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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?