Rutgers Center for State Health Policy

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Consultation for Johnson & Johnson on the J&J Caregivers Program: A Report on State Context

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Introduction

This report defines important aspects of the national and state context for the "Practice in Action" component of the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program. Currently in its first year of implementation, "Practice in Action" provides one-year grants to local communities to initiate caregiving support activities or to expand, refine, or replicate existing efforts. In its second year of operations, the program is moving from an initial focus on New Jersey to implementation in five states. In order to assist with site selection, technical assistance, evaluation, and sustainability, this report describes: 1) the national context for caregiving, including key policy trends and important characteristics of the target population that cannot be defined at the state level, and 2) key aspects of the caregiving environment in the program states, including socioeconomic and demographic characteristics of each state overall, size and demographic characteristics of the disabled population, key existing public and private supports for caregivers, and the supply of informal and formal caregivers.

Background

In February of 2001, Johnson & Johnson (J&J) awarded a grant to the Rosalynn Carter Institute for Human Development (RCI) at Georgia Southwestern State University for a program to support caregivers. The Caregivers Program has two components - "Practice in Action" (initially called the "Field Study") and "Science to Practice". The "Science to Practice" component - which is outside the scope of this consultation -- is designed to advance the science of caregiving and inform its practice. The "Science to Practice" project has two main activities: 1) Convene four expert advisory panels on caregiving that will initiate a series of caregiving books. 2) Produce a synthesis of the evidence on caregiving best practices and the conditions under which these practices succeed. This report is designed to assist with the "Practice in Action" component of the Caregivers Program. Through "Practice in Action," local community agencies are provided with one-year grants of $25,000 to initiate a caregiving collaborative for creating a new effort, to refine or extend an existing effort, or to replicate an existing model. The effects of the program, as described by leaders, are intended to be both "direct" and "indirect." Direct effects are those on the caregivers and care recipients who are supported by the project. Indirect effects include promoting new thinking and activity in the

caregiving field by encouraging local communities to design new initiatives; setting a standard for program design through the competitive grant selection process; and generating new models of caregiver support for replication.

For its first year, "Practice in Action" awarded grants to four sites in New Jersey. A committee made up of experts in the caregiving field selected the sites with assistance from RCI. RCI is currently providing the sites with ongoing technical assistance, including self-evaluation. For the second year of the grant, the Request for Proposal (RFP) has been reissued in New Jersey, in three additional states-California, Georgia, and Florida - and in the commonwealth of Puerto Rico. One site will be funded per state. Site selection is to take place at the end of May.

In order to enhance site selection, technical assistance, evaluation, and program sustainability, J&J has requested that CSHP identify and describe important aspects of the national and state contexts for caregiving.

Methods

This report is based on two research activities: 1) Identify important aspects of the national and state contexts for caregiving. 2) Describe these aspects of the national and state context. Important aspects of the national and state contexts for caregiving were identified in three ways: first, through the existing expertise of the CSHP staff on caregiving issues; second, through review of recent policy developments in caregiving and expert policy briefs; and third, through interviews with representatives of J&J (n=1), RCI (n=3), the site selection committee (n=3), and the New Jersey grantee sites (n=4). As relevant, respondents were asked to think about the ways in which context had affected, was expected to affect, or should affect: dissemination of the RFP, site selection, proposal development, project implementation and performance, the technical assistance process, project evaluation, and future sustainability.

Once important aspects of the national and state context were identified, descriptions of these key aspects were generated in three ways: 1) through use of existing datasets, 2) through review of existing information about the policy and political context available on the internet and in policy briefs, and 3) through interviews with an expert on caregiving in each state.

Results

Key Aspects of the Caregiving Context

Through the methods described above, the following aspects of the national caregiving context were defined as important: aspects of the target population for which current state-level data are not available (age, health insurance status, and poverty status as it relates to level of disability); and trends in policy and the labor force.

The aspects of the state caregiving context defined as important were: socioeconomic and demographic characteristics of the state (age, racial/ethnic composition, income levels, and percent rural), characteristics of the population with disabilities (percent elderly, percent living alone, and percent in poverty), existing supports, and supply of informal and formal caregivers.

National Context

In any given year, tens of millions of Americans receive help with activities of daily living. These individuals receive assistance from family and friends and from professional caregivers. Society faces the challenge of making sure that sufficient care is provided to these individuals, that the care provided is of high quality, and that the caregivers receive the supports that they need for this important but difficult work.

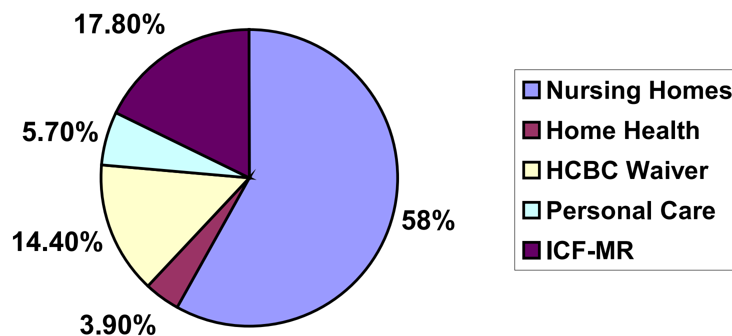
The most important aspect of the current context for caregiving is the dominance of "informal" care, i.e. the care provided by family and friends. Families and friends are still the backbone of caregiving. Currently, families and friends provide most of the care to the chronically ill and/or disabled (Feder et al, 2000). In 1997, 20 million people received informal care from approximately 26 million caregivers whose work was estimated at $196 billion (Arno, Levine & Memmott, 1999). While informal caregiving honors bonds of affection, substitutes for more costly care, and can help to preempt institutionalization; it also entails enormous emotional and logistical challenges for caregivers. Additionally, it can thrust them into an endeavor for which they may lack key skills and knowledge. Therefore, the public and private sectors have attempted to increase supports for these informal caregivers. The National Family Caregiver Support Program (NFCSP) is the most important national development in this arena. The NFCSP began in 2001 as a result of the Older Americans Act Amendments of 2000 (US Administration on Aging, 2002). The program disseminated $113 million to states to improve referral to programs and access to services; to provide supportive services to caregivers such as counseling, training, and respite care; and to provide limited supplemental services (US Administration on Aging, 2002).

While families and friends provide the bulk of caregiving, the large and important professional caregiving workforce faces key challenges as well. Koller et al (2002) categorize workforce issues into four interrelated areas. They are supply/demand, worker competency, quality of care, and quality of work-life for the workers (Koller, et al 2002). Three points stand out in their analysis. First, the workforce supply is inadequate as compared to demand and suffers from high turnover rates, with nursing home staff turnover rates ranging from 45%-105%. Workforce turnover is also an issue for home health care. In 1994, there was a 19% turnover rate that grew to 28% by 2000 (Stone, 2001). Second, professional caregiving is difficult and challenging work. Insufficient training and insufficient support jeopardize the quality of care, as well as diminishing the quality of work life for

caregivers. Feder et al (2000) note that the quality of professional care-both in the institutional and home and community-based sectors-is of paramount concern, and is not resolved simply through higher payments. Related to these issues is the low remuneration of front-line caregivers. In 2000, the median hourly wage of a personal or home care aide was $7.50, with home health care service workers particularly poorly paid at $6.49/hour (US Department of Labor, 2002). Low remuneration fails to reflect the importance of the work done by these caregivers, and limits the labor force supply, the quality of the workforce, and the incentive to provide high-quality care.

The importance of actively supporting informal caregivers and shaping the formal caregiving workforce is increasing with the move to keep the chronically ill and disabled out of institutions and in the community. The long-term care system has historically been biased towards institutionalization. For example, Medicaid - the most important payer of long-term care expenditures at 38% of the total in 1996 - now spends 58% of its expenditures in nursing homes and 18% on intermediate care facilities for the mentally retarded, with only 14.4% going to home and community-based waivers, 5.7% to personal care, and 3.9% to home health aides [See Figure 1]. However, there has been a trend nationally and in many states to "balance" long-term care toward more home and community-based care. This is reflected in a variety of developments. In the financing arena, states have for a number of years been increasing their use of Medicaid home and community-based options, and other financing sources - such as the Older Americans Act. On the legal front, the Supreme Court, in its 1999 Olmstead Decision ruled that it is a violation of the Americans with Disabilities Act for people to be institutionalized if it is medically unjustifiable.

Figure 1. Medicaid Expenditures for LTC Services - 1997
Total Expenditure: $56.1 Billion



This decision has generated a new flurry of activity in the financing arena. In particular, in 2001 the Centers for Medicare and Medicaid Services (CMS) awarded 52 grants totaling just under $60 million to 37 states and Guam to roll out programs to increase home and community-based care,

including some supports for informal caregivers. This year CMS is awarding another $50 million. In all, 48 states and three territories are now working with Real Choice Systems Change grants ($76 million), Community Integrated Personal Assistance Support Services ($13 million) and Nursing Facility Transition ($20 million) grants to improve communities' capacity to provide home and community-based care.

The movement towards increasing home and community-based care will bring more dollars to the support of informal caregivers, but also more challenges. It is not only the amount of support available for informal caregivers that will be crucial, but the type. There is a great deal still to be learned about the best way to support informal caregivers, particularly given the diversity of their needs and preferences. In recent years, experimentation in caregiver support programs has focused on promoting flexibility and diversity of supports, increasing consumer direction of care, and allowing for payments to family and friend caregivers. There is more experimentation to be done in these areas, as well as others.

On the professional front, the move towards home and community-based care also creates new challenges. In 2000, there were 414,000 home care workers as compared to 2.1 million aides working in skilled facilities. The number of home and community-based care workers is expected to increase by 36% or more by 2010 (US Department of Labor, 2002), an enormous influx of workers into this field. However, issues of labor supply and remuneration remain unresolved, and quality assurance in the home and community-based sectors is particularly undeveloped.

Characteristics of the target population that were of interest to our respondents and only available nationally are captured in Figures 2 and 3 and in Tables N1-N3. Three points stand out. First, an important point given RCI's current interest in supporting caregivers of children is that the percentage of children with a disability jumps dramatically for the age group 6-14. Second, among adults, disabilities are more prevalent among the elderly. However, there are far higher rates of uninsurance for disabled people who are between 25 and 64 years of age. Third, having severe disabilities increases the chances of being impoverished, creating a particularly needy population.

In sum, as long-term care is "rebalanced" towards the home and community-based sectors, there is an increased need-and increased opportunity-to address the emotional and logistical challenges of informal caregivers (the major source of caregiving), as well as the challenges of creating and supporting a professional workforce supplying high-quality care. There is a great deal still to be learned about how to meet these challenges, especially given the diversity of care recipient and caregiver needs. Some key elements of diversity include care recipient age, insurance status, level of disability, and poverty status; particularly of interest are the high levels of disability in older children, the high levels of uninsurance among non-elderly disabled adults, and the high levels of poverty among the severely disabled.

Figure 2. Disability Prevalence by Age: 1997 (US Census Bureau, Americans with Disabilities, Feb 2001)

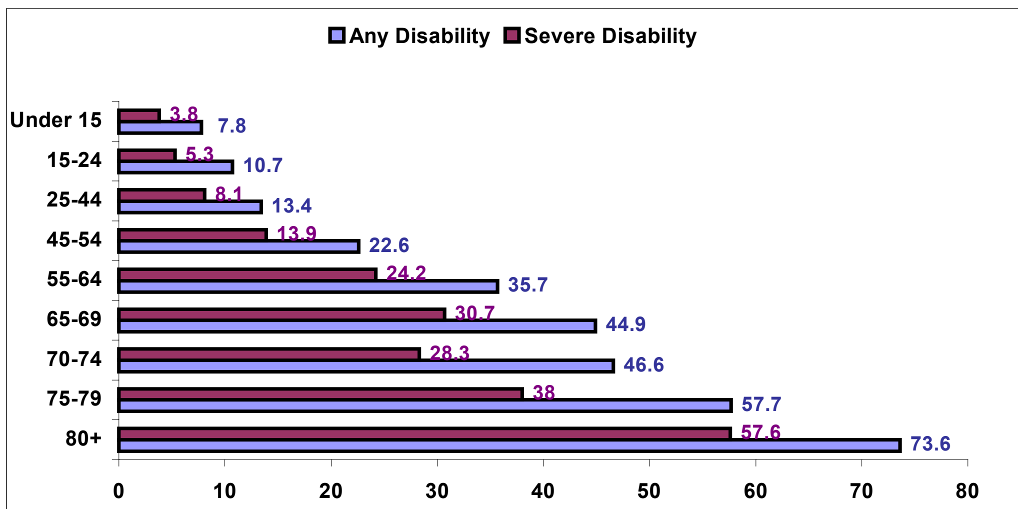


Figure 3. 1997 Poverty Status by Disability Status

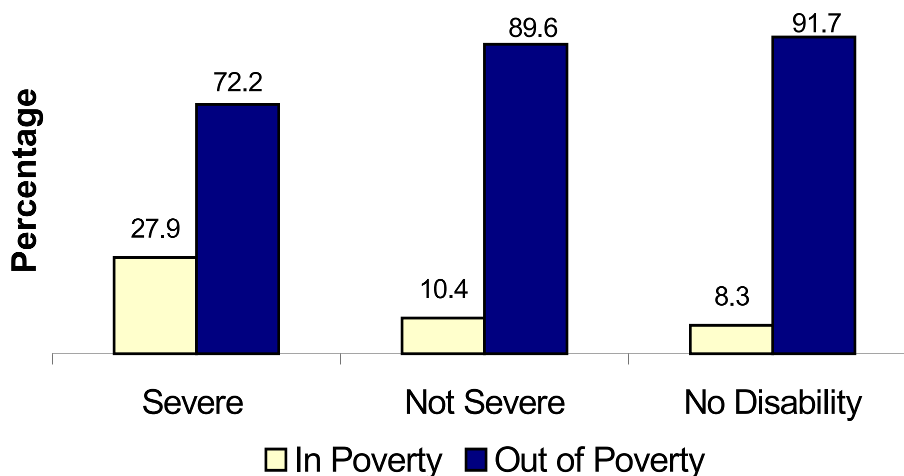


Table N-1: Prevalence of Disability, Children Under 15 Years of Age – Nationwide

Age	Percentage
Age under 3	2.0
3-5	3.4
6-14	11.2

* US Census Bureau, 1996 Survey of Income and Program Participation: August-November 1997

Table N-2: Health Insurance Coverage Status of Individuals 25 – 64 Years Old | by Disability Severity

Type of Disability	Private/Military Insurance	Medicaid	No Insurance
Severe	47.5	32.5	17.2
Not Severe	79.7	4.8	16.3
No Disability	82.3	2.7	14.4

* US Census Bureau, 1996 Survey of Income and Program Participation: August-November 1997

Table N-3: Health Insurance Coverage Status of Individuals 65 Years and Older by Disability Severity

Type of Disability	Private/Military Insurance	Medicaid	No Insurance
Severe	67.0	18.0	0.6
Not Severe	78.1	8.0	0.4
No Disability	79.7	5.0	1.2

* US Census Bureau, 1996 Survey of Income and Program Participation: August-November 1997

State Context

Socioeconomic and Demographic Characteristics of the States

We examined four socioeconomic and demographic features of the grant recipient states: the size of the elderly population, racial/ethnic composition of the population overall and the elderly specifically, income levels, and size of the rural population. Florida's most notable demographic

feature-and one that is certainly relevant to caregiving-is the size of its elderly population; in relative terms, it is the largest in the nation. (See Table S-1). In contrast, California, Puerto Rico, and Georgia all have small elderly populations, although in all three cases these are growing faster than the national average. New Jersey has a moderately sized, slower-growing elderly population.

Table S-1: Total Population and Population 65 and over, 2000

State/ Commonwealth	Total Population	Percent of the Population 65 and Over, 2000	State Rank on Proportion of the Population that is Elderly, 2000	Percent Growth in Absolute Number of Elderly since 1990
Florida	15,982,378	17.6%	1	18.5%
New Jersey	8,414,350	13.2%	18	7.9%
Puerto Rico	3,808,610	11.2%	42	24.7%
California	33,871,648	10.6%	46	14.7%
Georgia	8,186,453	9.6%	49	20.0%
National Average	281,421,906	12.4%	--	12.0%

The states vary in their racial/ethnic composition (See Table S-2). All (except Puerto Rico, for which no data were available) have a majority White population (ranging from 59.5% in Claifornia to 78.0% in Florida), with New Jersey showing diversity across the board; California having large Hispanic, Asian, and "other" populations; Florida having sizable African-American and Hispanic populations; and Georgia having a large African-American community. While no data were available on Puerto Rico's racial/ethnic make-up, it could be argued that the classifications used in the continental United States do not capture how Puerto Ricans subjectively see themselves. The commonwealth clearly has unique linguistic needs. While the elderly population in each state does not perfectly mirror the racial and ethnic composition of the general population-it tends to have a larger number of Whites-the elderly nonetheless include significant numbers of minorities in all states (See Figures 4-7).

Table S-2: State Population by Race and Hispanic Origin, 2000

Race								
State	**Black/ African American Alone**	**Amer. Indian/ Alaska Native Alone**	**Native Hawaiian/ Pacific Islander Alone**	**Asian Alone**	**Two or More Races**	**Other Race**	**White Alone**	**Hispanic Origin**
California	6.7%	1.0%	0.3%	10.9%	4.7%	16.8%	59.5%	32.4%
Florida	14.6%	0.3%	0.1%	1.7%	2.4%	3.0%	78.0%	16.8%
Georgia	28.7%	0.3%	0.1%	2.1%	1.4%	2.4%	65.1%	5.3%
New Jersey	13.6	0.2	---	5.7%	2.5%	5.4%	72.6%	13.3
Puerto Rico	Not available.							
National Average	12.3%	0.9%	0.1%	3.6%	2.4%	5.5%	69.1%	12.5 %

Figure 4. California Elder Population by Percentage of Race

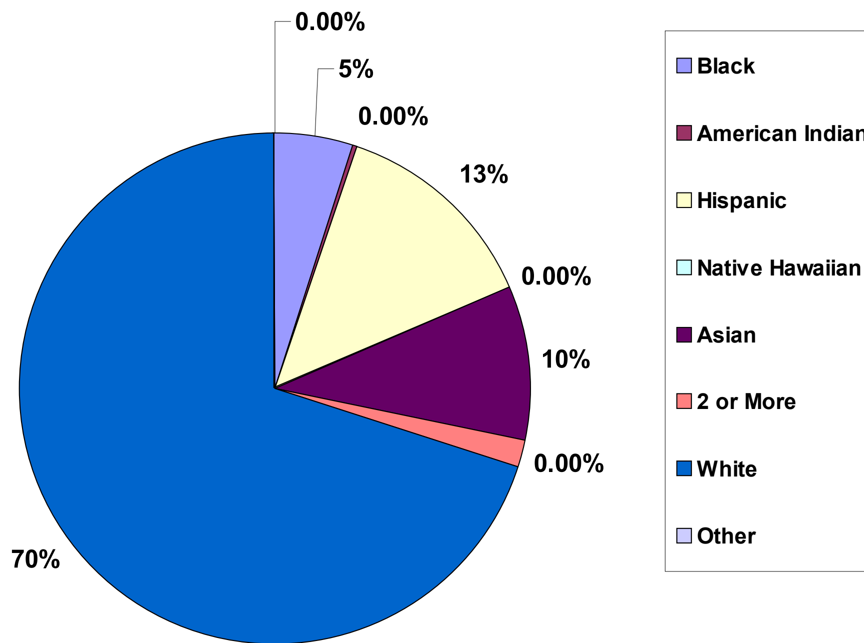


Figure 5. Georgia Elder Population by Race

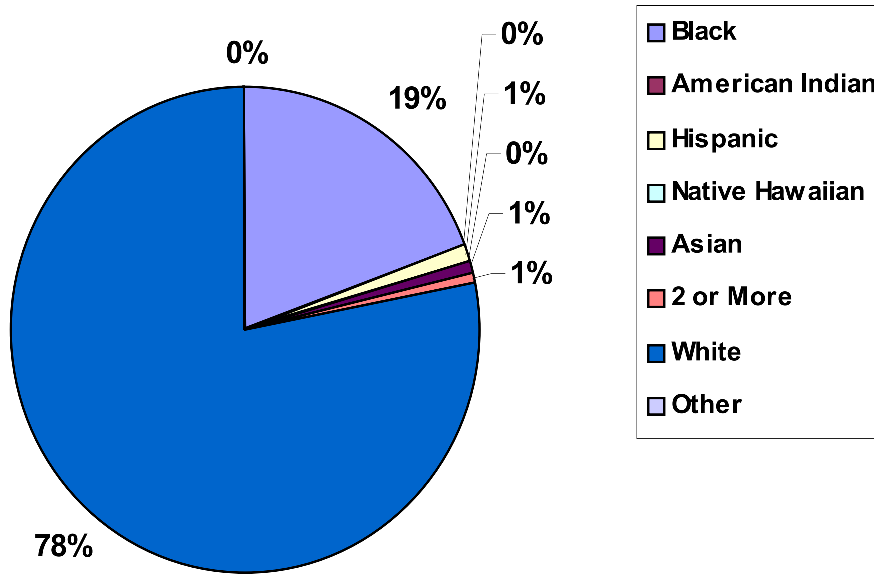


Figure 6. Florida Elder Population by Race

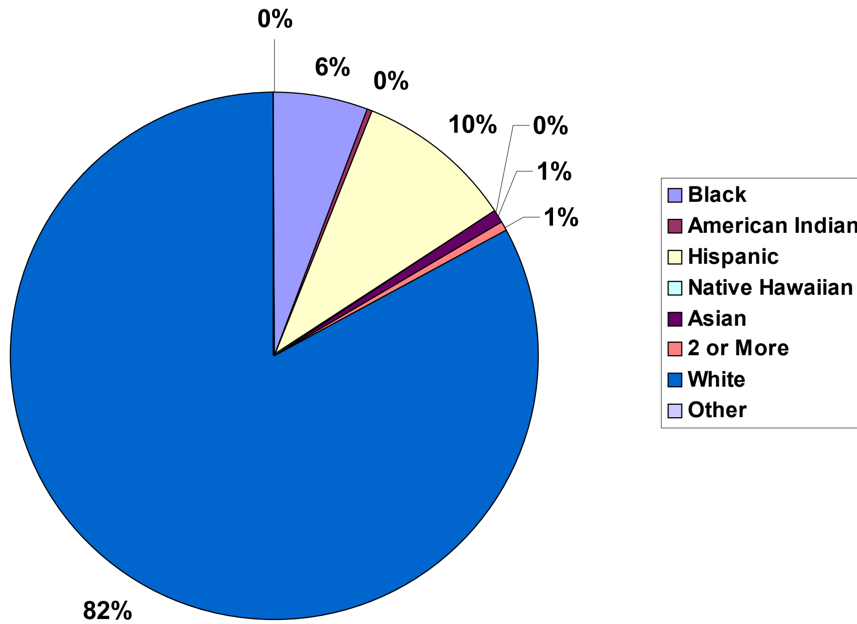
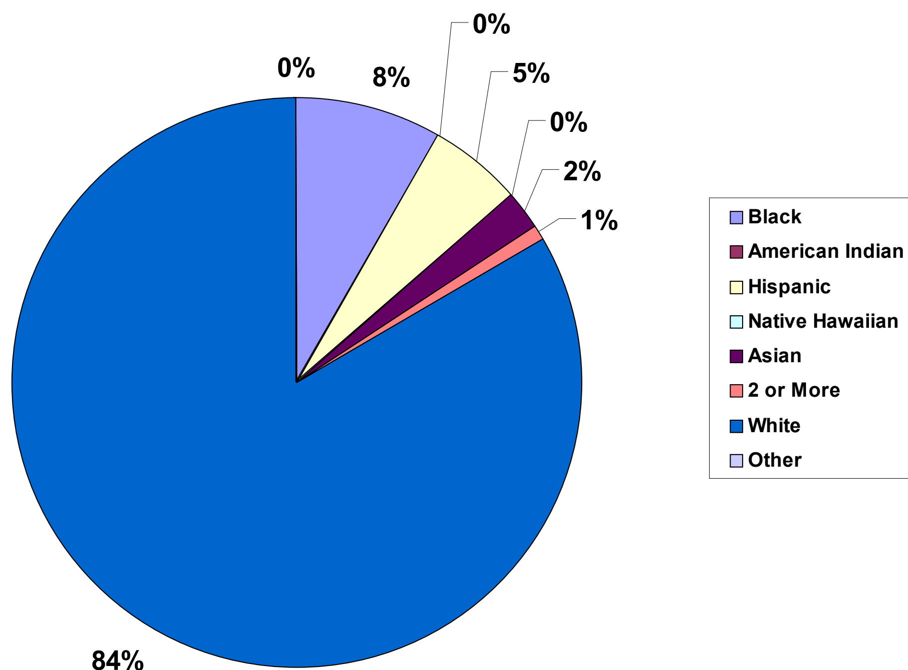


Figure 7. New Jersey Elder Population by Race



Our state interviewees provided more detailed information about racial/ethnic diversity in their states and its relationship to caregiving needs. The Florida interviewee argued that the state's large Hispanic population is not receiving services in proportion to its numbers, mostly due to a lack of awareness of programs, and a lack of involvement in their development. Outreach to this community is currently a priority. She also notes that Florida has a large Haitian community with its own particular needs. In California, the interviewee raised the question of cultural appropriateness of services, and noted that there are differences between first and second-generation immigrants. The New Jersey respondent cited the state's great diversity and the need to go beyond outreach to African-American and Hispanic minorities, for example to the Eastern European and various Asian subgroups in the state. Like the Florida respondent, she commented that minorities were generally less likely to use available services. Georgia said that their metropolitan areas are diverse and they are generally successful in reaching to the populations there.

Looking at the states by income (see Table S-3), New Jersey and Puerto Rico present a dramatic contrast, with New Jersey having a high median income and relatively small - albeit still sizable - number of people living below the poverty line, and Puerto Rico having a low median income and a large impoverished population. California, Georgia, and Florida all have higher than average median incomes, but about the same number of people living below poverty as the national average.

Nonetheless, the California respondent argues that socioeconomic diversity is as important as racial/ethnic diversity in her state.

Table S-3: Population by Income, Fiscal Year 2001

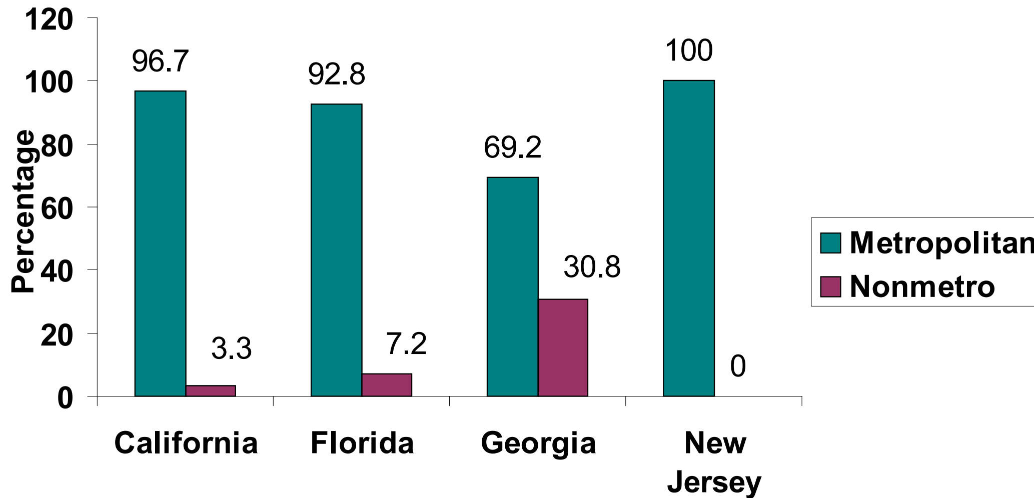
State	Median Household Income: Family of four	Percent of Population Below Poverty
California	$55,209	16.0%
Florida	$52,5814	14.4%
Georgia	$55,989	14.7%
New Jersey	$70,983	9.3%
Puerto Rico*	$9,988	58.9%
National Average	$37,005	13.3%

Finally, as shown through two different indicators (Table S-4 and Figure 8), Georgia-unlike the other states (with the probable exception of Puerto Rico, for which no data are available)-has a large rural population overall. Georgia's rural population is reported to be different than its metropolitan counterpart, because they have come "to take care of their own" and are therefore resistant to the state's interventions. The state attempts to overcome this challenge through the use of mobile day care unit. Another way Georgia is attempting to address the rural caregivers' needs is to expand their consumer-directed care model allowing consumers to pay family members and friends to provide care using state funds. Although Georgia's rural population is large, the other states may have pockets of rural populations with significant needs, as was noted to be the case for California.

Table S-4: Percent Urban and Rural by State: 1990

State	Percent Urban	Percent Rural
California	92.6	7.4
Florida	84.8	15.2
Georgia	63.2	36.8
New Jersey	89.4	10.6
Puerto Rico	Not available?	
National Average		

*1990 Census Data - http://www.census.gov/population/censusdata/urpop0090.txt



[1]A metropolitan area is a county containing one or more central cities with a combined population of at least 50,000, and any other counties that are economically and socially linked to the central city/county.

Population with Disabilities

Using self-care limitations as an indicator of disability, the four states show similar numbers of adult disabled - close to 4%, which is slightly higher than the national average (see Table S-5). (State-level data are not available on the size of the non-adult population with disabilities, and no data on Puerto Rico are available.) The states vary in the percentage of this population that is elderly, from about one-third in California and Georgia to close to half in Florida. Across the board, the elderly disabled population is much more likely to be living alone than the non-elderly. In Georgia, the disabled population is particularly likely to be poor, with one-quarter living below the poverty line. While in the other three states, the non-elderly disabled are somewhat more likely to be poor than the elderly disabled, in Georgia the opposite is true.

Table S-5: 1990 Civilian Non-Institutional Persons with Self-Care Limitations

State	% of Total Adult Population with SCL	% of SCL Population that's Elderly	% of SCL Population Living Alone	% of Non-elderly SCL Population Living Alone	% of Elderly SCL Population Living Alone	% of SCL Population Living Below Poverty	% of Non-Elderly SCL Population Living Below Poverty	% of Elderly SCL Population Living Below Poverty
California	3.80	32.20	15.74	8.6	30.7	17.18	19.6	12.2
Florida	3.71	46.92	19.47	10.6	29.5	20.36	22.6	17.9
Georgia	3.99	34.89	17.35	9.9	31.2	26.68	25.4	29.0
New Jersey	3.72	38.52%	19.06	8.5	31.0	15.12	15.8	14.0
National	3.42	39.56	19.34	10.5	32.8	19.24	23.9	20.1

* Disability 1990 Census Table 2: U.S. http://www.census.gov/hhes/www/disable/census/tables/tab2st.html

Existing Supports

Tables S-6 - S-16 and Figure 9 provide detail on what each state is currently doing to support care recipients and caregivers, including involvement in federal programs. The tables also address issues that are "in the works," as reflected in task forces, resolutions, and similar initiatives.

Table S-6: Florida—Key State Programs and Initiatives

Program	Description	Eligibility/Requirements
Alzheimer's Disease Initiative (ADI)[1]	Focuses on a defined population of dementia caregivers and operates in 68 ADI respite sites and four model day care centers. (memory disorders clinic, a brain bank, and a state advisory council)	♦ Age: 18+ ♦ Income Requirements: None ♦ Families and caregivers caring for persons with Alzheimer's or dementia
Alzheimer Caregiver Support Online[2]	Provides on-line caregiver education and support classes and links to Alzheimer's caregiver resources in local areas. Involves the University of Florida.	♦ Age: All ♦ Income Requirements: None

Program	Description	Eligibility/Requirements
Elder Ready Communities[3]	Assists communities in identifying areas of improvement to become Elder Ready by using their own community standards. Provides a survey instrument, which can be utilized by local community volunteers and creating action plans from those surveys. (will also create a dimension for frail and rural communities)	♦ Age: 65+ ♦ Income Requirements: None ♦ Will begin with St. Augustine and Miami and then expand to other areas
Respite for Elders Living in Everyday Families (RELIEF)[1]	Provides in-home assistance for a homebound older adult, who is not a member of the family unit. Draws primarily on volunteers: community and Vista, Americorp, and Senior Companions	♦ Age: 60+ ♦ Income Requirements: Low income clients only ♦ Caregivers of older adults
Developmental Disability Waiver Program[4]	Provides in-home assistance to participants. Largest waiver program in Florida. $800 million in funds for present fiscal year. Twenty-eight thousand people are served by the program and can also qualify to receive Medicaid benefits.	♦ Age: 21 and under (had to develop disability prior to the age of 18 ♦ Income Requirements: Make up to $1,500 a month maximum ♦ Meet Florida State Definition of developmental disability – which is different from the national definition.
Long-Term Care Community Diversion Pilot Project[5]	Tests the effectiveness of a long-term care program that uses managed care and outcome-based reimbursement principles. Offers less costly home and community-based services to frail elders who are at-risk of needing nursing home care by requiring the managed care organization to integrate the delivery of acute and long-term care services for these individuals.	♦ Age: 65+ ♦ Require help with 5 or more ADLs ♦ Require help with 4 ADLs & require supervision or administration of medication ♦ Require help with 2 ADLs ♦ Have a diagnosis of Alzheimer's disease or another type of dementia and require some help with three or more ADLs ♦ Have a diagnosis of a degenerative or chronic condition requiring daily nursing services

Program	Description	Eligibility/Requirements
Family Support Project[4]	Creates training programs for home health aides. Partnership between the Administration on Developmental Disabilities and Nova Southeastern University. Will create credit-bearing courses. Begin with a focus on developmental disabilities. Then create other training courses.	♦ Class action suit is Florida created the requirement for developing training programs for home health aides specifically dealing with developmental disabilities
Home Care for the Elderly[1]	Provides small subsidies to caregivers to allow them to continue to provide in-home care. (average: $106/month) Special subsidies are for needed services or supplies.	♦ Age: 60+ ♦ Income Requirements: Low-income clients only ♦ Caregivers of frail older adults

Taskforces and Resolutions (Florida)

Task Force on the Availability and Affordability of Long-Term Care[6]	The Task Force's goal is to improve the affordability and availability of long-term care in Florida. It solicits recommendations that address statutory changes and are linked to one or more of the specific areas addressed in House Bill 1993. The four areas include: Home and community-based alternatives, Financing long-term care, Nursing home quality, and Lawsuits and long-term care

[1] Survey of Fifteen States' Caregiver Support Programs
[2] http://alzonline.net/
[3] http://www7.myflorida.com/doea/healthfamily/news/elderissues/doeanews072400b.html
[4] State Interview-Florida
[5] http://www.oppaga.state.fl.us/profiles/5033/
[6] http://www.fpeca.usf.edu/Task%20Force/Public%20Recommendations/requestforrecommendation.htm

Table S-7: California—Key State Programs and Initiatives

Program	Description	Eligibility/Requirements
Caregiver Resource Center[1]	Addresses the needs of families caring for cognitively impaired adults. Provides single points of entry for caregivers in the state.	♦ Age: 18+ ♦ Income Requirement: None ♦ Families and caregivers of persons with adult-onset cognitive impairments
Long Term Care Partnership[2]	Provides long-term care insurance at reduced rates for state residents.	♦ Purchase policies through selected insurers ♦ California residents
Regional Centers[1]	Provides fixed point of contacts for persons with developmental disabilities and their families	♦ Age: All ages ♦ Income Requirement: None ♦ Children and adults with developmental disabilities and their families
Academic Centers[3]	Provide Diagnostic evaluations and research in this field. Approximately 9 to 11 throughout the state affiliated with Stanford and the UC system. Also provide follow-up and are a good referral source for other existing programs	♦ Centers not totally funded by the state.
In Home Support Service[3]	Provides personal assistance and is administered through the Department of Social Services (funded primarily through Federal waivers)	♦ Income: low-income eligible
Independent Living Centers[3]	Provides home modifications, training for sensory impairments, advocacy, and lead charge (in area of consumer directed services). Run by the Department of Rehabilitation	♦ For persons with disabilities
Alzheimer's Day Care Resource Centers[1,4]	Attempts to prevent premature or inappropriate institutionalization; provide training; increase public awareness; and provide respite and support for caregivers – Part of 1984 legislation	♦ Age: All ages ♦ Income Requirement: None ♦ Individuals with Alzheimer's or related diseases and their families.

Taskforces, Resolutions, and Initiatives (California)

Assembly Bill 1347	Establishes staff training and education requirements for skilled nursing facil and intermediate care facilities that advertise or promote special care, specia programming or special environments for people with Alzheimer's or related dementia. (However there is no money attached to this bill)
Governor's Aging with Dignity Initiative[5,6]	Includes the development and administration of a $14,250,000 local assistar grants program (over a two-year period) for implementation and expansion o community-based adult care alternatives to nursing homes. The award of 28 totaling almost $14.3 million to public and private organizations that will provi innovative long-term care alternatives to seniors and functionally impaired ac (Development grant not ongoing)
California Dept of Aging – the Older Americans Act & the Older Californians Act[7]	Home- and community-based long-term care programs for seniors and adult functional impairments within the State of California. Services include: in-hor services, congregate and home-delivered meals, a system of multipurpose s service programs, community service employment, advocacy and protection health insurance counseling, case management, Alzheimer's day care and a day health care programs

[1] Survey of Fifteen States' Caregiver Support Programs
[2] http://www.dhs.ca.gov/cpltc/html/consumer.htm
[3] State Interview – California
[4] There are other day care programs besides the Alzheimer's Day Care Resource Centers that are also licens The Brookdale Foundation has provided small grants to begin caregiver support programs. These are small programs often informal and at the county level.
[5] The 28 selected proposals fell within three specific target categories: Partnership Building and Planning; Innovation Coordination and Collaborative Partnerships; and Access for Special Populations. These proposals focused on prevention; serving diverse populations; honoring choice, dignity, independence and quality of life; improving access and user information services; using technologies; supporting caregivers; and developing service and planning coordination, among others.
[6] http://www.aging.state.ca.us/html/programs/ltc_innovation_grants/index.htm
[7] http://www.aging.state.ca.us/html/aboutcda/bios.htm

Table S-8: Georgia—Key State Programs and Initiatives

Program	Description	Eligibility/Requirements
Community Care Services Program (CCSP)[1]	Provides support and direction to the Aging Network to ensure that Georgians eligible for nursing home care have the option of remaining in their homes or communities. Provides Adult Day Health, Alternative Living Services, Emergency Response System, Home Delivered Meals, Home Delivered Services, Personal Support Services, and Respite care	♦ Medicaid eligible or potentially eligible ♦ Eligible for a nursing home level of care determined by the CCSP care coordinator ♦ Functionally impaired ♦ Have unmet need for care ♦ Able to have health and safety needs adequately met in the community within the cost limits established for the Community Care Services Program
"Gateway"[2]	Provides information on and access to home and community-based services.	♦ Elder Georgians, their families, and caregivers
HICARE[2]	Assists with Medicare, Medicaid, supplemental insurance (Medigap), long-term care insurance and other health insurance issues. Also provides a toll-free information line. (Volunteer based – more than 200 trained)	♦ Senior and disabled population
Long-Term Care Ombudsman Program[3]	Works to improve the quality of life of residents in nursing homes and personal care homes by acting as their independent advocate. Ombudsman staff and volunteers informally investigate and resolve complaints on behalf of residents.	♦ Served: 227,990 persons.
Non-Medicaid HCBS[3]	A variety of HCBS and caregiver supports funded with a mix of federal and state funds.	♦ Senior and disabled population

Program	Description	Eligibility/Requirements
Tools for Life: Governor's Council on Developmental Disabilities[4]	Creates systems change for people with developmental disabilities and their families to: Increase independence, inclusion, integration, and productivity for people with disabilities through such activities as public policy research, analysis, and reform, project demonstrations, and education and training	♦ Serving people with developmental disabilities and their families ♦ Funded by Federal grants through the Developmental Disabilities Act
ELAP[3]	Provides legal representation, information and education in civil legal matters. Served 37,995 seniors in fiscal year 2001.	♦ Age: 60+

Taskforces and Resolutions (Georgia)

House Resolution 275	Urges the Dept of Community Health to provide incentives and, where appropriate, wage pass-throughs to nursing homes for the purposes of increasing staff levels above minimum requirements. The resolution also urges the department to provide incentives to help facilities recruit, train and retain direct-care staff

[1] http://www2.state.ga.us/ga.comcare/elgble.html
[2] http://www2.state.ga.us/Departments/DHR/SFY2001JusttheFacts-final.PDF
[3] Survey of Fifteen States' Caregiver Support Programs
[4] http://www.ga-ddcouncil.org/

Table S-9: New Jersey—Key State Programs and Initiatives

Program	Description	Eligibility/Requirements
Statewide Respite Care Program[1,2]	Provides respite for elderly and functionally impaired persons to relieve their unpaid caregivers. RN evaluates caregiver need at home. (Care Management, Support Groups, and Respite Care). Provides counseling and education for up to 6 visits.	♦ Age: 18+ ♦ Income Requirement: Low and moderate ♦ Families and caregivers of individuals with chronic physical or mental disabilities
Enhanced Community Options (ECO) – Caregiver Assistance Program (CAP) & Assisted Living/Alternate Family Care (AL/AC) are within ECO[3]	Offers several care alternatives (through Medicaid Waivers) to individuals who would otherwise qualify for placement in a nursing facility. (In-home component is CAP and residential component is AL/AC)	♦ Individuals must be 65 or over, **or** 21 through age 64 and determined disabled by the Social Security Administration or Medicaid's Disability Review Section, **and** Assessed by the Department of Health and Senior Services Long Term Care Field Office as in need of a nursing facility level of care, **and** meet financial eligibility
Adult Day Services for Persons w/ Alzheimer's Disease or Related Disorder[1]	Provides structured, individualized programming in a safe environment designed to maximize client's functional abilities.	♦ Age: 60+ ♦ Income Requirement: Low and moderate income only ♦ Individuals with Alzheimer's disease or dementia and their families
Jersey Assistance for Community Caregiving (JACC)[4]	Offers several care alternatives (through Medicaid Waivers) to individuals who would otherwise qualify for placement in a nursing facility.	♦ Age: 60+ ♦ Individuals who are financially ineligible for Medicaid or Medicaid waiver services ♦ JACC services are limited to $600.00 per month; $7,200.00 annually per person

Program	Description	Eligibility/Requirements
New Jersey Adult Day Services Association[5]	Meets the needs of adults with functional impairments through an individual plan of care	♦ Age: 18+ ♦ Adults with functional impairments ♦ Fee based services
NJ EASE (New Jersey Easy Access, Single Entry)[2,6]	Endeavors to create a consumer-focused statewide system that aids access to services and promotes informed personal choice, dignity and the use of high quality and cost-effective services. Has a toll-free information number for information on services throughout the entire state. Also received funding from the Administration on Aging to develop caregiver components and policies that help coordinate the different existing programs.	♦ Age: 60+ ♦ Seniors and their family members ♦ Twenty Counties are online: Atlantic, Bergen, Burlington, Camden, Cape May, Cumberland, Essex, Gloucester, Hudson, Mercer, Middlesex, Monmouth, Morris, Ocean, Passaic, Salem, Somerset, Sussex, Union, and Warren ♦ Income Requirement: None
Area Agencies on Aging[2]	Meets the needs of local caregivers. Uses the 3.9 million received from the Older Americans Act (Family Caregiver Support Program).	♦ One in each county – 21 total ♦ Anyone caring for someone age 60+ or someone 60+ caring for a younger relative 18 and under is eligible
Caring for You, Caring for Me[2]	Provides a 10 hour support course developed by the Rosalyn Carter Institute. The Department of Health and Senior Services funds local agencies that provide the course	♦ Course for caregivers
Community Choice Initiative[7]	Increases awareness of the choices in long term care. Helps nursing facility residents and hospital patients explore various community-based alternatives by providing information about in-home services, housing alternatives, and community programs.	♦ Senior citizens, people with disabilities, and their families

Program	Description	Eligibility/Requirements
Division of Developmental Disabilities[8]	Serves more than 30,000 people with developmental disabilities. Provides case management, residential services, and various family support services that help recipient and family.	♦ Eligibility: People with developmental disabilities, which are evident before age 22 and are lifelong, hindering a person's ability to live without assistance

[1] Survey of Fifteen States' Caregiver Support Programs
[2] State Interview – New Jersey
[3] http://www.state.nj.us/health/seniors.htm
[4] http://www.state.nj.us/health/consumer/jacc.htm
[5] http://www2.umdnj.edu/~coyne/njadsweb.htm
[6] http://www.state.nj.us/health/senior/sanjease.htm
[7] http://www.state.nj.us/health/consumer/choice/
[8] http://www.state.nj.us/humanservices/ddd/index.html

Table S-10: Puerto Rico—Key State Programs and Initiatives

Program	Description	Eligibility/Requirements
Apoyo Quidadores[1]	Provides some respite relief. Program began two years ago with federal funding through the Older Americans Act. It was the first formal caregiver support program on the island. However, the program is small and understaffed (8 workers in the two offices). Not able to meet all of the demand for services. Had to pull the publicity because of the overwhelming amount of calls recieved	♦ Two regional offices serving entire island
Administration for Families and Children	Serves more than 20,600 seniors at 16 adult day care and 13 other sites providing companionship, nutritional support, recreation, and other services. (886 RSVP volunteers)	♦ Age: 65+
Governor's Office for the Aged Senior Companion Program	Serves 140 frail seniors through a Senior Companions program. (all but 10 diagnosed with Alzheimer's Disease) 15 new Senior Companions will soon begin serving 30 patients in the west coast island of Aguadilla. (Volunteer based)	♦ Age: 65+ ♦ Individuals with Alzheimer's disease or dementia

[1] State Interview – Puerto Rico – Interview also identified a large unmet need for more respite nurses, funding for home modifications, and education and training (for illness awareness, how to care for patients, and access to care)

Table S-11: 2001 Systems Change Grant Recipients [1]

Type of Grant	State	Preliminary Award
Nursing Facility Transitions, Independent Living Partnership	Georgia	$400,000
Nursing Facility Transitions, State Programs	Georgia	$627,211
Real Choice Systems Change	Florida	$2,000,000
Real Choice Systems Change	New Jersey	$2,000,000

[1] http://www.hcfa.gov/medicaid/systemschange/default.htm

Table S-12: 2002 Systems Change Grant Recipients[1]

Type of Grant	State	Organization	Preliminary Award
Nursing Facility Transitions, Independent Living Partnership	New Jersey	Resources for Independent Living Inc.	$400,000
Nursing Facility Transitions, Independent Living Partnership	California	Community Resources for Independence	$337,500
Nursing Facility Transitions, State Programs	California	Dept. of Health Services, Medi-Cal operations Division	$600,000
Nursing Facility Transitions, State Programs	New Jersey	Dept. of Health and Senior Services	$600,000
Real Choice Systems Change	California	Dept. of Social Services	$1,385,000
Real Choice Systems Change	Georgia	Georgia Dept. of Human Resources	$1,385,000

[1]http://www.hcfa.gov/medicaid/systemschange/default.htm

Table S-13: Section 811 Program Grants Awarded by State[1]:

State	Amount
California	$12,654,300
Florida	$5,361,100
Georgia	$1,726,500
New Jersey	$4,681,000

[1] http://www.hud.gov/news/release.cfm?content=pr01-111.cfm

Table S-14: Assisted Living Conversion Program[1]

State	Amount	Purpose
Florida	$2,539,290	Convert 42 units into assisted living to meet the special physical needs of very low income persons with disabilities and the frail elderly who have limitations in three or more activities of daily living. Supportive Services will be provided to maintain the residents at the highest level of function.
Georgia	$268,668	Convert 15 apartment living units on the second floor into 13 assisted living units, community and office space, storage, and a dining/kitchen area.

[1] http://www.hud.gov/content/releases/assistedliving.pdf

Table S-15: National Family Caregiver Support Program FY 2002 Funding Allocations for States[1]

State	Allocation
Florida	$10,010,315
California	$12,565,808
Georgia	$2,640,289
New Jersey	$3,945,892
Puerto Rico	$1,399,720
National Total	$127,908,000

[1] http://www.aoa.gov/pressroom/Pr2002/NFCSP-funding-02.html#chart

Table S-16: Estimated Number of Informal Caregivers and Caregiving Hours by State, 1997[1,2]

State	Number of Caregivers Capita	Caregiving Hours per Capita
California	.09	83
Florida	.09	86
Georgia	.09	81
New Jersey	.09	88
Puerto Rico	Not available	

1 These averages were calculated using the whole numbers provided by the 1997 Alheimer's Association Study and divided by the states' population (provided in Table S-1).
2 1997 Alzheimer's Association Study - http://alz.org/media/news/1999/chart.htm (http://www.alz.org/media/news/current/020102statereport.htm)

State Programs and Initiatives

Overall, Puerto Rico stands out from the other states in the paucity of existing state supports for care recipients and caregivers. California is particularly known as a frontrunner in long-term care and caregiver support.

In each state, respondents identified ongoing needs that are not met by their current supports. In Florida, an advisory group has identified a need for more training of the workforce, and more

empowerment and education of consumers, including consumer-directed care. In California, our respondent saw a need for caregiver support services for middle-income individuals and others that fall outside of current program eligibility, and for programs that meet the psychosocial needs of caregivers in general. In New Jersey, the respondent stressed the importance of meeting the needs of racial/ethnic minorities.

Through focus groups, Georgia's caregivers identified the following needs: more training and better access to information and referral; and more direct services such as respite, in-home, and transportation. In addition, they also asked for financial assistance with medications and the availability of emergency services for caregivers.

Because Puerto Rico's programs are still new and small, our respondent noted that many types of caregiver supports and networks are needed. She particularly specified the need for qualified professionals to provide respite care, and the need for home modification. In general, she noted that service locations and transportation gaps create barriers to accessing those services that do exist. Finally, as in Florida, education and training were seen as important needs - in this case, for caregivers, families, and care recipients.

In addition to the activities of the public sector, the private sector supports caregiving activity as well, for example, in Georgia the Red Cross Caregiving Program trains people to develop skills and knowledge to provide care. Most notably, the Robert Wood Johnson Foundation's Faith in Action volunteers work in communities across the country to care for their neighbors who face disability or chronic conditions by providing simple assistance. The intention is to allow them to maintain their independence for as long as possible. This national movement of interfaith volunteers includes local Faith in Action programs that bring together religious congregations, community organizations, hospices, clinics and hospitals. Locals are active in all 50 states, Puerto Rico, and the US Virgin Islands, including 67 in California, 38 in Florida, 52 in Georgia, 21 in New Jersey, and 3 in Puerto Rico. (http://www.fiavolunteers.org/get_involved/index.cfm)

Supply of Formal and Informal Caregivers

Table S-17 shows remarkable consistency in the caregivers per capita and caregiving hours per capita for the program states. In contrast, Tables S-18 and S-19 show wide variation in the supply of front-line professional caregivers. For both home health aides and institutionally-based aides, Puerto Rico has the smallest per capita workforce by far. New Jersey has a very high per capita supply of home health aides and pays them more than do other states, although it should be noted that the state's cost of living is also high. It should also be noted that, despite this relatively good supply of home health aides, New Jersey's public programs confront shortages in certain locations (generally more rural) and certain times (generally economic upturns).

Table S-17: Home Health Aide Supply by State[1]

State	Supply	Per Capita Supply	Mean Hourly	Mean Annual
California	33,210	0.000980	$9.56	$19,880
Florida	23,550	0.001473	$8.54	$17,760
Georgia	6,420	0.000784	$7.68	$15,980
New Jersey	21,870	0.002599	$9.16	$19,060
Puerto Rico	920	0.0002416	$6.44	$13,400
National	561,120	0.000402	$8.71	$18,110

[1] http://stats.bls.gov/oes/2000/oes_ca.htm

Table S-18: Nursing Aide, Orderly, and Attendant Supply by State[1]

State	Supply	Per Capita Supply	Mean Hourly	Mean Annual
California	91,620	0.00270	$9.54	$19,840
Florida	65,510	0.00410	$8.73	$18,150
Georgia	31,270	0.00382	$7.82	$16,260
New Jersey	37,370	0.00444	$10.85	$22,570
Puerto Rico	2,390	0.00063	$6.44	$13,400
National	1,273,460	.0045	$9.18	$19,100

[1] http://stats.bls.gov/oes/2000/oes_ca.htm National Population 2000: 281,421,906

Future Directions

A key concern for the J&J program is the sustainability and replicability of grantee achievements. One approach to optimizing that would be through forging effective partnerships. In Florida, our respondent would like to see more programs collaborate on education and training with higher educational institutions, vocational institutes, or even schools. She would also like to see the recipient of the J&J/RCI grant partner with state agencies if possible. In Puerto Rico, the respondent saw great potential for partnerships with schools, churches, and other volunteer organizations. In New Jersey and California, perhaps because activity levels there are high, respondents stressed the potential for partnering with existing networks. Georgia's respondent suggests partnering with Area Agencies on Aging, congregations, the AARP and RCI.

Respondents also noted the need to get the most "bang for the buck" with small, one-time grants. One suggests that such grants should be focused on having an effect in a specific community, suggesting as a model the Brookdale grants. Another suggests leveraging grants by requiring clients to pay a cost-share. Another suggests the importance of giving grants to existing organizations, with extensive grassroots networks or other infrastructure to maintain the program after the first year.

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