleague, Donna Butts, who is Executive Director of Generations United in Washington, D.C. I believe we ought not to reinvent the wheel, and we ought to seek, as we try to solve problems in New Jersey, some of the best practice which has occurred elsewhere. Generations United is the primary, national organization which attempts to bring the strengths of all generations to bear and raise intergenerational harmony. They have a center on grandparents raising grandchildren, with a policy initiative, with grant funding -- I believe from their Retirement Research Foundation -- where their main mission is to bring information to individuals like yourself. So we ought not to reinvent the wheel.

Here are some of the notable ideas, facts, and concerns presented at the national level by Donna Butts, which, by my reckoning, are of equal importance and accuracy here in New Jersey:

Number one, intergenerational family caregiving of all kinds is on the rise. That includes middle-aged adults caring for elderly parents and children, as well as grandparents and other relatives raising children. Grandparent caregivers provide important care for millions of children whose parents are unwilling or unable to do so.

Number two, grandparent caregivers have great difficulty accessing supportive services. They provide this marvelous and important safety net to America's children by holding families together, yet they encounter-- It seems

every way they turn, they encounter different obstacles. And our job really, again, is not to build lots of new programs for these people, but rather to try to remove as many obstacles as we can.

In New Jersey, there is a crucial need to remove the barriers accessing services. We must ensure that grandparents serving as primary caregivers have every right and every service afforded to the biological parents as they raise their children. Also, grandparents need and deserve additional supportive services that are sensitive to their strengths and to their vulnerabilities.

As you contemplate the needs of grandparent caregivers, I hope you will realize that the grandparents may well be caring for their own frail, elder parent as well. In the 1980s, we in gerontology turned our attention from the frailties of the older generation and the declines of aging to the needs of the sandwich generation, and you're probably familiar with that term.

The sandwich generation refers to that person, usually a daughter, who was and still is often overwhelmed by the responsibilities of caring for minor children and for aging parents and probably holding down a full-time job as well. But it seems to me that the term sandwich generation does need to be altered somewhat, because it's become a club sandwich. There are not just three levels in the family any more. It's kind of like a triple-decker. There are more persons than ever, generally women, who have joined this club, and by all accounts, it is not a country club by any stretch of the imagination.

These are women in their 50s, for example, caring for six grandchildren while their grandchildren's mother is a drug addict, and they're caring for their 75-year-old mother or mother-in-law, who is suffering from

Alzheimer's disease. So there's really no wonder that one of the respondents in a study I conducted on caregiving several years ago referred to her burden as suffocating and lamented, "Will I ever be young again?" So many of these folks caught in the middle have planned carefully, saved frugally, and taken care, only to find themselves thrust into this new world order that seems so unfair and so unreal. They clearly need much help including mental health counseling and support. We're coming around to realize this, I believe.

You know, even Microsoft is coming around -- big Microsoft Corporation. In 1989, when I conducted my study on caregivers, the Microsoft Word dictionary didn't know the word caregiver. It didn't exist. And Microsoft Word tries to help us all with our grammar and our spelling, and it offered me three options of what it thought I was trying to write. The three options were carnivore, caressive, and cease-fire. I'd be willing to wager that many -- and I'm not a gambling person -- but I'd be willing to wager that many grandparents raising their grandchildren can relate to these words. While they're trying to caress and nurture the youngest generation, they often feel as if they are being eaten alive with no assistance. All they need is a cease-fire. All they need is some respite from the duties that they have to take on. All they need is some respect. Don't forget the strengths model that I referred to: carnivore, caressive, cease-fire. They're up to the task if we help them.

The new, improved MS Word 97 includes caregivers, so there's no mysterious creative fodder for an academician like myself. But you know what, as I prepared the talk, the word grandparenting was not in their dictionary either. Grandparent is, of course, but every time I typed in

grandparenting, a red underline appeared. See, this active role of the grandparent is really very new. Grandparents were, you know, rocking chairs, buy them presents, visit them at Christmas time. But we have a new word in our lexicon that isn't in Office 97 yet -- this active, caring, providing person.

So anyway, you know, if you type, yourself, that you can add words to your own dictionary and then you won't get the red underline. But for me it was very important to let that computer keep underlining the word grandparenting on my computer. First thing this morning, as I was brushing up on this whole thing, because it really-- We need to have our attentions focused over and over again on this special new role.

So "Over the river and through the woods to grandmother's house we go," has been replaced with "to grandmother's house we stay." For a growing number of older Americans, for a growing number of young Americans, there are caregivers who are the grandparents. You've seen many of the statistics, so I won't share them all with you here, but the numbers are increasing -- about a 24 percent increase in grandparent-headed households from 1990 through 1997.

Grandparent caregivers, as I've noted before, have often stepped forward to care for children whose own parents are unable or unwilling to do so. Many grandparent caregivers are ineligible for many of the services for which biological parents are entitled. For example, it's often difficult for grandparents to obtain medical care for grandchildren.

I heard a case recently. Start of the school year, time to put the child in school. The child needs health insurance to be allowed into school the

first day. The grandparent's health company doesn't allow the grandparent to put the child on as a dependent, because they're not the biological child. The school says, "Sorry, no health insurance, no enrollment." I'm sure you've heard in your earlier testimonies and you will continue here today to hear similar situations.

So grandparents as caregivers have many strengths and many needs. The areas to be addressed can be broken into the domains of legal assistance, health and mental health assistance, education, and housing. I'm sure that you've encountered specific recommendations in each of these areas.

Noting that I've gone beyond the time that I intended, I won't cite the specifics here, but I am at your service if you need me to provide you with additional information, suggestions in the future.

"There's no one solution or one response that will fix the problems and enable the families to live healthier lives. Therefore, programmers and policy makers must take into consideration the unique needs of these families and approach the families with a continuum of service options." That was a quote from Donna Butts.

As I conclude my remarks, I'd like to again return to the word caregiver and my trusty computer. No red lines in Microsoft Office 97 as I typed the word caregiver at 6:45 a.m. today. It really is a word, and it really can be extended to you and to my students. If we add true, deep caring to our studies, we are most likely to succeed at our endeavor. So I want to thank you as individuals and thank you as a Task Force for your role as caregivers for the grandparents and their grandchildren. I would hope that you don't seek quick solutions. I would hope that you think carefully about what you have heard

and read, and I would hope that you don't rush your report and offer the quick fix to our citizens. I really think you are up to the task of changing our world for the better, because, again, you simply need to help others provide their care to their family members. You need to tear down many barriers and build a few bridges as you support the interdependence of the generations.

Thank you.

ASSEMBLYMAN LeFEVRE: Thank you, Professor Burdick.

Are there any questions of the professor by members of the Task Force?

ASSEMBLYMAN THOMPSON: Dr. Burdick, you suggested that we not reinvent the wheel, that there are many programs out there that are already working in other places -- that we consider adopting these. Are there some that we do not currently have that are working in other states that you would recommend?

DR. BURDICK: Programs in New Jersey that are perhaps slow to develop-- As a psychologist, I believe strongly in providing mental health support services. I've worked and Anne-Michelle Marsden and Howard Berger and Jerry Del Rosso, Dick Squires-- We've worked pretty hard to support existing natural support systems. That is, Atlantic County's Caregiver Support Group, and I think we can go much further in New Jersey to help those grassroot efforts. You've moved that way by the previous bill to this one, doing studies in six counties. There's a lot in place that we can just nurture.

Some of the specifics occur at the national level and with the assistance of states. Specific ones don't come to mind at the moment. There is an initiative of the Older Americans Act, for the first time, to consider the

needs of multiple generations in a family resiliency project. I'd be glad to do some further research and give you a few items of the most appropriate programs. I think Illinois does a wonderful job.

ASSEMBLYMAN THOMPSON: Thank you.

ASSEMBLYMAN LeFEVRE: Thank you, Professor.

We appreciate your very valuable input and welcome the printout that you've given to us and that will be a part of the permanent record.

We must move along. We have an extensive list of speakers, and we also have a deadline. There's a whole group of folks who want to come in here and eat lunch about 1:00. So we don't want to shortchange anybody, but it's important that we don't keep them waiting, too.

We are going to move along and ask Keith Egan to come to the microphone, who is the Executive Director of the South Jersey AIDS Alliance.

Welcome.

KEITH EGAN: Hi.

ASSEMBLYMAN LeFEVRE: We're also going to make a change here. (referring to PA microphone) If you could just bear with us for 30 seconds.

MR. EGAN: I will. I will be happy to do that, believe me.

ASSEMBLYMAN LeFEVRE: The microphones that you see placed in front of you -- there are two sets -- one is for the transcriber, so she can pick up the testimony, as well as the intercom.

Again, welcome.

MR. EGAN: Are we ready now?

ASSEMBLYMAN LeFEVRE: Yes.

MR. EGAN: Okay.

Good morning, ladies -- lady, I should say -- and gentlemen, members of the Assembly. Thank you for giving South Jersey AIDS Alliance the opportunity to speak on this very, very important subject.

When we were first asked to do this, we spent some time putting together a little survey that we gave to our case managers out in the field. We operate in three counties. The instrument addressed the grandparent questions, specifically, and touched on a number--

ASSEMBLYMAN LeFEVRE: If you could just bend that towards you, Keith. It will pick you up if you just get it in your direction. (referring to PA microphone) There you go.

MR. EGAN: How's that? Better?

ASSEMBLYMAN LeFEVRE: That's good.

MR. EGAN: Okay. Do I need to back up, or do we have it so far?

ASSEMBLYMAN LeFEVRE: You're fine.

MR. EGAN: Thank you.

Now I have to find out where I was.

Okay. So we touched on a number of points that we felt were germane to the questions raised by this Task Force. The responses we received were reviewed. We tallied the things up, and we came up with some data that we decided to present in three parts.

First was a simple numerical breakdown describing the types of relationships involving the grandparents that we actually see in the AIDS Alliance; a description of the services that are out there and how they impact on this group and where those services fall short; and then, of course, some

suggestions for ways in which we can better reach this segment of the affected population.

The Alliance currently provides services to people who are infected, actually have the disease; affected in some way, are related to people who have the disease but don't have it themselves; or at risk of being infected with HIV and AIDS in Atlantic, Cape May, and Cumberland counties. Among those people we serve, there are 34 who are grandparents and occupy a significant position in the care of their grandchildren. Among these, we currently number 23 HIV positive clients who are too sick to care for their children, so that the primary care of those children then falls upon the shoulders of grandparents. Thus, the grandparents provide an essential support to the HIV positive parents of their grandchildren. Really, the grandparents in these cases are providing primary care. Another 4 are grandparents raising children who have been orphaned by parents who have died from AIDS. And we also serve 7 grandparents who have full custody of their grandchildren, because the HIV parents have been either removed by the courts or have deserted the children.

The issues surrounding the role of grandparents as caregivers or support persons to grandchildren who are infected, or really more commonly who are affected by HIV-AIDS, are complex and far-reaching. To illustrate just how emotionally charged these situations can be, please note the following descriptions of the kinds of problems and choices that face these grandparents. These were provided by one of our case managers who works in the field, and they work with our clients every day. This lady works in Cape May County, and she does really a tremendous job.

“I currently am giving a lot of emotional support to a grandmother who I met last year when she called me and begged me not to bail her daughter out of jail. She felt this -- jail -- was the safest place for her. Grandma has two of the client’s four children. The other two are in foster care, because Grandma simply cannot afford to keep all four, nor could she keep up with all four -- they are small. The guilt of not being able to take care of all the kids combined with the knowledge that her daughter continues to abuse drugs and prostitute herself makes every day a living hell. She loves her grandchildren and takes great joy in them, but it is difficult. She is one of two grandmothers I work with. Both have called me looking for their daughters and fearing the worst. They ask, ‘Have I seen their daughters?’ They’ve just had a dream or a premonition that something is wrong, that they are in jail or worse. There is also a sense of guilt surrounding their children’s state, addicted and HIV positive. They ask themselves, ‘What did they do to let this happen?’”

The Alliance provides services to grandparents and grandchildren in these groups in varying degrees. For example, we are able to offer food and nutritional support, transportation, case management, support group services, and holiday specific services -- for example, Christmas -- to some but not all of them. The 23 that have parents still living with them who are unable to care for them are eligible for services. The remaining 11 that we talked about, where the children are orphaned or they’ve been deserted, are not.

The problem from which this arises has to do with who is infected with the disease in most cases-- I’m sorry. In most cases, it’s the parents of the children, while the grandparents and grandchildren are HIV negative. Again, they are affected rather than infected.

Most of our services, and for that matter most services in the community, are funded through grants and/or other HIV specific funding sources either in whole or part. These sources issue criteria for and place restrictions on how we may spend the money they give us. In most cases, these preclude services to people who are not infected.

Essentially, those grandparents who are not infected and raising the HIV negative offspring of their infected children do not qualify for most of the HIV targeted assistance available throughout the community. This is especially true if the children are orphaned or abandoned.

Sadder yet is the fact that grandparents often do not qualify for financial assistance for the care of the children. For example, if children go into foster homes, the foster parents are paid a stipend for the care of each child, each month. Grandparents are family. If they take in the children when the parents die or leave, they get nothing. They're expected to care for them.

Grandparents may hesitate to try to get assistance, because they fear the conditions, restrictions, or constraints placed on them by the assisting organizations, for example, DYFS. I'm not trying to pound DYFS here, but it is a good example. They fear that they're going to be so stringent that they will be unable to comply and will lose the children.

I don't have this in my paper, but one specific incident comes to mind. We had a lady who was a grandmother, who was caring for four children in her small apartment -- four grandchildren. She became very ill and had to be hospitalized for 10 days, and her greatest fear was that while she was in the hospital those children were going to be going into the DYFS system and

be taken away from her, because her apartment would be too small or she wouldn't meet the criteria.

And she was terrified by this, because she loved these children and wanted to care for them. She was giving them as much love and attention as she was able to do.

Yet, one of the problems that we have is that once kids get out of these homes and get into a system where they're locked in there, they're looked at just like every other kid in the system, and they're looked at in the same way the kids that are coming from homes where parenting isn't very good or there isn't any love. So there are issues there that need to be dealt with.

Finally, there is an ever-present fear of what happens to the children if the -- well, I just mentioned this, I'm sorry -- grandparent becomes ill. This can have a devastating effect on the family structure, especially if it's long-term illness. There is often simply no one to take over the care of the children if this happens. These children typically become wards of the New Jersey Division of Youth and Family Services, who place them in foster care. This can be problematic as well, since foster care, as well meaning as it may be, can result in splitting up what's left of an already devastated family by placing brothers and sisters among different homes.

The paramount question raised by this situation is, obviously, "What can be done to help?" The answers are relatively simple. There should be funding appropriated expressly for people in this situation. Programs should be developed and target affected family members of HIV positive parents, living and dead. These programs should include all of the services funded for people who are living with AIDS, or HIV, and additional needed

services that were identified in our survey, chiefly, targeted outreach to identify these children and their caregivers, then get them into service.

These are highly needed services. Since these people fall through the funding cracks, there is currently no real effort being made to identify them. Similarly, once identified, there is no mechanism to get them into service. Once in service, highly specific programs such as baby-sitting, respite, clothing assistance, and family counseling may be in order for this population.

Thank you.

ASSEMBLYMAN LeFEVRE: Thank you, Keith.

MR. EGAN: Thank you.

ASSEMBLYMAN LeFEVRE: Before our next speaker, we are going to get this worked out. (referring to PA microphone problems)

Thank you, Keith, for your comments.

MR. EGAN: You're welcome.

ASSEMBLYMAN LeFEVRE: Are there any questions of Mr. Egan?

Yes, sir.

MR. DORN: I know a lady in Atlantic County. She's a grandparent. Like you said, grandparents get nothing, because they're family. What can she do to help herself? She is always financially stressed. Like I said, she doesn't get anything. Is there anything she can do? Anyone she can call or any agencies?

MR. EGAN: Well, this is-- Obviously, this is not specific to what we do, but a good thing to do would be to talk to some of the other social services agencies in the area, get into a case management situation somewhere.

I think that's one of the most important things. Because case managers, even if it's for a service that deals with older people, if it's not specific to grandparenting but specific to some condition she has, because she's poor, because she's in danger of being homeless, maybe simply because she needs charity care -- right? -- if she can get into the system that way and get a case manager, case managers are tuned into the network of services available. They may be able to provide her with some help and guidance.

MR. DORN: Okay. Thank you.

MR. EGAN: You're welcome.

MR. BERGER: Keith, you have indicated that your group is aware of what the problem is. Now, since we're a Task Force dealing with the entire state, are there groups similar to yours around the state that can kick in and help us?

MR. EGAN: Sure. There are agencies throughout the entire state of New Jersey who provide services to people who have HIV and AIDS. New Jersey is one of the major recipients of Federal funding to provide services through the Ryan White Care Act, Titles I and II, in the State of New Jersey. I was the Title I, Care Act Administrator for Cumberland County for some time, and I know that -- simply being in that system, I'm aware of the numbers of people who are in it. I mean, lots of money comes into this state to specifically deal with HIV and AIDS. None of that money, though, goes to this situation.

ASSEMBLYMAN LeFEVRE: Keith, if you take that mike and move that mike over to one side. (referring to PA microphone) That's it. It will work. It will work.

MR. EGAN: This is a test, right? (laughter)

ASSEMBLYMAN THOMPSON: Now you got it.

MR. EGAN: It's not going to work. (referring to PA microphone)

How about if I just talk loud? Would that be better?

ASSEMBLYMAN LeFEVRE: There you go. Yes.

MR. EGAN: Okay. Anything else?

ASSEMBLYMAN LeFEVRE: One other question, by Anne-Michelle.

MS. MARSDEN: I hear that you are prepared, if there was additional funding for your type of agency, to look toward these individuals that-- What was that? PW kind of funding?

MR. EGAN: PLWH -- People living with HIV and AIDS.

MS. MARSDEN: With Aids. And that is State funding?

MR. EGAN: Well, we receive all sorts of funding. We're an agency that specifically provides those services now.

MS. MARSDEN: Correct. Are you actually available to expand your services--

MR. EGAN: Absolutely.

MS. MARSDEN: --to those individuals?

MR. EGAN: Certainly.

MS. MARSDEN: You would be speaking specifically to the grandparents who -- the child is either living or deceased--

MR. EGAN: Right.

MS. MARSDEN: --but separated, but neither of those individuals are--

MR. EGAN: HIV positive.

MS. MARSDEN: --HIV positive?

MR. EGAN: Right.

MS. MARSDEN: But you would still choose to care--

MR. EGAN: We would. Sure.

MS. MARSDEN: --for and about them?

MR. EGAN: Because they are people who have been profoundly affected by this disease. It has touched their lives. It has done terrible things to their family.

MS. MARSDEN: Thank you.

MR. EGAN: You're welcome.

MR. DORN: Mr. Chairman, can I ask him one more question, please?

ASSEMBLYMAN LeFEVRE: Mr. Dorn. Sure.

MR. DORN: Keith, I want to get some phone numbers from you--

MR. EGAN: Sure.

MR. DORN: --or a case manager or an agency that I could give this lady.

MR. EGAN: What I can do is give you the number of my agency.

MR. DORN: Okay. Fine.

MR. EGAN: If you want to call somebody there, I will give you one of my cards, in fact. You call somebody over there, or you give me yours, and we can call you and work up a whole list, fax them over to you, of places people can call.

MR. DORN: Thank you.

MR. EGAN: No problem.

ASSEMBLYMAN LeFEVRE: Thank you very much.

MR. EGAN: You're welcome.

ASSEMBLYMAN LeFEVRE: Your input has been very valuable.

MR. EGAN: Thank you.

ASSEMBLYMAN LeFEVRE: Sorry. I apologize for the little--
(referring to the PA microphone problems)

MR. EGAN: That's all right. It may be better for the next guy,
right?

ASSEMBLYMAN LeFEVRE: We'd like to also now call on
Barbara Norris, who is a grandparent raising grandchildren.

Welcome, Mrs. Norris. If you could sit in that left chair -- right
chair, to you.

B A R B A R A N O R R I S: I'm Barbara Norris, and I'm from
Pleasantville. I belong to the group Grandparents Raising Grandchildren of
Atlantic County, which was started about nine or ten years ago.

I raised my grandchild from 9 years old to 19, which is 10 years,
and they're very difficult years. I am a divorced person, and I raised him by
myself, but I had no funds. For the first three years, I had no idea where to go,
what to do. I did it on my own, on my wages, and it was very difficult. And
a friend told me about the group I belong to, and they told me to go over to
Welfare and apply for welfare for the child.

When you go over there, you have to present every bill, your
wages, everything. I think that's wrong. The first time I went, I got
everything, got \$162 a month. I got the medical card, no food stamps. That

came in regularly. You had to go every six months for reevaluation, and you have the same person for the whole time. I went over to Northfield for this.

My last year that he was in high school, they changed it over to Atlantic City. I went over there. He was in his senior year. He was 18 then. And when I went over, my caseworker hadn't worked there any more. I went in and I waited for about two hours, and they finally got me in, and I got this lady which was very rude. She was gone on her lunch hour. I guess I distorted (*sic*) her lunch or something. I don't know.

But when I went in and she found that he was 18, she says, "Well, you shouldn't be on welfare now." And I said, "Well, excuse me. I didn't know." So she had all these papers written up, and when she heard he was 18, she tore them up and threw them in the basket very rudely, and she says, "You don't get nothing." And I'm looking at her, and I said, "What am I supposed to do?" I said, "He's still in high school." "Well, that don't count." So I said, "What can I do?" Well, she said, "He can get a job and help you out." I said, "Excuse me." You know, I didn't think that was any of her business, personally.

So I left and she said, "Well, apply for food stamps." So I did. I went over and I waited and waited. I went over three times. By the time I got food stamps -- this is August now -- by October I got my food stamps. I got my food voucher in the mail for \$10. Now, I don't know what I was supposed to do with it, so I called the lady up. I thought it was a mistake. I called her up, and I said, "Well, did you make a mistake?" She said, "Oh, no. You make too much money." I'm going, "Really." I said, "What am I supposed to do with \$10?" And she goes, "Well, that's for his food." I said, "Well, would you

like to have him for a month and raise him on \$10? No.” And then she goes, “Well--” That was the end of that.

So I went back six months later. I took all my bills. I made sure I didn't pay any of them. I made sure of that. She said, “Oh, you'll get more.” I said, “I hope I do.” I got \$22 worth of stamps that time. Well, his mother was paying \$20 a month, so I got \$80, and \$10 was \$90 -- almost \$100 a month to raise him on. Well, I was only working, like, 30 hours a week at this time. I had no insurance. I applied three times for his insurance. His insurance never came through which he was supposed to have. Thank God he was healthy. I had no insurance. He worked on weekends and bought his own clothes. He was supposed to have a lot of things, but he just didn't have them, because I couldn't afford them. I got no assistance whatsoever, so he had to go to the dentist. I guess he was in his 14th year. He went to the dentist, and up to 14 years old you can have two dental examinations. When it's 14 and over, you only have one. I think this is a little stupid, because you still get cavities no matter what age you are, 11 or 14 or 15. So I provided the care for him. I went and got the money together, and he went. And thank God for that, he had a cavity. He couldn't go for another six months for a dental examination.

I think this is wrong. They're very crude over there. They don't care. You got to present everything -- your whole life -- to get something for your grandchild. I think this is wrong. I think this should be very cut and clear when you go in. You say you're a grandparent, you go under a program or something. Or the caregiving bills coming up-- The kin giving bill coming up-- There should be something coming up, because it's very expensive to raise

a child, especially a teenager. I want to tell you it wasn't easy. He's 21 years old, and he's okay. He's still living, even with my aggravation and everything. But I mean, it's hard, and nobody wants to go through what I've been through for one child, and I know there's a lot of them have more than one, and I really feel for those people.

Thank you. (applause)

ASSEMBLYMAN LeFEVRE: Thank you very much, Ms. Norris. I know it took a lot on your part to testify, and we appreciate your comments.

Moving along, our next speaker will be John Kozak, who is a representative of the AARP State Legislative Committee.

John Kozak? (no response)

He had signed up to speak previously before today, but I guess did not get here.

Moving along, Shermaine Gunter-Gary, the Director of Human Services for the Department of Human Services of Atlantic City. (no response)

She had signed up previously and, I guess, couldn't stay.

We also have signed up as a speaker Oscar Ernst. Oscar I know is here. He is the District Manager for the Social Security Administration.

Welcome, Oscar. We appreciate you taking time from your busy schedule to be with us and appreciate it very much.

O S C A R P. E R N S T J R.: Thank you, Assemblyman LeFevre and distinguished members of the Task Force, and members of the audience. I hope to bring some information, however limited it is, that may be of some help. I welcome the opportunity to provide information to the New Jersey

Task Force on Grandparenting about Social Security. My presentation is entitled: Grandparents Raising Grandchildren -- What Social Security Benefits May Be Payable.

When a grandparent stands in place of the natural parents, there are limited circumstances under which Social Security benefits may be payable for the grandchildren. Although the grandparent will not qualify for any increased benefit in his or her own right, the children cared for by the grandparent may qualify for monthly benefits if the grandparent is retired at 62 or older, disabled, or deceased, when certain requirements are met. There are very few of these benefits being paid to children, to be direct with you. However, since grandparenting is on the increase, perhaps just knowing that it's a possibility can be of help.

Grandparents and Social Security are synonymous, but most people are not aware of the limited possibility of Social Security benefits being payable to the grandchild based on the work record of the grandparent. A basic concept of Social Security is that it helps partially replace support lost because of retirement, disability, or death of an insured worker. When a grandparent has stepped in place of the child's mother and father, then a limited possibility exists that when a benefit is otherwise payable to the grandparent because of retirement age 62 or later, disability, or to survivors at death, a grandchild might also qualify for a monthly payment. For purposes of benefits payable because of the retirement or disability of the grandparent, the grandchild's natural or adoptive parents must be deceased or disabled, and it has to be at certain times.

For survivor benefits, the same provision applies, with one additional possibility. A dependent grandchild legally adopted by the insured worker's spouse, the surviving grandparent, may qualify if the natural or adoptive parent or stepparent was not living in the same household and making regular contributions to the child's support at the time the insured grandparent died. The dependency of the grandchild must also be established.

When grandparents take over the responsibility of raising grandchildren, the grandchildren may qualify for Social Security benefits under certain limited circumstances. Indeed, they're limited. A dependent grandchild or stepgrandchild of the worker or spouse -- worker or spouse being the grandparents -- may qualify for Social Security payments if the grandchild's natural or adoptive parents are deceased or disabled. When? At the time the worker -- grandparent -- became entitled to retirement or disability insurance benefits or died. In other words, the relationship -- the caregiving, the taking over of responsibility -- has to exist before those events, or at the time of those events, or at the beginning of the worker's period of disability which continued until the worker became entitled to disability or retirement, insurance benefits, or died.

And then the alternative, the additional possible situation, would be the grandchild was legally adopted by the worker's surviving spouse in an adoption decreed by a court or competent jurisdiction within the United States, and the grandchild's natural or adopting parent or stepparent was not living in the same household and making regular contributions to the child's support at the time the insured died. So that's when it's possible that there

might be a payment made to the grandchild, on the insured grandparent's work record, under Social Security.

But the grandchild or stepgrandchild must be dependent upon the worker. To be dependent upon the worker, the child must have begun living with the worker before the age of 18 -- so we see it's limited -- and lived with the worker in the United States and received at least one-half support from the worker for a particular period of time. That is, for the year before the month the worker became entitled to retirement or disability insurance benefits or died, or if the worker had a period of disability that lasted until he or she became entitled to benefits or died for the year immediately before the month in which the period of disability began.

As a generalization, if a grandparent is applying for Social Security benefits, they're asked whether they have any children, and included in that category are dependent grandchildren. So even though listening to what I just said, you have to be a Philadelphia lawyer to follow all the ifs, ands, ors, or buts. The interviewers at Social Security will be glad to take up any questions in that regard at the time a claim is made.

Grandparents can also become representative payees for the children who may qualify for Social Security benefits on the earnings record of their insured parent, who is either retired at 62 or older, or who qualifies for disability benefits, or who is deceased.

One of the previous witnesses indicated that there were children of parents who happen to be disabled with AIDS. That's a possibility that there would be a monthly benefit payable to the disabled worker's account. And if that grandchild of the disabled worker were in the care of the

grandparent, then there might be some money coming into the household in that the grandparent may become the representative payee; that is, act on behalf of the child to receive and use the benefits on behalf of the child.

In a pamphlet that's available on the side table there (indicating table) and attached to my testimony, it lists the categories of children who can qualify for benefits. Briefly, if the child is unmarried and under 18; or under age 19 but in secondary school or lower as a full-time student; or age 18 and older and severely disabled, with the disability beginning before the age of 22, those are all circumstances when a child's benefits might be paid, and they might be paid as a grandchild if the stipulations were met.

Additionally, Supplemental Security Income payments may be possible if the child is in dire straits. That is, is blind or otherwise severely disabled and has limited or no assets and income. There's a flyer, SSI in New Jersey, on the reverse side (indicating pamphlet) that indicates up to \$377.65 may be payable to an individual living in someone's household and receiving support and maintenance; that is, a person who is disabled, in the context of a child. This child would also qualify for Medicaid in that situation. Unfortunately, there's no provision for payment of the benefit, under the SSI Program, to a child who is in good health.

In any case, applications have limited retroactivity. So if a person thinks that they may be payable, they should inquire promptly at their Social Security office. They can call Social Security's toll free number, which is 1-800-772-1213, to arrange for a telephone or in-office interview. That phone number is available from 7:00 in the morning to 7:00 at night. For further information, people may contact their nearest Social Security office. The office

serving the greater Atlantic City area is at the Expressway Corporate Center, 100 Decadon Drive, Suite 111, Egg Harbor Township, New Jersey.

ASSEMBLYMAN LeFEVRE: Thank you, Mr. Ernst. That gives us some hope that there are some opportunities out there that we really weren't aware of prior to today. This is the first time we've heard any input from the Social Security Administration, and we do thank you.

Any questions of any of the members?

Assemblyman.

ASSEMBLYMAN THOMPSON: A child that is HIV infected would be considered to be disabled and qualify for SSI, possibly?

MR. ERNST: Well, a person may have HIV infection, but it would have to be well along so that they would be considered disabled.

ASSEMBLYMAN THOMPSON: I'm referring to the child.

MR. ERNST: Yes.

ASSEMBLYMAN THOMPSON: It would have to be well along in the child for them to--

MR. ERNST: Right. In other words, the child would have to be considered disabled. The person may have the HIV infection, but it may not be showing up in the way of adverse impact on the child at the point in time.

ASSEMBLYMAN THOMPSON: I'm thinking in terms of, for example, some children are born HIV infected.

MR. ERNST: Yes.

ASSEMBLYMAN THOMPSON: It's kind of hard to tell at that stage what the impact on the child is, but still it would be questionable of whether or not they qualify at that point.

MR. ERNST: In the situation where there's a question as to whether or not the child's condition is such that the answer is not known, I would recommend to the responsible person involved to make an application on behalf of that child. If it's denied, then it's denied based on the facts. If the child does meet the rather severe definition of disability that would apply, then, by making an application, there may be something payable and there may be Medicaid to help pay with expenses, related expenses.

ASSEMBLYMAN THOMPSON: It was also said one of the criteria for the child living with a grandparent to qualify for, not SSI, but for some Social Security payment, was that the parent needed to either be deceased or disabled. Is drug addiction considered a disability in that sense, related to a parent?

MR. ERNST: The definition that is used for disability is one that, if the only reason that the person is unable to work is because of addiction, then there would not be a benefit payable to that "insured worker." If the person was addicted and has ravaged their body so, because of that -- so that even if the addictive drug was withdrawn they would not be able to work, then they would receive a benefit, because the body has been damaged so much that they are unable to work.

ASSEMBLYMAN THOMPSON: I raised that specific question because, of course, of the number of the incidences of grandparents raising grandchildren, because the parents of the child are drug addicted.

MR. ERNST: Right.

ASSEMBLYMAN THOMPSON: Thank you.

ASSEMBLYMAN LeFEVRE: Thank you, Mr. Ernst.

Again, if anybody that's here would like to contact the Social Security Office in Egg Harbor Township, Mr. Ernst is still here. Have you left anything behind in the way of information? There's something on the back table that--

MR. ERNST: There's pamphlets on the side table. (indicating side table)

ASSEMBLYMAN LeFEVRE: There's pamphlets on the side table, on the side of the room. (indicating table)

Thank you again, and thank you for your audiovisual help, too. Thank you.

If we could move along, I'd like to invite up Barbara Cook, who is a grandparent raising grandchildren.

Barbara, welcome.

BARBARA COOK: Thank you.

We are here today, because we are grandparents raising grandchildren. None of us asked to do this. The reason we are doing it is, because we are concerned about the abuse and neglect of these innocent victims.

Children should have rights, but at this point in time, all too many rights are given to parents, especially the mothers.

ASSEMBLYMAN LeFEVRE: If you could bring that closer to you. (referring to PA microphone) Thank you.

MS. COOK: No matter what a mother does, most people are afraid to take the children away from their mother because they think it hurts them emotionally. Courts keep giving mothers a second chance, even when

they don't comply with court orders. It hurts the children more being in a scary, neglectful, abusive situation. There are horror stories of what parents do to their own children.

We grandparents have elected to not just sit back. We did something for these children. We fought for their custody. In many cases, it's hard, and it's expensive. The children I know living with grandparents are thriving on the love and care that they are receiving.

Our granddaughter is such a happy, loving child now. She runs, sings, hugs, and plays without fears of anyone taking her away. Her favorite toy is her puppy. She is very secure. She knows where she is sleeping every night. She is not fearful of being left alone in a car. She is fed every day. She has many friends to play with. The future for her may not be as wonderful when she is exposed to more and more supposedly normal families, or when she is older and knows more about her parents and what they did. She might need a psychologist to help her along.

Some grandparents back away because of financial reasons. Our resources are very limited. It is sad for those little ones who have no one fighting for them. They are stuck in bad situations.

I personally don't know of any place to turn to for help or assistance. My neighbor showed me an ad from Boston College, doing a survey on grandparents raising grandchildren, and I responded. Because of that survey, I eventually came in contact with real grandparents, and it was so nice going out with another grandmother and hearing the child call out for Granny instead of Mom all the time. Society frowns on us, but I am proud of how we helped our little one.

The key issues for me are:

One, we need support from our laws and from the courts. Parents have rights which they abuse. We need to help these children until they become responsible adults and can make responsible decisions. We don't want them following their parents' ways.

We need financial help for legal expenses. Mothers get court-appointed lawyers, because they don't work and have no money. We who go and get up for work every day to make ends meet get no help.

These children will need some kind of psychiatric help in the future, if not now -- facing their adolescence scares us. We need an organization to help us deal with this. Medical coverage is a concern. I was able to add my grandchild to my coverage, but other people cannot.

College will be a big issue. We will need a lot of help with this aspect of their lives financially, but realize their country gives interest-free loans to healthy foreigners who come to this country. What will be given for our own citizens in need?

Adoption: I am told the children are safer when you can adopt them, but there are two problems. First of all, the parent has to sign the papers, and most of them don't truly care about their children, but they will never sign the papers and let you have them. And the second one is, some of the benefits that they are currently receiving will be rescinded if you adopt the child.

I don't have solutions to our problems. That is why I am here today asking for help. Thank you. (applause)

ASSEMBLYMAN LeFEVRE: Many of the suggestions that you've made in your comments, we have heard, and particularly the issue dealing with if you have to go into court to seek the custody of your grandchild. Many times your daughter or son are eligible for legal assistance, whereas you pay it out of your pocket.

MS. COOK: Yes.

ASSEMBLYMAN LeFEVRE: And we've heard that, too, before.
Thank you.

Any comments or questions?

ASSEMBLYMAN BARNES: I would like to say I'm very impressed with your presentation. Individuals like you make us feel as though we're doing the right thing by listening to the testimony and then coming back and writing a report that we, hopefully, will incorporate into legislation to help people like you. I take my hat off to you. I think you're a real hero, along with the other grandmother down there. But you're both so young looking. I didn't realize you were grandmothers. (laughter)

ASSEMBLYMAN LeFEVRE: Watch it. (laughter)

Mr. Berger.

MR. BERGER: Barbara, you echo what we've heard in two previous hearings up in Paterson and up in Middlesex County in Old Bridge. Have you approached any of the agencies down here to get some help?

MS. COOK: No. No.

MR. BERGER: Are you familiar with KidCare in New Jersey?

MS. COOK: No.

MR. BERGER: There's an agency that can help you.

MS. COOK: Okay.

MR. BERGER: KidCare. Yes. So if you're going to stay here, approach me afterward, and we'll tell--

MS. COOK: Okay.

MR. BERGER: --you how to get in contact with them.

MS. COOK: Thank you.

ASSEMBLYMAN LeFEVRE: Thank you, Barbara.

Our next speaker is Gwen Anthony. Gwen is Executive Director of AtlantiCare Foundation.

Welcome, Gwen.

G W E N D O L Y N A N T H O N Y: Thank you.

I appreciate the opportunity to speak here today. I don't believe that there's any more powerful testimony than those you've already heard from the grandparents who are raising grandchildren. I happen to be a grandparent myself, with three of them, and it can be very, very difficult.

However, what I'd like to talk about is from a health-care provider's perspective, the fact that for AtlantiCare, one of things that we realize is that caring goes way beyond the walls of our organization, way beyond the hospital. And we recognized our ignorance, if you will, or the fact that to believe that as a health-care system we knew enough about what grandparents, as well as teenagers and all others that we care for -- to think that we knew enough about that and be able to impose solutions was actually an exercise in futility.

So what we did was to begin to get more familiar and more understanding about what individuals living in our communities are facing

today. That, in fact, if we wanted to craft effective strategies, we had to be more of a partner with communities, as opposed to assuming we knew what people needed. We see the end result in our neonatal intensive care units and in our trauma units. We're very effective using our technology and health care and patching people up, so to speak, and sending them back out to the world. But what we didn't know enough about is why, what we were seeing in our emergency rooms.

So as we got more into the community and began to learn -- shut up and listened to what people were saying and what people were living through -- what we found and what emerged to us was that there were a great deal of problems as it relates to our children. We got more involved with parents and school systems, and we talked to a lot of people in the community. And ultimately, we evolved a program that we called Success by Six, which is really the organization of individuals, agencies around the issues impacting child well-being, specifically between the ages of zero and six.

But as we started to probe even further into that, what we found was that there were a lot of grandparents raising grandchildren, and I don't think that I could add more in terms of the barriers that they have already articulated here. So what I can say is that what I believe would be helpful as far as what we would offer here today, is really in the approach at how to find solutions to what people are facing today. And what we realize is that it is not a single dimension. That the problems people face are not single dimensioned, and that, in fact, as a health-care provider, we can't possibly, alone, find solutions to what people need to help them navigate their life.

And so our approach has been to really organize the community itself around these issues based on what they define as health, looking at health much more broadly than just the fact that you don't have a particular disease.

To that end, we would really highly recommend that systems that are complex are really a disincentive. We find that it is very, very difficult to get people to work together, because if you fund single entities to work on a particular issue, that is what people are going to do. There's not a lot of incentive to come together to be more efficient in breaking down some of the barriers between agencies and having us work together in a collaborative model.

And so our approach has been one in which we invite the many diverse sectors of the community to come around the table and bring their strengths of their organization -- be it funding, be it technology, be it manpower, whatever it takes to approach the problems in a very consistent process -- to identify what the priorities are, to organize those priorities in such a way that we can begin to approach them with specific goals, specific objectives to be able to measure what it is that we -- that the output that is produced from our projects, and to really look at what programs and models are effective. We have many programs. We have many models, but are we questioning which are effective, which are producing results, which are the ones that, in fact, are meeting the needs, in this case, of grandparents? How well are the services integrated?

The systems are very difficult to navigate. It's very difficult for me to navigate some of the systems, much less people who don't understand them. They don't understand the language that we speak inside of some of our agencies.

A great example is in our emergency room. Parents and grandparents come through our emergency room, and a physician or a nurse may actually think they're teaching you about how to care for yourself, but people go out and don't know what you said.

We started to work with the community around the issue of black infant mortality. And when we started that, we were talking about SIDS as one of the leading causes. And when we went to groups of seniors, they said, "SIDS? What are you talking about?" And we said, "Well, crib death." And they understood crib death, but not the language necessarily of SIDS. So we have to be careful what it is that we are, in fact, saying, how we're saying it, and whether we're being sensitive to what people can understand, not just from words but in terms of culture diversity. There is a very diverse community, very different ways of how people perceive health and how they access the system, what services they specifically need from one culture to another.

So these are all the things that need to be taken into consideration. But I would like to really close by saying that I strongly, strongly suggest that whatever the model is, that it's one that is collaborative, that is efficient, that can demonstrate results, that does include grandparents as well as social service providers, other organizations that bring to the table ideas that can ultimately be brought together to craft solutions that work toward whatever the issues our grandparents are facing today.

ASSEMBLYMAN LeFEVRE: Thank you, Gwen. I think we all agree with you. Hopefully, as we go about our work, that we come up with something that comes close to what you're suggesting that we need.

Thank you.

MS. ANTHONY: Thank you.

ASSEMBLYMAN LeFEVRE: Any questions?

MR. BERGER: Can I ask one question, Ken?

ASSEMBLYMAN LeFEVRE: Howard.

MR. BERGER: Gwen, AtlantiCare, of course, is the umbrella or the organization for Atlantic City Medical Center. Am I right?

MS. ANTHONY: That's right.

MR. BERGER: That's what you are. You represent Atlantic City Medical Center. When kids come to the emergency room, do you refer them to a pediatrician?

MS. ANTHONY: What we found in our work in the community-- And as a matter of fact, one of the nurses in the emergency room said, "Do you realize that over 50 percent of the kids coming through here are not insured?" They were being, as a matter of fact, referred to charity care. And I said, "Charity care?" Don't you know we have New Jersey KidCare? And we found that there was a huge gap in, I guess, the knowledge of the fact that KidCare, even though there are a lot of posters and newspaper articles, many families don't know that KidCare exists. And more than that, it's a very complex process to fill out the forms.

So what we've done, at Atlantic City Medical Center, is begin to organize a group of people to look at how we can not only help people get, apply for, and receive New Jersey KidCare, but also help them get a medical home, if you will, a primary care provider, some specialty care if required. But the first thing is--

We didn't know ourselves how many people were not accessing New Jersey KidCare. I guess we took it for granted that, because it was there, people were taking advantage of it. So what we do is, as they come into our system now, we are putting in place processes that allow us to work with families to refer them to wherever the most appropriate service is they need. It's not as concise or concrete as it needs to be yet, but it is part of the work that we're doing.

MR. BERGER: Now, you're a part of the New Jersey Hospital Association, which is the umbrella for all hospitals in New Jersey. Are other hospitals doing the same, what you've described here today?

MS. ANTHONY: Well, there's a lot of conversation. I don't know how much of it is real. I know that we all recognize the need to pay a lot of attention to that. In regard to the work that we do, there are other hospitals we work with. We work with Shore Memorial, for instance, right here in our local community. While we might be, in one regard, competitors on some, there are some things that you just don't compete on. And in terms of well-being of children, that's one of the things that we do not compete on. So, whether or not people are giving it as much focus or attention as it needs, I don't really know. But I do know, as Atlantic City Medical Center, we can't afford not to.

MR. BERGER: Thank you.

ASSEMBLYMAN LeFEVRE: Thank you.

Any other questions? (no response)

Again, thank you, Ms. Anthony, and we appreciate your time coming today. We appreciate it.

MS. ANTHONY: Thank you.

ASSEMBLYMAN LeFEVRE: At this point, I'd like to bring up and invite Lynne Evans, a grandparent. She had signed up previously.

LYNNE EVANS: Thank you.

ASSEMBLYMAN LeFEVRE: Welcome.

MS. EVANS: My name is Lynne Evans and I live in Margate. I came to Atlantic City in November of '95, from New York, where my granddaughter, Jordan, was receiving public assistance, and that was \$490 a month. Back in '93, '94, and '95, they had the cards, which Atlantic County has now, and you would take it to the supermarket twice a month. It wasn't 490 in one fell swoop. It was twice a month. And then, when I moved to Atlantic County, I was totally shocked that now she was receiving 162. I know it's New York, and I know how the cost of living is more there, and so on, and so forth, but it was a major shock.

Then Jordan, she was able to get social services and-- However, she wasn't eligible for food stamps, which I really needed for her. So it took me a year to prove that, yes, Jordan should be getting food stamps. Then Jordan received SSI. Because of her birth circumstances, which was addicted at birth, she has many, many issues. She has an IEP, an individualized education plan, through the Margate School system, which I transferred or we had transferred from New York. She had early intervention in New York, where they came to the house initially to work with the children of that particular birth circumstance. And with the early intervention, it was just marvelous from the onset of the intervention. She still is monitored in her IEP, and she receives services, occupational therapy.

She is very impulsive. You just don't know when the impulsivity will start acting out. She's diagnosed ADHD, and she receives counseling and hippotherapy. And the one major problem that I'm facing right now is that her hippotherapy, which is horseback riding, was covered under Medicaid, but now she graduated from hippotherapy after two years, and she's doing therapeutic riding for the handicapped, and that is not covered under Medicaid, because it is not given by an occupational therapist. I just called Medicaid, and that's the real reason that she's not covered any longer.

And she did so well with her hippo that I didn't want to have her lose that therapeutic riding. So that's a real hardship of \$100 a month in addition to her other therapies, which I try to incorporate the music therapy in her IEP. I had two meetings with the child study teams, because I couldn't afford the music therapy.

And the reason that Jordan needs all the therapies is because her psychologist and M.D., through Children's Seashore House in Atlantic City, told me early on, when she was three, that I must keep this child busy, because she's three or four times more likely to become addicted with alcohol, drugs, whatever, than a typical child. So I must keep her busy, and at this point, I'm knocking myself out trying to keep her in therapies, keep her busy so that she will have a focus in her future years and hoping that one of these therapies will really, really click, and she'll be so interested in that, that aside from her schoolwork and her therapy of choice -- but not therapy at that point.

I've had custody of Jordan since she's about 17 months old. She was also approved for DDD. At first, she was turned down, Division of Developmental Disabilities, because they seemed to approve FAS, Fetal

Alcohol Syndrome children, and they didn't have fetal drug effects on the list at DDD. So it got to the point where the, I guess, psychological investigator did come to the house. I have a lot of research information, both medical, psychological. I had gotten a lot of assistance from Children's Seashore House and also from Thomas Jefferson University in Philadelphia. I had to more or less prove to DDD that fetal drug effects mirror FAS so closely that those children were falling through the cracks, because FAS was in place and FAE was not -- or I don't know if it is now.

I did testify at the coalition back in '97, the six-county pilot. I also tried to get into a support system when I first arrived here, because I was -- I guess you could say, rather spoiled from New York, because I was in GRO -- Grandparents Reaching Out, Inc. -- which had been incorporated in '91, and I happen to serve on the board of GRO.

They did legislative work. They were up in Albany by the busload. I mean, they accomplished so much at GRO. We had monthly meetings. I did PR and communications for GRO. We had a national convention in Maryland. And when I moved here, I kind of missed the support -- or I really did, not kind of.

So I went to the coalition and I also tried to have my own meeting at Borders. I just talked to the woman at Borders, and she set it up. There are maybe four people, three or four, but I saw the rest of them, like, lurking on the outskirts. They were listening, but they felt maybe-- Some people do feel that it is a stigma that the reason you're with your grandchild raising them is because you didn't do a proper job with your child. So I could just see, I mean,

they were my age and listening intently, but wouldn't come in. So I guess I could have pursued that.

I know Lois Holloway had a group, but I don't know, I just was so spoiled from GRO that I didn't want the initial beginning of a group. Maybe that would have been support anyway. When I came here, there was really a lack of information when I needed it, because of the bureaucratic delays which were then, and I feel still now, although it has improved.

We are a special population, and we need to be treated as a special population. I'm grateful for the medical, the early intervention. I don't know how Jordan would be now without that, because when she left the hospital, they said, "Oh, she'll be fine," and that was after a month and a half of weaning. Staying at the hospital, they said, "She'd be fine," and I can still hear those words.

The schools, I feel-- I mean, I'm happy that she's in her program. Margate is excellent. The IEP -- I always have to brush up on the latest, because I have to be one step ahead of the child study team, I feel. The schools need more information on the children of the grandparents and how to treat them.

Now, we get "Dear Parents, Dear Guardian, Caregiver," which is very nice, but I know that Jordan, even though she really doesn't talk about it, they never say, "Your mommy, daddy or your granny." I'm granny through and through. I'm sure every day when she hears, "Your mommy and your daddy period," it comes right to her, "And your Granny," in her own head, because that's how she's been raised, and that's what she knows. But I think

just a little more from the schools. The teachers maybe could have a little training, a little extra something, for that reason in particular.

The stress level and the energy level are really big factors in raising grandchildren. Even though she did receive a stipend from DDD, I had to map out what my needs were for that stipend. My needs were a car to get her to her therapies. I was approved for the stipend. I did also mention regular therapeutic riding and the other therapies. They'll be social issues down the line. That's why the schools have to know socially-- Social groups have to know that more and more children who are being raised by grandparents -- and there are more and more.

In Margate, I said to the secretary, "Any more people this year?" She said, "Two." Last year it was three. This year it was two, but you don't know what will happen during the school term. But I see some issues arising as they get into adolescence. Maybe the anger will come out. Maybe they'll feel, "Geez, my granny is really too tired to do this." I mean, to get myself up for a science fair at, like, 7:30 after a day of running, telephone, just everything that is involved with raising a grandchild, it's a tough thing to get up to go to that science fair and act like a young mother, because you don't want the child slighted.

As far as finances, I did contact Mr. Dickerson -- I believe it's Clarence Dickerson -- over a year ago, and he wrote two letters. Jordan's father happens to be living in Zimbabwe, Africa. And he, Mr. Dickerson, was kind enough to try to contact the high court of Zimbabwe, to no avail, because there's no currency exchange rate. Zim dollars have no currency value in the United States, so that was out the window.

Let's see, more of the long-term issues. As I stated, there will be more and more reasons why the schools and other social organizations really have to be on top of these children and to know more about their feelings and their behaviors. They have to understand their behaviors. There may be anger. It may be acting out. They don't really get the attention, I'm sure. Some of the grandparents see the look in the grandchild's eye.

I took Jordan, through the Sunshine Foundation, this summer to the Music Pier. They had a play for children. And sitting behind us was, like, a typical lovely family. Jordan wasn't watching that. She was watching the family the whole time. So it's the insensitivity that really has to be brought to light.

Thank you. (applause)

ASSEMBLYMAN LeFEVRE: Thank you, Mrs. Evans.

We'll continue to move along. Again, this is not always the easiest task to sit and hear stories that we've heard, and it doesn't get any easier. We thank Mrs. Evans for sharing her thoughts.

Susan Jester would like to speak next. Susan is the Senior Community Development Officer with the New Jersey Housing and Mortgage Finance Agency.

Welcome.

S U S A N J E S T E R: Thank you very much. I guess I can talk fast. But I'm from California, so we don't talk fast out there.

Good afternoon or good morning, Mr. Chairman and Task Force members, I'm delighted to be here representing the New Jersey Housing and Mortgage Finance Agency.

And the reason I'm here is to share with you and make you aware of a recently approved program by the Agency that has direct impact on grandparents, kinship caregivers, and preadoptive families. The program, which is a mortgage finance program, is called the Home Ownership for Permanency Program, and it was designed and created for grandparents, kinship caregivers, and folks that are in the process of adopting foster-care kids. It provides a below market rate interest for home ownership. And when I say below, I mean as low as 1 percent for home ownership, for a home improvement, and a refinancing package, in addition to financing for accessibility improvements on a home where there's adoption taking place or grandma's taking kids.

I need to tell you how the program came about, because it directly relates to a couple of the other speakers and the testimony that they've given to you. In 1996, the Agency, which is not a social service agency, as you know -- the HMFA is financed by the sale of mortgage revenue bonds for the purpose of making loans to low- and moderate-income families and first-time home buyers -- took up a sort of social service oriented program called the Scattered Site AIDS Housing Program. It was a public-private partnership between HMFA, the Federal Home Loan Bank, the AFL-CIO Pension Trust, and a couple of other individual agencies in the state, DCA being a primary one, where we went and bought, literally, 64 units of housing around the state in numerous cities, rehabed through construction, rebuilt, and turned them over to four different nonprofit agencies in the state to run and maintain as housing for homeless individuals with HIV and their families.

The first phase of those units is completed, and as a result of the last two years of occupancy of those units, some issues began to arise that brought us to this point today.

Number one, the issue of orphans of AIDS. When I came to the agency a year and a half ago, I came with a background of working for a number of years, since 1983 actually, as an advocate, executive director, fund-raiser in all different kinds of capacities for people with HIV, and various assorted organizations nationally. So I'm very familiar with the issue of HIV. And, as well, I have an HIV positive son. So I'm very familiar with it.

The history of women in AIDS is of primary concern in New Jersey. New Jersey has the highest rate of infected women with HIV in the nation proportionately, and it's growing three times faster than anybody else in the nation. The age group of those women is 18 to 45 years old. So we're talking about the childbearing ages and the highest number of women in the United States with HIV. So what is happening is, over the last 10 years in particular, and more importantly over the last three to five years, an accelerated number of women are dying, because New Jersey also has the highest death rate amongst women with HIV, consequently, leaving multiple numbers of children as orphans in this state. Right now, the estimated number in Essex County alone is 5000 children orphaned from HIV. The predicted numbers by the year 2001 is like 20,000 orphaned children from HIV.

And that brings us to grandma and auntie and uncles and older siblings. We have seen a number of cases in our Scattered Site AIDS Housing, where a mother has died, auntie has died, dad has died, and grandma is taking care of three, four, five siblings. The problem is that grandma is usually living

in a two- or three-room apartment somewhere. She is somebody, most often my age -- which is 55, and in an extremely low income -- low to moderate income bracket.

I have with me the survey of the Grandparents Caregivers for Essex County, and out of the 100 people surveyed, 19 were grandparents of children because the parents were deceased. The other numbers were because of incarceration and substance abuse, all of which lead somewhere down the road usually to HIV infection. The average income was below \$8050 of these grandparents. This is a current statistic. The marital status, 40 of them are widowed. The age group over 49 to 59 -- 57 of them were in that age group.

So as I began to take a look at the Scattered Site AIDS Housing Project and was asked by our Executive Director to come up with a plan for a housing program which could be financed by HMFA -- not a subsidy, but some way to finance or help people finance housing -- I started looking at this group of people, which then lead me to the DYFS and to the foster care numbers in the State of New Jersey and a lot of personal research in interviewing families.

And I found exactly what the statistics show. Grandmothers, mid-50s, low income, would gladly take their grandchildren if they had a larger accommodation housing situation for them. And housing is a major issue. I don't mean subsidized housing. I just mean housing, whether it be adding on or whatever.

So as we began to partner up with, and we did, with DYFS and the Department of Human Services and work together, which is a recommendation I would make that you make a recommendation of -- partnering of state agencies to address these issues. We had a very good partnership, and we've

actually got the program approved and passed by our board of directors. We've made actually eight loans as we're sitting here. We had 70 referrals right off the bat. And of those first 70, I went out and interviewed 10 of the families. I interviewed grandmothers, 56 years old making \$16,000 a year, trying to take care of three and four and five kids. And I also met a lot of people my age that were willing to adopt or were foster care parents, but needed a larger home or needed to add on or do something that would accommodate a larger family.

So that is how that program came to be, and I don't believe there is anything else like it in the United States right now. The object of it was and is to reduce the number of kids in foster care, to keep siblings together, and to provide permanency to orphaned, abandoned, abused, neglected children through the means of giving home ownership opportunities to people who would not normally be able to qualify for a loan. But you can get quite a house at 1 percent.

I wanted to share just a couple of things with you, because I know the Assemblyman from Paterson is here. The Paterson Coalition for Housing is one of our management groups that manages the AIDS housing in Paterson, and I asked them to give me some of their case studies. And I'll just read a couple of them to you.

"Grandmother, age 54, of four children in her custody; children ages 14, 10, 6, and 5 years. M.C.'s daughter is HIV positive, with a history of drug use and prostitution. One child is HIV positive. The children were placed in M.C.'s custody by DYFS. M.C. has a limited income of SSI for herself and for the four children, no other income in the household. M.C. is

the sole caretaker. She needs affordable housing, day-care services, assistance in the home with daily chores.”

Here’s a grandfather, “age 77, of two children in his custody; children ages 15 and 11. The daughter is deceased due to AIDS contracted via sexual contact. His income is SSI for himself and survivor’s benefits for the two granddaughters. He’s the sole caretaker. Neither one of the children is HIV positive.”

So you heard testimony earlier, which is quite true and what I discovered, that the kids who are HIV negative really fall through the cracks. Because the minute mom dies, everything stops. The pattern and the history of DYFS in the past has been if they can find a parent or a blood relative to sort of shift the children over to, then they do that, but that means that a licensed foster caregiver is making about three times as much money taking care of children as the blood relative is. In other words, grandma gets \$165 a month, period, for her grandchild. And the other major tragedy in these situations with HIV death is that most of these kids are in sibling groups, and they get split up. So not only are they dealing with the death of mom and whoever else in the family, but the minute they go into foster care, it’s very difficult to keep siblings together. That was a key component of the program, the permanency program in terms of housing finance, to keep families together.

And I will say this last thing about HIV in New Jersey. It is a family issue. It is most definitely a family values issue. It is impacting many, many, many members of the family. The choices are, I think, as State agencies and governmental entities, you can just sort of cast all these kids out into the

waters and see what kind of individuals they grow up to be, after being shifted around in foster care 42 times in over 19 years, or we can figure out a way to support the family members that are left. And I don't mean necessarily by writing a check, because that's not what we're doing. But there's a lot of ways that you, as legislators, and we, as State employees, can work together to provide the kind of support services and housing opportunities for grandparents and for relative caregivers that we should and could and morally should do, or we're going to suffer the consequences 30 years from now when all those kids have grown up.

ASSEMBLYMAN LeFEVRE: Thank you, Susan. Excellent testimony, and we thank you for that information.

MS. JESTER: Well, I'm happy to answer any question.

ASSEMBLYMAN LeFEVRE: Anyone who has any questions, we're going to have to say, could you ask them after the meeting, because we're working against the clock at the point.

We still have a couple of people. I know this young lady would like to say a few words.

MARTHA CLARK: My name is Martha Clark, and I'm raising my two great-grands, not grands.

ASSEMBLYMAN LeFEVRE: You're raising your two great-grands?

MS. CLARK: Two great-grands. One just turned -- three months tomorrow, and one is four years old. I had her ever since she was two months old. I'm getting assistance for these children. It's not something that I want, but I'm on a fixed income. I worked all my life, and I'm on total disability.

My husband worked for the city of Atlantic City all his life, for 30-some years, so I'm figuring we're getting some back of what we put in. But when you go to the system to try -- I'm not putting anybody down -- to get help, they make you feel like-- They put you down. They make you feel like you're getting something for nothing, and you're just coming to get the money because you can get it.

It's not that way. These children really need help. Their mother is on coke. She is a cocaine addict, and both of these children were born with cocaine in their system. DYFS took both of these children, and I took them from DYFS, because I was raised in the south, and my parents never let one of the family members go out of the family, regardless to how they had to take care of them. We kept them together, and this is my belief, too. And when I go to try to get help, they make me feel like I'm nothing. It makes me feel awful bad.

I'm not putting this caseworker down. This baby is going on three months, will be three months old tomorrow, and I haven't gotten a Medicare card for her yet. And when I called the social worker, she cuts me off real short. I'm not trying to make her lose her job. I just want a Medicare card for this child, because she's having withdraws. I sit up sometime all night. I take her to the medical center down there. Sometimes I'm down there from 11:30 to, like, 4:30, and I'm a cancer survivor. But the Lord healed my body, and I'm able to raise these children.

So I'm not looking for a handout. I'm just looking for some insurance for these children. So if there's anybody here -- I'm a fast talker, too (indicating speed) (laughter) -- if there's anyone here today that can help me

get this Medicare card, because this baby really needs it. Because sometimes it's not what you know, but it's who you know.

ASSEMBLYMAN LeFEVRE: I hope we can be of help to you.

MS. CLARK: I would appreciate it.

ASSEMBLYMAN LeFEVRE: Before you leave, we'll make sure we get your phone number.

MS. CLARK: Thank you for the time. (applause)

ASSEMBLYMAN LeFEVRE: Thank you.

We still have two other individuals who did sign up. I'm not sure if they're still here.

Rosabel Koss, former chair of the New Jersey State Commission on Aging. We apologize for the time factor. If you can share with us your thoughts briefly, we'd appreciate it. Thank you for coming.

R O S A B E L S. K O S S, Ed.D.: I'll try to make this fast.

I'm a Professor Emeritus in Health and Physical Education and former Director of Teacher Education from Ramapo College of New Jersey. Between 1991 and 1997, I was appointed to serve to the New Jersey Commission on Aging. I was Chair of the Commission during my second term. At this time in my retirement, I was also a grandparent helping to raise two grandchildren while their mother went to college.

While serving on the Commission on Aging, a number of hearings were held throughout the state to listen to senior citizens and their concerns. Grandparents raising grandchildren and other kinship cares emerged as an ever growing issue and was studied in depth by the Legislative Committee of the Commission on Aging. The result was Senate Bill No. 494 in 1996, in which

six counties were given grants to do private studies. These counties were Atlantic, Bergen, Essex, Mercer, Middlesex, and Monmouth. Each county was to establish a coalition of 11 members, appointed by the board of freeholders, to identify the needs of grandparents raising their grandchildren; to match areas of need with an awareness of existing resources; to provide a comprehensive resource guide for grandparents based on existing programs and services; and to recommend programs and services where they do not exist.

Coalitions were to do an interim report. I have seen four of the six interim reports. These were given to me by the Assistant Commissioner of Health and Human Services, Ruth Reader. In a cursory review of these reports, I gleaned the following. Overall, New Jersey lags behind other states in addressing the concerns of kinship care. Most of the issues were financial and legal. Each county developed in-depth listings of resources now available within their county. Support groups, where established, are helpful. In one instance, gerontology students at a local college helped with support groups. You heard from Dr. Burdick, and those were his groups. Special needs children are underserved, as you have also heard. Grandchildren living with grandparents were often the result of addiction, neglect, and verbal or physical abuse. Financial help requires more than \$176 a month from Social Security. Grandparents need the same benefits as are paid to foster parents. Legal custody and adoptions are too hard for most grandparents. There is a resistance and often fear on part of grandparents to report addictions and neglect on the part of their own children. They would rather struggle through than risk losing their child to foster parents.

Essex County came through with a resolution that legislation be enacted to provide support for related caregivers comparable to those enjoyed by unrelated foster parents. The Essex County Needs Study ranks health concerns including insurance, financial support, and respite as important, in that order.

Mercer County cited grandparents as being frightened of governmental systems that could be of assistance, and raised the questions of how to care for children with special needs as a result of addictions and neglect. Parents of children were apt to have drug problems, yet received the child support. Numbers of grandparents raising children were found to be on the increase, while grandparents do not understand or wish to be involved with legal custody.

Essex County shared demography on their needs assessment:

- 49 percent of grandparents reported were 60 years or over and 7 percent were over 75.
- 72 percent of the children were 10 to 17 years of age where college was of concern.
- 35 percent of the respondents were widows.
- 84 percent were city dwellers.
- 42 percent have incomes under \$8050.
- 42 percent were on welfare.
- 77 percent rent their homes.

As to cases:

- 48 percent reported substance abuse.
- 17 percent deceased parents.

- 16 percent parents were incarcerated.

Sorely needed is legislation affording grandparents the same legal rights as parents when grandparenting, without having to take legal action.

Cape May County, which is the county where I reside, was not one of the counties awarded a study grant, but our Human Services Department has sponsored, with DYFS and the Rutgers Extension Service, two workshop/seminars for grandparents, which finally evolved into a support group under the direction of the Rutgers Extension Program.

The above information, along with what I have learned from Cape May County grandparents, leads me to believe we need legislation to fulfill the following needs:

- Health insurance for children.
- Special services for special needs children.
- The same financial support for grandparents as is available for foster parents.
- A greater understanding of the reluctance and fear on the part of grandparents to use legal measures for custody and child support. Grandparents do not want to inform or place fault or shame on their own children and should not be required to do so. In fact, we have learned that in some instances parents may remove the child from the home of grandparents if the grandparents resort to legal action.

My bottom-line plea is for legislation which will give grandparents the same rights and support as those accorded to foster parents.

Thank you. (applause)

ASSEMBLYMAN LeFEVRE: Thank you, Dr. Koss.

I'd like to now call upon Lois Holloway, who is in the back. I should mention to you that Lois is a special individual who, sometime in the early 1990s, had the vision to begin a Grandparents Raising Grandchildren group here in Atlantic County. And we welcome you, Mrs. Holloway. Mrs. Holloway is also a grandparent who raised grandchildren.

LOIS M. HOLLOWAY: Thank you.

Well, good morning to everyone. Our Assemblyman has already introduced me, but I also would like to say that I started this group in 1991 for the reason -- because my first grandchild was murdered at 8 years old. He was spending the weekend somewhere with some friends, just for the weekend. I'm sure this was due to drugs. They did a fire bomb in the house where he was, and he burned to death. I really never got over it.

This has been 20-some years ago now, but it inspired me to-- When I saw *60 Minutes* on the TV one day talking about grandparents years ago, it made me want to do something for children and grandparents.

You see, 30 years ago, I started raising my first grandchild, my second grandchild, and I also adopted her as my own. The reason was due to drugs, was due to incarceration, and things like that. But not having any brothers and sisters of my own, this was a great thing for me. It just inspired me to go around and find people that felt like I feel concerning children, because that's my greatest thing in life, believe me. I found out. I went around, and I got everyone that I could to come in and ask for their help, get me information, and everything they could concerning this. Because remember, grandparents have been raising grandchildren long before this has been public, long before this has come out. We have done it.

Now, as I say, because this button is so small (referring to pin on lapel) I can't say Grandparents Raising Grandchildren, as I have, of Atlantic County, but it is Grandparents and Caregivers of Atlantic County, because now they have the kin. I looked up one day -- I have 30 grandchildren -- I was a widow by that time. There was children coming -- one by one of my grandchildren -- coming to stay with me -- nanny. Now it so happens that it ends up being six.

I used to belong to five PTAs, running from one to the other. Because when I adopted my own grandchild 30 years ago, I was 40. So here I am saying, "How can I help these others that need the help?" because they didn't have grandparents groups. So what I did, I talked with them. You would be surprised to know what these grandparents could tell you.

There's a grandparent in my group. The lady just spoke before -- Barbara Norris. Everything you heard her say was true on behalf of herself. We also have a lady in our group, she's raising grandchildren. She raised grandchildren, great-grand -- she raised her own grandchildren. She raised their children. She had cancer. She has a hip operation. She had a heart attack, everything you could think, but that was one lady that was always at our meetings.

It is so many things that grandparents ask for. The most I've heard today, which I know this myself, is housing. They need housing bad, because they are waiting to retire as I was, waiting to travel. A lot of them just want to be at peace. They want to lay back and rest, because they've worked all their life, like I've heard others say today. Okay.

Now they want to go into a senior citizen place, which I have just given up my home to one of my daughters to go into a senior citizen place, and I can't begin to tell you how happy I am about that. Because I'd rather have someone inside the family than outside to take care of me. They say, "We can't find housing." We can't take them in a senior place. And even if we could, there is not enough room. Plus, they let you know on the lease when you come in, you only have a certain amount of time that you can have your children come to visit you, how many days, and everything like that.

One hundred and sixty-two dollars a month to take care of a child that is an infant, that is preschool, that is high school, or whatever, is impossible. The Division of Youth and Family Services-- Believe me, if you are not kin, you can get money. You can get food vouchers. You can get Medicaid, which-- We do get Medicaid plus the 162, but there's so much more. I know people that are taking care of children from the outside. Not all of them are bad. That's why, I guess, grandparents and everything, and caregivers are taking care of these children, because they do not want to place them in a home where they still have to worry about them day in and day out, because you hear so much is happening to them.

So what do they do? They struggle. They struggle. They are sick. This lady I was telling you about, everything. Now she looks up to me one day and she says to me, "Mrs. Holloway, I'm so happy." She says, "I don't have any children anymore. I moved back into an apartment. I don't have to keep a house going. And, at last, after having cancer, after having hip operations, after having a heart attack," she said, "I'm working part time," and she said, "I am so happy." And I'm happy for her.

I do not have to continue with the grandparent group, because out of my 30 grandchildren and the 6 that I raised -- I am not doing it any more -- but the point is I do have shared custody of the 30-year-old child that I adopted 30 years ago. I do have shared custody of that. Why? Not because she had a problem, but because after my husband died, it was a hard thing for her to accept, because she thought that I should do-- My husband being 25 years older than me, you can imagine how old he was when we adopted her. She thought that I should give her what she wanted, where I believe in giving a child what they need. And that is what I was raised to believe.

Now this day in time, children-- Oh, they have so much peer pressure. If they don't wear those shoes that Michael Jordan did, if they don't wear the clothes that Liz has, they don't feel like they can be accepted. But I didn't do that with my children.

But I want you to know this. I have two girls, not including the adopted one, two girls who went to drugs. One is 50 years old, and she is still associated with drugs. I've raised her two children from the time that they were small, but I'm so happy that the girl has gone into the military right after she graduated from Holy Spirit School. The boy has gone on his way, and he has his family, but it wasn't easy. I collected money, Social Security. I collected Social Security from her father's death. I had to get the boy and had to ask for help, which was that \$162, which no one can do anything with \$162, but I made it.

But to sit back as a parent, a grandparent, and know that you're going to raise these children and you look up and all your life savings that you have sacrificed, the pain and suffering that you have -- remember, I'm a widow

now, I was -- and here I am dribbling my money, just dribbling. Because if you keep going to the bank, honey, and taking out and don't put anything back, you won't have nothing too long. So what I did was I wanted these children in my home. I had been interviewed many a time. They said, "Why do you continue to work with this grandparent?"

We even had an office. We sacrificed, my vice president and I, Alice Lancaster. We sacrificed. We went and found an office, a beautiful office. The Realtor was such a nice, wonderful guy. He did not charge us what he should. Okay. We had the office. We kept it a year. We couldn't afford to pay any more. I paid every month for this office myself, because it was something I believed in. It was something that I wanted to do and something I want to continue.

These grandparents need all the help they can find. I have heard them -- called me night and day, which I wish that I could get a hot line. I wish once again I could get an office. We hoped that one day that we would be Grandparents Raising Grandchildren of Atlantic County. We hoped that one day that we would be able to have a day care somewhere where they can -- those grandparents were so frustrated -- drop the children off for maybe a couple of hours. If they wanted to go shopping, wanted to go to the doctors, they could drop them off. They needed it. They cannot take it.

I know what HIV is, too. I have been associated with that, not personally, but I know about HIV. I know how hard it is. I am just so fortunate to know that I have this 50-year-old woman, and she has shot drugs since she was 19 years old, and she's still clean as far as HIV. Okay. But there are others not as fortunate as me, because I've seen the babies. I go to all kinds

of meetings. I go to Washington to the conference and things. I can't get enough in here. I want to know everything there is to know about what I can do to help grandparents raising grandchildren.

So this is why-- I know, Ken, you know I was so thrilled when you called us and asked us to do the tape on TV for you. And I told you, I said, don't ever get me talking about grandparents, I said, because I can't simmer down.

ASSEMBLYMAN LeFEVRE: That's okay.

MS. HOLLOWAY: My worker, my other one, was a consolation to us. He spoke earlier, that was Dave Burdick. And the first one is John McGlermit (phonetic spelling). We have known each other for years, but he has been so helpful.

But what I ask, is there anything, money wise, for grandparents? Is there anything that you can continue to do for us in order that we can go on? Because I have a hard worker, a vice president just like me, and we will go to the limit. We pick them up. We take our car and pick them up. I go on speaking engagements, and I want you to know, what do I get for the speaking engagement -- a box lunch. I don't need a box lunch. I need gas for the car so I can get to you. So I can hear all these things.

Now, Michelle is helping us, and I think-- Was her name Halfpenny?

MS. MARSDEN: Gretchen.

MS. HOLLOWAY: Gretchen Halfpenny (phonetic spelling), and they are both also trying to help us.

I just want to ask you, please don't stop.

ASSEMBLYMAN LeFEVRE: Well, we won't. I think your point about the financing end of this is very important.

MS. HOLLOWAY: Yes.

ASSEMBLYMAN LeFEVRE: That's the message that we've gotten throughout.

MS. HOLLOWAY: All right.

ASSEMBLYMAN LeFEVRE: We are now out of time.

MS. HOLLOWAY: All right. Good. Okay.

ASSEMBLYMAN LeFEVRE: Thank you, Lois, very much.

MS. HOLLOWAY: That cuts me off. Okay.

ASSEMBLYMAN LeFEVRE: Thank you.

MS. HOLLOWAY: Thanks a lot.

Can I just one minute -- just read this before we close? I want you gentlemen to hear, just a second. It's called the *Golden Years*. This is what I wrote for the book. "We think of freedom, travel, and grandchildren who visit, and then go home. Real life has shown me that this is not always the case. No one told me that spouses can die young. We may bury a grandchild, and that dreams can shatter. Raising grandchildren by myself has been a challenge. I know from personal experience how much joy they can bring to your life. Sharing my experiences with others will hopefully make someone else's path a little easier."

Thank you. (applause)

ASSEMBLYMAN LeFEVRE: Thank you, Lois.

We do have one last-- Frankly, we've run out of time, but Judy Hawkinson is from the Workforce Readiness Center at Salem County

Community College. I know she is here. She has also submitted-- (affirmative response from audience) We have your hard copy of your testimony, and I know you brought along Barbara Smith, also. We thank you for coming, but your comments will be part of the final record. We do appreciate your coming, but we have run out of time.

Thank you all for attending. Thank you, all the Task Force members. We still have much more ahead of us, and we'll let them take over their building.

Thank you, Adrienne Epstein, for allowing us the hospitality, and we do appreciate it very much.

Thank you.

(MEETING CONCLUDED)