

**TESTIMONY OF
Bentley Lipscomb
Florida Department of Elder Affairs
BEFORE THE
Special Committee on Aging
September 10, 1998**

By Secretary Lipscomb:

Good afternoon. I am pleased to be here today to bring you greetings from your future -that is to say, Florida.

Florida IS the future for aging issues.

The Sunshine State has a higher percentage of elders in its population than any other state.

Over the next 20 years, many other states will be where Florida is today, demographically.

We in Florida believe that the issues that we are grappling with today will be the challenges of long-term care for other states and the nation in the future.

But wait, you may say. Today's topic is family caregiving, not long-term care programs.

I would reply: Family caregiving IS long-term care.

I don't think we can say too often or too strongly . . .

... that the vast majority of elder care is not delivered in skilled nursing facilities or other institutions, but at home.

The families of America meet the real challenge of aging.

Our challenge is to help support them.

We have come to that conclusion in Florida because we see the contributions that families make to elder care every day.

But sometimes, it helps to have the numbers.

Recently, our Department revised its standard client assessment instrument as part of our effort to target resources to those clients who need help most.

The researcher who undertook this challenge at our request was Dr. William Weissert of the University of Michigan School of Public Health.

Dr. Weissert did some sophisticated statistical analysis of almost 20,000 case files of Florida elders.

His findings underscore the vital importance of caregivers in elder care:

A client without a committed primary caregiver is almost FIVE TIMES MORE LIKELY to be recommended for placement in a nursing home than one with a caregiver.

The Caregiver Factor is more than TWICE AS SIGNIFICANT AS CANCER in predicting whether an individual is institutionalized. . .

Three times as significant as stroke...

Four times as significant as dementia.

These are interesting findings. They underscore the importance of caregiving . . .

... And they can help us make the case to policymakers for effective caregiver support programs.

But before we make the case to others, we should do some listening, too.

On Oct. 19 and 20, our department will sponsor the first-ever state-sponsored Caregiver Forum in Sarasota.

We will focus on helping caregivers of patients suffering from Alzheimer's Disease and Parkinson's Disease.

We are organizing this forum to give caregivers the opportunity to interact with other caregivers... .. to learn from each other ...

... and to offer their insights to professionals.

Caregivers are telling us that they like this approach.

Many caregivers tell us that they sometimes feel "talked down to" by the professionals.

Caregivers also like another aspect of the forum.

We have provided for day care for frail patients while caregivers attend the sessions.

That means that caregivers can get a needed break from the unrelenting strain they are under.

That brings me to my next point: The importance of respite in supporting caregivers.

In Florida, we believe that respite can play a crucial role in supporting caregivers through respite programs.

But we also have found that different caregivers have different needs.

So we have developed a number of strategies to help different caregiver populations.

One of the first successes we had was FAVOR -- Florida Alzheimers Volunteers Offering Respite.

This program provides respite for low-income or minority families who are caring for Alzheimer's

families.

We have almost 200 FAVOR volunteers in this program, and they have provided service to more than 400 families per year.

We want to express our thanks to the Administration on Aging and to the Congress for its support of this model program.

We also want to express our thanks for the valuable assistance we have gotten from the Americorps program.

We have two of the very few Americorps projects that focus on elder respite care.

More than 100 Americorps members provide respite to almost 1,000 clients and caregivers.

Of course, Florida has a higher proportion of older people in its population than any other state.

So our state has developed its own programs.

Our Department's Alzheimer's Disease Initiative provides respite service in all 67 counties in Florida.

We provide both in-home and facility-based services to the caregivers of Alzheimer's victims.

Also, we recently launched a new respite-service initiative called Respite for Elders Living In Everyday Families.

This program places special emphasis on serving unserved or underserved families - particularly low-income families.

RELIEF provides respite on evenings and weekends, when those families have few respite options.

Its sponsor, Sen. Bettye Holzendorf of Jacksonville, told us that this was one of the easiest bills she ever passed.

It seemed every legislator had a caregiver and patient in his or her family.

Just three months after Sen. Holzendorf began working on her idea, the program had cleared the Legislature.

In the first nine months, we have enlisted almost 160 volunteers who have provided 36,000 hours of service.

We attribute this program's fast start to the fact that policymakers see the need for caregiver support.

They see the need not in staff studies or research projects, but in their own families and neighborhoods.

And they have been willing to support this initiative for that reason.

While we have had some successes, we can do a lot more to support family caregivers.

Your staff has asked me to identify some of these challenges to effective caregiving.

I've touched on some...

Attitudes toward caregivers...and funding, of course.

We meet less than 2 percent of the respite need for Alzheimer's in Florida.

We cannot afford to allow this situation to continue.

By spending a few hundred or a thousand dollars to support a family caregiver at home, we may be able to avoid institutionalization at a cost to Medicaid of \$31,000 per year in Florida.

Other challenges emerged from a recent meeting with the Americorps members who give respite and support to caregiving families.

They told heartbreaking stories...

... Stories of octogenarian caregivers with serious health problems trying to lift and turn and bathe patients bigger than themselves.

... Stories of caregivers battling not only the day-to-day challenges of caregiving but loneliness and isolation as well.

But I believe that the most significant barrier lies not in caregiver support...

... but in the fundamentals of long-term care.

America has no long-term care system today.

We have pieces of long-term care, and some of those pieces do a good job.

But we have no coherent system that supports elders and families as aging increases dependency.

Creating that system as this Nation heads into the Longevity Revolution must be our highest priority.

Caregiver support must be a major part of that system.

Thank you.