Caregiving in Georgia

A State Report from the
Georgia Caregiver Resource Center

Prepared by Dr. Kathy Scott, R.N., C.,
For the Georgia Division of Aging Services

Winter, 2002

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Dr. Scott conducted the focus group research and prepared the report.

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Focus Group Participants
Last, but certainly not least, we want to acknowledge and thank the many focus group participants who were willing to share their time and experiences in order to assist others in gaining a better understanding of caregiving for older adults in Georgia.

Individuals whose photographs are included in this report are not actual caregivers interviewed for this research.

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DHR

Jim Martin, Commissioner
Maria Greene, Division Director

Georgia Department of Human Resources
Division of Aging Services • Two Peachtree Street, NW • Suite 9.398 • Atlanta, Georgia 30303-3142 • (404) 657-5258

Dear Friend,

Family caregivers play a significant role in maintaining the health and independence of older persons. According to a national study conducted by the National Alliance for Caregiving and AARP, more than one in four U.S. households have been involved in caring for a frail older person in the previous twelve-month period.

Since Georgia has one of the fastest growing elderly population in the United States, the Division of Aging Services (DAS) has been intensifying its efforts to look at where we should go with programs and services for older persons and their caregivers.

We also know that there is an abiding interest in caregiving at both the state and federal levels, and we needed to assure ourselves that our programming addressed the issues and concerns of consumers, not just second-guessed their needs. We decided that we should not substitute our judgment in pre-supposing the concerns of various types of caregivers.

We had some resources, but not a great deal. DAS staff began brainstorming, and approached Dr. Kathy Scott, a consultant to aging programs, about working with us to plan and conduct focus groups around the state so that we could hear directly from a variety of caregivers.

The Division anticipated that this feedback might not always be as complimentary or positive in nature as we would like, but we realized that it would be the basis for the improvement of our service system, rather than a threat to our existence. We were ready to subject ourselves to the same scrutiny as any other partner in the long-term care community.

Our operating principle has been that the truth may hurt sometimes, but can truly be liberating if individuals, organizations, and communities are open to taking some risks and are committed to the continuous improvement of the long term care system. Our goal was, and continues to be, to define issues, so that we can make informed decisions about where we should commit our resources, both fiscal and human, in program development.

We sincerely hope that the findings and recommendations in this report will be valuable to our partners in the aging network, service providers, legislators, and policy makers, as we strive to improve the quality of life for older Georgians and their caregivers.

Sincerely,

Maria Greene

Maria Greene, Director
Division of Aging Services

Serving Older Georgians and Their Families

Preface

The National Family Caregiver Support Program, signed into law by President Bill Clinton in January, 2000, is designed to help families sustain their efforts to care for an older relative who has a chronic illness or disability. The program, which is administered by the Division of Aging in partnership with Area Agencies on Aging, includes providing the following five basic components:

1. Information about resources that will help families in their caregiver roles;
2. Assistance to families in locating services from a variety of private and voluntary agencies;
3. Caregiver counseling, training and peer support to help them better cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
4. Respite care provided in a home, an adult day care center, or over a weekend in a nursing home or a residential setting such as an assisted living facility; and
5. Limited supplemental services to fill a gap that cannot be filled in any other manner.

The **Division of Aging** and the **Georgia Caregiver Resource Center** believe that the most effective and efficient programs are those that are designed and implemented with direction and perspective from the persons who will utilize the services. It is the hope of the Division that the information contained within this report, data obtained from Georgia's caregivers, will reach many different audiences and serve as a guide to those persons legislating, funding, designing, implementing, and experiencing programs related to caregiving of older adults.

If the information appears to suggest an urgent or crisis situation in caregiving, then the translation to paper has been successful. Caregiving is a public health issue that demands and deserves attention. This state report is intended to be a step in that direction.

Georgia Caregiver Resource Center

The **Georgia Caregiver Resource Center (GCRC)** was initially funded in 1992 by the Georgia General Assembly, to provide information, services, and training to caregivers throughout the state. A part of the Division of Aging Services, GCRC funding to the aging network has facilitated the development of new day care programs and has provided in-home respite, enabling caregivers a break from their 24-hour-a-day caregiving responsibilities.

In conjunction with an Alzheimer's Demonstration Grant received from the U. S. Administration on Aging, GCRC funds have been utilized to conduct Alzheimer's education/training events all across Georgia. More than 8,500 family caregivers, health care professionals, clergy, law enforcement personnel, and the general public have learned more about Alzheimer's Disease, coping skills, and available programs and services. These events were sponsored by 12 Area Agencies on Aging and the Division of Aging Services.

GCRC, through the caregiver focus groups described in this report, continues to expand its efforts to assist family and professional caregivers. GCRC's strategic plan is described later in this report.

The Division of Aging Services (DAS) is one of five Divisions within the Georgia Department of Human Resources, the state department charged with the responsibility for administering human service programs for the State of Georgia. The Division of Aging Services provides state leadership, manages contracts with lead agencies (Area Agencies on Aging), administers federal and state funding, and provides programmatic direction, regulations/guidelines and continuously seeks to improve the effectiveness and efficiency of the services provided to elderly Georgians and their families.

Area Agencies on Aging (AAAs) are designated by DAS to provide local responsibility for the implementation of services. Currently, twelve Area Agencies are identified by DAS across the state of Georgia by geographical boundaries called Planning and Service Areas (PSAs). The Area Agencies on Aging are the primary focal points for aging services within the State. All community-based services for the elderly are coordinated through these agencies. The Area Agency on Aging is responsible for the quality of service through its contractual arrangements with service providers, and for monitoring their performance. A list of Georgia's Area Agencies on Aging is located in the References/Appendices section of this report.

A. Vision Statement

Guiding and sustaining Georgia's caregivers.

Mission Statement

In partnership with the state aging network, the Division will provide leadership to establish a comprehensive array of programs and services for Georgia's increasing number of older adults and their caregivers.

B. Value Statements

In providing programs and services for Georgia's caregivers, certain values are basic in all that we do. The values that are an integral part of our work include the following:

Consumer-Centered Care: We believe that caregivers and care recipients should be involved in the planning and service delivery to the fullest extent that they are able to participate.

Quality: We believe that services should be delivered as planned and promised, in a manner acceptable to the caregivers and the care recipients.

Flexibility: We recognize the need to be open to new ideas and new ways of delivering services, always keeping in mind that serving caregivers and care recipients is our ultimate goal.

Dignity: We respect our basic self-worth and that of all people. We are dedicated to preserving the human dignity of all older Georgians.

Empowerment: We believe in the right to self-determination for all our customers. We support the right of caregivers to make choices and assume responsibility for their own decisions.

Accountability: We are good stewards of the trust and resources that have been placed with us. We base our decisions on data analysis. Our services produce the desired results that can be measured.

C. Initiatives

The Division proposes four initiatives that will fully implement the Georgia Caregiver Resource Center. Each initiative is designed to ensure that caregivers are able to access information and resources in a variety of ways. The components are to provide leadership in the following areas:

1. Research and Strategic Planning
2. Education and Training
3. Program and Resource Development
4. Information Dissemination

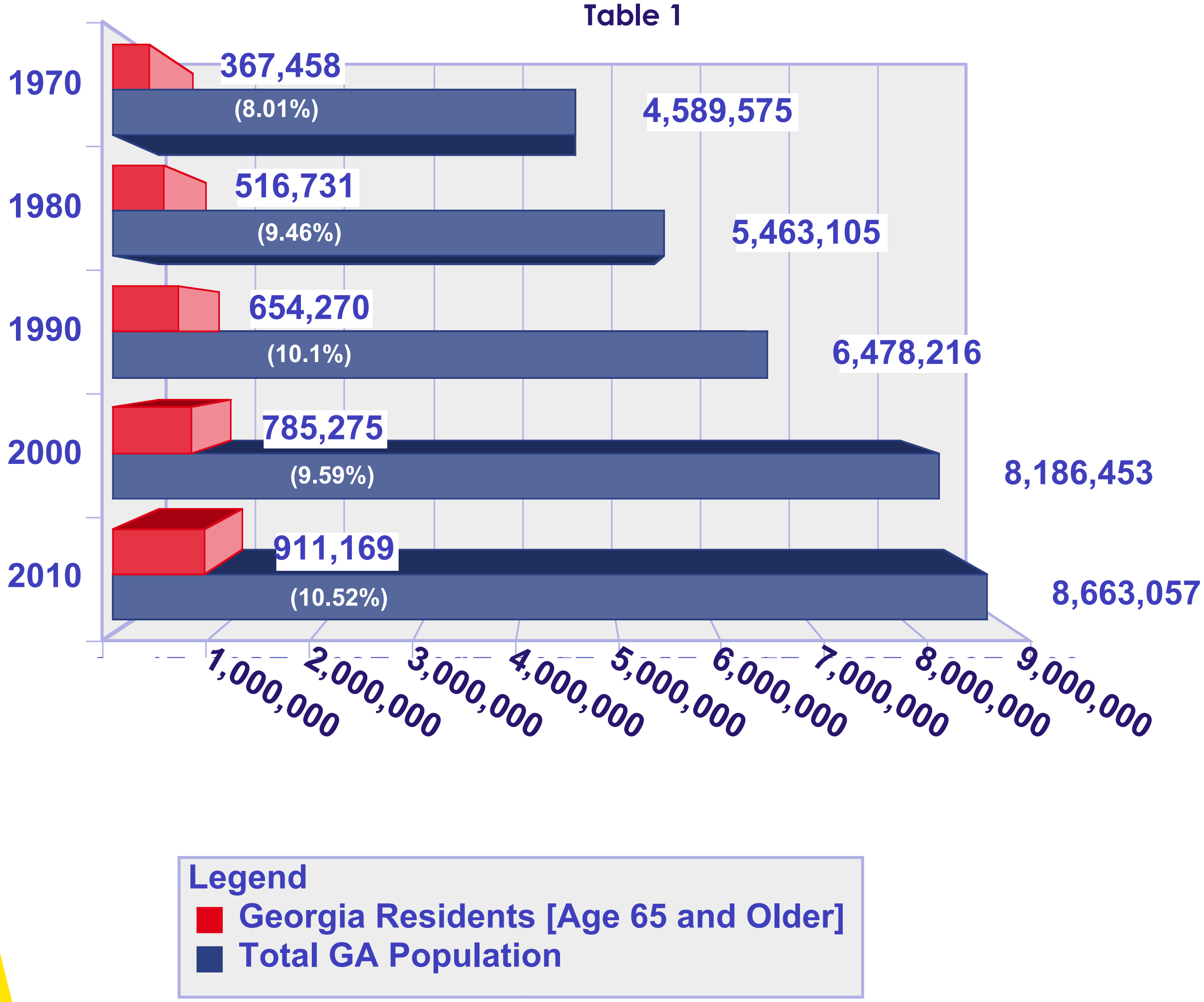
Introduction:

Aging Are Us!!

We are all familiar with the adage, the "Graying of America." But the significance in and the impact of this phenomenon often get overlooked or underestimated. (See Table 1)

Georgia Trend in Population, Ages 65+ [37]

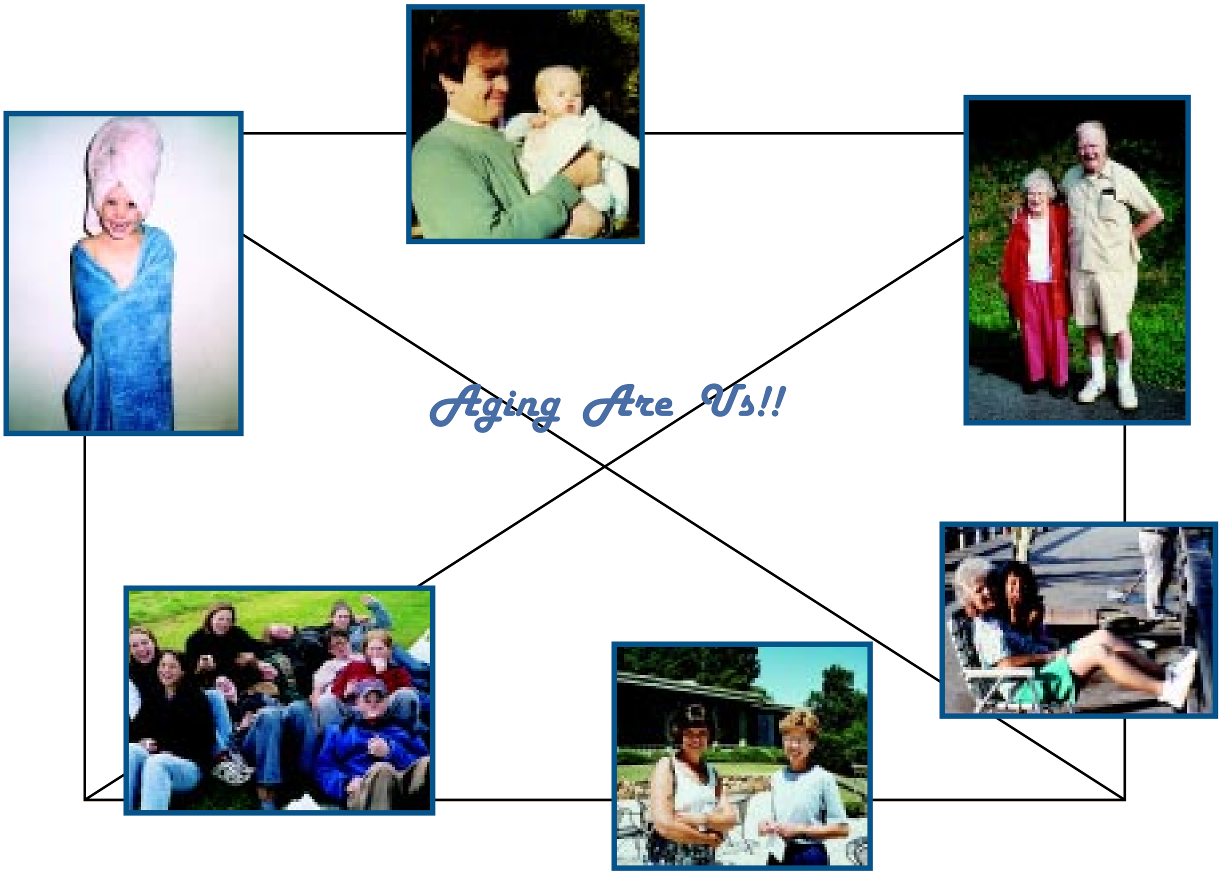
Table 1



Nationwide, there will be a dramatic increase in persons 65 and older between 2010 and 2030 as the "baby boomers" become "senior boomers". Even older Americans are now living longer, with life expectancy at 65 outpacing the gains in life expectancy at birth[20]. Currently, one out of 8 persons over the age of 65 is 84 years old or older. At the crest of the senior boom, there will be 4 times as many people 84 years and older as there are now. Georgia data indicates similar trends, as reflected in Table 1.

While we are living longer, we cannot necessarily conclude that we are living healthier. The majority of older adults have one or more chronic illnesses. According to Tennstedt[37], approximately 25% of all people aged 65 and over in the U.S. are in need of some form of long-term care. A 1999 report by the American Academy of Actuaries[37] purported that the numbers of severely disabled older adults will increase to 90% by the year 2040...requiring assistance for personal care (bathing, toileting), domestic care (cleaning, cooking), and skilled care from paid agencies and institutions.

Discussion surrounding the "Graying of America" often takes place as if it were an "us" versus "them" phenomenon. But for the readers of this report, make no mistake--we are all doing it and you are encouraged to read this report from the perspective of being both a potential caregiver as well as a potential care recipient. Indeed, Aging Are Us![35]



Executive Summary of Caregiving

A. Caregiver Facts

Caregiving is a universal issue. The majority of us have been involved in caregiving in some form or another, either in providing care or receiving care. If we have not, it is very likely we will be at some point during our lives. Nearly one out of every four U.S. households [22.4 million] provides care to a friend or relative over the age of 50 years[5]. According to the AoA, 65% of non-institutionalized older adults needing assistance depend solely on family and friends.

B. Caregiver Context

Caregiving for older adults has always been a role that families and friends have assumed, although it may vary in form, level, intensity, and length. There are now many contextual factors that are re-shaping the reality of the caregiving role and supply. Included in the many factors are

a) decreasing birth rates,
b) decreasing family size,
c) increasing geographic mobility,
d) delayed childbearing,
e) growing rates of divorce and marital disruption, and
f) the increasing number of women in the workforce.

C. Caregiving Costs

Caregiving to older adults can be an extraordinarily happy and satisfying experience. It can be a time of reflection that benefits both members of the caregiving dyad. However, the costs of care provided to an older adult can be high. It can take its toll financially, emotionally, physically, socially, and spiritually on caregivers. The following serves to exemplify the seriousness of this issue:

- Approximately 2/3 of working caregivers report increased conflicts and challenges between their paid work and caregiving, leading to the need to change their work schedules, to work fewer hours, to pass up promotions, or to take unpaid leave of absence[8,9]. Between 9-12% of caregivers have had to quit their jobs to provide care, which translates into loss of direct income and benefits, increased out of pocket expenses, decreased social security contribution/credit, and loss of retirement benefits[8,10].
- As might be expected, social participation decreases dramatically for caregivers. The lack of time also includes less interaction with children, spouses, and less time for oneself [8,20], all of which can have very high costs.
- Caregiving can significantly impact the health of the caregiver. The addition of responsibilities along with the uncertainty of caregiving can place very heavy emotional strain on the caregiver. Caregivers use prescriptive medications two to three times more often for depression, anxiety, and insomnia than non-caregivers[9,16]. Caregivers are

also more likely to develop physical illnesses because of a weakened immune system associated with the caregiver stress.

All of these factors lead to the reality that the demand for caregiving far outweighs the supply of potential caregivers and will only become more imbalanced in the next few decades [see Illustration 1] [20].

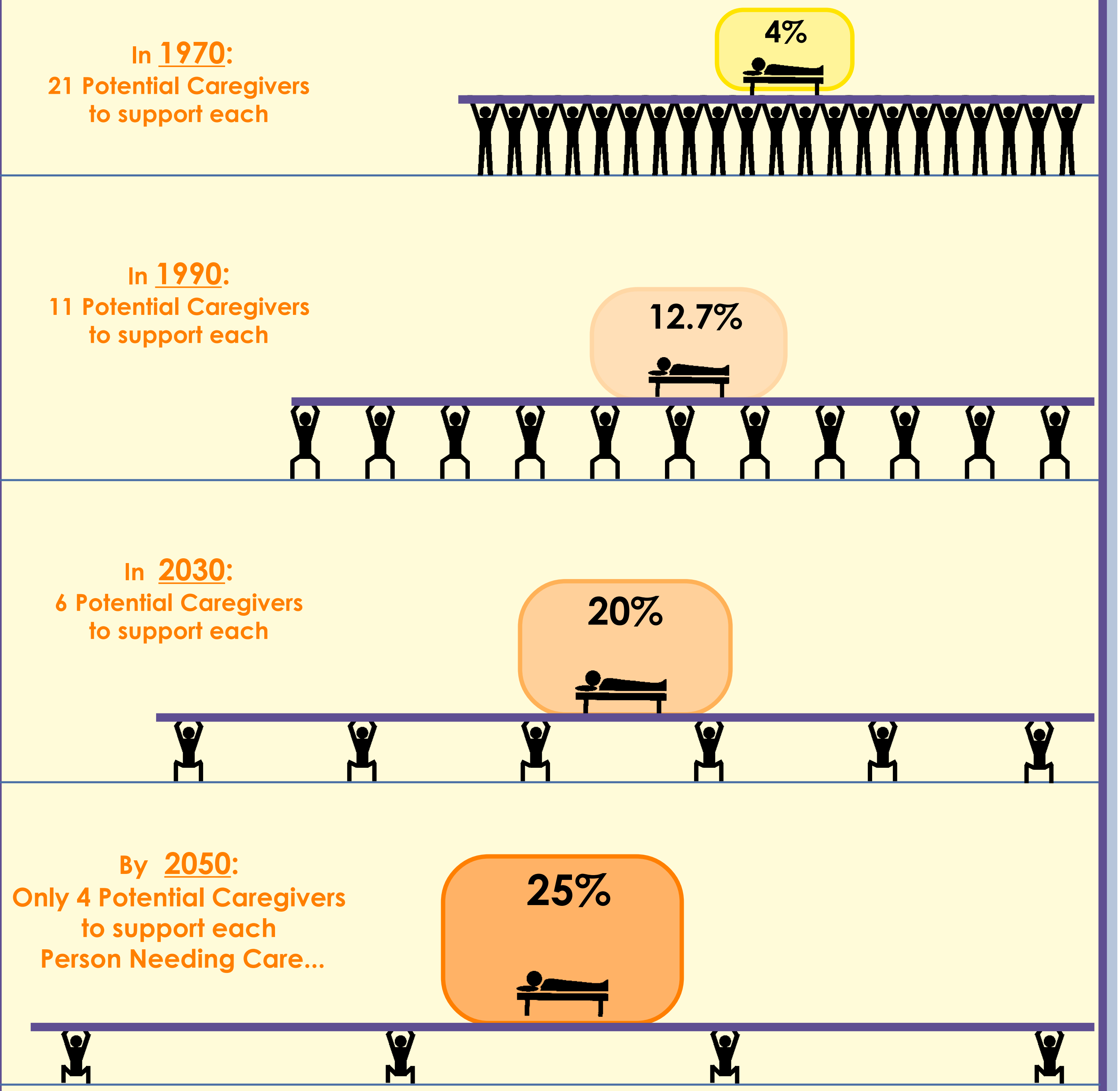
D. Caregiver Challenges

Caregiving in this country is making itself known through sheer volume. Individually and collectively, members of this society will be affected by this phenomenon in a number of ways.

The challenges of caregiving are many. The primary challenge is to address this issue before it becomes more of a crisis...to further understand the needs of those receiving care, to hear the needs of those providing care, and to create a broad-based system to support the caregiving relationship in the most appropriate setting and in the most cost-effective manner.

The demand for caregiving far outweighs the supply of potential caregivers and will only become more imbalanced in the next few decades...The primary challenge is to address this issue before it becomes more of a crisis.

Ashes, Ashes, We All Fall Down...



In **1970**:
21 Potential Caregivers
to support each

In **1990**:
11 Potential Caregivers
to support each

In **2030**:
6 Potential Caregivers
to support each

By **2050**:
Only 4 Potential Caregivers
to support each
Person Needing Care...

The Direction of Caregiving for Older Adults

Illustration 1

Overview and Background of Study

Focus Group Method

A. Research Approach

A phenomenological design was used to explore the experiences of caregivers of older adults in the state of Georgia. A focus group approach was the primary data collection method used to elicit the shared meaning of everyday experiences from particular subgroups.[21] The advantage of the focus group approach is the synergy created among the members of each group which:

1. fosters the production of information that is difficult to obtain in individual interviews;
2. emphasizes participants' interactions and points of views;
3. provides opportunities for participants to validate information shared by others;
4. clarifies arguments and reveals diversity in perspective; and
5. facilitates the collection of a large amount of information in a relatively short time.

B. Sample and Setting

The population of interest was people who give care to older adults in the state of Georgia. Although family members provide the majority of care to older adults, there are also many others that constitute the larger pool of caregivers to this population. A decision was made to recruit persons with varying perceptions of the caregiving experience who would most likely represent all persons who are providing care to older adults in this state.

Focus group participants were selected from six groups in six different locations in Georgia.

Group 1: Traditional/Non-Professional

This group, from West Central and Southwest Georgia, included family and friends providing care to one or more older adult(s) in a rural setting. Consistent with national trends, the majority were women (75%) and included spouses, daughters, and granddaughters. The male caregivers were spouses of those receiving care.

Group 2: Non-Traditional/ Non-Professional

This group consisted of diverse community members from an inner city, urban area of the state who were providing some form of volunteer care or assistance to older adults at various sites. Again, the group was primarily women (75%) who assisted in a respite care facility, made nursing home visits, provided transportation to church members, and other similar activities. Also included in this group was a member from a local church providing care to gay individuals.

Group 3: Traditional/Professional

This group of caregivers was from the Northeast and East Central part of the state. Participants in this group included paid professionals who are traditionally involved in the care of older adults, such as registered nurses, social workers, and senior center directors. There was one male in the group, a business owner.

Group 4: Non-Traditional/Professional

This group of caregivers from rural and urban Central Georgia were also paid professionals. While extraordinarily important to the industry, this group has not had a lengthy or large presence in the arena of caregiving for older adults. Included in this group were professionals such as eldercare attorneys, discharge planners, care managers, and hospice nurses. Five of 8 were female.

Group 5: Traditional/Non-Para Professional

This group of caregivers was from rural South Georgia. All of the participants in this group were female nursing assistants from home health care who operated under the regulations of Medicare and/or Medicaid.

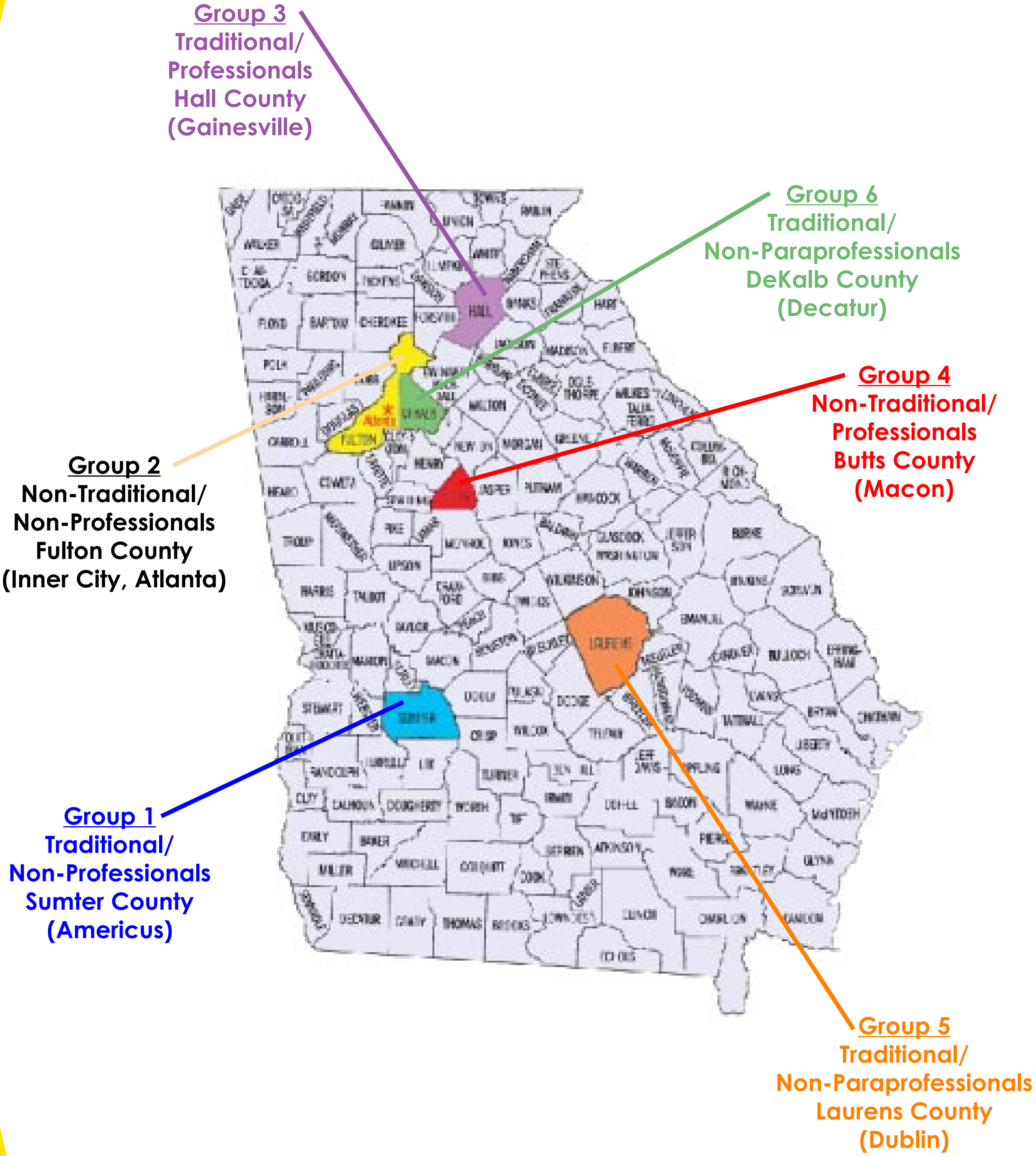
Group 6: Traditional/Non-Para Professional

This group of caregivers from the metropolitan area of the state were also nursing assistants. However, these nursing assistants were from the home care industry, operating out of a private pay industry.

Focus Group Sample Demographic Data

Table 2

	GENDER		AGE	RACE			
	Female	**Male**	**Range**	**African-American**	**Hispanic/ Latino**	**Caucasian**	**Other**
Group 1 Traditional Non-Professional (n=12)	9	3	40-80	0	0	11	1
Group 2 Non-Traditional, Non-Professional (n=11)	9	2	29-80	6	0	5	0
Group 3 Traditional Professional (n=14)	13	1	38-61	2	0	12	0
Group 4 Non-Tradional, Professional (n=8)	5	3	33-52	3	0	5	0
Group 5 Traditional Non-Paraprofessional (n=11)	11	0	26-69	6	0	5	0
Group 6 Traditional Non-Paraprofessional (n=8)	8	0	35-56	7	1	0	0
Total (N=64)	55 (85.9%)	9 (14.1%)	26-80	24 (37.5%)	1 (1.56%)	38 (59.4%)	1 (1.56%)


Group 3
Traditional/
Professionals
Hall County
(Gainesville)
Group 6
Traditional/
Non-Paraprofessionals
DeKalb County
(Decatur)
Group 4
Non-Traditional/
Professionals
Butts County
(Macon)
Group 2
Non-Traditional/
Non-Professionals
Fulton County
(Inner City, Atlanta)
Group 1
Traditional/
Non-Professionals
Sumter County
(Americus)
Group 5
Traditional/
Non-Paraprofessionals
Laurens County
(Dublin)
HALL
DEKALB
Atlanta
FULTON
LAURENS
SUMTER

C. Focus Group Procedures

It is generally recommended that focus groups be limited to ten to twelve participants to allow for maximum participation. Following that recommendation, these steps were taken:

1. Agencies located in the varying parts of the state with knowledge of persons who met the criteria of interest from each of the six sub-groups were asked to provide names and numbers of potential participants;
2. Recruitment letters were then sent to potential participants explaining the intent to conduct focus groups in their area and requesting their participation;
3. Each person who agreed to participate was then contacted by telephone.

Sixty-four of the 72 who were recruited agreed to participate in the focus groups. All groups were of the same approximate size.

The focus group team consisted of a four-person planning group who first identified the need to conduct focus groups as a way to gain a broad understanding of the caregiving experience to older adults. This team included a manager from the Division of Aging, an aging consultant who conducted all six focus groups, and two persons who served as non-participant observers during the group sessions. The team identified the different caregiver categories, the areas of the state to conduct the focus groups, and the intermediaries in the varying parts of the state who assisted to identify potential participants, and also assisted in the final analysis of the data.

D. Data Analysis

All focus group discussions were audiotaped and transcribed verbatim, omitting any identifying information about participants. After each session, discussion was held and observation notes were recorded by the group moderator and the non-participant observers to document any non-verbal data or activities during the meeting not picked up by the recorder.

Analysis of the data was completed by the group moderator using a phenomenological methodology developed by Colaizzi and adapted by Scott[34]. Verbatim transcripts from the audiotapes, observations notes and demographic data provided the basis for analysis. The data was initially analyzed by group. After each analysis, the interpretation was sent to the participants to clarify previous comments and to provide feedback on the interpretations of the data. The data was then analyzed collectively across groups. Themes were organized based on common phenomena or experiences across the six caregiver groups. The essence of the sessions and the development of themes across all six groups were reviewed by other team members and one outside person for credibility purposes.

Focus Group Results

Each focus group was comprised of different types of caregivers. Themes were deducted from each individual group to reflect their experience. An analysis was also conducted to determine the themes that existed throughout each of the six focus groups and themes that each group had in common. Out of the context of "Compassion Fatigue and Frustration," three major themes emerged for these caregivers:

1. Lack of Information
2. Needs Exceed Availability
3. Ageist Providers

Contextual Perspectives

The overarching theme that provides the context for the three experiential themes is what is referred to as **"Compassion Fatigue and Frustration"**[33]. **Context** is defined as the conditions or circumstances which affect something.[44] For example, one's context, or value system of past experiences, could influence which woman is seen first in illustration 2 (i.e., the older or the younger woman). Moreover, one's context can greatly influence how s/he perceives, for example, the need to place a loved one in a nursing home.

While all of the caregiver participants seemed to enter their caregiving role for various reasons, a common thread throughout was that they all seemingly accepted the role and wanted to do a good job. This was evidenced, in part, by the fact that all who were invited to participate in these groups did actually participate, and often at considerable cost and effort to do so. However, despite the motivation and effort of these caregivers, another common thread was that they were all quite weary and frustrated. The statement on the next page by a granddaughter caregiver exemplifies this overarching theme.

Contextual Perspectives

Illustration 2

"Well, I had to quit my job to take care of her and just like some of these others, you never know what she's gonna do or whatever. It's just day by day. Like one morning, I got up, she got up before I did. I walked into the living room and I smelled gas. And as I got closer to the kitchen and what she had done, she was going to fix her a cup of coffee and we have a gas stove. And she turned it on and she didn't notice that the flame didn't catch, and she turned her back and didn't pay no more attention to the pot and the gas was just building up and we had to open doors and windows and then one day last week, I was sitting in the living room and she was in the kitchen, and she was going to fix herself a cup of coffee and she put the pot on the stove without water in it and the next thing I knew the smoke detector went off—scared me half to death. Here I was jumping up trying to find where the fire was at. And now she's at the point where she don't want to take a bath and I don't have…..it's hard for me to talk…(starts crying). I was raised you don't talk back to your elders and it's hard. And my sister she lives here with my mother in Montezuma and my father, they're divorced and both remarried, my father lives in Florida and I don't have any help. And I don't know who to turn to ask for help.

"We're tried everything. Like last week we tried to get her in the tub, even my husband tried to get her in the tub. She picked up a flashlight and she was going to hit us with it. I went and ran her water and I told her, 'If you don't go ahead and get in your water's going to get cold.' 'I'm not taking a bath.' And there we've been in her house since November and she hasn't taken a bath yet."

Story told by granddaughter caregiver in February, 2000.

Frustration seemed to be high because of underlying beliefs and expectations regarding caregiving responsibility. Within each of the groups there was finger pointing, not necessarily consciously, as to WHO should be doing WHAT, and WHEN, but in their estimation was not! There was a great deal of assumption of **who "should" assume responsibility for certain caregiving activities.** These beliefs regarding caregiving responsibilities served as a constant source of tension among caregiver groups and seemed to shape the experience of caregiving, leading to more frustration and fatigue.

Churches: "And I'm not sure that the churches are stepping up to the plate. I've been here a long time and raised in the church, but I'm not sure if the church is doing what needs to be done."

"Churches should have more programs, teaching-type programs about the disease." (Alzheimer's Disease)

Families: "And like the other two were talking, everybody leaves you. Her brothers and sisters, and she had six, never called, came, never sent a card…Our own children, two churches, and she taught Sunday School for ten years, nobody!"

Doctors: "This is the big thing that I see is that the physicians do not give out enough information to the people…you just don't see the information in the doctor's offices. The doctors are so rushed…you're not addressing the whole person… The doctor needs to have a staff person (to give out information)."

Government: "You need money put into programs so that you don't have people going back to the hospital, staying in the hospital because they can't get transportation back to the nursing home. There are so many services that need to be funded to keep people out of the acute care."

When the caregiving experience did not conform to their expectations, it served as a major source of tension and, at times, anger.

Yet another source of frustration clearly evident in all groups was that the caregivers' expectations of the ideal or desire for care was not what was available [did not exist, was not enough, or not in their area] or seemingly affordable to them or the care recipient. **When the caregiving experience did not conform to their expectations**, it served as a major source of tension and, at times, anger.

Non-Paid or Family Caregiver:

Sitters

"She was finally able to send me a lady once a week for the 4 hours, which allowed me to go to Columbus and buy groceries and like you were saying, it is not enough time. By the time I drive to Columbus and back it is almost 2 hours. So to buy groceries and do whatever else I have to do business-wise, banking, whatever, it just ate it up…I never have a minute to call my own."

Nursing Assistants

"You have to have a new one (nursing assistant) every week, you got to train them that day and it takes all of your time to get them into the routine and then the next week they send someone else and then you've got to go through all that again."

Respite Care

"You can take your patient out there and leave them for $100 a day. Well, you can't do a whole lot of that if you're an average person, like we all are….I think they need to have respite on weekends and at night. Because it's hard…I think there should be some program for 24 hour respite…and we need some funds."

Discharge Planning

"I think the hospital and doctors should say we know what you need when you go home…your bathroom, you can't get in…we were not prepared [to go home.]"

Everyone's caregiving filter was slightly different, but frustration abounded when their beliefs and expectations did not square with reality. It seemed that the caregiver participants were continually looking externally for the cause or the party responsible for their frustrations; a phenomenon referred to as the "blaming and shaming" of caregiving [35].

Paid Caregiver Non/Paraprofessional

Types of Clients

"I had a case where this person had a dog. We went in to take care of this woman. She had a dog that was real old, real ill. My agency has a tendency to say, 'You're going to love this person, they are really nice. You won't have a problem.' Even though they never met the person before. [This is a hot issue.] Well, I got there, she was real nice. There was no problem with her. But the dog was a sick dog. We had to give the dog insulin. We had to groom the dog. Take the dog out 3 times in my shift, which was a 12-hour shift, take the dog out 3 times. Well, I happened to mention to one of the other caregivers that I don't like taking care of the dog. I don't. I just don't. And when I tried to give the dog insulin, the dog growled at me. And I thought, you do it, to my patient. She got upset to me because I was scared to do it. And I mentioned it to the other caregiver, I don't like doing this, I really don't like taking care of this dog. She went back and told the client and I was dismissed. I was glad because, when you go in a place, they tell you [that] you have this client you are going to care for. They don't tell you everything that goes along with caring for that client."

Caregiving Politics

"I worked for an agency one time that I had to go to an assisted living to take care of somebody for them and I went at 7:00 in the morning and she was covered in BM from her head to her feet and she was living in an assisted living. So I cleaned her and I complained about it and called the agency…. Then somebody called me, the supervisor called from the agency. 'Do you know we have a lot of patients in that assisted living and we don't want to make any trouble for them because we don't want to lose any patients?' "

Caregiving Environment

You go in and find cat feces all over the house. And when the husband is highly intoxicated, he goes to the bathroom – he may have feces all over the floor or the commode. It's not my job to clean up behind this person. But it's unsanitary to leave it there because then if somebody came in from the state behind me and they saw – how could she just leave this? Well, it's not my job to clean up the husband; you know what I'm saying. So to me that's unsanitary to have the animal feces all over the house then the husband is no better. The house is just filthy. I mean that it just is not sanitary. "

Number of Clients

"You're taking care of a lot of clients…you end up taking care of everybody. You even become the babysitter sometimes."

It is from the context of "Compassion Fatigue and Frustration" that the three major experiential themes were derived.

Three Major Experiential Themes

1. Lack of Information / Coordination of Resources

The need for more information was evident in each of the groups, no matter whether or not they were professionals or the length of time they'd been providing care. At times, it was clearly articulated that they needed more information about what services and products were available, clarity on what those services provided, and help in locating the services or products and the reimbursement source of the services but that it was very difficult to get to. In some cases, these individuals had portions of information but not enough to act on. Most expressed the idea that while information might be available, it was often hidden or obscured or so loosely coordinated that gathering all necessary information was a challenge and sometimes not worth the effort. For instance:

- "You have to be a very aggressive person to dig out all this information. I didn't know it was there and they don't tell you anything, but if you just keep at it and you find out one thing, then you find something else."
- "And I've called DFACS that don't even know what's available in the rest of the community. We at least need our own agencies to know what each other's doing...we don't even know that."
- "If we started out around this table, I bet we could come up with 100 services that people in this room [professional care givers] don't know about. And it's access to this information and getting this information out....the communication is not there. There is so much that needs to be out there."
- "We (Home Care Agency) get calls 3, 4, 5 times a week with people needing something that we don't do but don't know where to refer."
- "Alzheimer's Association puts out a lot of information about the disease, I'll give them an A+. But they tell me nothing about where I can receive help. That was my big problem."
- "The doctors don't even know the resources there."

And lastly, the participants identified that there was much misinformation in the communities that affected the caregiving experience. For example:

- "A lot of misinformation on the part of adult children who are still, well they haven't even discussed this (Power of Attorney) in the first place. ….There's a lot of myth of legal issues surrounding old age and guardianship and powers of attorney."
- "A lot of myths around Medicaid reimbursement for nursing homes."

Most expressed the idea that while information might be available, it was often hidden or obscured or so loosely coordinated that gathering all necessary information was a challenge and sometimes not worth the effort.

2. Needs Exceed Availability

A second major theme from the focus groups was "Needs Exceed Availability." Frustration and even a sense of impotence were evident in this theme. The words speak for themselves as these care providers attempted to explain the experience when there was not enough funding or service for medications, transportation, home care, geriatricians, nursing assistants, and even nursing home beds. This theme was undergirded by the ethical dilemma whereby the majority of the caregivers had been educated and/or encouraged to carefully assess and assist the care recipient to access resources necessary for care…and yet, many times they were unable to fully meet their needs or find the resources identified as needed. This phenomenon was particularly true as it related to transportation, medications, and home care. For example:

Transportation:

- [Senior Center Director] "I want to go back to transportation. We don't even have a hospital. I spend a good amount of time just arranging for transportation, people to doctors, to hospitals, to specialists, to imaging centers. I have 3 churches that have mobility teams, and transportation is a big issue. It takes a lot of my time trying to organize a volunteer to take them to Gainesville. It may take a half a day or it may take 6 hours. All for one person."

- "The Medicaid transportation system is the biggest disaster we've had in years. We're talking about repeatedly we've had people have to stay extra nights in the hospital because their services didn't pick them up to take them to the nursing homes."

Medications:

- "Everybody falls through the cracks....if you need a meal, we can give you a meal. If you need transportation, we can give you transportation. But what if you need someone to give you medication. There's nobody to do that. Because if you don't get your medication, then all of the meals I send are not going to help you."

- "Getting back to this medication, when patients can't afford it, they do without it. You find a lot who do without it because they can't afford it...when they don't take the medication, that causes other problems. That means they have to be hospitalized..."

- "We had to admit 10 patients to the hospital strictly because they did not have their medicine to take because they couldn't buy it; they didn't have money to buy it. They did not have Medicaid because they have too much money. Medicare doesn't pay for it. By the time they've paid for their living expenses, it was a choice of, 'Do I buy food or do I buy medicine?' And they chose food over medicine."

It is a real paradox to enter a profession because you want to help people, then discover repeatedly that you cannot due to the lack of resources.

Home Care:

- "...it's almost daily somebody comes in with a need and we go out there. They don't need it 3 months from now, 4 months from now. We just went to a funeral last week of somebody in that position. We sent somebody into the home with no reimbursement to help while we could, but how much can you do this? We're too slow to respond."
- "And if they're slow or they have problems or they get sick while you're there, they have to go to the bathroom, you clean them up. They have to go to the bathroom again, well, it takes a lot of time sometimes...and a lot of people that are in management don't understand the things...I mean, I understand the financial aspects of it; you got to be able to live within the guidelines of the Medicare program. I understand that. But you know when you're working with people, things don't always go like the guidelines say to go. 'Well, you can't go to the bathroom; I've got to go.' "

This phenomenon may help to account for some of the turnover in this industry. It is a real paradox to enter a profession because you want to help people, then discover repeatedly that you cannot due to the lack of resources.

3. Ageist Providers

Ageism is discrimination against individuals based on age alone. It lurks around in many different forms including apathy, complacency, and ignorance related to older adults. Ageism was strongly reflected in the participants' message related to caregiving. In each of the six groups, the conversation took place at one time or another that the persons providing care were not adequately trained, educated, monitored, or supported enough to take care of the older population. This comment was inclusive of everyone from the family, physicians providing primary care, registered nurses, social workers, and nursing assistants involved in some aspect of the older adults' care in an institution, home, or community. In each and every group the insinuation was how ageism compounded the frustration and fatigue of caregiving. Some of the participants were hesitant to make a direct statement and were quite soft in the way they assessed the situation. Others were not so timid; in fact, they were adamant and angry!

Inadequately Educated:

- "...because the internists are not trained, they don't have much experience with gerontology and they are stumped and they make very stupid comments to families."

- "My mother complained that medical people, especially physicians, treat older people as though they were children. Condescending."

- "With our client and personal care homes we are spending a large portion of our time trying to undo damage that has been done because their doctors don't understand the geriatric population. They don't understand the effects of medications on older people, which are different than the effects on younger people. They're not medicating them appropriately and we're having to go behind their backs, up to the nurses, trying to manipulate them because it is hard to address them directly. And I think there are a whole lot of doctors out there that need much more understanding of geriatric medicine."

Inadequately Supported:

- "...supposed to see 6 people a day in 8 hours, you're not supposed to do any overtime. But some of these people, they're old, they're slow, and I can't just tell somebody like that hurry up so I can get to my next one so I can get through and not do overtime. I can't do that."
- We expect someone making minimum wage to bathe, diaper, feed someone that they don't know and not have any particular close feeling for and yet we're expecting them to do it lovingly as we would do it."
- "Contract labor pays $6 an hour. And I say you can't afford to work for $6 an hour and raise your own transportation, pay your own social security and your taxes. I said, "What planet are you from?" I mean, common sense tells you, if you only make $2, you pay 35% tax, then you have the use of your car. Anybody who's worked there for a living, they're going in the hole."

In each of the six groups, the conversation took place at one time or another that the persons providing care were not adequately trained, educated, monitored, or supported enough to take care of the older population.

Inadequately Monitored:

- "I think the hardest thing was finding help. Competent help. That probably caused me more frustration than my husband did. The help was so bad. Not reliable. So many of them (nursing assistants) had no training, if they came from an agency. They were not reliable at all, most of them...or doing what you asked them to do. I had to ask them not to send several different ones they were so bad. You had to have them but to find competent ones?"
- "I think another thing we're going to have to realize that the people need to be high quality people giving the care. We pay very little. As long as there's a family member there, they are very attentive, but once the family member leave, the attention stops. And I think part of that is simply because these people are not trained."
- "I've had to cancel a doctor's appointment because they (nursing assistants) did not show up."

Recommendations

The following are recommendations that were common to the six groups of participants. It is the hope of the Division of Aging that each recommendation be viewed carefully and considered with due care. These were the comments and suggestions that the focus group participants stated would facilitate continued, quality care for older adults and their caregivers in this state.

Information

What

1 **Community Resources/Providers** - Many of the participants wanted and needed to know what kind of service providers were available to assist in caring for the older adult in their own communities and at large. Often bogged down in the everyday activities of caregiving, they either didn't have time to find out or didn't know where to begin. Many simply did not know the questions to ask, or when they did, they felt like they had to go to too many different places to get the answers.

2 **Community Resources/Products** - Participants also wanted information on products that might assist in the caregiving process. Some had heard of certain products, like an emergency response system or Velcro clothing, but didn't really understand what they were, how they could be beneficial to them, or how to obtain the products.

3 **Low Cost/No Cost Medications** - This was a repeated topic in all groups. Given the number of medications most older adults are taking, the associated costs, and implications of doing without other needed items because of the costs, all groups identified the need to get financial assistance with medications.

4 **Emergency Services** - There was a thread of concern in each of the groups as to what would happen to the older person being cared for if the primary caregiver were unable to provide that care, such as when the caregiver had to have surgery. Expressed within the groups was the need for more information on who, if anybody, was available to "step in" until arrangements could be made.

5 **Home Preparation** - Most groups expressed the need to have more information provided to caregivers on what preparation [change in physical structure, equipment, etc] is needed to care for an older person in the home safely. Several described situations where an older adult was discharged from the hospital without any preparation and in one instance, the husband could not even get his wife's wheelchair through the door.

6 **Reimbursement Systems** - The need for more information on who pays for what, when, and how much was evident in each of the groups. Much confusion still exists on the differences between Medicare and Medicaid and other reimbursement systems. The confusion often creates expectations of what will be provided, only to become a major disappointment and at times, a setback, when it doesn't bear out.

7 **Legal Issues** - Across the groups there were legal questions that needed answers ranging from basic questions related to the Living Will to more complex issues on financial and Power of Attorney issues.

8 **Future Planning** - More information was requested by the groups on issues like the A,B,C's of planning a funeral and how to avoid getting the estate tied up in court. Also included were issues related to role loss.

How

1 **Create a 1-800 System of Information** - Each of the groups talked about how scattered information on services and products seemed to be, adding to the frustration and stress of the caregiving day. A central source, like a 1-800 number came up in each group...a place where both family and professional caregivers could call and get the information they needed without spending hours on the phone tracking people, places, and products.

2 **Use the Media** - Several groups mentioned how each of them uses different sources to get information on a daily basis, such as the radio, the television, and/or the newspaper. Hence, they felt it would be a good way to publicize information on caregiving and community resources and to reach a larger audience.

3 **Place information in doctors' offices** - While many stated they did not always get information from their doctor, they did say that they would read what is available in the office. Since many are making frequent or regular doctors' visits, they saw this as a way to get information on a routine basis.

4 **Place caregivers on boards of organizations** - There was a strong direction from these groups to include actual caregivers on boards related to older adults and caregiving. This was viewed as a way to get "the real picture" to those making decisions on their behalf.

Direct Services

What

1 **Counseling and Advance Planners** - There were requests for the direct services of professionals such as care managers who could provide an overall evaluation of the older adult and help caregivers sort out exactly what services were needed and where to obtain them.

2 **Expansion of Respite** - The need for caregiver respite was evident in all groups. In some situations, the request was for extended hours in the evening and on weekends. For many, respite was not available in their community in any form, so the request was for any hours of respite.

3 **Expansion of Home Services** - Those involved with or receiving home services, such as personal hygiene care by a paraprofessional, stated that there was not enough time allotted for each client. The request was that the time and the frequency allowed for home visits be extended to account for the "reality" of the situation.

4 **Expansion of Transportation** - Transportation seemed to be an irritant for almost all participants as it was virtually unavailable to most. As they stated, you can have all of the resources and providers in the world, but if you can't get to them, they are useless. There was a strong cry for an increase in transportation venues.

5 **Financial Assistance with Medications** - While some participants wanted information on how to obtain low costs medications, others had gone that route with little to no results. The recommendation from them was a program, such as vouchers, to assist in actually paying for the medications.

6 **Emergency Services for Caregivers** - Again, there was concern voiced that there may be a time during an emergency when the primary caregiver could not provide the necessary care. These persons wanted to see communities provide a program where someone could step in temporarily until other arrangements could be made.

7 **Creation of a 1-800 Information System** - Once again, the 1-800 system came up as a way to address the many concerns voiced throughout the focus groups.

How

1 **Streamline Services** - The recommendation here was related to the frustration in having to go to many different agencies/groups for each individual service needed. Their wish was for a more consolidated approach in order to decrease fragmentation and the resulting frustration.

2 **More Supervision/Quality Control/Accountability for Services** - Most participants expressed their concern about what they viewed as loosely controlled/supervised services. If the provider did not deliver what was promised, they felt like they did not have anyone to turn to for recourse. The recommendation was to provide more oversight to those providing services in order to increase accountability and standards.

3 **Creation of Exchange Program** - Many of the participants recognized that it was not possible for "someone else" to provide all of the needed services. Their recommendation was for caregivers to exchange their talents and skills with each other. For instance, caregiver #1 might be able to provide transportation to the grocery store every week for caregiver #2 if caregiver #2 would provide a 2-hour respite for caregiver #1 every week.

Providers

What

1 **More training and sensitivity for ALL levels** - Repeated concern was expressed regarding service providers who were ill-prepared to care for older adults and their caregivers. The recommendation was to have more training for all levels of providers to provide knowledge about older adults and to address the attitudes toward older adults. The contention was that without adequate knowledge and sensitivity to this group, quality or compassionate care could not be delivered, only adding to the frustration and fatigue of their caregivers.

2 **Vouchers/Support for Family Caregivers** - Comments were made that caregivers often lost time at work or had to give up their jobs to provide care. Moreover, the services available by traditional reimbursement sources, such as Medicare, were not always the best services for the individual older adult. The recommendation was made that money be put into vouchers to be used by families to purchase the services they saw that would best fit their needs.

3 **More Support for Nursing Assistants/Home Care Aides** - Much discussion took place in every group regarding the demands on nursing assistants/ home care aides with very little reward [wages, benefits, respect, acknowledgment] and that, in fact, the lack of support may help to account for the large turnover in this industry. There was a strong consensus that, for the work they did, they deserved more recognition and reward.

How

1 **Increase pay/benefits/respect for nursing assistant/home care aids** - Over and over there was support that the wages for this group should be increased significantly along with a benefit package.

2 **More supervision/oversight of home care staff** - While it was strongly recommended that the support for home care staff should be increased, an equally strong message came through that there should be more oversight for these individuals. Having someone monitor their hours and the quality of their care was noted as something rarely witnessed but desperately needed.

3 **Decrease administrative costs of programs** - The concern here was that too much of available funds were spent on administration rather than the programs themselves.

4 **Screen potential home clients more efficiently** - Numerous times it was mentioned that home care agencies would accept clients without screening them properly. As a result, the home care staff felt like they would go into situations that they were inadequately informed about or prepared for. The recommendation was to gather more information about the situation before hiring someone for that job in order to avoid potential disagreements or points of tension.

5 **Provide incentives and recognition for nursing assistants/home care aids** - This recommendation is along the line of more support for nursing assistants. However, this area included more than an increase in wages or benefits. The recommendation was to look at ways to increase the self-worth and self-image of the nursing assistant such as “Nursing Assistant of the Year” award.

6 **Include nursing assistants/home care aids in care planning** - Since nursing assistants spend the majority of the time with the client, the recommendation was that they provide their input by being included in the care planning meetings at their agencies.

Training

What

1 **Course on Compassion for Health Care Providers** - Examples were provided throughout the focus groups of how health care providers could be insensitive or seemingly uncaring toward older adults. While it was actively debated whether compassion could be taught, it was strongly recommended that such a course be developed and offered to all levels of health care providers.

2 **Communication Skills** - The recommendation for this course was also meant for all providers to incorporate clarity, compassion, and respect into their daily communication. How each could better communicate with their older clients [including those with dementia] and their families, how health care providers could better communicate among their peers, and how professionals could improve their skills in communicating with other team members, like the paraprofessionals.

3 **Legal Issues** - Most participants felt like they did not have enough information regarding the legal issues encountered in caregiving and would like to have more courses offered in this area.

4 **Personal Care/Hygiene** - Many participants, including the nursing assistants, felt like they needed more class work and practice/clinical in this area. There was a special need for this in areas where the older adult had dementia and may resist personal hygiene.

5 **Normal Aging Issues** - The question insinuated by many participants was, "What constitutes normal aging?" Not having the answer left many in uncertain situations of knowing the correct action to take during caregiving. The request was more classes on normal aging changes and challenges.

6 **Ageist Issues** - Repeated concerns about the attitude and treatment of older adults by health care providers, particularly their physicians, led to this recommendation. Class work on examining our own values and biases about the older population was suggested as a way to make people more aware of their actions and the associated consequences to them, the older adult, and the caregiver.

7 **Alzheimer's and Other Like Dementias** - Much discussion took place on the special challenges for everyone involved in the care of someone with Alzheimer's Disease and other dementias. Requests were made to keep workshops, seminars, and classes offered in the community for all to participate.

8 **Complexities of Caregiving** - Each group of caregivers discussed the notion that "other groups" [i.e. other caregivers, legislators] did not quite understand the caregiving responsibilities, tasks, and toll of what they did. Although never directly stated per se, the inference was that they would like a forum to relay that information in order to come to a better understanding and perhaps change in perspective of each other.

9 **Community Resources** - Related to wanting written information and a 1-800 number to learn more about community resources was the suggestion that seminars be held to make people more aware of what is available to older adults and their caregivers.

How

1 **Extended Training for Nursing Assistants with Clinical Time** - Despite the number of hours nursing assistants spent in training, participants did not feel like it was enough. Even many of the nursing assistants in the focus groups felt ill-prepared for the care they were charged with and wanted more clinical hours or "hands on" before being assigned a client.

2 **More Advanced Seminars for Health Care Providers** - Many of the professionals in the focus groups requested more advanced seminars on gerontological issues including dementia care, falls, and medications.

Georgia Caregivers Resource Center

Strategic Plan

In partnership with the state aging network, the Georgia Caregiver Resource Center (GCRC) will provide leadership to establish a comprehensive array of programs and services for Georgia's increasing number of older adults and their caregivers.

To fully implement the work of the GCRC, four initiatives have been established. Short-term plans for the GCRC are described under each of the initiatives.

1. Research and Strategic Planning

Additional caregiver focus groups are planned to add to the data provided in this report. These groups will be held in various parts of the state, and will target ombudsmen and nursing assistants working in assisted living, among other groups.

On behalf of the aging network, the GCRC will also seek additional funding for caregiver programs and services, including funds for demonstration grants.

2. Education and Training

The findings and recommendations from the caregiver focus groups were utilized by the Division in selecting topics for caregiver education and training. With input from the Area Agency on Aging (AAA) network, a format of one-day education/training forums was selected. Three forums will be held in various parts of the state each year, and respite will be provided, enabling family caregivers to attend.

The GCRC works collaboratively with other organizations, such as the Rosalynn Carter Institute (RCI), in promoting RCI's programs and services for family and professional caregivers, and with the Georgia Gerontology Society's Annual Conference by coordinating workshop tracks and plenary sessions on caregiving issues. GCRC will also work with the newly formed Georgia Alliance for Staffing Solutions, which will be addressing the problem of long term care staffing on a number of fronts.

3. Program and Resource Development

The GCRC will be establishing an Advisory Committee to assist in carrying out its mission statement. A list of caregiver websites has been developed, which has been disseminated to the AAA network and will be more widely circulated in the future. Plans are underway to expand the Division's webpage to include a linkage to state and national caregiving resources.

4. Information Dissemination

The GCRC will identify groups of caregivers and their particular needs and interests, developing and/or obtaining targeted information, products, and services for these groups. Groups will include but not be limited to grandparents caring for grandchildren as well as caregivers of persons with chronic or degenerative diseases, such as Alzheimer's Disease.

Appendices
and
References

Caregiver Focus Group
Sample Questions

1.) Please describe your caregiving experiences.
2.) What has this experience meant to you?
3.) How is it that you came to be in this role as a caregiver to an older adult?
4.) Describe the aspects of the caregiving experience that have been the most surprising to you.
5.) Describe the aspects of the caregiving experience, if any, that have been the most satisfactory to you.
6.) What specifically made these aspects satisfactory to you?
7.) Describe the aspects of the caregiving experience, if any, that have been the most challenging or difficult for you.
8.) What specifically made these aspects challenging or difficult?
9.) What would assist to diminish or reduce the difficulty?
10.) Describe those things [products, services, people, education sources], if any, that have been the most useful to you in your caregiving experiences.
11.) How did you hear about these things?
12.) The most helpful way for you to learn about these things is what?
13.) What would you have done without these things?
14.) What other things might have been useful to you in implementing your role?
15.) If you had a crystal ball and you could have known that you would be involved in this caregiving experience years ago, what would you have done differently for yourself or those you are working with, if anything?
16.) What areas, if any, do you see related to caregiving that need to be addressed by health care providers?
17.) If you were in charge of caregiving for the state, what sort of programs would you put into place immediately? In five years? Down the road?

Appendix A: **Caregiver Focus Group Sample Questions**

Georgia Caregiver Resource Center,
A Part of the Georgia Division of Aging Services

Organization	Address & Phone	Web Address
Administration on Aging (AoA)	330 Independence Ave., SW Washington, DC 20201 Eldercare Locator: 1-800-677-1116 AoA Information Center: 202-619-7501 FAX: 202-260-1012	www.aoa.gov
Alzheimer's Association	919 North Michigan Avenue Suite 1100 Chicago, Illinois 60611-1676 Phone: 800-272-3900 312-335-8700 FAX: 312-335-1110	www.alz.org
Alzheimer's.com		www.alzheimers.com
American Association of Geriatric Psychiatry	7910 Woodmont Avenue Bethesda, MD 20814-3004 Phone: 301-654-7850 FAX: 301-654-4137	www.aagpgpa.org
American Association of Homes & Services for the Aging	2519 Connecticut Ave., NW Washington, DC 20008-1520 Phone: 202-783-2242 FAX: 202-783-2255	www.aahsa.org
American Association of Retired Persons (AARP)	601 E Street, NW Washington, DC 20049 1-800-424-3410	www.aarp.org
American Health Assistance Foundation	15825 Shady Grove Road Suite 140 Rockville, MD 20850 Phone: 301-948-3244 FAX: 301-258-9454 Toll Free: 1-800-437-2423	www.ahaf.org
American Health Care Association	1201 L Street, NW Washington, DC 20005 Phone: 202-842-4444 202-842-3860	www.ahca.org
Caregiver Survivor Resource		www.caregiver.com

Caregiving Internet Resources

Organization	Address & Phone	Web Address
Caregiver Zone		www.caregiverzone.com
Caregivers-AgeNet Eldercare Network	17 Applegate Ct. Madison, WI 53713 Phone: 608-256-0488	www.caregivers.com/index.asp
Caregiver-Today's Caregiver Magazine	6365 Taft Street, Suite 3006 Hollywood, FL 33024 Phone: 954-893-0550 FAX: 954-893-1779	www.caregiver.com
Caregiving Newsletter	Tad Publishing Company P.O. Box 224 Park Ridge, Illinois 60068 Phone: 847-823-0639	www.caregiving.com
Careguide, Inc.	210 N. University Dr, Suite 700 Coral Springs, FL 33071 Phone: 954-796-3727	www.careguide.com
CareScout	36 Washington Street, Suite 250 Wellesley Hills, MA 02481 Phone: 781-431-7033 781-431-7034	www.carescout.com
Carethere	635 Clyde Avenue Mountain View, CA 94043 Phone: 1-888-236-3961	www.carethere.com
Eldercare	Eldercare Online Richard O'Boyle 54 Amuxen Court Islip, NY 11751 **No phone numbers given	www.ec-online.net
ElderWeb	1305 Chadwick Drive Normal, Illinois 61761 Phone: 309-451-3319 FAX: 866-422-8995	www.elderweb.com
Empowering Caregivers		www.care-givers.com
Family Caregiver Alliance	690 Market Street, Suite 600 San Francisco, CA 94104 Phone: 415-434-3388 FAX: 415-434-3508	www.caregiver.org

Caregiving Internet Resources

Organization	Address & Phone	Web Address
Getcare	700 Murmansk St. Suite 4, Building 590 Oakland, CA 94607 Phone: 510-986-6700 FAX: 510-986-6707 Toll Free: 1-888-438-2273 (1-888-Get Care)	www.getcare.com
Go 60	335 Old Quarry Road, N Larkspur, CA 94939 Phone: 415-464-0511 FAX: 415-464-0105	www.go60.com/caregiving/htm
Health A to Z	Cedar Brook Corporation Park 3 Cedarbrook Drive Cranbury, NJ 08512 Phone: 609-409-8200 FAX: 609-409-8130	www.HealthAtoZ.com
Healthy Caregiver	The Healthy Caregiver Magazine 12 West Willow Grove Ave. PMB 190 Philadelphia, PA 19118-3952 Phone: 215-753-1780	www.healthycaregiver.com
Innovative Caregiving Resources	P.O. Box 17809 Salt Lake City, Utah 84117-0809 Phone: 801-272-9806 Toll-Free: 800-249-5600 FAX: 801-272-9805	www.videorespite.com
Medscout	4676 Commercial St., SE Suite 135 Salem, Oregon 97302-1902 Phone: 503-769-6565 FAX: 503-769-9676	www.medscout.com
National Family Caregivers Association (NFCA)	10400 Connecticut Avenue, #500 Kensington, MD 20895-3944 Phone: 1-800-896-3650 FAX: 301-942-2302	www.nfcacares.org

Caregiving Internet Resources

Organization	Address & Phone	Web Address
National Institute on Aging	Building 31, Room 5C27 31 Center Drive, MSC 2292 Bethesda, MD 20892 Phone: 301-496-1752	www.nih.gov/nia
Resources for Aging – The Caregiver Sourcebook	1265 Erie Avenue North Tonawanda, NY 14120 Phone: 716-693-3554 FAX: 716-693-5099 Order Desk: 1-888-243-4636 (1-888-Age Info)	www.ageinfo.com
Rosalynn Carter Institute for Human Development	Georgia Southwestern State University 800 Wheatley Street Americus, GA 31709 Phone: 229-928-1234 FAX: 229-928-2663	www.rci.gsw.edu
South Georgia Care-Net	109 W. Moore Street Valdosta, GA Phone: 229-293-6145	www.valdosta.edu/sowk/CareNet.html
ThirdAge	ThirdAge Media 585 Howard St., First Floor San Francisco, CA 94105-3001	www.thirdage.com/family/caregiving
Transitions, Inc.	1121 Douglas Avenue South Minneapolis, MN 55403 Phone: 612-998-5077	www.asktransitions.com

Area Agencies on Aging / Lead Agencies

Planning & Service Area		Area Agency on Aging Director Name of Agency Address and Phone Number
Atlanta Regional Commission		Cheryll Schramm, AAA Director Atlanta Regional Commission 40 Courtland Street, N.E. Atlanta, GA 30303 Tel: 404 / 463-3100 FAX: 404 / 463-3264 Aging Connection: 404 / 463-3333 Toll Free: 800-676-2433
Cherokee Clayton Cobb DeKalb Douglas	Fayette Fulton Gwinnett Henry Rockdale	
Central Savannah River		Jeanette Cummings, AAA Director Central Savannah River RDC 3023 Riverwatch Parkway, Suite A Augusta, GA 30907-2016 P.O. Box 2800 Augusta, GA 30914-2800 Tel: 706 / 210-2018 FAX: 706 / 210-2024 Toll Free: 1-888-922-4464
Burke Columbia Glascock Hancock Jefferson Jenkins Lincoln	McDuffie Richmond Screven Taliaferro Warren Washington Wilkes	
Coastal Georgia		Eleanor Helms, AAA Director Coastal Georgia RDC P.O. Box 1917 Brunswick, GA 31521-1917 Tel: 912 / 264-7363 Ext. 228 Information Link #: 1-800-580-6860 FAX: 912 / 262-2313 Physical Address: 127 F Street, 31520
Bryan Bulloch Camden Chatham Effingham	Glynn Liberty Long McIntosh	

Area Agencies on Aging / Lead Agencies

PLANNING & SERVICE AREA		AREA AGENCY ON AGING DIRECTOR NAME OF AGENCY ADDRESS AND PHONE NUMBER
Coosa Valley / Northwest Georgia		Debbie Studdard, AAA Director Area Agency on Aging of Northwest Georgia P.O. Box 1793 Rome, GA 30162-1793 Tel: 706 / 295-6485 FAX: 706 / 802-5508 Screening for Services: 1-800-759-2963 or 706 / 802-5506 Physical Address: 1 Jackson Hill Drive, 30161
Bartow Catoosa Chattooga Dade Fannin Floyd Gilmer Gordon	Haralson Murray Paulding Pickens Polk Walker Whitfield	
Georgia Mountains		Pat Viles Freeman, AAA Director Legacy Link, Inc. P.O. Box 2534 Gainesville, GA 30503-2534 Tel: 770 / 538-2650 FAX: 770 / 538-2660 Toll Free: 800 / 845-5465 Physical Address: 508 Oak St, Suite 1, 30501
Banks Dawson Forsyth Franklin Habersham Hall Hart	Lumpkin Rabun Stephens Towns Union White	
Heart of Georgia Altamaha		Gail Thompson, AAA Director Heart of Georgia Altamaha RDC P.O. Drawer 1260 Baxley, GA 31515 Tel: 912 / 367-3648 FAX: 912 / 367-3640 Toll Free: 888 / 367-9913 Physical Address: 505 West Parker Street, Appling County
Appling Bleckley Candler Dodge Emanuel Evans Jeff Davis Johnson Laurens	Montgomery Tattnall Telfair Toombs Treutlen Wayne Wheeler Wilcox	

Area Agencies on Aging / Lead Agencies

Planning & Service Area		**Area Agency on Aging Director Name of Agency Address and Phone Number**
Middle Georgia		Amy Tribble, AAA Director Middle Georgia RDC 175-C Emery Highway Macon, GA 31217 Tel: 478 / 751-6466 FAX: 478 / 751-6517 Toll Free: 888 / 548-1456
Baldwin Bibb Crawford Houston Jones Monroe	Peach Pulaski Putnam Twiggs Wilkinson	
Northeast Georgia		Peggy Jenkins, AAA Director Northeast Georgia RDC 305 Research Drive Athens, GA 30610-2795 Tel: 706 / 369-5650 FAX: 706 / 369-5792 Toll Free: 800 / 474-7540
Barrow Clarke Elbert Greene Jackson Jasper	Madison Morgan Newton Oconee Oglethorpe Walton	
Southeast Georgia / South Georgia		Southeast Georgia RDC 3395 Harris Road Waycross, GA 31503-8958 Tel: 912 / 285-6097 FAX: 912 / 285-6126 Toll Free: 1-888-732-4464
Atkinson Bacon Berrien Brantley Brooks Charlton Clinch Coffee Cook	Echols Ben Hill Irwin Lanier Lowndes Pierce Tift Turner Ware	

Area Agencies on Aging / Lead Agencies

PLANNING & SERVICE AREA		AREA AGENCY ON AGING DIRECTOR NAME OF AGENCY ADDRESS AND PHONE NUMBER
Southern Crescent **(Formerly Chattahoochee-Flint/McIntosh Trail)**		Bobby Buchanan, AAA Director Southern Crescent AAA P.O. Box 1600 Franklin, GA 30217-1600 Tel: 706 / 675-6721 (Atl. 770 / 854-6026) FAX: 706 / 675-0448 Toll Free: 1-866-854-5652 Physical Address: 13273 GA Hwy. 34 East
Butts Carroll Coweta Heard Lamar	Meriwether Pike Spalding Troup Upson	
Southwest Georgia		Kay Hind, AAA Director Southwest Georgia COA 308 Flint Avenue Albany GA 31701-2508 Tel: 229 / 432-1124 FAX: 229 / 483-0995 Toll Free: 800 / 282-6612
Baker Calhoun Colquitt Decatur Dougherty Early Grady	Lee Miller Mitchell Seminole Terrell Thomas Worth	
West Central Georgia **(Formerly Lower Chattahoochee/ Middle Flint)**		Jewel Fuller-Demars, AAA Director West Central Georgia AAA 1428 Second Avenue P.O. Box 1908 Columbus, GA 31902-1908 Tel: 706 / 256-2910 FAX: 706 / 256-2908 Toll Free: 1-800-249-7468
Chattahoochee Clay Crisp Dooley Harris Macon Marion Muscogee	Quitman Randolph Schley Stewart Sumter Talbot Taylor Webster	

References

1. AARP & National Alliance for Caregiving, (June, 1997). Family caregiving in the U.S. Findings from a National Survey.
2. AARP, (1983). A profile of older Americans.
3. AARP, (1999). A profile of older Americans. http://research.aarp.org/general/profile99.pdf
4. AARP, (2000). Across the states. Profile of Long Term Care Systems (4th ed.). Washington, D.C.: Public Policy Institute
5. AARP, (2000). Caregiving and long-term care. http://research.aarp.org/health/fs82_caregiving.html
6. Administration on Aging (1997). Grandparents as caregivers. http://www.aoa.gov/may97/Grandparents.html
7. Administration on Aging (2001). Family Caregiving – Fact Sheet – Older Americans Month. May, 2001 – The many faces of aging. http://www.aoa.dhhs.gov/may2001/factsheets/family-caregiving.html
8. Administration on Aging, (Fall, 2000). America's families care: A report on the needs of America's family caregivers http://www.aoa.dhhs.gov/carenetwork/report.html
9. Administration on Aging, (May, 1999). Family caregiver fact sheet. http://www.aoa.dhhs.gov/May99/caregiver.html
10. American Society on Aging. Profile of informal and family caregivers. http://www.careguide.com
11. Bowers, B., & Becker, M. (1992). Nurse's aides in nursing homes: The relationship between organization and quality. The Gerontologist, 32, 360-366.
12. Chapin, R., & Dobbs-Kepper, D., (2001). Aging in place in assisted living: Philosophy versus policy. The Gerontologist, 41, 43-50.
13. Desai, M. M., Lentzner, H. R., & Weeks, J. D. (2001). Unmet need for personal assistance with activities of daily living among older adults. The Gerontologist, 41, 82-88.
14. Doty, P., Jackson, M. E., & Crown, W. (1998). The impact of female caregivers' employment status on patterns of formal and informal eldercare. The Gerontologist, 38, 331-341.
15. Family Caregiver Alliance. Fact sheet: Selected caregiver statistics. http://www.caregiver.org/factsheets/caregiver_statsC.html
16. Formal Caregivers. http://www.duckandcats.com/caregiving.htm
17. Friedman, S. M., Duab, C., Cresci, K., & Keyser, R. (1999). A comparison of job satisfaction among nursing assistants in nursing homes and the program of all-inclusive care for the elderly. (PACE). The Gerontologist, 39, 434-439.
18. Health Insurance Association of America. Consumer information: Guide to long-term healthcare. http://www.hiaa.org/cons/guideltc.html
19. Hughes, S. L., Giobbie-Hurder, A., Weaver, F. M., Kubal, J. D., & Henderson, W. (1999). Relationship between caregiver burden and health-related quality of life. The Gerontologist, 39, 534-545.
20. Institute for Health and Aging (1996). Chronic Care in America: A 21 Century Challenge.
21. Krueger, R. A. (1994) Focus groups: A practical guide for applied research (2nd ed.) London: Sage Publications
22. McCallion, P., Toseland, R. W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with dementia. The Gerontologist, 39, 546-558.
23. MetLife Mature Market Institute, (1999). The MetLife juggling act study: Balancing caregiving with work and the costs involved. http://www.caregiving.org/content/reports/JugglingStudy.pdf
24. Montgomery, R. J. V., & Kosloski, K. D. Change, Continuity, and Diversity Among Caregivers

References

25. National Family Caregivers Association. (Oct., 2000). NFCA caregivers survey July, 2000. http://www.nfcacares.org/PRSurvey2000.html

26. Navaie-Waliser, M., Feldman, P.H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2001).
Long-term care provision: Striking a balance between informal and formal caregiving. http://www.academyhealth.org/2001/abstracts/longtermcare/waliser.htm

27. Older Women's League. (1996). Faces of caregiving. 1996 Mother's Day Report.

28. Older Women's League. (2001). Faces of caregiving. 2001 Mother's Day Report.

29. Patient Assessment Tool – Lawton's instrumental activities of daily living (IADL) scale. http://www.acsu.buffalo.edu/~drstall/iadl.html

30. Pedlar, D. J., & Biegel, D. E. (1999). The impact of family caregiver attitudes on the use of community services for dementia care. Journal of Applied Gerontology, 18, 201-221.

31. Scott, C. B. (1990) The meaning of adult day care within the context of the caregiving relationship: Perceptions of older adults and their female caregivers. Unpublished Dissertation.

32. Scott, C. B. (1993) Circular victimization in the caregiving relationship. Western Journal of Nursing Research, 15 (2), 230-245.

33. Scott, C. B. (1994) Compassion fatigue: Caring for older relatives. Southeast Conference on Aging, GA.

34. Scott, C. B. (1995) On the road to aging. Keynote Address to the Northeast Conference on Aging, GA.

35. Scott, C. B. (2000) Caregiving in Georgia: A view from the frontline. Plenary Session at Georgia Gerontology Society, GA.

36. Tennstedt, S. L., Crawford, S. L., & McKinlay, J. B. (1993). Is family care on the decline? A longitudinal investigation of the substitution of formal long-term care services for informal care.
The Milbank Quarterly, 71, 601-624.

37. Tennstedt, S. L. (1999) Family caregiving in an aging society. Presented at the US Administration on Aging Symposium: Longevity in the New American Century, Baltimore, MD, March 29, 1999.

38. U.S. Bureau of the Census, 1990 Census Population. Profile of general demographic characteristics for Georgia: 1990.
http://www.census.gov/Press-Release/www/2001/tables/dp_ga_1990.pdf

39. U.S. Census Bureau, Census 2000. Profile of general demographic characteristics: 2000. Georgia. http://www.census.gov/prod/cen2000/dp1/2kh13.pdf

40. U.S. Census Bureau, Census 2000. Profile of general demographic characteristics: 2000. United States. http://www.census.gov/prod/cen2000/dp1/2khoo.pdf

41. U.S. Census Bureau, Statistical abstracts of the United States: 2000 (Health and Nutrition). http://www.census.gov/prod/2001pubs/statab/sec03.pdf

42. U.S. Census Bureau, Statistical abstracts of the United States: 2000 (Income, Expenditures, and Wealth). http://www.census.gov/prod/2001pubs/statab/sec14.pdf

43. U.S. Census Bureau, Statistical abstracts of the United States: 2000 (Vital Statistics). http://www.census.gov/prod/2001pubs/statab/sec02.pdf

44. Webster's Encyclopedic Dictionary of the English Language. (1991) New York: Lexicon Publications, Inc.

45. Your Care (2000). A synopsis: 2000 family caregiver survey results. http://www.caregiving.com/yourcare/html/survey2000.htm