

## CAREGIVING IN GEORGIA

### **The Role of Caregiver Focus Groups in the Implementation of the National Family Caregiver Support Program**

In anticipation of the passage of the National Family Caregiver Support Program (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 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, bringing the total number of groups to eleven conducted around the state.*

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.

**1. 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:

- DAS executed contracts with Atlanta Legal Aid Society and the Georgia Legal Services program to provide legal assistance to grandparents raising grandchildren on issues such as custody, adoption, Living Wills, and housing.
- All AAA regions provide information and referral to grandparents raising grandchildren. Several AAAs printed Resource Guides for grandparents.
- DAS executed a contract with Jewish Family & Career Services to implement the Navigator Program. Navigators are part-time workers (usually grandparents) who work in DHR offices, helping other grandparents raising grandchildren to access programs and services.
- DAS contracts with the Atlanta Legal Aid Society to enhance the Senior Legal Hotline to be able to receive calls from grandparents of any age raising grandchildren. Thus, Georgia has a Relative Caregiver Hotline.
- 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
- *Two Caregiving in Georgia* reports, with support from AARP, have 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 reports can be accessed via the Division of Aging Services website, which is <http://aging.dhr.georgia.gov/> .
- A list of Caregiving Internet Resources has been compiled and disseminated to AAAs

- DAS in partnership with the University of Georgia launched a new website ([www.livewellagewell.info](http://www.livewellagewell.info)) to provide information on healthy living for people aged 50 and older, their families and caregivers. The website also provides information on health topics with links to additional information and community resources

## 2. 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:

- DAS receives \$600,000 from the Governor's office to develop statewide kinship care programs for grandparents raising grandchildren and other relative caregivers. Programs provided include 45 support groups, case management, special educational and recreational programs for grandparents and children, and summer camp scholarships, enabling children to attend camp while at the same time providing respite for grandparents.
- DAS, in collaboration with the Gerontology Institute of Georgia State University, conducted focus groups around the state with grandparents raising grandchildren in order to identify programs and services most needed by grandparents and relative caregivers.
- AAAs received \$3,000,000 of new state funds in SFY08 to provide respite care to families.
- Fifteen congregations around Georgia begin respite programs through the Congregational Respite program, providing 20,000 hours of respite per year for family caregivers.
- AAAs allocated over \$750,000 of new funding available through the National Family Caregiver Support Program for respite services
- All AAA regions have 1-800 numbers, and one statewide toll-free number is now in operation.
- 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, was expanded to additional areas in Georgia.
- Several AAAs are expanding options available to family caregivers for overnight in-home or out-of-home respite

- The Rosalynn Carter Institute received funding from the U.S. Administration on Aging to develop CARE-NETs within all 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

### 3. 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:

- DAS launched the Powerful Tools for Caregivers (PTC) education/training curriculum in the state, in collaboration with the University of Georgia Cooperative Extension and the Rosalynn Carter Caregiving Institute. PTC is a six week curriculum which teaches family caregivers tools to increase their self-care and confidence.
- DAS implements Congregational Respite statewide, in collaboration with the Alzheimer's Association, which provides training and technical assistance to congregations regarding how to develop day care and support team models of respite care for their congregants and the surrounding communities.
- 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, 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

#### **4. 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

## Georgia Division of Aging Services

### Caregiver Focus Groups

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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.

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