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BABY BOOMERS AT THE GATE: ENHANCING INDEPENDENCE THROUGH INNOVATION AND TECHNOLOGY

HEARING

BEFORE THE

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UNITED STATES SENATE

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BABY BOOMERS AT THE GATE: ENHANCING INDEPENDENCE THROUGH INNOVATION AND TECHNOLOGY

TUESDAY, MAY 20, 2003

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee convened, pursuant to notice, at 2:05 p.m., in room SD–628, Dirksen Senate Office Building, Hon. Larry Craig (chairman of the committee) presiding.

Present: Senators Craig and Breaux.

OPENING STATEMENT OF SENATOR LARRY CRAIG, CHAIRMAN

The CHAIRMAN. The Senate Special Committee on Aging will convene. Let me first of all thank our panelists for their flexibility in meeting the scheduling change that we had that pushed this hearing into the afternoon. I want to thank you for that.

Also, I want to thank Senator Breaux for being here. Yesterday, he held, I think, a very successful hearing by all accounts dealing with senior access, and certain protocols and other activities that relate to the formulation and development of pharmaceuticals and other interests and issues.

Both John Breaux and I work to share this committee and its authority. We think this is certainly an issue for all Americans. It is not a partisan issue. The business of aging, I think we find that Democrats and Republicans age at about the same rate. [Laughter.]

Senator BREAUX. I'm aging faster. [Laughter.]

The CHAIRMAN. Just wanted to check him out and see if he was awake there. No.

But good afternoon to all of you. I am pleased to convene this hearing in recognition of Older Americans' Month and to explore a wide range of policy issues impacting older Americans and their families. Such an ongoing dialog is imperative since the first wave of baby boomers will turn 60 in less than 3 years.

Today, we will hear testimony from various innovative thinkers. We will hear about the Older Americans Act and the Family Careviger Program, a new approach to Medicaid service delivery, plans for modernizing our nation's senior centers, and the technological opportunities available to seniors.

It is estimated that in 2006, over three million baby boomers will turn 60 and become eligible for older Americans services. This new wave of seniors will have a very different set of characteristics from

the previous generation. It is, therefore, critical that we in Congress review and design national policies to address these new demands.

I believe the central strategy for meeting the new challenges of the 21st century is that of innovation, new and bold programs and technologies that enhance independence for all older Americans. Today's testimony will highlight some of these innovations.

We will hear about the Older Americans Act and its newest addition, the National Family Caregivers Program. It is well known that family caregivers are on the front lines of long-term care for older persons in this country. It is important that these programs continue to evolve and assist family caregivers so they can meet the challenges of caring for loved ones in their own homes. A new approach in providing these services to caregiver will be shared with us today.

I look forward to the testimony on Medicaid consumer-directed services pilot project, a new concept that allows seniors and their families to direct their own care. An example of a self-directed service is that of cash and counseling program, which will allow older persons who have trouble managing their finances to hire a financial manager of their choice.

National Senior Center Week, which ended last Sunday, was a national recognition of the importance of senior centers. Of equal importance is the need to vigorously explore a new vision for our nation's senior centers. Although senior centers are created and funded at the local level, they serve as critical delivery points for various Older Americans Act services. I look forward to the testimony on how senior centers will evolve to meet the interests and the demands of a new generation of older Americans in the 21st century.

Finally, assistive technologies are also becoming a major tool for older Americans. Promising areas of computers to human interaction that will allow older Americans to live more independently will be discussed.

So before I turn to and introduce our first witness of our panel this afternoon, let me turn to my colleague from Louisiana, the senior Senator, John Breaux. John.

OPENING STATEMENT OF SENATOR BREAUX

Senator BREAUX. Thank you very much, Mr. Chairman. Thanks again for holding today's hearing. I would just point out how important it is to talk about where we are headed. We are truly in a perfect storm, if you would, as far as the aging of America is concerned in the sense that we are about to receive a huge number, the largest in generations, of individuals who will be becoming eligible for senior programs, 77 million baby boomers. On top of the large number of people who are going to become eligible, that large number of people are living a lot longer than any other generation in American history. So we have a double problem of having a lot more people who will live a lot longer.

I have jokingly said many times said that good news and the bad news is that people are living a lot longer, and the bad news is that people are living a lot longer. How will we take care of them? Who is going to pay the bills? How much is it going to cost? How are

we going to be able to do what we as a society need to do with regard to allowing people to live not just longer lives, but also healthier lives and happier lives as they get older?

So that is the real challenge of America, among the most serious challenges, and everything seems to be coming together at one time, which is truly a perfect storm as far as the geographics are concerned. So hopefully, we will hear some ideas today about how to address these problems. Thank you.

The CHAIRMAN. John, thank you very much.

Our first panel today is Assistant Secretary Josefina Carbonell. Josefina, welcome before the committee. The Assistant Secretary will discuss issues related to the Older Americans Act, will address the rebalancing of the long-term care system, the importance of family caregiving and the challenges the Older Americans Act programs face in the demand of the new baby boomers, much as my colleague has referred to.

So with that, Assistant Secretary, welcome.

STATEMENT OF JOSEFINA G. CARBONELL, ASSISTANT SECRETARY FOR AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Ms. CARBONELL. Thank you very much, Chairman Craig, Senator Breaux, and members of the committee for inviting me to testify at this very important hearing. It is especially important during Older Americans' Month. This month, and this year's theme, is "What We Do Makes a Difference."

As we have discussed before, both globally and here in the U.S., we are witnessing one of society's greatest achievements, an extension of longevity due to advancements in medicine, public health, and technology. At the Department of Health and Human Services, we are updating and reenergizing old programs and developing new ones that empower and serve older Americans in their communities.

Also I am pleased to announce that today, the Departments of Labor and Health and Human Services have transmitted a Report to Congress that examines the future supply of long-term care workers in relation to the aging baby boom generation. Ensuring the adequacy and the availability of direct care workers is a critical goal of the Administration and we have been taking steps to prepare for the increased demand for direct care workers. Our report recommends how to retain existing long-term care workers and attract new pools of them. It urges continued support of many of the Bush Administration's existing efforts to address the growing demand for long-term care workers.

Let me begin with the Administration's initiative aimed at rebalancing the long-term care system to create real choices in home and community-based care. Currently, 75 percent of public long-term care funding goes to institutional care, while many people prefer to remain at home.

Our guiding principles for caring communities are that we give seniors and family caregivers affordable choices and options; that they have control over their consumer choices and what kinds of programs they wish to access; that the information is there for them to access the programs; that we make sure that we support

the family caregivers, one of our key components of the rebalancing long-term care system initiative; and that quality services be available.

In the 2004 budget, the President has proposed a $1.75 billion program titled "The Money Follows the Person Rebalancing Initiative," as well as State systems change demonstrations that promote home and community-based care alternatives. These initiatives represent an historic turning point in Federal long-term care policy.

Shortly, the Administration on Aging and CMS will jointly issue a competitive grant announcement to develop one-stop shop resource centers. This program will make it easier for consumers to learn about and access existing long-term care options, including alternatives to institutional care.

Family caregivers are a key component to ensuring that older Americans can continue to remain at home. More than 23 million Americans are providing assistance to a family member, and interestingly enough, 30 percent of the current workforce is caring for a relative. If we were to pay for these services, it would cost $257 billion per year. This is more than the amount spent on formal home care and nursing home care combined.

According to our national data, one out of four caregivers report difficulty providing care because of their own physical limitation. More than six in ten take care of someone who is at least 75 years old. Eighty-eight percent report that our services have helped them provide care longer, and 95 percent of our caregivers are very or somewhat satisfied with the services that they have received.

At listening sessions in communities throughout the country, I hear the recurring difficulties. Whether it is the 51-year-old son who is the sole caregiver for his blind mother, the 80-year-old woman who is struggling to bathe, feed, and care for her 102-year-old mother, or the grandmother who lives on a working farm in Idaho and is struggling to take care of her grandchildren, the message is the same. Just give me a little help, a little hope, a little relief, and I can take care of my loved one in my own home. Caregivers tell me that the Family Caregiver Program is the best program that the government provides and many people have thanked me with tears in their eyes.

Let me just share a couple of other personal stories. A disabled individual is caring for his wife with Alzheimer's and in need of 24-hour care. With help from the Arkansas Caregiver Program, she is bathed and gotten ready to attend adult day care. This results in time for him to receive his own therapy and attend to his own needs. Twice, an elderly Kentucky grandmother had put off needed surgery because she would be unable to care for her 11-year-old grandson. The program arranged for home care and personal care for her own needs following the surgery. The North Carolina program installed a wheelchair ramp in the home of a daughter so that she could get her father in and out of the house without having to carry him.

Technology is also playing a very important role in addressing the two greatest concerns of caregivers, safety in the bathroom and transporting the care recipient. Things from non-skid surfaces to grab bars and other safety features are being installed in bath-

rooms and in homes across this country. Videos are instructing caregivers on the best way and the safest techniques for getting disabled individuals in and out of vehicles. Nurses are electronically monitoring frail elders and their caregivers in between doctors' visits.

So you see that the caregiver program is really creating a new way of doing business in the aging network by focusing on caregivers while allowing consumers to have choices.

Our data further indicates that over 3.8 million caregivers have been empowered with information in the last year and approximately 436,000 caregivers have been served, far exceeding our target of 250,000. Significant numbers have also been reached with intensive direct services in counseling, training, respite, and many other supplemental services.

We look forward to releasing the complete caregiver report at our national summit in September, which is designed to strengthen the capacity of State and community service networks.

Today, I am delighted to release the new PSA called, "Who Cares for the Caregivers?" currently being sent to over 3,000 stations throughout the country. We would like to let you be the first to preview this 30-second spot following my testimony.

As you see, the administration is taking comprehensive action to prepare for the aging of the baby boom population. An important component of this effort will be the National Aging Services Network, which is well positioned with assets to shape our future, including a deeply ingrained focus on the consumer; on commitment to early intervention and the social model of care; a national network grounded in the community and capable of delivering an extensive array of low-cost services; a proven track record in leveraging resources; and the capacity to reach out and serve private-pay consumers as well as consumers who are low-income, culturally diverse, and isolated.

We cannot afford to maintain the status quo. By working together to create systems of care at home as well as institutional settings, we can develop a comprehensive approach to health and long-term care that truly reflects the needs and preferences of older Americans.

Now is the time to join forces to ensure that the promise of independence, choice, and dignity is fulfilled for all Americans. Thank you very much, and I would be pleased to answer any questions you might have.

The CHAIRMAN. Thank you. You had a video that you wanted to show? We will watch this first. [A videotape was shown.]

Well, that was simple and straight forward. Thank you. That obviously communicates a very clear message. Thank you very much for your testimony, Madam Secretary.

[The prepared statement of Ms. Carbonell follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Washington, D.C. 20201

Testimony of

Josefina G. Carbonell

Assistant Secretary for Aging

U.S. Department of Health and Human Services

before the

Special Committee on Aging

United States Senate

May 20, 2003

Thank you very much, Chairman Craig, Senator Breaux, and Members of the Committee for inviting me to testify at this important hearing on innovative services and technologies that can help empower our growing numbers of older Americans. It is especially appropriate during Older Americans Month, 2003 for which our theme is "What We Do Makes a Difference."

Both globally and here in the United States we are witnessing one of society's greatest achievements – an extension of human longevity more dramatic than the preceding 4,500 years. Advancements in medicine, public health, and technology make it increasingly commonplace for people to live 80, 90, 100 or more years. With the first of the baby boom generation reaching age 60 in less than three years, we must update and re-energize old programs and comprehensively develop new ones that can better empower and serve older Americans in their communities and in settings that work best for them. For example, the types of senior centers that were familiar to our parents and grandparents twenty years ago will transform to community and family centers of the future, with more of an appeal across the generations.

I am also pleased to announce that today, the Departments of Labor (DOL) and Health and Human Services (HHS) have transmitted a Report to Congress that examines the future supply of long-term care workers in relation to the aging baby boom generation. Ensuring the adequacy and availability of direct care workers is a critical goal of the Administration, and we have been taking steps to prepare for the increased demand for direct care workers. HHS has estimated that the demand for direct care workers in long-term care settings will grow from approximately 1.9 million workers in 2000 to somewhere between 5.7 and 6.6 million workers in 2050. This increase, over 200 percent, in demand will be occurring at a time when the supply of workers who have

traditionally filled these jobs is expected to increase only slightly. Our report, which I have brought copies of for Members of the Committee, makes recommendations on how to retain existing long-term care workers and attract new pools of workers. It urges continued support of many of the Bush Administration's existing efforts to address the growing demand for long-term care workers. These include:

- Supporting State and local initiatives that increase the recruitment and retention of direct care workers – such as the DOL's Workforce Investment System, Registered Apprenticeship Programs, and HHS' Real Choice System Change Grants, and the National Initiative for Direct Care Workers in Long-Term Care Settings;
- Continuing to support the training and education of long-term care workers through programs such as the One-Stop Career Centers system established under the Workforce Investment Act (WIA), programs for youth and adults funded under the WIA, Pilot Demonstration Programs, H-1C Labor Attestation Programs, the National Panel on Nursing, and HHS' Medicaid Infrastructure Grants, Advanced Education Nursing Program, Nursing Education and Practice Program, Nursing Workforce Diversity, and Nursing Education Loan Repayment and Scholarship Programs;
- Continuing to examine issues of worker compensation, benefits, and safety through programs and projects such as DOL's Occupational Safety and Health Administration's National Emphasis Program, and HHS' National Clearinghouse of Innovative Provider Practices;
- Supporting ways to find new sources of workers and insure the adequacy of the existing workforce through DOL's Transition Assistance Program, and HHS' Nursing Workforce Diversity Program;
- Continuing to support research that provides more information to policymakers on the quality and availability of the long-term care workforce such as HHS' Regional

Workforce Studies, National Survey of Nurses, Nursing Forecasting Model, Direct Care Workforce Survey, and through the work of DOL's Bureau of Labor Statistics.

One recommendation has specific relevance to the subject of today's hearing. Our Departments have recommended that we need to explore new technologies in recruitment, education and training, record keeping and patient care. Staff at both Departments are actively implementing these and other recommendations.

Now I would like to take a few minutes to give you an overview of how the President, the Department of Health and Human Services, and the Administration on Aging (AoA) are working in partnership with communities and families to support longevity and productive aging. My remarks will focus on three priority initiatives designed to empower older persons and to better support their preferences and needs. These priorities are:

- To make it easier for older people to access an integrated array of health and social supports by re-balancing the long-term care system;
- To help older people stay active and healthy through health promotion and disease prevention activities; and
- To support families' efforts to care for their loved ones at home and in their communities.

Rebalancing the Long-Term Care System

Let me begin with the Administration's initiative aimed at rebalancing the long-term care system to create real choices in home and community-based care. Currently, 75 percent of public long-term care funding goes to institutional care, while many people prefer to remain at home.

If we are to support and expand our network of caring communities to enhance the long-term independence of aging baby boomers, our system of care should be designed to provide all Americans with the following opportunities:

- Affordable choices and options that promote people's independence and dignity and their preference to remain at home.
- Consumer control and meaningful involvement in the design and delivery of the programs and services that affect their lives.
- Information that empowers people to make informed decisions.
- Easy access to a full range of health, long-term care and environmental supports.
- Support for family caregivers – our most important partners in caring for older Americans.
- Assurances that people are getting the highest quality of care available.

In his 2004 budget request for CMS, the President has proposed a $1.75 billion program over five years to encourage states to transition people from nursing homes or other long-term care institutions to the community. Under this proposal, the "Money Follows the Person" Rebalancing Initiative, Federal funds would provide financial incentives for States to develop and implement strategies to re-balance their long-term care systems in a way that is responsive to consumer needs and preferences. The centerpiece of the program is a focus on individuals who are unnecessarily in long-term care institutions when their preferences and needs would be better met in a community setting.

The President's FY 2004 budget would also fund State systems change projects and demonstration programs that promote home and community-based care alternatives, including those designed to provide respite care services. These, and other re-balancing initiatives represent an historic turning point in Federal long-term care policy.

In concert, we are launching several initiatives this year to support the establishment of a more balanced, consumer-oriented system of care.

- Within the next several weeks, the Administration on Aging and the Centers for Medicare and Medicaid Services (CMS) will jointly issue a competitive grants announcement to support the efforts of States to empower consumers by developing "one stop-shop entry points" to long-term care, called resource centers. This program will make it easier for consumers to learn about and access existing care options, including alternatives to institutional care.
- We will also issue a grant announcement to support the work of our area agencies on aging and community service providers to develop evidence-based models that help to prevent and/or reduce the risk of chronic conditions among the elderly.
- We will be working with the CMS, the Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and other agencies on a technical assistance program that will help States learn about the most promising practices in state efforts to-date at rebalancing long-term care.

Working in partnership with States and area agencies on aging, local community service providers, and thousands of dedicated volunteers and advocates for almost 40 years, the Older Americans Act has helped to establish a strong foundation for providing more home and community-based care. Today, Older Americans Act programs serve more than 7 million older adults annually -- 3 million of whom have intensive care needs. We need to continue to work to provide greater access to home and community-based systems of care.

Health Promotion/Disease Prevention

The Administration is leading a focused initiative on Health Promotion and Disease Prevention activities for persons of all ages. Just yesterday you heard testimony from Dr. James Marks of the Centers for Disease Control and Prevention in which he indicated that we must be more aggressive in addressing the prevention of disease and disability among older Americans.

The statistics related to this topic are alarming – three out of five American adults are overweight or obese. The costs are distressing – an estimated $117 billion is lost to our economy each year due to this epidemic. The problem is growing – since 1990, the prevalence of obesity has increased by 50 percent. And the effects are deadly serious – sedentary lifestyles and inadequate diets account for 14 percent of all deaths in the United States.

Scientific evidence reveals that we can significantly reduce at least five major chronic conditions – diabetes, heart disease, cancer, depression, and arthritis – through increased physical activity and improved nutrition. These benefits can be seen among persons of all ages.

A far-reaching prevention strategy was launched earlier this month by HHS Secretary Tommy Thompson. The $15 million "Steps to a HealthierUS" initiative, which advances President Bush's HealthierUS goal of helping Americans live better, longer, and healthier lives, will support innovative community-based programs that demonstrate approaches to reduce the prevalence and impact of diabetes, asthma, and obesity. The President's fiscal year 2004 budget proposal would substantially increase the investment in this initiative to a total of $125 million. As Secretary Thompson said in announcing this initiative, "The

communities awarded these grants will help lead the country in changing our healthcare model from one that only treats the sick to one that successfully promotes better health."

The Administration on Aging is a partner in this effort, fostering greater collaboration between aging network providers at the State and local level with public health departments and community health centers. We are also sponsoring a "USA on the Move: Steps to Healthy Aging" program, focused on empowering older individuals to eat better and to move more. By late summer, we will produce a *Guide to Eating Better and Moving More.* This guide will be designed to help communities establish walking programs for older individuals. It will be available in print and on our web site, and include materials for program managers, as well as for consumers.

In addition, as part of our health promotion activities, step counters are being used as a pilot demonstration at nutrition projects throughout the country to inspire older individuals to walk more. Program goals center around the number of steps participants take per day, and are customized for each individual based on age, functional ability, cultural preferences, or health status.

Support for Family Caregivers

The key to ensuring that older Americans can continue to remain at home is the support they receive from family caregivers. More than 23 million Americans are providing compassionate assistance to a family member, neighbor or friend. Approximately 30 percent of the current workforce has some responsibility caring for a relative. This rate is expected to increase to 54 percent by 2008.

If we were to pay for the care provided by these relatives and friends to their loved ones, a recent study estimates that it would cost $257 billion per year. This is more than the amount spent on formal home care and nursing home care combined.

At listening sessions in communities throughout the country, one of the recurring messages I hear time and time again is the considerable physical demands, emotional distress, and losses caregivers experience. Whether it is the 51 year-old son who, as the sole caregiver for his blind mother, spends his workday worrying how she is doing, or the 80 year-old woman who is struggling to bathe, feed, and care for her 102 year-old mother, or the grandmother who lives on a working farm in Idaho and is struggling to take care of her grandchildren – the message is the same – just give me a little help – a little hope – a little relief, and I can take care of my loved one in my home.

Staying in the home is what the caregiver and those who need caregiving, overwhelmingly prefer. Yet caregivers face serious difficulties. According to national data the Administration on Aging collected about individuals who provide caregiver support to elderly individuals served by the Older Americans Act:

- One out of four (24 percent) report difficulty providing care because of their own physical limitation.
- Nearly two out of five (37 percent) are also providing care for someone else.
- More than six in ten (65 percent) take care of someone who is at least 75 years old.

Other recent research indicates that caregivers suffer a mortality rate 63 percent higher than that of non-caregivers.

The National Family Caregiver Support Program

It is for these reasons that, in community after community throughout the country, caregivers tell me that the National Family Caregiver Support Program is the best program the government provides. Many people have thanked me for the program with tears in their eyes.

Findings from AoA's national data about caregivers who received assistance under the National Family Caregiver Support Program reveal that:

- 88 percent report that Older Americans Act services help them provide care longer than they would have been able to without the services.
- 72 percent report that the services help a lot in their efforts to provide care.
- 95 percent are very or somewhat satisfied with the Older Americans Act services provided to the elderly person they serve.

Let me share just a few of the stories of the tens of thousands of caregivers the program supports.

A disabled individual is caring for his wife who is diagnosed with Alzheimer's disease. He does not want his wife to go to a nursing home, but he is unable to help her with her personal care and the fact that she needs 24 hour care. By receiving help from the caregiver program in Arkansas, he has been able to take his spouse to adult day care five days a week for four hours per day. He has also hired a woman who bathes his wife and helps her get up and get ready to go to the adult day care center. With this assistance, the husband now has time to receive his own therapy and complete his personal business without worrying about his wife.

An elderly Kentucky grandmother has sole caregiving responsibilities for her eleven year-old grandson. She had twice put off needed outpatient surgery because she knew she would be unable to temporarily care for her grandson. After hearing about the National Family Caregiver Support Program, she was able to arrange housekeeping and chore assistance, as well as temporary personal care assistance for her own needs following the surgery.

In Alaska, a 47 year-old son who is responsible for running a food shipping business struggled with being the sole cargiver for his 78 year-old mother who is legally blind, has diabetes and arthritis. His mother's chronic conditions made her prone to falls and she was not able to prepare her meals or control her strict diet. The Alaska caregiver program provided the necessary assistance for arranging a Senior Companion to provide respite services and assist with meals during the week. What had been a caregiving crisis is now a stabilized situation.

A woman in North Carolina is the sole caregiver for her father, who is wheelchair bound. The daughter was carrying her father up and down the steps each time she had to take him out of the house. A volunteer from a local church referred her to the National Family Caregiver Support Program, where she received assistance installing a wheelchair ramp for her home.

Focus groups and community listening sessions inform us that safety is a major concern of caregivers, and that safety in the bathroom and while transporting the person they are caring for are the two greatest areas of concern. Assistive technology through the National Family Caregiver Support Program is playing an important role in addressing these concerns. Non-skid surfaces, grab bars, and other safety features are being installed in bathrooms. Videos have been made to instruct caregivers on the best

and safest techniques for getting disabled individuals in and out of vehicles. Caregiver program funds are also being used in places like Monmouth County, New Jersey to connect frail elders and their caregivers with nurses through a system that allows older persons to be electronically monitored in between visits to the doctor's office.

Since the enactment of the caregiver program, States and localities have demonstrated a great deal of creativity in forming new local partnerships, improving access to a wide range of services, conducting outreach to special populations, and providing flexible services that can respond to the unique needs of consumers.

The data further indicate that over 3.8 million caregivers have been empowered with information about caregiver programs and services through the National Family Caregiver Support Program. There are indications that States also have made significant strides in addressing the needs of individuals with a variety of services. These data indicate that States provided access assistance to approximately 436,000 caregivers, which significantly exceeds the agency targets to serve 250,000 caregivers. Significant numbers of caregivers have also been reached with intensive, direct services. The data also indicate that States served almost 180,000 caregivers with counseling and training services; provided respite to over 70,000 caregivers; and provided supplemental services designed to complement other care to over 50,000 caregivers.

The caregiver program is creating a new way of doing business in the aging network by focusing on caregivers, not care recipients. It is promoting creativity at the State and local level, while allowing consumers to have choices. As States have implemented this new program the national data gathered begins to reveal the following innovative activities:

- Building a new infrastructure for the support of caregivers and developing partnerships with the business community, faith-based organizations, rural health systems, and universities.
- Developing a single point of entry for caregiver access and promoting consumer directed services.
- Conducting consumer listening sessions to address priorities in the development of flexible service standards and new models of service delivery.
- Administering, piloting, and testing consumer-directed strategies by putting families first.
- Tailoring special messages, information, and program promotion strategies to reach special populations, including the rural, grandparents, low-income individuals, minorities, the hearing impaired, and limited English-speaking caregivers.

Similar advancements for members of Indian Tribes are also being made under the Native American Caregiver Support Program. The building blocks of a caregiver support infrastructure are being created that are heightening awareness and establishing culturally appropriate access to services. All of the programs are administering public awareness campaigns; nearly all of the programs (92 percent) are providing respite services; approximately two-thirds (64 percent) are providing support groups or individual counseling; and over half (58 percent) are providing caregiver training.

We plan to release the complete report of our findings and data at a national summit entitled, "Creating Caring Communities" in September. The purpose of this summit will be to bring together aging, health, and long-term care providers and practitioners from across the country to strengthen the capacity of State and community services networks to:

- Promote policy and program changes at the State and local level that would make the long-term care system more balanced and responsive to the needs and preferences of older people and their family caregivers;
- Develop and operate innovative programs at the State and local level that will help older people to remain at home and support family caregivers; and
- Promote strategies and tools at the State and local level to prevent chronic diseases and eliminate risk factors that cause them.

In advance of this effort, I am announcing at this hearing the release of a new public service campaign called, "Who Cares for the Caregivers?" This campaign is designed to inform caregivers that assistance is available in their communities, and how to access them. Today I am sending the television and radio Public Service Announcements in English and Spanish to radio and TV stations throughout the country. I would like to let you be the first to preview these 30-second spots following my testimony.

Conclusion

In short, the best way for us to comprehensively prepare for the aging of the baby boom population is to create incentives for all sectors of our society to actively be involved. That is what the Administration is undertaking, through the many activities I have just described, as well as others.

An important component of this effort will be the national network on aging, which is well-positioned to successfully shape and address our future by building caring communities, and by expanding and providing community-based services. These assets include:

- A deeply ingrained focus on the consumer that's inherent in our ethic of care.
- Our commitment to early intervention, and the social model of care.
- A national network that is grounded in the community and capable of delivering an extensive array of low-cost services.
- A proven track record in leveraging other resources on behalf of the people we serve.
- A history of working under capped funding and managing defined budget.
- The capacity to reach out to and serve private-pay consumers, as well as consumers who are low-income, culturally diverse and isolated.

These assets are the building blocks we will use to thrive in the changing health and long-term care environment.

We cannot afford to maintain the status quo. We need to continue to work together to create systems of care in home and community-based care settings as well as in institutional settings that can best meet the needs of older Americans.

We must work together to develop a comprehensive approach to health and long-term care that focuses on the community and truly reflects the needs and preferences of older Americans. We know what we do through the Older Americans Act makes a difference! We must work in partnership to make sure that EVERY community is a caring community.

Thank you very much. I would be pleased to answer any questions you may have.

The CHAIRMAN. Currently, would an 80-year-old woman, say, taking care of her 55-year-old disabled daughter be able to receive family caregiving services?

Ms. CARBONELL. Any person over the age of 60 can receive any kind of benefits from the Older Americans Act, from 3(b) supportive services in senior centers, adult day care, home care, respite, to meals and other services that are provided under the Act. So the answer is yes, Senator, an 80-year-old woman can receive respite services and other supportive services available through the entire service network provided under all the titles in the Older Americans Act.

The CHAIRMAN. In your view, how will the Older Americans Act need to evolve to meet the demands of this new wave of boomers that we are talking about and the demographics of them, I guess I would say, different from previous generations that we hope are currently covered under existing law?

Ms. CARBONELL. As indicated, of course, in our written testimony and as we heard from both Senators speaking about the tremendous challenge ahead of us, I think we are looking at a future where the senior centers will look a little different than the senior centers for my mother and my grandmother looked 20, 25 years ago.

So we are looking at how senior centers are evolving in many communities across this country. We are looking at more a comprehensive holistic approach to the scope and the availability of services. We are looking at a transformation from just serving an older population, to serving a multi-generational population and becoming more like community and family centers.

So, therefore, the appeal across generations is going to be critical as the challenges of the baby boom generation evolve. We are going to see the availability or the need to provide better choices, to have better linkages, through technology, to caregivers across the country. That is why the new Family Caregivers Program has given us the ability to add an additional component to our base programs to ensure that we are serving the younger caregiver, or the caregiver aging with multiple generational challenges.

We are looking at the possibility of many of the senior centers having both health clubs and Starbucks coffee houses and community houses where people will remain active within the community for a multi-generational purpose.

We need to ensure that senior centers of the future, obviously, continue to address many of the challenges of the health needs to maintain people healthy and active in their communities. We need to ensure that the nutrition program, which is one of our key programs within the Older Americans Act, continues to evolve and improve to ensure that we get better outcomes on reducing malnutrition and improving health outcomes for individuals. Also, the availability of leisure and volunteer activities, employment opportunities, where they can seek a homemaker that can assist them at home, but at the same time maybe seek a part-time employment or volunteer opportunity in their community.

The CHAIRMAN. I don't think there is any question. I have had several discussions over the last couple of years about the design of the new center as really a point of full contact for seniors and

the services that are provided for them and their needs, certainly unique and different from the kind that we see today.

Dominant in my State of Idaho in many senior centers is a quilting room. Quilting, obviously a delightful art form and a pastime of many older Americans and now has become almost a modern art form again. But ironically, the newest request to go in beside that quilting room is a computer room.

Ms. CARBONELL. Absolutely.

The CHAIRMAN. With about 11 million seniors now online, I think it demonstrates even more that kind of transition.

The Administration on Aging has been working on performance outcome measures for services provided under the Older Americans Act. Can you please give us an update on your progress as it relates to those reviews?

Ms. CARBONELL. We are very excited with the outcomes that we are generating. We have taken a step back and really readdressed our issues of reporting. So we have taken a first job at ensuring that we reduce the reporting formats for programs to ensure that we get the kind and the quality of data that we need, not excessive data with no outcomes at the end.

Not only are we reaching the numbers of individuals that we set our goals to reach, just in the actual production of the numbers, as we saw with the National Family Caregivers Programs, but we are making a difference, ensuring that we target—a high percentage to those most at risk or those most vulnerable.

For instance, 30 percent of the clients served in the Older Americans Act programs are elderly poor. That means that we are targeting our priority to those in most need. We also are over-serving. Thirty percent of the clients are in rural communities, compared to 24 on a national basis. In particular, States where we know that the rural issues are critical, with our new National Family Caregivers, we are expanding our availability to have comprehensive collaborations with the health care providers and others in the community that we had not had the opportunity to do. We are serving a large percentage of people that are from minority at-risk communities.

We are leveraging some interesting dollars. Even with States' economic downturn, overall States are leveraging about $2 for every $1 of the AOA dollar put in many of the States. For intensive services, like in-home care, we are leveraging $3 to every $1 AOA dollar.

We are seeing excellent increases in recruiting of volunteers for the senior Medicare patrols, as well as who are ombudsmen within the communities, and improving the outcomes of the Ombudsman program by working together with CMS on their new quality initiative, both in the nursing home and obviously in the home health area.

The CHAIRMAN. Thank you. Will you do a white paper on those findings, or how will they be reported to us?

Ms. CARBONELL. They will be reported—we have an annual report which is our own specific annual report——

The CHAIRMAN. It will show up in those?

Ms. CARBONELL [continuing]. That we are proud to—it is hot off the press.

The CHAIRMAN. OK.

Ms. CARBONELL. It is not out. It will be out at the end of this week, but we have brought a copy that we will leave with you.

The CHAIRMAN. Fine.

Ms. CARBONELL. In addition, the final outcome data of the national surveys, which is a new survey that has been added to the outcome measurements and performance data, will be ready later this summer, and those will be released and we will be glad to provide them to Congress and to the Chair.

The CHAIRMAN. Super. Thank you.

I am going to turn to my colleague, Senator Breaux. A vote has just started. I am going to run and vote and come back and we will do tag team here so that we can keep our hearing going. John?

Senator BREAUX. Thank you, Mr. Chairman. Thank you, Madam Secretary.

You mentioned in your testimony that the President's budget for 2004 requests for CMS a $1.75 billion program to encourage a transition of people from nursing homes or other long-term care institutions back to the community, and you correctly point out that we really have an institutional bias in long-term care in this country in keeping people in institutional care. An awful lot of people, in fact, need long-term, 24-hour-a-day, 7-day-a-week care, but there are an awful lot of them that are in institutional care like nursing homes that don't need to be there.

Yet, almost 75 percent of all the money we appropriate is being used principally through the Medicaid program to put people in nursing homes. It is really an embarrassment, because you have got to spend yourself poor to get money to get long-term care, which is a real embarrassment as a society, but that is a whole other point.

How would the money that the President is proposing be used to end this institutional bias that we are talking about?

Ms. CARBONELL. Well, I think that—not only the rebalancing initiative, but several other initiatives, including the New Freedom and the systems change grants, have allowed and are beginning to allow many States the opportunity to begin to rebalance their systems. In the rebalancing proposal, the opportunity, if they wish, to invest in shifting folks from a nursing home into home and community-based care. It provides a 1-year, 100 percent Federal reimbursement for all costs to move and to pay for services to move individuals from a nursing home into home and community-based care. That is virtually how we envision the framework that was proposed to Congress for the 2004 budget.

In anticipation of those changes, we have been working and there have been system choice grants already given out to States which have allowed States to begin to address removing barriers, institutional and infrastructure barriers, that prevent individuals from living independently in their own homes. So it has addressed structural changes and reimbursements at the State level for making those changes, both policy and resource-wise.

Senator BREAUX. Of course, the problem at the State level is that the States can do that now simply by requesting a waiver from HHS to use their State Medicaid funds for non-institutional care, like assisted living facilities. The problem has been that they don't

want to do it. The problem has been that they have a bias toward nursing homes, in many cases because of the political strength of the nursing homes that prevent legislators from allowing them to make the request.

My concern is I don't understand how this is going to help the situation, because the problem is with the States not wanting to do it. They can do it now.

Ms. CARBONELL. Well, they can do it now, right now, Senator, but the current reimbursement mechanism would be the same match that the States have at the current time. With the rebalancing proposal, it provides 100 percent Federal reimbursement to States for one year, so they can begin to shift it. That, coupled with the fact that the Administration on Aging is partnering with CMS to create, again, the involvement of a single-entry or one-stop-shop place where people can turn for help and assistance, where there will be one single entry point in the system to long-term care, that will allow the individual better choices. Right now those programs are fragmented.

So some States, a few of the States, have their long-term care system, including their Medicare waiver programs, managed by the aging network, the aging State unit. But the rest of the States have, of course, their Medicaid waiver and long-term care program managed by their State health or Medicaid agency.

Senator BREAUX. So are we saying that under this proposal, the State would get the same amount of money under Medicaid plus the States would divide up $1.75 billion in addition to be used for non-institutional care?

Ms. CARBONELL. Correct. That means that it is an historic investment, a change in the way that we offer incentives to States to begin to shift policy and resources to home and community-based care to create more balance.

Senator BREAUX. This is not a subtraction from what they would normally get under Medicaid?

Ms. CARBONELL. This proposal is an addition and it is 100 percent for one-year. This one-year reimbursement at 100 percent for States wishing to pilot and to begin to shift policy and programs to home and community-based care.

Senator BREAUX. So a State will get 100 percent with no State match to allow them to move out of a nursing home?

Ms. CARBONELL. For the first year, sir, yes, and the rest of the years, it comes back to the State match as stipulated.

Senator BREAUX. Why are we doing a 100 percent match? Aren't we just telling the States we are going to pay 100 percent of the cost if somebody moves out of a nursing home?

Ms. CARBONELL. Well, this is an historic turning point——

Senator BREAUX. It certainly is.

Ms. CARBONELL [continuing]. We feel very confident that a 1-year, coupled with other supports will help. I am not CMS so I defer that kind of question to my colleagues——

Senator BREAUX. What happens, then, if we do it for 1 year and a State moves 20 percent of their nursing home population into an assisted living facility and the Federal Government picks it all up? What happens to those people when the Federal Government sunsets it after one year?

Ms. CARBONELL. Well, in those States where we have seen the experience of shifting resources, a consolidation of resources and programs into one single entity for long-term care, the experience and the studies and the data have shown that they have actually reduced their costs in general, and have improved the number of people being able to be served under home and community-based services by mixing of services available both in-home and community-based care and nursing home.

So that means that, No. 1, people have been able to successfully be transitioned out of nursing homes into home and community-based care programs. We know that the data shows that those States that have invested dollars in shifting to home and community-based care have done so cost effectively and have been able to continue to do so.

Senator BREAUX. I have no qualms with the principle that it is cheaper and, I think, more convenient and a better degree of care for a large number of people to be in non-institutionalized care. I think that is what we ought to be encouraging States to do, something that they can do now but they don't in most cases.

I need to learn more about this $1.75 billion and how it would actually work. I think it is the right thing to try and ultimately accomplished. I am not certain that this is the best way to do it because I am concerned about if we do it to them for one shot and then the next year it is not there, they are going to be left with an awful lot of people hanging in facilities that they didn't think they were going there for one year. All of a sudden, the money is not going to be there in the second year and what happens to all of those people?

Ms. CARBONELL. We would like to follow up with you, Senator, and bring you additional information with my colleague at CMS, Tom Scully. Obviously, that is not just the only thing it involves. Obviously, our role at the Administration on Aging is that the administration and the aging network is one of the largest providers of home and community-based care throughout this country and we are ready, we are experienced, we have proven to be cost effective, and we are ready to take on the next step, which means work collaboratively, partnering with CMS, because you have got an existing structure that is evident throughout 29,000 providers and communities. We are doing it for the grant monies right now and in many cases, about 30 percent of the States, the aging network is managing and operating the Medicare waiver home and community-based care services in communities.

So we are—the one-stop-shop initiative will give us the ability to partner with CMS to ensure that we integrate the service systems at the community level and that we incentivize and award competitive grants that will be released later on this month to do just that, to begin to shift——

Senator BREAUX. We will follow up on that.

Ms. CARBONELL. Thank you.

Senator BREAUX. You are aware, apparently, of our hearing yesterday, because you reference it in your testimony. I think that what we learned yesterday is that there is an enormous bias in America, in our own country, against seniors in a lot of areas. One of the most important areas is the general area of health care.

Our medical schools do not have enough geriatric degrees. Only five schools in the entire United States medical schools out of 125 have full departments of geriatrics. Yet all of them have full departments in pediatrics.

We have clinical trials for prescription drugs that are ongoing that do not fully utilize, if hardly at all, seniors in the testing, even though most of the people who take prescription drugs, over half are seniors, but they are not involved in the clinical trials to develop the drugs and to ensure that they are safe.

We have a bias and a lack of utilization among seniors in preventative care programs that are available to others. We have, I think, a lack of understanding of depression among seniors. The highest suicide rates in this country is not among teenagers but among seniors, and we had testimony that doctors don't recognize it because they haven't been trained. Too many times, seniors are just dismissed as being, well, they are old people. They are going to die anyway.

I think that we as a society need to be striving for not just getting seniors to live longer, but to live better lives. I have said it a million times. Part of living better lives is to make sure that they have access to the same type of quality preventative services and health services that someone who is in their 20's or 50's or even younger.

So, I mean, what can the Administration on Aging, when you look out over America and you see this discrimination against aging and people who are seniors, what can the Administration on Aging do to become a leader in this area, to eliminate these biases that currently exist?

Ms. CARBONELL. At the Administration on Aging, obviously is the chief advocate for aging and older Americans across the country, we not only are taking a chief advocacy role, but we are actually running programs and collaborating with other agencies to ensure that we begin to tear down those barriers that ensure not only quality of care for our seniors, but a better quality of life, obviously.

If you look at the report released today on, long-term care workers in relation to the aging baby boom generation, you will see substantial recommendations in to Congress based on the kinds of urgency that there is to address not only the shortages of professional workers, but also ensure that paraprofessional quality training continues to happen.

We are working with HRSA inasmuch as the Health Resource Services Administration is addressing geriatric education in their 2003, spending approximately $12 million in continuing to fund geriatric education centers across this country.

We are working with the Agency for Health Research and Quality, AHRQ, to ensure that there is safety in medications and that the medications' overuse is addressed and the safety and products of the medication are there. FDA is expanding its consumer information opportunities, and that includes the working relationship between FDA and AOA, to improve that consumer information education.

On mental health, we have just developed and are about to launch by the end of this month a tool kit that SAMHSA has pro-

vided to ensure that we address mental health, depression, substance abuse, and other issues in older populations.

So we are taking active steps with our partners in CMS to address prevention services and the expansion of prevention services.

The whole Medicare proposal before you in the 2004 budget, the President's 2004 budget, obviously not only aspires to provide for prescription drug benefits for seniors, but it is looking at a more comprehensive reform as we improve the capacity to do prevention and screenings for all Medicare beneficiaries.

So we are taking active steps with CDC in our aging State programs. Our aging network providers are partnering in ten specific communities across this country where there is high incidence of risk behaviors and health disparities. We are co-funding with CDC initiatives in this program with public health providers and our community aging providers.

Senator BREAUX. Thank you. Thank you, Mr. Chairman.

The CHAIRMAN. John, thank you.

One last question, Madam Secretary, before we turn to our next panel group. I understand the administration has been involved in a series of listening sessions. What exactly have you learned from people out there receiving and providing older Americans' services?

Ms. CARBONELL. Well, the most important thing is that the flexibility and the ability of many of our providers with the new reauthorized Act has awarded us the flexibility needed to address consumer choice at the local level. So the improved capacity for program sharing, for having the new Family Caregiver Program, has allowed us the opportunity to create new partnerships and collaborations at the State level, whether you are looking at private sector elder care programs or benefit programs being matched together with many of our Area Agencies on Aging and caregiver providers in the community.

I just came back from a town hall session in Orange County, CA. We held that town hall meeting in collaboration with the aging network and the disability advocates. We were able to come together as one to address some of the barrier removals and some of the challenges that we both have both in the aging and disability communities to promote independence in communities, and address better opportunities for home and community-based care.

We are looking, obviously, at hearing from seniors, like I mentioned, particularly in the area of grandparents. We see that there are challenges in many of the grandparents raising grandchildren that we need to continue to address as we move forward, and the National Family Caregiver Program evolves and there are obviously opportunities as the reauthorization of the Older Americans Act becomes evident just in 2005.

The CHAIRMAN. Thank you. Thank you very much for your testimony, the work you are doing, and all of the efforts well underway. I think all of us kind of view, whether we are at the policy level or the implementation of that policy, at your level, kind of feel we are in that interesting transitional time out there into a relatively known field, at the same time with expectations and demands that are not yet known in many respects as it relates to the aging of America.

But we thank you very much for that testimony and look forward to our continued work with you.

Ms. CARBONELL. Thank you.

The CHAIRMAN. Thanks for being here.

Let us ask, then, the next group of panelists to come forward, please, Maria Greene, Kevin Mahoney, Ron Aday, and Gregory Abowd.

Mr. Mahoney, we will try to deal with you in dispatch. We understand you have a family problem or concern and we will move you through as quickly as possible.

Let me thank our panelists for being with us. I recognize Maria Greene, Director of the Georgia Division on Aging. She will visit with us today about the features of Georgia's family caregiving efforts, including a mobile day care program.

Maria, welcome, and we look forward to your testimony.

Ms. Greene. Thank you.

The CHAIRMAN. Please proceed.

STATEMENT OF MARIA GREENE, DIRECTOR, GEORGIA DEPARTMENT OF HUMAN RESOURCES, DIVISION OF AGING SERVICES, ATLANTA, GA

Ms. GREENE. Good afternoon, Senator Craig. Thank you for the opportunity to come this afternoon. I am Maria Greene, Director of the Georgia Department of Human Resources, Division of Aging Services. Also with me today is Mr. Cliff Burt, Caregiver Specialist responsible for Georgia's caregiver program.

I would like to share information with you about five innovative caregiver initiatives. They are caregiver research, assessment, mediation, consumer-directed care, and mobile day care.

Georgia conducted 11 focus groups to solicit input from family and professional caregivers regarding needs and gaps in services. We found that caregivers need more information, more direct services, training for themselves, and better trained non-ageist providers. The results of the focus groups have been used to integrate the National Family Caregiver Program into the existing delivery system, expansion of existing services, and development of new programs and services.

Georgia was awarded grants from the Administration on Aging to participate in the performance outcomes measurement project. The Division participated in the development of instruments that measure caregiver support and satisfaction, nutrition risk, physical functioning, and emotional well-being. We tested these instruments over a 3-year period. We are encouraging Area Agencies on Aging to use the instruments in determining service outcomes, quality and client satisfaction, and how best to manage using data.

We understand, Senator Craig, that the committee has an interest in mediation. Georgia is one of the three States participating in a caregiver demonstration grant received by the Center for Social Gerontology in Ann Arbor, MI. The goal of the project is to use mediation to assist frail older persons and their family caregivers to address and resolve problems and disputes which all too frequently arise when families face the physical, emotional, and financial demands of providing care. Elder law attorneys using mediation skills have helped many families resolve conflicts.

We value the philosophy of consumer-directed care. Preliminary studies have found that 77 percent of caregivers utilize funds to hire someone to provide care, and 80 percent of the caregivers hired someone they know as opposed to agency personnel. Caregivers who participate in the program are considerably more satisfied with those services than those who receive traditional services.

I will share with you a story told to me recently. The caregiver for 94-year-old Mr. K called the local Area Agency on Aging about using some of the fund from the self-directed care program to make needed bathroom repairs. The caregiver utilized some of the self-directed funds to purchase needed materials and secured volunteers to make the necessary repairs. Consequently, her father is able to bathe by himself for the first time in many years. The caregiver stated that her dad never had a tub and had to use a very small shower stall. Her father, who last year would not bathe, has to be coaxed out of the tub. She and her father would like to thank all of those responsible for the program.

Given the well-documented long-term care staffing crisis in the nation, the unavailability of services, and fewer workers in rural areas, it should come as no surprise that our preliminary findings show that family caregivers wholeheartedly embrace self-directed care.

Through funding provided by the Administration on Aging, Georgia developed the mobile day care program. Mobile day care enables communities to have their own day care programs while sharing staff who travel between locations. Mobile day care has proved to be a great respite care alternative. Its flexibility with part- and full-time staff positions helps to retain qualified staff. Perhaps its greatest values is that it builds trust in rural communities and thus becomes the precursor of a full-time day care program.

Georgia's ability to do caregiver research, assessment, mediation, consumer-directed care, and mobile day care has enabled us to create new partnerships and paradigms to meet the diverse and increasing needs of caregivers. One of the National Family Caregiver Support Program's hallmarks has been the component of supplement services, which has enabled the aging network the flexibility needed to become more innovative. The product of that flexibility is improved service delivery, new services, and increased empowerment for caregivers. Also, the demonstration grants have allowed States like Georgia to pilot new delivery of care systems, gather consumer satisfaction data, and to manage programs using those data.

Mr. Chairman, with your permission, may we show a short clip of the mobile day care video.

The CHAIRMAN. Surely.

Ms. GREENE. Thank you. [A videotape was shown.]

Thank you.

The CHAIRMAN. Thank you. Thank you very much for that testimony and the video.

[The prepared statement of Ms. Greene follows:]

Jim Martin, Commissioner
Maria Greene, Division Director

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WRITTEN TESTIMONY OF MARIA GREENE
BEFORE THE UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING

Good morning, Mr. Chairman, and Members of the Committee. I am Maria Greene, Director of the Georgia Department of Human Resources Division of Aging Services. Also, Cliff Burt, Caregiver Specialist, is here with me today. I would like to publicly acknowledge his dedicated work in helping to establish Georgia's Caregiver Programs. I have been asked to share how innovations in the implementation of the National Family Caregiver Support Program have empowered caregivers to more effectively take care of their loved ones.

CONSUMER DIRECTED CARE

The first area I would like to discuss is consumer directed care. The concepts and development of consumer directed care support President Bush's Freedom Initiative by tearing down barriers to equality faced by many people with disabilities. A number of states including Georgia consider consumer directed care as one strategy for tearing down those barriers.

The Division of Aging Services has been promoting self-directed care as a service option for caregivers since 1996. Georgia's philosophy regarding self-directed care is perhaps best espoused by the Blue Ribbon Task Force on Community Based Services, charged with making specific recommendations to the Governor and the General Assembly on the status of community based programs. The Committee, in their report issued in January, 2001 stated:

> *"Consumer-directed control asserts that there is a need to assure that individuals and their families have the opportunity to be the decision makers concerning the supports that are needed and how they best can be provided. It allows individuals to personalize the support they need, rather than fit into the service models the system has created for them. It allows the State to re-examine the present assumptions regarding long term care with an eye toward making it more cost-effective, as well as bringing it into line with the aspirations of individual consumers and their families".*

In the fall of 2001, the Georgia Division of Aging Services was awarded a grant from the U. S. Administration on Aging (AoA) with funding from the National Family Caregiver Support Program to develop five self-directed care programs.

The aging community has increasingly become interested in self-directed care as an option designed to maximize consumer choice and enhance empowerment. Recent self-

directed care projects have focused primarily on the developmentally disabled with Medicaid and foundation funding. The Georgia project objectives are to:

- Increase service options by developing five self-directed care projects in rural areas that can be replicated in other states.
- Evaluate the effects of self-directed care by adapting and administering to caregivers participating in voucher programs the *Caregiver Support and Satisfaction Survey*, currently in use by states participating in the Administration on Aging's Performance Outcome Measurement Project (POMP).
  Expected products are:
- Develop a replication manual developed in Year Two, and field-tested during Year Three, incorporating additional input from Georgia's aging network
- Conduct a professional evaluation of caregiver support and satisfaction, comparing responses of those caregivers utilizing vouchers to those receiving traditional services. The evaluation will assist policy makers and program administrators in developing new options for service delivery.

Characteristics of self-directed care, often referred to as consumer direction, include:
1) Services are home/community based; Individuals: 2) are involved in assessing their own needs 3) Determine how and by whom needs will be met 4) Define the job description/tasks of the worker 5) Deem the competency of the worker, and 6) Monitor the quality of the service. The benefits of consumer directed services include independence, autonomy, control and determination; self esteem is maximized; personal lifestyle and preference is maintained; and satisfaction with the services is maximized.

I would like to tell you of a story shared by someone recently served through the program. The caregiver for ninety-four year old Mr. K. recently called the local Area Agency on Aging about using some funds from the self directed care program to make needed bathroom repairs, including replacing a rotten floor and the installation of a tub to replace a small shower. Caregivers can often best determine their own priorities. The caregiver utilized caregiver funds to purchase needed materials and secured volunteers to make the necessary repairs.

Consequently, her father is able to bathe by himself for the first time in many years. The caregiver stated that her dad never had a tub and had to use a very small shower stall. Now, her father, who last year would not bathe, has to be coaxed out of the tub. Her father now insists that each visitor look at his new bathroom. Mr. K. is again proud of his home. Mrs. W., the caregiver, wants me to thank all those responsible for the program. She states her family has been blessed beyond measure.

By September, 2003, a draft replication manual will be completed, which will include several models for replication, and will include useful information for family caregivers who want to hire family or friends to provide services. The Division has consulted with Sue Flanagan, consultant, a nationally recognized expert on self-directed care, in developing our program.

Of our pilot projects currently underway in Georgia which are funded through a caregiver demonstration grant from the Administration on Aging, preliminary surveys conducted have found that 77% of all caregivers utilize funds to hire someone to provide care to their loved one; further, 80% of the caregivers hired someone they know, as opposed to an agency, to provide care. Caregivers who participate in the program are considerably more satisfied with the services they receive than those caregivers receiving services through the traditional system.

Given the well documented long-term care staffing crisis in the nation, the unavailability of services in some rural areas, fewer resources (including workers) in rural areas, and the fact that most of Georgia's 159 counties are rural, it should come as no surprise that our preliminary findings show that family caregivers whole-heartedly embrace self-directed care.

OUTCOME MEASURES

The next area we would like to highlight is outcome measures.

Georgia applied for and was awarded grants from the Administration on Aging to participate in the Performance Outcomes Measurement Project (POMP). The POMP effort was designed to:

· Identify performance measures currently in use by the aging network
· Participate in case studies of best-practice approaches to performance measures
· Participate in a series of forums and work sessions to refine performance outcome measures
· Share data with the Administration on Aging and Governmental Performance Results Act (GPRA)

The Division, with the assistance of James Kautz, PhD., participated in the development of indicators and measures of numerous instruments with 14 other states. Instruments that were utilized in Georgia were:

- Caregiver Support and Satisfaction Survey
- Nutrition Risk Survey
- Behavioral Risk Factor Surveillance
- Home Care Satisfaction Measure
    - Homemaker Services
    - Physical Functioning
    - Emotional Well-being
    - Social Functioning

The Division tested these instruments over a three-year period, and has shared the results of the surveys conducted with those instruments with our partners in the aging network. We are encouraging use of the instruments in the aging network as valuable tools in determining service outcomes, quality and client satisfaction.

There are a number of challenges in working with outcomes measures, such as:

- Attribution—who gets the credit for an outcome? Was it the formal service intervention, or the support of church member?
- Extenuating circumstances—we can do our best, but the individual who makes poor health choices may become chronically ill.
- Cost. The cost for professional interviewers is expensive. We did have better participation with phone surveys instead of other tried and failed alternatives.

INNOVATIONS IN CAREGIVING

We would like to highlight a couple of programs which we have developed that have benefited caregivers.

Mobile Day Care
Through funding provided by the Administration on Aging, Georgia developed the *Mobile Day Care* program. *Mobile Day Care* enables communities to have their own day care programs while "sharing" staff who travel between locations. Though the term mobile day care conjures images of a facility that moves, it is actually the staff, along with materials and supplies needed for the day that are mobile. Leaving early each morning, staff travel to a rural site, transporting needed program materials with them. Space for these sites is provided by churches and senior centers. Depending on the needs of the community, each site is open for five or six hours per day, one to three days per week.

Utilizing funds from the Administration on Aging's (AoA) Alzheimer's Demonstration Grants to the States program, the Greater Georgia Chapter Alzheimer's Association developed the innovative concept, and the program was implemented by the Augusta Area Chapter Alzheimer's Association, with technical assistance from the Central River Savannah Area (CSRA) Area Agency on Aging.

Though initially developed for caregivers of persons with Alzheimer's Disease, mobile day care is a program which can serve all caregivers of older persons, and is a service option which may be viable whether it is serving a rural county or the borough of a large metropolitan area.

Site Locations
The Augusta Area Chapter's mobile day care program has sites in McDuffie and Burke Counties, with funding provided by AoA and the Brookdale Foundation. Two other mobile day care programs were funded with demonstration grant funds from AoA and the state of Georgia. The Athens Community Council on Aging, Inc. has sites in Elberton, Greene, and Newton Counties, and the McIntosh Trail/ Mental Health/Mental Retardation Community Service Board opened two sites in Butts and Upson Counties.

Units of Service
Typically, Georgia's experience has shown that a mobile day care program with two sites, operating two days a week in one county, and three days per week in another county, can provide an average of 585 hours per month to 12-14 persons. Caregivers in these communities

express overwhelming appreciation for the program, which has given them much needed respite in geographic areas where assistance is limited or not otherwise available.

Though staffing for each program differs, most programs have between 1 ½ to 2 paid Full Time Equivalents. Volunteers assist staff with program activities, such as providing stories and poems from the past, which have proven to be effective in stimulating reminiscence programs.

New day care programs are frequently difficult to sustain due to insufficient enrollment. However, the mobile day care concept spreads staff costs between two sites, thus increasing the chance that at least one of the new sites will generate enough referrals and increased enrollment to maintain the program in at least one community. Since funding for new services continues to decrease due to budget consolidations and reductions, mobile day care would seem to provide both diminished risk and a greater chance of success than the establishment of a traditional (one site, five day- per-week) program. Caregivers in rural settings frequently have no access to day care, respite, or a support group, and mobile day care program offers respite that otherwise would not be available.

Mobile Day Care's flexibility with part and full time staff positions helps to retain qualified staff. Perhaps its greatest value is that it builds trust in rural communities, and thus becomes the precursor of a full time day care program in areas that are not even familiar with the concept of day care.

Georgia's *Mobile Day Care* program has been referenced in a number of reports and publications as a best practice model worthy of replication, including AARP and Fordham University, and was recently featured in the rural health section of *Successful Farming Magazine*. Upon request, an eight minute video about the mobile day care program is also available.

Georgia Caregiver Mediation Project

We understand, Senator Craig, that the Committee has an interest in mediation, and wanted to mention the Georgia Caregiver Mediation Project.

The Georgia Division of Aging Services, in collaboration with the Center for Social Gerontology of Ann Arbor, Michigan, grantee, and the Vermont Department of Aging and Disabilities, is one of three states participating in a Caregiver Mediation Project, with funds provided in a Title IIIE caregiver demonstration grant from the Administration on Aging. Penelope Hommel, Co-Director of the Center in Ann Arbor, testified before this Committee in February concerning mediation in general and mentioned this project as well.

The goal of the project is to use mediation to assist frail older persons and their family caregivers to address and resolve problems and disputes which all too frequently arise when families face the physical, emotional, and financial demands of providing long term care to an older family member.

The of use mediation protects the autonomy and dignity of older persons while assisting and enabling family caregivers to resolve problems, which if left unresolved, could destroy the family and caregiver support system and could result in institutionalization, or in financial exploitation, neglect or abuse. Mediation is a process in which people involved in a dispute meet in a private setting to work out a solution to their problem with the help of a neutral person, the mediator.

For the duration of the project, there will be no cost to the parties. The mediators will be paid a nominal fee per case. Participation in this project is completely voluntary. Mediation does not proceed unless the parties agree to participate.

The ultimate goal is to move this valuable service from an innovative concept into the mainstream of the caregiver support systems of each of the pilot state sites.

The Georgia project has concentrated on spreading information about the program in order to generate referrals, and disseminating information about program services. To assist with growth of the project and referrals, an advisory group was developed that includes members from entities such as local probate courts, dispute resolution offices, Area Agencies on Aging, local aging services providers, hospitals and others serving our target population.

Mediators selected to participate in this project have received an intensive 20 hour training in basic mediation skills and an additional 20 hours training in mediating Adult Guardianship and Family Caregiver cases. All have years of experience mediating difficult cases.

The Project is working to generate appropriate referrals to the program. The Project Managers are conducting trainings with Court personnel, and groups with whom the advisory group members are connected in order to assist them in gaining a better understanding of the mediation process to generate referrals. As a result of this project, a discussion has begun that this could be the right time for legislation requiring mediation prior to filing for guardianship.

The cases that have come to the Project thus far have resulted in 50% being assigned to mediators but all receiving 5-10 hours of intake and pre-screening to discuss the issues with the relevant parties who might need to participate in the process. This assists the mediator in having all the necessary parties at the table but more importantly, assists in appropriately defining which cases this process can best address.

Our experience with the project raised the following issues:

A. Capacity To Mediate
Concern was raised early on about the proposed ward's lack of capacity in pre-petition (guardianship) cases or in those cases that have been filed. It was made clear first of all that 1) the proposed ward's capacity was not what was being mediated; 2) and it was clarified that even if the care recipient is completely impaired, it does not necessarily preclude mediation where the issue(s) to be mediated involve what the caregiver will do for the benefit of the care recipient.

B. Protection of Rights
There has been additional discussion on the protection of the rights of the proposed ward or older person/care recipient in mediation.

In Georgia, our Older Americans Act Title III B legal Services Program providers, or ELAP (Elderly Legal Assistance Program) have been trained as mediators and on how to represent their clients in mediations. In exchange for receiving this valuable training, it was agreed that they would make themselves available if appropriate, to provide representation to the older care recipient in mediation.

To initiate the Caregiver Mediation Project Process, one need only contact the project line which is established within the Division of Aging Services or contact either of the Project Managers and refer a case or request mediation. That call is returned by one of the project managers, our Georgia Legal Services Developer and the Managing Attorney of the Georgia Senior Legal Hotline. They determine whether or not the case is appropriate for caregiver mediation. If not, the process ends there. If the case is deemed appropriate, intake/screening is conducted and the case will be assigned to a mediator.

The mediator completes the pre-mediation process and sets the case for mediation if appropriate. The pre-mediation process may include meetings with the parties to determine some of the issues and the dynamics of the parties. Once mediation begins, it continues until either an agreement is reached or until it is determined that an agreement cannot be reached. If an agreement is reached, it is written and the parties sign it. The mediation is concluded and the mediator asks for the parties to evaluate the process.

Mediation services are not well understood by much of the aging network or by family caregivers, so referral sources are not always able to identify appropriate cases. Family caregivers may be reluctant to participate voluntarily in mediation not only because they don't understand its potential value, but also because they do not think of themselves to be "caregivers." They look at "caregivers" as only paid professionals, so some time is being spent familiarizing families with the terminology and getting them to accept the fact that it is okay to think of themselves in this way and then to look at how mediation might be of benefit in their particular situation. The vast majority of the referrals the Project has received have not resulted in a formal mediation; however mediation skills have been used to resolve conflicts.

Having said that, however, we do believe that clients and providers have benefited from participation in the interviews that comprise the screening services and the problem solving skills modeled throughout each phase of the program. We are attempting to address these problems through continued meetings with referral sources. Mediation can be a valuable tool in avoiding unnecessary guardianships.

Caregiver Focus Groups

In anticipation of the passage of the NFCSP, the Division of Aging Services, with the assistance of the regional Area Agencies on Aging (AAAs), conducted six caregiver focus groups across

Georgia prior to the new program's enactment. The Division desired to solicit input from caregivers regarding needs and gaps in services, which could be shared with AAAs to assist them: 1) integrate the NFCSP into the existing service delivery system, and 2) make informed decisions regarding how to allocate the additional funds. Georgia Caregiver Resource Center (GCRC) funds were utilized to work with a consultant to design and conduct the groups, and to analyze their results. A diverse range of caregivers was recruited, including family caregivers, elder-law attorneys, discharge planners, care managers, ombudsmen, nursing assistants, neighbors, and volunteers, among others.

An additional five focus groups have been conducted since the receipt of the first NFCSP funds.

Facilitated by Dr. Kathy Scott, R.N., C., each of the eleven groups targeted a particular group of caregivers. For example, participants from four focus groups were family caregivers; participants from two groups were nursing assistants that worked for home health care agencies or nursing homes. One hundred and twenty-three caregivers participated in groups in Americus, Dublin, Macon, Gainesville, Decatur, Atlanta, Savannah, Tifton, and Calhoun.

The focus group approach was the primary data collection method used to elicit the shared meaning of everyday experiences of caregivers in Georgia. The focus group approach: 1) fosters the production of information that is difficult to obtain in individual interviews; 2) facilitates the collection of a large amount of information in a relatively short period of time; 3) emphasizes participants' interactions and points of views; 4) provides opportunities for participants to validate information shared by others; and 5) clarifies differences of opinion and reveals diversity in perspective.

Major themes highlighted in the report focused around:

1. Lack of information;
2. Coordination of available resources;
3. Inadequately educated providers;
4. Inadequately supported (availability of resources) service providers; and
5. Inadequately monitored service providers.

A number of recommendations were generated under each of the following categories listed below to be explored as potential approaches to support caregivers. Some of these recommendations would require funding while others could include "no cost" interventions such as including family caregivers on social service organization boards.

Recommendations – Information (create a two way flow of information):

- Community resources / Providers
- Community resources / products
- How to obtain medications (if without money)
- Emergency services
- Future planning
- Home preparation if caring for older adults in home.
- Information on reimbursement systems

- Legal issues (power of attorney, abuse, guardianship, donor issues)
- Create 1-800 system
- Use Media (TV, radio, paper)
- Place information cards in doctor's offices
- Place caregivers on boards of organizations

The following activities and initiatives have occurred since the findings/recommendations listed above were identified:

- Caregiver focus group findings were shared with Area Agencies on Aging (AAAs) for use in developing their four year Area Plans. The results were also shared at the Rosalynn Carter Annual Caregiving Conference, and the Annual Women's Health Forum. A presentation was made at the Division's Annual Nutrition Conference, with a new track, *Balancing Careers and Caregiving*
- Five additional focus groups have been conducted with Long Term Care Ombudsman program staff and family caregivers from across Georgia
- *Caregiving in Georgia* report, with support from AARP, has been printed and disseminated statewide to selected committees of the Georgia General Assembly, AAAs, AARP, members of COAGE, Georgia Council on Aging, and other public and private sector organizations. The report can be accessed via the Department of Human Resources website, which is www.dhr.state.ga.us, and going to the home page for the Division of Aging Services.
- A report summarizing the findings from the five additional focus groups is slated for publication.
- A list of Caregiving Internet Resources has been compiled and disseminated to AAAs

Recommendations – Direct Services:

- Streamline services to decrease fragmentation
- Expansion of respite (increased hours, weekends, nights)
- Expansion of home services - Community Care Services Program (CCSP)
- Expansion of transportation
- Financial assistance with medications
- More supervision / accountability of services
- Emergency services (back-up) for caregivers
- Creations of 1-800 information system
- Creation of exchange program
- Counseling (CM) & advanced planners

The following activities and initiatives have occurred since the findings/recommendations listed above were identified:

- The Georgia Cares program has been designed and implemented state-wide to educate and help seniors apply for all available low cost prescription drug assistance programs
- Georgia's *Mobile Day Care* program, an innovative service delivery model which enables rural communities to have their own day care program several days per week while sharing staff that travel between locations, has been featured in the rural health section of *Successful Farming Magazine*.
- AAAs allocated over $750,000 of new funding available through the National Family Caregiver Support Program for respite services
- Several AAAs are expanding options available to family caregivers for overnight in-home or out-of-home respite
- The Rosalynn Carter Institute has received funding from the U.S. Adminstration on Aging to develop CARE-NETs within six AAA regions of Georgia. CARE-NETs are collaborative networks of representatives of professional and family caregiving organizations as well as individuals, that work together to develop service and educational programs for caregivers
- Several AAAs are providing counseling for caregivers either in the home or through forums
- Several AAAs have developed programs and services for grandparents raising grandchildren, including counseling, support groups, health monitoring, and mentoring
- A number of AAAs are employing caregiver specialists to assist family caregivers

Recommendations – Training:

- Ageist Issues
- Alzheimer's & other like dementia
- Normal aging issues
- Complexities of caregiving
- More advanced seminars for home care providers (HCP's)
- Legal issues
- Community resources (providers / products)
- Personal care / hygiene
- Communication skills
- Course on compassion for HCP's
- Extended training for nursing assistants with clinical time

The following activities and initiatives have occurred since the findings/recommendations listed above were identified:

- With leadership provided by the Georgia Council on Aging, the Georgia Alliance for Staffing Solutions was formed. This network of 30 agencies and organizations has sponsored two forums to explore possible solutions to the crisis in long-term care staffing.
- With funding from the Georgia Caregiver Resource Center (GCRC), the Division provides funding to four AAAs per year to develop regional caregivers forums. Some

forums will provide respite care to care receivers, enabling family caregivers to be able to attend. Rosalynn Carter Institute has presented at some of these events.

- Division staff chaired Plenary Sessions and workshop tracks at several Georgia Gerontology Society Annual Meeting which highlighted issues such as the crisis in long term care staffing, developing career ladders for nursing assistants, and self-directed care voucher programs.
- Area Agencies on Aging sponsored caregivers trainings and forums with funding from the National Family Caregiver Support Program.
- Beginning in 2002, the Greater Georgia Chapter of the Alzheimer's Association received funding from the Georgia General Assembly to provide 26 education/training sessions to family and professional caregivers around the state each year. The funding is on-going.
- The State office of AARP has begun an education/training program to enhance the knowledge and skills of nursing aides, with sessions provided across the state.
- Through CARE-NETs established by the Rosalynn Carter Institute and participating Area Agencies on Aging, several *Caring For You, Caring For Me* forums for family caregivers have been conducted

Recommendations – Service Providers:

- Increase pay / benefits / respect for nursing assistants (NA's)
- Vouchers / support for family caregivers
- More training and sensitivity for ALL levels
- Doctors needs to be more team players
- More supervision / oversight of staff
- Decrease administrative costs
- Agencies need to screen clients needs better
- Decrease administrative costs
- Include NA's in care planning

The following activities and initiatives have occurred since the findings/recommendations listed above were identified:

- Through a national competitive grant process, the Division received funding from the U.S. Administration on Aging (AoA) for a self-directed care program, enabling caregivers to be able to hire family and friends to provide services. Georgia received the third highest grant awarded by AoA, for these funds from the National Family Caregiver Support Program.
- Division and AARP were successful in developing a special track for nursing assistants at the 2001 Georgia Gerontology Society Meeting; over 140 nursing assistants attended.
- The Georgia Alliance for Staffing Solutions was formed, and has conducted two forums to address long term care staffing issues (see more detail under Training section above).
- Numerous education/training initiatives have begun, and are listed above in the Training section.
- Policies and Procedures for adult day care/adult health, in-home respite, senior centers, homemaker, nutrition services, and personal care have been developed or revised. These

policies establish requirements to be followed when Area Agencies on Aging provide or contract for the provision of services.

- Review guides to assist Division staff to measure compliance and performance of services have been developed or revised. These guides are for nutrition services, case management, home repair, respite, information and referral, elder legal assistance programs, outreach, and adult day care/day health.

Caregiver Burden Scale

In collaboration with Dr. Rhonda Montgomery, a prominent researcher on caregiver issues in the United States from the University of Wisconsin, the Division of Aging Services and Area Agencies on Aging (AAAs), are field testing a new Caregiver Burden Scale. Called the Montgomery-Borgatta Caregiver Burden Scale, AAAs are helping to determine the instruments uses for: 1) prioritizing caregivers for receiving services; 2) targeting services more efficiently and effectively; and 3) identification of needed caregiver resources for long-range program planning and development.

We are particularly interested in determining whether the instrument can assist staff in predicting the "reachable moment" when the provision of services to caregivers will have the most impact, as well as guide intervention strategies.

CARE-NETs

Under a grant funded by the AoA's National Family Caregiver Support Program, the Rosalynn Carter Institute, in partnership with the Georgia Division of Aging and six of its Area Agencies on Aging, has established six new caregiving leadership coalitions in Georgia. The model for such coalitions, called CARE-NETs, was developed by former First Lady Rosalynn Carter in 1990 when the first CARE-NET was established in the West Central region of Georgia.

Since 2001, six new CARE-NETs have been established in Georgia in the following geographical areas: Albany, South Metro, Metro, North Georgia, Heart of Georgia, and Coastal areas. The Albany, South Metro, Heart of Georgia, and Coastal areas all have by-laws adopted and an organization in place. The Metro and North Georgia areas have adopted Mission, Goal, and Objective statements and have an organization in place.

All six of the CARE-NETs have projects underway. The Southwest Georgia CARE-NET (Albany) is sponsoring five two-hour sessions on *Caring for You, Caring for Me.* The Southern Crescent CARE-NET (South Metro) sponsored a one-day workshop called *Caring for the Caregiver*. The Atlanta CARE-NET (Metro) has planned a *Caring for You, Caring for Me,* Leadership Preparation Workshop. The Coastal Georgia CARE-NET sponsored a one-day forum on caregiving in cooperation with the Coastal AAA, and is making arrangements for offering the Leadership Preparation Workshop of *Caring for You, Caring for Me.* The Heart of Georgia CARE-NET is planning for the one day *Caring for the Caregiver* workshop.

The Project Staff is working to complete a new instrument to measure community caregiving capacity, the Community Caregiving Capacity Index (CCCI). At present, initial data collection

has been completed. All CARE-NET members of the six CARE-NETs are participating in this process and are enlisting members of their local caregiving community to participate.
For more information, please contact: Rosalynn Carter Institute for Human Development, 800 Wheatley Street. Americus, GA 31709
229.928.1234, rci@rci.gsw.edu, www.rosalynncarter.org.

Aging and Long Term Care Information System

Developed by the Atlanta Regional Commission's Area Agency on Aging and CyberPath, this innovative system contains numerous components, including:

- *Elder Services Program (ESP)*, a comprehensive software program with client and provider service components, and
- *CONNECT*, the provider/service component, which has nearly 14,000 listings statewide of providers serving clients and caregivers, separated into 42 categories of services.

For more information, contact Cheryll Schramm, Director, Atlanta Regional Commission Area Agency on Aging, at cschramm@atlantaregional.com

Assistive Technology

A number of Georgia's Area Agencies on Aging provide home modifications and low technology devices. For example, CSRA Area Agency on Aging contracts with Walton Options for Independent Living, Inc. They provide assistive devices and adaptive equipment to eligible seniors in their 14 county regions. Equipment devices include but are not limited to wheelchair ramps and doorway renovations, hand–held showerheads, grab bars, and transfer benches.

Another example of assistive technology is the Division's caregiver demonstration grant. Southern Crescent Area Agency on Aging's self-directed care program has focused on safety in the home. The AAA has contracted with Care Link AmeriCorps to provide a multi-faceted system for caregivers and care receivers with a variety of supplemental services. Additional partners in the project include the Troup County Fire Department, the Division of Public Health's Chronic Disease Prevention Coordinator, the Rehabilitation/Department of Labor, and the city inspector, who assessed all construction needs, drew plans, identified supplies and cost for each site, and was available for post construction inspections as needed.

- Five hundred families and caregivers have been reached through education regarding safety and how to help prevent falls.
- Education events have been attended by 333 individuals.
- Approximately 100 caregivers were assisted with either the installation of wheelchair ramps, handrails, carbon monoxide detectors, elevated toilet seats, transfer benches, and/or handheld showers.

Georgia Generations Magazine

With leadership from the Atlanta Regional Commission Area Agency on Aging, Georgia's AAAs developed and funded a caregiver magazine, entitled, *Georgia Generations*. Published quarterly by JAM Publications, the magazine has featured topics such as affordable prescription drugs, grandparenting, depression, and personal histories. Additionally, each feature includes an article written by each Area Agency on Aging regarding particular programs and services within their respective regions.

Senior Centers

The Senior Center program in Fulton County within the Atlanta Regional Commission's (ARC) Area Agency on Aging is unique and worthy of replication. In a collaborative endeavor using Older Americans Act monies provided by ARC, and funding provided by Fulton County local government, most of Fulton County's senior centers offer the following:

- Serve persons of diverse cultural backgrounds
- Primary care physician and nurse on site
- Specialized nutrition
- Teaching foreign languages
- Health and Wellness programs, including cholesterol and diabetes management programs
- Exercise rooms staffed by certified exercise specialists
- Various health screenings
- Medications management programs
- Recreational programs
- Arts and crafts programs
- Ability to allow individuals to get driving license renewals, and pay tax and utility bills
- Therapeutic swimming pools
- Computer labs

INTEGRATION OF IIIE INTO LONG TERM CARE PLANNING AND OLMSTEAD

Long Term Care Planning

Long term care encompasses the organization, delivery, financing, administration and coordination of an array of services designed to assist people who are limited in their ability to function independently over a relatively long period of time. Georgia's long-term care and support services are designed to help individuals and family caregivers:

- Perform basic life functions.
- Improve skills and capabilities to maximize independence and function.
- Establish and maintain social and personal relationships in the individual's own neighborhood and community.
- Care for family members with functional limitations.

- Provide comfort, supervision and support to people with an irreversible illnesses or conditions.

Services provided include (but are not limited to) assessment; care management and coordination of services and supports for assistance in eating, bathing, dressing, getting in and out of bed, moving about the living area, doing housework, managing illness symptoms including taking medications; rehabilitative services; adaptive aids; transportation; nursing homes; and other

residential services. It also includes medical treatment and skilled and therapeutic care for the management of chronic and long term conditions.

Georgia, like other states, has struggled with how to deal with the costs of care and the access to long term care services. The Division of Aging Services has been proactive in its participation in statewide workgroups to address these issues. As part of this participation, the Division has worked with the AAAs to develop their position as the community's GATEWAY to a coordinated system of services. These services, including long term care, will promote independence and well-being for older Georgians, their families, and their communities.

In each of the twelve regional Area Agencies on Aging, specialized staff are assigned to receive inquiries, primarily by telephone, regarding services and resources. The staff use an electronic data base which contains information about service providers in the area. Information and assistance as well as intake and screening are integral components of GATEWAY. If services are available, care coordination staff complete a face-to-face assessment. If there are no openings immediately available, staff enter the applicant's name into the waiting list, along with the scores for functional ability and the need for care, obtained through the screening process. The system automatically ranks the applicants in order of the severity of functional impairment and unmet need for care. Staff use these two criteria, in addition to the length of time on the waiting list, to determine entry to a service or program, once an opening occurs.

Intake and screening staff re-screen applicants who remain on a waiting list every 120 days, to verify their situations and document any changes in status which may have occurred since the last contact.

With the availability of Title IIIE funding available, for the first time the caregiver has become the client. Requests for services for caregivers are screened in the same fashion as all other applications for service through GATEWAY. When a caregiver is assessed for service, information about the caregiver and care receiver are entered into Georgia's data base for client services (AIMS). When deemed appropriate by screeners, AAAs can also access the Montgomery-Borgatta Caregiver Burden Scale to assist with either care planning, or providing indications for depression and the need for further screening and referral for appropriate interventions.

Olmstead Decision

Since the 1999 Supreme Court decision, Olmstead v. L.C., the DHR Division of Aging Services has participated in planning and implementation of the decision. As mentioned earlier, in

December 1999 the Blue Ribbon Task Force recommendations formed a basis for a number of efforts to enhance community living for persons with disabilities.

In April of 2000, the Department of Human Resources was designated as the lead agency to apply for and carry out the activities of a grant from the Center for Health Strategies. The Olmstead Committee was formed from a broad group of stakeholders including consumers of services, members of consumers' families, advocates, providers of services to persons with disabilities, leaders of the Department of Community Health (the state Medicaid agency), the Department of Human Resources, including persons from Aging, Mental Health/Developmentally

Disabled/Addictive Diseases, Department of Family and Children's Services, and the Office of Regulatory Services. Early in 2002, the Olmstead Planning Committee presented its recommendations to the Commissioners on strategic directions and broad parameters for addressing the Olmstead decision.

In November 2002, Governor Sonny Perdue was elected and his office is reviewing the final Olmstead Plan. State planning is ongoing and budget enhancements are in the Governor's budget. The commitment of the Governor is evident in the budget proposal through Olmstead-related allocations to move individuals from institutional to community care. The budget proposal includes enhancements for the Division of Aging Services Community Care Services Program (see www.georgiacommunitycare.org for additional information on the Division's Medicaid Waiver program to assist persons at risk of nursing home placement to live in the community).

Guiding principles of a plan will reflect certain philosophies:

- Person-centered planning and care
- Moving individuals to the most integrated services appropriate
- Collaboration with various stakeholders, and
- Equitable allocation of resources

Items which would be addressed include but are not limited to:

- ensuring the involvement of individuals with disabilities, older adults, family members, and advocates in the State Working Plan development and implementation process.
- ensuring the necessary coordination and collaboration across state agencies for a comprehensive, effectively working plan.
- preventing or correcting current and future premature or inappropriate institutionalizations of individuals with disabilities and older adults.
- identifying opportunities to reduce the waiting lists for home and community-based services.
- addressing complex issues, such as housing, transportation, and workforce development, recruitment and retention that are not reflected in service dollars, but are necessary to remove barriers to community integration.
- addressing transition and assessment issues to help individuals who choose to move from institutions to community-based services.
- utilizing innovative action steps of the President's New Freedom Initiative funding to enhance the state's efforts.

- assuring quality of care of all participants receiving services.

The State has received a Systems Change Grant that will address barriers to community based care, such as housing and workforce issues. There is a necessity of service providers to increase funding of direct care workers and to address training and development issues. Additionally, Georgia, like most states, is experiencing a nursing shortage that impacts efforts to move appropriate individuals from institutional to community care.

Numerous additional issues addressing individual choice, management of waiting lists, individual plan development, current availability of community-integrated services, education and outreach,

planned transitions and service expansions, housing, transportation, and assistive technology are included in the Working Plan, and Action Steps developed for all of these issues.

The Division of Aging Services will continue to be involved as appropriate to ensure that the needs of older persons and their caregivers are met as changes are made for these individuals at risk of institutionalization or currently institutionalized who may meet the conditions as stipulated in the Olmstead decision.

PROJECTED NUMBER OF CLIENTS SERVED BY TITLE IIIE IN STATE FISCAL YEAR 2003 (ENDS JUNE 30, 2003):

Number of Persons receiving group services, including public education, provision of information at health fairs *31,199*

Number of Persons receiving one-on-one information and assistance, care management, counseling, respite, day care, home modification, self directed care *1,238*

Note: These numbers are not unduplicated. Some caregivers may receive services monthly, and may also receive more than one service.

TRACKING AND REPORTING TITLE IIIE

The Aging Information Management System (AIMS) is the integrated, centralized data base system developed in Georgia to access client, financial, and services data to all levels of the aging network. *AIMS* produces accurate reports to meet reporting requirements for federal, state, and local agencies. It saves historical client data used to assess impact of services provided to clients over time. It enables the aging network to evaluate the quality of services, and manage programs more effectively.

With the implementation of the National Family Caregiver Support Program, a number of changes were made to the client registration screens, so that screeners would know what data elements to enter into the system on caregivers as clients. Modifications were also made to the system so that the care receiver who makes the caregiver eligible for service is listed on the screen.

A number of new reports have been developed in *AIMS* to assist the Georgia aging network in collecting accurate data for the Title IIIE program. These include:

- Caregiver -Care Receiver Demographic Report
- Caregiver-Care Receiver Demographic Report by Fund Source
- Caregiver-Care Receiver Summary of Services
- Caregiver Expenditure Report
- Caregiver Service Summary Report

CONCLUSION

In conclusion, we hope that this Committee will recognize the value of mediation and incorporate it as an essential/integral piece of the national caregiver support system in the Older Americans Act.

The creation of the National Family Caregiver Support Program has enabled states to create new partnerships and paradigms to meet the diverse and increasing needs of caregivers.
One of the program's hallmarks has been the component of "supplemental services", which has enabled the aging network the flexibility needed to become innovative. The product of that flexibility is improved service delivery, new services, and increased empowerment for caregivers. Also, the National Family Caregiver Support Program demonstration grants have allowed states like Georgia to pilot new delivery of care systems, gather consumer satisfaction data and to manage programs using data.

Thank you for the opportunity to testify. May I answer any questions?

The CHAIRMAN. Now, let us turn to Kevin Mahoney, Program Manager for a demonstration project which highlights innovations in consumer directed care. Would you please proceed? Thank you.

Dr. MAHONEY. If I might just have a second to get this set up.

The CHAIRMAN. All right. Thank you. I want to also say that you are a National Program Director at Cash and Counseling Demonstration Project in Chestnut Hill——

Dr. MAHONEY. At Boston College.

The CHAIRMAN. There we go. Thank you. Now we have it all out.

STATEMENT OF KEVIN J. MAHONEY, PH.D., NATIONAL PROGRAM DIRECTOR, CASH AND COUNSELING DEMONSTRATION AND EVALUATION PROJECT, BOSTON COLLEGE GRADUATE SCHOOL OF SOCIAL WORKS, CHESTNUT HILL, MA

Dr. MAHONEY. Thank you, Mr. Chairman and members of the committee. Today in most States, whether you are elderly or a younger person with disabilities, if you are on Medicaid and you need help with such basic things as bathing, dressing, getting out of bed, you rarely have any choice over who helps you, when they come, or what they do. But for years, people in the disability community have been saying, if I had more control over these services, my life would be a lot better and I think I could do it for the same amount of money or less.

The Cash and Counseling Demonstration and Evaluation is, in fact, a real major test of just that idea. It is a test of one of the ultimate forms of consumer direction, where people are given the choice between traditional services from agencies or managing the equivalent amount of a cash allowance themselves with supports. It is a major test, one that involves over 6,700 people in three States who have been randomly assigned for this demonstration.

Janice Maddox is a perfect example of the desire of seniors to have more control over who enters their home and who provides intimate care. At 75, Mrs. Maddox does not have the best health. She has diabetes and glaucoma and is confined to a wheelchair possibly as a result of several strokes. But despite her physical frailty, Mrs. Maddox possesses a tremendous asset, an extensive support network of family and friends who want to help her continue to live independently.

For 5 years, Mrs. Maddox received personal assistance services from aides sent to her by an agency that contracted with Medicaid. Then her daughter read about Arkansas's Cash and Counseling Program in the newspaper. Mrs. Maddox enrolled and her oldest daughter, Johnetta Thurman, became her representative decision-maker. Mrs. Maddox's monthly allowance through Cash and Counseling pays her adult granddaughter to spend at least 2 hours a day, 7 days a week, attending to Mrs. Maddox's needs. Her allowance is also used to pay her grandson $10 a week to do odd jobs around the house and helps cover the cost of such things as over-the-counter medications and toiletries.

Mrs. Maddox's daughter, who lives in Chicago and travels frequently to Arkansas to make sure her mother's needs are being met, believes the program has made an immense impact in improving the quality of her mother's life. She says, "There is just something about having family look after her. She doesn't get nearly as

many allergic reactions or bedsores now, and I think that's because when it's your own you're looking after, you pay more attention."

The Cash and Counseling Demonstration and Evaluation is really a rather unusual creature. It is completely co-funded by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation at HHS. It operates under Medicaid waivers granted by the Centers for Medicare and Medicaid Services. The quantitative evaluation that I am going to present to you, the first results, was done by Mathematica Policy Research. The qualitative evaluation that is my favorite follows about 25 people close up and personal in each of the three States and tells how this really affects their lives.

The program takes place in three States, Arkansas, Florida, and New Jersey. In all three States, it includes older people and younger adults with disabilities. Florida is different. They also include children with developmental services.

What I would like to do in these few minutes today is present the first of our research results. they are from Arkansas which was the first State to implement this. To Arkansas's credit, they implemented the cash and counseling option within a month of when they got the Federal waivers. These particular findings that we get to share today are from a controlled experiment, so in Arkansas, we had a little over 2,000 people enrolled. Half of them were randomly assigned to the traditional system, half to managing the cash allowance.

When we looked at quality of care measures, we looked at four: satisfaction, reduction in unmet need, health outcomes, and affects on overall quality of life.

Just a key to sort of give a picture of this, the left side are younger adults with disabilities. The right side are the elderly. The red bars are the treatment group. Those are the people that got to manage the cash allowance. The "C" is the control, is the traditional system. Whenever you see an asterisk, it is statistically significant. The more asterisks, the more statistically significant. Rarely will you in your lifetime as a researcher get a chance to see that kind of results, over 20 percentage points improvement in some of these measures of satisfaction.

When you turn to the second measure, unmet needs, you start seeing reduction, major reductions there.

The results people were really looking for the most were the health outcomes, and I am pleased to be able to report that basically the health outcomes were either as good, or where there were differences, they favored the people who managed their own allowance. You can see the elderly had fewer contractures while younger persons with disabilities had fewer bedsores. Overall life satisfaction was also improved. The final slide shows the schedule for the rest of our reports.

Each of these three States is looking at making cash and counseling a permanent option. The Robert Wood Johnson Foundation and HHS are looking at how we can expand this option to other States. Thanks.

The CHAIRMAN. Thank you very much for that testimony. That is exciting, you are right, to see those kinds of results, Kevin, are very impressive.

[The prepared statement of Dr. Mahoney follows:]

BOSTON COLLEGE

GRADUATE SCHOOL OF SOCIAL WORK

Written Statement of Kevin J. Mahoney, Ph.D.

National Program Director

Cash and Counseling Demonstration and Evaluation

Before the Senate Special Committee on Aging

May 20, 2003

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Written Statement of Kevin J. Mahoney, PH.D.
National Program Director
Cash and Counseling Demonstration and Evaluation

Mr. Chairman and Members of the committee, good morning. My name is Dr. Kevin J. Mahoney. I am the National Program Director for the Cash and Counseling Demonstration and Evaluation and a faculty member at the Boston College Graduate School of Social Work. Thank you for inviting me to testify this morning.

Today, in most states, whether you are an elderly individual or a younger person with disabilities, if you need Medicaid assistance to perform major activities of daily living like bathing, dressing, toileting, transferring or eating you will rarely have much say over who helps you or when they come, never mind what they actually do. But, for years, persons with disabilities have been saying, "If I had more control over my services, my quality of life would improve and I could meet my needs for the same amount of money or less." The Cash and Counseling Demonstration is, at its heart, a policy-driven evaluation of this basic belief.

Janice Maddox is a perfect example of the desire of seniors to have more control over who enters their home and who provides intimate care.

At 75, Ms. Maddox does not have the best health. She has diabetes and glaucoma and is confined to a wheelchair, possibly as a result of several strokes. She needs help getting in and out of bed, dressing, bathing, meeting her dietary requirements, taking her medications, and keeping up with her housework.

But despite her physical frailty, Mrs. Maddox possesses a tremendous asset: an extensive support network of friends and family who want to help her continue to live independently. Her many children, grandchildren, great-grandchildren, siblings, and extended family, including neighbors, provide a continual stream of sound and motion for Mrs. Maddox, a widow, to watch bemusedly from her wheelchair.

For five years, Mrs. Maddox received personal assistance services from aides sent to her by an agency that contracted with Medicaid. Then her daughter read about Arkansas' Cash & Counseling program, in the newspaper. Mrs. Maddox enrolled, and her oldest daughter, Johnetta Thurman, became her representative decision maker.

Mrs. Maddox's monthly allowance through Cash & Counseling pays her adult granddaughter to spend at least two hours a day, seven days week, attending to Mrs. Maddox's needs. Her allowance is also used to pay her

grandson $10 a week to do odd jobs around the house and helps cover the cost of over-the-counter medications and toiletries.

Ms. Maddox's daughter, who lives in Chicago and travels frequently to Arkansas to make sure her mother's needs are being met, believes the program has made an immense impact in improving the quality of her mother's life. "There's just something about having family look after her. She doesn't get nearly as many allergic reactions or bed sores now, and I think that's because when it's your own you're looking after, you pay more attention."

The Cash and Counseling Demonstration and Evaluation (CCDE), funded by the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services, is a test of one of the most unfettered forms of consumer direction -- offering elders and younger persons with disabilities a cash allowance in place of agency-delivered services. It operates under a research and demonstration waiver granted by the Centers for Medicare and Medicaid Services (CMS). The purpose of this project is to determine whether cash allowances maximize consumer choice and promote program efficiencies.

In the states where the program is being implemented Arkansas, Florida and New Jersey, consumers who meet project eligibility criteria and express interest in participating in CCDE are randomly assigned to participate in the program (managing a cash allowance to purchase services) or serve as a control group and receive services through the state's existing system. The evaluation compares outcomes for consumers receiving traditional service packages with those receiving cash allowances with respect to cost, quality, and satisfaction.

My presentation today summarizes findings about the effects of Cash and Counseling on well-being, unmet needs, health outcomes, and consumer satisfaction. It focuses on the first of the demonstration programs to be implemented, Arkansas's IndependentChoices. Mathematica Policy Research, Inc. conducted the evaluation.

Demonstration Tests a New Model of Medicaid Personal Assistance

Medicaid beneficiaries who have disabilities and receive supportive services from home care or case management agencies often report that they have little control over who provides their care, when they receive it, and how it is delivered. For some, this lack of control over basic, often intimate, assistance leads to dissatisfaction, unmet needs, and diminished quality of life. Many states are expanding opportunities for interested Medicaid

beneficiaries to direct their disability-related supportive services by letting them control the budget for their approved care. This approach could enable beneficiaries to better meet their care needs, without increasing public costs. However, critics fear that such options jeopardize consumer health and safety.

In the Arkansas Cash and Counseling demonstration, called IndependentChoices, consumers had the opportunity to receive a monthly allowance, which they could use to hire their choice of caregivers (except spouses) and to buy other services or goods (such as assistive devices and home modifications) to meet their personal care needs. Allowances were equal to the number of hours of care consumers were expected to receive under the traditional Medicaid program, and averaged about $320 per month. Consumers were required to develop written plans for managing the allowance and have them approved by counselors. In addition, virtually all consumers chose to have the program's fiscal agents write checks for their purchases and withhold payroll taxes for caregivers hired with the allowance. Consumers who were unable or unwilling to manage the allowance themselves could designate a representative, such as a family member, to do so for them.

Demonstration's Randomized Design and Comprehensive Survey Data Yield Definitive Results

Cash and Counseling was designed to provide definitive evidence about its effects on a variety of outcomes, including many that pertained to care quality. Enrollment into the Arkansas demonstration, which occurred between December 1998 and April 2001, and was open to interested Arkansans who were at least 18 years old and who were eligible for personal care services under the state Medicaid plan. The 2,008 adults who volunteered for the demonstration completed a baseline telephone interview and then were randomly assigned to direct their own supportive services as IndependentChoices consumers (the treatment group) or to rely as usual on services from home care agencies (the control group).

Data on quality of care outcomes were collected nine months later, when all treatment and control group members (or their proxy respondents) were asked to complete a follow-up telephone interview. The 1,739 survey respondents answered factual questions about disability-related adverse events and health problems, and gave their opinions about (1) satisfaction with care, (2) unmet needs for assistance with daily activities, (3) quality of life, (4) general health status, (5) self-care, and (6) ability to perform daily activities without help from others. Demonstration evaluators then used

statistical models to compare the treatment and control groups on these outcomes for nonelderly and elderly sample members, while controlling for a comprehensive set of characteristics that were measured during the baseline interviews.

Consumer Satisfaction Improved Markedly, with No Adverse Health Effects

The resulting analysis showed that the Arkansas Medicaid beneficiaries who had the opportunity to direct their personal care services themselves received better care than the control group, which relied on services from agencies. IndependentChoices significantly increased the proportion of consumers who were very satisfied with their care and their paid caregivers, and thinned the ranks of the dissatisfied. Specifically, IndependentChoices consumers were much more satisfied with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way paid caregivers performed their tasks. The program also reduced some unmet needs for personal assistance services and substantially enhanced consumers' quality of life. Moreover, it produced these improvements without compromising consumer health or functioning. Both elderly and nonelderly adults had better experiences under

IndependentChoices than under agency-directed services, though impacts on most outcomes were larger for the nonelderly.

Findings About Costs, Caregiver Outcomes, and Implementation Are Also Needed

Although the quality and consumer satisfaction results suggest that the Cash and Counseling model, as implemented under IndependentChoices, benefits users of personal care services, other issues must be examined before the model's desirability can be fully confirmed. Public costs could increase or decrease under IndependentChoices - - a critical factor in times of state budget crises. In companion analyses, evaluators will examine how IndependentChoices may have affected the use and cost of personal care, acute care, and long-term care, as funded by Medicaid or Medicare. They also will examine program effects on consumers' informal and paid caregivers, and explore implementation lessons of interest to states. Evaluators will repeat these analyses for Florida and New Jersey and compare the results across all three states.

Cash & Counseling Consumer Profiles

Often the best way to see the effects of a program is by looking at how it affects individuals.

Grace Wall: Aging with Independence

Grace Wall, of Zephyrhills, Fla., has always been independent. But at 83, with a host of health problems that include congestive heart failure, two hip replacements, loss of sight in one eye, and lung cancer, that independence is harder to maintain.

For six years, Mrs. Wall took care of her paralyzed husband before he died in 1991. Now she lives alone in a mobile home. She gets her health care through Medicaid, as well as various personal assistance services, such as help with shopping and housekeeping – things that she has difficulty doing on her own now.

Mrs. Wall used to get those services through a Medicaid contractor. But in September 2000, she enrolled in Consumer Directed Care (CDC), Florida's Cash & Counseling program. Mrs. Wall says that CDC has changed her life.

"I just feel better," she says. "This gets what I need to get done without much fuss."

Now Mrs. Wall can hire people she knows and trusts to help her. A good portion of her $437 monthly budget goes toward buying medications and health care supplies. She also uses the money for transportation and to maintain her home.

At first, Mrs. Wall admits that she was daunted by the paperwork. But her CDC consultant has helped her through that and Mrs. Wall says the rewards have been well worth the effort.

Mrs. Wall says CDC has enabled her to do things she wouldn't otherwise have been able to do and made difficult tasks simpler for her. She also feels more secure with help that is close at hand and accountable to her. Agency workers, she notes, were not always there for her when she needed them. "Now I can rely on my worker, and I couldn't before. I can get help when I need it."

Tammy Svihla: Getting Help on Her Own Terms

Single motherhood is tough for a woman on a limited income, but Tammy Svihla, who has multiple sclerosis (MS), does it all from a wheelchair without complaining.

Not much ruffles this 36-year-old mother of three. She's conquered many problems, and she's not about to give in to MS.

She lives in a rented two-story house in High Bridge, N.J., with her two youngest children (her eldest lives nearby with his grandparents). Although she is a take-charge type of person, she needs help with some of the basics, like dressing, showering, getting up and down the stairs, cooking, cleaning, and shopping. Ms. Svihla says she gladly accepts help when it comes on her own terms. "I've had a string of personal care aides through here, and most of them never lasted very long," she says.

A former retail store manager, Ms. Svihla jumped at the chance to direct her own care through New Jersey's Personal Preference program. "I saw it as an opportunity to take control – to decide for myself who walks through my front door," she says. "That's very important when you have young children in the house."

Today, Ms. Svihla employs two reliable, handpicked helpers: a neighbor and an aide she found by posting flyers in her neighborhood. Ms. Svihla manages her monthly $1,035 allowance herself, with minimal assistance from a bookkeeper provided by the program. About half of the money covers payroll and taxes, and the rest pays for personal care items and goods for her home, including incontinence pads, an air conditioner and fans, and touch lamps. She's also purchased some home office equipment to help her manage her paperwork better.

Personal Preference, it turns out, is exactly what Ms. Svihla needed. "This program just makes sense," she says. "Others should know about it."

Lessons Learned

Consumers like Cash & Counseling. Across all three states, clients express high levels of satisfaction.

- In Arkansas, 96 percent of clients say they would recommend the program to others; 82 percent say the program has improved their lives, and 65 percent say the program has improved their lives a great deal.
- In New Jersey, 97 percent of clients say they would recommend the program to others seeking more control over their personal care.

However, Cash & Counseling is not for everyone. For some, the traditional service delivery system works well because they are unable or don't want to make decisions about their care and arrange their own services.

Many consumers hire family members or friends to be their personal caregivers. This may be a reason why satisfaction with the program is so high – consumers are hiring people they know and trust to work for them.

- In New Jersey, 63 percent of clients used their monthly budgets to hire family members, while 20 percent hired friends, neighbors, or church members.

- In Arkansas, Cash & Counseling consumers were more satisfied with their relationships with their paid caregivers than were consumers receiving traditional services.

Many consumers use the program's financial planning and bookkeeping services and find them helpful. These services can reduce clients' fears of being overwhelmed by paperwork.

- In Florida, 80 percent of Cash & Counseling clients used a program consultant to help develop their purchasing plans; of those, 90 percent found the assistance useful. Ninety-eight percent of Florida clients said the program's bookkeeper was managing their financial responsibilities for them.

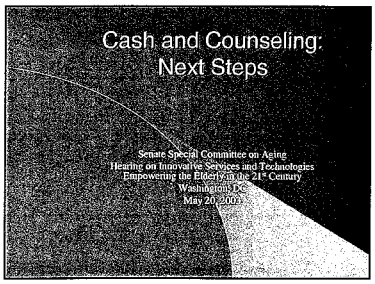
There have been no major instances of fraud or abuse. Consumers are managing their budgets responsibly and spending their money the way the program intends.

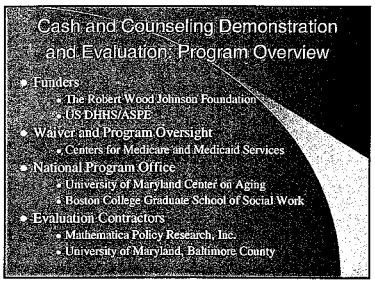
Looking Ahead

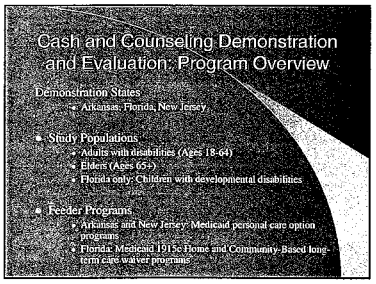
Each of the three Cash and Counseling states is working to make consumer-directed care a *permanent* option for disabled and elderly Medicaid beneficiaries. In fact, Florida has already enacted legislation to that effect. At the federal level, the Centers for Medicare & Medicaid Services (CMS) have issued model waiver templates encouraging states to develop consumer-directed waiver program options. Simultaneously, New Jersey and Arkansas have asked CMS to clarify its policy to allow states to pay for a wide array of assistive devices and home renovations under Medicaid's personal care benefit – without having to rely on waivers.

Meanwhile, The Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation, the Centers for Medicare and Medicaid Services and the Administration on Aging are exploring the feasibility of expanding the Cash & Counseling demonstration to other states.

I appreciate your invitation to participate in this hearing and look forward to your questions and comments. For follow-up questions, I can be reached at Kevin.mahoney@bc.edu or by calling (617) 552-4039.


Cash and Counseling:
Next Steps
Senate Special Committee on Aging
Hearing on Innovative Services and Technologies
Empowering the Elderly in the 21st Century
Washington, D.C.
May 20, 2004


Cash and Counseling Demonstration and Evaluation: Program Overview
Funders
The Robert Wood Johnson Foundation
US DHHS/ASPE
Waiver and Program Oversight
Centers for Medicare and Medicaid Services
National Program Office
University of Maryland Center on Aging
Boston College Graduate School of Social Work
Evaluation Contractors
Mathematica Policy Research, Inc.
University of Maryland, Baltimore County


Cash and Counseling Demonstration and Evaluation: Program Overview
Demonstration States
Arkansas, Florida, New Jersey
Study Populations
Adults with disabilities (Ages 18-64)
Elders (Ages 65+)
Florida only: Children with developmental disabilities
Feeder Programs
Arkansas and New Jersey: Medicaid personal care option programs
Florida: Medicaid 1915c Home and Community-Based long-term care waiver programs

For More Information on the CCDE

www.umd.edu/aging

Cash and Counseling Demonstration and Evaluation: Program Overview

- Phase 1: Selecting states and evaluator
  (October 1995-October 1996)
- Phase 2: Planning and Development
  (October 1996-November 1998)
- Phase 3: Implementation
  (December 1998-Present)

Final reports expected:
November 2002-January 2005

Basic Model for Cash and Counseling Demonstration and Evaluation

- Step 1: Consumers receive traditional assessment and care plan
- Step 2: A dollar value is assigned to that care plan
- Step 3: Consumers receive enough information to make unbiased personal choice between managing individualized budget or receiving traditional agency-delivered services

Basic Model for Cash and Counseling Demonstration and Evaluation

- Step 4: Consumers who want to participate are ***randomized*** into cash allowance or traditional services groups
- Step 5: Cash allowance group provided with counseling and fiscal intermediary supports
- Step 6: Consumer and counselor develop cash plan to meet consumer's personal assistance needs

Basic Model for Cash and Counseling Demonstration and Evaluation

- Consumers may appoint someone to help them manage the cash allowance
- Almost all of the participants chose to utilize a fiscal intermediary
- Consumers in cash allowance group may return to traditional services at anytime

The CHAIRMAN. Now, let us turn to Dr. Ron Aday. Dr. Aday is Director of Aging Studies, Middle Tennessee State University. Welcome, Doctor.

STATEMENT OF RONALD H. ADAY, PH.D., DIRECTOR OF AGING STUDIES, MIDDLE TENNESSEE STATE UNIVERSITY, MURFREESBORO, TN

Dr. ADAY. Thank you, Senator Craig. It is a pleasure to be here today to discuss the significance of senior centers and the important role that they will play in meeting the diverse needs of our nation's baby boomers.

The challenge, of course, centers around the diversity of this population, as you mentioned earlier, in terms of ethnicity, the well, the frail, and, of course, an age span from 60 to 100 or more. So it is a tremendous challenge that we are facing.

This year, senior centers are celebrating their 60th year as an entity and are serving over ten million clients annually at approximately 1,400 senior centers. They have a strong infrastructure, a dedicated staff that certainly has demonstrated an openness to exploring ways of how to meet the upcoming challenges for serving the baby boomer generation.

There are several ways that senior centers might be able to empower this group in the coming decades. I think it is very important to provide what I refer to as survival skills for the baby boomers and, of course, in many cases, their aging parents, as well.

One of the research outcomes I have recently found in surveying senior centers from seven States and approximately 20 senior centers, was that the senior center environment is conducive to the establishment of social support networks, where seniors feel responsible for each other and assist each other in order to help maintain their independence. About 85 percent of the sample reported that friends they have made at the senior center provided them with a sense of emotional security and someone that they can depend on in time of need.

Eighty-five percent also said that they provided some type of assistance to their friends that they had made at the senior center. I think that is very significant as we look at how to create a more independent baby boomer generation as they progress in age. This social network, of course, combats depression, loneliness, especially for those that live alone. We have a large number of female senior center users in particular that live alone.

Another, main area where senior centers can certainly empower and help our baby boomers is through what has been termed self-care initiatives. Most senior centers currently provide health and wellness programming, which brings about positive behavioral changes. In the future, chronic care clinics will emerge as an even more important component of senior centers.

The senior center that I have been serving on the board for for the last 12 or 15 years, when we reconstructed the new senior center that we opened 4 or 5 years ago, we actually built within that construction a nurse-on-duty program. It was actually in place, and so we have a nurse that comes there 2 days a week, provides a clinic. She also works at the university where I do. It is a partnership between the university and the senior center. They bring nurs-

ing students to the senior center and provide assistance and screening, and she has at the present time 400 open cases where she sees on a regular basis, providing screening and drug management kinds of—and information to them.

A third area that we see, I think, is really looking at the baby boomers in the future, who many of them will want to continue to work into their 70's. That is one of the things that the literature tells us. But the senior center can evolve, I think, to provide retirement counseling for those that may choose to retire, but also retraining and employment for those that want to continue. We know that based on advanced technology, that many of us will phase in and out of several careers over a lifetime and the senior center can certainly be the environment where baby boomers in their 60's might be able to come and get retrained. Senior centers in this way will serve as continuing education centers, where they will provide programming and innovations and it will be, I think, beyond computer skills. We talk about computer skills today. While computer labs are found in many senior centers today, additional computer and other new information will be important technological to baby boomers in order to remain current in the 21st Century.

Also, another, senior centers are now getting involved in what we call civic engagement programming, and that is trying to find a balance between leisure and recreational activities as well as civic commitment. We know that we need to utilize the services and the potential that baby boomers have as they age and as they enter into the long-term care continuum. So we want to utilize their services, and so attracting them to the senior center for their education, for their skills, for volunteer work, is going to be extremely important.

Finally, a connection to other generations is also very important and senior centers can play a very important role in this process, by providing adult day services, services for helping family caregivers, grandparents' support groups, latchkey children telephone assistance, and also mentoring for juvenile diversion programs, to maintain a few examples.

While senior centers are now recognized as one of the most widely utilized services created by the Older Americans Act, they are in some ways still the very best kept secret based on the outcome measures that are telling us we really can't afford not to utilize the senior center network to its fullest in the coming decades. If given the adequate resources, senior centers will help make aging a new adventure for our baby boomers. Thank you very much.

The CHAIRMAN. Thank you very much, Doctor. The concept of a new or futuristic senior center was brought to my attention some months ago when a group met with me in Boise, ID, to talk about creating, if you will, a kind of model of a future center. I think, clearly, with the dynamics of this aging group, you are right. I have oftentimes thought how computer centers are important today. All of these folks entering will be mostly computer literate. They will simply be wanting to advance themselves in those skills as that part of our technology evolves, along with a lot of others.

I often have thought, yes, and they need an employment center or an employment contact and maybe even some training. So certainly what you have talked about seems to clearly be a part of

what others are visiting about and what some are thinking about in a sincere and direct way. Thank you.

[The prepared statement of Dr. Aday follows:]

Written Statement of

Ronald H. Aday, Ph.D.
Director of Aging Studies
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Murfreesboro, TN 37132

for the

U. S. Senate Special Committee On Aging
Dirksen Senate Office Building
Tuesday, May 20, 2003

on the

Evolving Role of the Senior Center in the 21st Century

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The senior center as we know it today was first introduced in New York city in 1943 to provide educational and recreational activities as well as other case management services to assist the elderly members in maintaining their independence in the community. Sixty years later, senior centers are now recognized as one of the most widely utilized services created by the Older Americans Act of 1965. Multipurpose senior centers have been identified as preferred, focal points for comprehensive and coordinated services delivery to elderly people. As diverse as the seniors who attend them, the National Institute of Senior Centers (NISC) estimates that over 10 million older adults are provided services annually by approximately 14,000 senior centers. Given the number and importance of senior centers in the service delivery network it is imperative that they continue to evolve to meet the unique needs of the "Baby Boomer" generation.

Who Uses Senior Centers?

Based on a recent survey (Aday, 2003) of approximately 20 senior centers in seven states it was found that older adults who currently frequent senior centers are typically in their mid-seventies with about one-third over the age of 80. Most users are single Caucasian females who are relatively well educated compared to seniors a decade or so ago. Although varying from center to center, about one-half of senior participants live alone. Seventy-five percent of center users come to the center 1-3 times a week and usually spend an average of 3.3 hours per day. Many senior center participants come for specific educational or health promotional programming rather than spending the entire day at the center. While about one-third have been attending senior centers for three years or less, 50% report participating for seven or more years. Only 20% have failed to complete high school and the same number (20%) are college graduates. The majority report receiving helpful information, increased knowledge, and learning new skills, which contribute to their continued independence.

How Do Senior Centers Empower The Elderly?

For older persons at risk of losing their self-sufficiency, senior centers are an entry point to an array of services that will assist them as they "age in place." Senior centers offer a wide range of health, education, recreation, volunteer and other social interaction opportunities for their participants that enhance dignity, support independence, and encourage community involvement. Centers are also a resource for the entire community, providing services and information on aging, and assisting family and friends who care for older persons. Senior centers can optimally provide a social environment conducive to the development of a social support system reducing loneliness and depression.

Although additional research is needed, we are beginning to get a clearer picture of the positive influence senior centers can have on successful aging. A recent survey (see Executive Summary and Accompanying Tables) of 734 senior center participants residing in California, Florida, Iowa, Main, New Hampshire, Texas, and Tennessee produced a variety of research outcomes suggesting the important role senior centers play in the lives of older adults when it comes to their physical and mental well-being. Selected results of this survey are described below:

- About 90% of seniors reported their health to be the same or better than the previous year;
- Almost half feel less lonely (46%), laugh more frequently (49%), have reduced their levels of stress (48%), feel more satisfied with life (43%), and have increased or started exercising regularly (40%);
- About one-quarter have more energy (22%), worry less about the future (23%), and feel more independent (28%);
- Practicing healthy behavior was positively associated with the number of educational and health promotion programs attended ($r = 52$; $p < .001$);
- Participants who make positive behavioral changes were more likely to enjoy a more positive outlook on life ($r = .55$; $p < .001$);
- Engaging in health promotional activities also enhances the feeling of empowerment by maintaining a more independent lifestyle ($r = .37$; $P < .001$).

As these research findings suggest, senior centers of the 21st Century have the potential to bring together a broad and varied program of services and activities that enable older persons to develop a greater feeling of empowerment.

Additional research has demonstrated that centers with structured health and wellness programs generated even greater changes in health behaviors and emotional well-being (Cambell & Aday, 2001). In this Nurse on Duty Chronic Care Clinic housed in a comprehensive senior center, we found that seniors took comfort in assuming self-care initiatives and those who consulted more frequently with the nurse reported their physical and mental health were significantly improved.

A significant body of research indicates that social support is a key determinant of successful aging. Senior centers also offer opportunities for social interaction, friendship, and ego integrity and feelings of self-worth, which successfully counters social isolation and loneliness that can threaten the mental and physical health of senior adults. Again using the information from the comprehensive survey of senior centers, it is evident that senior centers create opportunities for social networks and empowerment.

- Over 90% indicated that they have developed very close friendships at their senior center and the majority do engage in social activities outside of the center with friends made at the center;
- About 85% reported that the friends they have made at the senior center provide them with a sense of emotional security and someone they can depend on when needed;
- Approximately 85% said they provide some type of assistance to senior center friends and 22% do so pretty or very often;
- Over 50% reported receiving some type of assistance such as transportation, personal gifts, emotional support, and companionship;
- Senior center friends call each other on the average of 2.7 times each week just to check on each other;
- Women who live alone (n=274) were more likely to engage in supportive activities outside of the center compared to married females ($t = 2.38$; $p < .01$);
- Live alone females were also more likely to rely on friends at the senior center ($t = 2.4$; $p < .01$), and receive greater emotional support ($t = 2.3$; $p < .01$) than their married counterparts;

- Older live alone women also reported that the center friendships reduced their loneliness ($p = 3.03$; $p < .003$) and tend to influence their feeling of being more independent $t = 2.3$; $p < .01$).

How Should 21st Century Senior Centers Evolve?

Senior centers are faced with providing services to an increasing number of frail elderly while integrating a tremendous influx of baby boomers into the system. Some centers are already providing adult day care/respite services for participants in early stages of dementia. Other centers are more focused on preventative programs for the well elderly. Although there is little consensus on what constitutes the necessary components of a successful senior center model, a goal that most can agree on is the essential role senior centers can play in assisting a diverse group of older adults to age in a successful and productive manner. Rowe and Kahn (1998) identified three key components of successful aging: (1) low risk of disease and disease-related disability, (2) maintaining a high level of mental and physical functioning, and (3) active engagement with life. Many of the factors associated with successful aging can be found at senior centers, which provides opportunities to: (1) participate in disease prevention and health promotion activities; (2) maintain and develop social relationships and a strong support system, (3) develop emotional supports; (4) develop and maintain a positive mental attitude; (5) learn new skills and information; (6) participate in educational and other mentally stimulating programs (7) engage in voluntary and other productive activities (Beisgen & Kraitchman, 2003, p. 11).

Senior centers of the 21st Century have the potential to bring together a broad and varied program of services and activities that enable older persons to develop and maintain health-promoting behavior. Almost any center can offer a health promotion/health maintenance program. And if they do not offer all the components that contribute specifically to health promotion --- nutrition education, fitness and exercise programs, behavior modification, and support groups— they have the potential to do so. While some centers lack adequate resources, each community abounds with the potential resources that centers can tap in unique and creative ways. There are

volunteers, students of relevant disciplines, retired professionals, representatives of voluntary health-related organizations, and a host of other resources that can be brought together to create comprehensive programs and services for the elderly attending senior centers.

As the Senior Neighbors of Chattanooga, Inc., Model in Table 1 (See Appendix) suggests, other programs and services that contribute to socialization and the continuation of a viable social support system will vary according to community resources and interest. Certainly, a comprehensive senior center may very well offer opportunities for intergenerational programs, work and retirement counseling, leisure and education, family care services including adult day care or respite care services, and information and referral. Creative centers will consist of those that use their respective community resources to the fullest.

While the focus of the OAA is on minority, low income, socially isolated, and frail elderly, it is important that senior centers recruit older adults from all socio-economic, education, and health levels. It is the latter group, which often provides an abundance of volunteers and support workers. Thus, it is imperative that senior centers rethink the role they are to play in the 21st Century. It has been suggested that if centers are unable to broaden their range of services and funding sources, they will not be able to adequately meeting the needs of the baby boom generation (Miller, Jogan, & Spitze, 1993).

What Are Some Challenges Facing Senior Centers?

Senior centers are faced with numerous concerns, which will affect them well into this century. In addition to funding woes, space issues, etc., questions remain as to how centers can attract young seniors who can provide leadership and volunteer services while at the same time responding to the frequent users, which are increasingly frail. It has also been suggested that the baby boom generation will not easily identify with old age as previous generations have in the past. The young-old of the future will more likely be in the 65-70 age category as many boomers will work into their 70s. This is evident by the fact that some 4 million Americans over the age of 65

are now seeking work to keep pace with the rise in health care costs and to replenish retirement nest eggs. The challenge of attracting seniors in their 50s and 60s will be even more difficult in the future, especially given the current image and lack of creative programming found in some senior centers.

These challenges have not going unnoticed and the National Institute of Senior Centers (NISC) and other state senior center organizations are engaged in exploring ways to meet the coming challenge. Table 2 provides a sampling of the challenges facing senior centers across America. As Table 2 illustrates (see Appendix), NISC has become actively involved in developing a strategy to educate the public about the value of senior centers. Their efforts to identify effective outcome-based measures and the call for senior center accreditation will serve to strengthen the mission of the evolving senior center. Additional recommendations are located in the Tennessee Task Force Report included as an attachment to this report.

Summary

As the graying of America continues, changes in attitudes and policies toward aging will be necessary. Inherent in the aging of America is the absolute need for people to grow old with the highest levels of health, vitality and independence. For this to occur, the concept of health and well-being as it relates to the older segment of the population must include the ability to function effectively in society, to exercise self-reliance, and to achieve a high quality of life. Social policy related to the delivery of health care can no longer be construed in the traditional manner of medical care or illness management. Preventive programs common in senior centers will serve to empower the elderly and provide a key element in managing the tremendous demand of baby boomers on our health care system. This holistic framework of caring for the aging, must be the senior center model for the 21st century.

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Appendix

Table I. Senior Neighbors of Chattanooga Model for 21St Century Senior Center Programming/Services

Health and Fitness Division – Wellness programming in senior centers are relatively inexpensive and very cost effective as an illness prevention activity. The government currently spends very little on health prevention of chronic diseases. The senior center could provide a leading role in meeting the objectives of Healthy People 2000. Health and fitness activities are varied including senior games, senior athletic clubs, health education programs, seniors as athletic trainers, exercise programs including weight resistance, aerobics, dancing, etc. Other centers may also focus on health maintenance and intervention by offering chronic care clinics, health screening and ADL assessment, drug management education, healthy aging education programs such as coping or reducing stress, weight control and management, and immunization.

Intergenerational Division – IG programs can improve relationships and understanding between generations. In addition IG programs in senior centers can be of a real value to the community. Numerous models of mentoring exist such as juvenile diversion, latch-key companionship and telephone assurance, IG art programming, grandparent resource rooms, grandparent support groups, IG trips and fitness programs, and IG Service-Learning opportunities linking high school and college students with senior center participants to mention a few.

Retirement Division (Non-Paid/Paid). Baby boomers as they move into old age will be the most educated of any group of seniors to date. Utilizing the skills of these older adults will be vital to the survival of the senior center. Senior centers will provide the opportunity for senior leadership through non-paid activities such as community advocates, teachers, board members, and mentors. Providing seniors a purpose in life will be important to their overall emotional well being. Retirement counseling and employment programs (retraining) and employment pools provided at the center can also assist older adults in the pursuit of successful aging. Of course, involvement in RSVP activities can be the cornerstone of this division.

Leisure and Education Division – An important component of successful aging is to remain socially connected. Leisure and educational programs provide these opportunities. Educational classes such as foreign languages, computer groups (chat-rooms), horticulture therapy, community gardens, travel opportunities, oral-history projects, lecture series, art history, folklore, reading and discussion groups, college courses, creative arts, music groups, arts and craft, quilting groups, woodworking, painting, field trips are examples of activities within this division.

Family Care Division – Providing support to family caregivers will be an important function of 21st Century senior centers. Support groups such as Alzheimer's, Parkinson, Grandparent, Parent, Cancer, and Grief are natural activities for senior centers. Other care-giving activities include: care-giving resource room and referral, caregiver conferences, baby boomers as caregiver workshops. Other activities include caregiver outreach including nursing home outreach, transportation services, counseling, and referrals. Included in this division would also be Adult Day Care or Respite Care services provided in selected centers. On-line support groups can also be directed from the senior center via volunteers.

living-will services, speaking engagements, booths at community events, organizations, and businesses, speaking engagements, public services announcements, radio and television, feature articles, telephone/community directories, newsletters, internet web pages, billboards, promotional items, brochures, insurance counseling, forum to meet the candidates, investing, financial planning, and legal services.

Administrative/Research Division As the baby boomers transition toward old age, the demand for senior services will be overwhelming. It will be necessary to develop strategies for measuring program utility and impact. In their current administrative state, most senior centers are not equipped with the necessary staff to evaluate program impact. Senior Center Advisory Boards will need the necessary skills to successfully monitor program success or have funds made available to contract for research services. Volunteers from the academic community could be utilized more fully to determine program success, if board members don't possess these skills.

Table 2. A Sampling of Senior Center Challenges for the 21st Century

- Overcoming public misconceptions about senior center programming and services typically offered…There still exist the view that bingo and congregate meals are still the centerpiece for senior centers programming. [Developing marketing strategies to educate the public or other decision-makers on the value of senior centers].

- Projecting a more professional image of senior centers, which reflects the complete range of comprehensive services and educational activities provided. [NISC has recently implemented a guideline of standards enabling centers to become accredited]

- Providing strategies to promote and deliver more off-site programs and/or taking services to the senior adults: [Satellite programs are becoming more frequent with centers now operating in shopping malls and other non-traditional venues].

- Finding ways to refocus resources through the use of volunteers. [It is imperative that this country doesn't loose all the young-old baby boomers to gated retirement communities. Greater efforts must be made to attract the services of this highly educated group of potential volunteers and eventual uses of senior services].

- Recognizing the differences between urban and rural centers in programming and finding ways to enhance access to services in rural areas [Centers are diverse with some small centers unable to offer comprehensive programming, yet services are solely needed].

- Recognizing the need to establish strong leadership roles with other community organizations, which serve seniors. [Marketing senior centers as the focal point for comprehensive services in the community to other agencies such as churches, social groups, and hospitals, which offer similar services in urban communities can enhance community standing].

- Recruiting board members who can contribute programming ideas as well as offer financial and community support to the center [As senior center programming and services becomes more sophisticated, policymakers will also need advanced knowledge].

- Assuring funders that resources are being used responsibly [Developing outcome-based measures and standardized reporting systems to improve accountability].

- Overcoming a lack of adequate senior center research staff and research funds [More research monies should be directed toward senior centers through such organizations as NISC to encourage increased research opportunities].

The CHAIRMAN. Now, let us turn to Dr. Gregory Abowd, Associate Professor, College of Computing at Georgia Institute of Technology in Atlanta, GA. His research interests lie in human-to-computer interaction—hmm, I need some of your courses.

Dr. ABOWD. We all do.

The CHAIRMAN. I don't interact well. [Laughter.]

Dr. ABOWD. It is not your fault.

The CHAIRMAN. The smart home, or the aware home research initiative, or the smart home project for aging Americans. Thank you. Please proceed.

STATEMENT OF GREGORY D. ABOWD, ASSOCIATE PROFESSOR, COLLEGE OF COMPUTING, AND GVU CENTER DIRECTOR, AWARE HOME RESEARCH INITIATIVE, GEORGIA INSTITUTE OF TECHNOLOGY

Dr. ABOWD. Mr. Chairman, thank you for giving me this opportunity to speak about such an important topic and to allow me to talk about how I think this country can use high technology or advanced technology to meet the needs of an increasing aged population.

I have a very simple message, and that is that advanced technology holds great promise for promoting healthy and independent aging, but we must be more proactive to realize this promise. Aging is not a disease, and while there is significant research exploring how technology can provide assistance for individuals coping with disabilities or disease as they grow older, the role of technology in enhancing the lives of older but otherwise healthy Americans is not well understood or appreciated.

I am a computer scientist and an expert in the area of ubiquitous computing, meaning the spread of computing artifacts throughout the physical world to support everyday activities. Though my work presents great technical challenges, the motivation to work in this area is largely the human-centered agenda of providing assistance in our everyday lives.

Over the past 5 years, with support from the National Science Foundation, the State of Georgia, and several major computing companies, we have been exploring ubiquitous computing in the home. We refer to our efforts as the Aware Home Research Initiative, with the challenge of creating a home that serves its inhabitants because it is empowered with an awareness of their whereabouts and activities.

A major motivation for this work is that an aware home, properly connected to trusted caregivers, can provide the assistance needed for otherwise healthy individuals to cope with the natural declines related to aging. Advanced technologies can be pleasingly woven into the fabric of our homes, allowing us to age in place. An aware home can promote independence and quality of life for an aging population, and there are tremendous social and economic incentives to do this.

Now, what do I mean by advanced technological supports? In my written statement, I catalog a wide variety of technological supports for an aging population. To summarize for you here, there are three categories of interest. First, you have assistive devices that compensate for motor, sensory, or cognitive deficiencies. Then you

have monitor and response systems that provide both emergency response to crisis situations as well as early warning for less critical and emerging problems. Finally, we have communication aids that provide a link between an individual and a network of formal and informal caregivers.

The greatest promise for advanced technology lie with the cognitive aids, the monitoring of trends, and novel communication aids. I will demonstrate some of these technologies at the end of my statement, with your permission.

Now, who will benefit from these technological supports? First and obviously, we provide assistance directly to the individual in an attempt to support their independence and quality of life.

Second, this technology provides support for distributed family members and other more formal caregivers who share the financial and emotional burden of coping with the challenges of aging.

Third, with the increase of broad-band networking into and out of the home, we have greater capability to support the activities of larger institutions providing medical, emergency, or other social services.

Finally, scientific evidence of a quantifiable benefit of advanced technology for healthy aging will encourage the development of profitable business plans that drive private investment and commercial success in this important market.

Now, what role does advanced technology research play? One of the key indicators of independence is the measured performance by an individual in activities of daily living. The role for advanced technology, therefore, is the detection, measurement, and even improvement of an individual's performance with these various activities in their living environment.

Until now, most assessment of independence has been done by humans and this solution won't scale to provide proactive support for a large population. Hence, advanced technology is necessary. In my written statement, I have surveyed emerging technological aids, but I must stress that there remain significant advances in technologies of sensing and long-term analysis of human behaviors that will not occur unless sufficient funding is made available.

I want to make two recommendations to the committee. First, we need basic technology research for sensing and measuring these activities of daily living. The funding for these basic technological advancements could be administered by agencies such as the NSF that traditionally fund scientific and engineering developments that eventually benefit society.

Second, we need large-scale test beds for evaluating technology for healthy aging. Research into how best technology serves the aging should be administered by groups whose mandates focus on public health concerns. This funding will make sure that the technology is well matched to the needs of the community. It will also lay groundwork for a healthy aging industry that will bring the research success to the marketplace.

With the permission of the Chairman, I would like a few minutes to demonstrate three separate projects that bring to life some of the ideas I have been talking about that we have been working on at Georgia Tech.

The CHAIRMAN. Please, go ahead.

Dr. ABOWD. I want to demonstrate three separate projects that are taking place at Georgia Tech as part of the Aware Home Research Initiative.

In the first demonstration, we focus on the potential for automatically detecting behaviors. Even with proper initial training, people often misuse home health care devices, such as the blood glucose monitor that is pictured here. I am sorry you can't see on the monitor. Advanced computer vision algorithms can observe the use of a device and automatically detect when a sequence of actions is done incorrectly, providing an opportunity to give immediate training advice. The video shown here at the top demonstrates how our computer vision algorithms track hands and various objects to label the actions as a user attempts to calibrate the blood glucose meter.

An important form of cognitive aid is one that compensates for near-term memory lapses. When an activity such as cooking is interrupted, what visual cues provide the right information to pick up where you left off? In the Aware Home, we have instrumented the kitchen area with cameras looking down at the countertop, shown in the bottom figure. An LCD panel is updated with salient images of the cooking activity as it is occurring. When interrupted, a simply glance at the display shows the most recent activity.

Now, I am going to switch to a live demonstration. What you see here is the image on the LCD panel that is being updated occasionally with images being detected by a wizard sitting outside the kitchen determining when a significant activity occurs. The bottom right figure in this collage is updated to show you the most recent activity, and the numbers in the various panels indicate repeated activities, such as one, two, or three cups of the same ingredient being placed in the bowl. So that when someone glances at the collage, they can determine where they would have left off, and frequently in our controlled studies, it has been the repeated measures activities that get forgotten. So you don't remember the number of cups of flour that you have put in.

Now, we don't currently have the ability to automatically detect the salient images to produce this collage, but we have been simulating the collage in controlled studies to determine its value, and given the progress on detecting simple activities, as I showed on the previous example with the blood glucose monitor, I hold very great hope that we will be able to provide these kinds of visual reminders automatically in the home of the future.

In my last example, I want to contrast with the previous two. In the previous two examples, we showed services that stayed within the home and serviced the individual. This last demonstration is about connecting to caregivers, in particular, the natural support group of family and friends who want to maintain peace of mind for the well-being of older parents or loved ones.

The digital family portrait shown here is an ordinary picture of a loved one that has been augmented with information in the frame to communicate how that person is doing over the last month. This is an aesthetically pleasing way to keep in touch with the everyday well-being of a loved one and it can be modified to support the normal monitoring activities of professional caregivers and assisted living facilities or naturally occurring retirement com-

munities, referred to as NORCs. I can also demonstrate this, but for the sake of time, I would like to thank you for your patience.

The CHAIRMAN. Doctor, thank you very much for that testimony. I was telling staff, earlier in the day, I took a tour of a smart home that a large software company in Seattle, WA, developed. I guess for sake of not promoting advertising, I won't mention the name.

Dr. ABOWD. They don't sponsor us, either, so—— [Laughter.]

The CHAIRMAN. I found it very fascinating. It would do about everything you asked it to do by just simply voice command, and certainly could be adapted to someone with disabilities or someone with problems. It could make their life a good deal easier, including monitoring.

I think I was recalling the thing most fascinating about it, in the evening before the person retired, they could go to their laptop or their computer and activate an automatic in-place e-mail to a loved one somewhere else telling them that they were safe and retiring for the evening, the very similar kind of thing that you see in retirement centers today in individual apartments and living facilities that go to a central station to monitor a person's activities. I thought, hmm, a most useful approach.

Thank you for that testimony.

[The prepared statement of Dr. Abowd follows:]

Statement by

Dr. Gregory D. Abowd

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Director, Aware Home Research Initiative
Georgia Institute of Technology

The Role of Technology for an Aging Population

Submitted to the

Special Committee on Aging
United States Senate

May 20, 2003

Mr. Chairman, Committee Members, and staff: I am Gregory Abowd, Associate Professor in the College of Computing and Director of the Aware Home Research Initiative at the Georgia Institute of Technology. I am thankful for this opportunity to testify today concerning how this country can meet the needs of an increasing aged population. My message today is a rather simple one, and that is we should look for ways in which technology can promote healthy and independent aging. We should more aggressively provide opportunities for scientific, engineering, government and commercial organizations to collaborate on large-scale efforts that provably meet the needs of the individuals, their families, their caregivers and the social and medical institutions that provide services to older adults.

The problems of our aging society are real, both in economic and social terms, and I believe many people in key positions understand this. The role of technology in enhancing the lives of older but otherwise healthy Americans is not well understood or appreciated. I will try to demonstrate some of the possibilities for technology that are being explored in research environments today. If these technologies were widely available, it would mean that older adults would be able to live more safely, independently and maintain a quality of life that they enjoyed in their younger years. While we all probably aspire to live long lives, we also hope to live healthy lives that don't cause undue burden to others. Realizing this goal will take investment in research, student training, and strategic partnerships with industry and government.

Background

I am a computer scientist working in the area of Human-Computer Interaction, the relationship between people and the computing artifacts they use. My particular area of interest is in an area called "ubiquitous computing," a term used to mean the proliferation of computing artifacts throughout our environment in support of our everyday activities in those environments. The vision of ubiquitous computing was first espoused by the late Mark Weiser, then working at the Xerox Palo Alto Research Center (PARC). Though the technological challenges of a world of constantly available and pervasive computing services are great, the motivation to work in this area is largely the human-centered agenda of providing assistance in our everyday lives.

Over the past five years, together with several colleagues at Georgia Tech and with the financial support from the State of Georgia through the Georgia Research Alliance, the National Science Foundation and several major computing companies (Motorola, Intel and Hewlett-Packard), we have been exploring the implications of ubiquitous computing technologies in the home. We refer to our efforts under the title of the Aware Home Research Initiative (http://www.awarehome.gatech.edu) because we believe that there are many intellectual challenges in creating a home environment that is made automatically aware of the whereabouts and activities of its occupants and can provide relevant services to inhabitants of that home as a result. A major motivation for this work is that awareness technologies can provide the assistance needed for otherwise healthy individuals to cope with the natural declines related to aging while staying in their own homes. Many refer to this goal as "aging in place." The reason I am speaking to you today is because many people believe that the type of research we are conducting in the Aware Home Research Initiative at Georgia Tech is promising. While I and my colleagues are flattered by that assessment, we deeply believe that significantly more large-scale efforts are needed to really make an impact with technology for the general problem of aging in place.

The Problem

There are several ways we can understand the challenges of an aging population. First is to see the problem as an issue of the cost of healthcare. Second, we can consider the social issue that underpins why people desire to "age in place." Third, we should understand the continuum of living environments in which aging individuals reside. We describe each of these issues more fully below.

Healthcare costs: The U.S. healthcare system is under severe stress and the situation will deteriorate rapidly after 2010, when the first wave of baby boomers reaches retirement age. The Congressional Budget Office states that "the financing problems in the near term will be dwarfed by the crisis that could occur as the baby-boom generation reaches age 65." (Antos, 1997) While the U.S. is the leader in healthcare expenditures, with more than 14% of the GDP devoted to healthcare and yearly increases of 1/3% (Smith *et al.*, 1997; Levit *et al.*, 2002)), it ranks only 37th in overall healthcare system performance (WHO, 2000). Reflecting dissatisfaction with the present healthcare system, US consumers spent $27 billion on health improvement and maintenance outside the established health care system in 1997 (Eisenberg *et al.*, 1998). Soon, the impact of the aging baby-boomer population will be felt: in 2030, nearly 1 out of 2 households will include someone who needs help performing basic activities of daily living (RW Johnson Foundation, 1996) and labor-intensive interventions will become impractical because of personnel shortage and cost. . Much has been written about this baby-boomer cohort, and it has been noted that compared with today's seniors, the boomer vanguard is better educated and more technologically adept. Thus, this cohort of people, as they age, may increasingly look to technology to help them maintain their health and independence, and to optimize their living environments.

Social costs: Across our lifespan, our living environment, or home, takes on great personal meaning. This meaning may reflect the attainment, or lack thereof, of any of a number of different dimensions, including status and achievement (e.g., home ownership), responsibility (e.g., maintaining a family home), security (e.g., safety), autonomy and privacy (e.g., personal choice and freedom). These different aspects of housing may take on different salience throughout an individual's lifespan. At the end of life, independence, autonomy, and safety are especially relevant. Older adults strive to maintain their independence and autonomy in a safe living environment. In addition to personal meaning, living environments have societal and political relevance as well. These include issues of affordability, adequacy, accessibility, and appropriateness of housing (Maddox, 2001). Thus, living environments are a critical issue for elderly adults, and for our society, as America ages. Repeated surveys from the American Association of Retired Persons (AARP) reflect the strong desire by older adults to remain in their own homes.

Where do older adults live? There are three main types of living environments for aging adults: independent living (e.g., private housing), assisted living, and nursing homes. According to the 2000 U.S. Census, approximately 95% of adults aged 65 and older reside in private households (Cohen & Miller, 2000). Given the preference of elderly adults to "age in place," private homes will remain an important housing option in the future, particularly for the young-old (under 85), and will be important targets for increased technology to help elders remain there.

Assisted living housing provides an option for older adults lacking complete functional independence to live independently for as long as possible, in communities designed to provide the security of having reliable services available for use as needed (Maddox, 2001). The consumer demand for housing that is private, provides needed services, is "non-institutional," and provides residents with choice and control has been very high. Private-sector developers have been responsive to consumer demand, and the number of assisted living facilities in the United States has grown dramatically. By 1998, there were at least 28,000 assisted living facilities in the US (Mollica, 1998). It has been estimated that as many as 1.5 million elderly adults currently reside in assisted living housing (U.S. General Accounting Office, 1999) and this trend is expected to continue.

Prior to the development of assisted living housing, nursing homes were the only option for elderly adults who needed health care services that could not be provided at home. In contrast to assisted living facilities, nursing homes are a more medical environment, characterized by minimal personal autonomy and maximal dependence on formal caregivers. Uniformed nursing

assistants provide 80-90% of all direct care in this setting. Nursing homes were considered to be a long-term care facility; that is, elderly adults who were too physically frail, too cognitively impaired, or too socially isolated to remain at home moved into a nursing home, and most lived there until death. Admission to a nursing home was often feared and avoided for many reasons, including the connotation of these facilities as "the last stop" before death, the poor quality of care provided in them, and the lack of autonomy and privacy. Since 1986, improvements motivated by the Institute on Medicine have removed some of the stigma of skilled nursing. Currently, there are approximately 17,000 nursing homes in the United States, providing care for over 1.6 million elders (U.S. GAO, 1999). Whether or not one lives in a nursing home is highly age-related, with almost half of all residents falling in the age 85 and over category (U.S. GAO, 1999).

Independent living, assisted living housing, and nursing homes are often viewed on a continuum. The most healthy, most independent elders live at home; the most frail, most dependent elders live in nursing homes. Indeed, over the past decade or so, continuing care retirement communities (CCRC) have been developed to capitalize on this continuum of care model.

One important kind of retirement community to consider, especially when we want to think about technological assistance, are naturally occurring retirement communities (NORCs), defined by the AARP as a "building or neighborhood where more than 50% of the residents are over 60." NORCs have been recognized as an important kind of community since the 1980's and in 1992 AARP estimated that 27% of older people lived in a NORC, largely due to the desire to age in place.

It is going to be easiest to explore the impact of technologies for healthy and independent aging in newly constructed CCRCs. Initially, the technology will be more expensive and it will be more cost-effective to build it into new construction. Baby boomers choosing to move into these new CCRCs will have the finances to pay for this, and in fact will expect these kinds of services to support their long-term health and independence. But the ultimate success in this area will depend on being able to retrofit lower-income NORCs with commodity technologies that also promote health and independence, providing families with peace of mind for aging parents and reducing the burden on the government and other institutions who would otherwise have to pay for the necessary care.

The Goal for Technology

What role can and should technology play for assisting an aging population? I would break this answer down into a couple of key categories:

- Providing assistance to the individual who wishes to maintain independence and quality of life.
- Providing support for distributed family members and other caregivers who share the financial and emotional burden of coping with the challenges of aging.
- Providing mechanisms for larger social/government institutions (medical, police, social workers) to provide their services more effectively without incurring unmanageable cost.
- Providing marketable services with profitable business plans that will encourage private investment and commercial success in this important market.

One of the key determinants for where one chooses to live is the level of independence that can be maintained by that individual in that environment. There are quantitative measures for determining independence, referred to as the various classes of Activities of Daily Living, or ADLs. Though I will not go into a detailed discussion of ADLs, it is important to note that researchers have tried to use performance on ADLs as a measure of independence. This suggests that a key goal for assistive technology is the extent to which it empowers an individual to

maintain adequate performance for these activities. It is also important to maintain strong social connections with natural support groups (e.g., family and friends) and encourage active physical and intellectual routines, proper diet and compliance with medication regimes.

Forms of Technological Assistance

I will review a variety of technologies that have been developed to support the independence and security of an aging population in a variety of living environments. The categories of technology we consider are:

- *assistive devices* that compensate for motor, sensory or cognitive difficulties;
- *monitor and response systems*, both for emergency response to crisis situations and for early warning for less critical and emerging problems; and
- *social communication aids*.

Assistive devices

As is well known, aging results in changes to many human capabilities (Mynatt & Rogers, 2002). Age-related changes in motor movement include slowing, inability to make continuous motions, and lack of or variable coordination (Vercruyssen, 1997). Sensory difficulties are also common, and much is known about changes in vision and audition (Schneider & Picora-Fuller, 2000, Schaie, 2003). For many years, devices that replace or compensate for deficiencies in motor and sensory capabilities have been readily available, and many of these are suitable for both the young and the old. Difficulties in gross motor movement are mitigated either by devices that perform the motor function, such as powered wheelchairs and stair climbers, or provide assistance, such as well-placed grab bars in bathrooms or power-assisted chairs that facilitate sitting and rising. Hearing aids and low-light visual cues are available to assist those declining senses. These physical deficiencies make it hard to operate a lot of the small appliances and controls that are commonplace in homes today. Researchers at places like the University of Florida's Rehabilitation Engineering Research Center on Technology for Successful Aging (http://www.rerc.ufl.edu/) evaluate the effectiveness of a variety of designs for adaptive household appliances and controls. At the Georgia Institute of Technology, computer vision researchers have prototyped the Gesture Pendant as a wearable device to control a variety of home appliances through simple hand gestures (Starner *et al.*, 2000).

More recently, the field of cognitive aging has matured and we better understand how changes in cognitive function occur as part of the natural process of aging (Craik & Salthouse, 2000; Schaie, 2003). Declines are apparent in attributes such as the capacity of working memory, online reasoning, and the ability to attend to more than one source of information. Other abilities remain largely intact, such as recall of rehearsed material, vocabulary and reading and ability to focus on a single source of information.

Technological support for cognitive aging, often referred to as *cognitive orthotics*, is a very promising direction for research, evidenced by a recent survey on assistive technology for cognition by LoPresti *et al.*, (in press). The applications of cognitive orthotics range from simple reminder systems to more elaborate interactive robotic assistants.

LoPresti *et al.* provide a useful categorization of cognitive orthotics along two separate dimensions. The technological interventions are first distinguished by whether they support executive function or information processing. Executive functions include planning, task sequencing and prioritization, self-monitoring, problem solving and self-initiation and adaptability. These executive skills are related to memory, attention and orientation. Information processing concerns the ability of the brain to properly process and integrate sensory information, with deficiencies leading to problems in the processing of visual-spatial, auditory, sensory-motor and language information, as well as difficulties in understanding social cues. The second

dimension for technological aids concerns whether they attempt to strengthen a person's intrinsic abilities or seek to provide extrinsic support. Intrinsic aids are often classified as rehabilitation technologies, while extrinsic aids are considered as compensation technologies. I emphasize the extrinsic, or compensation technologies, to address issues of support for aging of otherwise healthy individuals. This whole area of cognitive orthotics is of growing interest. For example, the reader is referred to the results of a 2002 workshop on cognitive aids from within the Computer Science community (see http://www.cs.washington.edu/homes/kautz/ubicog/). Also, Jorge *et al.* (2001) reports on a recent workshop relating ubiquitous computing and universal access in providing for the elderly. The National Science Foundation will co-sponsor an international workshop on the theme of technologies for aging in June 2003 in London.

Some cognitive orthotics work focuses on support for extreme cognitive dysfunction, such as Alzheimer's disease or severe dementia. For example, within the Gloucester Smart House consortium (http://www.bath.ac.uk/bimc/projects/smart/) devices such as a locator for lost possessions are designed to be usable by people with dementia and their caretakers in order to prolong independent living. Mihailidis *et al.* (2000) conducted a pilot study, and observed that a person with severe dementia would complete an activity of daily living in response to a computerized device that used a recorded voice for cueing. The computerized device monitored and prompted a subject through hand washing. In response to problems discovered with their first prototype, Mihailidis *et al.* (2001) used artificial intelligence to develop a new cognitive orthotic for people with moderate-to-severe dementia.

There is also work that aims to design systems for people in the less severe stages of memory impairment. Many people have difficulty locating important objects around the home, and commercial versions of the Gloucester Smart House object location system are available at high-end consumer outlets like The Sharper Image. These solutions work for a small number of specialized objects, like keys. One of the research efforts at the University of Rochester's Center for Future Health (http://www.futurehealth.rochester.edu) involves computer vision researchers trying to develop more flexible object tracking systems to assist with the location of a wider variety of lost objects within the home. The Nursebot project at Carnegie Mellon University, University of Pittsburgh and University of Michigan (http://www-2.cs.cmu.edu/~nursebot/) has been investigating ways that a robotic assistant, Pearl, can assist in eldercare (Montemerlo *et al.* 2002). One of the cognitive aids being developed uses a system called Autominder, developed by Pollack and colleagues at Michigan, to remind an older person about his or her activities of daily living (Pollack *et al.*, 2003). Several commercial products provide support for prospective memory aids. Within the Aware Home Research Initiative at the Georgia Institute of Technology (http://www.awarehome.gatech.edu), researchers are focusing on short-term retrospective memory. Mynatt and Rogers (2002) proposed initial designs for a visual collage to assist one to resume routine cooking tasks after an interruption. This simulated memory aid records and displays salient near-term actions from a recipe so that, upon resumption from an interruption, the cook can determine things like how many cups of flour have already been added to the mixing bowl.

Many cognitive orthotics are designed to support prospective memory, that is, remembering tasks that need to be performed and carrying out these tasks at the appropriate time (Ellis, 1996). This work has progressed from using very basic and inexpensive timing technologies (e.g., calendars, timers and watches) to much more sophisticated and forward-thinking applications of artificial intelligence. One of the most important examples of prospective memory tasks is medication compliance. Medication compliance devices range from plastic boxes divided into sections labeled by times and day, to electronic systems that provide auditory cues (Fernie & Fernie, 1996). For an individual living alone, remembering to take medication at the right time and in the right order can make the difference between remaining independent or not.

Monitor and response systems

We have all seen the classic "I've fallen and I can't get up!" commercials. This caricature is sometimes humorous, but it is representative of an important class of technology that provides monitoring of health and well-being status, communication to interested parties, and in some cases provides automated responses to perform some corrective action. These monitor/response systems can operate in the short-term to sense a crisis situation, such as a fall, and provide a way to make a call for help. Medical alert systems (e.g., LifeFone, http://www.lifefone.com/) allow a greater degree of freedom for an older person, and peace of mind for adult children, by allowing independence while providing a safety net in case of medical crisis. Some devices might automatically detect a crisis (such as a fall). Others depend on activation by the individual (or someone nearby) to initiate a call for help. Monitoring systems are characterized by:

- What information is being recorded or transmitted? It could be medical information (e.g., heart rate, respiration, blood pressure, medication compliance, incontinence), movement data (e.g., restlessness in bed, gait patterns), or simply awareness information (e.g., a video transmission to a relative).
- Over what period of time is data analyzed? The capture of information can be for instantaneous purposes only (e.g., a "GrannyCam" usually transmits images over the Internet to be viewed in real-time only) or over a period of time for trend analysis, as you would expect for vital signs in a telemedicine application or in medication monitoring for compliance in a home or assisted living environment.
- How is information reported to relevant individuals? Medical alert systems provide a phone call to a response agency. Telemedicine applications report over a secure channel to an electronic patient record that can be consulted by trusted medical professionals or even by the individual being monitored. Cameras are used to provide easy monitoring for family (usually over the Internet, serving an important social communication function discussed below) or remote caregivers (at a nursing station, for example).
- What is the role of the elderly person in using the technology? Does the monitoring require any instrumentation or active cooperation on the part of the individual being monitored? For example, do they have to wear an infrared badge for a positioning system, or is it passive,with the environment instrumented to measure a naturally-occurring phenomenon using devices such as a motion detector or face recognition system?

There are many examples of these monitoring systems for an aging population. Some address the safety and security of individuals who may wander. Devices can either prevent undesired wandering (e.g., automatically closing doors or gates to a house or community grounds to protect Alzheimer's patients) or remind others to take corrective action (e.g., at nighttime when someone inappropriately leaves the bed). A system like the Vigil Integrated Care Management System™ (http://www.vigil-inc.com/), which can detect cases of incontinence via special moisture sensors on bedsheets, allows staff to schedule pre-emptive nighttime wakings to prevent accidents in the future. Simple load sensors in the beds of residents at Elite Care's Oatfield Estates Cluster in Milwaukie, Oregon (http://www.elite-care.com) feed a visualization to allow caretakers to detect periods of restlessness in the night. Some of the more advanced research in this area is trying to use passive means to perform early detection of chronic, but treatable conditions. For example, researchers at the University of Rochester's Center for Future Health (http://www.futurehealth.rochester.edu/) are using computer vision techniques to determine asymmetries in gait patterns during visits to the doctor. These data can provide early warning of the possible onset of a wide range of common neurological and musculoskeletal disorders such as stroke, Parkinson's disease and arthritis. Similarly, the same vision technology that underlies the Gesture Pendant (Starner *et al.*, 2000) can detect asymmetric tremors indicative of Parkinson's

disease and can be used to track the effectiveness of medication regimes to control the disease. Though the monitoring technology is not used in these cases to treat the condition of an individual, early detection can increase the effectiveness of medical intervention and counseling for the afflicted. But with most of these research projects, the technology is unproven and significant challenges remain to make them viable.

Cognitive orthotics discussed earlier rely on context-sensitive reminders, and these often require a way to monitor a person's environment and activities (LoPresti *et al.*, in press). Some research is focused on monitoring ADL tasks in the home using a variety of sensing technologies. Sensors and switches attached to various objects, or optical and audio sensors embedded in the environment, are used to detect which task a person is performing. Trials with several subjects indicate that this method of tracking a person's actions is a good way to monitor the state of a person's health and independence (Bai *et al.*, 2000; Nambu *et al.*, 2000). Friedman (1993) developed a wearable microcomputer with a location-sensing system and additional sensors to determine task-related information. Using these inputs, together with the user's schedule, the computer provided voice prompts as needed and only as needed to help the user maintain his or her schedule. Continued evidence of difficulty adhering to the schedule would cause the computer to automatically call for human assistance (Friedman, 1993). By only providing prompts as needed, the system could "fade" (gradually reduce) cues and therefore decrease the user's dependence on them. Because the system does not rely solely on a timed schedule to determine the user's possible activities, it could allow more user independence.

Social communication aids

The social aspects of aging, are also an important part of the equation in determining the health, safety, functioning, and autonomy of elderly adults, Peace of mind is an important element for the individual and a distributed family (Mynatt & Rogers, 2002). Geographic distance between extended family members exacerbates the problem by denying the casual daily contact that naturally occurs when families are co-located" (Mynatt, *et al.*, 2001).

Technology can connect individuals with information. Over the past decade, the burgeoning Internet has introduced a wealth of health information to many who would otherwise not have access to it. More relevant to this chapter, technology can connect individuals with other individuals or groups. Synchronous forms of communication, such as videophones or "smart intercoms" (Nagel *et al.*, 2001), present compelling visions of seamless communication aids, but have not experienced any substantial use. Asynchronous forms of communication, such as electronic mail, newsgroups and online forums (e.g., SeniorNet http://www.seniornet.org/php/) are all examples of communication technologies that have hit the mainstream. When seniors see clear benefits of communication technologies, acceptance is likely (Melenhorst *et al.*, 2001) and there is evidence that they are willing and capable of learning new skills.

Mynatt and colleagues (2001) suggest a particularly novel asynchronous communication aid as part of the Aware Home Research Initiative. A digital family portrait is an electronic equivalent of the picture of a loved one that we often find in our own homes. However, the digital family portrait is also used to portray a qualitative and dynamic account of the well being of the subject by means of icons embedded in the frame of the picture. Monitoring systems in the home of the subject are used to provide summaries of the daily life. The digital family portrait shows a history of one month's activity, providing an aesthetically acceptable communication aid aimed directly at supporting awareness for a distant adult child. This use of technology is trying to approximate the subtle peace of mind that comes from physical proximity.

Conclusions

I would like to conclude this statement with a few important points. Aging is not a disease; today, we better understand the physical, sensory and cognitive impact of the aging process. Ultimately,

a healthy older population is economically favorable, and technology can assist in promoting health and independence. However, there have not been sufficient explorations to date to demonstrate and measure the impact of technology on healthy aging. Though I have surveyed a lot of potential technological aids, I must stress that there remains significant advances in technologies of sensing and long-term analysis of human behaviors that will not occur unless sufficient funding is made available. What is needed at this time is investment in large-scale test beds for exploring technology for healthy aging. The challenge of technological support for healthy aging is not entirely the government's responsibility. However, without sufficient quantitative evidence of the economic impact of these technologies, few business plans will be developed to commercialize these technologies and insurance companies will have little to base financial incentives that would encourage private investment in these technologies. While it ultimately will not be the (local, state or national) government's responsibility to finance the use of technology for healthy aging, proactive and aggressive government initiatives are necessary to bootstrap the process. Research organizations that fund technology research, such as the National Science Foundation, must make technology for healthy aging part of their charter. Organizations that promote preventive healthcare or combating health deterioration, such as the National Institutes on Health, Health and Human Services, and the Department of Education, must modify their charters to encourage the development of newer technologies. These investments will increase the likelihood that research activities larger than the Aware Home Research Initiative will contribute to this country's need to support the long-term health of its aging population.

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The CHAIRMAN. I am going to turn to Dr. Mahoney now, and then if you wish, at the end of this—I have got a couple of questions of you, Doctor—if you need to depart, please do so and we thank you again for being here today and your patience with us.

You were giving us a variety of work that is going on, studies of comparatives. What percentage of the participants in this demonstration project classify as older Americans?

Dr. MAHONEY. In Arkansas, from which I just presented the data——

The CHAIRMAN. Yes.

Dr. MAHONEY [continuing]. About 72 percent of the individuals that took part were elderly, and that certainly dispels the myths that older people aren't interested in managing services themselves. The percentages change in the other States, but maybe 50 percent in New Jersey, and just by nature of the demonstration, maybe about a third in Florida.

The CHAIRMAN. That is fascinating to hear, and absolutely, they are concerned about that kind of management. It is a matter of controlling their own lives or having some say in it and feeling comfortable about it, I would guess.

Does the study you reference in your testimony consist of a side-by-side comparison of older Americans receiving services in the traditional fashion compared to those applying consumer-directed choices?

Dr. MAHONEY. If I understand correctly, exactly. People who volunteered to take part in the demonstration were, in fact, randomly assigned, so half of them went to the traditional system, half of them got the chance to manage the cash allowance, and with that kind of numbers, given that we had about 6,700 people enroll in the three States, this is a very powerful way of evaluating these impacts.

The CHAIRMAN. Does your study conclude that better services can be achieved at the same costs? Is there a net cost savings?

Dr. MAHONEY. I knew you would ask that. As I was showing, the cost results will be our next effort.

The CHAIRMAN. OK.

Dr. MAHONEY. We are hoping those will come out over the summer. The good news is, at this stage, for instance, for Arkansas, they are meeting the Center for Medicare and Medicaid Service's budget neutrality requirements, so their research and demonstration waiver has just been extended another 5 years, and they have been able to get rid of the randomization, so at this point, everyone who wants to be part of this demonstration can be.

The CHAIRMAN. Excellent. As you know, rural areas often face challenges accessing services. Has the demonstration project been implemented in rural areas of the host States, and if so, what has been the results?

Dr. MAHONEY. The demonstration was in the whole State of Arkansas, the whole State of New Jersey, and in Florida, for elderly people and adults with disabilities, the lower two-thirds of the State, children for the whole State. This is a demonstration particularly helpful in rural areas and where it is very hard for agencies to serve, where the worker shortage was at its worst.

One of the things we found in Arkansas was if you interviewed the people 9 months after they came in, for people who were getting the cash allowance, 95 percent of them were getting personal assistance services, whereas for those in the traditional side, only about two-thirds of the adults with disabilities and only about 80 percent of the elderly were getting their care plans met. So in times of worker shortage, and especially in rural areas, this is a wonderful, a wonderful choice.

The CHAIRMAN. Back me up a bit. You are saying those that were under the cash plan.

Dr. MAHONEY. Right.

The CHAIRMAN. Actually were getting greater levels of service than those under the traditional programs.

Dr. MAHONEY. Right. Well, for instance, in the treatment group the consumer got a cash allowance exactly equal to what that person would have received under the traditional program, but they got to decide how to spend it on meeting their personal care needs. They had to develop a individualized plan. They could hire friends, family, people who wouldn't have been in the workforce. They could renovate their homes, or buy assistive devices. Whereas in the traditional system, where there was such trouble finding aides and workers, in many cases people just didn't get the services that were called for in the care plan.

The CHAIRMAN. I am treading into water that I will be a little cautious on, because I have all the respect in the world for professional, well-skilled, trained caregivers, but are we suggesting by this that there are others capable of rendering care and service to a given senior that they can seek out who may not be as well trained or trained in some areas as a professionally trained person, but certainly are capable of delivering those services, and as a result, the service got delivered?

Dr. MAHONEY. Right. I think that is fair. I am involved in caring for my mother. In so many cases, basic services that families provide aren't skilled medical services.

The CHAIRMAN. No.

Dr. MAHONEY. This is help bathing, dressing, toileting.

The CHAIRMAN. Exactly.

Dr. MAHONEY. Remember what we found here. Those results show that the health effects were either the same or where they differed better for those who manage their own allowance. The younger adults with disabilities had fewer bedsores when they could choose people who really knew them and had a personal relationship.

The CHAIRMAN. That is fascinating. Well, I trust you will keep the committee and our staff abreast of your work and the conclusions, the balance of the work you are doing. As our time and our focus permits, we will have you back to give us an analysis of the studies when they are completed.

Dr. MAHONEY. We would very much enjoy that. Thank you.

The CHAIRMAN. Thank you. I find those findings fascinating. I appreciate your time, and please feel free to leave if you feel it necessary based on your schedule.

Dr. MAHONEY. Thank you for your consideration. Thank you.

The CHAIRMAN. Now, let me turn to you, Ms. Greene. What you are doing in the flexibility you are offering, is exciting. What challenges has your agency faced in implementing the Family Caregiver Support Program in Georgia, challenges and/or obstacles?

Ms. GREENE. Well, when we did our caregiver focus groups to find out what our citizens or caregivers said they wanted or didn't want, we recognized right away that we had some challenges. They said that they wanted more information, assistance and referral. They wanted more training for themselves. They felt that our current providers needed more training, that they were agist. They requested more respite care.

Probably the most challenging, but the one that we had a lot of interest from other organizations, was with the training aspect. We have coordinated with AARP, the Georgia Gerontology Society, a staffing solutions workgroup, the Alzheimer's associations, all came together to address the issue of not only training informal caregivers better, our personnel staff. That has been very interesting and I have really enjoyed the collaborative work with all the different associations to help make that happen.

The CHAIRMAN. In what ways could the self-directed approach you have mentioned be applied in the delivery of other aging services?

Ms. GREENE. We were talking most recently about we have a dire need for transportation, especially most of the counties in Georgia are rural counties. We were talking about the possibility of hiring or making arrangements for friends and neighbors also to transport people to services, and so that is another consideration that we are looking for. But we have a real need that we need to address in transportation that our current level of fund sources, from all different fund levels, is not an adequate amount to meet the transport needs.

The CHAIRMAN. Now, here is a question that dovetails with the work that Dr. Mahoney is doing and it was a question lingering in the back of my mind that I think, well, certainly with the program you have established, Doctor—or let me ask the question and feel free, if you would, to come in after Ms. Greene to talk about this approach.

Some concerns have been expressed that allowing families to hire relatives and friends to provide care might result in the misuse of funds. What has been your experience in Georgia?

Ms. GREENE. So far, we have not seen any misuse of funds, probably better management of the funds. We have a service coordinator in every region, so the family members and the care receiver develop a plan or they decide how they can best use the funds. Right now, there is an average of $1,200 to $1,500 spent a year. So they just call their service coordinator and they say, "This is what we really need." Mom has had another stroke. Now she is in a wheelchair. We really need to build a ramp, for example. The service coordinator then OKs the expenditure of the funds and then they are reimbursed for the service. So we really have not seen any misuse of the funds.

The CHAIRMAN. Doctor, do you wish to comment on that?

Dr. MAHONEY. I will put it in this context. The Arkansas project got underway in December 1998, New Jersey a year later, and

Florida in June of 2000. We have had no major instances of fraud and abuse. In this context, of people who hired their own personal assistance workers, I think about 75 percent hired some level of family member and maybe another 17 percent hired people they knew through church, through their neighborhood: One of the things you end up finding is that they have hired people that had a real personal relationship that made a difference. That is not to say that we don't have important monitoring and quality management processes in each of these States, which again, I would be pleased to share.

The CHAIRMAN. Thank you. This February, I held a hearing on the misuse of guardianships over the elderly. I was disturbed by accounts that the wishes of older Americans and their families are oftentimes ignored by persons bringing forth these actions. How does Georgia's mediation program prevent this type of undue control over a person's life?

Ms. GREENE. The people who have been trained to be mediators have worked actively with the Probate Judges' Association, and in Fulton County, which is the largest probate office in the State, they have agreed that prior to—when someone comes to the court to petition that they become a guardian of someone, that they are then provided information and educated about the mediation process. It is not mandated by the court, but it is strongly encouraged by the court that they go through the mediation process.

So we are real excited about the relationships with the probate judges and that we have the largest county agreeing to work with us actively to seek mediation with families. So a lot of it, I think, is education, not only to the families about a mediation option, but also to the court system, that it is a viable option that could work and also save a lot of grief and financial cost.

The CHAIRMAN. Thank you very much for your being here and your testimony and the work you are doing. I find all of that very fascinating.

I had one other question as it related to mobile day care. Does the program have a wellness screening component in it?

Ms. GREENE. Yes, sir, it does. In fact, we have a statewide wellness program and it is done in conjunction with all of our other service components, and so they are screened to what ability they might be able to participate in exercise, nutrition education, medications management.

The CHAIRMAN. Good. Thank you. Thank you very much.

Dr. Aday, the work you are doing is fascinating to me because it is always intriguing to me about anyone's ability to successfully predict the future or at least to look outward and determine what needs might be. For a baby boomer that has just turned 60 and is relatively healthy and active, what would be the appeal for this older American to attend a senior center? I am assuming when I ask that question that this 60-year-old would be attending a senior center of today.

Dr. ADAY. Since I turn 60 next year, I will try to answer that as best I can.

The CHAIRMAN. Oh, my goodness. We are getting truly personal testimony here. Thank you.

Dr. ADAY. Personal testimony. [Laughter.]

I think when we look at today as well as the future, I think that the senior center certainly provides different functions. Certainly, a 60-year-old could come to the center for a very different reason than maybe that person's aging parent. You might come to the senior center to bring your aging parent, as we have adult day services in our center, to drop them off, and you might want to go then engage in a day trip and then return that evening, for example.

But as I mentioned earlier, I think some of the other activities that we see already going on in senior centers do include things like retirement counseling and retirement training. We have lifelong learning that has been a steadfast component of senior centers for a number of years. So those are some of the kinds of activities, educational classes that might be inviting. Basically, if you have partnerships with local universities, they can offer topics that would attract a 60-year-old.

I think some other factors that would also attract when you are talking about coming into a senior center, would be the opportunity to provide leadership skills on a community senior center board. We know that if our senior centers are going to become more sophisticated, the governing boards must also be sophisticated, and so we have to attract really quality people in leadership roles that can move senior centers forward in the 21st century. I have observed that very thing happen in my community. It just so happened that the people on that board and on our city council who were assigned to the advisory board enabled us to do some very progressive things.

So I think that you have to have forward-looking people and many of those are going to come from the young-old group. Someone who can come and provide leadership and volunteer services and assist with your other older clients that are also participating in senior center programs.

The CHAIRMAN. How many senior centers in this country today have that kind of appeal to them, from your understanding and study?

Dr. ADAY. The recent research that I did, and it wasn't a random sample, but certainly 90 percent of the respondents indicated they were very satisfied with the knowledge and information that they were getting at their senior centers. We know that senior centers, of course, are very diverse. Some of them are open on a part-time basis. They may have just a director and that is all that person does. They are very limited in terms of funds.

On the other hand, you have multi-purpose senior centers, and I don't know the exact number that would fall into that category. I think we do need some additional research really to look at where we are today as far as providing this myriad of services and then also looking at what kind of projections, what kind of plans these 1,300 or 1,400 senior centers have in the future and what they have currently in place.

We know that NISC and other organizations are providing leadership with getting senior centers accredited, so they will become accredited entities which will, give senior centers a much more professional kind of appeal and it also enables, I think, the people that are funding senior centers to know that they have a quality product. But I don't know the exact number that are certainly in what

we call the progressive mode now as far as providing these kind of services.

The CHAIRMAN. The one thing that I often hear from 65-year-olds is, well, I don't go to senior centers. They are for old folks. But the kind of center you are talking about, with those kinds of dynamics and services and opportunities in them, wouldn't classify in that sense. So 10 or 15 years down the road, should we be calling them senior centers?

Dr. ADAY. That is certainly an issue that is being discussed in the network at the present time. I don't think there are really any conclusions that have been drawn, whether you want to call them centers for vital aging or even taking the term "senior" out of it.

I was very excited when I became a senior in high school because I had seniority. [Laughter.]

When I became a senior in college, likewise. When I became a senior professor. So it seems like we like to be a senior executive, but when it comes to equating the term senior we have difficulty accepting it with age. It goes back to what I think Senator Breaux was talking about. We have kind of implanted this ageism, well, now, I can't be a part of that group and rather look forward to it. So I think it really speaks to our society when we have trouble embracing where we are chronologically.

So I think each center or each community will have to make that decision, since senior centers are built and primarily funded at the local level. They will determine what they are going to be termed and what will be the best way of getting people there.

It could be marketing. I think one of the issues we have here is just the stereotype that senior centers provide congregate meals and bingo. So it is just a lack of knowledge of what really goes on in senior centers.

The senior center campus that I work with is really more like a high school. If you go into it, you have a computer lab and you have classrooms and you have all these classes. So inside, the decor looks more like an educational unit than it would what we call the traditional senior center. Now, not all senior centers, of course, are at that particular stage, but I think part of it is going to be dealing with how we market ourselves and how we can appeal and attract that younger person coming in.

We do know that the baby boomers are going to be much more educated than today. I think by 2030, twice as many will have a college diploma as today. The research that I conducted in seven States, 20 percent had college degrees that were coming to the senior center. So we are seeing a different kind of clientele and they are going to be demanding different kinds of services. I think when you get more of those people to come they tell their friends about it. Word of mouth in many cases is the best way that you can market a good product. I think what we are talking about today is evolving, and so this is not going to happen overnight, but I think over a period of time. We should see an evolvement and a change in the clientele and a new mission for senior centers.

The CHAIRMAN. Thank you very much for your testimony and the work you are doing. I find it fascinating, because it really is a part of the quality of life that these baby boomers are going to be moving toward, and I think they are going to be a group of our citizens

who are going to be a good deal more demanding simply by their level of entry into that community of interest and their uniquenesses that will be very different from their parents.

Dr. ADAY. They have had an impact at every stage.

The CHAIRMAN. Oh, yes.

Dr. ADAY. This will be no different.

The CHAIRMAN. Now, how, Doctor, can we move technology into that senior community? Let us talk about the home that you are talking about and the sophistication involved. In your opinion, how long will it be before the average person will have access to the sophisticated technologies like the awareness home that you have demonstrated here?

Dr. ABOWD. It depends on what kind of service you are talking about. Some of the demonstrations that we have done and technology we have built, for example, the digital family portrait, is all done with technology and capability that we have today. There is no real magic behind a project like that.

What we are lacking with something like that is a business plan that would encourage people to invest in and provide this kind of service to distribute to family members, for example, although on that note, we have had a number of people who have seen the digital family portrait and have on their own essentially mocked up their own version of sensing in their parents' home, with a way to dial up and produce information to a central server that then can provide information at any place the individual desires.

The best way to leverage off the kind of existing technology we have in the homes today is to not require identity to be part of the sensed equation. So if you were to use the basic motion-detecting sensors that are in home security systems right now and you used that information for a household that has one or two family members, you can make very good inferences about where an individual is, or even more importantly, how much that individual is moving around, so you can communicate to someone else in a secure way about that. So for those kinds of applications, we could do that today.

For some of the more sophisticated applications that require understanding of an activity, like the blood glucose meter example I gave, where you are trying to understand where someone is in a relatively simple and straightforward sequential process, that is possible to do today in the laboratories, but in very controlled settings. It wouldn't work if I just deployed that in anyone's home without any control over the ambient lighting. So there needs to be a significant amount of advances in making those algorithms more robust, and I think we are talking a 5- to 10-year horizon before the research is robust enough to be able to produce those kinds of services.

But before we have those kinds of capabilities, we want to be able to get a glimpse of what that future would be like and to evaluate what services would be important and which ones would not. That is why a project—why I showed you the cook's collage, the reminder system in the kitchen. It is being done with smoke and mirrors, but it is being used to conduct controlled studies to find out if we could get the technology to do that automatically, would it be a valuable memory service in the home, so that we can

inform the advanced technology research about what kinds of problems they do need to solve in the next 5 to 10 years because we see the value in terms of helping an older population.

The CHAIRMAN. I recently reviewed a technology that would have to have a cooperative effort of the food manufacturer with certain software programs, but there was a code on the back of a given container of food that when moved across a scanner could project up on a screen a large read-out of how to prepare that food, or the simple instructions that might be beyond the visual capability of the person. It would simply plant out on the kitchen screen that could be used for a multitude of other purposes as to how to program the—or it may even program the microwave itself, preparing it for that particular food. Have you looked at any of those or seen any of those kinds of technologies?

Dr. ABOWD. Yes, I have. What is very interesting about the kind of technology you are talking about is it is becoming very affordable to essentially tag all items with—in the past, we have used bar codes, so we can use optical scanning to be able to read them. But there are problems with line of sight, being able to see the code.

With the kind of technology you are referring to, one of which is radio frequency identification tags, or RFID, you don't need line of sight and you can essentially fashion a region of space that can read a code on any tagged item that comes near it. So, for example, placing something on the countertop, the counter then knows what is placed on top of it and there are a lot of activities or possibilities you can leverage on top of that.

So it is because these kinds of simple sensing technologies are now commodity technologies that work very reliably that we can provide these kind of services. One simple example we have done in the aware home, and we are one of the first to do this kind of activity, is we have used that RFID technology in a slightly different way, to provide location information for individuals and objects within the house. So we fashioned floor mats that sit at various strategic points in the house and individuals wearing non-powered tags somewhere below the knee, usually attached to the shoe or around the ankle, then just need to walk in the aware home and it will pick up what room or what location they are in.

That information feeds directly into something like the digital family portrait. It also feeds into a variety of other kinds of applications that can leverage off that room level awareness. So it is a very exciting time from the sensing perspective, because we can now realize these kinds of applications in the living environments like a home.

The CHAIRMAN. You have mentioned several technologies. Any others that you see that are going to be a direct asset to this kind of home?

Dr. ABOWD. I think a critical kind of technology, I talked about doing a purpose-built laboratory like the aware home. Also, there are continuing care retirement communities that are being special built for which you can, at the time you construct the building, can put in special kinds of technologies.

But the real problem is being able to retrofit existing communities. So these naturally occurring retirement communities with the technology to provide the same kind of capabilities, and there,

I think, wireless technologies are advancing to the point where we will be able to retrofit relatively easily lots of sensing and communication capabilities that won't require you to tear down the walls and won't be all that difficult to be able to put into homes. So that is when you will start to see the real mass market effect.

The CHAIRMAN. Well, I concur with you. Obviously, the rather simple process now of creating wireless technology for your home, for your laptop and all of that, is really phenomenally simple and relatively inexpensive. Of course, all new—not all, many new homes are now being wired with that kind of capability, so that is very positive.

The interesting thing about the new technologies is that the baby boomers won't be as hostile to them, obviously, as the generation before them, and quite understandably so. Also, the best part about it is if they don't understand them, they can just ask their grandkids. [Laughter.]

They will give them a rather simple explanation of how to do it, because they will have figured it out a long time before that.

Doctor, we thank you very much for your testimony and your work. Those are exciting new opportunities, I think, as we move along, and we appreciate it very much.

Dr. ABOWD. Thank you for the opportunity to present it.

The CHAIRMAN. To all of you, thank you very much for being with the committee today and helping us build a record in these areas. We believe it is extremely important as we look at especially the opportunity and the challenge of this baby boomer generation that is about to be upon us, and as a member of that generation, I am going to be as demanding as any of the rest of us, I suspect. But I also want our public policy to be prepared for us when we get there.

Thank you all very much for being with the committee today. The committee will stand adjourned.

[Whereupon, at 3:53 p.m., the committee was adjourned.]

APPENDIX

Statement

Center for Aging Services Technologies
American Association of Homes and Services for the Aging

U. S. Senate Special Committee on Aging

"Baby Boomers at the Gate:
Enhancing Independence Through Innovation and Technology"

May 20, 2003

The American Association of Homes and Services for the Aging (AAHSA) appreciates the Committee's decision to hold a hearing on aging technologies. AAHSA represents more than 5,600 mission-driven, not-for-profit senior housing and assisted living facilities, nursing homes, continuing care retirement communities, and community service organizations. Every day, our members serve more than one million older persons across the country. AAHSA is committed to advancing the vision of healthy, affordable, and ethical aging services for America.

Many think tanks have identified the upcoming aging care crisis as the issue of the 21st century. Every seven seconds another baby boomer turns 50 years old. As they have done in other facets of American life, this generation of 77 million boomers will change the way society looks at aging care issues, as they provide care for their parents and relatives today and, next, as they begin to need aging care services themselves.

Elder care needs are growing so rapidly that studies predict that by 2005 elder care will surpass child care in level of significance to American families. Last year alone, American businesses lost over 40 billion dollars in employee productivity, as people had to leave work to take care of elderly relatives. Adequate facilities, financial resources and caregivers will not be available in 15 years to deal with this generation. Technology has made longer life possible, and technology can help us solve some of the problems that

have arisen with longer lifespans.

Now is the time to start planning how technology can respond to an aging society's need for services. Our country has spent billions of dollars to enable people to attain longer life, but has not made adequate investment in the services needed to support the aging population and maintain their quality of life.

The power and potential of technology may be the most important opportunity to help seniors maintain their quality of life and to help facilities provide a subsequent higher level of service with lower staffing demands. Policymakers must craft policies that will spur innovation, encourage business investment and rapidly commercialize technology-based products and services that facilitate independent living and support the needs of aging care facilities.

To these ends the American Association of Homes and Services for the Aging (AAHSA) has launched the Center for Aging Services Technologies (CAST). This new program, has opened channels among research labs, Fortune 500 technology companies, facility administrators and government representatives. CAST's executive director is Russell Bodoff, vice president of technology & business development for the American Association of Homes and Services for the Aging, and CAST's chairman is Eric Dishman, manager, Proactive Health Research for Intel, and chair, Intel Research Council AIM Health Subcommittee. CAST is focusing on the application of technology solutions to the aging services challenges faced by the global community. It is the largest such initiative to date. A list of current CAST participants appears at the end of this statement.

The CAST agenda includes: Identifying new technologies under development; gaining an understanding of how technology can assist caregivers; and identifying new approaches to policy issues that will impact how technology will be used successfully and priced effectively. Much of CAST's work focuses on applying technologies originally developed for other purposes to the field of aging.

Technologies under initial review include:

Enabling Technologies
These types of technologies help maintain independence and allow the opportunity for older persons to continue living in their own homes or in independent living settings for as long as possible.

Enhancing Operational Systems and Human Resources Management
Technology can reduce labor costs while improving productivity and the work environment. New systems can enhance the ability to foster positive health, security, and quality of life for residents.

Connection
Technology can help the senior or resident stay in contact with family and friends. These connections are important in maintaining relationships, educational opportunities, and personal growth.

CAST has established six task groups and others will be added as needs are identified.

These task groups include:

Task Group #1
Create an "information clearinghouse" for technology products and research relevant to aging services.

Task Group #2
Commission a study that illustrates the business case for technology development in aging services. Develop initial numbers on market size and potential return on investment.

Task group #3
Launch a campaign targeting key government agencies and policymakers around aging technology research needs (i.e. policy issues such as reimbursement & privacy, the need for federal funding to support such research).

Task group #4
With convincing collateral in hand (see #2 above), conduct a campaign of key technology and other companies to educate about the need/opportunity for aging-oriented technology research and development.

Task Group #5
Develop a process for collecting, prioritizing, and communicating the needs of the aging services industry as a means of seeding pilot research projects with technology companies and universities.

Task Group #6
Develop an initiative to help drive standards for electronic wellness records that meet the needs of all stages of the aging services continuum. Interface with and provide prospective and direction to HL7. HL7 is a national standards effort for the exchange, management and integration of data that support clinical patient care and the management, delivery and evaluation of health care services. Specifically, to create flexible, cost-effective approaches, standards, guidelines, methodologies, and related services for interoperability between health care information systems.

Recently, CAST completed an initial survey to identify technologies being used by providers, recognize future technological needs, and determine financial investment for new technologies over the next three years. The survey was seen as a significant starting point to gain a better understanding of providers' and consumers' technology needs.

The Department of Health and Human Services (HHS) considers this survey to be of vital importance in the effort to understand the technological demands of America's aging population. HHS has requested from the Center a list of the ten most significant problems facing providers of aging services in implementing new technologies.

CAST plans to share its findings with the public and all members of this committee in June through a white paper, entitled "State of Aging Technologies 2003," so awareness of the technological needs of the aging population can be broadly understood. This is of critical importance for policymakers, researchers, technology companies and providers of aging services. CAST intends to update this report annually.

In April 2003, the Center, in conjunction with the American Association of Homes and Services for the Aging, sponsored the largest conference on aging services technologies to date. The "Future of Aging Services Conference" was a groundbreaking event that brought together CAST leadership, technology companies, university researchers, as well as leading national and international aging services providers. A number of diplomats also joined the conference to witness and participate in this groundbreaking event. Our approach is global, and we will continue to investigate and interpret how other countries are using technology in aging and how that technology might be applied in the United States.

During the April conference, CAST leadership had the opportunity to meet with Senator Craig's staff and discussed a hearing on aging technologies. We applaud the Senator's interest in aging technologies and thank him for holding this important hearing. We look forward to continued work with Senator Craig, distinguished committee members, and committee staff in the future so that aging services technologies meet the demands ahead.

Cast Participants:
Companies:
Arthur Shuster Inc.
Bayer
Bell South
Direct Supply Healthcare Equipment
General Electric
Gerontological Solutions, Inc.(GSI)
Hewlett-Packard
Hoffman Corporation
Honeywell
IBM
Infotech Strategies-CSPP
Intel
Intouch Health
Lifeline Systems
Maytag
Merck Institute of Aging & Health
Motorola
New Life Management and Development, Inc.
Philips Medical Systems
Sodexho USA
Triple G Systems
Vigil Health Solutions
Ziegler Capital Markets Group

Universities:
MIT-Media Lab
SUNY- School of Health Technology & Management
Texas Tech- University Health Sciences Center
University of Florida-Rehabilitation Engineering Research Center on Technology for Successful Aging
University of Rochester- Center for Future Health
University of Virginia- Medical Automation Research Center

Facility Members:
ACTS Retirement-Life Communities, Inc.
Cedar Community West Bend
Front Porch
Manor Care Inc.
Masonic Homes of California
Northeast Health & The Eddy
Ohio Presbyterian Retirement Services
Rest Haven Christian Services
The Evangelical Lutheran Good Samaritan Society
The Jewish Home & Hospital Lifecare System
The Osborn

Other Interested Groups:
Alzheimer's Association
Medical House Call Program
Minnesota Department of Human Services
National Institute on Disability & Rehabilitation Research
Oregon Alliance of Senior & Health Services (OASHS)
Polisher Research Institute
The Robert Wood Johnson Foundation

Statement for the Record
U.S. Senate Special Committee on Aging Hearing
"Baby Boomers at the Gate: Enhancing Independence through Innovation and Technology"

May 20, 2003
2:00 PM
628 Dirksen Senate Office Building

Tobey Gordon Dichter
Founder, CEO
Generations on Line
(Generations on Line is a not-for-profit national program devoted to Internet access and literacy for the elderly)

It is society's obligation to ensure that our oldest and probably wisest generations have the adequate resources to enhance their lives and continue to contribute in meaningful ways.

As this hearing looks at the Baby Boomers confronting new technologies, we should also remember their living parents, who are even more disadvantaged and could potentially benefit greatly.

A 53-year-old working woman is more productive if she can check up on her 80-year old mother in the morning through a quick email. (IBM and AT&T have recognized this and funded a large program towards the effort.)

That 80-year-old grandmother is more independent and engaged in the intergenerational richness of her family if she can correspond with grandchildren and distant relatives, pursue her hobbies, research her own medical questions, shop online, and volunteer her time in an office. (AARP recognized this and sponsored a mailing to 10,000 baby boomers in Pennsylvania last Grandparents Day).

Beyond the many millions of active, vibrant elders who work hard, play hard and live fulfilled existences are millions of others who are just sitting it out.

One small but powerful tool is the Internet. As society increasingly uses electronics to connect them to resources, families, friends, and commerce

– more than 21 million Americans over 65 are becoming marginalized. They do not understand the new vocabulary in every commercial; they cannot access resources which are no longer available on paper; and they are terribly intimidated by the confusing and costly requirements of cyberspace.

In visiting senior centers, long-term care facilities, retirement homes and libraries across the country as we introduce Generations on Line (a not-for-profit software tutorial that simplifies the Internet for seniors), I have witnessed firsthand the excitement and high leverage from small investments in Internet resources for the Baby Boomers and the elderly. We have also seen the converse.

We should promote Internet literacy and access for rich and poor, urban and rural, English speaking and non-English speaking.

This is not only good policy, it is good economics.

COST SAVINGS:
Equipping public and private institutions that serve seniors with the most simple computer, connection and tutorial can quickly result in enormous savings for states and agencies. Universal Internet access and literacy could dramatically reduce redundant staff phone lines and multi-million-dollar mailings.

MORALE, INDEPENDENCE, JOB REENTRY
From filing taxes online to banking online, the nation is imploring and incenting Baby Boomers and their parents to choose the Internet instead of the mail. It was recently announced that the US Savings Bond will be sold only on the Internet. Discounts are available exclusively on the Internet. Information about the latest news at the federal, local and community level is increasingly available only on the Internet.

Beyond this, the Internet can help overcome loneliness, boredom and lack of self efficacy. In the three years devoted to closing the gap for seniors, we have heard endlessly: "They are leaving us behind." Seniors are confused, embarrassed and intimidated by computers and therefore deprived of the rich potential of the Internet for them.

The longer this goes, the more isolated they feel and more defensive about not enrolling in classes. Cost is a factor, but free Internet is available at nearly every public library across the country, if only they knew how to use it and weren't afraid to try.

Every senior center, retirement community, nursing home and assisted living center should be allowed a senior rate for connectivity, should be

equipped with public access free computers, and should have a simple teaching tutorial to guide the patrons on to the Internet.

The cost averages seventy-five cents a person. To bring the richness of the world to their fingers, the stimulation to their minds, and their great grandchildren to their eyes is value for money.

We applaud Senator Craig and others in Congress who have focused on this issue.

Submitted by

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