GIMME A BREAK: RESPITE CARE SERVICES IN OTHER STATES

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FOREWORD

This study was prepared in response to House Concurrent Resolution No. 187, House Draft 1. The Concurrent Resolution requested the Legislative Reference Bureau to study respite care policies and programs in other states, particularly those programs that focus on family caregivers who provide care to individuals aged 60 years or older or to chronically ill adults. This study also presents an overview of other states' statutory definitions of respite care and evaluation procedures used to evaluate the respite care programs that states provide.

The Bureau extends its appreciation to Jill Kagan of the Access to Respite Care and Help (ARCH) National Respite Network, the Hawaii Executive Office on Aging, and industry professionals in caregiver support and respite care for assisting the Bureau in this study.

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FACT SHEET

In responding to House Concurrent Resolution 187, House Draft 1 (2007), the Bureau reviewed how respite care programs and states define "respite care." The Bureau also researched other states' respite care programs, particularly those that offer respite care options to caregivers who are caring for older adults or adults with chronic illnesses. Finally, the Bureau looked at how five states assess their respite care programs. The salient findings of the review are highlighted below.

I. Background and Definitions of Respite Care

- There are 44 million family caregivers who provide unpaid care on a regular basis to adults with disabilities or chronic conditions. Although respite care is the most requested service by caregivers, respite care services may be unavailable, inaccessible, unused, or unaffordable to a majority of caregivers.

- A 2006 national study found that nearly all caregivers wish for a significant amount of respite care. But respite care is in short supply. A 2004 study found that only five percent of caregivers were receiving respite care.

- A general definition of "respite care" refers to services that provide "temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly."

- Respite care services can decrease the stresses of persons and families who provide care and it can also delay the need for institutionalization of the care recipient. Respite care can occur in the home, the community, a nursing home, or an institutional health care facility.

- Respite care can occur during the day or evening, overnight, for several days, or for weekends only. Some states have service caps on respite care, ranging from 4 hours per week, to 100 days per year, to a $3,500 limit on benefits per year. Other states have variable or no caps on services.

- Respite care may be categorized as planned or crisis respite care. Planned respite care is recurrent and occurs over extended periods of time. Crisis respite care occurs on short notice, usually during a family emergency or a crisis situation.

- While all 50 states and the District of Columbia provide some level of respite care through programs and services, there are at least 16 states that include a definition of “respite care” or "respite care services" in their statutes.

- Statutory provisions for respite care vary. Some states focus on services for older adults who have specific conditions or chronic diseases, while other states' statutes

make no reference to a care recipient's age or specific impairment or to financial need. Several states' statutes specify the types of settings in which respite care services may occur.

II. Respite Care Policies and Programs in Other States

- Although there are stand alone respite care programs, respite care options are most often included within a package of caregiver support services that includes information, access to training and education, case management, legal assistance, homemaker and chore assistance, transportation, or other services that assist caregivers.

- States design their respite care services by considering policy issues such as program concept, source of funding, scope of programs and services, and mode of service delivery. Other policy considerations in program design may include whether a program is legislatively mandated, the process for eligibility determination, the amount or limit of respite care benefits, and method of outreach.

- Other major policy considerations are flexibility and consumer control. Some respite care programs allow family caregivers to determine the kinds of services and who will provide those services, including respite care, for their family member. Other programs specify that respite care must be provided by an agency provider or an independent provider who is not a family member. Still, other programs do accommodate family members, relatives, or friends as providers of *paid* respite care services and will pay them directly for their services.

- There are primarily two federally-funded programs that offer respite care options: the National Family Caregiver Support Program (NFCSP) and the Home and Community-Based (HCBS) Medicaid Waiver Program. All 50 states and the District of Columbia receive NFCSP funds, which are allocated through a federal formula grant. In contrast, states have to apply for a waiver to implement the HCBS program. The waiver allows states to use Medicaid funds for non-medical expenses such as respite care. Forty-one states and the District of Columbia offer respite care through the HCBS waiver program.

- Another federal initiative is the Lifespan Respite Care Act of 2006. The Act authorizes competitive grants to states to collaborate with public, private, or non-profit networks to make quality respite care services available and accessible to family caregivers regardless of the care recipient's age or disability. However, the federal Lifespan Respite Care Act of 2006 is currently unfunded. The Act was based upon model state lifespan respite care programs in Oregon, Nebraska, Wisconsin, and Oklahoma, which provide respite care to caregivers and individuals regardless of age, special need, or situation.

- In addition to federally funded programs and initiatives, thirty-one states operate separate state respite care programs using state general funds or other state sources. Some states supplement their operating funds with a variety of other sources such as tobacco settlement funds, lottery funds, client-cost share, or voluntary client contributions.

III. Assessing State Respite Care Programs

- The evaluation procedures and criteria used to assess respite care programs may differ from state to state due to differences in the program's mission and operational objectives and whether the program services primarily benefit the caregiver, the care recipient, or both.

- The methods used to assess respite care programs include annual reports, program analyses, focus groups, surveys and studies of respite care services and implementation methods. The Bureau selected existing evaluation and assessment information from five states: California, Delaware, New Jersey, Pennsylvania, and Wisconsin.

- An evaluation of the partnership between the California Inland Caregiver Resource Center and the San Bernardino County Department of Aging and Adult Services to provide respite care services utilized three assessment methods: analysis of the relationship between respite need, utilization, and outcomes; individual interviews with staff of the two agencies; and facilitation of two caregiver focus groups. The evaluators found that the greatest benefit of the agencies' respite care services appears to be a reduction in the caregivers' feelings of overwork, overload, helplessness, and worry and a reduction in the factors that contribute to a caregiver's depression.

- The Delaware Caregiver Support Coalition conducted surveys, research, and discussions to examine how respite care was being provided statewide. Among issues and themes related to the shortcomings of Delaware's current respite care system are: caregivers' lack of awareness and understanding about the concept of respite care; gaps in availability of respite care services for those caring for persons with mental illnesses or behavioral disorders, as well as for younger individuals; and an inadequate supply of respite care options, specifically for emergency care and in-home care.

- The New Jersey Respite Care Program utilized two types of evaluative data: interviews with program staff from state and county levels and an analysis of the program's computerized administrative data. Staff interviews addressed program design, operations, strengths, and weaknesses. Administrative data files contained data elements such as care recipient characteristics, financial conditions of program participation, utilization, and expenditures. The study concluded that, from a staff perspective at the local and state levels, the program is being implemented well.

- Researchers designed a survey instrument to evaluate the Pennsylvania Elder Caregivers of Adults with Disabilities Pilot Project. The survey instrument consisted of questions about the caregiver's family, supports the family received, satisfaction levels, accessibility and flexibility to staff and services, choice and control, and other areas. The survey was used by evaluators to conduct face-to-face interviews with the caregivers enrolled in the pilot project. The evaluation showed that respite care was identified by the caregivers as the service they needed most. The caregivers also noted that the additional supports they could use include more respite care services, help with maintenance around the home, and transportation assistance.

- In Wisconsin, seven respite care programs throughout the state participated in a program that tested data collection instruments that were designed to evaluate outcomes of planned and crisis respite care. Evaluators used self-report questionnaires, face-to-face interviews, mail-outs, and telephone interviews. Evaluators found that data collected through the instruments held promise for measuring certain areas believed to indicate the effectiveness of respite care. These areas include decreasing family stress, preventing or delaying out-of-home placements; decreasing the likelihood of family destruction or family break up; and increasing the quality of family relationships.

- The evaluation information reviewed by the Bureau reflects that the five states were similarly concerned about: accurate needs assessment of caregivers; difficulty in finding an adequate supply of service providers; standardized data collection; and funds to continue evaluation efforts.

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Chapter 1

INTRODUCTION

Nature of the Study

During the Regular Session of 2007, the Legislature adopted House Concurrent Resolution No. 187, House Draft 1, entitled "Requesting the Legislative Reference Bureau to Study Respite Care Policies and Programs in Other States and the Executive Office on Aging to Conduct an Inventory of Respite Care Services in Hawaii." The concurrent resolution notes that fourteen to twenty-one percent of adults in the State of Hawaii serve as caregivers to persons aged 60 years or older. Respite care programs provide temporary relief for caregivers so that they may attend to other personal and professional obligations. This report responds to the request that the Legislative Reference Bureau review other states' respite care policies and programs, particularly those programs that focus on family caregivers who provide care to individuals aged 60 years or older or to chronically ill adults. A copy of the resolution is included as Appendix A.

Background

There are 44 million family caregivers who provide unpaid care on a regular basis to adults with disabilities or chronic conditions. [1] The majority of those who receive care are older adults, with nearly eight in ten care recipients aged 50 years or older.[2] The need for family caregivers is expected to increase, especially as Hawaii's older adult population is projected to grow at a rate three times faster than Hawaii's total population.[3]

Family and friends who care for their older, sick, or disabled loved ones often need help and other support systems such as respite care. Respite care is a service provided to those who are sick, frail, or disabled in residential homes, day centers, nursing homes, and hospices. Respite care services also benefit caregivers by temporarily relieving them from the stress and burden of their caregiving responsibilities.

Many local and state surveys indicate that respite care services are in great demand. A 2006 national study found that nearly all caregivers wish for a significant amount of respite care.[4] But respite is in short supply. In a 2004 study, caregivers reported that their most frequently unmet needs were "finding time for myself" (35%), "managing emotional and physical stress" (29%), and "balancing work and family responsibilities" (29%).[5] However, only five percent of caregivers were receiving respite care.[6]

Respite care may be categorized as planned or crisis respite care. Planned respite care tends to be recurrent and occurring over extended periods of time. Crisis respite care occurs on short notice, usually during a family emergency or a crisis situation. There are common barriers

that hinder family caregivers from receiving respite care. Respite care programs may be unavailable, inaccessible, unused, or unaffordable to a majority of caregivers.

Scope and Organization of the Study

This study will discuss other states' respite care programs that focus primarily on family caregivers whose care recipients are aged 60 years or older or adults with disabilities or chronic illnesses. It will also look at how states define the term "respite care," the types of respite care policies and programs operating in several other states, and procedures used by other states to assess the quality of the respite care they provide.

The remainder of this report is organized as follows:

(1) Chapter 2 presents general and state statutory definitions of "respite care";

(2) Chapter 3 discusses model respite care programs in other states;

(3) Chapter 4 focuses on evaluation procedures and other methods used by other states to assess the quality of their respite care services; and

(4) Chapter 5 presents conclusions.

Endnotes

[1] *Caregiving in the U.S.*, National Alliance for Caregiving and the American Association of Retired Persons, April 2004, p. 6.

[2] Ibid., p. 9

[3] "Profile of Hawaii's Older Adults and Their Caregivers," Hawaii Executive Office on Aging, May 2004, p. 2.

[4] *Caregivers in Decline, A Close-up Look at the Health Risks of Caring for a Loved One*, September 2006, p. 32.

[5] *Caregiving in the U.S.*, National Alliance for Caregiving and the American Association of Retired Persons, April 2004, p. 14.

[6] Ibid., p. 70.

Chapter 2

DEFINITIONS OF RESPITE CARE

Introduction

Respite care can encompass an assortment of services, occur in a range of settings, and vary in duration. The primary objectives of respite care are commonly understood to be caregiver relief and delayed institutionalization for the care recipient.[1] In a 1999 study of 33 caregiver support programs in 15 key states, some programs describe respite care as anything that enhances the caregiver's quality of life.[2] Other respite care programs include the education of informal caregivers, cash subsidies, or transportation services as part of their respite care options. For example, Florida's Home Care Program for the Elderly provides cash subsidies to caregivers as a form of respite.[3]

General Definitions of Respite Care

Although respite care is primarily geared to relieve the caregiver, it often encompasses services for the care recipient. For example, the Access to Respite Care and Help (ARCH) National Respite Network[4] defines respite care as "temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly."[5] The ARCH definition can include respite care services for the care recipient, such as adult day care, in-home care, or overnight at a nursing facility.

The Administration on Aging, United States Department of Health and Human Services (DHHS), defines respite care as encompassing "a wide variety of services, including traditional home-based care, as well as adult day care, skilled nursing, home health, and short term institutional care.[6] The DHHS notes that respite care benefits caregivers even though it can be in the form of services for the care recipient, such as:

(1) Adult day care that provides care and companionship for frail and disabled persons who need assistance or supervision during the day;

(2) Informal or volunteer respite care from other family members, friends, neighbors, or church volunteers who offer to stay with the elderly individual while the caregiver is away or doing errands; and

(3) In-home respite care that includes companion services for the care recipient; homemaker services to assist with housekeeping chores, preparing meals, or shopping; personal care services to help the care recipient bathe, get dressed, or exercise; and skilled care services to assist the family caregiver in tending to the care recipient's medical needs, such as when administering medications.

However, in a study of state policy trends and model programs in respite care, the Family Caregiver Alliance defines respite care as "brief, short-term services to a *care recipient* designed to provide relief to an informal primary caregiver."[7] Thus, the term respite care has been used to refer to services for the caregiver, care recipient, or both. Differences in definitions of respite care may reflect differences in program concepts and objectives, scope of the program, who the program's clients are, or how respite fits into the individual state's larger long-term care continuum.

Definitions of Respite Care in State Statutes

While all 50 states and the District of Columbia provide some level of respite care through programs and services, at least 16 states have a definition of "respite care" or "respite care services" in their statutes: Alaska, Arizona, California, Colorado, Connecticut, Florida, Illinois, Louisiana, Michigan, Missouri, New Jersey, Pennsylvania, Rhode Island, Texas, Virginia, and Washington. For a table of the definitions of "respite," "respite care," "respite care services," or "family respite care" in states' statutes, see Appendix B.

These states' statutes generally describe the duration of respite care as short term, temporary, intermittent, supplementary, or substitute care.[8] Only Florida,[9] New Jersey,[10] and Pennsylvania[11] include emergency respite care as part of their definition of respite care services.

A majority of the 16 states specifies that respite or respite care services are to provide relief for families, caregivers, or other providers: Arizona, California, Colorado, Florida, Illinois, Louisiana, Michigan, New Jersey, Pennsylvania, Rhode Island, and Washington. Alaska's definition of "family respite care" explicitly states that it is the "intermittent and substitute care that provides *relief for a family caregiver or adult foster home provider*..."[12] Arizona's statute provides that the program is to "provide respite care *for caregivers* ...."[13] California statutes refer to respite care as "providing *relief from the stresses of constant care provision* ...."[14] and for respite care to be "available to both *family caretakers* and persons referred by the regional centers for the developmentally disabled."[15] Connecticut's definition of "respite care services" states in pertinent part: "[S]upport services which provide short-term *relief from the demands of ongoing care for an individual* ...."[16] In contrast, however, the statutory language of Missouri's, Texas', and Virginia's definitions of "respite care" seems focused solely on care to the care recipient, without any implied relief to a caregiver.[17]

Four states focus respite care services on those who are or who care for older adults by requiring that care recipients be elderly persons, functionally dependent older adults, or adults with chronic dementia or Alzheimer's disease, or mental disorder.[18] Four other states specifically include as care recipients frail, aged, elderly, or infirm persons, along with other functionally disabled or impaired or mentally disordered persons.[19] Another six states make no reference to age considerations in their definitions, focusing instead on the inability of the person to care for him or herself.[20] Finally, two states make no specific reference to the condition of the care recipient in their definition of "respite care."[21] New Jersey's statute is the only one that specifically includes peer support and training for caregivers as part of respite care services.[22] A number of states' statutes list types of settings for respite care services within the definition.[23]

In defining respite care services, state statutes most frequently define the services provided as temporary or short-term care or supervision. A few states' definitions further clarify that respite care services include homemaker services, companion services, personal care services, and other "related" or "appropriate" services. Adult day services are expressly included in four states' definitions. Only one state's definition expressly provides peer support and training for caregivers. For a comparison of respite care services as provided by state statutes defining "respite care" or "respite care services," see Appendix X.

Conclusion

As noted earlier in this chapter, individual program definitions of respite care can include respite options geared for the caregiver, care recipient, or both. These different theoretical approaches reflect how a respite program views its mission and operational objectives, which may result in a distinct standard in the design of its respite services. Some states, despite the existence of state-funded respite options within its caregiver support programs, may not have a specific statutory definition of respite care.

For the purposes of this study, the terms “respite,” “respite care,” and “respite care services” refer to services for either the care recipient or caregiver that:

(1) Decrease the stresses of persons and families who provide care; or

(2) Delay the need for institutionalization of the care recipient.

Endnotes

[1] Mina Silberberg, "Respite Care: State Policy Trends and Model Programs," Family Caregiver Alliance, October 2001, p. 4.

[2] Ibid., citing Lynn Feinberg, *Survey of Fifteen States' Caregiver Support Programs*, Family Caregiver Alliance, 1999.

[3] Department of Elder Affairs, State of Florida. The subsidy payment is made to the caregiver for support and health maintenance and to assist with food, housing, clothing, and medical care of the care recipient, who must be at risk for nursing home placement.

[4] The Access to Respite Care and Help (ARCH) National Respite Network is a non-profit organization whose members are respite providers, family caregivers, disability and other community and faith-based organizations, state agencies, state respite coalitions, and the National Respite Coalition, an advocacy organization that works to preserve and promote respite in national, state, and local policies and programs. The ARCH Respite Network also provides a respite locator service to help caregivers and professionals locate respite services in their community.

[5] Website: http://www.archrespite.org/index.htm.

[6] Website: http://www.aoa.gov/press/fact/alpha/fact_respite.asp.

[7] Mina Silberberg, Ph.D., “Respite Care: State Policy Trends and Model Programs,” Policy Brief No. 4, Family Caregiver Alliance, 2001, p.1.

[8] Only Pennsylvania mentions "regular" service or similar language.

[9] Section 400.021, Florida Statutes.

[10] Section 30:4F-8, New Jersey Statutes.

[11] 62 PS Section 3063, Pennsylvania Statutes.

[12] Section 47.65.290(4), Alaska Statutes (emphasis added).

[13] Section 46-193, Arizona Revised Code (emphasis added).

[14] Section 4362.5, California Welfare and Institutions Code (emphasis added).

[15] Section 4418.6, California Welfare and Institutions Code (emphasis added).

[16] Section 17b-349e, Connecticut General Statutes Annotated (emphasis added).

[17] *See e.g.,* Missouri (care...and services for persons having Alzheimer's disease and related disorders"), Texas ("care needed by a person during respite care"), and Virginia ("provision of supplementary care and protection for aged, infirm, or disabled adults").

[18] The states are Arizona, Connecticut, Missouri, and Pennsylvania.

[19] These are California ("frail elderly persons, functionally impaired adults or mentally disordered persons"), Illinois ("frail or disabled adults"), Louisiana ("person with a disability or an infirm elderly person"), and Virginia ("aged, infirm or disabled adult").

[20] *See e.g.,* Alaska ("person who is at risk of institutional placement"), Florida ("individual who, without home-based care, would otherwise require institutional care"), Michigan ("individual whose health and welfare would be jeopardized if left unattended"), New Jersey ("functionally impaired adult"), Rhode Island ("clients who cannot entirely care for themselves"), and Washington ("adults with functional disabilities).

[21] *See e.g.,* Colorado ("client") and Texas ("person").

[22] Section 30:4F-8, New Jersey Statutes.

[23] *See e.g.,* Alaska ("home of a client or the caregiver, including adult foster care home if that is the client's residence), California ("home or in an out-of home setting, such as day care center or short-term placements in in-patient facilities", "institution", or "community-based program"), Colorado ("in the home or in a facility"), Florida ("nursing home"), Illinois ("in the home, in a day care setting during the day, overnight, [or] in a substitute residential setting such as a long-term care facility"), Louisiana ("in the home" or "in a facility"), New Jersey ("adult day care" or "short-term inpatient care in a facility"), Rhode Island ("inside or outside the home"), Virginia ("includes, but is not limited to adult day care services"), and Washington ("adult day services").

Chapter 3

RESPITE CARE POLICIES AND PROGRAMS

Introduction

Family caregiving is a demanding task with many challenges for those who provide care for a relative who is ill, injured, or frail. Because of the broad and long-term nature of their caregiving responsibilities, caregivers often experience stress, physical and mental health ailments, or burnout. Respite care provides time off for family caregivers to meet their own needs, take care of other responsibilities, or relax. Respite care services can be provided during part of a day or for several weeks and could include anything from: allowing the caregiver to nap, bathe, or otherwise rejuvenate him or herself; giving the caregiver a short break to attend a doctor's appointment, a church service, or a movie; allowing the caregiver a more extended break to take a much-needed vacation, simply visit friends or relatives, or schedule elective surgery.

While respite care is designed with the needs of the caregiver in mind, respite programs typically provide services for the care recipient, who is often an older adult with a range of physical or mental disabilities. Various public and private agencies operate respite care programs, including both for-profit and not-for-profit organizations. Respite care programs differ with respect to their definitions of respite, target populations, eligibility criteria, and the amount and type of respite offered. The programs can encompass traditional home-based care, as well as adult day care, skilled nursing, home health, and short-term institutional care.[1] Most respite care programs rely on contributions from participants, who pay a preset amount or on a sliding scale according to their financial resources.

Respite Care Policy Issues

States vary in how they design respite care services. Respite care can be provided on its own or as part of a larger package of supports. Policy considerations in how states design their respite care services include program concept, funding, scope of the program, program services, and mode of service delivery. Other operational policies considered may include whether a program is legislatively mandated, the process for eligibility determination, the amount of or limit on benefits, the mechanism for setting reimbursement rates, the approach to service planning, how the program is administered, and method of outreach.[2] Flexibility and consumer control, which allow the care recipient or caregiver to choose what best suits him or her, are also major policy considerations. A policy issue for states is who should provide the care and whether family members should be paid to provide respite services or whether respite care services should be provided through an agency, independent provider, or volunteer.

Three Models of Respite Care

There are generally three types of respite care models based on where the respite care service is provided: in the community, in the home, or in an institution.

Adult day care. Adult day care is a structured, community-based comprehensive program that provides a variety of health, social, and related support services in a protective setting during any part of a day but on less than a twenty-four-hour basis.[3] The program usually offers health and therapeutic services for participants, individual and group activities, and shared meals. Adult day care is designed to provide care and companionship for frail or disabled persons who need assistance or supervision during the day.

In-home care. In-home respite care takes place in the home in which the care recipient lives. It can occur on a regular or occasional basis and can take place during the day or evening hours.[4] In-home care provides personal or essential care for the care recipient or provides companionship or supervision. Some agencies that provide in-home care rely on trained volunteers to provide the respite care. For example, the Visiting Nurse Association of America created a partnership with older adults in Senior Companion Programs in 18 cities across the United States. The Senior Companion Program trains volunteers to assist older clients and their families by developing a relationship with dependent elders and, in the process, provides family caregivers much-needed respite.[5] In-home respite generally involves four types of services[6] for the care recipient:

(1) Companion services to help the family caregiver supervise, entertain, or just visit with the care recipient when he or she is lonely and wants company;

(2) Homemaker services to assist with housekeeping chores, preparing meals, or shopping;

(3) Personal care services to help the care recipient bathe, get dressed, go to the bathroom, or exercise; and

(4) Skilled care services to assist the family caregiver in tending to the care recipient's medical needs, such as when administering medications.

Facility- or institution-based care. This type of respite care differs from in-home and adult day programs in that it provides overnight and extended services. A bed in a nursing home or health care facility may be available for both planned and emergency respite stays, such as when a caregiver plans a vacation or a short weekend of relaxation.[7]

Respite Care Services and Funding

Respite care is most often included in a package of services that provide a variety of caregiver support services such as information, access to training and education, case management, legal assistance, homemaker and chore assistance, transportation, and other services to help caregivers. The following information on respite care programs and policies in

other states is organized according to the type of primary funding that states use to operate their respite care programs.

Federally-Funded Respite Options

Federal funds allow states to leverage their resources. Federal funding may have implications for program concept and program design, as states must follow requirements regarding eligibility rules and program administration.

National Family Caregiver Support Program (NFCSP). The enactment of the Older Americans Act Amendments of 2000[8] created the National Family Caregiver Support Program, which was modeled on caregiver support programs in states like Wisconsin, New Jersey, and California. NFCSP funds are used to provide information and assistance to access support services, counseling, training, and respite care. Through a federal formula grant, all states receive funds to work in partnership with area agencies on aging and local and community service providers to implement multi-faceted systems of support for family caregivers.

In fiscal year 2006, the Hawaii Executive Office on Aging (EOA) received $778,000 through the NFCSP. The actual amount spent on respite care services is unavailable from the Hawaii EOA as each county agency on aging has discretionary authority to fund caregiver services based upon the unique needs of their communities.

The National Association of State Units on Aging and the National Conference of State Legislatures have compiled information from various sources[9] about NFCSP-funded respite care and state-operated programs that support family caregivers and programs related to caregiving. The resulting compendium, *Family Caregiver Support, State Facts at a Glance,*[10] offers a profile of each state's or jurisdiction's policies on respite care. The major points of the compendium with respect to NFCSP-funded respite programs are summarized below.

Twenty-six states use state general revenues to supplement their NFCSP allocation grant funds.[11] Ten of those states use a combination of state, local, or county funds; voluntary client contributions; or private donors to add to their federal NFCSP grant.[12] Pennsylvania also adds tobacco funds, lottery funds, and a client share to fund its NFCSP respite care options.[13]

With regard to respite care options and eligibility requirements under the NFCSP, the report revealed that 26 states and the District of Columbia offer four types of comprehensive respite care services: adult day care, in-home, overnight in an institution or facility, and weekend or camp respite care. The states that offer all of these services are Alabama, Arizona, Colorado, Connecticut, Florida, Georgia, Hawaii, Indiana, Kansas, Maryland, Massachusetts, Michigan, Mississippi, Nebraska, New Hampshire, North Dakota, Ohio, Oregon, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, Virginia, Wisconsin, and Wyoming. An additional 15 states do not offer overnight, weekend, or camp respite options.[14] Another seven states offer three types of respite care options: adult day, in-home, and overnight.[15] Louisiana and Nevada offer only in-home respite care.

Eleven states[16] and the District of Columbia specify a monetary cap on respite care services. The caps on services range from $500 per person, per year in Maine to $3,500 per person, per year in Connecticut. Other states limit the number of respite care service hours allowed per person, per year, varying from an average of 8 hours per week in Arizona, to not more than seven consecutive days per year in Kansas, to 116 hours per year in Wisconsin, to 32 hours per month in Mississippi.

While some state-funded respite care programs do not require a minimum age for the care recipient, the NFCSP requires the care recipient to be at least 60 years old or older. Additionally, 46 states require the care recipient to have a physical or cognitive impairment or be unable to perform at least two activities of daily living (i.e., eating, bathing, walking, using the restroom, feeding oneself, etc.) to qualify for NFCSP-funded respite care services.[17] Thirty states and the District of Columbia require additional criteria relating to the care recipient, that is, in addition to having a physical or cognitive impairment, the care recipient *must* have a diagnosis of dementia or a related disorder; require supervision; or have a cognitive or mental impairment that requires substantial supervision.[18]

Most caregivers must also meet an age requirement. Twenty-one states require the caregiver to be 18 years of age or older,[19] while 28 states and the District of Columbia do not specify a minimum age. Wisconsin also requires the caregiver to live with the care recipient, and Florida requires the caregiver to be at least 19 years of age or older.

For more detailed information on the respite care options and eligibility requirements of NFCSP-funded respite care services offered on a state-by-state basis, see Appendix C.

Medicaid Home and Community-Based Services Waiver Program. Respite care is not covered as a regular Medicaid benefit because it is considered a non-medical expense. However, several Medicaid programs allow states the flexibility to operate Medicaid-funded programs by waiving federal Medicaid requirements. The Home and Community-Based Services (HCBS) Section 1915(c) Waiver Program is one type of waiver program and the only Medicaid program that pays for non-medical services such as respite care, case management, and environmental modifications in home and community settings.[20] Some states use HCBS funds for direct payments to respite care providers for adult day care, overnight, and weekend respite care services.[21]

The National Association of State Units on Aging and the National Conference of State Legislatures have compiled information about respite care services that are funded through the HCBS Section 1915(c) Waiver Program in their February 2006 publication, *Family Caregiver Support, State Facts at a Glance.*[22] The major points are summarized below.

Forty-one states and the District of Columbia offer respite care services through HCBS funds. In 14 of those states, the HCBS funds are supplemented by state general funds: Connecticut, Illinois, Kansas, Massachusetts, Michigan, Missouri, Nevada, New Hampshire, New Mexico, Ohio, Oregon, South Carolina, Texas, and Virginia. Pennsylvania supplements its waiver program with state tobacco funds. Seven other states do not operate HCBS-funded caregiver support programs: Alaska, Kentucky, New York, Tennessee, Vermont, Washington, and West Virginia. However, Tennessee and Vermont offer respite care services in programs that are funded by another type of Medicaid waiver program, the Research and Demonstration

Project (Section 1115) Waiver Program. Tennessee's Alzheimer's Demonstration Project and Vermont's Dementia Respite Program offer adult day, in-home, and institutional respite care options.

Of the states that offer respite care through HCBS funds, at least 16 states have no service caps on its respite care options.[23] At least three states have variable caps based upon need: Illinois, Indiana, and Iowa. Like the service caps on respite services funded by NFCSP funds, service caps on respite options funded by HCBS funds vary in terms of hours, days, and monetary amounts allowed per person, per year. Maryland caps respite care services at 168 hours per person, per year, while Mississippi's cap is 40 hours per month. Colorado caps services at 30 days per year. Monetary caps on services range from $1,000 per person, per month in New Jersey to $4,281 per year in Maine.

For a more detailed list of the states' respite care services funded through the federal HCBS waiver program, see Appendix D.

Lifespan Respite Care Act of 2006. The Lifespan Respite Care Act of 2006[24] was based on model lifespan respite systems in Oregon, Nebraska, Wisconsin, and Oklahoma, states that provide a coordinated system of access to affordable, community-based respite services for the lifespan of the care recipient. The Lifespan Respite Care Act of 2006 was signed into law on December 21, 2006. It authorizes competitive federal grants to states' Aging and Disability Resource Centers, in collaboration with a public or private non-profit state respite coalition or organization. The purpose of the Lifespan Respite Care Act is to make quality respite care services available and accessible to family caregivers regardless of the care recipient's age or disability.[25] The Act, which did not appropriate funds in 2006, is intended to allow state grantees to identify, coordinate, and build on federal, state, and local respite care resources and funding streams. The Act would also help support, expand, and streamline planned and emergency respite care services, recruitment training for community-based providers, and caregiver training. In its 2007 session, Congress appropriated $2 million to fund the Act through an appropriation bill.[26] However, the appropriation bill was vetoed by President Bush on November 13, 2007, and the House failed to override the veto on November 15, 2007.[27]

State Initiatives in Respite Care

Many caregiver support programs, which often include a respite care component, began as state level initiatives. This section will discuss state efforts in lifespan respite, as well as other model respite care programs funded primarily through state general revenues and state sources such as tobacco or lottery funds.

State Lifespan Respite Programs. Lifespan respite programs assist families with finding and using respite care services and operate on the guiding principle that everyone is eligible for community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need, or situation.[28] "Individuals" includes care recipients who have special needs or are at risk of abuse or neglect. "Special needs" criteria include any disability; any chronic or terminal illness; or a physical, emotional, cognitive, or mental health condition requiring ongoing care and supervision. Thus, while care recipients include the elderly, they are not the primary focus of the Lifespan Respite Programs.[29]

The states of Oregon, Nebraska, Wisconsin, and Oklahoma have been recognized as having model lifespan respite programs. A 2004 study of these states' lifespan respite programs offers a detailed comparison of the states' legislation, infrastructure, funding, and operations.[30] The study compares the states' definition of "caregiver," "respite care," "special needs," and "respite provider." It also compares lead agency requirements, administration and governing board makeup, and program elements such as planning, training, cultural competency, and provider recruitment. Highlights of the comparison chart are included below.

In 1997, Oregon was the first state to pass legislation to implement a lifespan respite program.[31] Administered by the Oregon Department of Human Services (ODHS), the Oregon Lifespan Respite Program provides respite care services by disseminating respite related information to the community, providing recruitment and training of respite care providers, connecting individuals or families with providers, and linking individuals or families with respite care payment resources. The ODHS implements these services by distributing state funds through contracts to local sponsoring agencies or local networks. The ODHS also joins with local respite partnerships to help plan, develop, and implement respite care options that reflect each community's strengths and needs. ODHS provides technical assistance on partnership development, meeting facilitation, problem solving, and strategic planning.[32]

When the program began in 1998, only 16 counties received assistance with establishing respite care networks. In 2000, local networks served 24 of Oregon's 36 counties. Since 2001, all counties in Oregon have established respite care networks.[33] Each local network has an advisory committee made up of community partners and consumers. The local networks have their own registries of respite care providers and often share recruitment and training activities with other entities.

The Nebraska Lifespan Respite Program, Respite Subsidy Plan Across the Lifespan, was created by legislation in 1999.[34] The program is funded with tobacco settlement funds and is implemented by the Nebraska Health and Human Services System (NHHSS). The NHHSS contracts with six local entities, each called a respite network, that are responsible for information and referral for families needing access to respite care; recruitment of respite care providers; marketing activities to increase public awareness of respite care; coordinating training opportunities for providers and consumers; and conducting quality assurance and program evaluation.[35] Like Oregon's program, the Nebraska lifespan respite program is explicitly for the purpose of responding to respite care needs before families and caregivers are in crisis. Nebraska emphasizes accessing an array of respite care services built on community support and providing respite care services that are driven by community strengths, needs, and resources.

In 1999, Wisconsin became the third state in the nation to pass lifespan respite care legislation.[36] It authorized the Wisconsin Department of Health and Family Services to contract with a private nonprofit organization, the Respite Care Association of Wisconsin (RCAW) to administer the program and distribute state grant funds equally among five administrative regions of the state. RCAW may distribute grants to a county department, a Native American tribe or band, or a community-based private entity that is operated for profit. In addition to conducting lifespan respite care projects, grantees must also contribute matching funds, develop best practice guidelines and a training curriculum, and create an advisory committee. The RCAW promotes the exchange of information and coordination among lifespan respite care

entities and acts as a statewide clearinghouse of information about respite care programs and resources.[37]

The Oklahoma Respite Resource Network (ORRN) is a collaboration of public and private agencies that support the development of volunteer respite programs such as the Respite Provider Registry, which provides a listing of agency respite providers, and the Respite Voucher Program, which provides funding assistance for the purchase of respite services. Financially eligible families receive a voucher that can be used for paying professionals, family, or friends for respite care services up to three months from the date of issuance.

Although ORRN was not established by statute, the Respite Voucher Program is funded by the Oklahoma Department of Human Services. The voucher program, which began in 2000, is the cornerstone of the state's lifespan respite program. The voucher system is unique in that it allows families maximum control over who provides respite services for their family member. Family caregivers hire their own providers and negotiate payment.[38] Vouchers can be used for the purchase of respite care in the setting of the family's choice. Caregivers with an annual household income of less than $60,000 may be eligible to receive vouchers for respite care. For caregivers applying for a family member aged 60 years or older, there is no income limitation.[39]

Other State-Funded Respite Care Initiatives. The National Association of State Units on Aging and the National Conference of State Legislatures 2006 report discussed previously[40] also provides information on respite care services that are funded primarily through state general funds. The major points of the report regarding state-funded respite care services are summarized below.

Thirty-one states have caregiver support programs that offer respite care options as part of a package of services.[41] Of the 31 states, seven also have stand alone programs that offer only respite care services.[42] Some states require care recipients to meet one or a combination of the following eligibility criteria: impairment in at least one activity of daily living, a diagnosis of dementia or a related disorder, being at risk for institutionalization, or needing a nursing home level of care.[43]

Twenty-one states (68%) offer comprehensive options for respite services: adult day, in-home, overnight, or weekend respite care.[44] California also offers weekend caregiver retreats. As with the federal NFCSP and Medicaid waiver programs, caps on services vary in terms of hours, days, weeks, and dollar amounts. California's Caregiver Resource Centers have a cap of $3,600 per person, per year, while Florida's Respite for Elders Living in Everyday Families allows a maximum of 4 hours of care per week, per person. New York's respite program limits services to 100 days per person, per year.

The sources of state funds for respite care services are also varied. The New Jersey Statewide Respite Care Program, which has been operational since 1988, has historically been financed by state casino revenue funds and supplemented by client cost-share. In addition to state general funds, several states use tobacco settlement funds: Florida, Michigan, Nebraska, and Nevada. Pennsylvania supplements its state funds with tobacco settlement and lottery funds.

For additional information on state-funded programs, see Appendix E.

Conclusion

There are a variety of respite care services in other states. Policy considerations for the design of respite care services include the program's concept, scope, services, mode of service delivery, and funding. States are also setting policies on service flexibility and consumer control practices, which can provide a balance between freedom to choose respite care options and management accountability.

Respite care is most often included in a package of services that provide a variety of caregiver support services. Comprehensive respite services are provided in a variety of settings, the most common of which are adult day care, in-home care, and facility- or institution-based care.

The two major federally-funded respite care programs are the NFCSP (National Family Caregiver Support Program) and the HCBS (Home and Community-Based Services) Medicaid Waiver Program. The NFCSP was enacted in 2000 and was modeled after state respite care programs. All 50 states and the District of Columbia receive NFCSP-funds, which are allocated through a federal formula grant. In contrast, states have to apply for a Medicaid waiver to implement the federal HCBS program so that states may use Medicaid funds for non-medical expenses such as respite care. Forty-three states and the District of Columbia offer respite services though HCBS waiver programs. Another federal initiative, the Lifespan Respite Care Act of 2006, is currently unfunded. It passed the 2007 Congress with a $2 million appropriation, but was vetoed in November by President Bush.

Thirty-one states have implemented state-funded respite care programs. Some supplement their program funds with a variety of other sources such as tobacco, lottery, client-cost share, and voluntary client contributions. Four states—Oregon, Nebraska, Wisconsin, and Oklahoma—have initiated model lifespan respite programs, which provide respite to caregivers and individuals regardless of age, special need, or situation.

Endnotes

[1] U.S. Department of Health and Human Services, Administration on Aging, Respite Care Fact Sheet. Website: http://www.eldercare.gov/eldercare/Public/resources/fact_sheets/respite_care_pf.asp.

[2] Mina Silberberg, Respite Care: State Policy Trends and Model Programs, Family Caregiver Alliance, 2001, p. 3.

[3] Karen A. Roberto, citing National Council on Aging (2001). http://family.jrank.org/pages/1402/Respite-Care.html.

[4] Ibid.

[5] Ibid, citing Fisher and Schaffer (1993).

[6] U.S. Department of Health and Human Services, Administration on Aging, Respite Care Fact Sheet. Website: http://www.eldercare.gov/eldercare/Public/resources/fact_sheets/respite_care_pf.asp.

[7] Karen A. Roberto, citing Lawton et al., (1991). http://family.jrank.org/pages/1402/Respite-Care.html.

[8] Public Law 106-501.

[9] The report's authors cite source information that includes results from the National Association of State Units on Aging email surveys to the State Family Caregiver Support Program contacts, June 2005; Family Caregiver Alliance and National Center on Caregiving's *The State of the States in Family Caregiver Support: A 50-State Study*, 2004;

the National Family Caregiver Association's *Prevalence and Economic Value of Family Caregiving,: State-by-State Analysis*, 2000; and U.S. Census Bureau, Census 2000.

[10] Greg Link, Virginia Dize, et al, *Family Caregiver Support, State Facts at a Glance*, National Association of State Units on Aging and the National Conference of State Legislatures, February 2006.

[11] The 26 states are: California, Delaware, Florida, Georgia, Hawaii, Kansas, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, Montana, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Vermont, Utah, and Wyoming.

[12] The ten states are: California, Hawaii, Massachusetts, Montana, New Mexico, New York, North Carolina, Oklahoma, Pennsylvania, and Rhode Island.

[13] See notes 11 and 12.

[14] The 15 states are: Idaho, Illinois, Iowa, Maine, Minnesota, Missouri, Montana, New Mexico, New York, North Carolina, Oklahoma, Rhode Island, Tennessee, Texas, and Washington.

[15] The seven states are: Alaska, Arkansas, California, Delaware, Kentucky, New Jersey, and West Virginia.

[16] The states are: Arkansas, Colorado, Connecticut, Maine, Maryland, Nebraska, New Hampshire, North Dakota, Oklahoma, South Dakota, and Vermont.

[17] Massachusetts, Nevada, New Jersey, and West Virginia do not require care recipients to have an impairment with two or more activities of daily living.

[18] The 30 states that require an impairment with two activities of daily living *and* a diagnosis of dementia or a related disorder and/or require supervision are: Alaska, Arkansas, Colorado, Connecticut, Florida, Georgia, Hawaii, Indiana, Iowa, Kansas, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, Oklahoma, Oregon, Rhode Island, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia, and Wyoming.

[19] The 21 states are Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Indiana, Kansas, Maine, Massachusetts, Minnesota, New Mexico, New York, North Carolina, North Dakota, Pennsylvania, South Carolina, Utah, Washington, and Wisconsin.

[20] U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services website. http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/.

[21] Greg Link, Virginia Dize, et al., *Family Caregiver Support, State Facts at a Glance*, National Association of State Units on Aging and the National Conference of State Legislatures, February 2006.

[22] Ibid.

[23] The 16 states are: Connecticut, Florida, Georgia, Hawaii, Massachusetts, Michigan, Missouri, Montana, Nebraska, Nevada, Ohio, Oregon, Pennsylvania, South Dakota, Utah, and Wisconsin.

[24] Public Law 109-442, 120 Stat. 3288.

[25] Hawaii is in the process of establishing an Aging and Disability Resource Center.

[26] On July 19, 2007, the United States House of Representatives included $10 million to fund the Act as part of the Labor and Health and Human Services budget bill, HR 3043. However, in final deliberations with the Senate, the final appropriation amount was reduced to $2 million.

[27] Telephone interview on November 19, 2007, with staff of Senator Daniel K. Akaka.

[28] Linda Baker and Maggie Edgar, *Statewide Lifespan Respite Programs: A Study of 4 State Programs*, ARCH National Resource Center for Respite and Crisis Care Services, August 2004, p. 5.

[29] Ibid., p.15. Four states: Nebraska, Oklahoma, Oregon, and Wisconsin, reported information on the age and number of clients the program served in 12 months, from approximately March 2003 to March 2004. The breakdown of each state's elderly client population receiving respite care services by age and the percentage of clients aged 60 and older are noted in the table below.

STATE	AGE OF CLIENT	NUMBER OF CLIENTS	% OF TOTAL CLIENTS
Nebraska	Over 65	160	37%
Oklahoma	Over 60	2,312	68%
Oregon*	Over 60	479	25%
Wisconsin	Over 65	58	17%

*Not all of the respite care networks in Oregon track the ages of their clients, but those that do reported these figures.

The study also asked the states to indicate any conditions or disabilities their client population had. Since the state responses did not link the disability or condition to the age of the client, the number of clients who are adults with disabilities is undetermined.

[30] Ibid. The study, *Statewide Lifespan Respite Programs: A Study of 4 State Programs*, ARCH National Resource Center for Respite and Crisis Care Services, August 2004 is available at http://www.archrespite.org/LifespanRespiteReportFINAL9_30_04.pdf.

[31] Section 409.458, Oregon Revised Statutes.

[32] *Building Oregon's Lifespan Respite Care System*, Oregon Department of Human Services, p. 8. Document available at http://www.oregon.gov/DHS/spd/caregiving/ls_respite.shtml.

[33] Ibid., p. 12.

[34] Section 68-1524, Nebraska Revised Statutes.

[35] Nebraska Department of Health and Human Services website at http://www.hhs.state.ne.us/hcs/respite-network.htm.

[36] Section 46.986, Wisconsin Statutes and Annotations.

[37] Linda Baker and Maggie Edgar, *Statewide Lifespan Respite Programs: A Study of 4 State Programs*, ARCH National Resource Center for Respite and Crisis Care Services, August 2004, p. 22.

[38] Ibid., pp. 7-8.

[39] "Oklahoma Respite Resource Network, Providing the Gift of Time," Oklahoma Commission for Human Services, August 2003, p. 5.

[40] See note 10, supra, and accompanying text..

[41] The states are: Alaska, California, Connecticut, Florida, Hawaii, Indiana, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Nebraska, Nevada, Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Virginia, Wisconsin, and Wyoming.

[42] The states and their programs are: Alaska (Adult Day Services Program), California (Adult Day Health Care Program, Linkages, and Respite Purchase of Services Program), Kentucky (Adult Day Alzheimer's Respite Program), Michigan (Caregiver Respite Program, State/Escheat Respite Program), Nebraska (Respite Subsidy Program Across the Lifespan), New York (Respite Program), and Oklahoma (Respite Resource Network). These programs are considered "stand alone" programs because they offer only respite care services, as opposed to additional types of caregiver support services such as education, training, legal assistance, etc..

[43] For example, California's Caregiver Resource Centers requires care recipients to have an adult onset cognitive disorder. Florida's Community Care for the Elderly Program requires care recipients to meet a nursing home level of care although they are being cared for at home by a caregiver. Michigan's Caregiver Respite Program requires care recipients to have a disability, but participants in its State/Escheat Respite Program must have at least two impairments in performing an activity of daily living or a cognitive impairment. The New Jersey Statewide Respite Care Program requires care recipients to have a chronic physical or mental disability.

[44] The states are: California, Connecticut, Florida, Maine, Maryland, Massachusetts, Michigan, Minnesota, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Tennessee, Utah, and Wisconsin.

Chapter 4

ASSESSING THE QUALITY OF RESPITE CARE

States with respite programs assess the quality of respite care services in a variety of ways. The methods used by other states to assess the quality of respite care services include annual reports, program analyses, focus groups, surveys, and studies of respite care services and implementation methods. The Bureau selected evaluation information from five states: California, Delaware, New Jersey, Pennsylvania, and Wisconsin.

California

In 2002, the Inland Caregiver Resource Center (ICRC) and the San Bernardino County Department of Aging and Adult Services (DAAS) formed a collaborative partnership to deliver respite services to family caregivers. The ICRC, a state agency, is one of California's eleven caregiver resource centers, and the San Bernardino DAAS, a county agency, is one of California's thirty-three area agencies on aging.[1] In 2004 an evaluation was conducted of their respective respite programs.[2] The objectives of the evaluation were to:

(1) Explore the themes of respite need, utilization, and outcomes;

(2) Evaluate the current relationship between the ICRC and the San Bernardino DAAS; and

(3) Identify new respite domains, data elements, outcome measures, and client satisfaction survey questions to increase the quality and effectiveness of caregiver respite services.

Researchers used three evaluation methods: a comprehensive review of existing respite care literature that addressed respite need, utilization, and outcomes; individual interviews with ICRC and DAAS staff members to analyze the current relationship between ICRC and DAAS; and the facilitation of two caregiver focus groups to explore caregiver respite benefits administered by ICRC. Information gathered from the review of existing respite care literature on need, utilization, and outcomes was used to develop survey questions for the focus groups.

Each focus group participant was asked to complete a brief survey that covered a series of demographic questions related to the caregiver's respite experience. A facilitator guided the focus group discussion, which lasted approximately sixty to ninety minutes and was tape recorded and transcribed. Throughout the discussion, participants were asked several broad lead-in questions, as well as specific questions about their respite care experience.[3] The focus group discussions centered on the qualitative experience of respite—what was good, what was challenging, and how ICRC could improve the respite care benefit for caregivers. The first focus group consisted of six caregivers who had received a $1200 respite care benefit or an $800

respite care grant,[4] but no family consultation or other support services though ICRC. The second focus group consisted of seven caregivers who received a $1200 respite care benefit, along with extensive family consultation, caregiver assessment, and follow-up support services from ICRC prior to receiving their respite care benefit.

Researchers analyzed focus group transcripts to identify key categories or themes in the qualitative data collected and the relationships among the data. Key themes and issues that emerged from the first focus group were: gratitude, caregiver stress and isolation, limited informal social support, and lack of formal caregiver support and training. The second focus group had several predominant themes that were similar to those of the first group, specifically gratitude, limited family support, and caregiver stress and isolation. However, the second focus group acknowledged the positive effects of respite for the care recipient as well as the care giver;[5] the existence of a strong community network; and a "spirited recognition" of the value and "magic" of ICRC's caregiver support and assistance efforts. The second focus group overwhelmingly reported their respite experience as positive.[6]

Relationship between need, utilization, and outcomes

The evaluation found that no single conceptual model or approach definitively captures the relationship between need, utilization, and outcomes. It also found that a myriad of factors and characteristics influence a caregiver's decision to seek or not seek respite services or to use services for a long or short period of time. While need may be related to the number of impairments the care recipient has with activities of daily living or the level of burden experienced by the caregiver, other factors such as the flexibility of the respite service or the caregiver's ability to make choices regarding the respite benefit were found to be just as important.[7] Other variables affecting need and utilization included trusting a stranger to come into the home, having the time to prepare a loved one for day care, and caregivers' understanding of the benefits of respite for care recipients.

Current relationship between the ICRC and the San Bernardino DAAS

The evaluation found that ICRC and DAAS staff identified a primary area of confusion with regard to their joint efforts to serve caregivers through a respite care benefit program. Staffs highlighted a fundamental misunderstanding each agency had of the other agency's policies, internal processing system, and measures of accountability.[8] The following were identified as contributors to misunderstandings regarding the respite care contract between ICRC and the DAAS:

(1) Lack of familiarity with contractual obligations with respect to respite care benefits and the referral process;

(2) Slow processing in the delivery of respite care services by ICRC due to a respite care waiting list, which contributed to the DAAS staff perception that ICRC was not doing all they could;

(3) Difficulty of providing immediate or emergency respite care due to external administrative barriers such as obtaining a tuberculosis clearance and medical evaluations; and

(4) Confusion about repeat users and which agency should determine caregiver eligibility for repeat respite care benefits in a single fiscal year.

Recommendations to increase quality and effectiveness of caregiver respite services

Based on the information provided by focus group participants, evaluators found that the greatest benefit of respite care appears to be a reduction of the participants' feelings of being overworked and overloaded in their caregiving duties; a reduction of their feelings of helplessness, worry, strain, and burden; and a reduction of the factors contributing to a caregiver's depression. The study recommended that the ICRC administer a respite assessment instrument that would evaluate change in the aforementioned areas. The instrument is intended to capture basic information on the primary stressors a caregiver may be experiencing, the level of assistance a caregiver provides his or her care recipient, and how often a caregiver has to deal with a care recipient's problem behavior.[9] Behavior problems identified included the care recipient being verbally aggressive to others, engaging in behavior that is potentially dangerous to self or others, appearing anxious or worried, or doing things that embarrass the caregiver. The recommended survey instrument includes questions that focus on a caregiver's role, burden, and depression as measures in which a respite intervention is most likely able to yield change.[10] The caregiver respite survey instrument is attached as Appendix F.

Additionally, the evaluation outlined strategies for DAAS and ICRC to maximize their potential to reach and assist more caregivers within San Bernardino County. Among the specific recommendations were:

(1) Improve communication and collaboration by conducting regularly scheduled meetings between the two agencies as a way to produce creative strategies and receive an honest assessment of the quality and effectiveness of caregiver services being provided, with the goal of becoming a "best practice model" in caregiver programming;

(2) Provide every caregiver referred with a family consultation and caregiver assessment; and

(3) Regularly evaluate and hone caregiver interventions by more effectively identifying caregivers under extreme stress and in need of caregiver support services.

Delaware

In October 2005, the Delaware Caregivers Support Coalition issued a report on the results of a respite care needs assessment it conducted through two surveys.[11] The Coalition surveyed caregivers and consumers with one survey and service providers with another survey. Although the Coalition did not evaluate the actual programs of public or private respite care providers,[12] 23 service providers were contacted and 74% responded to the survey. The purpose of the surveys was to examine how respite care was being provided in the State of Delaware. The surveys and discussions conducted by the Coalition identified several themes related to issues or shortcomings of the current respite care system.

Information about respite care. There is a general lack of awareness and understanding about the concept of respite care by caregivers, and this may keep consumers from trying to access needed relief. Participation records from the Delaware Department of Health and Social Services indicate that only 20% of those eligible for respite care take advantage of the service.[13] The survey also found that since there is no central source of information about respite, caregivers and consumers may not know where to begin to identify options.

Supply of the number and type of respite care services. The Coalition's research has identified groups of less served populations. There are gaps in respite care services for those with certain disabilities, such as mental illness and behavioral disorders, as well as for younger individuals. The Coalition also found an inadequate supply of respite care options, specifically in emergency care and in-home care.

Affordability of respite care. Financial support for respite care is often tied to a specific disability, such as Alzheimer's disease or autism, and 55% of survey respondents indicated that they would not be able to afford respite care because they are already financially strained by the costs associated with care.

Quality of respite care. The survey found that the major concerns of caregivers with regard to quality of respite care are: the safety of their loved ones when they are not present to supervise; what will happen to their loved one when they are no longer able to provide care; finding caring, compassionate caregivers who understand the care recipients as well as their disability and who will provide dignified care and stimulation; and finding trustworthy caregivers to provide care in case of an emergency for respite care services.

New Jersey

Statewide Respite Care Program

In 2001 the Rutgers' Center for State Health Policy published its study of the New Jersey Statewide Respite Care Program (SRCP)[14] to provide useful information on program operations. The study utilized two types of data: interviews with program staff from state and county levels; and analysis of the program's computerized administrative data. Staff interviews addressed program design, operations, strengths and weaknesses, important program changes, and

contextual concerns.[15] Administrative data files contained data elements such as care recipient characteristics, financial conditions of program participation, utilization, and expenditures. The qualitative and quantitative data were analyzed together to assess the significance of program changes and program context.

The SRCP, operational since 1988, is financed by state casino revenue funds, tobacco settlement funds, and is supplemented from a client co-share based upon a sliding scale. The primary goals of the SRCP are to provide relief and support to unpaid caregivers of frail elderly or disabled adults and to delay institutional placements.[16] The program is administered locally by county coordinators who work for sponsor agencies that have contracted with the state Department of Health and Senior Services.

The study's findings encompassed the following program issues: mission and approach, participation by the target population, budget, statewide implementation, local implementation, program flexibility and convenience, service use and diversity, Alzheimer's disease and senile dementia, market restrictions, and benefits to clients.[17]

The study concluded that, from a staff perspective at both the local and state levels, the SRCP is being implemented well and performing well.[18] The program received high marks on program procedures, intra-program relationships, external relationships, and benefits to the client. Additionally, the study notes that qualitative and quantitative data reveal additional strengths, such as outreach to the poor, which were not mentioned by staff.

Community Care Program for the Elderly and Disabled

As a companion to its study on the SRCP, the Rutgers' Center for State Health Policy published a study of the New Jersey Community Care Program for the Elderly and Disabled (CCPED) in 2002.[19] The study utilized interviews with state and county program staff and analysis of CCPED's computerized administrative data. These data were used to describe the design and implementation of CCPED, with particular attention to respite service, important program changes, perceived strengths and weaknesses of the program, the client profile, and service use patterns.

CCPED began operations in 1983 and is funded through federal Medicaid dollars and state casino revenues. The purpose of CCPED is to help individuals stay in or return to the community rather than being cared for in an institutional setting.[20] The program provides eight types of services: medical day care, transportation, home health, prescription drugs, case management, respite, homemaker, and social day care. Because its emphasis is on preventing institutionalization, CCPED considers the care recipient as its primary client, not the caregiver.[21] Respite care is usually used in case of a caregiver emergency, vacation, illness, or other event and is generally offered to the care recipient in an institutional setting.

The study found that CCPED's implementation strengths include: flexibility, a client service orientation, open lines of communication, timely responses to concerns, and strong state support of the counties. Some challenges for CCPED also emerged in the study. Several interview respondents suggested that the program's emphasis on preventing institutionalization

and the program's philosophy of respecting consumer autonomy might be leading caregivers to provide services at home. The study noted that some care recipients may be so debilitated as to be unsafe in the home setting.[22] Another concern for interview respondents was the difficulty of locating and hiring an adequate number of service providers, particularly home health aides. Interview respondents emphasized that when home health aides are not available, they find it difficult to find nursing homes that will take clients for short-term stays. The availability of an adequate number of respite care options would help decrease the need for care recipients to be placed in short-term institutional care.

Pennsylvania

The Pennsylvania Elder Caregivers of Adults with Disabilities (ECAD) Pilot Project offers a variety of services to caregivers, including respite care. Begun in 2000, ECAD was designed to provide support to primary caregivers over the age of 60 who are caring for their adult relatives with disabilities. Temple University, which was contracted by the Pennsylvania Department of Aging, completed an evaluation of ECAD in 2004.[23]

A survey instrument was designed to evaluate the pilot project. The survey consisted of questions about the caregiver's family, supports the family received, satisfaction levels, accessibility and flexibility to staff and services, choice and control, how much life had changed, and other areas.[24] The survey was used by the evaluation researchers in conducting face-to-face interviews with the caregivers enrolled in the pilot project. Initial and post interviews were also conducted. Of the 103 elder caregivers who participated in the evaluation, 17% were caring for an adult over the age of 51.[25]

Respite care was identified by the caregivers as the service they needed most, followed by homemaker services, home renovation or modification, medical expenses and health-related items and general household expenses.[26] Nineteen percent of the caregivers also reported that they received reimbursement from ECAD for respite care.[27] The evaluation generally yielded positive results. More than 50% of the caregivers reported that the supports and services provided by the program were meeting their needs: most (64%) caregivers reported they received enough support and were appreciative of the reimbursement and support they received, and 5% stated that the support they received was more than enough; however, 30% stated that the support they received was not enough to help them care for their family member.[28] Caregivers noted that additional supports they could use include more respite care services, help with maintenance around the home, and transportation assistance.[29] Caregivers also reported high levels of satisfaction with the program and high levels of choice and control over the supports and services they received throughout the project.[30]

Wisconsin

In December 1999, a guidebook for evaluating and reporting outcomes in respite and crisis care programs was published by the ARCH National Respite Network in collaboration with the University of Carolina.[31] The guidebook explains what outcomes are and includes a set of instruments for evaluating the outcomes of respite and crisis care programs. The instruments used are self-report questionnaires designed to measure changes in the behavior or status of families and caregivers in areas such as stress, family relationships, risk of out-of-home placement, and risk of maltreatment—areas believed to be impacted by planned respite or crisis care.[32] The first set of questionnaires is designed to evaluate the outcomes of planned respite care,[33] while the second set of questionnaires is designed to evaluate crisis care outcomes. The questionnaire used to evaluate planned respite care services is attached as Appendix G.

From 2000 to 2002 the Respite Care Association of Wisconsin and the Lifespan Respite Care Networks participated in a program to test these data collection instruments. Seven respite care programs across Wisconsin were selected to participate as pilot sites. Face-to-face interviews and a combination of mail-outs followed up with telephone interviews were utilized. A follow-up report to the 1999 guidebook that describes the field testing process, outcomes of the field testing, and recommendations for use of the guidebook and instruments was published by the Respite Care Association of Wisconsin in 2003.[34]

The report found that data collected through the instruments hold promise for measuring the effectiveness of respite care on a variety of outcomes: decreasing family stress, preventing or delaying out-of-home placement, decreasing the likelihood of family destruction, and increasing the quality of family relationships.[35] The report noted that the data demonstrate the value of both planned and crisis respite care programs and makes a strong case for increased support of these programs.[36] The report further noted that the outcome evaluation process can be challenging and thus requires stable staff patterns and commitment of sufficient staff time. It recommended that sites that choose to participate in conducting outcome evaluations commit to spending the necessary staff or volunteer time to use a standardized method of data collection, which may require that subsidies be available for hiring data collectors.

Conclusion

As noted in chapter 2 of this study, the mission and operational objectives of respite care programs may vary depending on whether services primarily benefit the caregiver, care recipient, or both. As such, the evaluation and assessment criteria used may differ from state to state. However, the evaluation information found on the five states discussed in this chapter were similarly concerned about accurate needs assessment of caregivers, difficulty of finding an adequate number of qualified service providers, standardized data collection, and funding to continue evaluation efforts.

Endnotes

[1] DAAS administers the federally-funded Family Caregiver Support Program, which provides caregiver support, including in-home, day care, or institutional respite care services. The ICRC is one of three agencies contracted by DAAS to provide respite care services under the National Family Caregiver Support Program.

[2] Monique Parrish, *Respite Care: An Evaluation of Need, Utilization, and Efficacy, An Analysis of Inland Caregiver Resource Center and the San Bernardino County Department of Aging and Adult Services Respite Services*, LifeCourse Care, June 2004. See http://inlandcaregivers.radius3.com/media/ICRC_2004_Repite_Study.pdf.

[3] Ibid., p. 11.

[4] The $1200 respite care benefit through the National Family Caregiver Support Program (NFCSP) was designated to be spent within four months. The $800 respite care grant, a one-time benefit from DAAS, was designated to be spent within two months.

[5] An example of a positive effect on the care recipient was a husband feeling relieved that his caregiver wife finally got a break. Another caregiver reported it was beneficial for the care recipient have someone else to talk to, with whom the care recipient shared common interests such as a career or hobby.

[6] Monique Parrish, *Respite Care: An Evaluation of Need, Utilization, and Efficacy, An Analysis of Inland Caregiver Resource Center and the San Bernardino County Department of Aging and Adult Services Respite Services*, LifeCourse Care, June 2004, p. 22 and p. 24.

[7] Ibid., p. 11.

[8] Ibid., p. 16.

[9] Ibid., p. 31.

[10] The survey instrument would be administered bi-annually to all caregivers who have received a respite care service through ICRC.

[11] Delaware Caregivers Support Coalition, *Final Report: A Report of the Work of the Coalition Assessing the Needs of Respite Care in Delaware*, October 2005.

[12] Ibid., p 5. Public and private respite care providers in Delaware include the Division of Developmental Disabilities Services, the Division of Family Services, the Division of Services for Aging and Adults with Disabilities, the Department of Education, the Delaware Autism Program, Easter Seals, United Cerebral Palsy, the Mary Campbell Center, and Nurses 'n Kids.

[13] Delaware Caregivers Support Coalition, *Final Report: A Report of the Work of the Coalition Assessing the Needs of Respite Care in Delaware*, October 2005, p. 6

[14] Mina Silberberg, Ph.D. and Daniel Caruso, *New Jersey's Statewide Respite Care Program: A Study of Program Design, Implementation, Clients, and Services*, Rutgers Center for State Health Policy, The State University of New Jersey, September 24, 2001.

[15] Ibid. For interview questions, see Appendix I, Interview Protocols, pp. 47-51.

[16] Ibid., p. 1.

[17] Ibid., pp. 43-46.

[18] Ibid., p. 43.

[19] Mina Silberberg, Ph.D. and Daniel Caruso, *Respite Services in New Jersey's Community Care Program for the Elderly and Disabled*, Rutgers Center for State Health Policy, The State University of New Jersey, December 2002.

[20] Ibid., p. 1.

[21] Ibid., p. 41.

[22] Ibid., p. 42.

[23] Colleen A. McLaughlin and Celia S. Feinstein, *Elderly Caregivers of Adults with Disabilities Pilot Project Evaluation*, Temple University and Pennsylvania Department of Aging, September 2004.

[24] Ibid., p. 1.

[25] Ibid., p. 4.

[26] Ibid. Respite care was identified as the service most needed by 25% of the caregivers surveyed, followed by homemaker services at 19%. Medical expenses and health-related items and general household expenses were identified as the service most needed by 18% of the caregivers.

[27] Ibid., p. 7.

[28] Ibid., p. 9.

[29] Ibid., p. 19.

[30] Ibid., p. 18.

[31] Raymond Kirk, *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers*, ARCH National Resource Center for Respite and Crisis Care Services, December 1999.

[32] Respite Care Association of Wisconsin, Inc., *Report on Phase Two of the Outcome Evaluation Project*, 2003. Available at: http://209.249.161.24/pdfs/outcome.pdf.

[33] Specifically, the questionnaire designed to evaluate the outcomes of planned respite asks caregivers about stress, family relationships, separation and divorce, out-of-home placement, health related problems, and social activities. The questionnaire is included as Appendix A of the report, pp. 21-27.

[34] Respite Care Association of Wisconsin, Inc., *Report on Phase Two of the Outcome Evaluation Project*, 2003.

[35] Ibid., p. 18.

[36] Ibid.

Chapter 5

CONCLUSION

There does not appear to be any paradigm or prototype for respite care providers. Indeed, given the diversity that exists with respect to respite care programs, both among the various states and within particular states, it is difficult to even provide succinct and clear-cut descriptions of major program elements.

Respite care can encompass an assortment of services, occur in a range of settings, and vary in duration. While respite care is designed with the needs of the caregiver in mind, respite programs typically provide services for the care recipient, who is often, but not always, an older adult with a range of physical or mental disabilities. Other respite programs offer services to the caregiver or services that benefit the caregiver indirectly. Respite care programs differ with respect to their definition of respite, target population, eligibility criteria, and the amount and type of respite care services offered. Although states and programs may have various definitions of "respite," "respite care," or "respite care services," they generally agree that the goal of respite is to:

(1) Decrease the stresses of persons and families who provide care; or

(2) Delay the need for institutionalization of the care recipient.

Various public and private agencies operate respite care programs, including both for-profit and not-for-profit organizations. Federal funds and in many cases state funds, are used to support respite care programs, and the source and amount of funding has implications for the program concept and design. Many respite care programs also rely upon contributions from participants, who may pay a preset amount or on a sliding scale according to their financial resources. Respite care is most often included in a package of services that provide a variety of caregiver support services, such as information, access to training and education, case management, legal assistance, homemaker and chore assistance, transportation, and other services to help caregivers. Respite care services can include traditional home-based care, adult day care, skilled nursing, home health or adult day health care, and short-term institutional care.

There are also stand alone respite care programs, most notably lifespan respite care programs. Lifespan respite care provides a coordinated system of access to affordable, community-based respite care services for the lifespan of the care recipient regardless of age, disability, special need, or situation. Lifespan respite systems in Oregon, Nebraska, Wisconsin, and Oklahoma served as the model for the federal Lifespan Respite Care Act of 2006, which remains unfunded.

Two federally-funded respite care programs operated by states and implemented by area agencies on aging are the National Family Caregiver Support Program (NFCSP) and the Home and Community-Based Services (HCBS) Section 1915(c) Medicaid Waiver Program. The NFCSP was enacted in 2000 and was modeled after state respite care programs. All 50 states

and the District of Columbia receive NFCSP-funds, which are allocated through a federal formula grant. In contrast, states apply for and are allowed to use HCBS Medicaid waiver funds for non-medical expenses such as respite care. Forty-three states and the District of Columbia offer respite options though HCBS waiver programs. Some states use HCBS funds for direct payments to respite care providers for adult day care, overnight, and weekend respite care services.

Thirty-one states also operate state-funded respite care programs. Some states supplement their general revenue funding of these programs with a variety of other sources, such as tobacco settlement or lottery funds, client cost share, and voluntary client contributions. Most states require care recipients to meet one or a combination of the following eligibility criteria: impairment in at least one activity of daily living, a diagnosis of dementia or a related disorder, being at risk for institutionalization, or needing a nursing home level of care. As with federal NFCSP and Medicaid waiver programs, most states have caps on respite care services.

There are various assessment procedures that states use to evaluate the respite care programs they operate. Because program mission and objectives may vary from program to program, the evaluation and assessment criteria used may differ from state to state. The procedures used include process evaluations, outcome evaluations, annual reports, program analyses, focus groups, surveys, and studies of respite care services and implementation methods. A review of five states' assessment procedures found that the states had similar concerns about obtaining accurate needs assessments of caregivers, difficulty with finding an adequate number of qualified service providers, standardized data collection methods, and sufficient funds to continue evaluation efforts.

HOUSE OF REPRESENTATIVES
TWENTY-FOURTH LEGISLATURE, 2007
STATE OF HAWAII

H.C.R. NO. 187 H.D. 1

HOUSE RESOLUTION

REQUESTING THE LEGISLATIVE REFERENCE BUREAU TO STUDY RESPITE CARE POLICIES AND PROGRAMS IN OTHER STATES AND THE EXECUTIVE OFFICE ON AGING TO CONDUCT AN INVENTORY OF RESPITE CARE SERVICES IN HAWAII.

WHEREAS, family caregiver is the term used to refer to an unpaid individual, including a family member, friend, or neighbor, who provides full- or part-time care to another individual in need and either lives separately from or with the care recipient; and

WHEREAS, individuals who need the assistance of family caregivers typically have complex, chronic medical conditions and functional limitations; and

WHEREAS, it is estimated that fourteen to twenty-one per cent of adults, or 126,598 to 192,390 individuals, in the State provide regular care or assistance to another individual aged sixty years or older; and

WHEREAS, family caregivers provide an invaluable service and economic benefit to care recipients and State taxpayers by way of deferred paid caregiving and institutionalization; and

WHEREAS, nationally, if the work of family caregivers had to be replaced by paid home care staff, the estimated cost would be forty-five to ninety-four billion dollars per year; and

WHEREAS, sustainable family caregiving depends on meeting a family caregiver's own needs for support and respite care; and

WHEREAS, although there are different approaches to respite care, the basic objective is to provide a family caregiver with temporary relief from the responsibilities of caring for a care recipient so that the family caregiver can attend to other personal and professional obligations; and

WHEREAS, respite care can include a range of services such as medical or social adult day care or a short-term stay in a

nursing home or assisted living facility for the care recipient, a home health aide or home health companion, or a private duty nurse or adult foster care; and

WHEREAS, a study of respite care and the provision of respite care in other states would be helpful to establishing respite care programs for family caregivers in this State; now, therefore,

BE IT RESOLVED by the House of Representatives of the Twenty-fourth Legislature of the State of Hawaii, Regular Session of 2007, that the Legislative Reference Bureau is requested to study respite care; and

BE IT FURTHER RESOLVED that in conducting this study, the Legislative Reference Bureau is requested to:

(1) Focus on the provision of respite care to family caregivers who provide care to other individuals aged sixty years or older or to chronically ill adults; and

(2) Include a compilation of the definitions used to describe the term "respite care" in other states;

(3) Describe respite care policies and programs in other states;

(4) Describe procedures used by other states to assess the quality of respite care provided in those states; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau is requested to submit a report of its findings to the Legislature no later than twenty days prior to the convening of the Regular Session of 2008; and

BE IT FURTHER RESOLVED that the Executive Office on Aging is requested to conduct an inventory of the respite services provided in Hawaii that are supported by federal, state, and county funds, including a description of each program and the amount and source of funding; and

BE IT FURTHER RESOLVED that the Executive Office on Aging is requested to submit a report of its findings to the

Legislature no later than twenty days prior to the convening of the Regular Session of 2008; and

BE IT FURTHER RESOLVED that certified copies of this Resolution be transmitted to the Director of the Legislative Reference Bureau and the Executive Director of the Office on Aging.

Appendix B

STATE STATUTES RELATING TO RESPITE CARE

Alaska Statutes Service Programs for Older Alaskans and Other Adults §47.65.290	§47.65.290 In this chapter, "**family respite care**" means intermittent and substitute care that provides relief for a family caregiver or adult foster home provider by providing intermittent care in the form of companionship, temporary supervision, and minor personal care to a person who is at risk of institutional placement; the service may be provided either in the home of the client or the caregiver, including in an adult foster care home if that is the client's residence.
Arizona Revised Code Arizona Older Americans Act – Nonmedical Home and Community Based Care Services §46-193	§46-193 The department shall develop and implement a statewide program to provide **respite care** for care givers of the elderly. For the purposes of this section, **"respite care"** means short-term care and supervision services provided to an individual to relieve the care giver.
California Welfare and Institutions Code Comprehensive Act for Families and Caregivers of Brain-Impaired Adults §4362.5 California Welfare and Institutions Code Developmental Services §4418.6	§4362.5 **"Respite care"** means substitute care or supervision in support of the caregiver for the purposes of providing relief from the stresses of constant care provision and so as to enable the caregiver to pursue a normal routine and responsibilities. Respite care may be provided in the home or in an out-of-home setting, such as day care center or short-term placements in inpatient facilities. §44118.6 The department may establish within its family care program **respite care services** for the developmentally disabled. Such **respite care services** may be available to both family home caretakers and to persons referred by the regional centers for the developmentally disabled. For purposes of this section, **respite care** means temporary and intermittent care provided for short periods of time.

California Health and Safety Code California Community Care Facilities Act §1505.5 California Insurance Code Long-Term Care Insurance §10232.9	§1505.5 ...short term, time-limited basis to provide temporary **respite care** for frail elderly persons, functionally impaired adults, or mentally disordered person who need 24-hour supervision and who are being care for by a caretaker or caretakers. §10232.9 **"Respite care"** is short-term care provided in an institution, in the home, or in a community-based program, that is designed to relieve a primary care giver in the home. This is a separate benefit with its own conditions or eligibility and maximum benefit levels.
Colorado Revised Statutes Title 25.5 Health Care Policy and Financing §25.5-6.303	§25.5-6.03 "**Respite care services**" means services of a short-term nature provided to a client, in the home or in a facility approved by the state department, in order to temporarily relieve the family or other home providers from the care and maintenance of the client, including room and board, maintenance, personal care, and other related services.
Connecticut General Statutes Annotated Title 17B, Chapter 319Y. Long-Term Care §17b-349e	§17b-349e "**Respite care services**" means support services which provide short-term relief from the demands of ongoing care for an individual with Alzheimer's disease. ...**respite care** services may include but need not be limited to homemaker services, adult day care, temporary care in a licensed medical facility, home-health care or companion services.

Florida Statutes Title XXIX, Chapter 400. Nursing Homes and Related Health Care Facilities §400.021	§400.021 "**Respite care**" means admission to a nursing home for the purpose of providing a short period of rest or relief of emergency alternative care for the primary caregiver of an individual receiving care at home who, without home-based care, would otherwise require institutional care.
Illinois Compiled Statutes Chapter 3420, Act 10. Respite Program Act §320 ILCS 10/2	§320 ILCS 10/2 "**Respite care**" means the provision of intermittent and temporary substitute care or supervision of frail or disabled adults on behalf of and in the absence of the primary care-giver, for the purpose of providing relief from the stress or responsibilities concomitant with providing constant care, so as to enable the care-giver to continue the provision of care in the home. Respite care should be available to sustain the care-giver throughout the period of care-giving, which can vary from several months to a number of years. Respite care can be provided in the home, in a day care setting during the day, overnight, in a substitute residential setting such as a long-term care facility required to be licensed under the Nursing Home Care Act or the Assisted Living and Shared Housing Act, or for more extended periods of time on a temporary basis.
Louisiana Revised Statutes Title 40, Chapter 11, Part II-D. Licensing of Community-Based Services Providers §40:2120.2	§40:2120.2 "**Respite care services**" means the temporary care and supervision of a person with a disability or an infirm elderly person so that the primary caregiver can be relieved of such duties. Such services may be performed either in the home of the person with a disability or infirm elderly person or in a facility owned by the respite care services agency.

Michigan Compiled Laws Annotated Chapter 33. Michigan Lifespan Respite Services Resource Act §333.26522	§333.26522 "**Respite care**" means providing short-term relief to primary caregivers from the demands of ongoing care for an individual whose health and welfare would be jeopardized if left unattended.
Missouri Statutes Title XL, Chapter 660, Department of Social Services, Department of Aging §660.067	§660.067 "**Respite care**," means a program that provides temporary and short-term residential care, sustenance, supervision and other appropriate services for persons having Alzheimer's disease and related disorders who otherwise reside in their own or in a family home.
New Jersey Statutes Title 30, Subtitle 1B, Chaper 4F. Respite Care §30:4F-8	§30:4F-8 "**Respite**" or "**respite care**" means the provision of temporary, short-term care for, or the supervision of, an eligible person on behalf of the caregiver, in emergencies or on an intermittent basis to relieve the daily stresses and demands of caring for the functionally impaired adult. Respite may be provided hourly, daily, overnight or on weekends, may be paid or volunteer, but may not exceed service and cost limitations as determined by the commissioner. Respite includes, but is not limited to, the following services: (1) companion or sitter services; (2) homemaker and personal care services; (3) adult day care; (4) short-term inpatient care in a facility meeting standards which the commissioner determines to be appropriate to provide the care; (5) emergency care; and (6) peer support and training for caregivers.
Pennsylvania Statutes Title 62, Chapter 6. Family Caregiver Support Act 62 PS §3063	62 PS §3063 "**Respite care service**." A regular, intermittent or emergency service which provides the primary caregiver of a functionally dependent older adult or other adult suffering from a chronic dementia with relief from normal caregiving duties and responsibilities.

General Laws of Rhode Island Title 42, Chapter 66.3. Home and Community Services to the Elderly §42-66.3-1	§42-66.3-1 "**Respite care services**" means temporary care given inside or outside the home of a client who cannot entirely care for themselves and thereby offers relief to caregivers. For the purposes of this chapter, these services are provided by an agency funded by the department of elderly affairs to provide respite care services.
Texas Statutes and Codes Title 4, Subtitle B, Chapter 242, Subchapter G. §242.181	§242.181 "**Respite care**" means a written description of the medical care or the supervision and nonmedical care needed by a person during respite care.
Virginia Code Title 2.2, Subtitle I, Part C, Chapter 7, Article 3. Virginia Respite Care Program §2.2-714	§2.2-714 "**Respite care**" means the provision of supplementary care and protection for aged, infirm, or disabled adults. Respite care includes, but is not limited to, adult day care services.
Revised Code of Washington Title 74, Chapter 74.41. Respite Care Services §74.41.030	§74.41.030 "**Respite care services**" means relief care for families or other caregivers of adults with functional disabilities, eligibility for which shall be determined by the department by rule. The services provide temporary care or supervision of adults with functional disabilities in substitution for the caregiver. The term includes adult day services. "**Eligible participant for respite care services**" means an adult who needs substantially continuous care or supervision by reason of his or her functional disability and is also assessed as requiring placement into a long-term care facility in the absence of an unpaid family or other unpaid caregiver.

Appendix C

RESPITE OPTIONS FUNDED THROUGH THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Respite Options				Eligibility Requirements			
	ADULT DAY	IN HOME	OVER-NIGHT	WEEKEND/ CAMP	CAREGIVER MIN AGE	*ADL REQUIREMENT	OTHER CRITERIA	SERVICE CAP
Alabama	x	x	x	x	No minimum	Unable to do 2 instrumental ADL		No cap on services
Alaska	x	x			No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Arizona	x	x	x	x	No minimum	Unable to do 2 ADL or instrumental ADL	***or*** diagnosis of dementia or related disorder and/or require supervision	Average 8 hours per week and not more than 3 days per year for emergency services
Arkansas	x	x			18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$1,000 per year
California	x	x			18 or older	Unable to perform 2 or more ADL	***or*** have significant cognitive impairment	Cap on services not indicated
Colorado	x	x	x	x	18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Average of $250 to $500 per year
Connecticut	x	x	x	x	18 or older	Impairment in 2 ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$3,500 per year

*ADL refers to activities of daily living such as eating, bathing, walking, using the restroom, feeding oneself, etc.

Delaware	x	x			No minimum	Impairment in 2 ADL	***or*** diagnosis of dementia or related disorder and/or require supervision	60 hours per year
District of Columbia	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Florida	x	x	x	x	19 or older	Unable to do 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Georgia	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Hawaii	x	x	x	x	18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Variable cap by county
Idaho	x	x	x		No minimum	Physical or cognitive impairment	***and*** require 24-hour care or supervision	No cap on services
Illinois	x	x	x		18 or older	Impairment in 2 or more ADL		Variable caps based on need
Indiana	x	x	x	x	18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Cap on services not indicated
Iowa	x	x	x		No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services

Kansas	x	x	x	x	18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Not more than 7 consecutive days
Kentucky	x	x			No minimum	Impairment in 2 or more ADL	***or*** diagnosis of dementia or related disorder or require supervision	Services may be capped
Louisiana		x			No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	96 hours per year
Maine	x	x	x		18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$500 per year
Maryland	x	x	x	x	No minimum	Need assistance with 2 or more ADL	***or*** diagnosis of dementia or related disorder and/or require supervision	$599 per year
Massachusetts	x	x	x	x	18 or older			Cap on services not indicated
Michigan	x	x	x	x	No minimum	Need assistance with 2 or more ADL	***or*** have cognitive impairment	No cap on services
Minnesota	x	x	x		18 or older	Impairment in 2 or more ADL	***and/or*** have cognitive or mental impairment that requires *substantial* supervision	Cap on services not indicated
Mississippi	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	32 hours per month

Missouri	x	x		x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	12 to 20 hours per month
Montana	x	x	x		No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No caps on services
Nebraska	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$1,000 per year
Nevada		x			No minimum			No cap on services
New Hampshire	x	x	x	x	18 or older	Impairment in 2 or more ADL	***or*** diagnosis of dementia or related disorder and/or require supervision	Weekend respite must be in an assisted living or assisted nursing facility. All respite options are capped at $1,500 per year.
New Jersey	x	x			No minimum			No cap on services
New Mexico	x	x	x		18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
New York	x	x	x		18 or older	Impairment in 2 or more ADL	***or*** require supervision due to cognitive or mental impairment	Cap on services not indicated
North Carolina	x	x	x		18 or older	Impairment in 2 or more ADL	***and/or*** diagnosis of dementia or related disorder and/or require supervision	Variable local caps
North Dakota	x	x	x	x	18 or older	Impairment in 2 or more ADL	***or*** diagnosis of dementia or related disorder	$1,950 per year

Ohio	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Oklahoma	x	x	x		No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$200 to 400 per quarter
Oregon	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Variable local caps
Pennsylvania	x	x	x	x	18 or older	Impairment in 1 or more ADL		No cap on services
Rhode Island	x	x	x		No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	120 hours per year for non-Alzheimer's disease caregivers; 240 hours per year for caregivers of persons with Alzheimer's disease
South Carolina	x	x	x	x	18 or older	Unable to perform 2 or more ADL		Cap on services not indicated
South Dakota	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$4,000 per year
Tennessee	x	x	x		No minimum	Unable to perform 2 or more ADL	***or*** have a cognitive or other mental impairment that requires substantial supervision to prevent harm to self or others	Variable local caps

Texas	x	x	x		No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Utah	x	x	x	x	18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Variable yearly cap
Vermont	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	$100 to $1,500 per year
Virginia	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services
Washington	x	x	x		18 or older	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	Variable local service caps
West Virginia	x	x			No minimum		Diagnosis of dementia or related disorder and/or require supervision	No cap on services
Wisconsin	x	x	x	x	18 or older and live with the care recipient	Impairment in 2 or more ADL		116 hours per year
Wyoming	x	x	x	x	No minimum	Impairment in 2 or more ADL	***and*** diagnosis of dementia or related disorder and/or require supervision	No cap on services

Source: National Association of State Units on Aging and the National Conference of State Legislatures, February 2006.

Appendix D

RESPITE OPTIONS FUNDED BY THE MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER PROGRAM

	Adult Day	In Home	Over Night	Weekend/ Camp	NAME OF PROGRAM	CAP ON SERVICES
Alabama		x			Elderly and Disabled Waiver	720 hours per year
Arizona	x	x	x		Arizona Long-Term Care System	720 hours per year
Arkansas	x	x	x	x	ElderChoices Medicaid Waiver	600 hours per year
California	x	x	x	x	Multipurpose Senior Services Program	Cap on services not indicated
Colorado	x	x	x	x	Home and Community-Based Services for Elderly, Blind and Disabled	30 days per year
Connecticut	x x	x x	x x	x	Home Care Program for Elders *(Also funded by state general funds)* Personal Care Assistance State-Funded Pilot Program	No cap on services
Delaware	x	x	x		Elderly and Disabled Medicaid Waiver	336 hours per year
District of Columbia		x	x	x	Elderly and Physical Disabilities Waiver	6,480 hours per year

Florida	x	x	x	x	Aged and Disabled Adult Medicaid Home and Community-Based Services Waiver Program	No cap on services
Georgia	x	x	x	x	Community Care Services Program	No cap on services
Hawaii	x	x	x	x	Nursing Home Without Walls	No cap on services
Idaho	x	x			Home and Community-Based Services Aged and Disabled Waiver	$52 per day cap on in-home respite
Illinois	x x	x x			Community Care Program *(Also funded by state general funds)* Home Services Program *(Also funded by state general funds)*	Variable caps based on need Variable caps based on need
Indiana	x	x	x	x	Aged and Disabled Medicaid Waiver	Variable caps on services
Iowa	x	x	x	x	Elderly Waiver	Variable caps on services
Kansas	x	x	x		Frail Elderly Waiver Program *(Also funded by state general funds)*	180 hours per year
Maine	x	x	x		MaineCare	$4,281 per year
Maryland	x	x	x		Medicaid Waiver for Older Adults	168 hours per year

Massachusetts	x	x	x	x	Home and Community-Based Waiver *(Also funded by state general funds)*	No cap on services
Michigan	x	x	x		MI Choice *(Also funded by state general funds)*	No cap on services
Minnesota	x	x			Elderly Waiver Program	Cap on services not indicated
Mississippi	x	x	x		Elderly and Disabled Waiver	40 hours per month
Missouri	x	x	x		Aged and Disabled Waiver *(Also funded by state general funds)*	No cap on services
Montana	x	x	x		Home and Community-Based Services Program for Elderly and Physically Disabled *(Also funded by the federal Real Choice Systems Change grant)*	No cap on services
Nebraska	x	x	x	x	Aged and Disabled Waiver	No cap on services
Nevada	x	x	x	x	Community Home-Based Initiatives Program *(Also funded by state general funds, tobacco funds, and client contributions)*	No cap on services
New Hampshire	x	x	x	x	Elderly and Chronically Ill Waiver *(Also funded by state general funds)*	480 hours per year

New Jersey	x	x	x	x	Community Care Program for the Elderly and Disabled	30 days per year in a skilled nursing facility; 336 hours per year when provided in the home
	x	x	x	x	Enhanced Community Options	$1,000 per month
New Mexico		x			Disabled and Elderly Home and Community Based Services Waiver *(Also funded by state general funds)*	336 hours per year
North Carolina	x	x	x	x	Community Alternatives Program for Disabled Adults	30 days or 720 hours per year if respite is provided in a skilled nursing facility
North Dakota	x	x	x	x	Aged and Disabled Waiver	$565 per month
Ohio	x	x			PASSPORT HCBS Waiver Program *(Also funded by state general funds)*	No cap on services
Oklahoma		x	x	x	Advantage Program	Cap on services not indicated
Oregon	x	x	x		Medicaid Waiver/In-Home Care *(Also funded by state general funds and client contributions)*	No cap on services
Pennsylvania	x	x	x	x	Pennsylvania Department of Aging 60+ Medicaid Waiver *(Also funded by state tobacco funds)*	No cap on services

South Carolina	x		x		Elderly/Disabled Home and Community-Based Waiver *(Also funded by state general funds)*	21 days per year in a residential care facility; 14 days per year in a skilled nursing facility
South Dakota	x				Home and Community-Based Elderly Waiver	No cap on services
Texas		x	x		Community-Based Alternatives *(Also funded by state general funds)*	720 hours per year
Utah	x	x	x		Medicaid Aging Waiver	No cap on services
Virginia	x	x	x	x	Elderly and Disabled Waiver *(Also funded by federal Real Choice Systems Change grant and state general funds)*	720 hours per year
Wisconsin	x	x	x	x	Community Options Program Waiver	No cap on services
Wyoming	x	x			Home and Community-Based Services Waiver for Elderly and Physically Disabled	$900 per month

Source: *Family Caregiver Support, State Facts at a Glance,* National Association of State Units on Aging and the National Conference of State Legislatures, February 2006.

Appendix E

RESPITE OPTIONS FUNDED THROUGH STATE GENERAL FUNDS

	Respite Options						
	Adult Day	In Home	Over Night	Weekend/ Camp	Care recipient Minimum Age	NAME OF STATE-FUNDED PROGRAM	SERVICE CAP
Alaska	x	x			60 years or older	Senior In-Home Services	Service cap not indicated
	x				60 years or older	Adult Day Services Program	Service cap not indicated
California	x				18 years or older	Adult Day Health Care Program *(Also funded by Medicaid and client contributions)*	Service cap not indicated
	x				18 years or older	Alzheimer's Day Care Resource Centers *(Also funded by local resources and client share)*	Service cap not indicated
	x	x	x	x	18 years or older	Caregiver Resource Centers *(Also funded by client share)*	$3,600 annually
	x	x	x		18 years or older	Linkages *(Also funded by client share and Medicaid case management funds)*	Service cap not indicated
	x	x	x		Minimum age not indicated, but care recipient must be frail older person or adult	Respite Purchase of Services Program	$450 per year

Connecticut	x	x	x	x	No minimum age	Statewide Alzheimer's Respite Care Program *(Also funded by client contributions)*	$3,500 per year
Florida	x	x	x	x	18 years or older	Alzheimer's Disease Initiative (Also funded by voluntary contributions)	No cap on services
	x	x	x	x	60 years or older	Community Care for the Elderly *(Also funded by tobacco funds and voluntary contributions)*	No cap on services
	x	x	x	x	60 years or older	Home Care for the Elderly	No cap on services
	x				60 years or older	Respite for Elders Living in Everday Families (RELIEF) *(Also funded by tobacco funds)*	4 hours per week
Hawaii	x	x			60 years or older	Kupuna Care *(Also funded by voluntary contributions)*	No cap on services
Indiana	x			x	60 years or older	Community and Home Options to Institutional Care (CHOICE)	No cap on services
Kansas	x	x		x	Over 60 years	Senior Care Act Program	No cap on services
Kentucky		x			60 years or older	Homecare	Variable cap on services
		x	x		60 years or older	Adult Day Alzheimers Respite	Variable cap on services

Maine	x	x	x		18 years or older	Home-Based Care *(Also funded by client contributions)*	$3,800 per year
	x	x	x	x	Age not indicated	Partners in Caring *(Also funded by federal Alzheimer's Disease Demonstration Grant and client contributions)*	$3,800 per year
Maryland	x	x	x	x	18 years or older	Respite for Caregivers of Adults with Functional Disabilities	164 hours per year
Massachusetts	x	x	x	x	60 years or older	Home Care Program *(Also funded by voluntary client contributions)*	No caps on services
Michigan	x	x	x	x	18 years or older	Caregiver Respite Program *(Funded by tobacco settlement funds)*	No cap on services
	x	x	x	x	Caregiver or care recipient must be 60 years or older	State/Escheat Respite *(Funded by uncashed Blue Cross/Blue Shield checks returned to the Michigan Department of Treasury)*	No cap on services
Minnesota	x	x	x		65 years or older	Alternative Care Program	Cap not indicated
	x	x	x	x	65 years or older	State Respite/Community Service Grants	Cap not indicated
Nebraska	x	x	x	x	No minimum age	Respite Subsidy Program Across the Lifespan *(Funded by tobacco funds)*	$125 per month

Nevada	x	x	x	x	60 years or older	Independent Living Grant *(Funded by tobacco funds)*	No caps on services
New Hampshire	x	x	x	x	None indicated	Alzheimer's Disease and Related Memory Disorders Program	$1,200 per year
New Jersey	x				18 years or older	Adult Day Services Program for Persons with Alzheimer's Disease or Related Disorders *(Also funded by casino revenues and client contributions)*	Three days per week
	x	x	x	x	60 years or older	Jersey Assistance for Community Caregiving	$600 per month
	x	x	x	x	18 years or older	New Jersey Statewide Respite Care Program *(Funded by casino revenues and client contributions)*	$4,500 per year
New York	x	x	x	x	No minimum age; priority to those 60 years or older	Respite Program	100 days per year
North Carolina	x	x	x	x	Caregiver or care recipient must be 60 years of age or older	Respite Care Program *(Funded by state's home and community care block grant, local funds, and client contributions)*	No cap on services
North Dakota		x	x	x	No minimum age	Family Home Care	$565 per month
Ohio	x	x	x	x	No minimum age	Alzheimer's Respite Program *(Also funded by client contributions)*	No cap on services

Oklahoma	x	x	x	x	60 years or older	Respite Resource Network *(Also funded by federal funds)*	$1,600 per year
Oregon	x	x	x	x	No minimum age	Lifespan Respite Care Network *(Also funded by local/county funds)*	No cap on services
Pennsylvania	x	x	x	x	60 years or older	OPTIONS *Also funded by tobacco and lottery funds, client contributions, and federal funds)*	No cap on services
	x	x	x	x	18 years or older	Pennsylvania Family Caregiver Suppport Program *(Also funded by tobacco and lottery funds and client contributions)*	No cap on services
Rhode Island	x	x	x		60 years or older	Partners in CaRIng *(Also funded by client contributions and federal funds)*	240 hours a year for caregivers of people with Alzheimer's disease; 120 hours a year for caregivers of people without Alzheimer's disease
Tennessee	x	x	x	x	No minimum age	Family Support Grant Program	No cap on services
Texas	x	x	x		4 years or older	In-Home and Family Support Program	$1,200 per year, including copayments
Utah	x	x	x	x	18 years older	Home and Community-Based Alternatives	$750 per month

Virginia	x	x			60 years or older	Respite Care Initiative Grant *(Also funded by local/county funds and client contributions)*	35 hours per month
Wisconsin	x	x	x	x	No minimum age	Alzheimer's Family and Caregiver Support Program	$4,000 per year
Wyoming	x	x			18 years or older	Community-Based In-Home Services Program	No caps on services

Source: National Association of State Units on Aging and the National Conference of State Legislatures, February 2006.

Appendix E

Caregiver Respite Survey Instrument

Procedural Data

CRC Site Code #:___ ___ Client Code# : ___ ___ ___ ___ ___

CRC Staff Name: _____ Staff Code #: ___ ___ ___ ___

Date of Assessment: ___ ___ / ___ ___ / ___ ___
M M D D Y Y

Type of Respite benefit

In-Home _____ Adult Day Care _____ Residential _____

Amount of respite benefit _____

Length of Time of Respite Benefit

Two-month _____; Four-Month _____; 12-Month _____; > 12-Month _____

Used Respite Benefit Yes/No (Circle One):

If Yes, For the Entire Duration of the Benefit? Yes/NO

IF no, the reason for stopping: _____

Functional Level of the Care Receiver

Does [CR] currently have problems with the following activities?	NO	YES	DON'T KNOW N/A	COMMENTS
A. Eating	0	1	9	
B. Bathing/showering	0	1	9	
C. Dressing (choosing/putting on appropriate clothing)	0	1	9	
D. Grooming (brushing hair, teeth)	0	1	9	
E. Using the toilet	0	1	9	
F. Incontinence	0	1	9	
G. Transferring from bed/chair/car	0	1	9	
H. Preparing meals	0	1	9	
I. Staying alone, must be supervised	0	1	9	
J. Taking medications	0	1	9	

Source: Monique Parrish, Respite Care: An Evaluation of Need Utilization, and Efficacy, An Analysis of Inland Caregiver Resource Center and the San Bernardino County Department of Aging and Adult Respite Service, LifeCourse Care, June 2004. Reproduced with permission.

K. Managing money or finances	0	1	9	
L. Performing household chores	0	1	9	
M. Using the telephone	0	1	9	
N. Mobility	0	1	9	
O. Wandering, or the potential to wander	0	1	9	

Problematic Behavior –(Pearlin et al., 1990)

In the past week, on how many days did you personally have to deal with the following behavior of your (relative)? On how many days did (she/he):

	(No Days)	(1-2 days)	(3-4 days)	(5-7 days)
Keep you up at night	☐	☐	☐	☐
Repeat questions	☐	☐	☐	☐
Try to dress the wrong way	☐	☐	☐	☐
Have a bowel or bladder "accident"	☐	☐	☐	☐
Hide belongings and forget about them.	☐	☐	☐	☐
Cry easily	☐	☐	☐	☐
Act depressed or downhearted	☐	☐	☐	☐
Cling to you or follow you around.	☐	☐	☐	☐
Become restless or agitated.	☐	☐	☐	☐
Become irritable or angry.	☐	☐	☐	☐
Swear or use foul language	☐	☐	☐	☐
Become suspicious or believe someone is going to harm him/her	☐	☐	☐	☐
Threaten people	☐	☐	☐	☐
Show sexual behavior or interests at wrong time	☐	☐	☐	☐

Adapted Zarit Burden Interview (Bédard et al. 2001)

Family Consultant: Please read the Adapted Zarit Interview exactly as it is written in order to maintain the validity of the scale. Do not hand the paper to the caregiver to complete. See the Instruction Manual for further directions.

Do you feel...	NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS
...that because of the time you spend with [CR] that you don't have enough time for yourself?	0	1	2	3	4
...stressed between caring for [CR] and trying to meet other responsibilities (work/family)?	0	1	2	3	4
...angry when you are around the care receiver?	0	1	2	3	4
...that [CR] currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
...strained when you are around [CR]?	0	1	2	3	4
...that your health has suffered because of your involvement with [CR]?	0	1	2	3	4
...that you don't have as much privacy as you would like because of [CR]?	0	1	2	3	4
...that your social life has suffered because you are caring for [CR]?	0	1	2	3	4
...that you have lost control of your life since [CR]'s illness?	0	1	2	3	4
...uncertain about what to do about [CR]?	0	1	2	3	4
...you should be doing more for [CR]?	0	1	2	3	4
...you could do a better job in caring for [CR]?	0	1	2	3	4

Role Overload – (Pearlin et al., 1990)

Here are some statements about your energy level and the time it takes to do the things you have to do. Howe much does each statement describe you?

	(Completely) (Not at all)		(Quite a bit)	(Somewhat)
You are exhausted when you go to bed at night.	☐	☐	☐	☐
You have more things to do than you can handle	☐	☐	☐	☐
You don't have time for yourself	☐	☐	☐	☐
You work hard as a caregiver but never seem to make any progress	☐	☐	☐	☐

Role Captivity – (Pearlin et al., 1990)

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you:

	Very much	Somewhat	Just a little	Not at all
Wish you were free to lead a life of your own.	☐	☐	☐	☐
Feel trapped by your (relative's) illness.	☐	☐	☐	☐
Wish you could run away?	☐	☐	☐	☐

CES-D Questionnaire (Radloff 1977)

Below is a list of the ways you may have felt or behaved recently. For each statement, check the box that best describes how often you have felt this way during the past week.

During the Past Week:	Rarely or None of the Time (Less than 1 day)	Some of the Time (1-2 days)	Occasionally (3-4 days)	Most of the Time (5-7 days)
A. I was bothered by things that don't usually bother me.	☐	☐	☐	☐
B. I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
C. I felt that I could not shake the blues even with help from my family and friends	☐	☐	☐	☐
D. I felt that I was just as good as other people.	☐	☐	☐	☐
E. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
F. I felt depressed.	☐	☐	☐	☐
G. I felt that everything I did was an effort.	☐	☐	☐	☐
H. I felt hopeful about the future.	☐	☐	☐	☐
I. I thought my life had been a failure.	☐	☐	☐	☐
J. I felt fearful.	☐	☐	☐	☐
K. My sleep was restless.	☐	☐	☐	☐
L. I was happy.	☐	☐	☐	☐
M. I talked less than usual.	☐	☐	☐	☐
N. I felt lonely.	☐	☐	☐	☐
O. People were unfriendly.	☐	☐	☐	☐
P. I enjoyed life.	☐	☐	☐	☐
Q. I had crying spells.	☐	☐	☐	☐
R. I felt sad.	☐	☐	☐	☐
S. I felt that people disliked me.	☐	☐	☐	☐
T. I could not get "going."	☐	☐	☐	☐

Planned Respite Outcome Evaluation questionnaire: Form 2.2 (Page 1)

Family Id #_____ **Date questionnaire completed:** ____/____/____

1) How long have you been receiving respite care from this program or any other program?

- ☐ a) Less than 2 months
- ☐ b) More than 2 months but less than 6 months
- ☐ c) More than 6 months but less than a year
- ☐ d) More than 1 year, but less than 5
- ☐ e) More than 5 years, but less than 10
- ☐ f) 10 years or more

	Not at all Stressed	Slightly Stressed	Somewhat Stressed	Moderately Stressed	Quite Stressed	Very Stressed	Extremely Stressed
2a) Before receiving respite, how "stressed" were you as a result of caring for your family member?	1	2	3	4	5	6	7
2b) Now that you are receiving respite, how "stressed" are you as a result of caring for your family member?	1	2	3	4	5	6	7
2c) If respite care were to end, how "stressed" would you be as a result of caring for your family member?	1	2	3	4	5	6	7

Sometimes, caregiving responsibilities can cause strain between the caregiver and other family members. Please tell us about your family relationships before you began receiving respite.

	Not at all	Slightly	Somewhat	Moderately	Quite a bit	Very	Extremely
3.a) *Before* receiving respite, was your relationship with your spouse/partner in any way strained due to your caregiving responsibilities? *(If the family member is your spouse, please answer "NA")* ☐ NA	1	2	3	4	5	6	7
3.b) *Before* receiving respite, was your relationship with other family members in any way strained due to your caregiving responsibilities? ☐ NA	1	2	3	4	5	6	7
3.c) *Before* receiving respite, was your relationship with your family member needing care in any way strained due to your caregiving responsibilities?	1	2	3	4	5	6	7

Please tell us about your family relationships now that you are receiving respite.

	Not at all	Slightly	Somewhat	Moderately	Quite a bit	Very	Extremely
4a) Now that you are receiving respite, is your relationship with your spouse/partner in any way strained due to your caregiving responsibilities? *(If family member is your spouse, please answer "NA")* ☐ NA	1	2	3	4	5	6	7
4b) Now that you are receiving respite, is your relationship with your other family members in any way strained due to your caregiving responsibilities? ☐ NA	1	2	3	4	5	6	7

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Source: Report on Phase Two of the Respite Care Association of Wisconsin Outcome Evaluation Project, Respite Care Association of Wisconsin, Inc., 2003. Reproduced with permission.

Planned Respite Outcome Evaluation questionnaire: Form 2.2 (Page 2)

Please tell us about your family relationships *if respite care were to end*

	Not at all	Slightly	Somewhat	Moderately	Quite a bit	Very	Extremely
5.a) If respite ended, would your relationship with your spouse/partner become strained due to your caregiving responsibilities? (If your family member is your spouse, please answer "NA") ☐ NA	1	2	3	4	5	6	7
5.b) If respite ended, would your relationship with other family members become strained due to your caregiving responsibilities? ☐ NA	1	2	3	4	5	6	7
5.c) If respite ended, would your relationship with your family member needing care become strained due to your caregiving responsibilities?	1	2	3	4	5	6	7
6a) *Before* receiving respite, had you ever been divorced or separated from a spouse or partner?	1	2	3	4	5	6	7
6b) If your answer to Question #6a was "yes," was the divorce or separation related in any way to the care of a family member?	1	2	3	4	5	6	7

	Highly Unlikely	Quite Unlikely	Somewhat Unlikely	Not Sure	Somewhat Likely	Very Likely	Extremely Likely
6c) *Before* receiving respite, how likely was it that separation or divorce *might have* occurred in your family? (If a divorce or separation *did* occur, the answer would be "7".)	1	2	3	4	5	6	7

7a) *Since you have been receiving* respite, have you experienced a divorce or separation from your spouse or partner? ☐ Yes ☐ No ☐ NA

7b) If your answer to Question 6c was "yes," is/was the divorce or separation related in any way to the care of a family member? ☐ Yes ☐ No ☐ Not Sure ☐ NA

	Highly Unlikely	Quite Unlikely	Somewhat Unlikely	Not Sure	Somewhat Likely	Very Likely	Extremely Likely
7c) *Now that you are receiving respite* how likely is it that separation or divorce might occur in your family? ☐ NA	1	2	3	4	5	6	7
7d) *If respite were to end*, how likely is it that a separation or divorce might occur in your family? ☐ NA	1	2	3	4	5	6	7

8a) Before receiving respite, was your family member ever placed in some form of out-of-home living arrangement (such as foster care, nursing home, or other institutional care)? ☐ YES ☐ NO

	Not at all	Very little	Some	Moderately	Somewhat Seriously	Very Seriously	Extremely Seriously
8b) Before receiving respite, did you ever consider placing your family member in some form of out-of-home- living arrangement? (foster care, nursing home care, or other institutional care)?	1	2	3	4	5	6	7

8c) Since receiving respite, has your family member been placed in some form of out-of-home living arrangement (such as foster care, nursing home care, or other institutional care)? ☐ YES ☐ NO

Planned Respite Outcome Evaluation questionnaire: Form 2.2 (Page 2)

Sometimes an out of home living arrangement may be *desirable* for a family or family member who receives care. For example, a young adult with disabilities may be happier and more productive living independently or in a supportive living facility.

9a) Would you say that an out-of-home living arrangement is desirable for your family member in the foreseeable future (within 12 months)? ☐ YES ☐ NO

Sometimes an out of home living arrangement becomes *inevitable* for a family member who receives care. For example, a person's medical needs may become so great that a nursing home placement is the best possible option for caregiver and care recipient

9b) Would you say that an out-of-home-living arrangement is *inevitable* for your family member in the foreseeable future (within 12 months)? ☐ YES ☐ NO

If you answered "yes" to *either* 9a or 9b, skip questions 9c & 9d, and go directly to question 10a. If you answered "no" to *both* 9a or 9b, please answer 9c and 9d.

	Not at all	Very little	Some	Moderately	Somewhat Seriously	Very Seriously	Extremely Seriously
9c) Now that you are receiving respite, do you consider placing your family member in some form of out-of-home-living arrangement? (foster care, nursing home care, or other institutional care)?	1	2	3	4	5	6	7
9d) If respite care were to end, would you consider placing your family member in some form of out-of-home-living arrangement? (foster care, nursing home care, or other institutional care)?	1	2	3	4	5	6	7

	No risk	Low risk	Slight risk	Moderate risk	Consider-able risk	High risk	Extreme risk
10a) Before receiving respite, was there any risk that your family member might have been neglected or mistreated or in your home?	1	2	3	4	5	6	7
10b) Now that you are receiving respite, is there any risk that your family member might be neglected or mistreated in your home?	1	2	3	4	5	6	7
10c) If respite care were to end would there be any risk that your family member might be neglected or mistreated in your home?	1	2	3	4	5	6	7

	Not at all	Slightly	Somewhat	Moderately	Quite a bit	Very	Extremely
11a) Before respite, did your caregiving responsibilities contribute to any health problems you may have (physical, mental and/or emotional)?	1	2	3	4	5	6	7
11b) Now that you are receiving respite, do your caregiving responsibilities contribute to any health problems you may have (physical, mental and/or emotional)?	1	2	3	4	5	6	7
11c) If respite were to end, would your caregiving responsibilities contribute to any health problems you may have (physical, mental and/or emotional)?	1	2	3	4	5	6	7

Planned Respite Outcome Evaluation questionnaire: Form 2.2(Page 3)

	Not at all	Slightly	Somewhat	Moderately	Quite a bit	Very	Extremely
12a) Before respite, were your opportunities and time to engage in social/recreational activities of your choice sufficient?	1	2	3	4	5	6	7
12b) Now that you are receiving respite, are your opportunities and time to engage in social/recreational activities of your choice sufficient?	1	2	3	4	5	6	7
12c) If respite were to end, would your opportunities and time to engage in social/recreational activities of your choice be sufficient?	1	2	3	4	5	6	7

	Not at all	Slightly	Somewhat	Moderately	Quite	Very	Extremely
13) Is the amount of time you receive respite care sufficient to meet your needs?	1	2	3	4	5	6	7
14) Are your options for receiving respite appropriate to you and your family member's needs (center based, in your home, in the provider's home, at a recreational facility, hospital, camp, etc)?	1	2	3	4	5	6	7
15) If your family member expresses or demonstrates an opinion of the respite experience, is it positive? ☐NA (no opinion expressed or demonstrated)	1	2	3	4	5	6	7