

Grandparents and Other Relatives Raising Children: Respite Care

INTRODUCTION

“If I could just have an hour to myself every so often.” “My energy level is not the same as when I parented the first time.” “Other people don’t realize how hard it is... or how gratifying it is.” These are comments that grandparent and relative caregivers have made when asked about needing a break, or respite, from their daily caregiving responsibilities.

This fact sheet is about “grandfamilies” or families in which grandparents or other relatives are primarily responsible for caring for children who live with them. Reasons causing these grandfamilies to come together include parental substance abuse, military deployment, incarceration, poverty, HIV/AIDS, and death. Like most families, these caregivers occasionally need a break from their 24-hour, 365 days a year role.

Almost six million children across the country are living in households headed by grandparents or other relatives, according to the 2000 U.S. Census.¹ 4.4 million of these children are in grandparent-headed households, and another 1.5 million live in households headed by other relatives, such as aunts or uncles.² About 2.4 million grandparents are responsible for most of the basic needs of the children, but unfortunately similar Census data does not exist for the other relatives.³

The National Family Caregiver Support Program (NFCSP)⁴ 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 (HHS), 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 who are relative caregivers of children, and family caregivers. The Older American Act (OAA) was reauthorized in Congress in 2006, changing the age of eligibility from 60 to 55. This allows more than 400,000 families to be newly eligible.

One of the programs created under the NFCSP is respite care. Respite care allows temporary relief for those caregivers from their responsibilities. Area Agencies on Aging receive funding to provide or contract with a local agency respite services to caregivers.

RESPIRE 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 individuals at risk of

abuse and neglect.⁵ Children being raised by grandparents or other older relatives may have special needs resulting from a difficult start in life.

PURPOSE

The two main purposes of caregiver respite are: (1) to decrease individual and family stresses associated with caregiving, and (2) to postpone or avoid 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.⁶

TYPES OF RESPIRE

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.⁷



SETTINGS

Respite programs can occur in a variety of settings including families' homes, providers' homes, residential facilities, camps, 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 some combination thereof.⁸

WHY GRANDPARENTS AND OTHER RELATIVES RAISING CHILDREN NEED RESPIRE

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. There are many reasons why children come to be in their care of their grandparents. Some, such as parental substance abuse or premature death of a parent, can have long-term implications for the child's health and well-being. Older caregivers may also have health needs of their

own that make respite an important service to these families.

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 personal changes and problems that tax them emotionally and physically. Regardless of age, caregivers may need respite from their responsibilities in order to maintain the strength they need to effectively care for children.

RESPITE LEGISLATION

Responding to the growing need for respite care services for families, the Lifespan Respite Care Act was passed by Congress and signed into law in 2006 to coordinate respite care services for caregivers. However, the funds to support this important work have not yet been appropriated. Several states have also passed respite legislation, which establish state and local infrastructures for developing, providing, coordinating, and improving access to respite care for eligible residents.

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.

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: maintain a local list 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. For more information, contact Lee Girard 503-373-1726 lee.a.girard@state.or.us, or visit www.oregon.gov/DHS/spd/caregiving/lr_respite.shtml.

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 many different caregivers, including grandparents and other relatives raising grandchildren. If a caregiver is selected, 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 Brookdale Foundation's Relatives as Parents Program (RAPP) replication in behavioral health facilities, offering a variety of respite care services through its Grandparents Rearing Grandchildren Program. In this program, other older adults 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. Contact: 313-924-7860 or visit www.awbs.org/.

Pierce County, Washington Aging and Long Term Care AAA offers family counseling services and summer youth opportunities for children who are residents of Pierce County and are being raised by grandparent and other relative caregivers over age 55. Services are provided under subcontract with the local mental health agency, Child and Family Guidance Center. Summer youth activities for children ages 4 through 18, including day and residential camp opportunities, are provided in collaboration with local parks and recreation departments, as well as other organizations such as YMCA, Skyhawks, Salvation Army, local schools and community organizations who offer summer recreation activities. For more information, contact Connie Kline 253-798-3782 or ckline@co.pierce.wa.us, or Edith Owen, 253-565-4484 or edith@cfgcpc.org.

NATIONAL RESOURCES

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

ARCH National Respite Network and Resource Center assists and promotes the development of quality respite and crisis care programs, helps families locate respite and crisis care services, and serves as a strong voice for respite in all forums. ARCH also provides resource information on state coalitions for respite in each state and the District of Columbia. For more information 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 at 800-557-5238, info@NFPAinc.org, or visit 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 further information, please contact: Generations United (GU), 1331 H Street NW, Suite 900, Washington, D.C. 20005 202-289-3979, Fax: 202289-3952; email: gu@gu.org. The GU web site at www.gu.org contains additional information about grandfamilies.

Generations United (GU) is the national membership organization focused solely on improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. GU represents more than 100 national, state, and local organizations and individuals representing more than 70 million Americans. Since 1986, GU has served as a resource for educating policymakers and the public about the economic, social, and personal imperatives of intergenerational cooperation. GU acts as a catalyst for stimulating collaboration between aging, children, and youth organizations providing a forum to explore areas of common ground while celebrating the richness of each generation.



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¹ Lugaila, T. and Overturf, J. (March, 2004). Table1, Population Under 18 Years by Age and Relationship to Householder: 2000, in "Children and the Households They Live in: 2000," a Census 2000 Special Report. Washington, D.C.: U.S. Bureau of the Census.

² Ibid.

³ Simmons, T. and Lawler Dye, J. (October 2003). *Grandparents Living With Grandchildren: 2000 – Census 2000* Brief. Washington, D.C.: U.S. Bureau of the Census.

⁴ Public Law 106-501. Section 316.

⁵ Pruchno, R. (1999). Raising grandchildren: "The experiences of black and white grandmothers." *The Gerontologist* 39(2), 209-221.

⁶ Silberberg, M., (2001). "Respite care: State policy trends and model programs." Policy Brief No. Family Caregiver Alliance.

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

⁸ ARCH National Resource Center. (Accessed 2004) *2001 National Resource Network Local Program Survey Report*. Found at <http://www.archrespite.org>

