

A Report on Respite Services for Grandparents Raising Grandchildren (GRG) in Hawai'i



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**A REPORT ON RESPITE SERVICES FOR
GRANDPARENTS RAISING GRANDCHILDREN (GRG)
IN HAWAI'I**

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EXECUTIVE SUMMARY

There are approximately 10,000 grandparents responsible for meeting the basic needs of their grandchildren without the presence of their biological parents within the household. Many grandparents raising grandchildren (GRG) face additional challenges, including emotional and behavioral problems of their grandchildren, as well as their own health and financial difficulties. Act 204, Session Laws of Hawaii 2007, expanded the mandate of the Joint Legislative Committee on Family Caregiving to include GRG. This report examines the issues related to the provision of respite services to GRG in the state of Hawai'i.

The first category defines respite care in relation to the needs of GRG. This is important because GRG face different challenges than family caregivers for elderly relatives. The most notable difference between these groups is the range of impairment of the care recipient. GRG provide care for children with a range of function: Some require the same amount of care generally required by most children, others have mild physical or mental challenges, and still others have severe disabilities.

The second category is an overview of existing theoretical and legislative models of respite care. There are three types of theoretical models of respite care: Adult day care, in-home care, and facility or institution-based care. Of these, a day care model is the most applicable to respite care for most GRG. Federal definitions of respite care vary by act. The federal definition most useful for GRG was put forth by the Lifespan Respite Care Act and allows for the provision of respite services for caregivers of children with special needs. Many state-funded lifespan respite programs define respite care quite broadly, thus allowing for the provision of services to the greatest number of GRG.

The third category is an analysis of model respite programs in other states. Lifespan respite programs in Oregon, Nebraska, Wisconsin, and Oklahoma are characterized by several features. Respite services offered as part of these programs are all located in the community and coordinated by local 'experts' in respite care. Focus is on accessibility and providing care for families in need, regardless of age, race, ethnicity, special need or situation.

The fourth category is an inventory of the existing respite services for GRG in Hawai'i. There is a great deal of variation in respite services available to GRG by island. Oahu and Maui counties have the greatest number of services, while Kauai and the Big Island of Hawai'i have the fewest. Overall, there are many gaps in service including: Lack of transportation, limited availability of crisis care, few services available for children between 5-15 years, and the lack of

therapeutic services for children who do not have severe disabilities. The most positive aspects are the flexibility of many service providers to work with families on a case by case basis.

Further examination of respite care options for GRG must ensure that they are: (1) Culturally appropriate, (2) available to GRG of all legal statuses, (3) offered as part of a package of services, (4) use a lifespan respite model, (5) give priority to GRG who are sole providers for their grandchildren, and (6) contain an evaluation component. Legislative actions should formulate a clear definition of the conditions under which GRG need respite care and formulate a clear definition of respite care.

BACKGROUND AND ACKNOWLEDGEMENTS

In response to Senate Bill No. 2830, which was enacted as Act 220, SLH 2008, the Executive Office on Aging (EOA) contracted with the University of Hawaii (UH) Department of Family and Consumer Sciences, College of Tropical Agriculture and Human Resources to conduct an inventory of respite services in Hawaii for grandparents raising grandchildren. The Executive Office on Aging would like to thank and acknowledge Dr. Lori Yancura for preparing this report.

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SECTION 1: INTRODUCTION AND BACKGROUND

According to the most recent US Census (Simmons & Dye, 2003), there were 49,247 grandparents living in the same household as their grandchildren in Hawai'i. Of this number, an estimated 21.5% reported that they were head of the household, and that their grandchildren's parents were not living with them. Grandparents who are responsible for meeting the basic needs of their grandchildren are sometimes referred to as custodial grandparents, or grandparents raising grandchildren (GRG). The number of GRG is growing rapidly. Between 1990 and 2000, there was more than a 30% increase in children living in grandparent-headed households in the United States (AARP, 2003).

Like traditional family caregivers (i.e., those taking care of elderly family members), GRG often need support to provide adequate care for their grandchildren – especially when those grandchildren have special needs. One service that many GRG require is respite from their caregiving responsibilities. A recent needs assessment of GRG in Hawai'i found that respite care was rated among the most essential services by both GRG and service providers who work with GRG (Yancura, 2007). Despite this, the needs of GRG are often overlooked in policy decisions regarding respite care. However, Act 204, Session Laws of Hawaii 2007, specifically included GRG in the definition of family caregivers, thus creating a need to examine the provisions of respite services for GRG in Hawai'i.

The aim of this report is to examine the issues related to respite care for GRG, to summarize model respite programs for GRG in other states, and to identify existing respite services for GRG in Hawai'i. The remainder of this introduction provides background information on GRG in Hawaii and describes topics addressed in each subsequent section of this report.

Why are GRG Primary Caregivers for Their Grandchildren?

There are many reasons why grandparents assume sole responsibility for their grandchildren. The most common reasons cited in the literature are parental drug addiction, divorce, and child abuse (Fuller-Thompson & Minkler, 2000). Teen pregnancy, parental incarceration, or death of a parent are also common reasons why grandparents may provide primary care (Hayslip & Kaminski, 2005). A recent study found that the most common reasons that GRG in Hawai'i asserted for taking care of their grandchildren were that the children's parents were either habitual drug users (37.5%) or serving jail sentences (22.5%). In addition,

many GRG in Hawai'i take care of their grandchildren because of their parents demanding work schedules, or military redeployment (Yancura, 2007).

Hawaii is ethnically and culturally diverse, having the highest percentage of Native Hawaiians, Asians, and Other Pacific Islanders (NHAPI) in the nation (U.S. Census Bureau, 2006); therefore, the experience of GRG in Hawaii may differ than that of other states. Although there are variations between cultures, family relationships of NHAPI cultures generally place emphasis on family interrelationships, as characterized by strong emotional ties among family members throughout the lifespan, with the tendency for the needs of the family to be placed above the needs of the individual (Yee, DeBaryshe, Yuen, Kim, & McCubbin, 2006). These values result in GRG being the natural choice to take over raising grandchildren when a family faces problems. In the words of one grandparent advocate, "It's [taking care of grandchildren] what we've always done" (Chong, 2008).

Difficulties Faced by GRG

Many GRG face difficulties associated with their role as primary caregivers for their grandchildren. Some of these difficulties stem from the reasons why their grandchildren are in their care, the most common being parental use of illegal substances (Yancura, 2007). Prenatal drug exposure places infants at a higher risk of premature birth, low birth weight, incidence of infectious disease, and neurobehavioral problems. Less is known about the long-term effects, but it is most likely associated with learning disabilities and behavioral problems. Providing care for these children requires a unique set of parenting skills (ARCH, 1997).

In addition to physical disabilities, children in the care of their grandparents may also have behavioral and emotional problems, especially those with histories of parental violence or neglect. In comparison to children raised by their biological parents, children raised by their grandparents have been shown to exhibit higher levels of verbal and physical aggression toward other children, teachers, or their grandparents. However, they show lower levels than those being raised by non-relative caregivers in the foster care system (Glass & Huneycutt, 2003). Caring for grandchildren with emotional problems can be especially stressful for GRG.

Hayslip and Kaminski (2005) identified two distinct groups of custodial grandparents, defined in terms of the needs of their grandchildren. The first group of grandparents consists of those who are dealing with the usual demands of the parenting role. The second group of grandparents consists of those who are raising grandchildren with physical, emotional, or behavioral issues. This second group faces a unique set of challenges and may experience

more stress, often to the impairment of their own health. Therefore, grandparents who are raising children with such issues may especially benefit from respite services.

In addition to factors related to their grandchildren, GRG also have unique circumstances that suggest a need for respite care. GRG may be grieving over the losses that placed them in the role of custodial grandparent (Joslin, 2002), such as death, incarceration, or, drug addiction of their children (i.e. the parents of their grandchildren). Many grandparents, especially those who are dealing with these issues, may have difficulties with publicly recognizing or acknowledging this grief, which may result in an inability to seek or receive social support from others (Hayslip & Kaminski, 2005). GRG in Hawai'i refer to this feeling as shame.

GRG may also face difficulties due to advanced age. Given that the vast majority of GRG are older than most parents, raising children is a different task for GRG than it is for parents. Although some GRG are as young as 35 years-old, others are well into their 70's - some are even great-grandparents or step-great-grandparents to the children in their care (Glass & Huneycutt, 2003). Parenting can be demanding at any age, but can be especially difficult for GRG who have chronic health problems that hamper their ability to keep up with the demands of active children and teenagers.

Many GRG also burdened by additional costs associated with raising their grandchildren, such as health care, education, and in some cases, legal expenses (Hayslip & Kaminski, 2005). These matters are often complicated by the fact that many grandparents are retired, or have to reduce the number of hours they work in order to take care of their grandchildren. A study of GRG in Kaua'i found that over one-third of the grandparents surveyed retired early to provide care for grandchildren (Yancura, 2007).

In addition to financial burdens, some GRG face housing complications. GRG who are renters are particularly vulnerable, as demonstrated in a national study, which reported that 60% of GRG living below the poverty line were spending at least one-third of their household income on rent, and that 30% of GRG were living in overcrowded conditions (Fuller-Thompson & Minkler, 2003). Other GRG may live in senior housing communities that do not allow children, and still others have downsized into smaller dwellings.

Many GRG experience extreme psychological stress from their role, especially those who assumed care of their grandchildren abruptly and unexpectedly, as is often the case when their grandchildren's biological parents are incarcerated. Studies have shown that on average, GRG report more anxiety, depression, and physical health problems than their non-caregiving peers (Blustein, Chan & Guanais, 2004). Situational stressors associated with custodial

grandparenting may be compounded by the fact that GRG were not expecting to raise children at this point in their lives. Off-time social roles, or those that do not occur at normative times in the lifespan, are associated with psychological and emotional difficulties (Cooney & An, 2006). Despite these negative factors, many GRG also derive benefits, such as heightened feelings of morale and happiness from providing security and stability in their grandchildren's lives (Dellmann-Jenkins, M., Blankemeyer, M., & Olesh, M., 2002).

Why Many GRG Need Respite Care

The difficulties described above explain why GRG need respite from duties associated with raising their grandchildren. Of course, there is great variation in the need for respite. GRG who face few hardships, or who have strong family and social support networks, might not need respite services. Those who face many difficulties and have few avenues of support have a great need for respite services. In general, GRG who are single, female, and live in poverty face the most difficulties (Minkler & Fuller-Thompson, 2005).

Several research studies have suggested that GRG may benefit from respite care services (Bachman & Chase-Lansdale, 2005; Hayslip & Kaminski, 2005). However, a review of the literature for studies documenting positive outcomes for GRG as an immediate result of receiving respite care yielded no results. However, several studies provide evidence for correlations between lower levels of stress and increased well-being in GRG (Leder, Grinstead, & Torres, 2007; Sands, Goldberg-Glen, & Thornton, 2005). Respite care has also been shown to be effective in reducing stress of family caregivers for older adults (Levin, Moriarty, & Gorbach, 1993). Therefore, the likelihood that respite care will benefit GRG is quite high. There is a need for further research that will evaluate the effectiveness of respite programs, and examine the benefits of respite care for GRG in greater detail.

The final, most compelling reason for consideration of respite care for GRG in Hawai'i, is that grandparents in need have requested respite services. A recent needs assessment of GRG in Hawai'i (Yancura, 2007) conducted a series of focus groups with GRG, and held interviews with service providers on Oahu, Kaua'i, Maui, and the Big Island (Hilo). Respite care was rated a key concern by both service providers and grandparents.

Consistent with the scope of the National Family Caregiver Support Program, Act 204, Session Laws of Hawaii 2007, "expanded the mandate of the joint legislative committee on family caregiving by including grandparents of children age eighteen years and younger, or nineteen years of age or older with physical or cognitive limitations, in the Act's definition of

family caregiver” (SB2045). The inclusion of GRG as family caregivers indicates that an inventory of respite services for family caregivers must include services available to GRG.

Issues Addressed in This Report

The remaining sections of this report examine issues related to respite care for GRG in Hawai‘i and are organized as follows:

- **Section 2: Respite Care for Grandparents Raising Grandchildren** discusses similarities and differences in the roles of GRG and traditional family caregivers. It summarizes existing State and statutory definitions of respite and indicates how these might apply differently to GRG and traditional family caregivers.
- **Section 3: Model GRG Respite Programs in Other States** outlines key features of GRG respite programs in other states.
- **Section 4: Inventory of Programs for GRG in Hawai‘i** describes the methodology and results of a survey which identifies existing respite programs for GRG in Hawai‘i.
- **Section 5: Conclusions and Recommendations for Policy** summarizes the overall findings of this report and suggests implications of its findings for programs and policy.

SECTION 2: RESPITE CARE FOR GRANDPARENTS RAISING GRANDCHILDREN

The term respite care does not have a universal definition. A report issued by the Legislative Reference Bureau (LRB) of Hawai'i provided a broad definition of respite care as services that provide "temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly" (Bueno, 2007, p. iv). It also noted that the commonly understood goals of respite care are twofold: to provide relief for the care provider, and to delay or prevent institutionalization of the care recipient.

This definition allows for substantial variation in the types of services that may be classified as respite care. Respite services vary by setting, and may take place within the home, community, or an institution. They also vary by whether respite care is planned in advance or available in a crisis situation. There is variation in the duration of services as well, in which respite care may be offered for a few hours, or for a period of weeks or months. Furthermore, and most importantly in consideration of respite care for GRG, services vary on the anticipated outcome for the care recipient. Some services may be offered simply to relieve the caregiver, while others offer therapeutic benefit.

A clear definition of respite care must be determined before other policies are to be considered, such as program concept, source of funding, scope of programs and services, and mode of service delivery. Defining respite care is especially critical for GRG because they face different challenges than traditional family caregivers (i.e., those caring for elderly family members). This section considers issues related to respite care for GRG. It notes similarities and differences between GRG and traditional family caregivers and examines LRB findings with respect to existing state and statutory definitions and models of respite care.

Similarities and Differences between GRG and Traditional Family Caregivers

To date, most of the peer-reviewed literature on respite care has focused on traditional family caregivers, or individuals providing care to older family members (most commonly spouses or parents) who cannot care for themselves because of chronic disease or dementia (Pinquart & Sorenson, 2005; Strang, Haughey, Gerdner, & Teel, 1999). Therefore, existing conceptualizations of respite care may not be wholly applicable to the needs of GRG. A clear understanding of similarities and differences between GRG and traditional family caregivers is critical to the development of policies and programs to guide respite care for GRG.

The demands of GRG and that of traditional family caregiving are fundamentally similar in that they both involve caring for dependent family members who cannot care for themselves.

They also share the following characteristics:

- Neither type of caregivers typically receives monetary compensation for their work.
- Both types of caregiving involve the investment of a considerable amount of emotional, physical, and financial resources.
- Both types of caregiving are time-consuming, in many cases precluding care providers' participation in outside employment.
- Both types of caregivers often depend upon on assistance from others to fulfill their duties. This assistance may be informally provided by friends and family members, or formally provided by direct government aid or non-profit agencies.
- Both types of caregiving are motivated by a sense of duty or obligation to care.
- Both types of caregiving are typically characterized by strong emotional bonds.
- Both types of caregiving may occur at nearly any point in the adult lifespan, although most individuals providing care are in middle-to-late adulthood (aged between 45 and 70 years).
- Many individuals in both categories of care providers do not classify themselves as "family caregivers," and thus may not know that they are eligible for services.
- Both types of caregiving have been associated with poor mental and physical health outcomes such as depression and increased risk for chronic disease (Hayslip and Kaminski, 2005; Vitaliano, Zhang, & Scanlan, 2003).
- There are cultural differences in reasons for providing both types of care (Dilworth-Anderson, Brummett, Goodwin, Williams, Williams, & Siegler, 2005).
- Both types of caregiving involve some positive aspects, such as opportunities to provide support for a loved one, or mastery of new skills (Folkman, 1997; Glass, & Huneycutt, 2002).

There are also differences between the duties of GRG and traditional family caregivers.

Differences with the greatest implications for respite care are listed below:

- GRG are providing care to younger individuals than traditional family caregivers. This may have implications for the length of care given. Grandparents raising grandchildren who have severe disabilities might potentially be providing care for a longer period of time than those caring for frail elderly individuals. However, grandchildren without disabilities

are legally responsible for themselves upon reaching 18 years of age, so the duration of grandparent care may be shorter.

- The types of impairments differ among the two types of care providers. By definition, traditional family caregivers provide care to individuals with chronic impairments: physical disabilities, disease, and dementia. However GRG provide care for grandchildren with a greater range of function. Some may be healthy, within the normal range of physical and mental function for their ages. Others may have relatively mild problems stemming from prenatal and early family environments, such as learning disabilities and mild behavior problems. Still others may have severe impairments such as developmental disabilities or mental retardation.
- Although the number of grandparents raising grandchildren is growing, there are a greater number of traditional family caregivers.
- There is a more extensive formal support network available to traditional family caregivers.

Existing Models and Definitions of Respite Care as they Apply to GRG

As mentioned earlier, a report issued by the Legislative Reference Bureau (LRB) noted that the commonly understood goals of respite care are to provide relief for the care provider and delay institutionalization of the care recipient. The first goal has direct relevance to the needs of GRG in Hawai'i. In fact, GRG and agencies serving them have identified relief in the form of respite care as a priority need (Yancura, 2007). The second goal applies to GRG only if the term institutionalization is broadly defined to include child protective services. This broadening of the definition of institutionalization is an example of how existing models and definitions of respite care may need to be reconsidered for application to the needs of GRG. The following subsections briefly summarize models and definitions of respite care described in the LRB report (Bueno, 2007) and discuss their applicability to GRG.

Models of Respite Care

Bueno (2007) defines three types of respite care models based on where the respite care service is provided: Adult day care, in-home care, and facility or institution-based 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” (Bueno, 2007, p8). Day care programs typically offer activities and other therapeutic services. The day care model of respite services could be quite useful for GRG who are caring for grandchildren at all ranges of function, from those who

are healthy to those with severe disabilities. It would be especially useful for GRG providing care for children too young to attend school and for those providing care for school-aged children during summer months. In fact, respite care during the summer months has been rated as very important by GRG in Hawai'i (Yancura, 2003).

In-home respite care occurs in care recipients' homes. It can take place on a regular or occasional basis at any time during the day or evening and may include companion, homemaker, personal care, or skilled nursing services. This type of respite care is not likely to be useful for most GRG, with the exception of those whose grandchildren have severe disabilities.

Facility- or institution-based care supplies services for overnight and extended periods of time. For elderly patients, this type of care typically is furnished by placement in a nursing home or health care facility and may be provided for both planned and emergency stays. This model of care would be useful for GRG who are providing care for grandchildren with severe disabilities. It might also be useful for GRG who are providing care for healthier children, if it is offered in the form of a retreat or summer camp. One particularly interesting aspect of this program with respect to GRG is the availability of emergency stays. Many grandparents assume care for their grandchildren unexpectedly, due to incidents such as sudden arrest or domestic violence. In cases such as this, having children stay in temporary respite facilities for a few days would afford the grandparents time to prepare for grandchildren by preparing space in the house for them, obtaining beds and other essential items, and enrolling them in school (if applicable).

Federally-Funded Respite Options

Federally-funded respite options are applicable to GRG because states and programs that receive federal funds must meet eligibility requirements and follow program guidelines to receive funds from federal sources. There are three federal programs that have direct effects on respite care programs. As they currently stand, the first two programs have limited applicability for GRG. The last program shows the most promise for meeting the needs of GRG.

The first program, the **National Family Caregiver Support Program (NFCSP)** was created by the Older Americans Act Amendments of 2000. The Hawai'i Executive Office on Aging (EOA) received \$778,000 through the NFCSP in fiscal year 2006. These funds are administered by each county agency on aging and may be spent on a variety of services such as assistance, information, training, counseling and respite care. Up to 10% of these funds may be used to support grandparents and relative caregivers of children not more than 18 years of

age, including grandparents who are sole caregivers of children and those individuals who are affected by mental retardation or who have developmental disabilities.

The second program, the **Medicaid Home and Community-Based Services Waiver Program**, allows states to operate Medicaid-funded respite programs by waiving federal Medicaid requirements that prohibit payment for non-medical services, such as respite care and home modification. The Department of Human Services currently administers Hawaii's Medicaid Waiver Programs, but is limited to serving only GRG who meet strict eligibility requirements.

The third program, the **Lifespan Respite Care Act of 2006** was signed into law on December 21, 2006. It is based on a lifespan respite model, designed to "provide a coordinated system of accessible, community-based respite care services for family caregivers of children and adults with special needs." There are no limits to the age of the care recipient, but children must be identified as children with special needs. A child with a special need is broadly defined as "a person less than 18 years of age who requires care or supervision beyond that required of children generally to meet the child's basic needs or prevent physical self-injury or injury to others (ARCH, 2008)." This definition is the broadest among the federal definition, thus programs funded under this act might be able to provide respite care for GRG whose grandchildren have behavioral or learning disabilities, but are not severely disabled. The funding has not yet been appropriated for this act, so it is not a current resource for respite care for GRG.

State Initiatives in Respite Care

Several states have defined respite care broadly enough to benefit all GRG who require services. These programs are typically funded through general funds, although some states supplement this funding with casino, tobacco settlement, or lottery funds.

State Lifespan Respite Programs have limited eligibility requirements. They are designed to serve care providers of care recipients with special needs. Care recipients may be of any age. Special needs is broadly defined to include any disability, chronic or terminal illness; or other physical, emotional, and mental conditions requiring ongoing care and supervision. Most of these programs are based upon model programs in Oregon, Nebraska, Wisconsin, and Oklahoma. Section 3 of this document describes aspects of these programs that apply to respite care for GRG.

Several states have also developed **Other State-Funded Respite Care Initiatives**. The LRB report (Bueno, 2007) contains a table summarizing the respite options (adult day,

overnight, in-home, weekend/camp), minimum age, program name and service cap of the 31 states listed in the Family Caregiver Support: State Facts at a Glance booklet published by the National Conference of State Legislatures and the National Association of State Units on Aging. Of these 31 states, 8 do not have minimum care recipient age requirements for caregiver eligibility for services. The remaining 23 states have care recipient age requirements; care-recipients must be either at least 18 years of age (with a disability) or at least 60 years of age.

Summary

GRG differ from traditional family caregivers on a few key dimensions. The most notable dimension relevant to respite care is the range of impairment of the care recipient. GRG provide care for children with a great range of function, some require the same amount of care general required by most children, others have mild disabilities, and still others have severe disabilities. Children with disabilities require greater amounts of care.

The LRB report (Bueno, 2007) defines three types of respite care models: Adult day care, in-home care, and facility or institution-based care. Of these, a day care model is the most applicable to respite care for most GRG.

Federal definitions of respite care vary by act. The definition most useful for GRG was put forth by the Lifespan Respite Care Act. Although this act was passed in 2006, its funding has not yet been appropriated.

Many state funded lifespan respite programs define respite care quite broadly, thus allowing for the provision of services to the greatest number of GRG. The following section details these programs in four model states: Oregon, Nebraska, Wisconsin, and Oklahoma.

SECTION 3: MODEL RESPITE PROGRAMS FOR GRG IN OTHER STATES

The federal Lifespan Respite Care Act of 2006 was based upon successful lifespan respite programs in four states: Oregon, Nebraska, Wisconsin, and Oklahoma. The following section of this report describes aspects of these programs that directly apply to GRG. Much of the information about these programs comes from ARCH National Resource Center for Respite and Crisis Care Services (Baker & Edgar, 2004). More information about each of these programs may be found in their websites (provided in Appendix A of this report) and other discussions of how they relate to respite care for all caregivers in Hawai'i (Bueno, 2007; Arnsberger & Blumhardt, 2008) .

Oregon

The Oregon State Legislature created the Oregon Lifespan Respite Care Program in 1997. The goals of this program are to assist local communities in building respite access networks for all types of family and primary caregivers. It is implemented by the Oregon Department of Human Services, which contracts with agencies throughout the state to serve as a single local source of information for access and referral to respite care services. These agencies are also responsible for recruitment and training of respite care providers, coordination of other respite-related services, and connecting families with potential resources to pay for respite care.

Caregiver Definition is “any individual and/or family regardless of age, income, ethnicity, race, special need or situation.” (Oregon Administrative Rules, 411-044-0000 to 411-044-0040).

Type of Respite Care is tailored to families and individual needs, including: Adult day, in-home and overnight respite, counseling, education, training, information, and support groups.

Costs to Caregivers varies by service, respite coordinators will assist families in finding ways to fund respite care. There is no service cap.

Funding occurs through various sources: State general funds, local/county funds, family or caregiver funds, private and volunteer resources, and exchange of care among families or caregivers.

Nebraska

The Nebraska State Legislature created the Nebraska Respite Network in 1999. The goal of this program is to provide a statewide system for the coordination of respite resources across the lifespan. It is implemented by the Department of Health & Human Services, which

contracts with six regional agencies throughout the state to coordinate information and referral for families who need respite care. These agencies are also responsible for recruitment and training of respite care providers, marketing activities to increase the public's awareness of respite, quality assurance, and program evaluation.

Caregiver Definition is any individual providing ongoing care for an individual unable to care for himself or herself. The Lifespan Respite Subsidy Program is eligible to all caregivers who meet income guidelines.

Type of Respite Care includes adult day, in-home, overnight, or weekend/camp respite.

Costs to Caregivers. There is no cost to caregivers eligible for the Lifespan Respite Subsidy Program, but services are capped at \$125 per month. Families are permitted to bank up to three months of subsidies for a planned special event. One-time benefits are also available for families who do not have ongoing needs.

Funding: The Lifespan Respite Subsidy Program is funded by Tobacco funds and administered by the Nebraska Department of Health and Human Services/Division of Aging Services.

Wisconsin

The Wisconsin State Legislature authorized legislation for the Wisconsin Lifespan Program in 1999. The goal of this program is to ensure that coordinated, noncategorical respite services are available to families and caregivers regardless of age, disability or geographic location. It is implemented by the Respite Care Association of Wisconsin (RCAW) in collaboration with the Department of Health and Family Services. RCAW contracts with five regional lifespan networks throughout the state to offer technical assistance to these regional networks. The networks provide direct stipends and coordinate volunteer assistance to families.

Caregiver Definition is any individual who lives in the home of a person with special needs and provides care or supervision for that person.

Type of Respite Care varies by administering agency.

Costs to Caregivers depends upon service used. Vouchers for care may be administered by agencies.

Funding: Overall income is estimated to be derived from the following sources: 60% from state general funds; 10% from private contributions; 10% from United Way or other local funds; 10% from city and county general funds. Source of the remaining 10% is unknown.

Oklahoma

The Oklahoma Respite Resource Network began offering services in 2000. The goal of this program is to support families and caregivers by increasing the availability of respite care. It uses a preexisting information and referral system (OASIS) to link families to the program, respite services and training opportunities. This program is unique in that it was initiated by a partnership between state agencies, private agencies, and foundations that have pooled resources for respite care. These resources are distributed to families in need through a voucher program.

Caregiver definition is any individual providing ongoing care for an individual with special needs (broadly defined). Grandparent must be 55 or over or the grandchild must have a developmental disability.

Type of Respite Care: Adult day, in-home, overnight, and weekend/camp respite.

Costs to Caregivers: The Oklahoma Respite Resource Network promotes consumer control by combining service diversity, the family pay option and direct pay. Financially eligible families receive a voucher, the amount of which is determined by household income level. For three months from the date of issuance, families can use these vouchers to purchase the respite care that suits them, including paying professionals, family or friends.

Funding: Oklahoma estimates that 15% comes from state general funds; 10% from Community-Based Child Abuse Prevention; 5% from Promoting Safe and Stable Families Act; 2% from Adoption Assistance/Opportunities Act; 1% from Social Services Block Grant; 1% from Maternal & Child Health (Title V); 8% from Mental Health; 30% from other federal funds; 10% from services for the aging; 10% from TANF; and 5% from private and foundations. By expanding the number of agencies pooling resources, the budget increased from \$65,000 to \$1.8 million over a three year period.

Summary

These model lifespan respite programs are characterized by several features. Respite services offered as part of these programs are all located in the community and coordinated by local 'experts' in respite care. Focus is on accessibility and providing care for families in need, regardless of age, race, ethnicity, special need or situation.

One of the main reasons why these programs have been recognized as exemplary is they all have lifespan foci. These model programs recognize that the growing number of care providers in non-traditional families need respite care. Before these lifespan programs, respite programs were only able to serve those providing care for older care recipients. In other words, previous respite programs did not recognize that the need for respite care may be a product of

characteristics of the care provider as well as the care recipient. Because they are a vulnerable population for many reasons (discussed in the introduction to this report), GRG may have a lower threshold than parents for needing respite care. These programs have the ability to assist GRG who need respite care.

SECTION 4: INVENTORY OF RESPITE PROGRAMS FOR GRG IN HAWAI'I

A team of researchers at the University of Hawai'i at Manoa conducted a survey of agencies that provide respite for GRG in Hawai'i to determine access and availability of respite services for GRG. This section of the report describes the methodology of the study and presents its results. It also provides summaries of strengths and weaknesses in respite coverage for GRG for each island and the state as a whole.

Methodology

Identification of Possible Respite Services

The search for agencies providing respite services for GRG was based upon the notion that respite care should specifically serve the stated purpose of providing a rest for the caregiver. Therefore, basic preschool and childcare services were not included in this search.

Respite services for GRG were identified with a two-pronged strategy. Agencies were first identified by a search of consumer resources such as the Senior Assistance Handbooks and Family Caregiving Guides published by the county area agencies on aging, and an internet search using the Google search engine.

Agencies were also identified through telephone interviews with key service providers for GRG, such as the Queen Liliu'okalani Children's Center, Child and Family Service, and the Maui Area Agency on Aging. We also asked the respite care providers with whom we spoke if they were aware of any other providers offering respite services to GRG.

This search strategy yielded 48 possible service providers for respite care to GRG, including telephone referrals and multiple locations on neighbor islands. Of these, 23 were identified as direct service providers. This search strategy appeared to be comprehensive; we identified a greater number of agencies than many of the referral sources we called were able to offer. However, a few referral sources did not return our calls, even after repeated attempts.

Data from 11 of the 23 identified providers is not included in this report for the following reasons: 4 did not offer services for individuals providing care for recipients younger than 60 years of age (Kupuna Care, Catholic Charities, Project Dana, and Elder Care Services Program), 3 provided respite services only for individuals who had adopted a child from the child welfare system (Foster Family Programs of Hawai'i; Honolulu, Leeward, and Hilo offices); 2 did not offer respite services at some locations (Easter Seals on Kauai and Hawai'i), 1 was not

available by phone (Empowering Caregivers), and 1 had recently lost funding for intergenerational respite services (Ua Nani o Ke Anuenue Program).

Telephone Survey of Respite Providers

We contacted representatives from the 12 remaining agencies by telephone and asked them the following questions:

- What is the age range of your clients?
- What type of service do you provide? (health care, tutoring, cultural enrichment, etc.)
- What is the cost of your service?
- What options do you offer for length of stay?
- Do you provide transportation for your clients?
- Do you provide any accommodations for individuals with disabilities? If so, what type?
- Can grandparents raising grandchildren use your services?
- Is there a waiting list for your services? If so, how long is it?
- What procedure must be followed to obtain your services?
- What is your source of funding?

Results: Existing Respite Services for GRG

Honolulu. GRG in Honolulu have the largest number of respite programs available. These programs offer services to a range of families: Those with special needs or critically ill children and those who are stressed due to divorce or other family dysfunction. One notable gap in this coverage is that only one agency offering respite care for care providers in stressed families offers care for children over the age of 5. Another gap is that no agencies offering care for stressed families offers overnight care. Two other areas for improvement are the provision of transportation for families that might need it and the lack of emergency respite care.

Maui. GRG in Maui County have fewer respite care options than those on Oahu. Like Oahu, most options offered on Maui are for GRG providing care to children with disabilities, either those requiring nursing home care or those with severe developmental disabilities. Unfortunately for many GRG, learning disabilities are not covered. Although stressed families do not have as many options on Maui as they do on Oahu, one service provider is able to furnish overnight and weekend care to stressed families, which may be especially beneficial for GRG.

Kauai and Big Island of Hawai'i. The respite care options for GRG on Kauai and the Big Island of Hawai'i are quite limited. We were only able to locate one agency, which provides care

for children who require nursing home quality care. It appears that there is a great need for respite care for stressed families on these islands.

Table 1. Summary of Respite Services by Island/County

Island/County	Total # of Agencies	# of Agencies Caring for Special Needs Children	# of Agencies Caring for Stressed Families	Ages of Children	Length of Stay	Cost	Funding
Oahu	6	2 for special needs children 1 for critically ill children	3	No limits for in-home nursing quality care Day care for special needs children limited to ages 10-20 Only one agency for stressed families offers care for children older than 5 years.	Overnight care only available for special needs	Low or none for families that qualify	All but one funded by donation
Maui	3	2	1	No limits for in-home nursing quality care Day care for special needs children limited to ages 10-20	Overnight care available for stressed families	Low or none for families that qualify	All but one funded by donation
Hawai'i	1	1	0	No limits for in-home nursing care No care for children who do not qualify for nursing care	No respite for stressed families	None- but few services offered	State and federally funded
Kauai	1	1	0	No limits for in-home nursing care No care for children who do not qualify for nursing care	No respite for stressed families	None- but few services offered	State and federally funded

Summary of Survey of Respite Services for GRG in Hawai'i

There is great variation by island in the availability of respite services available for GRG in the state of Hawai'i. There are four main gaps in service common to all islands.

The first is the lack of transportation for services. With the exception of Nursing Home Without Walls, which provides in-home skilled nursing care, none of the agencies provided transportation for their clients. This can pose a serious barrier to service access, especially for low-income GRG.

The second gap is the unavailability of emergency services, except for on Maui. Lack of emergency services may be especially problematic for GRG caring for children whose parents are on drugs; parents' erratic behavior often leads to unexpected crises in such families.

The third gap has to do with care for school-age and adolescent children. Even on Oahu, the island with the most respite resources, there were few services available for children between the ages of 5 and 15 years, and those that are available provide care for a few hours, not on overnight or weekend bases.

The fourth gap is the lack of therapeutic services for children with relatively mild problems, such as emotional problems or learning disabilities. These services might be available to GRG, but are not labeled as respite services, so they did not emerge in our search.

Despite these gaps, there are positive features of many of the respite programs we surveyed. The first is that many programs recognize that families are systems and caregivers may need respite due to family circumstances as well as children's disability. The second is the flexibility and positive attitude of the care providers who took the time to speak with us. With a few exceptions, these programs are operating on donations. Their services could be expanded if they were to receive state funds, like the model lifespan respite programs of other states.

SECTION 5: CONCLUSIONS AND RECOMMENDATIONS FOR POLICY

Essential Considerations

1. **Respite care for GRG must be culturally appropriate.** Respite care offered to GRG must consider cultural variations in the meaning of family. Effective care and communication must be done in a culturally sensitive manner (Yancura, in press).
2. **Respite care should be available to GRG of all legal statuses.** Many GRG do not have legal custody of their grandchildren, typically due to financial difficulties or family discord. GRG in these difficult situations are the most in need of respite services (Generations United, 2002). Receipt of respite services should not depend upon custody, or even guardianship status.
3. **Respite care for GRG should be offered as part of a package of services.** GRG who need respite typically need other services, such as financial assistance and support groups. Model respite programs in other states use respite as part of a coordinated system of care to make sure the recipients get the assistance they need.
4. **Emphasis must be placed on programs and policies that assist grandparents who are sole providers for their grandchildren.** Some GRG are especially burdened because they are not receiving support from the childrens' biological parents or other family members. GRG with sole responsibility for grandchildren need the most assistance.
5. **Use a lifespan respite model.** A lifespan respite model recognizes that respite care depends upon circumstances rather than the age of the care recipient.
6. **Evaluation of respite programs is a critical component.** Although preliminary analyses of model programs show great promise (Baker & Edgar, 2004), there is little empirical evidence of the effectiveness of respite care in reducing stress in GRG. It is essential that any respite program for GRG include an evaluation component.

Actions

1. **Formulate a clear definition of the conditions under which GRG need respite care.**
 - a. **Define grandchildren's eligibility requirements.** Grandchildren's eligibility might consider such factors as health status and presence of behavioral, learning, or emotional problems.

b. **Define grandparents' eligibility requirements.** Grandparents' eligibility might consider such factors as age and income.

2. **Formulate a clear definition of respite care.** Issues to be considered include (1) whether respite care should include some therapeutic benefit to grandchildren, such as healthcare or tutoring, (2) whether respite should be provided on a day, in-home, or institutionalize models, and (3) whether respite should be provided on both planned and crisis levels.

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APPENDIX A

Further Information on Model Lifespan Respite Programs

Oregon Lifespan Respite Care Program
<http://www.oregon.gov/DHS/respite/>

The Nebraska Respite Network
<http://www.hhs.state.ne.us/hcs/Respite-Network.htm>

The Wisconsin Lifespan Program
<http://www.respitecarewi.org/programs/lifespan.html>

Oklahoma Respite Resource Network
<http://oasis.ouhsc.edu/rnn.htm>

State Policy Trends for Model Lifespan programs
http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2001_10_policybrief_4.pdf

Statewide Lifespan Respite Programs: A Study of 4 State Programs
http://www.archrespice.org/LifespanRespiteReportFINAL9_30_04.pdf

APPENDIX B

Table of Respite Services for GRG by Island/County

Agency	Age Served	Type of Service	Cost	Length of Stay	Transportation	Accommodations for Special Needs	Waiting List	Eligibility	Funding
Oahu									
Easter Seals Hawaii <i>Honolulu</i>	10 to 20 years	Childcare	Full day \$45 Half day \$25 After school service \$14-16 Camp \$150	After school service All day program when DOE schools not in session Camp / sleep-overs	No	Case by case Licensed to dispense medication	No	Children must have cognitive and/or developmental disabilities Learning disability does not qualify	Donation
Family Care Center <i>Pearl City</i>	18 mo to 18 years	Childcare	Free	Once a week Up to 6 months	No	Accessible building Handicap bathroom	No	Family Need	Donation
Hawaii Family Services <i>Waianae</i>	0 to 5 years	Childcare and snack	Free	3 hours a week Up to 18 months	No	Yes Try to accommodate as much as possible	No	Any primary caregiver can receive services - Use of other services at the agency is encouraged	DHS
HUGS <i>Honolulu</i>	0 to 21 years	Childcare	Free	2 Fridays a month from 5:30-9:30 pm	No	Case by case Do not dispense medicine	No	Children have life-threatening illnesses or are medically fragile (need doctors note)	Donation, Grants, Aloha United Way

Agency	Age Served	Type of Service	Cost	Length of Stay	Transportation	Accommodations for Special Needs	Waiting List	Eligibility	Funding
Nursing Home without Walls <i>Oahu</i>	All ages	In-home care ICF or SNF level of care Intermediate Care Facility Or Skilled Nursing Facility	No	Day Care (several hours)	Yes	Can assist with home habilitation	No	Clients who require nursing facility care Medicaid recipients	State-funded with matching federal funding
Parents and Children Together <i>Honolulu Kalihi</i>	0 to 5 years	Childcare	Free	Day care for 3 hours Up to one year	No	Handicap accessible buildings and services for children with special needs	No	Parents or caregivers are under stress, often due to divorce or family dysfunction	DHS
Maui									
Easter Seals Hawaii (see Oahu for details)									
Nursing Home without Walls (see Oahu for details)									
Keiki Kokua	0 to 18 years	Volunteer licensed foster parents take care of children, when clients need respite	Free.	Day half a day, overnight, weekend possible.	Yes	Case by case	No	Those in need Guardian-ship is not necessary	Donation Grants
Hawai'i									
Nursing Home without Walls (see Oahu for details)									
Kauai									
Nursing Home without Walls (see Oahu for details)									