

Note: this text is the basis of the ASA's oral remarks. It should be used with the understanding that some material may be added or omitted during her presentation.

**Remarks of Josefina Carbonell**

**Assistant Secretary for Aging**

**U.S. Department of Health and Human Services**

**“From Enactment to Action”**

**National Family Caregiver Support Program**

**Conference**

**Washington, D.C., Thursday, September 6, 2001**

**“Working Together to Ensure our First Steps are the *Right* Steps”**

**Introduction.**

Good morning. I want to thank *all* of you for coming together from across the United States to help implement the National Family Caregiver Support Program.

In a few moments, I will introduce to you the Deputy Secretary of the U.S. Department of Health and Human Services Claude Allen. I am so pleased that Claude could be here with us today to show the Department's support for and commitment to older Americans and their caregivers.

Today, I want to share with you some of the things we will be working to accomplish at this

conference. It is both an honor and a privilege to kick off THE VERY FIRST AoA Technical Assistance Conference on the National Family Caregiver Support Program. We live in a time when we are experiencing a lot of “FIRSTS” — and all of them are causes for celebration: to the aging network, to older Americans and their caregivers, and to me – both personally and professionally – as the new Assistant Secretary for Aging.

I believe that I am the FIRST Assistant Secretary in six years NOT to stand before you to give you the status of the pending reauthorization of the Older Americans Act! We can thank many of the people in this room for making that happen and for helping us to establish the National Family Caregiver Support Program – a vitally important and critically needed new program.

This also is the FIRST time we are meeting with a fully funded National Family Caregiver Support Program that is up and running throughout the United States. And we have the support of this Administration because President Bush has requested an increase for the Caregiver Program for Fiscal Year 2002 (request is \$127 million - currently funded at \$125 million).

And one of the very FIRST official acts of Secretary Tommy Thompson was the releasing of \$113 million in caregiver funds to the states in February of this year.

Being the “first” is both exciting and challenging. Yet, being “first” also brings with it responsibility and accountability. Today is our first step. And today and tomorrow present us with the opportunity to

ensure these *first steps* lead us in the right direction.

Over the next two days I hope to establish a healthy and productive dialogue that will allow *you* to let us know what you expect from us on the Federal level, and for *us* to identify how we can become partners and work together to help our nation's caregivers.

We all must keep in mind that the long-term viability of the National Family Caregiver Support Program will depend in large measure on our demonstrating positive *results* from the services provided and showing that the program outcomes have justified the resources invested. Congress recognized this need by requiring that states establish standards designed to assure the quality of services and that states collect data in a standardized way to enable evaluation of the program.

Additionally, the National Family Caregiver Support Program was developed on a strong research foundation. The importance of research continues to be acknowledged through the National Innovation Program, which is designed to demonstrate new approaches for developing services for families and other informal caregivers.

We need to begin working together right now to utilize these and other mechanisms to assure that the program, over the long run, meets the expectations of the families we serve, ourselves, the Congress, and the many other parties that are interested in this program.

I hope you join me in my dedication to the concept of aging services as *family services* – which is what the National Family Caregiver Support Program is really all about. Families *NEED* access to information, respite care, counseling, training, and supplemental services that can help them meet their *real life* challenges. As states and communities put into place the five components of the program to address these needs, I challenge all of you to be flexible, creative, and open to new ideas.

I believe that each of us will leave this two-day conference energized, enthusiastic and equipped with the information that is needed to carry out the National Family Caregiver Support Program in a way that is effective and consumer and family-oriented.

### **Points to Address During the Conference.**

This is my vision of what we hope to accomplish over the next two days.

#### **1. Learning from Each Other and Ensuring Flexibility.**

We will continue to learn from the states that *already* have caregiver programs in place. It is important for us to hear about some of the things that have worked for the states and some of the things that have not worked, so that those of you who are just beginning to implement *new* programs can gain valuable insight and avoid any unnecessary pitfalls.

Secretary Thompson has stressed, and I want to emphasize that I understand and *appreciate* the fact that every state – every community – every family – is different. This Administration is looking for, and

actively ENCOURAGING — flexibility on the state and local levels in implementing federal programs, including caregiving.

This conference presents a wonderful opportunity to gather and exchange information so we can integrate successful tools and strategies in the most appropriate and culturally proficient manner that can later be applied on a state, local, and regional basis.

In talking about “firsts” I want to say that I am excited to be the first Assistant Secretary who has worked at the grass-roots level as a service provider. *I UNDERSTAND* that those closest to the issues are those who are often the most likely to have some of the best solutions and ideas. I know from my *own* experiences that many of the lessons I learned as a service provider on a *local* basis are lessons that, I believe, can be applied on a national and *global* basis. And so we look to YOU for solutions as we all work to serve our older Americans and their caregivers more efficiently.

I know the issue of caregiving well, having been one for many years (for my aunts and now my own parents). So I know, first-hand, the joys and sorrows, the challenges and struggles that both older persons and their caregivers experience on a daily basis. One of my personal goals as your Assistant Secretary is to remain in close touch with other caregivers. As a caregiver, myself, I understand that *that* person, who is providing full-time care to his or her loved one, without a break in sight, knows what *they need the MOST*. So, I hope to be visiting with caregivers on an on-going basis over the next several years asking them how *we* can better serve *them and their families*.

As we work to develop the National Family Caregiver Support Program, it is important to hear what our caregivers are telling us they need and to shape the program accordingly. To help keep us focused on who we are here to serve, it is my pleasure that Carolyn Johnson, a caregiver, and founder of Caregivers in Action, is here with us today, and will be presenting a plenary session on the National Family Caregiver Support Program – from the Caregiver’s Perspective.

## **2. Implementing and Publicizing the Program Effectively.**

The second thing I hope we can accomplish here is to look for the most effective ways of implementing the program, measuring its effectiveness, and finding ways to expand, improve upon, and tailor it as necessary so that it fits the needs of individual consumers across America. I want to ensure that every single American knows about this program and knows how to access help in their own communities, especially those that are considered “hard-to-reach,” diverse, remote, poor, or disadvantaged. I ask all of you to think about how you might better publicize your programs and services. Older Americans and their caregivers are hungry for information and help – they just don’t know how to access it.

## **3. Focusing on Intergenerational Care.**

The third thing I’d like to strive for is to renew our focus on intergenerational care, which is one of my priorities. Some of you might be familiar with the program I ran in Florida. As the President of the Little Havana Activities and Nutrition Centers, I worked to ensure that our services and programs reached *across* generations. There, we had young people working as volunteers delivering meals to

homebound elderly and assisting in social and exercise activities. At the same time, we had older adults working with youth in education programs and as trained “elder” childcare workers in our Rainbow Day Care Centers providing day care services that would not otherwise be affordable to low-income working families. So in discussing how best to implement the National Family Caregiver Support Program and to maximize limited resources, I encourage you to consider innovative programs you might not have used before. For example, let us try to incorporate information about caregiving in health curricula in high schools and expand community service opportunities for high school students, whereby they provide support to caregivers, either formal or informal, for credit. I know of one high school in New Jersey that mandates such community service for their students. In this case, some of the students are working with older adults who are attending adult day service centers. Intergenerational programs are beneficial, cost effective, and rewarding.

#### **4. Incorporating the President’s Faith-Based Initiative.**

Fourth, I hope that you will look to ways to ensure that in-home and community-based care is available to help older adults achieve the promise their senior years bring, and that we can build upon the success achieved throughout the aging network so that all older Americans can lead engaged and productive lives in their communities. I hope you will think of “caregivers” not just in terms of the immediate family, but also those caregivers who assist older persons in the community such as those from faith-based organizations and all our volunteers. As you know, President Bush’s Faith-Based Initiative is a major effort to improve access of faith-based communities to federal programs. AoA already has the infrastructure in place through the Older Americans Act, so I ask you to look to ways to facilitate and

improve access to faith-based organizations to better serve our older population and their families. In addition, let's not forget to utilize these communities to conduct outreach to caregivers who may not be connected to the "aging network." The Robert Wood Johnson Foundation Faith in Action Initiatives provides an excellent source of volunteers, which can be used to supplement the services we provide under the National Family Caregiver Support Program.

#### **5. Ensuring Consumer Flexibility.**

And fifth, I hope you will join me in creating optimum flexibility for the consumer and ensuring that older persons have more options and choices about their health care and living arrangements. These are just some of the ideas I hope you will keep in mind. I am delighted that the National Family Caregiver Support Program recognizes the needs of grandparents raising grandchildren as well as the unique needs of Native American elders and their caregivers. Likewise, I am pleased that we will be able to assist those caregivers who are responsible for children with mental retardation or developmental disabilities, aged 18 years and younger. We must also strive to be innovative in how we implement the program for these special populations.

Together, we must also be prepared to face the challenges that lie ahead – specifically those of the baby boom generation. The year 2030 is right around the corner. By then, one in five people will be 65 or older. So while we work on implementing the program now for the first time, we must also keep an eye to the future. Again, we must ensure that these *first steps* lead us in the *right direction*.



**Closing.**

Before I close, I'd like to mention another "first." Very soon, I will be announcing the awards for innovative grants authorized under the Older Americans Act National Family Caregiver Support Program. I will also be announcing new grants to Native American caregivers. These grants will be another tool in helping us to identify innovative approaches to supporting caregivers and determining the value of replicating these models in communities across America.

Again, welcome to the first National Family Caregiver Support Program Technical Assistance conference! Today we take the *first steps* to create a program that is *first rate*. And we must never lose sight of the consumer for whom this program was designed – our older Americans and their caregivers – and the need to find ways to serve them best.

I thank you, and I hope you have a productive and meaningful exchange over the next two days. And with that, I'd like to introduce to the Deputy Secretary of HHS Claude Allen.