

**Informational Hearing  
of the**

**Senate Health Subcommittee on Aging and Long-Term Care**

**Senator Elaine Alquist, Chair**

*“Comprehensive Strategy to Support Family Caregivers”*

**November 15, 2005  
State Capitol  
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**SENATOR ELAINE ALQUIST:** I am Senator Elaine Alquist and I wanted to welcome all of you. And along with Senator Cox, we are here today, the Subcommittee on Aging and Long-Term Care, to look at California’s comprehensive strategy to support family caregivers.

Where is the? Right, right, right. I’d like to start off by saying “thank you” to the Family Caregiver Alliance, Burns Vick, health policy consultant, those who came up to participate in our hearing today, some of you for the first time—and it’ll be an easy experience for you, I’m sure. We will help to make it that way—and those of you who are attending, as well as my staff and, of course, Senator Cox. Senator Cox, would you like to make some opening comments?

**SENATOR DAVE COX:** Senator, thank you very much and thank you for holding this committee \_\_\_\_\_ today and this is a very important subject and I’m looking forward to the testimony. I do want to advise you, Madam Chair, I do have a conference call to take at 10 o’clock, so I’m going to have to excuse myself at about five minutes to 10 o’clock so I can participate in that call, then I’ll be back.

**SENATOR ALQUIST:** Okay.

**SENATOR COX:** But, thank you very much for holding this hearing.

**SENATOR ALQUIST:** Thank you. A few opening comments I’d like to make.

**SENATOR COX:** Madam Chair, I associate myself with those remarks I just made. Thank you very much.

**SENATOR ALQUIST:** Okay, yes. Those were Senator Dave Cox’s comments. Okay. Some opening comments—as some of you may know, my husband is 97 years old,

so I certainly, between that and chair of the Subcommittee on Aging and Long Term Care, I certainly identify and appreciate the services that you provide.

I'd like to share just a few, maybe more than a few statistics with you. And you all know these statistics, but there are going to be people who will be watching this who don't and it's really for them. More than 50 million Americans provide care for the chronically ill, disabled, or aged family members or friends during any given year. Given that about 12 percent of the population has a disability, and that's the general population, the role of a caregiver needs to be discussed and understood by policy makers. If you take the population is for the whole population is 12 percent. But if you take it for people ages 45-64, the number of those with disabilities increases to 16 percent. And if you take that population age 65 and older, 44 percent of the population—44 percent of us age 65 and older—have a disability. And I think that's something we really need to keep in mind.

And coupled with that large percentage of people, particularly 65 and older that have the 44 percent, I'd like to do the comparison with the baby boomers. There are 77 million baby boomers in the U.S. and as I've mentioned before, I'm 61 and that makes me a year older than the oldest baby boomer. In 15 years as many as 20 million of the baby boomers will be over the age of 65. In 25 years as many as 80 million people may be over the age of 65. So if 44 percent have a disability and require care, one can see the troubling consequence with these unprecedented demographics that we will have. And that will affect us both at the state—well, local, state, and national levels.

So in California there are 3.2 million caregivers providing 3.4 billion hours of informal care. I see a lot of people shaking their heads yes, because a lot of us are doing that, aren't we? Based on aging demographics and the statistics alone, those numbers may increase as much as tenfold over the next 25 years to respond to the aging baby boomers. And that does not include the people under the age of 65 who have disabilities, and there are quite a few.

Caregiving is no longer predominantly a woman's issue; men now make up 44 percent of a caregiving population. So, good for you guys. We're seeing you pitch in there to help, too. Most caregivers will spend 17 years caring for children and 18 years helping an elderly parent. Caregiving families tend to have lower incomes than non-caregiving families. Thirty-five percent of average American households have incomes under \$30,000. Among caregiving families that percentage is 43 percent. So if you are part of a caregiving

family, the percentage is going to be 43 percent who have incomes under \$30,000 dollars. So how do people do this? You know, how do we take care of everyone?

Family caregivers who provide 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses, the rate is six times higher. For those caring for a parent, the rate is twice as high. So I just wanted to throw out some of those numbers and statistics and sort of keep that in mind as we proceed with the hearing today.

So we're going to start with Panel 1. Panel 1, which is "Baby Boomers and Beyond: Who Will Care?" We start with Kathleen Kelly who I understand will then turn it over to Vicky Farrell for the 10 minutes that you have. So, you're giving part of your 10 minutes to her.

**MS. KATHLEEN KELLY:** Yes.

**SENATOR ALQUIST:** Welcome.

**MS. KELLY:** Thank you, Senator. I just wanted to express my appreciation for holding these hearings. I think caregivers in California are the unsung heroes of the long-term care system, and I will be speaking later and I'm going to turn the microphone over to Vicky Farrell, the president of the Association of California Caregivers to resource centers to talk about what we've learned in the past 20 years of administering the Caregiver Resource Center system in the State of California. Thank you.

**SENATOR ALQUIST:** Thank you. Welcome.

**MS. FARRELL:** Thank you. And thank you for the opportunity to come today and speak with you. And your statistics are right on, and I'll probably be readdressing some of those issues that you...

**SENATOR ALQUIST:** We thank Mr. MacLaughlin for those statistics.

**MR. ROBERT MacLAUGHLIN:** I thank them for it.

**SENATOR ALQUIST:** Oh, you got it from them? **(LAUGHTER)** Well, we thank you.

**MS. FARRELL:** And we hope that you have a copy of this report on our 20 years that we are celebrating today, and we really appreciate the opportunity—

**SENATOR ALQUIST:** And you may give us some extra copies to be sure we can distribute them to all of our committee members.

**MS. FARRELL:** Sure. We'd be happy to do that. We'll get them for you.

Two decades ago landmark legislation established the California Caregiver Resource Centers, known as the "CRCs", as we call them. Under the direction of the

Department of Mental Health, 11 Caregiver Resource Centers now offer services in every region of our state from Yreka to San Ysidro and have supplied information and education and respite and emotional support to more than a quarter million California families and friends who provide long-term care at home and offer support for their loved one who's suffering from a chronic, debilitating health condition.

These centers offer support groups of which there is one located here in the State Capitol that meets monthly here in the State Capitol for staff and Assembly members and Senate members. They also offer workshops, legal advice, and most importantly a shoulder to lean on when things get tough. It is these dedicated families, not institutions, who provide the long-term care in the United States, often at great physical and emotional and financial sacrifice. Caregiving is the backbone of the American long-term care system. The value of these services provided by informal caregivers is estimated at 257 billion annually. Here's a caregiver who states—it's Walt caring for his dad, Fred. "When I tell people that my dad is staying with me and that he's got Alzheimer's, they say, 'Oh, that must be so hard.' Sometimes it is hard, and it's no picnic for my dad, either. But, I'd much rather have him here than think about him being in a home somewhere."

Caregiving is rewarding, but also stressful and demanding. Caregivers are faced with their loved one's memory loss, behavioral and personality changes, round-the-clock care needs, and high care cost. Caregiving impacts both the physical and mental health of the caregiver, and can result in emotional distress and economic hardship for families. More than 50 percent of family caregivers who have been assessed at one of the CRCs report symptoms of clinical depression. Forty percent say that daily caregiving activities negatively impact their own physical health, as well.

To assist support caregivers, the CRCs offer a comprehensive range of services that are responsive to the needs of the families including counseling and our new psycho-educational groups. CRCs are the major providers for psycho-educational groups and skill building intervention for caregivers. These classes provide caregivers with short-term practical intervention—

**SENATOR ALQUIST:** It would be good not to just read the—because we have a time frame. And your written material will go into our final record, but just to hit the highlights would great, because we can read this also.

**MS. FARRELL:** Okay, great. Well, over the past 20 years that we have found that the majority of our caregivers have been women who are caring for a spouse and they're

age 61 and over. That was the, and before they actually contacted the CRC, they actually were, it was three to four years before while they were caregiving and then they contacted—

**SENATOR ALQUIST:** Before they asked for help?

**MS. FARRELL:** Yeah, before they asked for help. And then in the past year, in 2004, we found that that changed and it's actually today's caregivers are working women mostly caring for a parent rather than a spouse, and that most of them have been working and they're caring for their children, as well, so they're the baby boomer generation that you spoke about. And over half of the caregivers that are receiving services are employed outside the home. And the time that they actually contacted the CRC was reduced from three years to one year. So, that's quite a difference, because they're used to using the internet to find services and get resources that they need.

And over the years we have found that 47 percent of our caregivers are female, 52 percent of the care recipients are unable to perform three to five activities of daily living such as dressing and bathing and eating. Eighty-three percent of the care recipients live at home with a spouse or other relative. And we've also over the past few years doubled the number of ethnic caregivers that we're serving, so that has been a great increase in serving those particular populations.

The greatest need for caregivers was emotional support for 84 percent, and the other greatest need that they had was for respite care, which is at 47 percent. And you know how great respite is. And that includes some of our caregiver retreats and respite camps that we have for the caregivers.

Over the past, in 2005 we did a survey and over the past year, we have had, over the past 20 years there's been 250,000 callers with specially tailored, getting specially tailored information that's specially tailored to them so that they can get the right resources they need. Ninety thousand families were served with personalized consultation and care assistance, and 20,000 family caregivers with respite assistance and it provided them with a brief break in their care. And 15,000 members received help through a support group, and 6,000 individuals had caregiver-focused counseling.

**SENATOR ALQUIST:** Vicky, what are the main points you would like us to remember?

**MS. FARRELL:** I would like you to be aware that with the change in the population, the family caregivers will continue to provide the valuable care needed for their loved ones.

However, with the progress that's been made over the past 20 years, we need to be prepared for this future bloom of the baby boomers and we really need to be ready to be able to serve their needs and be able to meet their needs as the long-term care issues will become ever increasing in their population. Thank you for your time.

**SENATOR ALQUIST:** And Senator Cox, whenever you have questions, if you could just ask as we go, since it's just the two of us here. Okay, Ms. Feinberg, Director, National Center on Caregiving. Welcome.

**MS. LYNN FEINBERG:** Good morning.

**SENATOR ALQUIST:** Good morning.

**MS. FEINBERG:** Good morning, Senator Alquist and Senator David Cox, and members of the other subcommittee. I am Lynn Friss Feinberg, the Deputy Director of the National Center on Caregiving at the Family Caregiver Alliance in San Francisco. And we work to develop high quality, cost-effective programs and public policies for family caregivers throughout the country. And I appreciate the opportunity to be here today to talk about family caregiving, this very personal issue, from a national perspective.

When we think about long-term care, usually we think about an older person, elderly person living in a nursing home. But, the reality is that most long-term care is not institutional-based at all. The vast majority, 78 percent of adults who get long-term care at home get all their care exclusively from family and friends. Fourteen percent get a combination of informal care, as well as formal care, but only eight percent rely on formal care alone. So it's really a myth to think that most long-term care is provided in institutions settings.

**SENATOR ALQUIST:** That's a very important statistics for us that 78 percent get all their care from family and friends.

**MS. FEINBERG:** Exclusively from family and friends.

**SENATOR ALQUIST:** And only eight percent on the other end of the spectrum.

**MS. FEINBERG:** That's right. That's right. Caregiving which was once one of the most personal and private matters in family life is a growing public issue today. It is also an intensely personal issue affecting real people in our country in all walks of life. Now, while you mention the statistic about lower income families being affected by caregiving, I would say that caregiving affects everyone whether you are rich, middle income, or low income, and I think that's something that we need to remember, as well.

**SENATOR ALQUIST:** Yes.

**MS. FEINBERG:** Demographic trends do help explain why caregiver support is a growing issue for the federal government and state governments, as well, primarily because the future looks very unlike the past. Some of the statistic that you already mentioned—the boomers are aging, baby boomers like myself, and others, most everybody here in the room, many of us.

**SENATOR ALQUIST:** Can you also put into context for us, when you say state, it's both the state and federal, so I mean, other than things like Social Security, things of that nature, can you frame for us also what you think the federal government is doing?

**MS. FEINBERG:** Yes, well the federal government has enacted two major public laws that directly support families. One is the Family and Medical Leave Act that was enacted in 1993 by former President Clinton that provides unpaid leave for family caregivers across the country that are caring for a loved one, a relative with a chronic condition that may need a break from caregiving. But, it is unpaid. Of course, in our state we have paid family leave now. The other important federal law is the National Family caregivers Support Program as an amendment to the Older American Act of 2000 that created federal dollars to the states to provide caregiver support.

But, let me share with you some of the demographics. We know that as the baby boomers age and the first baby boomer cohort will begin to turn 65 in just six years. As baby boomers, like myself, seek help for our parents and later for themselves, we will impose our own values on our search for quality, compassionate, and affordable long-term care. Now, nationally, the population 65 and over is expected to double over the next 30 years growing from 35 million people in 2000, to an estimated one in five Americans or about 71 million people by the year 2030. But, the most dramatic growth is in the very old, those ages 85 and over, and those are the people that are most in need of long-term care. This age group is expected to grow from four million in 2000 to an estimated 8.9 million in the year 2030, and an estimated 19.4 million in 2050, a four-fold increase. Staggering.

There are various estimates of the number of the prevalence of family caregivers in the United States. Generally we use the statistic from AARP and the National Alliance for Caregiving that estimates that there are about 44.4 million Americans or more than one in five adults who provide unpaid care to another family member or friend. The estimated value of this care is staggering. As Vicky Farrell said, in 2000 informal caregiving for family and friends that is unpaid was estimated at \$257 billion per year, greatly exceeding the combined costs of nursing home care at 92 billion, and home health care at 32 billion.

Now while family members often undertake caregiving willingly and it is a great source of personal satisfaction, one of my messages today is that families need support services themselves. A body of research, a large body of research over the past 25 years has shown that caregivers can exact a high cost: health risks, financial burdens, legal quandaries, emotional strain, mental health problems, work place issues, and retirement and security. One recent study found that caregiving for a parent—

**SENATOR ALQUIST:** You have about five more minutes, so if you want to capsulize a little more, that would be great.

**MS. FEINBERG:** I will do—substantially increased a woman’s risk of living in poverty herself and receiving public assistance in later life, so there are long term consequences of caregiving.

I’m not going to go over the health effects of caregiving. Vicky Farrell has already done that. But, let me say that the research clearly shows that increased family stress and subsequently greater health care utilization often translates into higher costs for both families and society. Research shows that unrelieved caregiver burden is a major contributing factor to institutionalization of frail elders and adults with disabilities resulting oftentimes in higher public expenditures for nursing home costs.

**SENATOR ALQUIST:** And do we have a copy of your testimony?

**MS. FEINBERG:** I believe that you do.

**SENATOR ALQUIST:** We do?

**MS. LYNDA HANCOCK:** Yes.

**SENATOR ALQUIST:** Okay.

**MS. FEINBERG:** So, another important point is that—

**SENATOR COX:** I have question for the lady.

**SENATOR ALQUIST:** Senator Cox.

**SENATOR COX:** How does the State of California solve this problem that you’ve just outlined? And let me just go back and just give you some caveats here from the standpoint that families have changed. We’re not the same, it’s not the same as it was 20, 30, 40 years ago. The family unit no longer stays in the same community, so it’s maybe you’re born in New Jersey and you’ve moved to California and your parents are still in New Jersey, or your father—

**MS. FEINBERG:** That’s me! How did you know? **(LAUGHTER)**

**SENATOR COX:** I thought that was you. So the family unit no longer stays together in the same location. We frequently find both family members working because that's a standard of living of which they want and see to. And then frankly, we have folks, baby boomers who will arrive at their time of need with little or inadequate resources to take care of themselves. So tell me how you think government can solve the problems that you've just outlined based upon the caveat that I have just presented to you, which I believe to be accurate.

**MS. FEINBERG:** I would agree with you. I guess I have two major recommendations.

**SENATOR COX:** Okay.

**MS. FEINBERG:** The first is that family support; family caregiver support should be an explicit objective of every piece of long-term care legislation in the State of California. For too long family caregiving issues has been seen as a back burner issue, and it must go to the front. And that means that there has—

**SENATOR COX:** And how does the government do that?

**MS. FEINBERG:** One way is to continue to support the Caregiver Resource Centers, our State General Fund program in California. Another is to increase the coordination and the integration with the National Family Caregivers Support program, the federal program that comes down through the State Department of Aging down to the local agencies. Because as California continues to focus on long-term care reform and reducing reliance on nursing homes, the impacts of these policy shifts on family caregivers must be considered. Coordination of caregiver support services at both the state and local levels should be a priority. I believe that we must learn from our past mistakes in home and community-based care as we work to build a coherent and adequately funded caregiver support system. We should not recreate or contribute to the fragmentation of services that leave families confused and overwhelmed posing major barriers to finding and using the help they need.

In most other states in this country, states are building caregiver support services that are one-stop shops administered by one agency trying to make navigating the system easy for families. In California, I respectfully would say that we have a very confusing and fragmented home and community-based service system and a caregiver support system, as well.

**SENATOR ALQUIST:** Quick question. It certainly sounds like at some point we need greater coordination of services. And before we do that it sounds like we need to collect some data to be, so that we know what the issues really are and what we need to do about them. And so what are the four or five main things you think in terms of collecting data we need to pay attention to?

**MS. FEINBERG:** I think that we have quite a bit of data about family caregivers in California. Dr. Andy Sharlack at the University of California at Berkeley has done a statewide study estimating the prevalence of family caregivers in California estimated at about 1.8 million caregivers of people age 50 and over. But, of course, our caregiving population, that's a minimum number, because that would exclude family members that are caring for younger people with traumatic brain injuries, people with Huntington's disease that affects people earlier in life and what not.

So I think we have the data. We also have excellent data from the Caregiver Resource Centers.

**SENATOR ALQUIST:** So we have all the data we need to move forward.

**MS. FEINBERG:** What we need to do is to be able to take the information from families who are saying what their needs are and make sure that we have the adequate resources and that resources are coordinated well, so that families that need help know where to go for the help that they need in this state.

**SENATOR COX:** And you think that's something that your organization can't do without government assistance?

**MS. FEINBERG:** I think that we need the help of the Legislature to bring all of the stakeholders together in California that are providing caregiver support to figure out a better way, so that we don't have this totally crazy system of service delivery in our state for family caregivers.

**SENATOR ALQUIST:** Does the Department of Aging work closely with the Department of Mental Health to coordinate these services?

**MS. FEINBERG:** Not as well as it could be.

**SENATOR ALQUIST:** Could you mention one or two things where greater coordination would be appreciated?

**MS. FEINBERG:** I think it would be very helpful for the Department of Aging and the Department of Mental Health and other state government agencies to sit down at the table

again to figure out how these similar packages of services can be streamlined, because the focus should be a family-centered home and community-based service delivery system.

**SENATOR ALQUIST:** I realize we've asked you a lot of questions, which has taken some of the time. But, if you could, in closing, say what you would like to leave us with.

**MS. FEINBERG:** In closing I would just say that it's important to recognize as you continue your leadership efforts on aging and long-term care to truly recognize families as partners, not just as resources to older people; that it's really important to assess the families' needs and to make sure that the services that we have in place in California are easy to navigate, easy to understand, and easy to access. And we need much more money for respite care in the state of California.

**SENATOR ALQUIST:** Thank you very much.

**SENATOR COX:** So, let me just ask you. So that's your bottom line. You need more money for respite care. Is that what I heard you say?

**MS. FEINBERG:** No, that's not my bottom line. I think that that's important. I think that we need to do a better—

**SENATOR COX:** But, that was just one of those little gratuitous things that you threw in there.

**MS. FEINBERG:** Yes, I just threw that out, because that was important.

**SENATOR ALQUIST:** It would be one of your top five...

**MS. FEINBERG:** It would be one of my top five, yes.

**SENATOR ALQUIST:** ...with also coordination of services and all these other things.

**MS. FEINBERG:** That's right.

**SENATOR ALQUIST:** Okay, thank you very much.

**MS. FEINBERG:** Thank you.

**SENATOR ALQUIST:** Ms. Missaelides, Executive Director, California Association of Adult Day Services. Welcome.

**MS. LYDIA MISSAELIDES:** Thank you. Madame Chair, Senator Cox, good morning.

**SENATOR ALQUIST:** Good morning.

**SENATOR COX:** Good morning.

**SENATOR ALQUIST:** Καλημέρα.

**MS. MISSAELIDES:** Καλημέρα σε σας. I want to build a little bit on what Ms. Feinberg talked about. Some of you know me from my many years here working on aging and long-term care policy. I'm currently the Executive Director for the California Association for Adult Day Services. I'm also part of the Caregiving Club, a distinction I hold with great pride. My father passed away this summer of Alzheimer's Disease or complications thereof, and as someone who's worked in the system for a long time trying to get policy change enacted to support families and caregivers, it was, as many of us will attest when one's confronted with their own family's situation, it became personal.

**SENATOR ALQUIST:** Our thoughts are with you.

**MS. MISSAELIDES:** Thank you. And I feel pretty proud of what we did as a family, and to Mr. Cox's remarks, because we have—there are three daughters, because there is an intact family, because we live close together, we were able to provide a lot of support and help for my mom and dad. Basically, we utilized the Orange County Caregiver Resource Center initially. Great help. Didn't need a lot of support from them. And one of the points I want to make is...

**SENATOR ALQUIST:** But, you knew what you were doing, right?

**MS. MISSAELIDES:** Pardon me?

**SENATOR ALQUIST:** You knew what you were doing, more than most of us would know.

**MS. MISSAELIDES:** Well, I knew how to hook my mom up with them, and one of the points I want to make, and I'm departing, actually, from some of my prepared remarks, is that one never knows for each situation, each family, each individual, what's the key one or two things that's going to make a difference to help keep that family member at home. Now, for my mom, I would say one of the key things was because of the Caregiver Resource Center hooking her up with the support group, didn't cost her any money, didn't, I mean, it was a very simple thing, she found a caregiver whom she adores who was able to come to the house and my mom was able to pay privately out of her own pocket to get help to keep my dad at home for a number of years until my mother became very ill with cancer.

Now, that was maybe a small thing. And maybe a small part of what the CRC system does. But, for her, it was sort of the thing that launched her into her ability to feel like I can do this at home. I've got some help now. Then she was able to get some day care. Again, we paid out-of-pocket. He had a very nice experience there—Brea, Ms. Daucher's district, long way away from my parents. They have no services, day services in

her city, Placentia. So we had to drive and she had to make arrangements. I mean, it is not easy to care for a person at home with or without government resources, is kind of the point I'm trying to say. Families do everything that they can and there are other families who do not have much in the way of financial resources or family support.

**SENATOR ALQUIST:** Some families are not as intact as yours.

**MS. MISSAELIDES:** Again, to Mr. Cox's point, which was right on the mark, it is a different family structure that we're looking at today. So we have to think about that as we plan for the future, and I'd like to think of long-term care as a biological ecosystem almost where all the parts kind of need to be there and working together harmoniously or things begin to fall apart. And we all are interdependent on each other as people and in terms of providers.

And just like an ecosystem in our state, we worked on the long-term care, actually produced the *Long-Term Care Data Book* that I think I've shown to you before. It's very interesting to just look even county by county at the differences in sort of those ecological systems in different parts of the state. And in that book you can really see clearly where each county sits in terms of its services. Some are very rich in services, some very poor. Transportation, you know, is that an issue or not? What do wages look like? And so on. So, I think as we think forward in terms of how we're going to build supports for the future whether they're private or government, we really need to pay attention to individual needs.

**SENATOR ALQUIST:** Could we get a copy of the book for all of our committee members?

**MS. MISSAELIDES:** Yes. It's out of print, but we'll make that happen for you. Maybe I can work with Robert to do that.

**SENATOR ALQUIST:** Thank you.

**SENATOR COX:** Were the services in rural California look like the services in Orange County or is there a distinct and different circumstance there that also need to be considered?

**MS. MISSAELIDES:** Senator, there's quite a difference and I would say that you can look at some counties in our data book, and I will get that to all of you. And you will see for example, just looking at the service delivery system, some of those counties will be very high. What we did is we ranked all the counties in terms of how they relate to every other county. So you're ranked top third, middle third, bottom third. Many of those will be very high in nursing home beds, for example. And people living in nursing homes very low and

people receiving in-home support or day services. So, a big issue with rural communities is labor and transportation.

**SENATOR COX:** And they don't have the day care, they don't have the care facilities that you might find in the larger metropolitan areas.

**MS. MISSAELIDES:** Correct. That is correct. And barriers there are geographic, the are depressed economies, there are a number of things that—

**SENATOR ALQUIST:** And we have a whole panel on the rural part of this.

**MS. MISSAELIDES:** So I won't get into that any more, but you'll be able to see that when you browse through the data book.

And I think the other point I want to make today, I can't underscore enough, especially with my own personal situation is if caregivers—this is to Lynn's point. If caregivers stopped care today, the whole system would collapse. I mean literally. I know I've heard these statistics before, but I was again, you know, kind of taken aback by what Lynn said. And what I worry about because of the demographics that have been described, Mr. Cox's comments, your remarks, Ms. Alquist, is that if we don't think forward enough for this baby boomer bulge and do what we need to do to support caregivers, whether it's government, whether it's private sector, they will become an endangered species. And we do not have the capacity; we don't have the government funds. We don't have the ability to replace caregivers if we don't keep their health intact.

I think the last point I want to say is that caregivers in—caregivers really do need to be viewed as partners in care, so that service providers where we often have to follow rules that are not conducive to including family members in decision-making or in determining support—

**SENATOR ALQUIST:** So how do you envision that? How would that look to you?

**MS. MISSAELIDES:** Well, frankly, I think that what that would look like first is a major shift in how we view provision of services in the community. We do have an institutional bias in terms of the way government funding comes to our state and the way the state distributes funds. And it's a lot of rules, some of which are federal that we don't have a lot of control under over some of which are state. But, I think that we can make a strong public policy statement that as rules are enacted, as rules are changed, as rules are interpreted, that the focus of those people who implement the rules at the ground level must be with keeping the caregiver, the family, the constellation in mind as those decisions are made. And that is not often valued today.

**SENATOR ALQUIST:** And along that line, and I think that's one of the first things I learned many, many years ago when I recreated the Committee on Aging and Long-Term Care in the Assembly, but specifically, if only eight percent are receiving complete care in a facility and 78 percent are getting complete care with family and friends, family and friends, given those proportions are there things that we need to be doing differently in terms of funding to provide support? And in a realistic way, what could be done, because we are structured to do XYZ and it means a shift a little bit, and how...

**SENATOR COX:** Would your objective be then to move more into the category that has the fewest number there?

**SENATOR ALQUIST:** Yes. To move more into more resources—or not—additional resources into this to care for the 78 percent. I would be curious and maybe you already know this and if not we need to research it, but how many resources are going to the eight percent in the facilities and how many resources are going to the 78 percent that are being cared for by family and friends?

**MS. MISSAELIDES:** I don't know the answer to that.

**SENATOR ALQUIST:** Because I think that's instrumental, because I don't know about you, but I would like, you know, and I'm 61 and in my final years I would much rather, if possible—

**SENATOR COX:** You're ancient, just ancient.

**SENATOR ALQUIST:** I'm just ancient here.

**SENATOR COX:** You're just a baby, just a baby.

**SENATOR ALQUIST:** Right, I'm just a baby, yes. So I'd like to see that for the 78 percent of us who are going to be hopefully cared for more by family and friends, that we're getting an appropriate percentage of those resources.

**MS. MISSAELIDES:** It just seems to me, and I don't have—

**SENATOR ALQUIST:** So do we know? Do we kind of know that?

**MS. MISSAELIDES:** ...but it seems to me that a little bit of help can go a long ways towards that 78 to 80 percent, just a little bit, because a lot of those families are going to continue to be paying out of pocket.

**SENATOR ALQUIST:** Right. Do you have any suggestions, in closing, what we could do to help the 78 percent?

**MS. MISSAELIDES:** Yes, actually. One thing that I've been struggling with for many, many years—we haven't been able to make inroads—is how can we provide

incentives to the private sector to do more in supporting families and employees in their caregiving roles. And small things have been done—

**SENATOR COX:** How would you do that? What would you do?

**MS. MISSAELIDES:** Well, I'm not an expert on this area, but—

**SENATOR COX:** No, I'm just interested in your opinion, because just let me tell you and maybe the chair will extend your remarks just a moment, but it seems to me that the argument that you make with respect to if the caregivers stop giving is exactly the same argument that if you said families stop parenting.

**MS. MISSAELIDES:** Oh, I was just; I was using that to make a point, Mr. Cox. For example with my mother, she stopped caregiving not because she wanted to. She became ill, and my point was merely that families, that people do become ill from caregiving. Sorry if I misrepresented that.

**SENATOR COX:** This thing about Americans, State of California is that we all need to keep doing what we're doing. Doctors got to keep doctoring, police got to keep policing and families got to continue being families, and caregivers got to continue to be caregivers, and whether you like it or not, legislators need to legislate.

**MS. MISSAELIDES:** Sure.

**SENATOR COX:** So it is a situation, I mean, that I'm interested to know what the caregivers specifically think. Not just general terms, specifically think how do you fix the—if you think it's broken, what do you think needs to be done other than just applying more money to it? Or if money's the only solution, you know, I want to know is money the only solution? Does money fix it?

**MS. MISSAELIDES:** No. There will be other panels who are caregivers, but my remark on that is no. Money is not the only solution. There are, as I said earlier, many barriers that get in the way of communities trying to do a better job of coordinating services at the local level. We've got bits and pieces and people are not really often paid or given the time to take the, make the effort to collaborate with other services within the community. So, there are, I think, governmental barriers, frankly, in the way. So it is not only money, but money has to be part of the equation, because we need to, what we have we need to use more efficiently, and what we may need in the future is scary if we don't begin now.

**SENATOR COX:** I understand, and I'm trying to get there with you. I just need to—there just at some point in time there's got to be some specificity that says, look, the system is broken or it's not functioning the way it ought to, and if we just tinker it this way a little bit it

would be better. Is it going to be perfect? The answer from my vantage point, the answer is no. But, can it be better, Madam Chair, that's all I'm saying and I want to know with great specificity.

**SENATOR ALQUIST:** Right. We can do better. There was a bill held in Senate Rev and Tax this year that would have given a tax credit for caregivers--\$500 was it?

**MR. BURNS VICK:** Right.

**SENATOR ALQUIST:** Just to put that out there.

**MR. BURNS VICK:** AB 298.

**SENATOR ALQUIST:** AB 298? Thank you. Okay. Thank you very much.

**MS. MISSAELIDES:** Thank you for your time.

**SENATOR ALQUIST:** Next we have Ms. Fordyce, Dr. Fordyce, President, California Geriatric Society. Welcome.

**DR. MOIRA FORDYCE:** Thank you very much. Good morning, Senator Alquist, Senator Cox. Thank you for allowing me to speak to you on this important topic. I am a geriatrician. I have been a doctor for 43 years. I can hardly believe it. And most of that time I practiced geriatrics with great satisfaction. I specialized in hospice, home care, and nursing home care for more than 20 years. I have also been a caregiver. And what I would like to do is summarize first of all the effects of caregiving on caregiver health and some of the consequences. I would also like to speak to a very basic thing—the importance of listening to the caregiver. And I'm coming from the perspective of a medical professional. And you'd be amazed how often that does not happen.

I would also like to say just a word about the importance of physician or health professional assessment of the caregiver. And that doesn't happen often enough. Finally, just briefly to say a word that we must educate medical students on the role of the caregiver. This is extremely important. We know that caregiving can have dire consequences for the caregiver's health. And if you split it into somewhat artificially into physical, mental, and emotional issues, usually it's a combination of all three which is very difficult.

First of all, physical, diminished immune responses, and this we can show objectively by showing the B cells, the T cells. This means more infection. It also means higher incidence of cancer, because a strong immune system will destroy, search and destroy, cancer cells. Slower wound healing—we see that objectively in caregivers. Higher incidence of costly hospitalization, higher mortality rate, poorer general health, higher

incidence of headaches, gastrointestinal problems, and insomnia. And an increased risk of heart disease, and of course, chronic stress we know contributes significantly to the development of heart disease, mental problems, depression and anxiety. And the interesting thing is that these can persist even after the patient is perhaps admitted to a nursing home, has died, the caregiver can often still suffer depression, anxiety with guilt added to this sad picture.

Now, whenever we say depression, the next thought must be is suicide far behind? And yes, there is a higher incidence of suicide among caregivers. Also, alcohol and other substance use is higher among caregivers and this has serious implications for driving, operating machinery, as well as damage to health. Emotional consequences, exhaustion, and caregiver stress are real. And the signs of this can be anger at the patient, anger at themselves, moodiness, negative thoughts, lack of concentration, errors at work; and this is serious for the wage earner/caregiver. And of course emotional stress—we now know that it affects longevity adversely. And of course, that goes with the increased mortality I mentioned above.

Now, what a gloomy picture, but, does it need to be like this? Does it happen to everyone? I'm happy to say the answer is no. It doesn't need to be like this. We can change it. There are as many studies supporting the fact that good social support systems, family, friends, caregivers, volunteers, respite care, which we know is so important, that these can prevent the health consequences in caregivers. So, we are looking at this. Our fragmented support system, a lot has been said about that. And I know this—well, I can't help comparing it with my personal experience in Britain where I practiced medicine for 14 years. And my mother—I was caregiver for my mother when she got bowel cancer. It was so easy. She, unfortunately, it was not diagnosed early enough, and she ended up on hospice. It was one-stop shopping. The public health nurse was available 24 hours a day. The doctor made home visits. I could go to one place to get all the equipment we needed at the local Red Cross office. There were not reams of paperwork. There was no cost to the family. There was no, the worry was reduced terribly.

Now, when I look at our fragmented system—

**SENATOR COX:** And how many stops are there?

**DR. FORDYCE:** I'm sorry?

**SENATOR COX:** How many stops are there?

**DR. FORDYCE:** Stops? Too many; and in fact, that was what I was going to lead to next. On November the 10<sup>th</sup> there was an article in the New York Times, “When Experts Need Experts,” and this was describing the saga of two of the most respected national figures in gerontology and geriatrics, Robert and Rosalee Kane, famous, very famous people. When their elderly parents needed help, the Kanes could not navigate the long-term care system. And in fact, it was so bad that they have now formed a 600-member organization called Professionals with Personal Experience in Chronic Care. I’m a member of that organization. And they have published a book—Robert Kane and his sister—called It Shouldn’t Be This Way: The Failure of Long-Term Care—part memoir, part guidebook, part call to arms. Now if two experts in the field found it so difficult to organize care for their parents, what hope is there for the 77 million aging boomers and their caregivers? We can change this.

Now, a quick word on the importance of listening to the caregiver; basically, caregivers are our early warning system. And by “we” I’m talking health professionals; we don’t listen enough. In patients with dementing illnesses such as Alzheimer’s disease, there are studies which show clearly that the caregivers are right about change and condition more often than the health professionals involved, even if the health professionals are seeing the person often. And we ignore listening to the caregivers at our peril. And I have a lovely story about that, about one of my patients, but I won’t, I’ll move on.

**SENATOR ALQUIST:** Thank you.

**DR. FORDYCE:** The importance of physician assessment of the caregiver—we must keep our caregivers healthy. We’re hugely in their debt. We know this. A simple question to assess the caregiver is who is the main caregiver? And what I want to summarize here is a recent study talking about child caregivers—1.4 million of them in America under the age of 18—400,000 child caregivers under the age of 11. The young caregivers, interestingly enough, half of whom are boys, are more likely to come from low-income households, less likely to be from a two-parent home, more likely to experience depression, anxiety, feelings of isolation, more likely to experience disruptions in school. Now, that is serious. That can impact the whole of the rest of their life if they don’t get education; they’re less likely to get a good job, end up unemployed. It can affect their whole life.

Then, although women are the principal caregivers still, you had spoken about men. And male caregivers have special problems. In addition to the health problems I mentioned

above, they are often less willing to seek help. They're less willing to admit they're caring for an elderly relative, in particular. They don't talk with friends as much as women do, and they don't join support groups as readily as women do, though there are now many good support groups for men. Yes, I'll move on.

**SENATOR ALQUIST:** Right, if you could just sort of capsulize the main points, because—

**DR. FORDYCE:** I know. Time is of the essence. I understand.

**SENATOR ALQUIST:** And your testimony is so interesting. I'm assuming, too, that your written testimony we have.

**DR. FORDYCE:** Yes, it's more—it's got more in it than this. One thing I would really like to say, I am saying we must assess the caregivers. This is important. You will often hear doctors say, "Oh, no, no, no, no. We can't do that. It's all very well. We don't have the time." Now, I know from years of doing it that the better the initial evaluation of both patient and caregiver, the more time is saved in the long run. Not just time saved, but improved health, fewer costly medication or errors, fewer—

**SENATOR ALQUIST:** Dr. Fordyce, as an example, I am the major caregiver for my 97-year-old husband, the major caregiver. So if a doctor were to say to me, with my husband there, who's the major caregiver, and I say I am, then what happens? After the doctor asks the question, what does the doctor do with that information to help the caregiver?

**DR. FORDYCE:** The next thing, the next question the doctor should ask is how is your health? How do you feel? Are you sleeping well? Are you taking medications? Do you use alcohol? Can I help you? It might be that you would do that apart from your husband being there, but the geriatrician would do this, would ask about you and what your needs are and would try and link you up with help if you needed it.

**SENATOR ALQUIST:** So you're also—are you assuming that all of these people are going to be seeing a geriatrician?

**DR. FORDYCE:** No. I wish. I don't know. I don't—

**SENATOR ALQUIST:** So, that's another piece if you could speak to.

**DR. FORDYCE:** It's another piece. I don't think everybody needs to see a geriatrician. I think our main role is to be there and consult. The primary care provider whether that's doctor, nurse practitioner, physician's assistants who do a great job, they are

the primary care, you know, the professionals, health professionals. And the ideal thing is for them to consult with a geriatrician as needed, in the complex cases.

**SENATOR ALQUIST:** So, what we're really talking about is seeing that the primary care physician understands the precariousness of being a caregiver—

**DR. FORDYCE:** Yes.

**SENATOR ALQUIST:** ...and how the caregiver needs to be helped. But, the primary care physician it sounds to me like it's the primary care physician who needs to be really educated.

**DR. FORDYCE:** It is, definitely.

**SENATOR ALQUIST:** And how do you suggest we do that?

**DR. FORDYCE:** Well, it leads me to my next point, my final point, about educating medical students. Now, medical students really need this education. The physician assistant students I teach every year at Stanford are very savvy. Nurse practitioners with whom I worked are savvy about this. Medical students don't know about the importance of the caregiver. In fact, medical students have told me after I did a very good panel presentation about an elderly woman in our case study that they had never thought about what happens to their patient after they leave the acute hospital. So we need to educate them. And one way we can make this happen is make sure that in all the examinations, all the tests, the boards, the flex, there are questions about geriatrics and questions about caregivers and how to look after them.

**SENATOR ALQUIST:** Thank you very much.

**DR. FORDYCE:** So, those really were my main points, the child caregivers, the fragmentation of the system, and we can fix it. We're trying to do this.

**SENATOR ALQUIST:** Thank you very much.

**DR. FORDYCE:** Thank you.

**SENATOR ALQUIST:** And with that, we'll go to Panel 2—assessing the impact (financial and otherwise) of family caregivers who leave or reject employment in order to give care at home. Witnesses will focus on the plight of "middle class" families and caregivers who are employed, including a frank discussion on the psychological and emotional toll experienced by caregivers. Policy recommendations for the state will be proposed, including strategies for the state to encourage interagency coordination and promote policies that drive "outcomes" that benefit those being served.

We have three people who are part of this panel and what I would suggest in the essence of time is that if one person says a lot in one area, the following two could just say, "Gee, I agree with it," or just very minimal comments and then address other issues. Because what you really need to do is number one, educate us. And number two; educate all those who will be watching this.

So with that, we will start with Jean Coleman, nurse, former clinical nurse specialist at U.C. Davis, and long distance family caregiver. Welcome.

**MS. JEAN COLEMAN:** Thank you, Senator Alquist and members of the committee. I am a nurse practitioner and have worked in the field of geriatrics since 1981. For most of the past 20 years I have been involved with employment with the U.C. Davis Alzheimer's Disease Center. And from 1994 to 2005, I was the clinical program director. I've also worked on the boards of the Alzheimer's Association in the San Francisco Bay Area, and also the board of the Family Caregiver Alliance.

So, I think the gist of what I'm here to talk to you about is my experience as a long-distance caregiver and the demands of that working full time. You have my testimony. I am currently a full-time caregiver to my mother. But, my experience was from 1999 to 2005 in my caregiving role to my mother, I traveled to New Jersey on the average of four to five times a year. This had a huge impact on my work, my life. The things that have to be brought to mind are also just basic differences in terms of the cost of that travel, but the time commitment to negotiate systems based on the time change, I would begin my phone calls to New Jersey at five o'clock in the morning, or six o'clock in the morning, and then have to go to, you know, I'd be at work and sometimes I would be interrupted at work.

I want to mention that I felt I was employed with a very understanding and supportive group of people.

**SENATOR ALQUIST:** Could I just interject that in terms of your testimony, I mean, you are a clinical nurse specialist.

**MS. COLEMAN:** Nurse practitioner, yeah.

**SENATOR ALQUIST:** Nurse practitioner. So you have the training, you have the experience. So when you speak as a long-distance family caregiver, it's with—you have all this experience and knowledge that most of us aren't going to have when we are in your role.

**MS. COLEMAN:** Correct.

**SENATOR ALQUIST:** So, one thing you will address, I'm sure, is how it was for you, but also implications how it could be for someone who doesn't have the training and experience that you have.

**MS. COLEMAN:** I hope to address that in a way of the committee understanding the appreciation of the demands of long distance.

**SENATOR ALQUIST:** Right, and the ramifications of that.

**MS. COLEMAN:** And the need for us to recognize that long-distance caregiving especially for people employed full time is a nearly impossible task. And I do believe that we have some new written resource material out from Family Caregiver Alliance. I use their handbook. I downloaded it from the internet. We do have some resources. But, most people don't know that. And I think there is a need for California to premier the things that we do have available to us through Family Caregiver Alliance.

I think the other thing I wanted to bring up was the cost of parent care and long distance care on my husband and myself. In 2004 my father, in addition to me traveling to New Jersey four to five times a year to care for my mother and coordinate her care, which I have to say I was fairly successful at, but it was demanding. But, in July 2004, my father-in-law who resided in New Mexico was diagnosed with terminal colon cancer. And at that point, between July and December, my husband made—my husband and myself made four trips to Albuquerque and then in December, his father succumbed to his disease. But, when we looked back over how much money we had spent on our parents' care in 2004 alone, it was close to \$10,000. And I think, you know, we were fortunate enough to have those financial resources available for us. But, I really question and I wonder how many people in the middle class working who are in the same situation dealing with frail elderly parents. People do not have that ability.

**SENATOR ALQUIST:** I agree. You think about the average amount of money that's in a savings account.

**MS. COLEMAN:** Right, right.

**SENATOR ALQUIST:** I mean, one can tell that most people aren't going to have those resources.

**MS. COLEMAN:** Absolutely. I was working with people who couldn't fix their cars for a few hundred dollars. And just imagine them having to deal with what we were dealing with.

I want to mention the fact that in January, 2005, I made a decision to retire from the U.C. system. It was an early retirement. And my caregiving, my primary caregiving to my mother was not the primary reason for my retirement, but it clearly was one of the factors. Having experienced what my husband and I experienced in 2004 with both of our parents, you know, we were both exhausted. But, that was not the primary reason. I retired April 29<sup>th</sup>. I received a phone call from my mother's caregiver on May 1<sup>st</sup> that she had fallen and she was confused. And that began a cascade of a failing system that I had in place for the long-distance caregiving and the needs for my mother. I knew what the options were to look at because I have the expertise. But, I will tell you having the expertise does not help you deal with this emotionally. You've heard that from a number of people on the panel. And when it is you, it is clearly different than you dealing with a family in a conference room or having an assessment.

So we did make the decision to move her to California and be cared for by us, despite the fact that my mother could have been eligible for Medicaid in New Jersey and Medi-Cal here. Her resources are extremely limited. I did bring my mother to California in August. And in anticipation of that move, I want to tell you what happened when I began to negotiate the long-term care system which I thought I knew. She was on a health care retirement plan which did not cover Northern California. It was Aetna which covered New Jersey, New York, and Connecticut. I switched her to Oxford to be effective September 1<sup>st</sup>. However, I also made an inquiry to Kaiser, and they informed me, because I do believe that the Kaiser Senior Advantage Plan works for most people. I made an inquiry. I was informed by the representative that an application had to be received and reviewed. Once it was received and reviewed, we would be interviewed. And I said, well I don't think I can bring my mother down anyplace, you know, to be interviewed. And they said, oh, no, no, no. We'll come to the house. I clearly went through, you know, my concerns.

I then proceeded to take my mother to a new primary care physician in August when she arrived, knowing full well that I was going to be responsible for that bill. But come September 1<sup>st</sup>, will be covered under the new plan. On September 1<sup>st</sup>, I received her Oxford health plan card, but I also received a phone call from Kaiser welcoming us to the system. And I explained my confusion to the representative. And she said, "No, you have to fill out this disenrollment form."

**SENATOR ALQUIST:** So what was the confusion or what...

**MS. COLEMAN:** Well, apparently, the application was the way to that it was going to be accepted. It was an automatic. There was no interview or even a phone call except welcoming her to the system. And I said, well, we can't do this. And so I received the disenrollment form on September 10<sup>th</sup>, but I went and took my mother to a cardiologist. I renewed all of her medications, and in that period of time she went on oxygen. I began to get rejections of payment from Medicare and I began to get premium payments for Kaiser. I contacted Medicare and they said, well, no, your mother is in Kaiser so we are not covering any of the costs.

**SENATOR ALQUIST:** So there was a gap?

**MS. COLEMAN:** Well, under Medicare regulations, somehow Kaiser's application got there before the other one, or that had preeminence. I'm still trying to unravel the confusion. What we are left with is Kaiser certainly is not going to cover any of the costs, because my mother was not ever seen in the Kaiser system. When I contacted Medicare, Medicare is showing that she is enrolled in the Kaiser system, so they will not cover the physician bills and the oxygen that went into the place in the beginning of September. Now, the bill so far, \$1,500. And you know what? We can absorb that cost. But, my mother should have been covered during this time. As an expert in the field of long-term care issues, I thought I was communicating correctly. And it was total miscommunication and now we are left with paying the bill. I am trying to still unravel it, but that's the other part of what I'm doing. So much of my time is spent—

**SENATOR ALQUIST:** Have you figured out how it could have worked well?

**MS. COLEMAN:** No. At this point I have not. I have not had that time to do that. I think in closing in terms of my remarks, I really do want to make the point of the time-consuming nature of our long-term care. It's not only time consuming, it's confusing. It's perplexing. People such as myself who have worked in this field for so long are totally confused and we think we're asking the right questions.

And I wanted to make the point that my nursing experience clearly prepared me to take care of my mother's physical health. It really has been a gift. But, I clearly have been unprepared to navigate the system of long-term care to meet my mother's needs. And I do believe that the task of family caregiving is a labor of love, as well as the gift of time to spend with those who gave us the gift of life. And I really do want to make that point. The challenge of family caregiving especially for the middle class is that it's not reimbursed

financially, nor is it recognized by the current system. In addition, the system is very complex. And it's just a daunting task to undertake.

I urge legislators to address the issues faced by baby boomers and succeeding generations who are in the middle class and who fall through the cracks of the current system.

**SENATOR ALQUIST:** Thank you. I do want to thank you and have you spoken to your member of Congress on the Medicare issue?

**MS. COLEMAN:** No, I have not.

**SENATOR ALQUIST:** I would think that since they have responsibility at that level for that, I would think you'd, you might, I suggest that you might. And I really identify with a lot of your comments. My father, the Greek immigrant, would have been 100 years old this March 3<sup>rd</sup>. He was two and half years older than my husband, and so I had years where I was both caring—and my father died in '98. But, I had years where I was also making phone calls every morning back to Missouri and flying back and forth and doing those things.

**MS. COLEMAN:** It is quite a balancing act.

**SENATOR ALQUIST:** It is, and a tough one. Well, thank you for everything that you do.

**MS. COLEMAN:** Thank you, Senator.

**SENATOR ALQUIST:** Next we have—is it Devara? Ms. Berger?

**MS. DEVARA BERGER:** Devara.

**SENATOR ALQUIST:** Devara. Ms. Berger, former long-term care planner for California and middle class person who tried to avoid impoverishment as a caregiver while giving up full-time employment. Yes, welcome.

**MS. BERGER:** Thank you so much. Senator Alquist, I'm so grateful that you're holding this hearing today. All of us who are caregivers really greatly appreciate this. As you mentioned, I was a long term care planner for the State of California before President Reagan got rid of health planning. And I just want to say like Jean and Dr. Fordyce and various others that it doesn't really matter what your expertise is. Nothing prepares you for this and everything is a barrier sooner or later whether it's big or small.

My background is not just being a long-term care planner. I've been involved with public policy dealing with aging and long-term care issues for years. And for 10 years, I had my own health policy business and I addressed caregiving and end of life issues. My care

recipient was my husband, Derrick Pogson. He was a legislative staffer here years ago. He used to be the press secretary for Senator Jim Mills when he was the President pro Tem. I want to say that as far as impoverishment goes, I found one statistic when I was searching for something that mentioned this. And the Robert Wood Johnson support study which looked at end of life care in five major hospitals that looked at over 9,000 families. And these families had health insurance, Senator. Thirty percent of them went bankrupt. And that was about 1998, so I'm positive that percentage has gone up.

**SENATOR ALQUIST:** We would like to look at that study.

**MS. BERGER:** I can help Robert get that. So, I just want you to know that. The other thing, when we talk about impoverishment, I know I'm here to talk about fiscal impoverishment, but the mental, emotional, physical, spiritual, psychological impoverishment hits every single caregiver. And those impoverishments lead to their demise.

I am so happy that Dr. Fordyce identified the communication problem that exists and the lack of training with medical students, because that was the very first system problem that I encountered. What happened was my husband had a cramp. We ended up in a neurologist. I thought I was going to be told that my husband had a pinched nerve. Alone in a dark gloomy room a neurologist tells me instead that my husband has two brain impairments and he's going to die.

So I started my journey with ignorance and confusion and fear, because that physician was happy to do a "diagnose and adios," but never told me the course of the disease, the medications, the treatment options, or anything else, nor did that doctor once say to me, "How do you feel?" So, I want you to know that I totally agree with Dr. Fordyce that clinicians have a responsibility to family caregivers. They can't just provide that diagnosis. They have to at least direct us to the training and the education and the social support, so that we can start and maintain this journey that is extremely difficult.

Now, secondly, those of us who have loved ones with neurological impairments, they'll tell you neurological impairments are difficult to diagnose. Now, diagnostic procedures have gotten much better since I was a caregiver from 1991 until 1995. But, I received four diagnoses, because I didn't just get a second or third opinion, I got a fourth opinion. Two of those opinions said my husband had Parkinson's with dementia. And I couldn't even find anything on the literature on this incidentally when I tried to research it. Two other doctors, one from the Parkinson's Institute in Sunnyvale, which is highly

prestigious, and the Berkmyre Institute in Vienna, which is worldwide famous, they told me my husband had Parkinson's. But it was ultimately up to me, Senator, to figure out what the course of my husband's care should be.

Now, when did I conclusively know what killed my husband? Well, when I had a brain tissue autopsy. And by the way, this is such a gift, because it enables you to know conclusively, finally, what was it that led to the demise of your loved one. And what we found out was that my husband had Parkinson's and early onset Alzheimer's. Now, if I had had a correct diagnosis at the beginning, my journey would have been infinitely easier. There were medical procedures and medications and things I subjected my husband to that were totally unnecessary. But, I did them because I thought that these were going to address the symptoms and help him.

I want to hit another system problem that is really not discussed often enough. We don't do autopsies today the way we used to. Doctors learn how to diagnose better from autopsy reports. But, because autopsy reports aren't a cost center in hospitals, they're not done frequently, and usually the family has to pay for them. If we want to have a good medical system, we've got to have a way of training doctors better, and I think we need to look at what we are not doing regarding this issue of autopsies.

Now, I'm going to tell you something that all the caregivers experience which is huge, out-of-pocket expenditures, because our health insurance doesn't cover incontinence products. It doesn't cover wheelchair ramps. It doesn't cover home health aides. It doesn't cover a wide variety of durable medical equipment or medications that we need every single day. In 1994, I had to pay \$80 an hour for a home health aid. I don't know what they cost today, but \$80 an hour was a tremendous amount of money for me to calculate into whether I would get a mammogram, get my teeth cleaned, get my hair cut, go out for a cup of coffee. I felt too guilty and I felt too pressured to even spend that \$80. Maybe three or four times I did that throughout the—

**SENATOR ALQUIST:** I think a lot of women feel that way, and we shouldn't.

**MS. BERGER:** We do, though, because we are terrified that we won't have enough money. Now, my husband had to get a wheelchair, but insurance didn't cover wheelchair ramps. Because I was a long-term care planner and had worked in state government, I called a variety of state agencies. I called the Department of Health. I called the Department of Rehab.

**SENATOR ALQUIST:** So, have you written a book?

**MS. BERGER:** Yes, I have. **(LAUGHTER)** And I ended up at the Department of Housing and Community Development. I was told they had a list of contractors that would build wheelchair ramps. But, lo and behold, nobody ever updated that list. Every single contractor I called which were 14, except two, were still in business. Only two were in business. When I called them, and I only needed two simple ramps so I could get my husband out of the house, and because I have sunken living rooms, get him into one of my living rooms. One contractor wanted \$1,400. One contractor wanted \$2,000. And it was only through serendipity that I found a non-profit called “Harps” that does home repairs for seniors and I was able to get a ramp for \$600. But, Senator, there’s the lack of continuity. Insurance pays for the wheelchair, but doesn’t pay for the wheelchair ramps.

Now, as many caregivers do, I suffered extreme sleep deprivation. And what I looked for to help me initially was an adult day care center. I happened to live in Senator Cox’s district and I would like him to know that there aren’t any day care centers—

**SENATOR ALQUIST:** And this is being videotaped, so he will.

**MS. BERGER:** There aren’t adequate day care centers. The one that existed for me didn’t provide appropriate level of care. And my husband hated it. Plus it was expensive, so we only went there once. When I was towards 11 months of sleep deprivation, I decided I needed to put my husband in a nursing home for a few days so I could get some sleep. I contacted two nearby. First of all, they told me I was crazy. We’re not going to take your husband for two days. You’ve got to put him in for five. That’s our minimum. And it would cost me \$600. Senator, I didn’t want to put my husband in a nursing home for five days, nor did I want to spend that much money. I only wanted one or two days of respite.

**SENATOR ALQUIST:** So, what is it today? I don’t really know. Are there, can you give care, respite care in a nursing home for two days today?

**MS. BERGER:** Senator, I can’t answer that question, but I can check with people.

**SENATOR ALQUIST:** I would be interested in knowing.

**MS. BERGER:** And I’d be happy to do that for you and to look into it.

**SENATOR ALQUIST:** I mean, I think the general population would like to know.

**MS. BERGER:** I think Lydia Missaelides and various others can really help address that question.

**SENATOR ALQUIST:** Okay, \_\_\_\_\_.

**MS. BERGER:** What I want you to know is that I did suffer an emotional breakdown after 11 months of sleep deprivation. And I didn't have the luxury of enjoying that breakdown, because there was no one to care for my husband, so I really had to heal quickly. And what I want to say is that it was after this breakdown that somebody faxed me information that something called "Caregiver Resource Centers" existed. And one was only two miles from my home, and I want to tell you, Senator, that I wept when I learned that there was a resource to help me. Because, Senator, and I want Senator Cox to know this—I didn't reach out—

**SENATOR ALQUIST:** He will be back. He had a conference call.

**MS. BERGER:** I didn't reach out to government to help me. I dug into my own pocket. I did look into my community, so—

**SENATOR ALQUIST:** Well, we need to be reaching out to you. That's what this is all about.

**MS. BERGER:** Yes. One of the—

**SENATOR ALQUIST:** And in closing, I mean, your testimony is so interesting.

**MS. BERGER:** I want to get into some recommendations very quickly.

**SENATOR ALQUIST:** This would be the time. We only have a couple minutes.

**MS. BERGER:** Two of them deal directly with caregiving. One is that we have to stop under funding the CRC system. Here we have a successful system that's cost effective, and yet every year the Caregiver Resource Center has to go to the Legislature with a begging bowl. Then, when it approves the budget augmentation, governors veto it. And it makes absolutely no sense to me economically or any other way to do this. I mean, you have a successful system that is a bright, shining star. Fund it.

Secondly, the National Family Caregivers Support Program funnels the money in California through their Triple-A's which make the CRC systems go through a grant process to get money. And I think this is insane. I think this is ludicrous. Here you have centers that are experts in caregiving. Why are we making them getting grants? The money should go directly to them.

Now I want to make two global recommendations. Number one, I was a health planner. We had a fairly decent health system planning. We had a state health plan. We had regional districts. We don't have that today. We don't have an annual state plan where regional health system agencies feed uniform data into them. And this is one of the major

reasons we have this unbelievable mess, chaos, fragmented system. It's not the only reason, but it's a huge reason.

Tell me something that's major that you can do without planning and here we do it to the health care system. We don't do adequate health planning and we don't have adequate standardized, unified data.

**SENATOR ALQUIST:** And in closing . . .

**MS. BERGER:** And in closing, I'm asking that we improve access to palliative care and end of life care. Thank you so much.

**SENATOR ALQUIST:** Thank you. Thank you very much. That was very interesting. I just noticed that our panelists now, the earlier panelists, had 10 minutes and the panelists right here have five minutes. So, what I'm really suggesting is after minute one that whatever your major recommendations are, because we will not extend the time in the future, so . . .

Next we have Ms. Rosario, family caregiver residing in Campbell—challenges and the value of support services. Welcome.

**MS. TINA ROSARIO:** Good morning. First of all I would like to thank you for asking me to speak on Family Caregiver Alliance. I feel very honored to be here this morning. My name is Tina Rosario, and I'm currently caregiving for my mother-in-law in Campbell. We live in Campbell, California. Finding Family Caregiver Alliance was actually a 411 operator mistake. I was calling the Family In-Home Health Support Center to try to get some extra days of day care administered for my mother-in-law with some transportation. So, when I contacted Family Caregiver Alliance, Dawn Leesh had showed up for her scheduled appointment. And when she showed up, she asked me, you know, what my needs were and I had told her I was looking for more day care for my mother-in-law who is on SSI and we can only afford two days, and then I'm a student and I'm looking for extra days of day care. So when Dawn Lee showed up, she had asked me, you know, what my needs were and how I felt taking care of my mother-in-law who has Alzheimer's, and you know, some of what my frustrations were and that sort of thing. And I had told her that we had gotten a medical—what is it called? A medical, where you can, you know, help make a medical decision. And she...

**SENATOR ALQUIST:** Advanced directive?

**MS. ROSARIO:** Yeah, that. Thank you. Advanced directive, and at that time I thought that covered the financial end of it which, you know, at that time she made me

aware that that wasn't it. But, my mother-in-law is very difficult to take care of. I have six children. My youngest just graduated high school. And so we just inherited her with this disease, so she's at the beginning stages. But, she has eight surviving children besides, and my husband.

**SENATOR ALQUIST:** And you're doing all the care?

**MS. ROSARIO:** Yes. They don't speak to her, because she is such a difficult person, and so they haven't spoken to her for years. And so it's just us at the present time. But, she's in the beginning stages, and so she doesn't read, write, or drive. So a lot of her health care decisions are directly under us. We make sure that she's fed and her, you know, administer her meds on a daily basis, make all of her appointments for transportation, her day care, her, you know, medical situations. My husband takes care of all of her financial needs and pays all of her bills. And, you know, occasionally she likes to go to the Filipino dances, so we try to get her to be involved in some fun activities, as well. And the amount that Social Security pays for her, it--you know, includes all of what...

**SENATOR ALQUIST:** You know what I might suggest? You know, we've allotted five minutes for these segments here, and so I really need you, please, in the essence of time, just to capsulize your point.

**MS. ROSARIO:** Sure. My thing is that, you know, I've done some research here recently and it's for, for somebody to take care of my mother-in-law who's in my situation is that the centers charge anywhere from 4,900 to 5,200. But, they all get breaks and we don't. And so my concern is that what happens, you know, she's only on a \$1,400 a month income. What happens should she need long-term care, you know? And that's one of the concerns and Family Caregiver Alliance is phenomenal. When they came over they provided free legal service for us. They invited us to a caregiver retreat which they give. They have given us brochures on safe return with no questions asked and what were our financial means.

And I just, you know, in being here this morning, I just want to say that Family Caregiver Alliance has, they don't ask any questions. And at the day cares that I take my mother-in-law to, I've asked people, "Have you guys heard of Family Caregiver Alliance?" And they said, "No, we don't want anything to do with programs." And I said, "Well, why is that, because I'm new into it?" And they said it's because whenever somebody comes into their home, they want them to change this, provide that, or they need to call this program or they need to do this. And I said, "I promise you, no. They come in and assess your needs.

They provided what my needs were.” And so I just would like to say thank you this morning...

**SENATOR ALQUIST:** Thank you.

**MS. ROSARIO:** ...and if you would, they are a truly an organization to be modeled after.

**SENATOR ALQUIST:** Thank you. Thank you very much.

**MS. ROSARIO:** Thank you.

**SENATOR ALQUIST:** Next, we have the Panel 3—California’s Diversity: Ethnic and Rural Caregivers. Identifying and discussing some of the unique challenges faced by family caregivers within California’s rich diversity; geographic and cultural, a broad discussion of recommendations and solutions derived from education, training, and collaborative partnerships with higher education, and I would suggest to all our panelists to just hit the highlights, please, because we’re a little, we need to keep on this schedule. So first we have Ms. Benton who’s the executive director Los Angeles Caregiver Resource Center. Welcome.

**MS. DONNA BENTON:** Okay, I’ll hit the highlights.

**SENATOR ALQUIST:** Thank you.

**MS. BENTON:** But, before I hit the highlights, I just want to say “thank you” for letting me come here today. As you already know I’m the director of the Los Angeles Caregiver Resource Center. And until about four months ago, I was also the caregiver for my grandmother who died in June. In many ways I really fit the profile of a typical ethnic caregiver. I’m younger than the average non-ethnic caregiver. I began my responsibility some 15 years ago, and I work and I have a young child at home. Like many ethnic caregivers, I was caring for a single female who didn’t have any other income or source and who lived in my home. The, one of the problems with many of the things that happen with ethnic caregivers is that by having family members in your home, which is the preferred way of caregiving, you actually sometimes are reduced in the services that you can qualify for, because you’ve chosen to live with your family member.

Caregiving in my family is really what we do, and while what will also for many ethnic caregivers when they’re going through formalized assessments, the assessments will show that, oh, gee, there’s no stress for ethnic caregivers. They’re not depressed. Well, it’s because of the type of assessments that are done if the assessment protocol is not sensitive to—

**SENATOR ALQUIST:** Does the assessment protocol need to be fine tuned, and how so?

**MS. BENTON:** In some ways they need to be fine-tuned and make sure that they are standardized with ethnic caregivers in mind.

**SENATOR ALQUIST:** Standardized? Do you have some suggestion of what should be included?

**MS. BENTON:** I think part of that comes out of having an assessment that is clearly for the caregiver and using words that aren't offensive for many ethnic caregivers like many times they'll look for a burden instead of looking for the positive sides of caregiving. If you have caregiving assessments that look at the positive sides first, talk about family strengths, and then you're more likely to pull out those things that are stressful within the family. Just so you know my background, I'm also a geri-psychologist, so that's my other part of my professional life.

**SENATOR ALQUIST:** I though you would have some good responses, yes.

**MS. BENTON:** Yeah. I'm going to skip over the statistics, because it's already in what I have. But, one of the things is I think that when we're thinking about diverse cultures, we've been talking about caregiving. And for caregivers, the diversity is beyond ethnicity. I'm focusing on ethnicity, but you've heard, you've already heard about rural urban differences. You've heard about male/female differences. When it comes to ethnic cultures, one thing is obviously within California and I'm representing Los Angeles, we represent over 200 and some languages within the culture. And that means that we have to have programs that can address people in the language that they're comfortable with, both written and verbally.

I think it is also very important for us to have policies and programs that don't just look at things in general, but really have these individualized assessments. One of the, I'm in the Caregiver Resource Center system and I can really proudly say that the assessments have been delivered according to cultural differences. And I think that this is something that we need to encourage across any programs that are using and assessing caregivers that we really do need to look at having assessments that are culturally specific for ethnic groups. So that's one of my strong recommendations. I hope I've stayed within my minutes.

**SENATOR ALQUIST:** You were great. Thank you very much.

**MS. BENTON:** Thank you for letting me be here and enjoy.

**SENATOR ALQUIST:** Thank you very much. Next we have Ms. Yee, Donna Yee, issues facing the Asian-Pacific Islander communities. Is she here?

**UNIDENTIFIED:** Sorry, Ms. Yee has laryngitis, but I expect to have written testimony for her and will submit that to your office.

**SENATOR ALQUIST:** Thank you very much. Next we have Ms. Keith, Wanda Keith, family caregiver from Los Angeles on the need for culturally-competent support services.

**MS. WANDA KEITH:** Good morning.

**SENATOR ALQUIST:** And welcome.

**MS. KEITH:** Thank you. First of all I'd like to thank Senator Alquist and the Los Angeles Caregiver Resource Center for giving me this opportunity to speak out on behalf of caregivers. My story is long, but I'm going to give you a Reader's Digest version. My parents are still married. But, since my mother's stroke in 2001, she has been living with me. When my mother had her stroke, she was caring for my father who has Alzheimer's. I wanted to take both parents in, but due to my dad's difficult and often unmanageable behavior, I had to place him in a nursing facility nearby my home. However, I am still responsible for his care. I visit, keep his clothing clean, and make sure he is treated with respect. My mom continues to live with me. Her hospital bed and her bedside commode are set up in the dining room. It's the only room with no carpeting. I do have two brothers. One is an amputee living in Texas, and I think he has some dementia. My other brother lives in L.A. and is older, retired, and is my mother's favorite. When I call him, he promises to visit, but never does. I think it's too difficult for him to see our mother so dependent.

Besides my parents, I am caring for my grandchildren who are ages 11 and 13.

**SENATOR ALQUIST:** They're living with you?

**MS. KEITH:** Yes, they are. For nine years.

**SENATOR ALQUIST:** Bless you.

**MS. KEITH:** Thank you. I belong to a support group for my grandchildren, but could use one to talk about what I do for my parents. But, I don't have time to go to that many support groups, nor do I have someone to watch my kids and my mother. Over time, I have come to be very determined to find what I need, because no one is there to offer help. In my quest to find help caring for my mother, I turned to the Yellow Pages and found LACRC. With the respite grant from LACRC, I was finally able to take a deep breath.

**SENATOR ALQUIST:** And how did you use them?

**MS. KEITH:** I'm sorry?

**SENATOR ALQUIST:** How did you use them?

**MS. KEITH:** I hired someone to help me. I did. And she would take my mother out; took my mother to visit my dad and various different things like that, while I stayed home and took care of the house and the children. I had this grant for a nine-month period almost two years ago. But, once it ended, I was back to doing everything by myself, which meant a lot of things did not get done. I wish I was able to attend a 48-hour retreat, but I haven't been able to find someone to take care of my grandchildren and my mother for three days.

I think I have learned that taking a break is very important and I wish I could have more opportunity. I know that for the sustaining of my own health I need respite. I just learned that I am part of a sandwich generation. This is common for Black families in American history. But, in the past it was different. In the past it was pre-planned. The parents would be working, sending money back home, and would come and get the children when they got on their feet. Support has changed in the Black community, and so we need more outside support for our families and should not be ignored by the caregiving system.

As a mother, a daughter, and a Black woman who has often been perceived as strong and able to handle everything, the truth is I am a sensitive, delicate human being who has learned through tremendous hardship to reach out and ask and advocate. I feel fortunate to have the opportunity to be a voice for all who share this common, challenging, and rewarding experience called caregiving. If I had my way, I would love to be eligible for respite all the time, would love to have someone available to visit with my mom and take her to visit with my dad. I would like to see more support groups generated on behalf of their caregivers. I would like to see more services that provide assistance for children and older adults to be aware of and sensitive to caregiving issues. I know many women like myself—Black, single, and caring for both parents and grandchildren. Thank you very much.

**SENATOR ALQUIST:** Thank you very much. **(APPLAUSE)** Next, we have rural issues, and we'll start with Ms. Yarborough, Kathy Yarborough, executive director, Rural Health Design Network. Welcome.

**MS. KATHY YARBOROUGH:** Thank you very much for having me. I don't know if I can talk after that. I'm a wife, a daughter, and many times those two issues conflict and I haven't heard too many people talk about that. I have been a caregiver of my mother until she fell and broke her hip. And my dad and I were both gone, but my husband was at work

an hour away. So she was able to call my husband, he called 911, and talked to her on the phone for the hour it took to get the ambulance there. If you haven't guessed, I live in a rural community. And my expertise is rural community.

I'm a nurse and through a strange career move I became a hospital administrator in a rural community of a hospital that I was told they couldn't find a man for, so would I please take the job. **(LAUGHTER)** And so, my husband and I talked about it and decided that it might be an interesting opportunity. So I took over a hospital that had lost a million dollars, and the hospital's currently a lot of money and we have a new facility. And so I'm here to talk about rural hospitals, their impact on the communities when it comes to caregiving, and some of the work that we're currently doing in the Rural Health Design Network which is an organization which we started about five years ago to attempt to get rural communities, primarily hospitals, to rethink what their role is in providing wellness and health, not sick care. And I have to tell you that in my five years of trying to do what I think makes a lot of sense and that is that community health is not based on a hospital. It's based on community. So through a process of community-based health planning, we are trying to pull all caregivers together into a planning process to look at what type of services are needed for these rural communities. And I will tell you that the eight counties that I work with, every one of those counties has a rural hospital as the basic primary health provider—

**SENATOR ALQUIST:** What counties do you work with?

**MS. YARBOROUGH:** I work with Modoc County, Trinity County, Mendocino County, Kern County, Inyo County, Calaveras County, Plumas County, and one other and I can't think of what it is. But, they're traveled throughout the state. And I travel a lot, actually. After I leave here today, I drive to Kern County, and then on the weekend I have to be back to Inyo County. So I'm on the road a lot. And I'm the primary caregiver for my father; so many times he goes with me. And when my dad goes with me, it's not just my father, and I'm sure many of these people can say, it's the cat and the dog that have to go, also. **(LAUGHTER)**

So I have seen, you know, you have asked, you know, statistics, statistics—

**SENATOR ALQUIST:** What are the major points you'd like to share with us?

**MS. YARBOROUGH:** The major point is we have an uncoordinated healthcare delivery system in the State of California that is broken. And if we don't get communities back into taking responsibility for their own health and wellness, there's not enough money in the entire world that is going to keep everybody fixed. And we really need to start—I

enjoyed the comments from the last speaker, because they hit so much at home with the people that I deal with. I have people in my rural communities that aren't only taking care of their 96-year-old parents when they're also in their 60s, but they're also taking care of their grandkids. And so we have a caregiver issue that starts at age one and goes to over 100. And in rural communities it's lacking. We don't have hospice, we don't have respite. The—

**SENATOR ALQUIST:** You don't have hospice?

**MS. YARBOROUGH:** There's very little hospice in any of the rural--there's none in any of the rural communities that I work in, in their exact communities.

**SENATOR ALQUIST:** And why is that?

**MS. YARBOROUGH:** It's, nobody wants to pay for it. Nobody wants to pay for it and—

**SENATOR ALQUIST:** And it's required, because it was my legislation. It's required that HMOs cover hospice care. And that was years ago that was signed into law.

**MS. YARBOROUGH:** There's many things that are required by the state that don't exist. And they—

**SENATOR ALQUIST:** That's good to talk about, to work on.

**MS. YARBOROUGH:** That's right. I'll start just at a very beginning which is, you've got hospitals out there that haven't been inspected by the Department of Health Services because they know if they go in them they're going to find lots of problems. So if there's a problem, for example, in the state, the County of Modoc right now, they haven't been inspected for a number of years. Somebody filed a complaint. They're in there now with over 100 pages of corrections that the hospital needs to make. And they're losing about \$4 million this year, so how are they going to make these corrections?

**SENATOR ALQUIST:** I have a question. How much are the rural counties using TeleMedi?

**MS. YARBOROUGH:** The rural communities that are using telehealth and telemedicine are limited. And the problem, and this is my opinion, the problem is that we're putting the telehealth and telemedicine equipment in old, outdated buildings that people bypass and drive down the road. So we have, for example, there is one hospital that I am working with that is so old and has been so hanging on the edge of just closing, that you can actually see the tile glue that was put down 15 years ago, 50 years ago as you walk through the hallway. And we expect people to stop there?

You don't have my written report, but one of the things that I have a dream for is that we put the same energy in health and wellness in our rural communities as we do with Caltrans. We spend more money on Caltrans. We spent more money on CDF. We spend more money on most anything when it comes to rural communities than we do for the health and wellness. And I say health and wellness, because I don't think we should be focusing on acute care. I think we should be focusing on what it takes to make a community healthy and sustainable. And all of the parts have to be together. And we're talking about in this group with this testimony, we're talking about some of the most severe issues that we have.

Many of the caregivers that do exist in rural communities aren't on any roll, because, they don't contact anybody. They just take care of their neighbor, they take care of their mother, they take care of their father, and they take care of their loved ones without much help. The issue of caregivers taking care of each other and now taking care of that next generation. In the state of California I know you know the statistic, the state of California's almost twice what the nation is as far seniors taking care of their grandchildren. In most rural communities it's up to 20 percent. All you have to do is look at the local grocery stores in the afternoon and see the 65 and 70-year-olds that are still trudging to work making less than \$10 an hour providing care to their grandkids without any assistance because they don't want to go to any public agency because many times children are then taken away because they don't have the proper home or whatever. So that situation just compounds the situation that we have of the seniors trying to take care of seniors.

I will end with my dearest friend who is a little bit older than I, is practically crazy as I speak. She is taking care of her 95-year-old mother, and now her 95-year-old father-in-law in the same house. And I have become the caregiver of my friend, because I'm afraid she's going to lose her mind over this.

And then as a closing note, it's so complicated to access, you know. Everybody has talked about the system. I, too, consider myself a very intelligent person and somewhat educated. And I still have not figured out how to sign up my father for the pharmacy bill, let alone, manage how and why Medicare decides to pay or not pay. I spend hours on the phone, and I'm doing it for my father. But, there are many seniors out there taking care of each other trying to do that.

And then as just my last comment, one of the biggest expenses that has nothing, shows up nowhere on any statistic is the amount of money people have to spend on gas. That's even before it went up to over \$2 a gallon, driving to receive care. And the surveys

that we've done in the Rural Health Design Network, I have surveyed almost 10,000 people. The average distance that people drive for just primary care is 50 miles. To get any kind of specialty care if they can, it's over 75 miles. So add that up, and that is money that—

**SENATOR COX:** But, your point is what?

**MS. YARBOROUGH:** My point is it's costly. It's very costly to get care.

**SENATOR COX:** I represent 12 counties; the majority of them are rural. My experience is that people who live in some of the rural areas, they live there because they want to live there. It's not a function of the state government.

**MS. YARBOROUGH:** I didn't say it was.

**SENATOR COX:** Well, but, you're saying that, it's a fact of life that if you live in a rural area, you're going to have to drive farther. And if you have to drive farther, you're going to have to pay for gasoline, whatever the price of gasoline is, unless we bring back the horse and buggy. So, you're—

**MS. YARBOROUGH:** I'm just saying that's an additional add on when you're talking about care. You know, Mr. Cox, I don't want to disagree with you, and I know you represent many rural communities, but many of those people who live in rural communities don't want to live there any longer and they're moving. And we have done surveys on that that show that there are a tremendous amount of people that are leaving the rural communities and going to an urban, because they can't find the health services or their health needs.

**SENATOR COX:** I understand.

**MS. YARBOROUGH:** So, that's their decision. But, it's also having a tremendous impact on the infrastructure and the cost of living in these rural communities.

**SENATOR ALQUIST:** I would think also that for some people in rural communities to go back and live in urban areas could be extremely costly, funds that they don't have.

**MS. YARBOROUGH:** Well, the biggest issue is they lose their friends and their infrastructure already that is developed.

**SENATOR ALQUIST:** Which is very important. Well thank you.

**MS. YARBOROUGH:** But, those people are leaving.

**SENATOR ALQUIST:** Thank you very much.

**MS. YARBOROUGH:** You're welcome.

**SENATOR ALQUIST:** Thank you. Next we have Ms. Rossi, Suzanne Rossi, MFT, Executive Director, Mountain Caregiver Resource Center. Welcome.

**MS. SUZANNE ROSSI:** Thank you. Good morning and thank you for giving me this opportunity to speak with you about rural caregiving issues. I am the director of Mountain Caregiver Resource Center which covers nine of the northern-most counties in California. All of mine are very rural. And I'd like to just briefly address some of the challenges in providing services to these very rural areas.

First of all, time, just time getting to some of these places to provide the services is a big issue. If I send a staff member out to go visit a caregiving family, it may take them three hours to actually get there for that initial visit. I have tried to establish out-based, out-stationed offices in some of these larger rural counties like Siskiyou, but it is very costly to have offices there. It lessens the drive time for the staff member, but it is a costly endeavor.

Time's also a factor when we try to provide education and training to these families that live out in the rural areas. To teach some of our classes, which a lot of them are weekly classes, it may be, you know, at least a 300-mile roundtrip to get to an area where we can actually provide some education. That goes along with our support groups. To do monthly support groups, it's quite a ways to get from say, our Redding office out to Alturas in northern Modoc County. So that's a challenge.

Another challenge is the lack of resources. The Caregiver Resource Center's system is set up to provide some very specific services to caregivers such as respite and legal help and counseling. Legal consultation's very important. It helps the caregivers understand the maze of long-term care planning, what's a power of attorney, you know, advance directives. And that actually, if they know those things, it puts their mind at ease.

We know that respite's very vital. Giving a caregiver a break now and then can make all the difference in the world to a caregiver. After they have that rest, they can come back and they can be a better caregiver. They can be a stronger caregiver.

**SENATOR ALQUIST:** And if you could spend some time talking about the things that have not been mentioned so far, we would really appreciate it.

**MS. ROSSI:** Okay, well one of them is the fact that, again, in these rural areas, there's no services. To get an attorney, an elder law attorney, they do go up to some of the rural areas, but it may be once every few months. And then for a day and then there's a waiting list to see him. The respite's a big problem. I may have funding to provide respite to a caregiver in Alturas in Modoc County. But there are no services up there to contract with. There are no respite workers up there. There's no nursing agency. Again, there's no hospice.

**SENATOR ALQUIST:** Now, I think that's one of the biggest things that has been mentioned in terms of the rural care. I mean, even if there are, even if there's money, you don't have the caregivers for the respite care.

**MS. ROSSI:** Yeah, I have the money to spend in that county.

**SENATOR ALQUIST:** And I would think, too, in a rural environment a caregiver can feel more isolated to begin with, and then not to have the respite care exacerbates the issue.

**MS. ROSSI:** Right. So what I've done, what I did was a few years ago I developed a 12-hour certification course where I actually go into some of these areas and train respite workers. I put them through this 12-hour course, so then they can actually go in and provide respite for families. As of now, I've taught this course in 10 different areas. And I've provided training and certification to over 100 respite workers. And these are in areas like Tule Lake and Modoc County and Hayfork in Trinity County.

**SENATOR ALQUIST:** And are you using this model to help some of the other rural counties?

**MS. ROSSI:** I have it, all the curriculum. I have been talking with some other counties.

**SENATOR ALQUIST:** The networking, I think would be very valuable.

**MS. ROSSI:** Yes.

**SENATOR ALQUIST:** Are there some other comments you would like to make in closing?

**SENATOR COX:** I want to ask the question, do you have the flexibility to pay more in a rural area than you might pay in a suburban or urban area?

**MS. ROSSI:** As far as the cost of a service like an aide?

**SENATOR COX:** Yes. I understand the issue about time. Some of that, we make our own decisions about that. I understand that when you're trying to provide services, though, if you got to send somebody 150 miles to provide the service. So, my question is do you have flexibility spending your dollars?

**MS. ROSSI:** Yes, I do.

**SENATOR COX:** So, that's not a problem. You've got the flexibility. Do you have the rules and regulations that are sufficient to do that?

**MS. ROSSI:** Yes.

**SENATOR COX:** So, that's not the problem.

**MS. ROSSI:** It's the problem that there's no workers there.

**SENATOR COX:** Okay. Alright.

**MS. ROSSI:** There's nobody to actually, to buy, to do the service.

**SENATOR COX:** So there's no one, in fact, to provide the services, is what you've said.

**MS. ROSSI:** Right. Right. In many of the counties, in Trinity County, in Lassen County, in Modoc County there isn't a nursing agency to actually work with.

**SENATOR COX:** Is the solution then that in those areas to have a nursing agency?

**MS. ROSSI:** And/or be able to have some type of a registry that we can draw from, that we can actually, that I or one of my colleagues could actually train them to go onto a registry system. The problem with that, again, is the liability issues surrounding having a registry are huge.

**SENATOR ALQUIST:** Could you explain? More so in a rural area than in an urban area?

**MS. ROSSI:** Probably not more so, but just a lot of people will not tackle the idea of having a registry under their agency, because if something were to happen.

**SENATOR ALQUIST:** Okay, Senator Cox, did you want to say...

**SENATOR COX:** I'm also doing dual duty, and I apologize...

**SENATOR ALQUIST:** I understand. I'm just trying to figure out the communications here.

**SENATOR COX:** No, I was communicating to someone in the audience.

**SENATOR ALQUIST:** Hand signals. Oh, okay.

**SENATOR COX:** I apologize.

**SENATOR ALQUIST:** Because I was going to communicate back.

**SENATOR COX:** I particularly appreciate the testimony, and I apologize about being in and out, but I'm very much interested in this subject.

**SENATOR ALQUIST:** Yes, well what we're hearing, and I mentioned several minutes ago, was that you have the resources. You don't have the people.

**MS. ROSSI:** Right.

**SENATOR ALQUIST:** I mean, you could pay them, but you don't have the people even to train it sounds like in the rural areas.

**MS. ROSSI:** Yeah, it's very difficult. Yes, I mean, I have done this course for four or five people that actually come in for a two-day course.

**SENATOR ALQUIST:** Right, that's why I asked if you were using what you are doing as a model networking in some of the other counties, that this was something that was useful to some of the other counties, because it sounds to me also like you're all going to have to be helping each other, whatever we can do at the state level which obviously will take some time. But, we also know that we have to help each other and that's where a lot of this is going to begin. Thank you very much.

**MS. ROSSI:** Thank you.

**SENATOR ALQUIST:** Thank you. Mr.—is it Salinger?

**UNIDENTIFIED:** I'm sorry. Mr. Salinger had a death in the family. He was the caregiver that I was bringing down. He's one of our very rural caregivers.

**SENATOR ALQUIST:** Well, please express our sympathy. Next we have Panel 4, which is access issues, disability and technology, which will be a discussion of the challenges related to disability and access related matters faced by family caregivers as they struggle to provide quality home and community-based care and assistance to loved ones. How can technology help caregivers overcome the challenges of rural service delivery and availability? Does computer-based technology such as the Link to Care program offer solutions? What can technology do to assist and guide families, family caregivers in navigating the maze of publicly and privately funded programs and services? And first we have Ms. Kelly, MPA, executive director, Family Caregiver Alliance. Welcome.

**MS. KATHLEEN KELLY:** Thank you, Madam Chair, for allowing me to address my remarks to technology. I want to set aside my formal remarks and really focus in on the promise of technology, not that I feel that technology itself is a solution. Technology needs to be integrated within larger program structures for the most appropriate use, but it can offer some great promise in terms of extending services into areas such as rural communities, and also offer options and choices for families to receive information and support through other modes of communication rather than face to face.

This was an issue that we looked at within the Caregiver Resource Center system for about the past decade. Knowing that actually our demographics of caregivers were changing, almost everybody in the room probably has a story. We're all of the baby boomer age. That's a more typical caregiver issue, as you've heard today. And we also noted that three-fourths of U.S. households have internet access and that when looking at use studies of who was on the internet looking for what information, 80 percent of users had actually looked for health information. Primarily those were women that were looking for information

for themselves or most likely for a friend or family member. So we knew that the internet was going to be a great powerful tool 10 years ago when we started investigating this issue.

The interesting thing about the technology field is it offers a lot of opportunity for public/private partnerships to form. And we formed a number of these over the years. What the Link to Care program that you mentioned was done with California Endowment financing with a partnership with them, but also with the University of Wisconsin, Madison, where we looked at best practices, disease management models, and how we could incorporate that into an online environment for our families knowing that many of them were in the workplace, were very busy, and this offered an opportunity for them to, for families to really get qualified information. People who come to Link to Care have to be members of or clients of, excuse me, of the CRC itself and it's California specific. So the information they were getting was qualified and vetted. It's not that we have too little information. It's that we have too much.

**SENATOR ALQUIST:** We have too much information?

**MS. KELLY:** We have too much information. If Google is now trying to put every book online and families actually can go into the Library of Medicine and do searches of all the medical literature, we actually have an excess of information that's almost overwhelming.

**SENATOR ALQUIST:** So how should families access the internet when it comes to elder care and disability care?

**MS. KELLY:** Well, I think, okay, let me stop and say there's two kinds of components to the information that families are looking for. There's many, many qualified sources of information, you know, obviously including our site of information for consumers. And these are vetted—

**SENATOR ALQUIST:** And your site is called?

**MS. KELLY:** Caregiver.org.

**SENATOR ALQUIST:** Caregiver.org. So if somebody wants to—

**MS. KELLY:** But, we just one among many. I just want to make that—

**SENATOR ALQUIST:** Well, I want to put it out there, because people will be looking to seeing what we're saying in terms of where to go to get these resources on the internet.

**MS. KELLY:** Right. Well, there's the information components of which people can find all sorts of information about health services and health diagnostic information treatment and care plans and so on if they're savvy about using the internet. But, what

families actually don't find is local, very easily, local resources. For example, we work with families all over the country and including, obviously, California. If somebody from out-of-state was trying to find services in California, they'd have to do many searches, because there's really no single page that's within state government that really looks at the long-term care services in a one-stop shopping environment.

**SENATOR ALQUIST:** In your local community.

**MS. KELLY:** I'm just talking about on a state page; on any state page.

**SENATOR ALQUIST:** Statewide.

**MS. KELLY:** Because, the public information system as it exists on the internet actually reflects the fragmentation of the long-term care system. So every different piece of information is in a silo department—Department of Rehab, Department of Aging, Department of Mental Health and so on.

**SENATOR ALQUIST:** So we need something both that—

**MS. KELLY:** You need to collapse, kind of presence.

**SENATOR ALQUIST:** Condenses it both at the state level as well as local.

**MS. KELLY:** That's right.

**SENATOR ALQUIST:** So someone can go to Campbell or whatever and find the resource.

**MS. KELLY:** Find the information. Now, there are efforts underway on a county level with Network of Care which has combined the local resource information of components. It's not available in every county of California, nor is it easy to find if you're just looking for a state presence. So somehow these things have to be connected together and really have to be supported. But, that's one thing. When families come to us, they're looking not only for information about the diagnosis, but they're actually looking for where can I access services?

Now, for example, if you're looking at how people get to services, I have to say I went on just because I wanted to see if it was true, the Department of Motor Vehicles—the long chastised, I'm waiting in line Department of Motor Vehicles—has a way for people to renew you license, your registration, make appointments, everything online. I have to say within social service environment, there's really not a way to begin on line applications for any of the publicly funded programs in the State of California. There was some movement for enrolling children into the expanded Medi-Cal program online access that the California Health Care Foundation and others had worked on. But, there's not a component for long-

term care. So, you're looking at me. I'm a caregiver. My husband has cancer. There's not a way for me, the typical Californian, to really access these services in an online presence. So I think that would be one of my recommendations in terms of a take away message today is that we really need to combine these kinds of efforts a little more effectively.

The other component, I'm sorry that Senator Cox has left, but there are a number of infrastructure that's already in place—

**SENATOR ALQUIST:** It's being televised. He can still see it.

**MS. KELLY:** Okay—in the telemedicine, telehealth communities. We actually are doing another public/private partnership right now with the Bristol Meyers-Squibb Foundation. In Northern California, in rural areas utilizing the network that's been put in place with the Northern Sierra Rural Health Network, a combination of all of the community health clinics in the northern part of the states within nine counties, and we're utilizing their network to provide video conferencing capacity for consumer education.

**SENATOR ALQUIST:** I have a question. You know, we talked about video conferencing, oh, I remember my early years in the Assembly, you know, '97, '98, back there, both for education as well as for health care, the long distance, the rural, and have we progressed in the last seven, eight years in using telecommunications, teleconferencing for health care, or have we not and where do we need to take it?

**MS. KELLY:** For the network that's been put in place, they do utilize it for telemedicine consults and for professional education. What they hadn't used it for was for consumer education. Within other environments like the Veterans Administration, they probably do almost a million telemedicine consults a year primarily looking at radiology consults and specialty practices.

**SENATOR ALQUIST:** So they do it for veterans.

**MS. KELLY:** And you can do this within the rural health network, they also utilize the experts from outside of the area. If you don't have a neurologist, you can't have a neurology consult. And I think they most often work with the University of California at Davis.

**SENATOR ALQUIST:** So what do we do, I mean, we have some women who are veterans, but the majority are men, and so what do we do for women?

**MS. KELLY:** Within telemedicine consults?

**SENATOR ALQUIST:** Within telemedicine.

**MS. KELLY:** Well, within this Northern Sierra Rural Health Network...

**SENATOR ALQUIST:** Since women are still the majority of the caregivers.

**MS. KELLY:** Yeah. It's not the—well the Veterans operates its own universe. But, for the folks in the Northern Sierra Rural Health Network, that's actually health clinics and hospitals that are part of their membership. So everybody accesses the same kind of telemedicine consults. In fact, later on today we're doing a CMA-approved training out of U.C. Davis for primary care physicians on dementia and also on caregiving, how to diagnose and very practical kinds of information.

**SENATOR ALQUIST:** That would be very important, because what, people over 75, at least 20 percent have dementia?

**MS. KELLY:** Absolutely. And these are the first line of defense.

**SENATOR ALQUIST:** And it goes higher.

**MS. KELLY:** What Ms. Yarborough was alluding to, they really are the first line of defense.

The other thing I wanted to touch on is that there's kind of low level technologies that are in use and one of them we're experimenting right now with a program that will start later on this week and that's just using the telephone for very specific kinds of training for caregivers, so they can access this information for free.

**SENATOR ALQUIST:** How would that work?

**MS. KELLY:** You dial into a conference call and we have our staff that is going to be speaking, this week it happens to be on communication with siblings. And they can dial-in in the early evening hours from their home or at work during lunch time. And so this is—what I'm offering today is to look at the more expansive practice of technologies, integrating it into an existing \_\_\_\_ system.

**SENATOR ALQUIST:** And that program, which sounds very interesting—how about doing something like that statewide?

**MS. KELLY:** We are doing it statewide.

**SENATOR ALQUIST:** You are? Oh, okay. Sounds great.

**MS. KELLY:** Yes. This is a statewide program. And we borrowed the idea from cancer care in the northeast. So we really imported the best practice.

**SENATOR ALQUIST:** Great.

**MS. KELLY:** I just have one more—

**SENATOR ALQUIST:** And in closing?

**MS. KELLY:** Yes, I do. In the area of health care and chronic care management, I think there's a great deal to be learned from best practices looking at home monitoring for chronic care conditions that are hooked up within health systems. And this is something that I would actually urge further investigation and support in terms of integrating acute and long-term care systems, it is actually one of the ways to go and very frail individuals can be monitored at home with video phones; very low cost equipment. But, what that does is that it provides a way for the medical staff who are monitoring that person's care to have constant information and secondarily, it frees the caregiver from the constant worry of wondering where's the tipping point in the process of that person's care.

**SENATOR ALQUIST:** So is that being used now and how much?

**MS. KELLY:** It's being experimented with in some systems. Again, I have to point to my friends in the Veterans Administration. They have probably now close to 20 to 25,000 frail veterans, high-end users of hospitalizations and high end, multiple kinds of chronic care disabilities. And they've used a variety of different technologies, again employing it and embedding it within an existing service system so they can monitor them.

**SENATOR ALQUIST:** So they're using video?

**MS. KELLY:** They can use videophones; they can use Health Hero, Health Buddy which is a messaging system. You can use glucose monitoring equipment, things that read back into the health system that we'll be able to monitor whether there's any outliers.

**SENATOR ALQUIST:** And then who's doing the monitoring?

**MS. KELLY:** The, it's fed into the health record and when there's outliers in the kinds of readings that they get, then that's a trigger for somebody, a nurse, to call up the family and find out what's going on.

**SENATOR ALQUIST:** Are you, when I say you, the organization, are you actually videotaping some elderly folks when they're alone or what is—I'm trying to figure out exactly. Are you doing things like sending measurements to some computer and when the measurement is out of the paradigm; then somebody steps in to help.

**MS. KELLY:** It's usually the measurement, it goes into the computer and it steps out of a paradigm. But, there's low end, low cost videophones where nurses make routine telephone calls, which is a lot less money and a lot less time, on a daily basis to look at diabetes management, for example. That's a usual customary use of that particular technology. And so they can do a check in by video phone. It's something that we haven't

really implemented or looked at implementing. I would suggest that this would make some really excellent demonstration projects with some of our folks that live in outlying areas.

**SENATOR ALQUIST:** Thank you very much.

**MS. KELLY:** Thank you.

**SENATOR ALQUIST:** Thank you. Mr. Burns Vick, consultant, disability and independent living. Welcome.

**MR. BURNS VICK:** Thank you very much, Senator. I appreciate your leadership and being very engaged with your questions today. I'd be remiss if I didn't say you have excellent staff, which you know, and we appreciate all of their help.

**SENATOR ALQUIST:** Yes, we're very fortunate.

**MR. VICK:** And I'm glad Mr. Cox, Senator Cox is back, because I'll try to respond to couple of the questions. I've been around since '76 and been a consultant in the disability, mental health, aging, family caregiver world. I've done quite a bit of work in employment, special education, etcetera. I was involved when this system was first started. Former Assemblyman Art Agnos carried the legislation in '83-'84. It was the only new social program that former Governor Deukmejian signed into law, and he did it in part because this was a middle class program that was not going to be regulated. It was going to have a lot of flexibility between the contracting of the Department of Mental Health and now the 11 community-based non-profits that are, in fact, carrying out this good work.

Just for—I'm going to fill some gaps here. There's a separate line item for this system. It is under the Department of Mental Health. The total appropriation, which is a very small amount of money in the overall scheme of things, is 12.747 million for the entire system. That includes the voucher authorization to purchase respite or whatever is flexible and needed by families. Back to the Senator's question I heard earlier—do you have the authority to pay more, etcetera? There is flexibility. What's important there is that this is an outcome oriented program.

The public policy that was enunciated in the state statute which resonated with both sides of the aisles and everybody that supported this program is that the family caregiver, for the first time, is the client. And therein lies a little bit of a problem only in the sense that when you're trying to coordinate where so many programs and so much money goes toward the person with the disability, the person who has whatever condition, etcetera, requiring care and treatment and government involvement, if you will, it sometimes or can be a conflict. And that goes to the heart of one recommendation I'm going to make today

on access. And that is you will find that one of the biggest missing pieces here is technical assistance and referral for family caregivers to find out how to make their homes accessible, physically accessible. And I won't go into the details, but you have plenty of caregivers that will tell you that they spent thousands and thousands of dollars trying to find someone to build ramps, etcetera, those basic needs.

The public policy problem here goes to the interagency coordination problem which I hope you all will try to address, is that you have a number of state departments that are responsible for providing a range of support, if you will, and technical assistance on access, physical and programmatic access. And as people are fond of saying in Sacramento, there's these silos—Department of Rehab, Department of Mental Health, Department of Aging. Somehow there needs to be a central focal point. Maybe it's the Health and Human Services Agency should coordinate all of those programs and services or somehow come up with a website or something that allows—and remind folks that this is a middle class program. Fewer than 15 percent of those served are Medi-Cal eligible. So you're really talking about folks that, employed, want to pay taxes, want to find incentives to keep working and care for somebody at home. That's the real major broad brushstroke here. Access is a big issue.

Secondly, in the heart of the issue of interagency coordination, and I see your, and by the way, Senator, I think this is the first time since I've been here in '76 there's ever been a hearing just on family caregiving, paid, unpaid family caregiving. We've had a lot about in-home supportive services and workers there, but this is truly a milestone. And I appreciate, again, your doing this.

If this committee is in the nature of holding an interim study here, I think there are a couple of very good questions that could be asked of the Department of Aging in particular and the Department of Mental Health. You've heard earlier about the National Family Caregiver Support Program and you'll hear a witness on the next panel talking about it. There are 33 Triple-A's, the federal money, because of the Older Americans Act, comes to the California Department of Aging and goes down to the 33 Triple-A's. It is not an outcome-oriented system. A lot of, I'm fond of saying a lot of gold dust is spread around in contrast from the Triple-A's out to community-based groups. There is no coordination in my view. There is absolutely very little outcome orientation and for the State of California and I'm assuming this Legislature cares about the use of federal funds.

**SENATOR ALQUIST:** So does that mean the money can just be used any way...

**MR. VICK:** I couldn't hear. What?

**SENATOR ALQUIST:** Does that mean the money that comes down to the 33 local agencies; there are no criteria for using the money.

**MR. VICK:** That's correct and there's no state oversight. You're correct. No outcome orientation in the—

**SENATOR ALQUIST:** No outcome orientation, no accountability.

**MR. VICK:** Correct. That's exactly right.

**SENATOR ALQUIST:** So it sounds like we need—

**MR. VICK:** And quite frankly, you asked that question, several questions like could you tell us how much federal money, which is a lot more than this Caregiver Resource Center system gets, what are your outcomes. Let me just give you a simple, simple example. The fundamental public policy in this state's statutory scheme for the Caregiver Resource Center system is to either prolong or avoid out-of-home placement. You can easily quantify and there are reams of papers and documentation and research showing that for every maximum of \$425 a month voucher for respite care and for the family's support counseling and for the support groups that saves the state and the federal government a lot of money, because it would be just as easy to put somebody in a nursing home. You know why? Very simple. Because easy, you know, not emotionally, but otherwise, because the state and the federal government pays the entire tab. Now that's, you know, that's also a disincentive as a policy issue here. And I remember even former Governor Wilson tried to tackle this in the early '90s where he started talking about how can we get the counties to go with a share of costs if they, in fact, are going to, you know, have individuals in their district in nursing homes. Because if I, if you, for example, hopefully not, had to put Senator Alquist into some facility or program, it would be a whole different funding scheme than if you kept him at home, perhaps if he was eligible, he wouldn't be, but in home supportive services.

**SENATOR ALQUIST:** Yeah, I'm the program.

**MR. VICK:** Yeah, right. But, my point is that there is some policy issues about who pays for what and there's some major disincentives, and why this system is so easy to track in terms of outcomes. You can't, in my view and I hope you can prove me wrong, I don't believe you'll find the Department of Aging can tell you with any certainty what the outcomes are for all the money that they've been sprinkling around through the Triple-A's. So I think some fundamental questions are needed.

Now let me end, \_\_\_\_ me any time.

**SENATOR ALQUIST:** And we'll work on that.

**MR. VICK:** Okay, you can see me any time in Sacramento, as you know. So, I did want to mention that if there was a way to get some basic, maybe you would want to go through the Health and Human Services Agency. Maybe we can get Secretary Belshé to focus on this. But, how do we take all these different silos of programs and how do we somehow use—her favorite mechanism right now is the Olmstead Advisory Committee, which is a very important entity. It was established by executive order by the Governor when he vetoed Senator Chesbro's bill to establish an Olmstead council. What's important about that? Their whole focus is how do we enable individuals who receive public funding, Medicaid, Medi-Cal, instead of how can we help them spend their money if they want to? Where's the flexibility we need? But, what they're missing, and this is a key point for this particular hearing, is they are not actively engaged in looking at what does it take to divert people from nursing home placement? Divert people by family caregivers and others who support someone staying at home, not going into out-of-home placement.

So I think there's some mechanisms and I know you've got other witnesses who came a long way, but...

**SENATOR ALQUIST:** Some very good comments. Thank you so much.

**MR. VICK:** Yeah, I'm glad to give you some more. And thank you, Senator Cox, for joining us.

**SENATOR COX:** On the Triple-A's, now I'm not sure I understand all I know about this. But let me just ask you a question. Do they all have the same mission?

**MR. VICK:** I can't hear you, what?

**SENATOR COX:** Said the triple A, and I'm not sure I understand all there is to know about that. But, let me just ask that question. Do they all have the same mission?

**MR. VICK:** Not to my knowledge, and they're not the oversight.

**SENATOR COX:** So, and there are how many—

**MR. VICK:** There are 33 Area Agencies on Aging serving the state.

**SENATOR COX:** And so they don't all have, even though there is a director of—is there a director of Aging? Is that what they're called? That director of Aging doesn't have the ability to say to these Area Aging that, "Okay, here's your mission"?

**MR. VICK:** In my view they don't and a lot of it's predicated on having some authority to do some regional planning and so they will all tell you this is their plan for the

region. But what I think is missing in the context of where is—how do we get a coordinated, integrated, long-term care system is how do we get those 33 Triple-A's which kind of respond to the Department of Aging?

**SENATOR ALQUIST:** What I would like to see and is and we will work on it is some kind of legislation that would say these are the basic outcomes we need to have for all of our families. And you can even allow the different agencies and the different counties, because some are urban and some are rural, to have some flexibility in how they approach it. But, the outcomes should be consistent.

**MR. VICK:** Excellent. Excellent.

**SENATOR ALQUIST:** And then how do we pull resources and work with all the different silos, as you would say, to, you know, help produce that?

**MR. VICK:** Right and having a consumer-directed, family-supported system where the consumer really does make the decisions with others is important. Thank you again. I'm available, because I live here in Sacramento. I'd be glad to talk to you.

**SENATOR ALQUIST:** You're welcome. Thank you so much. Thank you. Next we have, is it Ms. Robinson? Assistant director, Fresno/Madera Area Agency on Aging. Welcome.

**MS. JEAN ROBINSON:** Thank you, Senator Alquist, Senator Cox, members of the Subcommittee. My name is Jean Robinson. I'm a certified rehabilitation counselor. I'm an assistant director and I work for one of those 33 Triple-A's.

**SENATOR ALQUIST:** Oh good!

**MS. ROBINSON:** The good news is our agency has vision, we use common sense, and we do it out of necessity. I want to talk about two key issues, how we have worked on collaboration to streamline systems within our agency and within our community.

Our agency is unique that we do do a lot of programs. We offer a lot of programs in house. Triple-A's have the opportunity to subcontract some services outside. We choose to do them in-house. And our focus has been case management with the goal of keeping people in their home to avoid nursing home placement.

**SENATOR ALQUIST:** Is what you're doing typical or atypical when you say in-house or out-of-house?

**MS. ROBINSON:** Typical, well, I'm going to say it's about two-thirds do it in-house, one-third do it outside under several different entities. What we found out in our case management programs is the issue of caregivers. When we initially enroll the client and I'll

refer to the client as the patient, the patient had to voluntarily participate in our program. They had to have informed consent. They had to sign releases. And we noticed three things happened over the years that we served our clients. They improved and stabilized and graduated from our program and no longer were dependent on the system because we taught them how to maneuver and contact their doctors and manage their medications and all those issues that were already discussed today. A lot of our clients did pass away in the home, but we saw a large group decline and they cognitively declined. And what happened is we were no longer able to obtain that consent. So now what was happening is indirectly I'm talking to the caregiver. But, the focus was still on the patient. How's the patient?

So what we realized within our own agency is we kept some of the funding from the family caregiver support program to administer a case management program in-house. So what we now have is a continuum of care. I'll start with the patient. When I no longer can dialogue with the patient, when they no longer can have—they're no longer my primary contact, I can close their case and now work with the family caregiver.

**SENATOR ALQUIST:** So could I, just to clarify what I'm hearing is that at the Caregiver Resource Centers, the client is the caregiver and with the area agencies, the 33 agencies, the client is the patient until you get to the point where the patient no longer can be—what is the word I want to use?

**MS. ROBINSON:** We don't put a diagnosis on it. When they cannot—

**SENATOR ALQUIST:** When does, where's that fine line? When does—

**MS. ROBINSON:** When they can no longer understand a conversation and their judgment's impaired.

**SENATOR COX:** So there's always a test of competency.

**MS. ROBINSON:** Pardon, sir?

**SENATOR COX:** So there's always a test of competency, because you can't give consent without competency.

**MS. ROBINSON:** What we find out is each month when I'm trying to make contact with that patient, they no longer can tell me what happened day to day. And they keep deferring. It's a common sense approach that all of a sudden I'm dependent on third party for information.

**SENATOR ALQUIST:** You see, I think there's a need for the patient to be the client and I think there's a need for the caregiver to be the client. And I think both of those services need to be provided, so one thing I'm going to—

**SENATOR COX:** At the same time?

**SENATOR ALQUIST:** I think they're both, yes. I think they're both really important.

**SENATOR COX:** I certainly would like to have some discussion about that, because I'm not certain that, I'm not certain that you can do that.

**MS. ROBINSON:** What we found in our agency, we actually talked about that, but we again, being efficient, duplication of services, because now I'm going to take two social service agencies and only provide services to one family. And we did address it. But, what we've done is we have been able to, when we initially get that patient, stabilize them, get all the equipment, meet their needs. And what we do when we transition over to caregiver, we are teaching the caregiver the tools they need to take care of the patient, but also to take care of themselves. And we've found that it's worked really well. That's what we've done in-house. We're the only triple A in-house so far that is doing a case management program that's worked successfully for the past year.

But, we've taken it one step further. And I want to talk about the collaboration with our CRCs.

**SENATOR ALQUIST:** So you are, right, you are working together which is why you are here.

**MS. ROBINSON:** Definitely. Yes. One of the things that we're really pleased with is our agency has decided we were able to purchase a piece of property. We call it our senior resource campus. And I just would like to read a list of some of the members on the campus. We have the Valley Caregiver Resource Center, Older Adult Mental Health, Adult Day Health Care Resource Center, Adult Protective Services, Health Insurance Counseling and Advocacy Program, the Ombudsman Program, Elder Abuse Detective Units both city and county, we have a Linkages Case Management Program for individuals 18 years and older who are at risk for placement in nursing homes, we have the Home Delivered Meal Program, In-Home Supportive Services, Public Authority, Respite Registry, the Multi-purpose Senior Services Program, Veterans Administration program, Senior Employment, and our in-house Family Caregiver Support Program, and finally information and assistance.

**SENATOR ALQUIST:** So what you've done basically is removed some of the silos and you're all working together.

**MS. ROBINSON:** We are all—

**SENATOR ALQUIST:** A wonderful role model.

**MS. ROBINSON:** We have city agencies represented, we have county agencies represented. We also, we're a special district of government. What we've done is we've gotten rid of all the layers and at a local level realized we're all serving the same client. And there might be a time when the client needs to be with Valley Caregiver Resource Center, and then they have a crisis in the family and they need to be followed by APS. We can walk over to APS, say here's this client, here's what's going on, close out the case. Let APS serve them. When APS gets them stabilized, they may realize that one of the key issues was the client really needed Older Adult Mental Health. So we're able to help the family, whether it's the patient or the caregiver, navigate the whole entire system. It truly is a one-stop shop. And for government purposes, it reduces duplication of services and it's very cost-effective.

And if I could convey one message—what we need to see happen is this needs to be carried out at a higher level. This isn't something that came down from the CRCs or CDA or Department of Mental Health. This is something that we chose to do because to us, it was good, common sense. Thank you.

**SENATOR ALQUIST:** Thank you so much. Thank you.

**SENATOR COX:** It's a good idea.

**SENATOR ALQUIST:** It is. Is there any public comment? We have one lady who would like to, who has not spoken and if you could identify who you are and limit it to two minutes.

**MS. CELIA ESCOVEL:** Thank you, Senator. I'm Celia Escovel. And I'm wearing three hats today. I'm an associate state director for ARP and I have a letter for your testimony on behalf of our over three million members in California, many of whom are caregivers. We work very closely and are part of a coalition with the CRCs. I am also here with the California Commission on Aging and chair of the Commission's committee on the Long Range Strategic Plan for an Aging California. And the Senator earlier asked, excuse me, some questions about what could be done. We already have a blue print in the state that we can start with that long-range strategic plan that does cut down some of these ...

**SENATOR COX:** Who is "we"?

**MS. ESCOVEL:** We meaning the State of California; we, the people of California have a long-range strategic plan.

**SENATOR COX:** But, who put together the blueprint?

**MS. ESCOVEL:** The blueprint was put together, mandated by Senator Vasconcellos' bill, 910. It was signed; the original plan was signed by the previous Governor right before he left. It is a living document. It can be adapted. It does address some of the issues that we have discussed today.

**SENATOR ALQUIST:** I was principal co-author on that bill.

**MS. ESCOVEL:** Exactly, so which is why I figured you would know about it. We already have a blueprint. It's a plan that can be changed, so we don't really need to reinvent the wheel.

I echo a lot of what has been said here today. I also come to you as a daughter who cared for a mother with dementia. And it is a huge issue. I think that everything that has been said today applies. I won't repeat what has been said, especially in two minutes. But, just to say to you, first of all, thank you, because this was stated this is the first time we have addressed the issue of the unpaid family caregivers. And just on a point where the Senator spoke earlier, Senator Cox, it's not a question of that we choose to live in a rural area or in an urban area, but as Californians, we should have the choice of services regardless where we choose to live in the state.

**SENATOR ALQUIST:** Thank you.

**SENATOR COX:** Well, you know, let me just say in all fairness, there's just sometimes that's not possible. You know, I recently was up in Modoc County and there was a person who was complaining about the bus service. Well, the reason you don't have a bus service from Modoc to Reno is because there's no ridership. And so there are just some things that are not practical.

**MS. ESCOVEL:** True, but health is practical for all of us.

**SENATOR COX:** Well, and I concur that health is, it's important. But, when you make that decision that you're going to live in a rural area, you also, I think, it comes with the recognition that some of the services that you might get in an urban area are not going to be there.

**MS. ESCOVEL:** Respectfully, we'll agree to disagree. I think as a taxpayer anywhere in California you should have some, in some cases will be limited as you say, limited access versus in an urban area, but as a taxpayer in the state, you should have access to some services even in a rural area.

**SENATOR COX:** Well, we don't have a disagreement about that. What we have a disagreement about is what those services are, I guess.

**MS. ESCOVEL:** Right and I think this is a critical service. Thank you.

**SENATOR ALQUIST:** Okay, Mr. Vick, you wanted one minute?

**MR. VICK:** I want to make a concrete suggestion. Back—long story short, there was an effort several years ago in the prior administration to see if we could have an interagency agreement between the Department of Aging and Mental Health in relation to the federal money that was coming in under the Older Americans Act. And we were told no. And the long-term care counsel was unsuccessful in trying to work with that. The point—there were people on waiting lists for respite and other services in this system where the state departments could have, if there had been a political will in my view, move some of the money, just some of it, into the system, take people off the waiting list and not have to redevelop the whole system.

**SENATOR COX:** Whose decision was that?

**MR. VICK:** And so I think the interagency agreement issue is something you might want to explore.

**SENATOR COX:** Whose decision is it to have an interagency agreement? Is that the secretary's decision to have an interagency agreement? Is that something that needs legislation and/or can the agency secretary make that determination?

**MR. VICK:** I think that it's possible and I think some good lawyer at the agency and maybe with the Legislature should research, is there a prohibition under the Older American Act for a state, any state, to use some of the money with existing structure in a state to do contracting? And if there's a decision saying no, then I'd do a little lawyer shopping. But I think you basically—basically the Legislature should try to require some interagency agreement. I think it can be done.

**SENATOR COX:** Let me just, Madam Chair?

**SENATOR ALQUIST:** Sure.

**SENATOR COX:** Is it a situation where, excuse me, is it a situation where, is it your belief that the secretary does not have the ability to say to—both of those departments come under the Secretary of Health, do they not?

**MR. VICK:** Correct.

**SENATOR COX:** And are you telling me that you don't believe the Secretary of Health, Ms. Belshé in this particular situation, has the authority to say, "Look, you two are going to work together whether you like it or not"? Are the agencies so strong and independent that they don't have to do, they don't have to work together?

**MR. VICK:** Two answers to your question. The first is yes, they can do it. The problem is I've been told there's a legal prohibition the way the Older Americans Act puts the purse strings, if you will, to the state on how the money's used. And that needs to be \_\_\_ first. I think Secretary Belshé could do that if she feels she has the legal authority. If not, then we need to go to our congressional delegation and say change the Act.

**SENATOR COX:** And this is federal?

**MR. VICK:** Correct; just federal under Older Americans Act.

**SENATOR COX:** I understand.

**MR. VICK:** This is the national Family Caregiver Support Program we mentioned earlier.

**SENATOR COX:** So, it's not really the California Legislature's job to amend the—it's the federal government. So, we need to deal with our congressional representatives.

**MR. VICK:** And I think if you all choose to send a letter in part of this interim study to Department of Aging or Secretary Belshé, asking that question, "Is there anything that prohibits an interagency agreement?" That would be a very worthwhile question.

**SENATOR ALQUIST:** We could do that.

**MR. VICK:** Thank you.

**SENATOR ALQUIST:** We're getting ready to close. Senator Cox, do you have some comments to make?

**SENATOR COX:** Well, Madam Chair, I thank you for holding these hearings and I apologize. Today, it was just one of those days for me, but I appreciate very much the testimony. I recognize the seriousness of the issue and the fact that we do, in fact, need reform. Now some, I suppose we're probably going to have disagreements as to how some of that will occur, but there's not anything in my mind that prohibits cooperation and seeing if we can't get the best out of the system recognizing it's probably not going to be perfect. But, I certainly want to thank you all who testified this morning. I'm very much interested in your responses. Even if we have disagreement, I'm interested to know what you have to say and to think because as people age, we have different kinds of problems.

I do want to elaborate, by the way, that if everybody stops doing what they're supposed to be doing, we got a more serious problem than caregivers. You know, caregivers stop giving, that's a problem. But, if teachers stop teaching and nurses stop nursing and legislators stop legislating and police stop policing, well, this whole thing comes apart.

But, we need to, we got some issues, Madam Chair, and I certainly look forward to working with you.

**SENATOR ALQUIST:** And I know, Senator Cox, that we share in the ultimate goal of wanting it to be a good situation for our elders.

**SENATOR COX:** Absolutely.

**SENATOR ALQUIST:** And some thoughts. First of all on a, for those who have not provided a copy of testimony, please give it to Ms. Hancock today. We would appreciate that. Some other thoughts—I thought this was a terrific hearing. And I want to commend and I know what it's like to be a caregiver, and what a choice of love it is and devotion, because everything else we have. And I do believe that we need to make it a little easier for family to take care of family; for caregivers to take care of family. And I do believe there is a way to do that. Certainly Senator Vasconcellos' legislation a couple years ago, SB 910, right?—which I was principal coauthor of—is one step. And I also see we need to go beyond that.

I think it was very clear in the hearing today that the baby boomers are getting older and what is kind of being held together with glue now is going to break apart at the seams in another 10 years. And so we shouldn't wait 'til 10 years from now to deal with it, but we should do it while we have the opportunity of building in some flexibility, some coordination of services. Certainly, what is being done with the Fresno/Madera area agency I think is a wonderful role model, and something that we all should be looking at.

To me a couple things that really popped out—one is that, you know, 78 percent of those elderly and disabled are being taken care of by family and friends. And on the other end it's eight percent that are being taken care of totally in the facility and so there needs to be some fairness to see that those that are being taken care of out of an act of devotion and love with family and friends have some kind of support in that area. I will tell you personally, my husband who's still mainly using a walker, but can barely stand up and for anything that requires more than 10 steps, you know, I put him in the wheelchair and there we go. Sometimes, you know, if we're out somewhere and I'm pushing him along in a wheelchair and I'm 61 and he's 97 and I'm doing okay, but it's uphill and what have you, I see these little old ladies, frail, pushing big, heavy men in wheelchairs. I don't know how they do it. And so there needs to be some accommodation to help people who are helping others that way. And so we need to look at the caregiver support systems, which I do believe are fragmented. And certainly we've heard from professionals who are having a very tough

time navigating the system. And so someone who doesn't have any experience in this area, I don't know how they do it. And to do it with very limited resources to boot, which in the end can make them almost have nothing later in their lives is not a way we should be treating people in California.

So, those are some of the issues. I know we need to work on the technology. We need to work on the rural issues. I think that this subcommittee cares a lot and that we will certainly be able to work together to work with you to take this a step further to make it the situation better than it is. So I want to thank you for coming. I know some of you came from great distances and had a lot of other places that you needed to be today. So thank you so much. We really appreciate it.

**SENATOR COX:** Madam Chair, before you adjourn, let me just suggest to you that perhaps I don't know whether how soon you plan to have another meeting, but certainly you ought to have some additional meetings and at some point in time we need to get into the discussion about folks arriving at the need for the type of care that we're talking about. There needs to be the resources there. There needs to be the incentive for the individual to accumulate those resources themselves. It's not just, so perhaps at another time we can talk about how we do that, whether or not it's some sort of tax incentive, whether or not it's an insurance program. We need to have some other discussion—

**SENATOR ALQUIST:** We would love to have that talk, and I mentioned earlier that there was a bill held in, and I'm on Rev & Tax, and I certainly would have voted for it, but it was held in Senate Rev & Tax. It's a Patty Berg bill, AB 298, that would have created a tax credit, would have extended the current tax credit which was what, \$500?—the maximum, and it was held in committee. And so, but I think to have another hearing specifically on some of the fine-tuned things we really need to do, I think is a great idea. And certainly we will have the time to do this. Thank you very much.

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