



North Carolina Department of Health and Human Services

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Michael F. Easley, Governor

Dempsey Benton, Secretary

March 20, 2008

The Honorable Vernon Malone, Co-Chair
North Carolina Study Commission on Aging
North Carolina General Assembly
Room 314, Legislative Office Building
Raleigh, NC 27603

Dear Senator Malone:

Session Law 2007-39 (House Bill 424), "Study Respite Care," required the department to study the availability and delivery of respite care and present its findings and recommendations, including any proposed statutory changes and new licensure categories, to the Study Commission on Aging on or before March 1, 2008. On February 29, 2008, I informed you that the report was being finalized and would be submitted to the Commission before its March 20, 2008 meeting. It is my pleasure to submit the required report at this time.

Please direct all questions concerning this report to Tara Larson, Acting Deputy Director for Clinical Policy and Programs in the Division of Medical Assistance at (919) 855-4260.

Sincerely,


Dempsey Benton

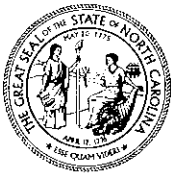
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Enclosure

cc: Dan Stewart
Jackie Sheppard
William W. Lawrence, Jr., M.D.
Dennis Streets
Robert Fitzgerald
Michael Lancaster, M.D.
Leza Wainwright
Lynn Muchmore

Jim Slate
Rob Kindsvatter
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Michael F. Easley, Governor

Dempsey Benton, Secretary

March 20, 2008

The Honorable Jean Farmer-Butterfield, Co-Chair
North Carolina Study Commission on Aging
North Carolina General Assembly
Room 611, Legislative Office Building
Raleigh, NC 27603

Dear Representative Farmer-Butterfield:

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Sincerely,

A handwritten signature in cursive script that reads "Dan Stewart for".

Dempsey Benton

DB:tl

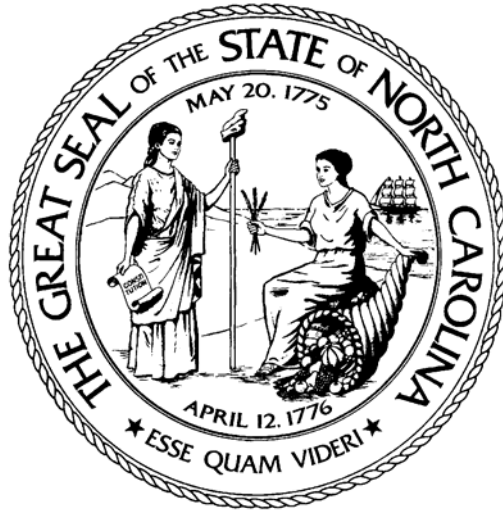
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**Study Respite Care
Session Law 2007-39**

**Report to the 2007 General Assembly
Study Commission on Aging**



**State of North Carolina
Department of Health and Human Services
Division of Medical Assistance**

March 20, 2008



**Study of Respite Care
General Assembly of NC Session Law 2007-39
(House Bill 424)**

**Prepared For: The North Carolina Study Commission on Aging
March 1, 2008**

Report and Recommendations

I. INTRODUCTION

On May 2, 2007, Session Law 2007-39 was enacted. This bill directs the Department of Health and Human Services (DHHS) to study Respite Care and recommend ways to improve North Carolina's current respite care delivery system. The Division of Health Service Regulation (DHSR, formerly Division of Facility Services), the Division of Medical Assistance (DMA) and the Division of Aging and Adult Services (DAAS) were given the responsibility to complete the work delineated in this bill.

A DHHS study group was formed to include community and other stakeholders with a core group of leadership representing the staff of DAAS, DMA, and DHSR. **(See Attachment A: Study Group Participants and Their Organizations)**

II. Session Law 2007-39 required the following

SECTION 1(a). The Department of Health and Human Services, Division of Facility Services, Division of Medical Assistance, and the Division of Aging and Adult Services, shall study the availability and delivery of respite care which provides temporary relief for family members and others who care for individuals with disabilities, chronic or terminal illnesses, dementia, or the elderly. The study shall examine the following:

- (1) The need and availability of respite care in North Carolina.
- (2) The delivery and licensing of respite care in other states and possible models for North Carolina.
- (3) The application process for a grant under the Lifespan Respite Care Act of 2006, 42 U.S.C.
- (4) The need for separate statutory language pertaining to respite care.
- (5) The need, proposed structure, and development timeline for a separate licensure category for respite care.
- (6) The development of a Medicaid Waiver covering a proposed new licensure category for respite care.

SECTION 1(b). In response to the study authorized in this section, the Department of Health and Human Services shall present findings and recommendations, including any proposed statutory changes and new licensure categories, to the Study Commission on Aging on or before March 1, 2008.

SECTION 2. This act is effective when it becomes law.

III. DEFINITION - RESPITE

The General Assembly defines a Respite Care Program under 143B-181.10 (a) as a service that is established to provide needed relief to caregivers of impaired adults who cannot be left alone because of a mental or physical problems; (b) limited to those unpaid primary caregivers who are caring for people years 60 years of age or older or their spouses or those unpaid primary caregivers 60 years of age or older who are caring for persons 18 years of age or older, who require constant supervision and who cannot be left alone either because of memory impairment, physical immobility or other problems that renders them unsafe alone.¹ **(For other state respite definitions, see Attachment B - NC Respite Regulations)**

Respite programs provide temporary relief for caregivers, enabling them to meet personal needs and supporting their efforts to provide the majority of care for their family member.² Respite programs primarily aim to serve the caregiver rather than the care recipient as often occurs in most services.

IV. NEED AND AVAILABILITY OF RESPITE CARE IN NORTH CAROLINA

It is a challenge to determine the exact need for respite services in North Carolina because the focus of service provision has traditionally been on the care recipient rather than the caregiver. Additionally, many caregivers receive relief from caregiving duties, but do not identify the service as respite and therefore, when surveyed about respite services they may use, the caregivers indicate that they do not use any. The explanation as to why caregivers do not identify the relief they receive from caregiving duties as respite is complex and uncertain. Reasons may include limited exposure to the word (respite) and its meaning as well as the multiple definitions of respite care that currently exist. These multiple definitions and levels of care are reflected in federal and state policies and funding sources. Additionally, there are a wide variety professionals and paraprofessionals involved with respite services.

Still, it is possible when looking at service data to identify the importance of respite. When reviewing the most recent report on the Special Assistance In-home Program (July 2007), of the 1,039 persons who received services through the Special Assistance In-Home program (FY '05-'06), 80% had a primary caregiver; 48% had a secondary caregiver; and 50% of the primary caregivers lived with the person receiving services. These caregivers were informal, unpaid caregivers and included relatives, friends, and neighbors.

The data available on waiting lists of the Division of Aging and Adult Services for services that may provide respite also illustrate the need for respite in North Carolina. The following table outlines the numbers of persons on waiting lists for services that may provide a form of respite as of July 2007 in North Carolina:

¹ NC General Statute

² Group Respite Policy and Procedures, July 1998p.1, III definition of service

Type of Respite Service	Number of Persons on Waiting List
Home Delivered Meals	3,649
In-Home Personal Care	3,343
Home Management	1,981
Adult Day Services	151
In-Home Respite	530
Family Caregiver Support Program	45*
Project C.A.R.E.	113**
Total	9,812

* This figure is based on data from 7/1/07-3/13/08

** This figure is the average over a year's time. Only Winston-Salem and Asheville sites maintain a waiting list. Charlotte-Mecklenburg Department of Social Services does not.

This figure of 9,812 North Carolinians waiting for services that may provide respite only includes persons who have inquired about services and does not include caregivers who may be in need of respite, and have not attempted to access these services. Further evidence of the importance of respite is evident in the experience of DAAS with Project C.A.R.E. (The Alzheimer's demonstration). DAAS has found through a performance-based survey that about 92% of client families report that Project C.A.R.E. services allowed them to provide care at home longer. Data on Project C.A.R.E. is especially important because the program assists people with Alzheimer's disease or other dementia. North Carolina currently has over 150,000 older adults with Alzheimer's disease. By 2030, this number is projected to rise to over 294,000. Over 70 percent of people with Alzheimer's disease are cared for at home by unpaid family and friends. As the number of people with Alzheimer's increases, so will the number of caregivers, thereby driving up the demand for caregiver support, including respite.

The possible economic impact of not providing adequate respite services is illustrated in data compiled by Peter S. Arno (see Attachment E). There were approximately one million caregivers in North Carolina providing an estimated total of \$10.7 billion dollars worth of services to care recipients in 2006. These findings appear to indicate that investing in respite care is important not only for the state's workforce and commerce, but for the preservation of state dollars associated with health and human services. If caregivers did not provide care to family and friends, many more care recipients might be institutionalized at the state's expense and the health of caregivers will worsen. For example, spousal caregivers of persons with Alzheimer's disease have a 63 percent greater risk of dying than non-caregiving persons of the same age and gender.

The paradigm shift to include caregivers' needs in service provision for the care recipient and to expand available respite services as part of the long-term care continuum has begun in North Carolina as evidenced by the 2001 Long-Term Care Plan by the North Carolina Institute of Medicine (IOM) Task Force on Long-Term Care to DHHS. One of the IOM priority recommendations under "Availability and Need for Long-Term Care Services", states: "The Department's long-term care policies and program activities should be designed to strengthen the capacity of families to perform caregiving functions."³ Another priority recommendation under "Financing Long-Term Care", states:

³ 2001 Institute of Medicine, LTC Plan p.49

“The Department should explore ways to invest in family caregiving so that it can be sustained as the primary resource for long-term care, reducing the risk for needing formal, publicly-financed services.”⁴ Further evidence of this paradigm shift in service provision is illustrated in the North Carolina Aging Services Plan 2007-2011 which includes as one of its 40 objectives, the development and incorporation of a caregiver assessment as part of family-centered care planning, and the expansion of caregiver support services.

The need for respite services in North Carolina is also emphasized within the vision and mission of DHHS’ Long-Term Services and Supports Cabinet (LTS Cabinet). The LTS Cabinet was formed by the IOM’s 2001 Long-Term Care Plan and was intended to include all DHHS Division Directors that affect long-term care policy.

- ***Vision Statement for the North Carolina LTS Cabinet***
People of all ages and their families live in inclusive, responsive communities where they have choices and control over their long-term services and supports.
- ***Mission Statement for the LTS Cabinet***
To create a statewide, integrated, person and family-centered system for those who need long-term services and supports so that they can live and participate more fully in communities of their choice.

Additionally, the DAAS’ North Carolina Performance Outcome Measures Project (POMP) points to the need for respite care services in North Carolina and the need for additional respite care services for caregivers already receiving services to reduce incidents of institutionalization for care recipients. In 2002, a survey was conducted of a representative sample of caregivers who received Home and Community Care Block Grant (HCCBG) services and caregivers receiving Family Caregiver Support Program (FCSP) services. In 2003, almost three-quarters of these same caregivers who were surveyed in 2002 were surveyed again. Caregivers in 2002 who indicated that they needed more respite and/or adult care services than they were currently receiving were significantly more likely to have placed the person they were caring for in a facility by 2003. Those that were receiving any type of in-home aide service (in-home respite, personal care, or homemaker) in 2002 were significantly less likely to have placed the person they were caring for in a facility by 2003.

Availability

Below is an inventory of respite availability by DHHS Divisions. Although other sources of respite funding may be available, those identified below are the primary sources of respite funding and programs within DHHS.

Division of Aging and Adult Services

HCCBG awards a combination of federal Older Americans Act funds and state appropriations to counties through Area Agencies on Aging (AAA) to serve adults at risk of institutionalization aged sixty (60) and over who require services to remain in

⁴ 2001 Institute of Medicine, LTC Plan p.96

the community. Through local planning, counties choose from eighteen services to meet identified needs to assist older adults avoid institutionalization and maintain their independence. These services can provide respite for the caregiver.

The State Adult Day Care Fund (SADCF) uses federal Social Services Block Grant funds and state appropriations to provide adult day care services to disabled adults age eighteen (18) and older who are at risk for institutionalization. These funds are administered through county departments of social services. These services also can provide respite for the caregiver.

Group Respite provides temporary relief for caregivers, enabling them to meet personal needs and supporting their efforts to provide the majority of care for their family member. Group Respite differs from adult day care or adult day health in relation to the number of hours a program may operate and that group respite providers are unable to provide any personal care to participants.

Group Respite is currently provided in only five (5) regions of the state with a total of five (5) programs.

Institutional Respite provides temporary relief for caregivers in a residential setting that meets the care recipients' needed level of care.

Adult Day Care, as defined in §131D-6, is the provision of group care and supervision in a place other than their usual place of abode on a less than 24-hour basis to adults 18 years and older who may be physically or mentally disabled.

Adult Day Health offers health care services in addition to the services offered by the Adult Day Care Program to adults 18 years and older that require health monitoring by trained medical staff.

To date, there are only 102 Adult Day Care Programs located in 56 counties throughout North Carolina. Fifty-five (55) of the 102 programs are adult day care and adult day health combination programs, forty-four (44) of the 102 programs are adult day care only programs, and three (3) of the 102 programs are adult day health only programs.

The North Carolina Family Caregiver Support Program (FCSP) was authorized by the Older Americans Act 2000. It is administered by DAAS in partnership with the State's 17 AAAs.

Caregivers served by the FCSP received one or more of the following services provided under the program's "scope of respite":

- In-home respite (personal care, homemaker, Senior Companions/home visitors)
- Community respite (adult day center, group respite center, mobile day respite, or other nonresidential program)
- Emergency respite program (in-home)
- Emergency respite program (out of home)

- Institutional respite (institutional setting such as a nursing home or assisted living for a short period of time)
- Summer camps, after-school programs or child day-care (for grandparents caring for grandchildren)
- Other short-term respite options (e.g., respite camps and caregiver retreats)
- Other as approved by DAAS

Additionally, under FCSP, caregivers are provided with information, access to services (including transportation), counseling, training, support groups, and supplemental services. Supplemental Services may be especially beneficial to working caregivers. Through the National Family Caregiver Support Program, in North Carolina, the Eastern Branch of the Cherokee Indians (EBCI), also receive respite.

Project C.A.R.E. (Caregiver Alternatives to Running on Empty) is specifically designed to provide respite care and support to caregivers of persons with dementia and is a federally funded Alzheimer's Demonstration Program. Families enrolled in the program received an annual spending cap of up to \$2000 and had the option to chose between adult day services, group respite, private or agency in-home care, and overnight residential respite.

Project C.A.R.E. is currently available in 14 western counties.

DAAS Funding Expenditures

SADCF: Including local match, \$4,540,264 was awarded in SFY 06-07. A total of \$4,443,626, or 97.9%, in State Adult Day Care Fund resources was expended to serve 1,396 older and adults with disabilities.

HCCBG: Including local match, \$6,095,200 of HCCBG funds were expended in communities to provide respite services. These respite services included: Institutional Respite; Group Respite; In-Home Aide Respite; Adult Day Care and Adult Day Health programs. A total of \$55,474,000, or 99.8%, in HCCBG funding was expended in communities to serve 59,177 older adults.

FCSP: During SFY 2006-07, the North Carolina Family Caregiver Support Program (FCSP) provided respite services to 1,533 unduplicated caregivers, or 41,330 units of service, at a cost of \$1,600,551.

Project C.A.R.E.: During SFY 2006-7, Project C.A.R.E., provided a total of \$229,419 for direct respite care services.

Division of Medical Assistance

Respite is also defined in Section 12.1.7 of **Medicaid's** Clinical Policy for the Community Alternative Program for Disabled Adults (CAP/DA). In this program, Respite care provides temporary support to the client's primary unpaid caregiver(s) by taking over the tasks of the caregiver(s) for a limited time. It may be used to meet a wide range of needs, including family emergencies; planned absences (such as

vacations, hospitalizations or business trips); relief from the daily responsibility and stress of caring for a special needs person; or to provide time for the caregiver(s) to shop, run errands, and perform other tasks. It may also be used to provide respite to the client from the primary caregiver(s). Respite is available as in-home respite, in which the respite worker goes into the client's home; or as institutional respite, in which the client goes into a facility that is licensed to provide an appropriate level of care.

In Section 11.1.6 of **Medicaid's** Community Alternative Program for Medically Fragile Children (CAP/C). Respite care provides temporary support to a family caring for a CAP/C child. It may be used as day, evening or overnight care to meet a range of client needs. These include family emergencies; planned absences, such as vacations, hospitalizations or business trips, relief from the stresses of caregiving, shopping and giving a child respite from his family. Respite care is available as in-home respite in which the respite worker goes into the client's home, and as institutional respite in which the client goes into a facility licenses to provide the appropriate level of care.

It is important to emphasize that Medicaid does fund Adult Day Health services (medical model) under its waiver programs. It does not fund Adult Day Care services (social model). This restriction in use of funds is typical nationwide as the focus of Medicaid is on health care delivery.

Additionally, Medicaid reimburses a "Short-Term Inpatient Care" (general and respite), which is provided in a hospice inpatient unit, a hospital, or nursing facility under a contractual arrangement with a hospice agency. The inpatient stay (general) is of a short duration either for the management of symptoms or for palliative care that cannot be provided in any other setting. An inpatient stay (respite) provides short-term relief for the caregiver. Relief for the hospice recipient's caregiver is available with either Medicare or Medicaid reimbursement.

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Respite under the CAPMR/DD program mirrors respite provided under CAP/DA in that it may provide:

- Intermittent relief for the caregiver.
- Accommodate a wide range of needs (i.e. emergencies, planned absences)
- Provide time for the caregiver to handle personal tasks and
- Provide respite to the client from the primary caregiver

These services are also tailored to individual or group recipients across private and provider operated settings. According to DMH, a person must meet the definition in §122-3 of having a developmental disability or a mental illness in order to receive respite care services.

DMH offers in-home respite, facility respite and institutional respite funded both with state dollars and through the waiver program. Those receiving CAP/MR/DD waiver respite services can receive Medicaid funding; while those receiving respite outside of the waiver may be eligible for respite through funding with state funds.

Therefore, within a waiver program, respite is basically provided as requested if it fits within the current individual's waiver budget for all waiver services whether the waiver be CAP/DA, CAP/C or CAP/MRDD. By report from the Medicaid Program Managers, respite is not utilized as often as it might be because of the limitation within CAP program funding.

The exception to this principle occurs within the CAP/MR/DD waiver which utilizes a flexible budget plan. Under this option, all of its waiver participants do not have a capped individual budget. This allows a pool of available funds to all participants under the waiver so that unused funds budgeted for individuals with less extensive needs could be utilized by those with more extensive needs.

Under the CAP/MR/DD waiver, both federal and state rules permit family members to become paid caregivers with the exception of legally responsible family members (parents/guardians of minor children and spouses). This mostly occurs in the delivery of personal care services with recipients employing closely related family members as their personal care attendant.

Division of Social Services

DSS provides respite care within the Family Support Child Welfare Section to families and children that meet the criteria and definition below through contracts with private providers located throughout the State. There are no financial eligibility requirements.

DSS does not have a definition of respite as a State statute or rule. However, DSS does use a definition based on the Friends NRC (National Referral Center in Chapel Hill, NC). NRC defines respite as follows:

“Short-term care services provided for families of children under the age of 18 living with natural, adoptive, foster parents or relatives, or any family who has taken on the role of caregiver who meet one or more of the following categories:

- The child(ren) are in danger of abuse or neglect;
- The child(ren) have experienced abuse or neglect;
- The child(ren) has/have developmental disabilities, chronic or terminal illnesses or mental health issues.”

Currently, DSS has eight (8) contracts, each for \$30,000 for a total of \$240,000 for this fiscal year. The contracts are renewed annually except in rebid years. For example, Youth Focus has one (1) contract with The Children's Home as the subcontract. The Jackson County FRC (Family Resource Center) has two (2) contracts, one for voucher-based respite and the other for center-based respite. In SFY 2006-07, DSS provided respite services to 288 unduplicated clients. The goal of respite is to enable the family to remain intact and to keep the child(ren) living in their home or community.

As shown in the **NC Expenditure By Respite Program charts (See Attachment C)**, one can see that there are differences in the amount of the total respite expenditures

within waiver programs. The information is primarily derived from paid claims data. It is evident that across funding streams and target populations, assumptions are made about medical needs, access to service or available data, but no matter what respite service, it is important to recognize the caregiver is primary to the success of all home and community based services. Without appropriate respite services, many consumers of publicly funded services would be in need of a higher and more expensive level of care.

County departments of social service agencies contract for respite services with local adult day care and adult day health providers to fund participants attending these programs through the SADCF. Medicaid, as the primary payor of long-term care services and supports, pays for respite only under its waiver programs.

In the CAP/MR/DD waiver, a "Respite Rate" reimburses only respite. In nursing facilities (NFs), the respite rate is the regular NF rate. In an Adult Care Home (ACH), Medicaid reimburses for personal care. Adult Day Health Services can be covered under Medicaid only through the waiver programs. Although we have expenditure data, the data is based on paid claims, and in many instances, is paid out of different pots of money for services that are not exactly the same by definition.

V. THE DELIVERY AND LICENSING OF RESPITE CARE IN OTHER STATES AND POSSIBLE MODELS FOR NORTH CAROLINA

The NC Respite Study Group reviewed *The State of the States in Family Caregiver Support: A 50-State Study* published November 2004 by the Family Caregiver Alliance in collaboration with the National Conference of State Legislatures. This study includes a series of data tables comparing how state programs responded to key survey questions. **(See Attachment F: Published Side by Side Comparison)**. This chart indicates that every state has at least one respite service for older adults and at least two (2) respite programs identified. A variety of programs was found in the states of California, Florida and New Jersey, each with six (6) different programs. In only one state, North Dakota, did the caregiver have to live with the care recipient in order to receive respite services. Only Minnesota, specifically mentioned that they paid for out-of-home respite provided by a friend or neighbor and only Hawaii, mentioned weekend support groups.

Because this study "Side by Side Comparison" chart was not as recent as the NC Respite Study Group would have preferred, the Study Group surveyed, via email, agencies from around the nation. Information on the provision of respite services was gathered to review best practices and possible models that may be useful in designing improved respite services in NC. The group also wanted to know which states currently licensed respite providers and what types of respite are offered by those providers. Twenty-five (25) states responded stating whether their state currently licensed respite care providers.

Among those states that responded **(See the table on page 11)**, 14 states currently provide a type of respite through licensed providers. They are represented in the following tables. Of these, only two (2) Licensure Categories are not found in NC--hospitals found in the States of Washington and Minnesota and Adult Foster Care found in Minnesota. Other respite service categories mirror most of those found in NC.

However, not all NC options are offered throughout the state and/or are available through each division of DHHS.

Populations targeted by DHHS respite programs include caregivers of persons with developmental disabilities, frail older adults, and persons with dementia and related disorders. Other State respite programs target medically fragile children in the CAP/C programs as well as children who are at risk for abuse or neglect and those who have developmental disabilities, chronic or terminal illness or mental health issues.

From a resource utilization perspective, Adult Day Care is the most common respite service provided to family caregivers nationwide. Whether this service is in greater demand than the others is unknown. Licensure for respite care in institutions is represented in six (6) states New Mexico, Idaho, Alabama, Missouri, Iowa and Washington that would be similar to NC's 24-hour respite in NFs, ACHs and State Developmental Centers.

In the research of other states and in the study group's discussion, it appears barriers to providing and coordinating a comprehensive program of respite care are similar in different states. Top barriers are listed as the complexity and fragmentation of different eligibility criteria, different target client populations, as well as different regulatory requirements. This is very evident in NC as we have both licensed and certified programs, several different funding streams and several different programs providing services to various target populations. While the fragmentation makes respite care more difficult to administer, it does provide for the needs of a diverse population.

Provider Licensure Categories and Respite Service Categories by State.

Provider Licensure Categories						
Alabama	Georgia	Idaho	Missouri	Illinois	Iowa	Minnesota
Institutional (overnight)	In home	License Adult Day	In Home	Adult Day Care	Nursing Facility	In Home
In Home	Adult Day Care	License Residential	Nursing Facility	In home	Adult Day Care	Medicaid-certified Hospital
Adult Day Program					In home	Adult Foster Home
Respite Service Categories						
Alabama	Georgia	Idaho	Missouri	Illinois	Iowa	Minnesota
Adult Day Services	Skill level 1	Adult Day	Advance Respite	Personal Assist.	Specialized Respite	Home Health
In home	Skill level 2	In Home	Advance Block	Homemaker	Group Respite	Personal Care
	Skill level 3		Advance Daily	In home		Adult Day Services
			Institutional			Care Companion
			Nurse Respite			Alzheimer's
Provider Licensure Categories						
Nebraska	New Mexico	New York	Oregon	Pennsylvania	North Dakota	Washington
Adult Day Services	Adult Day Care	Adult Day Services	In home	Home Health Care	Adult Day Care	Nursing Homes
In home	In home	In home	Adult Day Care	Homemaker	In home	Adult Day Health
	Institutional (overnight)					Home Health Care
						Hospitals
Respite Service Categories						
Nebraska	New Mexico	New York	Oregon	Pennsylvania	North Dakota	Washington
Early Development	Adult Day Care	Adult Day Services	In home	In home (overnight)	Adult Day Care	Nursing facility
Area Agency/Aging	Family Caregiver	In home	Adult Day Care	Adult Day Care	Adult Day Health	Adult Day Health

Model Programs

The Respite Study Group opted to highlight North Carolina's current respite care models in this report rather than adopt another state's respite care model, as the existing respite care models in North Carolina have proven to be successful in effectively serving targeted populations and addressing diverse and state specific needs. North Carolina has four (4) recognized Best Practice Model Programs. A brief description of each is included below:

1. **The North Carolina Alzheimer's Demonstration Program, Project C.A.R.E. (Caregiver Alternatives to Running on Empty)**, uses a family consultant model to provide consumer-directed respite care and comprehensive support to dementia caregivers. The goal of the program is to increase quality, access, choice, and use of respite and support services to low-income rural and minority families caring for a person with dementia at home or within a hospital setting. Through the integration of dementia-capable services and the development of family-centered and caregiver-focused community care networks, Project C.A.R.E. can help create a seamless, coordinated delivery system that is responsive to the needs, values and preferences of families caring for a member with Alzheimer's.

Project C.A.R.E. is administered through the Division of Aging and Adult Services (DAAS) with expert consultation and technical assistance provided by the Duke Aging Center Family Support Program. Project C.A.R.E. is implemented at the local level through Family Consultants employed by and/or supported through the local Alzheimer's Association. The program is currently based within the Mecklenburg County Department of Social Services and two area offices of the Western Carolina Alzheimer's Chapter. The Mountain Area office in Asheville serves as the project training and data management center for all new and existing program sites and staff.

Project C.A.R.E. employs Family Consultants with expertise in Alzheimer's disease and related disorders. The Consultants visit the homes of referred dementia caregivers in crisis and offer timely, individualized assessment, guidance, counseling, support, advocacy, coaching and education. Their aim is to match families with the most appropriate and preferred local respite and community services tailored to their unique situation and needs. Through Project C.A.R.E., dementia caregivers may spend up to \$2,000 a year toward respite services. Families are able to choose among a full continuum of consumer-directed care options, including adult day services, group respite, private or agency in-home care, and overnight residential respite. The Project C.A.R.E. model builds upon, enhances and sustains existing home and community-based services by using local providers to deliver respite care.

The personalized approach of the Family Consultant fosters family trust, offers individualized caregiving and coping skills, and encourages caregiver self-care. Project C.A.R.E. helps families learn the value of quality dementia-specific respite services and feel empowered to make self-directed, informed decisions about care. Special emphasis is placed on targeting underserved, low-income rural and minority communities that have limited knowledge of and access to dementia-specific respite care and support services. In 2004, Project C.A.R.E.

received the Geriatric Best Practice Award from the Southeast Regional Geriatric Best Practices Initiative. In 2005, the program received a National Innovative Program Clearinghouse Award from the National Alzheimer's Association and was featured at the National Conference of State Legislators as a national model for home and community based care coordination. Project C.A.R.E. was further recognized as a National Best Practice Model by the U.S. Administration on Aging and RTI International.

2. **JACKSON COUNTY FAMILY RESOURCE CENTER** was founded in 1995 when a taskforce sponsored open community meetings across the county. The data collected indicated a definite need to support and develop a family resource center whose mission would be to create a framework where families could access comprehensive services in an impartial and empowering environment. The primary focus is to support and enhance the presence of healthy children and strong families in a caring community, while fostering personal development.

Family Rest Stop is a good example of one of their model programs. In operation since September 1998, this respite program serves Jackson County and six (6) surrounding counties in western NC. Respite services are provided Saturdays from 9:00 a.m.-3:00 p.m. using the facilities of the Family Resource Center and the Webster Child Development Center. It is a time for children to relax, have fun and a time for parents to have a break from caregiving. Other highlighted services include Circle of Parents, Family Focus Classes, Family Caregiver and Voucher Respite, Ancillary Services, Volunteer Services, a resource library and others.

3. **A SMALL MIRACLE, INC.** is a CAP-MR/DD agency that provides comprehensive services to children and adults of all ages with all types of disabilities. It provides one-on-one services to children and adults in a 24-county region of Eastern-Central North Carolina, including respite care. Founded by a parent of a child with autism, the agency is particularly sensitive to the needs of families caring for autistic children. A Small Miracle, Inc. provides opportunities to network with other parents and information on doctors, dentists and other medical specialists

Individual Caregiver/Training and Education (ICTE) is a prime example of one of A Small Miracle's excellent services. ICTE allows family members to learn more about their loved one's disability as well as the best educational, therapeutic and biomedical interventions available to address them.

4. **SENIOR COMPANION RESPITE PROGRAM** is offered through a local Family Caregiver Support Program in eastern NC. This program targets family caregivers who live in rural areas. Respite care services are provided by peers. Peers may provide supervision, cueing and/or prompting a care recipient as well as providing companionship. Many times, the senior companions are neighbors and are generally known by the family caregiver. This program is working well in Jones County and Carteret County. During SFY 07-08, the program will be expanding into Craven County.

VI. THE APPLICATION FOR A GRANT UNDER THE LIFESPAN RESPITE CARE ACT OF 2006, 42 U.S.C.

(See Attachment D: Lifespan Respite Act of 2006, 42 U.S.C.)

The Lifespan Respite Act of 2006 was enacted to assist family members who are the primary caregivers for children and/or adults with special needs in accessing respite care services that are both affordable and of high quality. The program would be administered through Aging and Disability Resource Connections (ADRC) that would be part of the state's long term care system. DHHS is currently piloting the ADRC concept in several counties under several federal grants. The ADRC is to be a convenient, one-stop, no-wrong door approach to providing information and referral for long-term care services; counseling and planning to determine an individual's current or future long-term care needs; and assistance in applying for long-term care programs.

As of this writing, the Lifespan Respite Care Act of 2006, 42 U.S.C. has not received funding by Congress. Once funded, the DHHS/DAAS will make application for funding under this authority.

VII. THE NEED FOR SEPARATE STATUTORY LANGUAGE PERTAINING TO RESPITE CARE AND THE NEED, PROPOSED STRUCTURE AND DEVELOPMENT TIMELINE FOR A SEPARATE LICENSURE CATEGORY FOR RESPITE CARE.

The NC Respite Study Group did not see a need for separate statutory language for respite care. As one can see from **ATTACHMENT B**, there are separate state statutes and administrative codes for respite care that apply to the various programs in several divisions within DHHS. After a thorough review of these citations, the NC Respite Study Group believed that the existing Licensure and Certification systems of DHR and DAAS respectively, allow for all levels and types of respite care. What is needed is consistent state funding for the current respite care models available in North Carolina. For example, the national award winner, "Caregiver Alternatives to Running on Empty" (Project C.A.R.E.) is currently being funded by a one-year grant through the U.S. Administration on Aging's Alzheimer's Disease Demonstration Grants to States Program (ending June 30, 2008). Unless continuation funding is provided by the state, Project C.A.R.E. will cease to operate and will no longer be a source of respite services to caregivers in North Carolina.

VIII. THE DEVELOPMENT OF A MEDICAID WAIVER COVERING A PROPOSED NEW LICENSURE CATEGORY FOR RESPITE CARE.

NC Medicaid currently recognizes Respite as a billable service only under a waiver program. Medicaid does not recognize Respite as an optional service under its State Plan.

With the passage of the Deficit Reduction Act (DRA) of 2005, the Federal Government allowed states to determine which additional services to provide via a waiver based in the authority of this national legislation. States were eager to pursue such an innovative opportunity. However, since that time, Federal advice has been slow to reach the states, and it now appears that states will not be able to use this option as liberally as first thought. The Federal Government has decided that states will be able to have only

one waiver under the DRA authority. NC Medicaid has not made the decision how they will use their opportunity. To date, only a couple of states have developed a waiver.

However, the NC Respite Study Group agreed that the respite care delivery system in NC could be enhanced if Medicaid would consider the possibility of including respite as a State Plan Service. A respite service, defined as an Optional Medicaid State Plan Service, should be offered to all who qualify, regardless of where the recipient lives or the recipient's diagnosis. The service should be based on individual needs. The State may limit the definition, duration and scope of the respite service. Integral to this process would be an assessment of caregiver capability. DMA will use the information generated within the NC Respite Study Group to pursue an internal review of this option. Additional steps would include the development of a fiscal note and submission of a State Medicaid Plan Amendment (SPA). Because of the technological implications of initiating this new state plan service, if approved by the DHHS and CMS, the timeline would be determined based on the implementation of the new MMIS system. Cost of the system changes needed within the current system and the time needed to complete those changes would make any other timeline unworkable.

The initial impetus for building the case for a decision of this magnitude is the examination and documentation of caregiver support research and the viability, and documentation that respite care will result in the lowering of the overall cost of providing long-term care.

For example, caregivers who spend 40 hours or more are more than twice as likely as those spending fewer than 20 hours per week to say their health became a lot worse as a result of caregiving (23% vs. 9%). Similarly, caregivers who perform three or more Activities of Daily Living (ADLs) are almost twice as likely as those who are not performing any to say their health is a lot worse (19% vs. 10%). Seventy-five percent (75%) of these caregivers in declining health believe they did not have a choice of whether to take on their caregiving responsibility.⁵

IX RECOMMENDATIONS FOR IMPROVED RESPITE SERVICE PROVISION OF SERVICE WITHIN NC

The NC Respite Study Group recommends:

1. That the NC General Assembly
 - A. Secure a recurring state appropriation of \$500K to sustain Project C.A.R.E: "Caregiver Alternatives to Running on Empty" prior to June 30, 2008.
 - B. Support an increase in the State Adult Day Care Fund (SADCF). Increasing the SADCF would assist in expanding services as this fund is for adults 18 years of age and older whereas the HCCBG fund is restricted to adults 60 years of age and over.
 - C. Secure state funding to continue the expansion of Aging and Disability Resource Connections (ADRC) to increase information and access on

⁵ Caregivers in Decline, Evercare Study, Report of Findings , September 2006

respite services for caregivers. This would include creation and on-going maintenance of a statewide inventory system of respite care programs, services, and resources through the ADRC initiative and NCcareLINK to improve access and choices to respite care for caregivers and care recipients.

2. DAAS will further study the place of group respite programs in the long-term care continuum and assess the adequacy of service standards and funding.
3. Medicaid will continue to study the potential of Respite as a State Plan Service

List of Acronyms

AAA	Area Agency on Aging
ACH	Adult Care Home
ADC	Adult Day Care
ADDG	Alzheimer's Disease Demonstration Grants to States
ADH	Adult Day Health
ADRC	Aging and Disability Resource Connections
AOA	Administration on Aging
CAP/C	Community Alternatives Program for Medically Fragile Children
CAP/DA	Community Alternatives Program for Disabled Adults
CAP/MRDD	Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities
DAAS	Division of Aging and Adult Services
DHHS	Department of Health and Human Services
DHSR	Division of Health Service Regulation
DMA	Division of Medical Assistance
DMH/DD/SAS	Division of Mental Health/Developmental Disabilities and Substance Abuse
DRA	Deficit Reduction Act
DRIVE	Data Retrieval and Information Validation Engine
DSS	Division of Social Services
EBCI	Eastern Branch of the Cherokee Indians
FCA	National Center on Caregiving Family Caregiver Alliance
Friends NRC	Friends National Referral Center
FSCP	Family Caregiver Support Program
HCBS	Home and Community Based Services
HCCBG	Home and Community Care Block Grant
HHS	Health and Human Services
IOM	North Carolina Institute of Medicine Task Force on Long-Term Care
LTS	Long-term Services and Supports
MMIS	Medicaid Management Information Systems
MUST	Medicaid Uniform Screening Tool
NASUA	National Association of State Units on Aging
NCAC	North Carolina Administrative Code
NF	Nursing Facilities
NFCA	National Family Caregiver Association
Project C.A.R.E.	Caregiver Alternatives to Running on Empty
POMP	NC Performance Outcome Measures Project
UNC – CARES	University of North Carolina - Chapel Hill, Center for Aging Research and Educational Services
U.S.C.	United States Code

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ATTACHMENTS

Attachment A	Study Group Members and Their Organizations
Attachment B	NC Respite Regulations
Attachment C	NC Expenditures by Respite Program
Attachment D	Lifespan Respite Act
Attachment E	Estimated Prevalence and Economic Value of Family Caregiving, by State (2006)
Attachment F	Side by Side Comparison in Other States

Attachment A: Study Group Members and Their Organizations

Last	First	Organization
Artis*	Glenda	Division of Aging and Adult Services
Budzinski*	Julie	Division of Medical Assistance
Colvard	Tracy	Division of Medical Assistance
Comin	Margaret	Division of Medical Assistance
Cooper	Jerry	NC Assistant Living Association
Crane	Shannon	Division of Aging and Adult Services
Derence*	Karisa	Division of Aging and Adult Services
Grady	Elizabeth	Division of Medical Assistance
Gwyther	Lisa	Duke Bryan Alzheimer's Disease Research Center
Harper	Trish	Division of Medical Assistance
Jackson*	Charles	Division of Medical Assistance
Jenkins	Carol	Division of Medical Assistance
Johnson	Cedric	Division of Medical Assistance
Johnson	Teresa	NC Adult Day Services
Jones	Ellison	Triangle J Area on Aging
Joos	Cynthia	Division of Services for the Blind
Kingsberry	Adelle	Division of Medical Assistance
MaCleod	Jane	NC Respite Coalition
Morse	Margaret	Center for Aging Research and Educational Services, UNC
Reaves	Jean	NC Aging Study Commission
Salmon	Mary Anne	Center for Aging Research and Educational Services, UNC
Smith	Kathie	Association for Home & Hospice Care of NC
Speroff*	Beverly	Division of Health Service Regulation
Stancil	Candace	Division of Medical Assistance
Stephenson	Phyllis	NC Respite Coalition
Riddle*	Jody	Division of Aging and Adult Services
Urso*	Chris	Division of Aging and Adult Services
Waddle	Fred	NC Easter Seals
Waite	Linda	Division of Social Services
Wilson	Lou	NC Association of Long-term Care Facilities
Williamson	Sallie	Mid-East Commission Area Agency on Aging

* Indicates core planning group

Attachment B: North Carolina Respite Regulations

Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
Nursing Home	<p>§ 131E-101-(6) "Nursing home" means a facility, however named, which is advertised, announced, or maintained for the express or implied purpose of providing nursing or convalescent care for three or more persons</p> <p>Unrelated to the licensee.</p>	DHSR	<p>10 NCAC 13D.2001 "Respite care" means services provided for persons admitted to a nursing facility on a temporary basis, not to exceed 30 days.</p>	<p>10A NCAC 13D.2202 Admissions (a) No patient shall be admitted except by a physician or other persons legally authorized to admit patients. Admission shall be in accordance with facility policies and procedures.</p>	Yes	Medicaid under waiver & special hospice
Adult Care Home	<p>§ 131D-2 (1b) "Adult care home" is an assisted living residence in which the housing management provides 24-hour scheduled and unscheduled personal care services to two or more residents, either directly or, for scheduled needs, through formal written agreement with licensed home care or hospice agencies</p>	DHSR	<p>10 NCAC 13F.0907 (a) For the purposes of this Subchapter, respite care is defined as supervision, personal care and services provided for persons admitted to an adult care home on a temporary basis for temporary caregiver relief, not to exceed 30 days.</p>	<p>10A NCAC 13F.0701 Admission of Residents (a) Any adult (18 years of age or over) who, because of a temporary or chronic physical condition or mental disability, needs a substitute home may be admitted to an adult care home when, in the opinion of the resident, physician, family or social worker, and the administrator the services and accommodations of the home will meet his particular needs.</p>	Yes	Medicaid under waiver
Family Care Home	<p>§ 131D-2(5) "Family care home" means an adult care home having two to six residents.</p>	DHSR	<p>10 NCAC 13G.0907 (a) For the purposes of this Subchapter, respite care is defined as supervision, personal care and services provided for persons admitted to a family care home on a temporary basis for temporary caregiver relief, not to exceed 30 days.</p>	<p>10A NCAC 13F.0701 Admission of Residents (a) Any adult (18 years of age or over) who, because of a temporary or chronic physical condition or mental disability, needs a substitute home may be admitted to an adult care home when, in the opinion of the resident, physician, family or social worker, and the administrator the services and accommodations of the home will meet his particular needs.</p>	Yes	Medicaid under waiver

Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
DAAS Adult Day Care DAAS Adult Day Health	<p>§ 131D-6 (Adult Day Care) "Adult day care program" means the provision of group care and supervision in a place other than their usual place of abode on a less than</p> <p>24-hour basis to adults who may be physically or mentally disabled.</p> <p>10A NCAC 06S .0102 (Adult Day Health)</p> <p>"Adult day health services" is the provision of an organized program of services during the day in a community group setting for the purpose of supporting an adult's personal independence, and promoting his social, physical, and emotional well-being.</p>	DAAS Certified	<p>10A NCAC 06R 0201</p> <p>"Respite care," as a component of adult day care programs, means a service provided to give temporary relief to the family or caregiver. Primarily, respite is provided to families caring for children or adults with disabilities or families caring for frail or disabled older adults.</p> <p>10A NCAC 06S .0102</p> <p>Adult day health services is the provision of an organized program of services during the day in a community group setting for the purpose of supporting an adult's personal independence, and promoting his social, physical, and emotional well-being. Services must include health care services as defined in Rule .0403(a) of this Subchapter and a variety of program activities designed to meet the individual needs and interests of the participants, and referral to and assistance in using appropriate community resources. Also included are food and food services to provide a nutritional meal and snacks as appropriate to the program.</p>	<p>10A NCAC 71R .0903</p> <p>Day Care Services for Adults</p> <p>(b) Target Population. Adults who because of age, disability or handicap need the service to enable them to remain in or return to their own homes. Within the target population, eligible clients shall be provided day care services for adults in the following order of priority:</p> <p>(1) adults who require complete, full-time daytime supervision in order to live in their own home or prevent impending placement in substitute care (e.g. nursing home, domiciliary home), and adults who need the service as part of a protective services plan;</p> <p>(2) adults who need help for themselves with activities of daily living or support for their caregivers in order to maintain themselves in their own homes or both;</p> <p>(3) adults who need intervention in the form of enrichment and opportunities for social activities in order to prevent deterioration that would lead to placement in group care;</p> <p>(4) individuals who need time-limited support in making the transition from independent living to group care, or individuals who need time-limited support in making the transition from group care to independent living.</p>	No	<p>1) Medicaid under for Adult Day Health within a waiver program only</p> <p>2) Home and Community Care Block Grant (HCCBG) and State Adult Day Care Fund(SAD CF)</p>

Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
DAAS Adult Day Care DAAS Adult Day Health Continued...				10A NCAC 06S .0402 Additional Enrollment and Participation Requirements (a) Adult day health programs may serve persons 18 years of age or older who need day health services in order to support their independence and who require one or more of the following during the hours of the day health program: (1) Monitoring of a medical condition; or (2) Provision of assistance with or supervision of activities of daily living; or (3) Administration of medication, special feedings or provision of other treatment or services related to health care needs. (b) Day health programs shall not enroll or continue to serve persons whose needs exceed the capability of the program. (c) Each individual's service plan, in addition to the requirements set forth in 10A NCAC 06R .0501, shall include the health needs and the goals for meeting the health needs of the individual.		(SADCF)

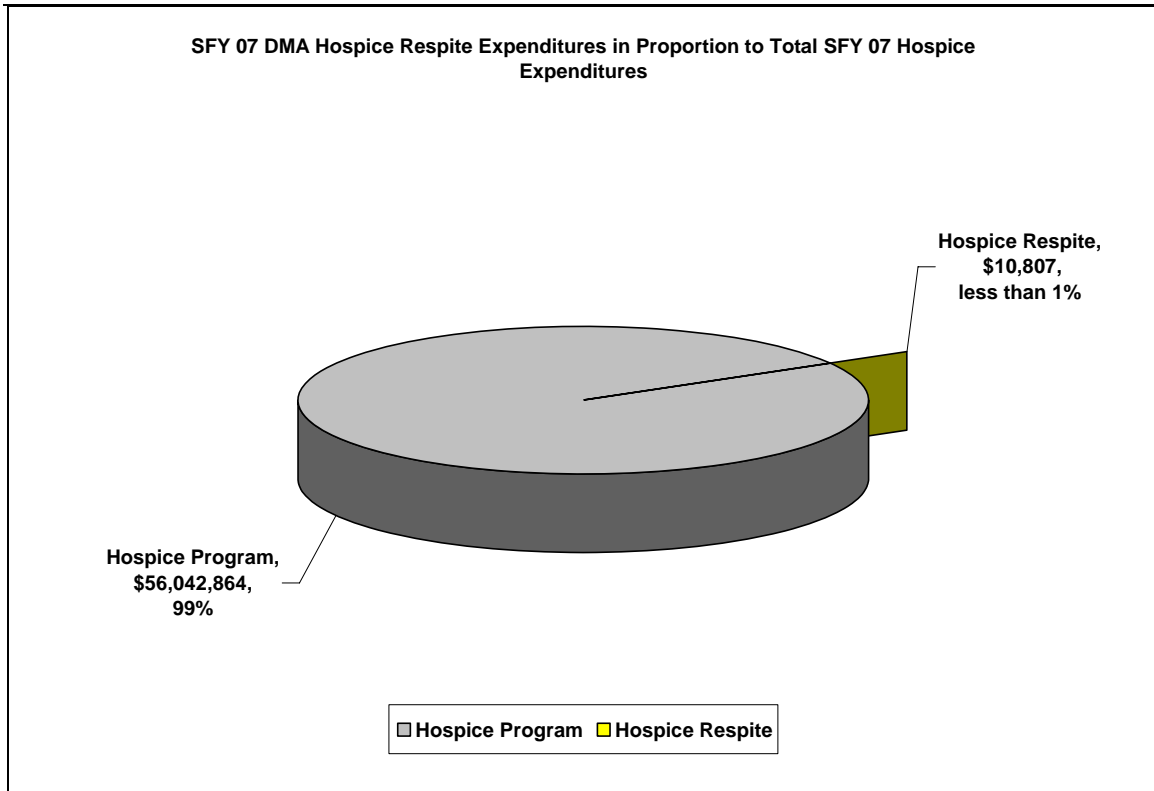
Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
<p>DAAS Sponsored Respite, Residential Respite (or "institutional respite") and Group Respite</p>	<p>Contracted Vendors Nursing Homes Residential Care Facilities and Assisted Living Facilities</p> <p>Individuals employed privately through a home health agency or as part of a government program</p>	<p>None</p>	<p>§ 143B-181.10 A respite care program is established to provide needed relief to caregivers of impaired adults who cannot be left alone because of mental or physical problems.</p> <p>10A NCAC 06B .0101 Institutional Respite Care Service is temporary placement of an individual who requires constant care or supervision, or both, out of his or her home to provide the primary, unpaid caregiver temporary relief from caregiving responsibilities</p> <p>§ 143B-181.10 A respite care program is established to provide needed relief to caregivers of impaired adults who cannot be left alone because of mental or physical problems.</p>	<p>§ 143B-181.10 Those eligible for respite care under the program established by this section are limited to those unpaid primary caregivers who are caring for people 60 years of age or older and their spouses, or those unpaid primary caregivers 60 years of age or older who are caring for persons 18 years of age or older, who require constant supervision and who cannot be left alone either because of memory impairment, physical immobility, or other problems that renders them unsafe alone.</p> <p>10A NCAC 06B .0201 SCREENING OF CLIENT</p> <p>(a) Screening is a preliminary process used to determine if client eligibility is met.</p> <p>(b) A screening instrument must be completed for each unpaid primary caregiver who requests service.</p> <p>(c) The screening instrument must address:</p> <p>(1) Caregiver identification information;</p> <p>(2) Ability of the person requiring care to perform activities of daily living;</p> <p>(3) Ability of the person requiring care to perform instrumental activities of daily living;</p> <p>(4) Physical functioning of the person requiring care;</p> <p>(5) Caregiver's perception of the emotional well-being of the person requiring care;</p> <p>(6) Extent of support provided by the primary caregiver;</p> <p>(7) Services currently received by the person requiring care or the caregiver</p>	<p>Yes (Institutional only when provided in a DHHS licensed facility).</p>	<p>1) State Funded 2) HCCBG 3) DAAS in consultation with the Councils of Government in each region of the State of North Carolina</p>

Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
DSS (all children)	Contracted Vendors (8 current providers)	DSS	As defined by Friends National Referral Center: Short-term care services provided for families of children under the age of 18 living with natural, adoptive, foster parents or relatives, or any family who has taken on the role of caregiver who meet one or more of the following categories: a) the child(ren) are in danger of abuse or neglect; b) the child(ren) have experienced abuse or neglect; c) The child(ren) has/have developmental disabilities, chronic or terminal illnesses	No statute	Yes	DSS State Funds
MH Community Respite Institutional	§ 122C-3 Facility means any person at one location whose primary purpose is to provide services for the care, treatment, habilitation, or rehabilitation of the mentally ill, the developmentally disabled, or substance abusers	DHSR	10A NCAC 27G .5101 (a) Community respite is a service which provides periodic relief for a family or family substitute on a temporary basis. While overnight care is available, community respite services may be provided for periods of less than 24 hours on a day or evening basis. Respite care may be provided by the following model: Center-based respite - the individual is served at a designated facility. While an overnight capacity is generally a part of this service, a respite center may provide respite services to individuals for periods of less than 24 hours on a day or evening basis.	§ 122C-3. 1) State Funded - Individuals must meet the state definition of a developmental disability or mental illness 2) Individual with a developmental disability meeting ICF-MR level of care	Yes-may be day or overnight	1) State Funded (DMH/DD/SAS) 2) CAP-MR/DD (Medicaid)

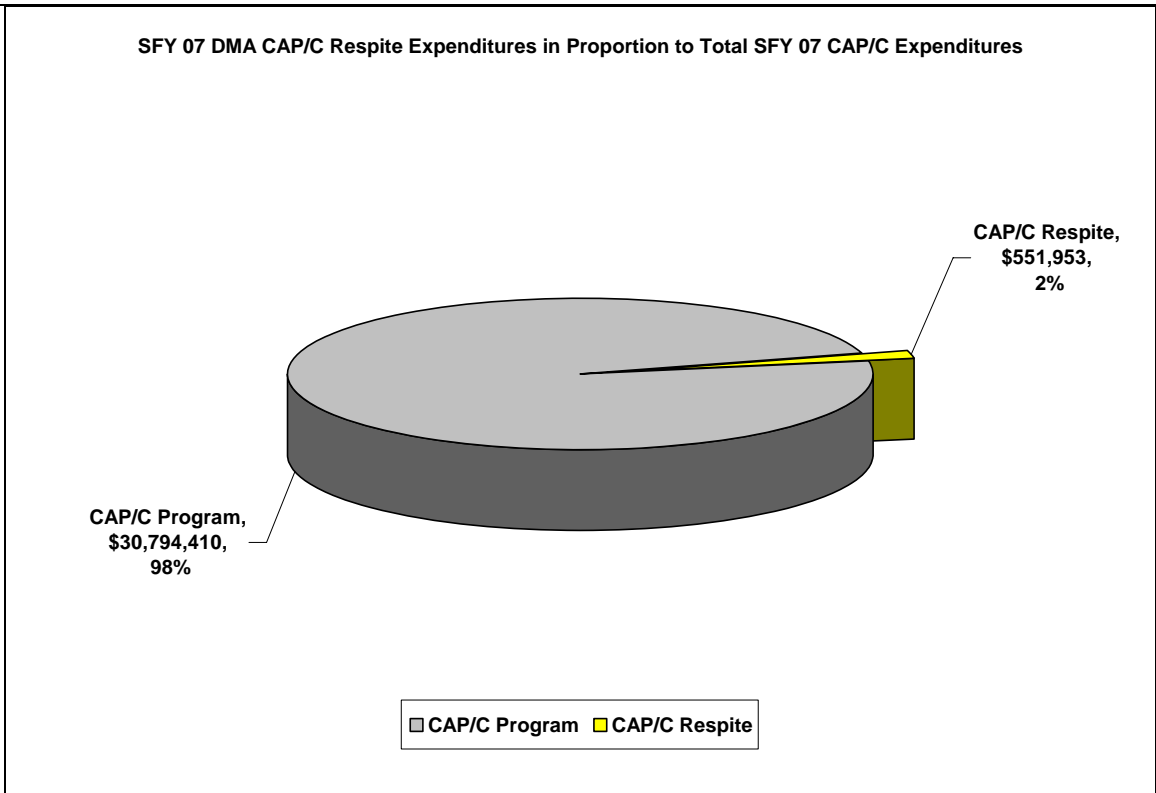
Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
MH Community Respite- In Private Home	§ 122C Private home respite means the individual is served in the provider's home or an hourly or overnight basis	DHSR-for licensable facilities	10A NCAC 27G .5101 Private home respite—the individual is served in the provider's home on an hourly or overnight basis. Private home respite services serving individuals are subject to licensure under G.S. 122C, Article 2, when: (1) more than two individuals are served concurrently; or; Either one or two children, two adults, or any combination thereof are served for a cumulative period of time exceeding 240 hours per calendar month.	§ 122C-3. 1) State Funded - Individuals must meet the state definition of a developmental disability or mental illness 2) Individual with a developmental disability meeting ICF-MR level of care	Yes-may be day or overnight, group, enhanced or nursing	1) State Funded (DMH/DD/SAS) 2) CAP-MR/DD (Medicaid)
MH Community Respite	§ 122C-3 Facility means any person at one location whose primary purpose is to provide services for the care, treatment, habilitation, or rehabilitation of the mentally ill, the developmentally disabled, or substance abusers	DHSR	10A NCAC 27G.5101 (a) Community respite is a service which provides periodic relief for a family or family substitute on a temporary basis. While overnight care is available, community respite services may be provided for periods of less than 24 hours on a day or evening basis. Respite care may be provided by the following model: Center-based respite - the individual is served at a designated facility. While an overnight capacity is generally a part of this service, a respite center may provide respite services to individuals for periods of less than 24 hours on a day or evening basis.	§ 122C-3. 1) State Funded - Individuals must meet the state definition of a developmental disability or mental illness 2) Individual with a developmental disability meeting ICF-MR level of care	Yes-may be day or overnight	1) State Funded (DMH/DD/SAS) 2) CAP-MR/DD (Medicaid)

Respite Type	Definition of Provider	Licensure/Certification	Respite Definition	Admissions/Eligibility/Rules	Overnight	Payor
MH Community Respite- In Private Home	§ 122C Private home respite means the individual is served in the provider's home or an hourly or overnight basis	DHSR-for licensable facilities	10A NCAC 27G .5101 Private home respite—the individual is served in the provider's home on an hourly or overnight basis. Private home respite services serving individuals are subject to licensure under G.S. 122C, Article 2, when: (2) more than two individuals are served concurrently; or; Either one or two children, two adults, or any combination thereof are served for a cumulative period of time exceeding 240 hours per calendar month.	§ 122C-3. 1) State Funded - Individuals must meet the state definition of a developmental disability or mental illness 2) Individual with a developmental disability meeting ICF-MR level of care	Yes-may be day or overnight	1) State Funded (DMH/DD/SAS) 2) CAP-MR/DD (Medicaid)

Attachment C: NC Expenditures by Respite Program

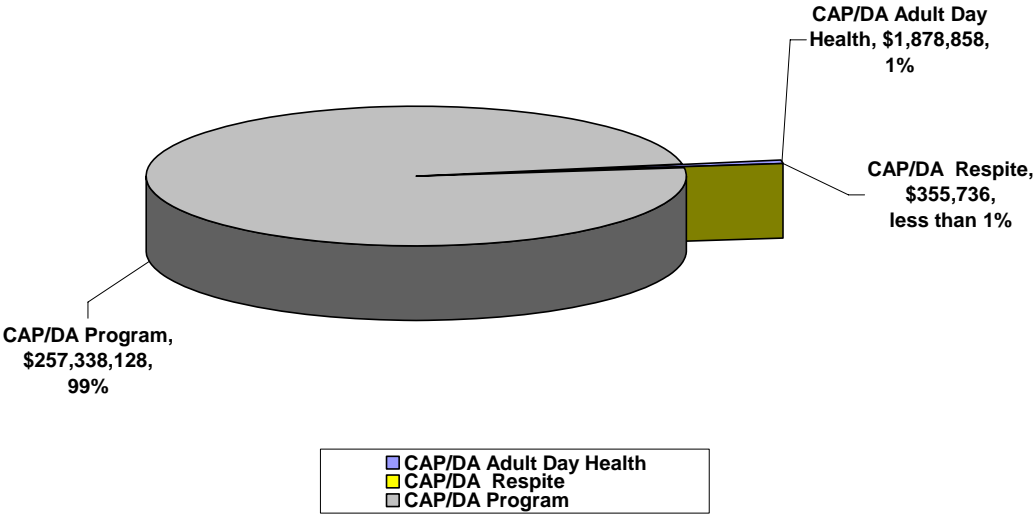


Source: 2007 DRIVE Claims Data

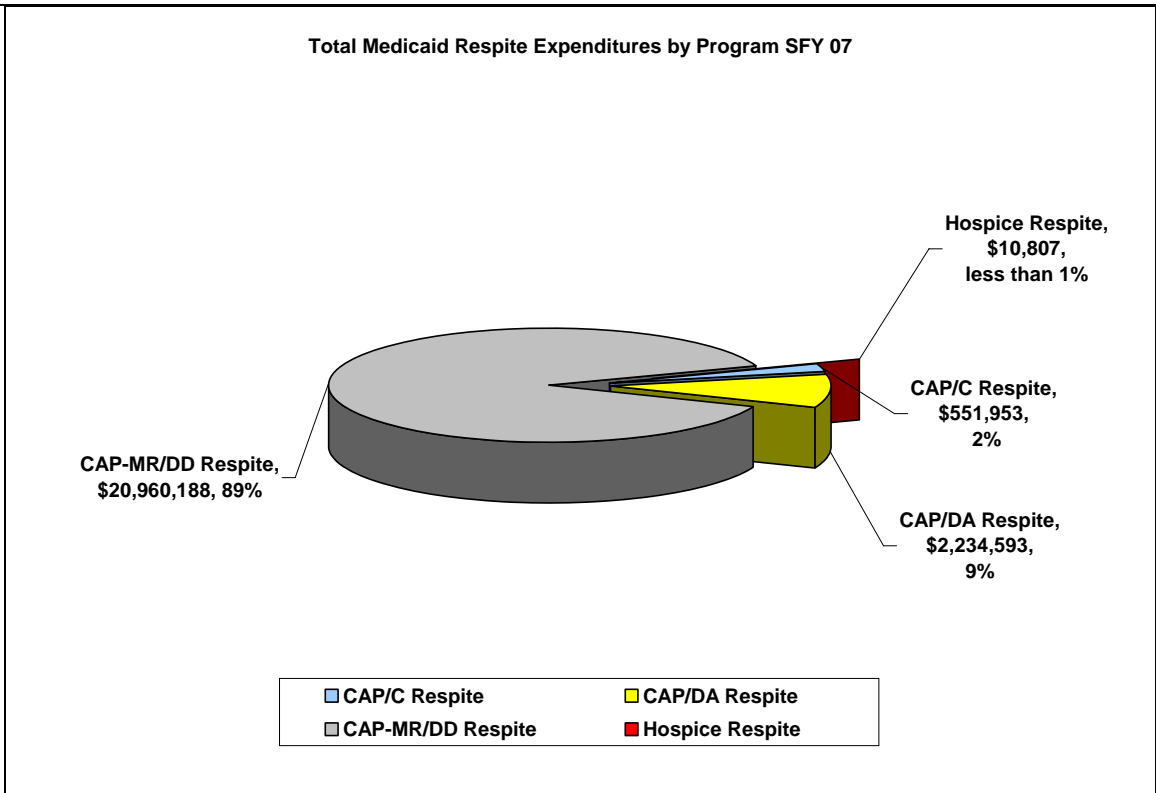


Source: 2007 DRIVE Claims Data

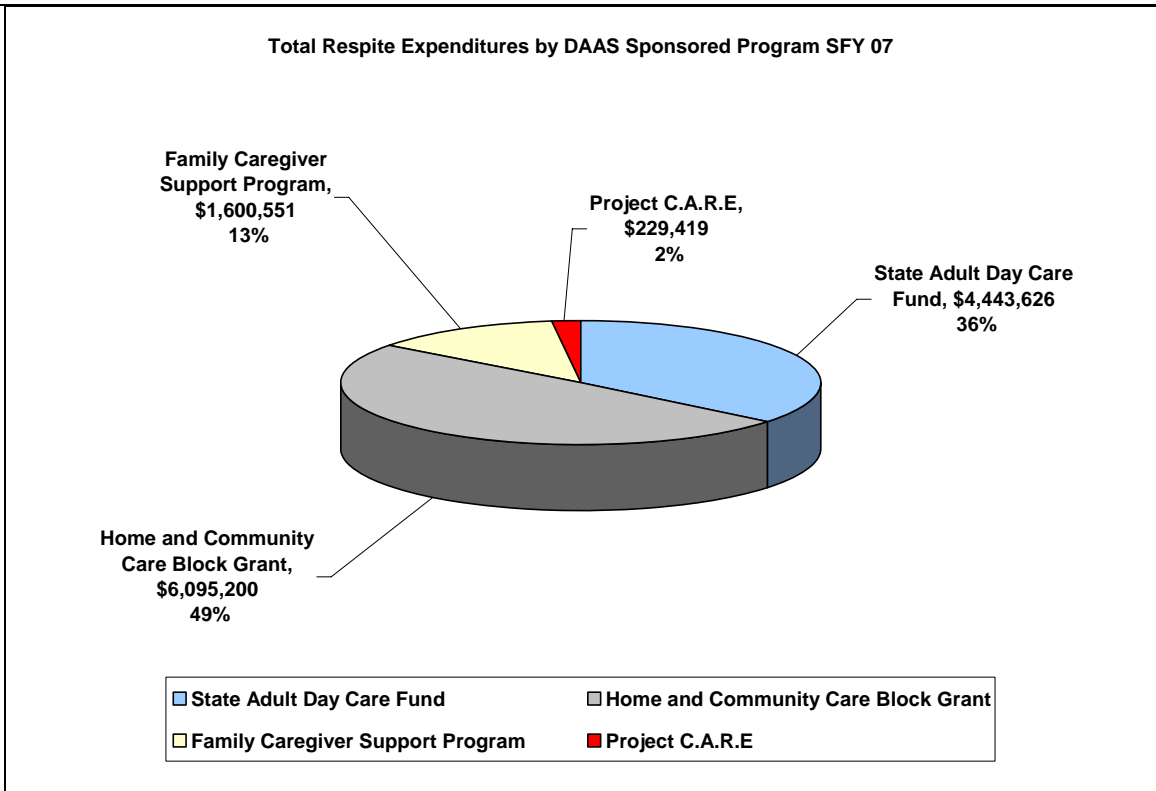
SFY 07 DMA CAP/DA Expenditures in Proportion to Total SFY 07 CAP/DA Expenditures



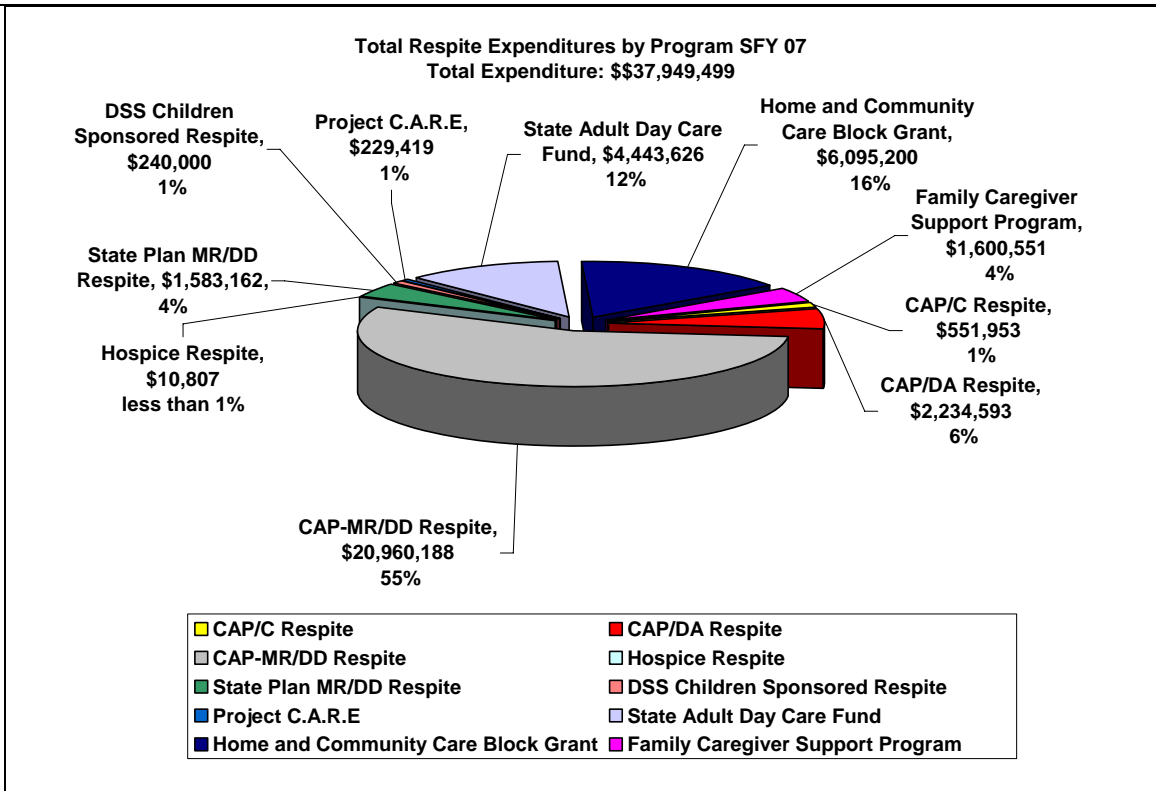
Source: 2007 DRIVE Claims Data



Source: Division of Mental Health and 2007 DRIVE Claims Data



Source: Division of Aging and Adult Services



Source: Division of Mental Health, Division of Social Services, Division of Aging and Adult Services and 2007 DRIVE Claims Data
*Family Support/Child Welfare Section

Attachment D: Lifespan Respite Act (H.R. 3248)

PUBLIC LAW 109–442—DEC. 21, 2006 120 STAT. 3291
Public Law 109–442
109th Congress
An Act

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.
Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Lifespan Respite Care Act of 2006”.

SEC. 2. LIFESPAN RESPITE CARE.

The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following:

“TITLE XXIX—LIFESPAN RESPITE CARE

“SEC. 2901. DEFINITIONS.

“In this title:

“(1) ADULT WITH A SPECIAL NEED.—The term ‘adult with a special need’ means a person 18 years of age or older who requires care or supervision to—

“(A) meet the person’s basic needs;

“(B) prevent physical self-injury or injury to others; or

“(C) avoid placement in an institutional facility.

“(2) AGING AND DISABILITY RESOURCE CENTER.—The term ‘aging and disability resource center’ means an entity administering a program established by the State, as part of the State’s system of long-term care, to provide a coordinated system for providing—

“(A) comprehensive information on available public and private long-term care programs, options, and resources;

“(B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and

“(C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient point of entry for such programs.

“(3) CHILD WITH A SPECIAL NEED.—The term ‘child with a special need’ means an individual less than 18 years of age^{42 USC 300ii}. Lifespan Respite Care Act of 2006.

Attachment D Continued

42 USC 201 note.

Dec. 21, 2006

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120 STAT. 3292 PUBLIC LAW 109-442—DEC. 21, 2006
age who requires care or supervision beyond that required of children generally to—

- “(A) meet the child’s basic needs; or
- “(B) prevent physical injury, self-injury, or injury to others.

“(4) ELIGIBLE STATE AGENCY.—The term ‘eligible State agency’ means a State agency that—

- “(A) administers the State’s program under the Older Americans Act of 1965, administers the State’s program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State’s programs under this title;
- “(B) is an aging and disability resource center;
- “(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and
- “(D) demonstrates—

- “(i) an ability to work with other State and community- based agencies;
- “(ii) an understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and
- “(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

“(5) FAMILY CAREGIVER.—The term ‘family caregiver’ means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.

“(6) LIFESPAN RESPITE CARE.—The term ‘lifespan respite care’ means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.

“(7) RESPITE CARE.—The term ‘respite care’ means planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

“(8) STATE.—The term ‘State’ means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

Attachment D Continued

“SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

“(a) PURPOSES.—The purposes of this section are—

- “(1) to expand and enhance respite care services to family caregivers;
- “(2) to improve the statewide dissemination and coordination of respite care; and
- “(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

“(b) AUTHORIZATION.—Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which an application is submitted pursuant to subsection (d). Intergovernmental relations. 42 USC 300ii-1.

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PUBLIC LAW 109-442—DEC. 21, 2006 120 STAT. 3293

“(c) FEDERAL LIFESPAN APPROACH.—In carrying out this section, the Secretary shall work in cooperation with the National Family Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

“(d) APPLICATION.—

“(1) SUBMISSION.—Each Governor desiring the eligible State agency of his or her State to receive a grant or cooperative agreement under this section shall submit an application on behalf of such agency to the Secretary at such time, in such manner, and containing such information as the Secretary shall require.

“(2) CONTENTS.—Each application submitted under this section shall include—

“(A) a description of the eligible State agency’s—

- “(i) ability to work with other State and community- based agencies;
- “(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and
- “(iii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients;

“(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of—

- “(i) the population of family caregivers;
- “(ii) the extent and nature of the respite care needs of that population;

Attachment D Continued

“(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

“(iv) existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;

“(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

“(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;

“(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;

“(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other VerDate 14-DEC-2004 11:52 Jan 03, 2007 Jkt 059139 PO 00442 Frm 00003 Fmt 6580 Sfmt 6581 E:\PUBLAW\PUBL442.109 APPS06 PsN: PUBL442 120 STAT. 3294 PUBLIC LAW 109-442—DEC. 21, 2006 Federal, State, and local funds, programs, contributions, other forms of reimbursements, personnel, and facilities;

“(ix) respite care services available to family caregivers in the eligible State agency’s State or locality, including unmet needs and how the eligible State agency’s plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs; “(x) the criteria used to identify family caregivers eligible for respite care services;

“(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and “(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating those results;

Attachment D Continued

“(C) assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and

“(D) a memorandum of agreement regarding the joint responsibility for the eligible State agency’s lifespan respite program between—

“(i) the eligible State agency; and

“(ii) a public or private nonprofit statewide respite coalition or organization.

“(E) PRIORITY; CONSIDERATIONS.—When awarding grants or cooperative agreements under this section, the Secretary shall—

“(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or enhancing lifespan respite care statewide; and

“(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents.

“(F) USE OF GRANT OR COOPERATIVE AGREEMENT FUNDS.—

“(1) IN GENERAL.—

“(A) REQUIRED USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds—

“(i) to develop or enhance lifespan respite care at the State and local levels;

“(ii) to provide respite care services for family caregivers caring for children or adults;

“(iii) to train and recruit respite care workers and volunteers;

“(iv) to provide information to caregivers about available respite and support services; and

“(v) to assist caregivers in gaining access to such services.

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“(B) OPTIONAL USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for—

“(i) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services;

“(ii) other services essential to the provision of respite care as the Secretary may specify; or

“(iii) training and education for new caregivers.

Attachment D Continued

“(2) SUBCONTRACTS.—Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities.

“(3) MATCHING FUNDS.—

“(A) IN GENERAL.—With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

“(B) DETERMINATION OF AMOUNT CONTRIBUTED.—Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

“(g) TERM OF GRANTS OR COOPERATIVE AGREEMENTS.—

“(1) IN GENERAL.—The Secretary shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

“(2) RENEWAL.—The Secretary may renew a grant or cooperative agreement under this section at the end of the term of the grant or cooperative agreement determined under paragraph (1).

“(h) MAINTENANCE OF EFFORT.—Funds made available under this section shall be used to supplement and not supplant other Federal, State, and local funds available for respite care services.

“SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.

“(a) ESTABLISHMENT.—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the ‘center’).

“(b) PURPOSES OF THE CENTER.—The center shall—

“(1) maintain a national database on lifespan respite care;

“(2) provide training and technical assistance to State, community, and nonprofit respite care programs; and

“(3) provide information, referral, and educational programs to the public on lifespan respite care.

Attachment D Continued

“SEC. 2904. REPORT.

“Not later than January 1, 2009, the Secretary shall report to the Congress on the activities undertaken under this title. Such report shall evaluate— 42 USC 300ii–3. 42 USC 300ii–2. VerDate 14-DEC-2004 11:52 Jan 03, 2007 Jkt 059139 PO 00442 Frm 00005 Fmt 6580 Sfmt 6581 E:\PUBLAW\PUBL442.109 APPS06 PsN: PUBL442

120 STAT. 3296 PUBLIC LAW 109–442—DEC. 21, 2006

LEGISLATIVE HISTORY—H.R. 3248:

HOUSE REPORTS: No. 109–716 (Comm. on Energy and Commerce).

CONGRESSIONAL RECORD, Vol. 152 (2006):

Dec. 6, considered and passed House.

Dec. 8, considered and passed Senate.

Æ

“(1) the number of States that have lifespan respite care programs;

“(2) the demographics of the caregivers receiving respite care services through grants or cooperative agreements under this title; and

“(3) the effectiveness of entities receiving grants or cooperative agreements under this title.

“SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.

“There are authorized to be appropriated to carry out this title—

“(1) \$30,000,000 for fiscal year 2007;

“(2) \$40,000,000 for fiscal year 2008;

“(3) \$53,330,000 for fiscal year 2009;

“(4) \$71,110,000 for fiscal year 2010; and

“(5) \$94,810,000 for fiscal year 2011.”.

SEC. 3. GAO REPORT ON LIFESPAN RESPITE CARE PROGRAMS.

Not later than January 1, 2011, the Comptroller General of the United States shall conduct an evaluation and submit a report to the Congress on the effectiveness of lifespan respite programs, including an analysis of cost benefits and improved efficiency in service delivery. Approved December 21, 2006.

Evaluation.

42 USC 300ii–4.

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Attachment E:

Table 1: Number of Caregivers and the Economic Value of Caregiving, by State, 2006

State	Total State Population	Number of Caregivers	Economic Value per Hour	Total Economic Value (millions)
Alabama	4,600,000	570,000	\$7.72	\$4,700
Alaska	670,000	68,000	\$12.28	\$900
Arizona	6,170,000	570,000	\$9.14	\$5,600
Arkansas	2,810,000	360,000	\$9.19	\$3,600
California	36,500,000	4,000,000	\$10.37	\$45,000
Colorado	4,750,000	540,000	\$10.68	\$6,200
Connecticut	3,500,000	380,000	\$11.65	\$4,800
Delaware	853,000	100,000	\$10.64	\$1,150
District of Columbia	582,000	59,000	\$10.11	\$640
Florida	18,090,000	1,720,000	\$9.29	\$17,300
Georgia	9,360,000	1,310,000	\$8.57	\$12,100
Hawaii	1,285,000	106,000	\$10.91	\$1,250
Idaho	1,466,000	162,000	\$8.70	\$1,520
Illinois (1)	12,830,000	1,500,000	\$9.98	\$16,200
Indiana	6,310,000	720,000	\$9.58	\$7,500
Iowa	2,980,000	310,000	\$10.59	\$3,500
Kansas	2,760,000	280,000	\$9.19	\$2,800
Kentucky	4,210,000	520,000	\$9.48	\$5,400
Louisiana	4,290,000	560,000	\$7.34	\$4,400
Maine	1,322,000	154,000	\$10.09	\$1,680
Maryland	5,620,000	600,000	\$9.79	\$6,300
Massachusetts	6,440,000	700,000	\$11.74	\$8,900
Michigan	10,100,000	1,280,000	\$9.71	\$13,400
Minnesota	5,170,000	610,000	\$10.91	\$7,100
Mississippi	2,910,000	460,000	\$7.66	\$3,800
Missouri	5,840,000	590,000	\$9.15	\$5,900
Montana	945,000	110,000	\$8.61	\$1,030
Nebraska	1,768,000	179,000	\$9.90	\$1,910
Nevada	2,500,000	260,000	\$10.47	\$3,000
New Hampshire	1,315,000	147,000	\$10.64	\$1,680
New Jersey	8,720,000	980,000	\$10.61	\$11,200
New Mexico	1,955,000	200,000	\$8.86	\$1,930
New York	19,310,000	2,200,000	\$10.27	\$24,000
North Carolina	8,860,000	1,080,000	\$9.14	\$10,700
North Dakota	636,000	56,000	\$9.10	\$550
Ohio	11,480,000	1,310,000	\$9.79	\$13,800
Oklahoma	3,580,000	370,000	\$8.67	\$3,500
Oregon	3,700,000	420,000	\$10.26	\$4,600
Pennsylvania	12,440,000	1,370,000	\$9.77	\$14,500
Rhode Island	1,068,000	117,000	\$11.41	\$1,440
South Carolina	4,320,000	560,000	\$9.01	\$5,500
South Dakota	782,000	86,000	\$9.40	\$880
Tennessee	6,040,000	770,000	\$8.71	\$7,200
Texas	23,500,000	2,700,000	\$8.21	\$24,000
Utah	2,550,000	330,000	\$9.06	\$3,200
Vermont (2)	624,000	56,000	\$10.57	\$640
Virginia	7,640,000	900,000	\$10.18	\$9,900
Washington	6,400,000	650,000	\$10.15	\$7,100
West Virginia	1,818,000	270,000	\$8.30	\$2,500
Wisconsin	5,560,000	600,000	\$10.45	\$6,800
Wyoming	515,000	55,000	\$9.74	\$570
United States	299,000,000	34,000,000	\$9.63	\$350,000

This table is unchanged from the original release. Notes: (1) Data on caregiving prevalence were missing for Illinois, so the national average prevalence was used; (2) in Vermont, the median wage for home health aides (one of the inputs to the value per hour calculation), was not available and was estimated as 1.084 times the median wage for personal care aides (the national ratio of the median wage of home health aides to personal care aides)

http://assests.aarp.org/rgcenter/:1/dd158r_caregiving.pdf

Attachment F: Side-by-Side Comparison in Other States ⁶

Table 5: Respite Care

Program	Provide Respite	Types of Respite Care Offered								CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites				
		Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
ALABAMA																				
FC	Alabama CARES	X				X	X	X												
MC	Elderly & Disabled Waiver	X				X	X					X						X	X	
ALASKA																				
FC	Family Caregiver Support Program	X			X	X						X			X					X
SC	Innovative Respite	X				X							X						X	
ARIZONA																				
FC	Family Caregiver Support Program	X			X	X	X	X				X		X						X
MC	AZ Long-Term Care System (ALTCS)	X			X	X	X					X		X				X		
SC	Non-Medical Home and Community Based Services	X			X	X	X	X				X		X						X
ARKANSAS																				
FC	Caring for the Caregiver Arkansas Caregivers	X			X	X	X					X		X						X
MC	ElderChoices Medicaid Waiver	X			X	X	X	X				X		X				X		
CALIFORNIA																				
FC	Family Caregiver Support Program	X			X	X	X	X				X			X					X
MC	Multipurpose Senior Services Program (MSSP)	X			X	X	X						X		X					X
SC	Adult Day Health Care Program	X			X							X			X					X
SC	Alzheimer's Day Care Resource Center (ADCRC)	X			X							X			X					X
SC	Caregiver Resource Centers (CRCs)	X			X	X	X	X				X		X				X		
SC	In-Home Supportive Services (IHSS)	X				X						X			X					X
COLORADO																				
FC	Family Caregiver Support Program	X			X	X	X	X				X		X				X	X	
MC	Home and Community-Based Services for the Elderly, Blind and Disabled	X			X	X	X						X	X				X		

Notes: Table is based on the Part 1 Survey (Question 20).
 Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
 Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
 CG=Caregiver; CR=Care Receiver; N/A=Not Applicable; NR=No Response; Svcs.=Services

⁶ The State of the States in Family Caregiver Support: A 50-State Study (NOVEMBER 2004) includes a series of data tables comparing how state programs responded to key survey questions. :Lynn Friss Feinberg, M.S.W; Sandra L. Newman, M.P.H.; Leslie Gray, M.P.H; Karen N. Kolb, M.S. all of the National Center on Caregiving; Family Caregiver Alliance In Collaboration With: Wendy Fox-Grage, M.P.A., M.S.G; National Conference of State Legislatures

Attachment F Continued

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
CONNECTICUT																		
FC	Family Caregiver Support Program	X		X	X	X	X	Live-in home health aide			X		X			X		
MC	Home Care Program for Elders	X		X	X	X	X				X			X				X
SC	Statewide Respite Care Program	X		X	X	X		Live-in home health aide			X		X			X		
SC	Personal Care Assistance State-Funded Pilot Program	X		X	X	X	X				X		X					X
DELAWARE																		
FC	CARE Delaware	X		X	X	X	X				X		X			X		
MC	Elderly & Disabled Waiver	X		X	X	X					X		X			X		
DISTRICT OF COLUMBIA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Elderly and Physical Disabilities Waiver	X			X	X	X			X			X			X		
FLORIDA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X		X	X	X	X				X			X				X
SC	Respite for Elders Living in Everyday Families (RELIEF)	X			X					X			X			X		
SC	Home Care for the Elderly	X		X	X	X	X			X				X				X
SC	Community Care for the Elderly	X		X	X	X	X				X			X				X
SC	Alzheimer's Disease Initiative	X		X	X	X	X				X			X				X
GEORGIA																		
FC	Family Caregiver Support Program	X		X	X	X	X	Extended respite (more than one weekend)			X			X				X
MC	Community Care Services Program (CCSP)	X		X	X	X	X				X			X				X
HAWAII																		
FC	Family Caregiver Support Program	X		X	X	X	X	Weekend support groups				X		X				X
MC	Nursing Home Without Walls	X		X	X	X	X			X				X				X
SC	Kupuna Care	X		X	X							X		X				X
IDAHO																		
FC	Family Caregiver Support Program	X		X	X	X				X				X				X
MC	HCBS Aged & Disabled Waiver	X		X	X					X			X			X		
SC	Senior Services Act, Respite Program	X		X	X	X				X				X				X

Attachment F Continued

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
ILLINOIS																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X				X	
MC	Community Care Program (CCP)	X		X								X			X			X
MC	Home Services program	X		X	X						X		X					X
INDIANA																		
FC	Caring and Compassion	X		X	X		X				X		X				X	
MC	Aged & Disabled Medicaid Waiver	X		X	X	X	X				X		X	X				X
SC	CHOICE	X			X		X				X			X				X
IOWA																		
FC	Iowa Family Caregiver	X		X	X	X					X			X				X
MC	Elderly Waiver	X		X	X	X	X				X			X				X
KANSAS																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X				X	
MC	Home & Community Based Frail Elder Waiver	X		X	X	X					X		X				X	
SC	Senior Care Act Program	X		X	X		X				X			X				X
KENTUCKY																		
FC	Family Caregiver Support Program	X		X	X						X		X					X
SC	Adult Day / Alzheimer's Respite	X		X	X		X				X			X				X
LOUISIANA																		
FC	Family Caregiver Support Program	X			X						X		X				X	
MC	Medicaid Home and Community-Based Waiver		X						X			X			X			X
MAINE																		
FC	Family Caregiver Program	X		X	X	X				X			X					X
MC	MaineCare	X		X	X	X					X		X					X
SC	Home-Based Care	X		X	X	X					X		X					X
SC	Partners in Caring	X		X	X	X	X				X		X					X
MARYLAND																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X					X
MC	Medicaid Waiver for Older Adults	X		X	X	X					X		X					X
SC	Respite for Caregivers of Adults with Functional Disabilities	X		X	X	X	X				X		X					X
MASSACHUSETTS																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X					X
MC	Home and Community-Based Waiver	X		X	X	X	X				X			X				X
SC	Home Care Program	X		X	X	X	X				X			X				X

Attachment F Continued

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
MICHIGAN																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	MI Choice	X		X	X	X					X			X				X
SC	State / Escheat Respite	X		X	X	X	X				X			X				X
SC	Caregiver Respite Program	X		X	X	X	X				X			X				X
MINNESOTA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Elderly Waiver	X		X	X	X		Out of home care provided by neighbor, friend, or family			X			X				X
SC	Alternative Care Program	X		X	X	X		Out of home care provided by neighbor, friend, or family			X			X				X
MISSISSIPPI																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Elderly and Disabled Waiver	X		X	X	X				X				X				X
MISSOURI																		
FC	Family Caregiver Support Program	X		X	X		X				X			X				X
MC	Aged and Disabled Waiver	X		X	X	X						X		X				X
MONTANA																		
FC	Family Caregiving Support	X		X	X	X				X				X				X
MC	Home and Community-Based Services Program for Elderly and Physically Disabled	X		X	X	X	X				X			X				X
NEBRASKA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Aged and Disabled Waiver	X		X	X	X	X	Individualized services			X			X				X
SC	Respite Subsidy Program Across the Lifespan	X		X	X	X	X			X				X				X
NEVADA																		
FC	Family Caregiver Support Program	X			X						X			X				X
MC	Community Home-Based Initiatives Program	X		X	X	X	X				X			X				X
SC	Independent Living Grant	X		X	X	X	X				X			X				X
SC	Community-Based Care Caregiving Training		X						X			X			X			X

Attachment F Continued

Type	Program Name	Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
		Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
NEW HAMPSHIRE																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X				X	
MC	Elderly and Chronically Ill Waiver	X		X	X	X	X				X		X				X	
NEW JERSEY																		
FC	Family Caregiver Support Program	X		X	X						X			X				X
MC	Community Care Program for the Elderly and Disabled	X		X	X	X	X	Assisted living			X		X				X	
MC	Enhanced Community Options (ECO)	X		X	X	X	X	Assisted living			X		X				X	
SC	New Jersey Statewide Respite Care Program (SRCP)	X		X	X	X	X				X		X				X	
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	X		X						X			X				X	
SC	Jersey Assistance for Community Caregiving	X		X	X	X	X	Assisted living			X		X				X	
NEW MEXICO																		
FC	Family Caregiver Support Program	X		X	X	X					X			X				X
MC	Disabled and Elderly Home and Community-Based Services Waiver	X			X					X			X				X	
NEW YORK																		
FC	Eldercare Family Support Program (EFSP)	X		X	X	X					X			X				X
SC	Respite Program	X		X	X	X	X				X		X				X	
NORTH CAROLINA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	X		X	X	X	X				X		X				X	
SC	Respite Care Program	X		X	X						X			X				X
NORTH DAKOTA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X			X	
MC	Aged & Disabled Waiver	X		X	X	X	X				X			X			X	
SC	Family Home Care	X			X	X	X				X			X			X	
OHIO																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	PASSPORT HCBS Waiver Program	X		X	X						X			X				X
SC	Alzheimer's Respite Program	X		X	X	X	X				X			X				X

Attachment F Continued

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
OKLAHOMA																		
FC	Family Caregiver Support Program	X		X	X	X					X		X					X
MC	Advantage Program	X			X	X				NR	NR	NR		X				
SC	Respite Resource Network	X		X	X	X	X				X		X			X		
OREGON																		
FC	Family Caregiver Support Program	X		X	X	X	X			NR	NR	NR	X					X
MC	Medicaid Waiver / In-Home Care	X		X	X	X						X		X				X
SC	Lifespan Respite Care Networks	X		X	X	X	X				X			X				X
PENNSYLVANIA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	PA Department of Aging 60+ Medicaid Waiver	X		X	X	X	X				X			X				X
SC	PA Family Caregiver Support Program	X		X	X	X	X			X				X				X
SC	OPTIONS	X		X	X	X	X				X			X				X
SC	BRIDGE	X		X	X	X	X				X			X				X
RHODE ISLAND																		
FC	Partners in CaRing	X		X	X	X					X		X			X		X
MC	Home and Community-Based Waiver		X						X		X	X			X			X
SOUTH CAROLINA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X					X
MC	Elderly / Disabled Home and Community-Based Waiver	X		X		X		Companion services			X		X			X		
SOUTH DAKOTA																		
FC	Caregiver Program	X		X	X	X	X	Weekly stay in a facility		X			X					X
MC	Home and Community-Based Elderly Waiver	X		X							X			X				X
TENNESSEE																		
FC	Family Caregiver Support Program	X		X	X	X	X					X	X					X
SC	Home and Community-Based Long-Term Care for Non-Medicaid Elderly and Adults with Disabilities		X						X			X			X			X
TEXAS																		
FC	Family Caregiver Support Program	X		X	X	X					X			X				X
MC	Community-Based Alternatives	X			X	X					X		X				X	
SC	Respite Care Program	X		X	X	X				X			X			X		
SC	In-Home and Family Support Program	X		X	X	X				X			X	X				X

Attachment F Continued

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/ Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A
UTAH																		
FC	Caregiver Support Program	X		X	X	X	X				X		X			X		
MC	Medicaid Aging Waiver	X		X	X	X					X			X				X
SC	Home and Community-Based Alternatives	X		X	X	X	X				X		NR	NR	NR			X
VERMONT																		
FC	Family Caregiver Support Program	X		X	X	X	X				X		X					X
MC	Home-Based Medicaid Waiver	X		X	X	X				NR	NR	NR	X			X		
VIRGINIA																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Elderly and Disabled Waiver	X		X	X	X	X			X			X			X		
SC	Caregiver Grant Program		X						X			X			X			X
SC	Respite Care Initiative Grant	X		X	X			Companion services; Hospice		X			X			X		
SC	Respite Care Grant Program 2003	X		X				Transportation to adult day care			X			X				X
WASHINGTON																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Community Options Program Entry System (COPEs)		X						X			X			X			X
SC	WA Family Caregiver Support Program	X		X	X	X	X				X			X				X
SC	Respite Care Services	X		X	X	X	X				X			X				X
WEST VIRGINIA																		
FC	Family Caregiver Support	X		X	X		X				X			X				X
MC	Medicaid Aged and Disabled Waiver		X						X			X			X			X
WISCONSIN																		
FC	Family Caregiver Support Program	X		X	X	X	X			X			X			X		
MC	Community Options Program Waiver (COP-W)	X		X	X	X	X			X				X				X
SC	Alzheimer's Family & Caregiver Support Program	X		X	X	X	X				X			X				X
WYOMING																		
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X
MC	Home and Community-Based Services Waiver for Elderly and Physically Disabled	X		X	X							X		X				X
SC	Community Based In-Home Services Program (CBIHS)	X		X	X			Chore services; Hospice			X			X				X