RESPITE CARE FOR ALL FAMILY CAREGIVERS: THE LIFESPAN RESPITE CARE ACT

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INTRODUCTION

The American family is the "central unit of social and political life."¹ Despite recent fluidity in the family structure,² many elder persons living in a non-institutionalized setting receive living assistance from a family member, the "family caregiver."³ Although the modern notion of a "family" is difficult to define,⁴ the family caregiver includes anyone who provides unpaid care and has a personal connection with the care recipient, such as blood relatives, friends and neighbors.⁵

2. Id. at 2 (the modern family is an intergenerational family formed by an increased life expectancy, multiple marriages, and different childbearing patterns).
4. POLICY PERSPECTIVES, supra note 1, at 2.
Although policymakers increasingly acknowledge the pivotal role of the family in providing care, attention to the assessment of the situation and well-being of the family caregiver has largely been ignored. The act of long-term caregiving can be distressing economically, physically, and psychologically to both the family caregiver and the family unit. Assessing the needs of the family caregiver provides a legitimate appraisal of those needs "as distinct, but related to the needs of the care recipient." The interests of family members need to be treated equally with the interests of the patient.

"Respite care is defined as the temporary . . . care of a dependent person in order to provide relief" to the family caregiver from the responsibility as a caregiver. When presented with a variety of options, caregivers prefer respite care. Numerous studies have shown that both caregivers and care recipients benefit from respite care. Caregivers have reported improved physical and emotional health, whereas respite care has brought a decline in institutionalization for care recipients.

Although states have recognized the importance of respite care in the last two decades and have begun to respond to this expanding need, the current programs are unable to meet the demand because of
inconsistent resources. The existing respite programs have been offered to caregivers in a variety of states as a “pilot demonstration program or as part of another on-going program.” The type of disability, age, and income of the care recipient dictate participation eligibility. Financing flows from a myriad of state, federal, and private sources. Most of these programs provide limited benefits and have created a fragmented system lacking an adequate infrastructure for developing, implementing, coordinating, and maintaining access to quality respite care for all family caregivers.

This paper emphasizes that respite care for family caregivers is not just an issue concerning our aging population but a family issue and a policy issue as well. Policymakers’ recognition that family caregivers provide most of the long-term care in this country has brought about The Lifespan Respite Care Act of 2003 (“The Act”) which tries to assist family caregivers in accessing affordable and high-quality respite care. The Act would establish a coordinated federal program to support development and implement state and local respite care infrastructures that would serve all family caregivers regardless of age, income, disability, or family situation.

To place in context the family caregiver vis-à-vis society, I begin with an analysis of the private and public responsibilities that society places on the family caregiver. I show that caregiving is a matter for

15. TERRI WHIRRETT, ARCH NATIONAL RESPIRE NETWORK AND RESOURCE CENTER, GUIDE TO FEDERAL FUNDING FOR RESPITE AND CRISIS CARE PROGRAMS 18, available at http://www.archrespite.org/archpubs.htm (last visited Jan. 31, 2004); see also RESPITE CARE LIMITATIONS, supra note 13, at 45.
16. RESPITE CARE LIMITATIONS, supra note 13, at 33.
17. WHIRRETT, supra note 15, at 18.
19. Id.
21. S. 538, 108th Cong., Preamble (1st Sess. 2003); see H.R. 1083, 108th Cong., Preamble (1st Sess. 2003) [hereinafter “the Act” will be used when referring to both bills].
both the family and the state. Second, I define the family caregiver and describe caregiver "burnout" that results from caregiving activities. I next analyze the current types of respite care available and the existing public funding programs while identifying the weaknesses of each program. Next, I provide an overview of international family caregiver policies. It is against this backdrop of existing domestic and international family caregiver policies that I then critically evaluate the LifeSpan Respite Care Act of 2003.

II. PRIVATE VERSUS PUBLIC CARE

In American society, because of the belief in the "autonomous individual" as the essential force that drives the efficiency-seeking market, the notion of public responsibility for dependent persons has been under attack.23 If "autonomy" defines the realm of the individual, and the family is the quintessential private institution, then the notion of family caregiving becomes hidden within the "private" realm.24 The perception that the "private" realm is more adequate for dealing with caregiving is firmly fixed within the "social contract" of relationships set among individuals, societal institutions, and the state.25 Such privatization of family caregiving, however, has created an unequal and gendered division of family labor by which women are burdened far more than men.26 The structural and economic considerations of family caregiving have not been presented alongside the balance between public subsidy and private self-sufficiency of institutionalized caregiving.

However, significant changes in our society, such as geographic separation, the number of women in the workforce, divorce rates, decreased family size, and delayed childbearing27 have contributed to changes in the dynamics of the family structure. Such changes require a shift from the private responsibility of caregiving to the public sector

24. Id. at 1405.
25. Id. at 1404 (the "social contract" represents an interwoven, collective set of responsibilities and entitlements).
26. Id. at 1406; see supra note 20, at 2.
27. POLICY PERSPECTIVES, supra note 1, at 21-27.
so that caregivers do not need to compromise elder care in order to work.\textsuperscript{28}

In addition, caretaking labor generates a public good by resolving societal dependencies. Dependency includes both “inevitable dependency” and “derivative dependency.” Specifically, inevitable dependency is the dependency of children and ill adults, whereas derivative dependency is defined as that of the person assuming caregiving responsibility.\textsuperscript{29}

Society needs to respond to these dependencies in order to preserve and perpetuate those workers and consumers that form its institutions. Caretaking labor, because of its public value, “creates a social debt” that “binds each and every member of society” and is owed to caregivers as a group.\textsuperscript{30}

Although caretaking includes material, psychological, and emotional costs, some recognition exists that caregiving provides a public benefit.\textsuperscript{31} However, little compensation and accommodations have been provided to the caregivers by societal institutions.\textsuperscript{32} This inequity should be addressed by public policies that subsidize and accommodate family caregivers so that basic social goods such as respite care are considered a public responsibility.\textsuperscript{33}

Caregiving is neither an exclusive private matter for the family nor an exclusive public matter for the state. Hence, caregiving should be viewed as both a public and private matter in a system in which the “family and the state share responsibility.”\textsuperscript{34}

The Act would assist family caregivers by identifying all previously existing and potentially available funds for respite care. As a private matter, the family remains the primary caregiver. However, in its public capacity, the Act would provide respite care that would permit temporary care for a dependent person in order to provide temporary relief to the family caregiver.

The objective of the Act is to provide affordable and quality respite care to family caregivers by reducing fragmentation and inaccessibility

\begin{itemize}
\item \textsuperscript{28} Fineman, \textit{supra} note 23, at 1405, 1411.
\item \textsuperscript{29} \textit{Id.} at 1409-10.
\item \textsuperscript{30} \textit{Id.} at 1411.
\item \textsuperscript{31} \textit{Id.}
\item \textsuperscript{32} \textit{Id.}
\item \textsuperscript{33} \textit{Id.} at 1412.
\end{itemize}
that is created by multiple eligibility criteria and made worse by a myriad of funding resources, provider shortages, waiting lists, and duplication of resources.

III. THE FAMILY CAREGIVER

The 20th century has experienced a significant demographic shift in which the number of Americans aged sixty-five and older has grown exponentially. This trend is expected to continue to escalate for the foreseeable future. The increase in life expectancy has focused increased attention on long-term care. Traditionally, long-term care has been viewed as acute care serviced in an institutionalized setting (formal care). However, long-term care also includes non-institutional services (informal care) such as assistance with basic activities of daily living (ADLs) and help with instrumental activities of daily living (IADLs). ADLs include bathing, dressing, or other personal care. IADLs include household chores, life management, medication management, and transportation. Non-institutional services (informal care) permit the elder person to remain independent and vibrant within the community for a longer period of time.

As the aging population increases, long-term care has emerged as a source of political power because of an increase in the “older vote.” Although this phenomenon appears to shape a “battle of the generations,” it has also been a democratic force for change.

37. Id. page or section.
38. Robyn I. Stone, Providing Long-term Care Benefits in Cash: Moving To A Disability Model, 20 Health Affairs 2 (2001); see Kapp, supra note 35, at 722.
39. Id.; see also Policy Perspectives, supra note 1, at 2 (formal care is provided by professionals, whereas informal care is provided by families).
40. Stone, supra note 38, at 2.
41. Id.
Motivation for change is also driven by older persons' strong preference to remain at home with their families for as long as possible. Similarly, economics drive the change from institutionalized care to informal care, as policymakers fight to control the costs of institutionalized long-term care, such as nursing homes.

Despite changes in the dynamics of the family structure caused by a variety of factors, evidence shows that family members frequently provide elder parents and relatives with "services such as personal care, assistance with household tasks, shelter, and transportation." Today the majority of non-institutional services in the United States are provided on an informal, non-paid basis by family members and friends of the older person who is in need of long-term care. It is estimated that nearly 26 million individuals, or one in four households, are currently caring for elderly family members or friends.

Although the work of the family caregiver has traditionally been unpaid, legislatures and courts have begun to recognize the importance of family caregivers by providing compensation for their work. In Powell v. State Compensation Insurance Fund, the appellant challenged the Workers' Compensation Court's denial of domiciliary care benefits paid from the State Compensation Insurance Fund. The appellant showed that his wife provided a wide variety of services that

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44. Heath, supra note 42, at 1534-1535.
46. Id.
47. POLICY PERSPECTIVES, supra note 1, at 21-27 (illustrating trends that impact family care to include increased geographic separation, number of women in the workforce, divorce rates, decreased family size, and delayed childbearing).
48. Wise, supra note 34, at 564.
49. Kapp, supra note 35, at 729.
50. Id.
52. Campo et al., supra note 36, at 1.
55. Id. at 880.
promoted his well-being. Throughout its decision, the court distinguished between professional care and "domiciliary care" provided by a family caregiver. The court stated that "domiciliary care" required a lower skill level than professional care. The court also emphasized that the family member has the opportunity to pursue other activities while performing caregiving activities. Nonetheless, the court held that the family caregiver should be compensated from the State Compensation Insurance Fund to the limited extent provided in Montana's Worker's Compensation Act.

In re Estate of Kenneth L. Smart provides an example of how the courts quantify the compensation value of the work provided by a family caregiver. In this case, the family caregiver provided a wide variety of services for the decedent. The court viewed the caregiver's services as part of an implied contract, and as such, the family caregiver was compensated from the decedent's estate. The court assigned a value of ten dollars an hour for the caregiving services, which was equivalent to hospital charges for homemaker/chore services. It is interesting to note that if the work of the family caregiver were to be replaced with formal caregiving, the estimated cost would be $200 billion per year.

IV. CAREGIVER BURDEN

Family caregivers for the elderly, chronically ill, or disabled persons provide care at enormous personal expense and burden. Caregiver

56. Id. (Services provided included preparing his meals, washing his clothes, monitoring his medicine intake and his blood sugar level.)
57. Id. at 882-883.
58. Id. at 884.
60. In re Smart, 1996 Minn. App. LEXIS 1108, at *2.
61. In re Smart, 1996 Minn. App. LEXIS 1108, at *2. (The caregiver "prepared the [care recipient's] meals, cleaned his house, ordered and prepared his medications, irrigated his nose so that he could breathe properly, and performed several other services ranging from domestic house chores to those normally performed by LPNs and RNs.").
64. Theis, supra note 12, at 32.
burden is a "multidimensional response to physical, psychological, emotional, social, and financial stresses associated with the caregiving experience." Psychological and emotional effects include emotional exhaustion, depersonalization, and lowered life satisfaction. Emotional exhaustion "is a depletion of emotional resources." Depersonalization is the development of negative feelings toward the care recipient, and lowered life satisfaction creates a self-sense of devaluation in the caregiver. Family caregivers endure negative psychological and emotional costs because of compromised relationships, sacrifices of one's own family and career, and social isolation, which in turn results in the deterioration of social support.

Financial consequences are manifested not only in the present financial situation of the family caregiver but also in the future through the loss of energy and time in developing skills that would increase the family caregiver's marketability. For example, some family caregivers stop working in order to provide care, whereas others experience an increase in absenteeism, lower productivity, and lost career opportunities.

It is estimated that U.S. employers spend $900 million a year because of employee absenteeism and almost $5 billion a year to replace workers that have quit because of family caregiving demands. Some studies report business losses reaching a staggering figure of about $12 billion a year, resulting from caregivers arriving to work late, leaving early, or being simply too exhausted to focus on work.

Caregiver burden affects the relationship between the caregiver and the care recipient. Historically, the medical profession has treated

65. Kasuya, supra note 8, at 119.
67. Id.
68. Id.
69. Kasuya, supra note 8, at 121.
70. Fineman, supra note 23, at 1412.
71. FAMILY CAREGIVER ALLIANCE, supra note 45, at 3.
74. PA. DEP'T OF AGING, supra note 66, at 3.
the relationship between the physician and the patient as each forming a "single unit." However, substantial evidence shows that social support dramatically impacts the well-being of a person. Given the mutual impact people have on each other's health, and the effect of caregiving on the caregiver, the medical community recommends that the care recipient (patient) and the caregiver be considered "a single unit of care." As such, the medical community recommends considering the "caregiver as a partner with the physician" in providing care to the care recipient. Therefore, assessing the needs of the family caregiver should be incorporated into the care plan for the care recipient.

Family caregivers constitute the "invisible laborers" that maintain the survival of both the health care system and the elderly. Various social programs have been instituted for alleviating the negative effects of caregiving and improving the caregiver's quality of life. Such programs include medical devices, personal/nursing care, home modification, home-delivered meal services, assistance with housework, financial information, support groups, respite care, adult day-care, and transportation services.

V. RESPITE CARE FOR FAMILY CAREGIVERS

Although a wide variety of caregiver programs have been instituted, numerous studies have shown that family caregivers preferably want relief or respite from caregiving. The medical community defines respite care as the "temporary physical, emotional or social care of a dependent person in order to provide relief from caregiving" to the

75. Minow, supra note 10, at 1174.
76. Id. at 1176.
77. Id. at 1179.
78. Id.
79. FEINBERG, supra note 3, at 4.
81. Id.
82. POLICY PERSPECTIVES, supra note 1, at 6.
83. Theis, supra note 12, at 32; see also Gilmour, supra note 11, at 547; Kagan, supra note 18, at 2.
family caregiver. Respite care programs provide "long-term care services on a temporary or intermittent basis" to the family caregiver.

As the role of the family caregiver has expanded, the need for temporary relief from caregiving responsibilities has created an increased demand for respite care. Services provided under respite care programs vary from volunteers providing short periods of companionship to short stays in institutions. Such respite services are provided either in the care recipient's home, in-home services, or in an institution, out-of-home services.

A. Institutional Respite Care

Institutional respite care includes holiday admissions or intermittent readmissions. Holiday admissions permit the family caregiver to vacation while the care recipient is placed in an institution for up to two weeks. Intermittent readmissions allow a plurality of short-term, scheduled admissions that allow the family caregiver to perform other activities.

The response of the family caregiver has oscillated between "acceptance" of respite from caregiving to "marked ambivalence," in which the family caregiver continues to have concerns about the negative impact of institutional respite on the care recipient. Studies have shown that caregivers' concerns with respite care "tended to center on increased confusion and dependency of the elder and disruption of home routines." Also, certain care recipients appear to reject institutional respite, "fearing that respite is the first step toward permanent placement."

84. Gilmour, supra note 11, at 546.
85. POLICY PERSPECTIVES, supra note 1, at 10.
86. RESPITE CARE LIMITATIONS, supra note 13, at 29.
87. Id. at 30.
88. See id. (out-of-home services include adult day-care centers, nursing homes, respite facilities, and hospitals).
89. RESPITE CARE LIMITATIONS, supra note 13, at 30.
90. Gilmour, supra note 11, at 549 (noting that the caregiver continued to visit the care recipient for protective reasons when "marked ambivalence" was present).
91. Montgomery, supra note 13, at 35.
92. Id. at 32.
B. Out-of-Home Community Care

Out-of-home community care is provided through adult day-care centers which care for the individual during the course of a day. The care recipients usually need only minimal assistance and/or supervision. Out-of-home community care allows the family caregivers to remain in their homes and enjoy moments of privacy with other members of their own families. An additional benefit is that the care recipient has the opportunity to be stimulated by new activities.

C. In-Home Respite Care

In-home respite care is provided in the home of the care recipient and consequently does not interrupt the home routine. Since care is provided by a sitter/companion, health aide, or nurse, the level of care varies with the skill of the respite care provider. Although common, volunteer respite programs in which a volunteer spends time with the care recipient are limited to the sitter/companion level of care and are unable to serve a large proportion of the population. In-home respite care varies from short periods of two to four hours with a maximum limit of 24 hours. Numerous studies show that in-home respite care provided by a health aide for short periods is the most frequently requested respite care service.

D. Comprehensive Respite Care

Comprehensive respite care programs include a combination of out-of-home and in-home services and as such provide programs with the most versatility and flexibility in meeting the needs of many clients. In light of the various needs and wishes of the care recipient, a wide variety of respite care programs can be established depending on the level of care and the duration and frequency of the respite period.

Taken as a group, the above mentioned respite care programs represent an effort on the part of state and local policymakers to support family caregivers within their jurisdiction. The results of a

93. Id. at 31.
94. Id. (Extended periods of several days is less common.)
95. Id. at 33.
96. Id. at 32.
97. Id. at 30.
nationwide survey, however, show that financing and delivery of respite care is uneven and that it varies widely by the level of care provided and the age, income, and diagnostic of the care recipient. For example, in California, "[v]ouchers are used with home care agencies, adult day programs or facilities that offer overnight respite." In California and Pennsylvania, respectively $350 and $200 per month are available to a household to purchase services or supplies for the care of a family member. In Pennsylvania the respite care program has “approximately 3,500 caregivers enrolled at any time.” In 1999, California had 2,500 families on the waiting list to receive the $350 voucher. In New Jersey the participants cannot have incomes above $29,300, a requirement more inclusive than in Pennsylvania where eligibility requirements allow only persons who have an income level of 380 percent below the federal poverty level. Although in Florida a cap on income eligibility does not exist, the majority of funding for respite care programs is available only to caregivers of people with Alzheimer’s disease. All other care recipients receive respite care as in-home volunteer services.

The Act recognizes the current situation as characterized by fragmented programs in which the quality of respite care is strongly dependent on the domicile, age, and disability of the care recipient. The Act eliminates fragmentation and duplication by identifying all previously existing funds potentially available for respite care, such that funds and services become more accessible to family caregivers to fill the existing gaps.

VI. FUNDING OF RESPITE CARE

Although historically in the United States elder care has been considered the family’s responsibility, federal and state governments

98. Whirrett, supra note 15, at 18; see also National Respite Coalition, supra note 14, at 1.
100. Id.
101. Id.
102. Id.
103. Id. at 12-13
104. Id.
105. S. 538, 108th Congress, §2901(b) (1st Sess. 2003); see also H.R. 1083, 108th Congress, §2901(b); see also National Respite Coalition, supra note 14, at 1.
106. Fineman, supra note 23, at 1411.
have initiated elaborate programs of social services for the elderly.\textsuperscript{107} Because of increasing demand, programs have been developed to help family caregivers with information, education, and access to respite services.\textsuperscript{108} However, such state programs have formed a fragmented system in which financing flows from multiple sources based on the type of disability, age and income of the care recipient.\textsuperscript{109} The objective of the Act is to identify all previously existing funds that are potentially available from such programs and create a unified system for developing, implementing, coordinating, and maintaining access to quality respite care for all family caregivers without duplication of resources.

Currently, funding for respite services is found in both federal and state statutes.\textsuperscript{110} Federal statutes require that funding be channeled to care recipients through state resources.\textsuperscript{111} The state in turn distributes these funds according to state statutes under federal guidelines.\textsuperscript{112}

\textit{A. Supplemental Security Income}

Supplemental Security Income (SSI) involves direct payments made from the Social Security Administration to a "disabled" person having an income below a certain level.\textsuperscript{113} In order to qualify as "disabled," a person must demonstrate a permanent physical or mental condition that results in severe functional limitations.\textsuperscript{114} However, because the benefits are reduced by one-third if the "disabled" person lives with a family member, the SSI program penalizes family members that live together because of their financial situation.\textsuperscript{115} Hence, the SSI program

\begin{itemize}
  \item[107.] WHIRRETT, \textit{supra} note 15, at 3.
  \item[108.] \textit{Id.}
  \item[109.] NATIONAL RESPITE COALITION, \textit{supra} note 14, at 1; see also FAMILY CAREGIVER ALLIANCE, \textit{supra} note 53, at 4.
  \item[110.] WHIRRETT, \textit{supra} note 15, at 3.
  \item[111.] \textit{Id.}
  \item[112.] \textit{Id.}
  \item[113.] WHIRRETT, \textit{supra} note 15, at 10.
\end{itemize}
operates to the detriment of elders living in the home of the family caregiver.\textsuperscript{116}

\textbf{B. Medicare}

Medicare is a federal program authorized under Title XVIII of the Social Security Act that is available to anyone aged sixty-five or older and eligible for social security benefits.\textsuperscript{117} However, because Medicare excludes the costs of custodial or non-skilled care,\textsuperscript{118} funding of respite care funding is not available under Medicare.\textsuperscript{119}

\textbf{C. Medicaid}

Medicaid is a state administered program under federal guidelines authorized under Title XIX of the Social Security Act.\textsuperscript{120} Coverage is available for persons deemed "categorically needy" or "medically needy."\textsuperscript{121} "Categorically needy" means that the care recipient's income is below a level set by the state, whereas "medically needy" means that the care recipient's income is too low to cover his medical needs.\textsuperscript{122} Although respite care is not considered a Medicaid benefit per se, Medicaid waivers allow states to use Medicaid funds for respite care services.\textsuperscript{123}

The most common waiver for respite services for the elderly is the "Aging and Disabled Waiver."\textsuperscript{124} Under this waiver, known as "1915(c)" or a Home and Community Based Service (HCBS) waiver,\textsuperscript{125} states can provide non-medical services not normally covered by the

\textsuperscript{116} \textit{Id.}
\textsuperscript{118} EMILY K. ABEL, \textit{WHO CARES FOR THE ELDERLY?} 12 (1991) ("Medicare emphasizes medically oriented home health care, not the social services many elderly persons need to live independently in the community.").
\textsuperscript{119} WHIRRETT, \textit{supra} note 15, at 3.
\textsuperscript{120} 42 U.S.C. §1396 (2000).
\textsuperscript{121} Wise, \textit{supra} note 34, at 582 (stating that the states have set income levels for eligibility so low that barely one in five elders that receive informal care are eligible for Medicaid).
\textsuperscript{122} \textit{Id.}
\textsuperscript{123} WHIRRETT, \textit{supra} note 15, at 3.
\textsuperscript{124} \textit{Id} at 5.
\textsuperscript{125} 42 U.S.C. 1396n(c)(1) (2000) (waivers known as "1915c" waivers are named after the Social Security Act that created them).
Medicaid program in order to prevent a care recipient from being institutionalized. Services covered include "case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care," and other services requested by the state.

HCBS waivers are the leading source of federal funding for respite care. In order for the states to receive funding under HCBS waivers, the states must prove to the federal government that the cost of "community-based care will not exceed the cost of nursing home care." However, eligibility for existing state waiver programs is narrowly targeted to certain individuals depending on the type of disability, age, income, and their state of domicile. This results in long waiting lists to receive respite care services.

In Boulet v. Cellucci, the court recognized the hardships experienced, often for years, by individuals placed on a waiting list. Further, the court emphasized that "seventy-two percent of those on the waiting lists were waiting for residential services," hence indirectly showing the need for respite care in today's changing family structure.

D. National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) is a federal program developed by the Administration on Aging (AoA) of the Department of Health and Human Services (HHS) and enacted in 2000 as an amendment to the Older American’s Act (OAA) of 1965.

127. Id.
128. Id.
129. Id.
130. Wise, supra note 34, at 583 ("Only about one in five elder persons who receive informal care... are eligible for Medicaid").
134. Id. at 66.
135. Id.
137. WHIRRETT, supra note 15, at 6
The NFCSP provides states with financial grants for home- and community-based services for the elderly. The size of the grant for each state is determined on a "congressionally mandated formula based on a proportionate share of the [population] aged seventy and older." It also requires states to work with local agencies that serve the elders and their caregivers. Included among the community-based services are meal programs, homemaker services, transportation, counseling, adult daycare, and short-term respite care. Each state has the flexibility to determine how much money is allocated to each service. Although all people over sixty years old are eligible, priority is given to "the elderly with the greatest economic and social need." The amount of funding is still limited in comparison to the resources allocated to Medicaid, for which fewer people are eligible.

E. Title XX Social Services Block Grant

Title XX Social Services Block Grant (SSBG) is a federal block grant allocated to states to provide social services for its residents. Respite care is a valid service under SSBG. The funds are noncompetitive and available to the states on a formula basis. Although the states have wide flexibility in determining how to allocate the funds, funding has decreased dramatically in the last decade. Consequently, the ability to assist family caregivers under this program has become limited.

138. Wise, supra note 34, at 587-588.
139. WHIRRETT, supra note 15, at 6.
140. Wise, supra note 34, at 588.
142. WHIRRETT, supra note 15, at 7.
146. WHIRRETT, supra note 15, at 10.
147. Id.
148. NATIONAL RESPITE COALITION, NEW PROGRAMS ENACTED AND FUNDED IN FY 2001 RELATED TO RESPITE 2 (2001), available at http://www.archrespite.org/NRCSummary%20of%20Programs%20for%202001.htm (last visited Jan. 31,
F. Family Leave Programs

(1) The Federal Family and Medical Leave Act of 1993150 (hereinafter "Leave Act") requires that a business with more than fifty employees allow employees to take up to twelve weeks of unpaid leave in a year to care for a family member.151 Although the Leave Act is intended to balance work and family, most families cannot afford unpaid leave. Thus, only 6.5 percent of workers have used the Act to take time off to care for dependent family members.152

(2) The California Paid Family Leave Act of 2002,153 signed into legislation on September 23, 2002, made California the first state to provide workers with paid leave to care for a family member.154 Specifically, the employee receives half-salary for up to six weeks a year while taking time off to care for the family member.155 The law requires employees to contribute an average of $2.75 per month by payroll deduction to a worker's disability fund.156 Twenty-seven states are currently considering legislation to establish similar programs.157 Since benefits will not be available until July 2004, data is not yet available to evaluate California's success or failure.158 However, the California law illustrates that a low-cost approach towards expanding family-leave programs can be created within the family caregiver's employment.

2004) (funding was set at $1.725 billion in 2001, decreasing from a high of $2.5 billion in 1997).
149. Family Caregiving and the Older American Act: Caring for the Caregiver, supra note 5, at 69; see also WHIRRETT, supra note 15, at 10.
153. CAL. UN. INS. CODE §§3300-3305 (West 2002).
155. Id.
157. Id. 
158. Id.
G. Payment of Family Caregivers

(1) Tax credits represent an indirect way of paying family caregivers that have a steady source of income. Federal tax credits range from twenty to thirty percent of the qualified caregiver's expenses.\(^{159}\) For a caregiver to qualify, the care recipient must qualify as a dependent, which means that the care recipient must receive at least fifty percent of his support from the caregiver claiming the credit.\(^{160}\) Hence, this scheme excludes the very poor caregiver that does not pay federal income taxes because he has forfeited work opportunities in order to provide care.\(^{161}\) State tax credits usually follow the federal tax scheme. However, states have discretion over whether to allow a state tax credit for elder care.\(^{162}\) The family caregiver is thus indirectly compensated and may now have the ability to hire an independent provider for respite care. It should be noted that many state tax credit programs are not available for eldercare.\(^{163}\)

(2) The California In-Home Supportive Services Program (IHSS)\(^{164}\) provides funds to directly pay the family caregivers for their caregiving services.\(^{165}\) About forty percent of caregivers hired through the IHSS are relatives of the care recipient.\(^{166}\) The program promotes independence of the elderly by allowing them to choose their own caregivers, while compensating family members who provide care.\(^{167}\)

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160. Wise, *supra* note 34, at 585 (a “dependent” is an individual “over half of whose support, for the calendar year in which the taxable year of the taxpayer begins, was received from the taxpayer. *See also*, I.R.C. §152(a) (1994)).
163. *Id.*
166. Wise, *supra* note 34, at 589.
H. Caregiver Support Programs

Caregiver Support Programs (CSP) were enacted by a variety of states to provide family caregivers with respite care and other support services. The programs are funded from general state revenues and are usually limited to care recipients having cognitive impairments, functional impairments, and development disabilities. Although these programs provide revenue to family caregivers, compensation is limited to only those "jurisdictions that have recognized the importance of family caregivers." The eligibility standards, delivery of services, and funding vary widely among the different states. New Jersey has the most extensive respite care program that is almost entirely funded from casino revenues. Other states, such as California and Pennsylvania, provide financial assistance directly to the caregiver to purchase respite care services. In Pennsylvania, the eligibility requirement is 380 percent of the federal poverty level, whereas in New Jersey, recipients cannot have yearly incomes above $29,300. Although these states have recognized the importance of family caregivers, the reduced budgets and jurisdictional application of existing funds have limited the assistance provided to family caregivers, thus resulting in long waiting lists.

I. Lifespan Respite Programs

Five states have enacted Lifespan Respite Programs for "caregivers of all ages with all types of disabilities." The programs are defined by a statewide approach that establishes "community-based networks"
as a central point of contact for families seeking respite care and related support, regardless of disability, age, or income.\textsuperscript{177}

The "community-based networks" develop local partnerships that establish respite care capacity\textsuperscript{178} to provide family caregivers with various resources. These include providing respite care information, training caregivers, recruiting paid and volunteer respite care workers, connecting family caregivers with respite care providers and financial resources, and expanding respite care services from existing services within the community.\textsuperscript{179} These local partnerships include "family caregivers, providers, State and Federal funded programs, Area Agencies on Aging, nonprofit organizations, health services, schools, local businesses, faith communities and volunteers."\textsuperscript{180} However, because lifespan respite programs have been enacted only in Oklahoma, Oregon, Wisconsin, Nebraska, and Maryland, the resulting benefits are limited to those family caregivers living within those jurisdictions.

In the last decade both federal and state governments have recognized the importance of family caregivers as an integral part of the health care system.\textsuperscript{181} Unfortunately, a fragmented program lacking an adequate infrastructure for developing, implementing, coordinating, and maintaining access to quality respite care characterizes the current situation.\textsuperscript{182}

Lifespan respite programs should be made available to all family caregivers regardless of disability, age, income, or the care recipient’s state of domicile. The Act recognizes the fragmentation and overlapping of the current programs in which the quality of respite care is strongly dependent on the domicile of the care recipient.\textsuperscript{183} The Act identifies all previously existing funds that are potentially available for respite care, and by eliminating fragmentation and duplication, funds and services become more accessible to families to fill existing gaps.

\textsuperscript{177} Id.
\textsuperscript{178} Id.
\textsuperscript{179} Id. at 16.
\textsuperscript{180} Id. at 15.
\textsuperscript{181} FAMILY CAREGIVER ALLIANCE, supra note 45, at 1.
\textsuperscript{182} Kagan, supra note 18, at 6; see also S. 538, 108th Congress §2901(a)(11)-(13) (1st Sess. 2003), and H.R. 1083, 108th Congress §2901(a)(13)-(15).
\textsuperscript{183} S. 538, 108th Congress §2903(a) (1st Sess. 2003) and H.R. 1083, 108th Congress §2903(a); see also, supra note 131, at 23.
VII. INTERNATIONAL INNOVATIONS

Although a number of foreign countries have filial responsibility legislation, the global trend is moving towards elder care as a responsibility to be shared by the family and the state.184

Direct payments to caregivers of the elderly are commonplace in other countries. In Sweden, municipalities employ family members as caregivers and view their work as an ordinary employment position. As such, the salary is based on the hours providing care, is considered income, and is subject to taxation. Furthermore, the family caregiver receives all benefits and pension credits that would accrue with any other type of employment.185 Germany offers a choice to its elderly citizens between “benefits in kind,” which include professional care services that permit the family caregiver to return or enter the labor market and “benefits in cash,” which compensate the family caregiver monetarily.186 In addition, the program contributes pension funds for the family caregiver.187

In other countries, family leave programs entitling employees to paid leave are guaranteed by the government. In Japan, employees can take up to three months of paid leave to care for a family member, and they are entitled to seventy-five percent of their salary.188 In Sweden, although caregiving is available to all employees and pays seventy-five percent of the employees’ salary, it is limited to sixty days during the care recipient’s lifetime.189

Respite care insurance that provides temporary housing and support for elders is commonplace in Western Europe and Israel.190 Germany provides respite care that allows family members up to four weeks of occasional relief from caregiving responsibilities.191 Sweden sponsors day care and sheltered housing to temporarily relieve family caregivers from some of their responsibilities.192 Japan has implemented some of

184. Wise, supra note 34, at 594.
185. Id. at 592 (Compensation is based on the family caregiver’s income, hence offering an incentive to persons of all socioeconomic classes to provide care.).
186. Id.
187. Id.
188. Id. at 593.
189. Id.
190. Id. at 594.
192. Wise, supra note 34, at 594.
the most comprehensive and innovative family caregiving programs including tele-working, counseling for family caregivers, and providing housing loans.\textsuperscript{193} 

VIII. THE LIFESPAN RESPITE CARE ACT OF 2003\textsuperscript{194}

A. The Olmstead Decision

In Olmstead \textit{v. L.C.},\textsuperscript{195} mentally disabled patients challenged their confinement by the state to an institution as unjustified segregation.\textsuperscript{196} Although the patients were medically suited for placement in a community-based treatment program, the state preferred continued institutionalization.\textsuperscript{197} The Supreme Court recognized that "unjustified institutional isolation"\textsuperscript{198} of persons with disabilities is a source of discrimination under the Americans with Disabilities Act of 1990.\textsuperscript{199} Specifically, the Court held that when persons that can benefit from a community setting are forced into an institutional placement, unwarranted assumptions that such persons are incapable of participating in community life are formed.\textsuperscript{200} Further, the Court concluded that institutional placement "severely diminishes the everyday life activities of individuals."\textsuperscript{201} In conclusion, the Court held that states are required to provide individuals with disabilities community-based treatment, rather than institutional-based treatment, when professionals determine that such treatment is appropriate, the affected persons do not oppose such treatment, and available resources exist.\textsuperscript{202}

\textsuperscript{193} Id.
\textsuperscript{196} Id. at 583.
\textsuperscript{197} Id. at 584.
\textsuperscript{198} Id. at 600.
\textsuperscript{199} Id. at 607.
\textsuperscript{200} Id.
\textsuperscript{201} Id. at 601 (stating that everyday life activities include family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment).
\textsuperscript{202} Id. at 607.
In response to the Supreme Court's decision in *Olmstead*, Presidential Executive Order No. 13217, issued on December 24, 2001, requires six Federal agencies to evaluate their policies, programs, statutes, and regulations in order to improve the availability of community-based services for qualified individuals with disabilities.

As a result, the Department of Health and Human Services (HHS) launched the National Caregiver Support Program (NFCSP) in February 2001 to provide a variety of "innovative and flexible service options to families and other informal caregivers" by providing grants to individual states. The grants are allocated based on a congressionally mandated formula of the population aged seventy and older of each state. The NFCSP is being introduced in all fifty states and six territories through the national network of the Administration on Aging (AoA) of the HHS. This program would allow states to include a fixed budget for respite care.

An interesting outcome from the Supreme Court's *Olmstead* decision has been the forging of an alliance between the aging and disabled communities, resulting in partnerships that include but are not limited to collaboration on grants, policy and procedures development, program development, strategic planning, etc. For example, in Louisiana, the aging and disabled communities combined forces to form the Louisiana People's Olmstead Planning Group (LaPOP). LaPOP developed and eventually implemented the passage of Senate Bill 855. This bill was signed into law and became Act 1147 that created the Disability Services and Supports System Planning Group (DSSS). The DSSS is "the entity responsible for the

205. WHIRRETT, supra note 15, at 6.
206. Id.
207. HHS REPORT 2001, supra note 204, at 10.
208. Id. at 11.
development of a plan to reform long-term care in the state of Louisiana."\textsuperscript{211}

Furthe\textsuperscript{r} the Supreme Court's \textit{Olmstead} decision and the resulting alliances, the Respite Care Act of 2003 promotes family caregiver support by seeking respite care for all family caregivers.

\textbf{B. The Lifespan Respite Care Act of 2003}

The Lifespan Respite Care Act, S. 538,\textsuperscript{212} was introduced in the U.S. Senate on March 5, 2003, by Sen. Clinton (D-NY), who upon its introduction stated, "The Lifespan Respite Care Act would give our caregivers a much needed break and help gather the strength they need to continue their vital work."\textsuperscript{213} A separate companion bill, H.R. 1083,\textsuperscript{214} was introduced on March 5, 2003, in the U.S. House of Representatives by Representatives Jim Langevin (D-RI) and Jim Greenwood (R-PA).\textsuperscript{215} On April 10, 2003, S. 538 passed the Senate by Unanimous Consent and was referred for further action to the House Energy and Commerce Committee.\textsuperscript{216} The Act would amend the Public Health Service Act to establish a program assisting family caregivers in accessing affordable and high-quality respite care.\textsuperscript{217} The Act defines a family caregiver as an unpaid person providing in-home monitoring, management, or supervision for a child or adult with a special need.\textsuperscript{218} Respite care is defined as planned or emergency care provided to an individual (adult or child) with a "special need"\textsuperscript{219} in

\begin{footnotesize}
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\item[\textsuperscript{211}] See Brackin Testimony, \textit{supra} note 209, at 2.
\item[\textsuperscript{212}] S. 538, 108th Cong. (1st Sess. 2003).
\item[\textsuperscript{214}] H.R. 1083, 108th Cong. (1st Sess. 2003) [hereinafter "the Act" will be used when referring to common elements of both bills].
\item[\textsuperscript{215}] NATIONAL RESPITE COALITION, \textit{supra} note 212, at 1.
\item[\textsuperscript{219}] S. 538, 108th Cong. §§2902(2)-(3) (1st Sess. 2003) (care is provided to an adult or child); H.R. 1083, 108th Cong. §2902(7)(1st Sess. 2003) (care is provided to an individual).
\end{itemize}
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order to provide relief to the family caregiver. ²²⁰ By defining the term “special need” as the “particular needs of an individual of any age who requires supervision because of a condition,”²²¹ H.R. 1083 promotes lifespan respite care programs for family caregivers “regardless of the individual’s age, race, ethnicity, or special need.”²²² However, the “special need” that triggers respite care services is the “condition” of the care recipient.²²³ H.R. 1083 provides an open-ended listing of conditions²²⁴ that encompass both disabilities and aging conditions.²²⁵ Although the listing is open-ended, H.R. 1083 limits to a certain degree respite care services to the “condition” of the care recipient.

S. 538, however, removes the listing of “conditions” for which a “special need” would arise for respite care services. Under S. 538, lifespan respite programs would be available for “family caregivers of children or adults with special needs.”²²⁶ By defining “special needs” as the “care or supervision to meet the person’s basic needs or, to avoid self-injury or injury to others,” S. 538 avoids limiting the availability of respite care services to individuals that have a certain “condition.”²²⁷ As such, S. 538 provides respite care for the family caregiver without taking into consideration the condition of the care recipient.

The Act recognizes that the current fragmented program lacks an adequate infrastructure for developing, implementing, coordinating, and maintaining access to quality respite care for all family caregivers.²²⁸ The Act provides an integrated approach to respite care by eliminating fragmentation of services and funding based on specific eligibility “conditions” such as age, income, disability, or the care recipient’s family situation. By identifying all previously existing funds that are potentially available for respite care, fragmentation and

²²² Id. at § 2902(4).
²²³ Id. at § 2902(1).
²²⁴ H.R. 1083, 108th Cong. §2902(1) (1st Sess. 2003) (includes mental retardation, physical disabilities, chronic illness, mental and emotional conditions, cognitive impairments, traumatic brain injury, and any other conditions established by regulation).
²²⁵ Id.
²²⁷ Id. at §§2902(2)-(3) (1st Sess. 2003).
duplication are eliminated, hence making funds and services more accessible to families or developing new services to fill existing gaps and promoting respite care. Specifically, the Act authorizes development of state and local lifespan respite care programs, evaluation of such programs, training and recruitment of respite care workers and volunteers, and family caregiving training. The Act's objective is to encourage states to establish lifespan respite care programs, which are defined as a "coordinated system of accessible, community-based respite services for family caregivers of individuals (children or adults with special needs)." The Act would promote and disseminate information regarding respite care using existing resources. As the flow of information grows, eventually a single system will be established that maximizes resources through better coordination. To this end the Act authorizes the formation of a National Lifespan Respite Resource Center that will maintain a national database on respite care, provide training and technical assistance to local programs, and provide information to the public.

S. 538 specifically authorizes $500,000 for each fiscal year between 2004 and 2008 to establish the National Lifespan Respite Resource Center. Hence, family caregivers across the nation will not be limited to services based on their domicile.

S. 538 provides an initial funding of $90.5 million for 2004 and "such sums as may be necessary for fiscal years 2005 through 2008." H.R. 1083, however, merely provides an all-catch amount of "such sums as may be necessary." Funding is provided on a competitive basis through grants to organizations that initiate or expand existing respite care programs. Fund recipients must be a state agency, a private or a

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public organization capable of operating on a statewide basis, a subdivision of a state that has a population of more than three million individuals, or any already recognized state respite coordinating agency. 237

In order for the Act to establish a unitary system that maximizes resources through improved coordination, efforts must be made on a statewide basis between already existing organizations such that additional funding of services does not contribute to the already duplicative and fragmented system. S. 538 permits states and other eligible grantees financial flexibility once a coordinating system is in place. Specifically, S. 538 restricts "mandatory funds" for the development of lifespan programs at the state and local level and for regulation of such programs by evaluating the effectiveness of the care provided. 238 Once a coordinating system is in place, "discretionary funds" may be allocated to state and local organizations for respite care services. These services include worker and volunteer training programs and information sessions for family caregivers to guide them in making informed decisions about respite care." Contrary to S. 538, H.R. 1083 has a more rigid spending scheme in which states and other eligible grantees do not have discretionary use of the funds. 240

To promote a national respite care program that encompasses all caregivers, coordination is required among multiple federal agencies. 241 Such correlation would ensure coordination of respite care services for all caregivers of all ages with "special needs" and avoid duplication of resources. H.R. 1083 empowers the Secretary of Health and Human Services to act through the Maternal and Child Health Bureau (MCHB) 242 of the Health Resources and Services Administration (HRSA) 243 and in cooperation with other federal programs. 244 S. 538,

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238. Id. at § 2903(g)(1)(A) (1st Sess. 2003).
239. Id. at § 2903(g)(1)(B).
241. Id. at § 2903(c).
242. MATERNAL AND CHILD HEALTH BUREAU (The Maternal and Child Health Bureau (MCHB) is a bureau of the Health Resources and Services Administration (HRSA) and it assures quality health care for parents and their children), at http://www.mchb.hrsa.gov/about/default.htm (last visited Jan. 31, 2004).
243. HEALTH RESOURCES AND SERVICES ADMINISTRATION (The Health Resources and Services Administration is the access agency of the U.S. Department of Health and Human Services and it assures "the availability of quality health care to low income, uninsured, isolated, vulnerable and special needs
however, empowers the Secretary of Health and Human Services (HHS) to work directly in cooperation with other federal programs that have experience with a wide variety of health conditions that require caregiving, hence allowing for a certain degree of flexibility in organizing a national respite care program.\textsuperscript{245}

It is submitted that S. 538 is designed to function as a collateral collaboration between different programs. H.R. 1083, however, has more of a targeted, rigid, and hierarchical structure because it specifically empowers the MCHB to work with other federal programs. Since the MCHB's primary mission is to provide quality care for the child-parent unit, the organizational scheme under H.R. 1083 does not fully take into consideration the wide variety of conditions that require caregiving.

Overall, S. 538 appears to be a more effective bill for providing respite care for family caregivers because it provides respite care for the family caregiver without taking into consideration the condition of the care recipient, allocates a specific amount of funding, requires collateral collaboration between multiple federal agencies, and permits eligible grantees financial flexibility though the discretionary use of funds, hence taking into consideration the unique characteristics of each local jurisdiction.

CONCLUSION

Society has a responsibility to facilitate assistance to the family caregivers, to their caregiving responsibilities, and to the care recipient. Although family caregivers provide a substantial benefit to society, they are under-compensated for the work they perform. Beyond the caregiving responsibilities, the family caregivers have a responsibility to themselves to regenerate their energy and resources populations and meets their unique health care needs") at http://www.hrsa.gov/about.htm (last visited Jan. 31, 2004).

\textsuperscript{244.} H.R. 1083, 108th Cong. § 2903(c) (1st Sess. 2003) (Other federal agencies include the National Family Caregiver Support Program of the Administration on Aging, the Administration on Developmental Disabilities, the Substance Abuse and Mental Health Services Administration, and the Administration for Children, Youth and Families.).

\textsuperscript{245.} S. 538, 108th Cong. § 2903(c) (1st Sess. 2003) (Other federal agencies include the National Family Caregiver Support Program of the Administration on Aging, the Administration on Developmental Disabilities, the Substance Abuse and Mental Health Services Administration, the Maternal and Child Health Bureau, and the Administration for Children, Youth and Families.).
in order to be productive members of society. A caregiver's life need not be completely forfeited to their caregiving responsibilities.

The Lifespan Respite Care Act of 2003 is a federal effort to coordinate existing respite care resources, eliminate fragmentation and duplication, and provide families with improved accessibility to respite care. The Act provides grants on a competitive basis to already existing state and local organizations to disseminate information and eventually establish a single system that maximizes resources through better coordination. Regardless of the care recipient's age, race, ethnicity, or special need, by providing respite care, the Act would allow all family caregivers emotional and spiritual regeneration to sustain their own health while providing continuous caregiving and enjoying a productive life.