

Grandparents and Other Relatives Raising Children: Respite Care

INTRODUCTION

According to the U.S. Census 2000, more than six million children across the country are living in households headed by grandparents or other relatives.¹ More than 2.4 million of these grandparents have the primary responsibility for meeting the basic needs of these children.² Factors such as parental substance abuse, incarceration, HIV/AIDS, death, poverty, and even military deployments are causing growing numbers of grandparents and other relatives to step forward to keep families together.

The National Family Caregiver Support Program (NFCSP)³ was created in 2000 as part of the Older Americans Act (OAA). Administered by the Administration on Aging (AoA) of the U.S. Department of Health and Human Services (DHHS), the NFCSP allows for all states, working in partnership with Area Agencies on Aging (AAA) and local community-service providers, to offer five categories of support services for grandparents and other relatives aged 60 and older who are relative caregivers of children, and family caregivers of individuals aged 60 and older.⁴

One of the five categories of supportive services provided under the NFCSP is respite care, designed to enable caregivers to be temporarily relieved from their caregiving responsibilities.⁵ Through the NFCSP, Area Agencies on Aging (AAAs) receive funding to provide respite services to grandparents and other relatives raising children. If there is already an established respite program, the AAA in that area may contract with that agency to provide services to these families with NFCSP funding. These types of collaborations maximize resources, decrease duplication of services, and increase communication between service systems.

RESPITE CARE TERMS

DEFINITION

Respite care provides relief to informal primary caregivers by providing short-term services to a care recipient. Care is primarily provided to people with: disabilities or other special needs, chronic or terminal illnesses, or to individuals at risk of abuse and neglect.⁶ Children being raised by grandparents or other relatives fit into these categories, and many have disabilities or other special needs.

PURPOSE

The two main purposes of caregiver respite are: (1) to decrease individual and family stresses associated with caregiving, and (2) to postpone the need for institutionalization of the care recipient. For grandparents and other relatives, respite may prevent the children they are raising from entering the formal foster care system. In all cases, the underlying values associated with respite care include support and preservation of family or caregiving relationships.⁷

TYPES OF RESPITE

There are two basic types of respite:

- Brief, regularly scheduled episodes, which allow caregivers to do routine chores and/or take a break, or
- Sporadic, longer periods, which allow caregivers to leave town for business or vacation, go into the hospital, or attend to another emergency.⁸

SETTINGS

Respite programs can occur in a variety of settings including families' homes,

providers' homes, camps, residential facilities, day care centers, recreational facilities, churches, therapeutic child development centers, family resource centers, schools, and senior centers. Programs are often administered by public or private welfare agencies, mental health agencies, religious institutions, family resource centers, childcare centers, aging service providers, or a combination thereof.⁹

WHY GRANDPARENTS AND OTHER RELATIVES RAISING CHILDREN NEED RESPITE

Grandparents and other relatives often take on the role of caregiver suddenly, with little or no warning. They may become caregivers because of a number of parental problems, and the children in these situations may exhibit a number of difficult behaviors. Relative caregivers may be dealing with adjusting to parenting a second time in combination with learning to address behavioral issues and stress caused by disruptions in family life. They may confront social, emotional, financial, and legal challenges that were not present when they raised their own children. Older or retired grandparents, in particular, may experience a tremendous sense of isolation and inequity as they watch their peers participate in leisure or retirement activities. As a result, the shock of having to bring up a child can be emotionally and physically overwhelming. Some form of respite may be necessary to assist older caregivers in providing a stable, healthy environment for children. Furthermore, regardless of age, most caregivers may need respite from their responsibilities in order to maintain the physical and emotional strength they need to effectively care for children. Respite care can provide a much-needed hiatus from the stress associated with raising children under challenging and often very difficult circumstances.

RESPITE LEGISLATION

Responding to the growing need for respite care services for families, there is pending federal legislation before Congress to coordinate respite care services for all caregivers. Several states (including: Oregon, Nebraska, and Wisconsin) have passed Lifespan Respite Acts, or other types of respite legislation, which establish state and local infrastructures for developing, providing, coordinating, and improving access to lifespan respite for residents of the state who are eligible for such services.

MODEL PROGRAMS

For grandparents and other relatives raising children, respite services are available through caregiving networks and NFCSP programs. Services can be administered by the AAAs, and those with whom they contract. Some of the examples below demonstrate how AAA NFCSP-funded respite programs address the respite needs of relative caregivers. Other examples show how states have creatively provide respite through other means.

Oregon's Lifespan Respite Program is one of the oldest respite programs in the country. The state provides start-up and ongoing funding to local networks to facilitate access to respite for all families and individuals. These networks serve to avert the fragmentation that occurs when different programs serve different individuals. These networks: maintain a database of trained in-home respite service providers; conduct outreach to caregivers and connect

them to services and payment options; provide referrals and related services; identify gaps in services available in communities; provide educational information and training on how to care for themselves and their loved ones; and deliver ongoing training for respite providers. This program is a model for the Respite Care Association of Wisconsin (RCAW) program that implements Lifespan Respite Care legislation in Wisconsin.

For more information on Oregon's program, contact: Lee Girard 503-947-1199, or lee.a.girard@state.or.us, or visit: www.oregoncares.org. Click on the link to "Lifespan Respite Network Information." For more information on the Wisconsin's program, contact: Jim Schroeder 608-222-2033, or jschroeder@respitecarewi.org.

The Oklahoma Respite Resource Network (ORRN) provides respite services for the Aging Services Division of the Oklahoma Department of Human Services. ORRN is a lifespan respite care initiative that uses federal, state, and private dollars to fund respite services to various categories of caregivers, including grandparents and other relatives raising grandchildren since 2000. The program has a simple application process and relatively few guidelines. Once a caregiver is approved for respite, DHS issues a voucher to purchase respite services. The voucher can be used to purchase respite service from any provider the caregiver chooses. To assist caregivers in selecting providers, the ORRN publishes a Respite Guide for Families and Providers. After the caregiver and respite provider complete the voucher form, DHS sends payment directly to the respite provider. For more information, contact: Robert Adams 405-521-4214, or Robert.Adams@okdhs.org.

Adult Well-Being Services of Detroit, Michigan is a participant in the GU/Brookdale Foundation's Relatives As Parent Program (RAPP) replication in behavioral health facilities, offering a variety of respite care services through its Grandparents Rearing Grandchildren Program. In this program, Foster Grandparents are trained to provide in-home care for children, allowing grandparents to accomplish essential tasks such as going to the doctor or shopping. Educational workshops, support groups and individual information and assistance are also available. For information, contact: (313) 833-3765, or visit <http://www.awbs.org/>.

Pierce County, Washington Aging and Long Term Care AAA uses NFCSP funds to offer summer respite opportunities to grandparent and other relative caregivers. The local mental health agency, Child and Family Guidance, with which the AAA subcontracts collaborated with local parks and recreation providers, and other organizations such as the YMCA, Easter Seals and Camp Fire, to pay for day and residential camp opportunities for school-age children of relative caregivers over age 60. For more information, contact: Connie Kline (253) 798-3782 or ckline@co.pierce.wa.us.

The Southwest Michigan Region IV Area Agency on Aging Senior Volunteer Programs adapted the national respite model developed by the National Council on Aging (NCOA), "Family Friends Program," to offer respite care for grandparents and other relatives raising children in high stress situations. This Michigan state-funded program uses NFCSP funds in addition to Strong Families/Safe Children and United Way support. Senior volunteers provide between 4 to 12 hours of in-home respite care. Volunteers also take children to planned activities outside the homes in order to help decrease the amount of stress caregivers may experience in raising children. For more information, contact: the AAA Senior Volunteer Programs 269-983-7058, or camelliapisegna@areaagencyonaging.org. Or visit: www.region-iv.org. For information on the Family Friends Program, visit: www.family-friends.org.

NATIONAL RESOURCES

Comprehensive national respite information and resources are available through the following:

ARCH National Respite Network and Resource Center. ARCH assists and promotes the development of quality respite and crisis care programs, helps families locate respite and crisis care services in their communities, and serves as a strong voice for respite in all forums. Resources on providing respite services are available, and include: *Bringing Respite to Your Community: A Start-Up Manual and Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers*. ARCH also provides resource information on state coalitions for respite in each state and the District of Columbia. For more information about ARCH contact: 919-490-5577, or www.archrespite.org.

National Foster Parent Association offers information and resources on advancing the state of respite programs through training, knowledge development and a respite care program model handbook. Other programs/products available include recruitment and retention of resource families, developing relationships with the schools, advocacy training and a speakers bureau. For more information, contact NFPA, (800) 557-5238, info@NFPAINC.org, www.NFPAINC.org.

CONCLUSION

Respite services can provide relative caregivers with temporary and much needed relief enabling them to better meet the challenges of raising children. State and national initiatives are supporting families by alleviating family and caregiver stress, stabilizing family life, and promoting a healthier, more balanced environment for children.

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For further information, please contact: Generations United (GU), 1333 H Street N.W., Suite 500W, Washington, D.C. 20005-4752 (202) 289-3979, Fax: (202) 289-3952; e-mail: gu@gu.org. The GU web site at www.gu.org contains additional information about grandparents and other relatives raising children.

Generations United (GU) is the only national membership organization focused solely on improving the lives of children, youth, and older people through intergenerational strategies, programs, and policies. GU represents more than 100 national, state, and local organizations representing more than 70 million Americans. GU serves as a resource for educating policymakers and the public about the economic, social, and personal imperatives of intergenerational cooperation. GU provides a forum for those working with children, youth, and older adults to explore areas of common ground while celebrating the richness of each generation.



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¹ U.S. Census Bureau, Census 2000. Summary File 1, Table P28, Relationship by Household Type for Population Under 18 Years.

² Simmons, T. & Dye, J.L. (October 2003.) *Grandparents Living with Grandchildren: 2000*. U.S. Census Bureau, Census 2000 Brief, C2KBR-31. U.S. Census Bureau, Washington, DC.

³ Public Law 106-501. Section 316.

⁴ For more information about the NFCSP, please go to www.gu.org for a fact sheet and user guide about the program or to the AoA website at www.aoa.gov

⁵ Public Law 106-501. Section 373(b)(1-5)

⁶ Pruchno, R. (1999). Raising grandchildren: "The experiences of black and white grandmothers." *The Gerontologist* 39(2), 209-221.

⁷ Silberberg, M., (2001). "Respite care: State policy trends and model programs." Policy Brief No. Family Caregiver Alliance.

⁸ Silberberg, M., (2001). "Respite care: State policy trends and model programs." Policy Brief No. Family Caregiver Alliance.

⁹ ARCH National Resource Center. (Accessed 2004) *2001 National Resource Network Local Program Survey Report*. Found at <http://www.archrespite.org/ARCH%20Network%20Program%20Survey%20Report%20for%20FY%202001-2.pdf>.

