

Grandparents and Other Relatives Raising Children: Their Inclusion in the National Family Caregiver Support Program

INTRODUCTION

According to the U.S. Census 2000, almost six million children across the country are living in households maintained by grandparents or other relatives.¹ The Census further found that nearly 5.8 million grandparents are living in households with one or more of their own grandchildren under the age of 18. More than 2.5 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.

On November 13, 2000, through the reauthorization of the Older Americans Act (OAA), the National Family Caregiver Support Program (NFCSP)³ became law. The U.S. Department of Health and Human Services, Administration on Aging (AoA) administers the program and provides funds to the states. They in turn fund Area Agencies on Aging (AAAs) to provide five categories of supportive services to grandparents and other relatives aged 60 and older who are relative caregivers of children, and family caregivers of individuals aged 60 and older.

In the spring of 1999, when the NFCSP was originally introduced in Congress, it did not include grandparents and other older relative caregivers of children. Instead, it was designed solely to provide services to family caregivers of individuals aged 60 and older. Generations United (GU) was supportive of the NFCSP and thought it was important to help caregivers. However, GU also thought it was important to acknowledge older individuals not only as the receivers of care, but also as the givers of care, which they so often are. As a result, GU worked to include grandparents and other relatives in the NFCSP by testifying before the relevant Senate Subcommittee, and submitting draft legislative language to include the caregivers of children in the law.

This fact sheet is intended to provide an overview of the provisions of the NFCSP and an idea of what some AAAs around the country are doing to help these families. It is hoped that the information in this fact sheet, in addition to the related user-friendly guide,⁴ will encourage other AAAs to replicate successful models and help support these families.

PROVISIONS OF THE NFCSP

Congress appropriated \$155.2 million to be spent for the NFCSP in 2003, more than a \$30 million increase from the NFCSP's first year in 2001. According to the law, the AoA releases the money to states based on each state's percentage of the population aged 70 and older.

The money that is distributed to states is allocated to the AAAs based on intrastate funding formulas. The AAAs provide support services to the caregivers or contract for service provision. Up to ten percent of the funding appropriated for the NFCSP can be used to provide support

services to grandparents or relatives over age 60 who are raising relatives' children.⁵ This limitation is in the law. Other than that, funds under the NFCSP are not earmarked. States and AAAs may use the funds to provide any and all of the five categories of support services authorized by the NFCSP to relative caregivers.

♥ DEFINITION OF GRANDPARENT OR OLDER RELATIVE WHO IS A RELATIVE CAREGIVER

The NFCSP defines "grandparent or older relative who is a relative caregiver"⁶ to mean:

a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and
– (A) lives with the child; (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and (C) has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally.

When GU submitted draft language to include relative caregivers in the NFCSP, it intentionally included the "informal" caregivers. Although there are few formal national studies on the issue, ample anecdotal evidence suggests that the majority of relative caregivers are "informal;" which means they are raising children without a legal relationship such as guardianship or legal custody. As a result, GU thought it was critical that they be included in the language of the law.

♥ SUPPORT SERVICES

The following are the five categories of support services delineated in the NFCSP:

- (1) **information** to caregivers about available services;
- (2) **assistance** to caregivers in gaining access to the services;
- (3) **individual counseling, organization of support groups, and training caregivers** to assist them in making decisions and solving problems relating to their caregiving roles;
- (4) **respite care** to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- (5) **supplemental services**, on a limited basis, to complement the care provided by caregivers.

These categories are written to be flexible and respond to the needs of the caregivers in the area being served. The fifth category, supplemental services, is particularly broad.

The NFCSP requires the AAAs to coordinate the provision of support services (or of the agency they contract with) with the activities of community agencies and voluntary organizations that are providing similar supportive services. Some of the most successful AAAs that serve these families are those that have collaborations with a broad range of

community based organizations, including organizations associated with serving children, such as schools and Head Start programs.

♥ PRIORITY LANGUAGE

The NFCSP includes a provision stating that states must give priority for services to older individuals with the greatest social and economic need, and to older individuals providing care and support to persons with mental retardation and related developmental disabilities. According to the AoA, children living with grandparents or other relative caregivers are not required to have mental retardation or related developmental disabilities in order for the caregiver to receive services. However, the children must be no more than 18 years of age, regardless of whether or not they have mental retardation or related developmental disabilities.⁷

♥ MATCHING AND MAINTENANCE OF EFFORT REQUIREMENTS

The NFCSP has a requirement that each state match 25% of its federal allocation. The NFCSP also includes a maintenance of effort requirement, which provides that funds made available through the NFCSP must supplement, not replace, any federal, state, or local funds spent by a state or local government to provide similar services.

AGING NETWORK SURVEY

In 2003, GU completed a survey of the aging network, Native American Tribes and primary health care centers. Survey results, which are summarized in GU's *A Guide to the National Family Caregiver Support Program and Its Inclusion of Grandparents and Other Relatives Raising Children*, indicate that the aging network has a great need for education and training concerning the issues and aspects of supporting grandparents and other relatives raising children. Data show these relative caregivers are not receiving the proportionate amount of services. Limited funding and the age limitation in the NFCSP are fundamental reasons why services are often unavailable.

PROGRAM EXAMPLES

Thanks to the NFCSP, many AAAs around the country have either started or expanded services to grandparents and other relatives raising children. These successful programs provide models to other AAAs that want to support the families. Consider, for example, the largest AAA in Michigan (AAA 1-B) which has been working to help these families since 1993. Among the supports it helps provide, it published and disseminated resource guides that are specially targeted towards relatives raising children for each of the six counties it serves.

Other AAAs, including ones in Delaware, Illinois, Kansas, Oklahoma, Oregon, Tennessee, Virginia, and Washington have been providing supportive services such as information and referral, counseling, support groups, and/or respite. The AAA in Big Stone Gap, Virginia provides extensive assessment and referral services to grandparents and other relatives raising children through its KinCare Program. Oklahoma's Department of Human Services, Aging Services Division helped develop the Oklahoma Respite Resource Network which, since March 2000, has been providing lifespan respite care to various categories of caregivers, including grandparents and other relatives raising children. Now, with NFCSP funds, the program has expanded and all eleven of Oklahoma's AAAs are involved. The AAAs have been promoting the respite program through presentations and other outreach activities.

Supplemental services, included in the NFCSP's fifth category of service, are also being provided to grandparents and other relatives raising children. For example, seven of the thirteen AAAs in Illinois are using NFCSP funds to provide legal services to grandparents and other relatives raising children.

Several of these AAAs use NFCSP funds in conjunction with other federal, state, and private funds, because the NFCSP funds alone are often not enough and cannot be used to reach the many relative caregivers under age 60.

For more information about these AAAs and their existing programs to help support grandparents and other relative caregivers of children, consult GU's accompanying NFCSP user guide.

CONCLUSION

The NFCSP is a federal program that provides much needed funding to AAAs wanting to support grandparents and other relatives raising children. To be most effective, the program will need increased funding and less restrictive age limitations. However, the NFCSP as it exists is a critical first step in helping support caregivers across the United States.

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For further information, please contact: Generations United, (202) 638-1263, Fax: (202) 638-7555, 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 national membership organization focused solely on promoting intergenerational strategies, programs, and policies. GU represents more than 100 national, state, and local organizations representing more than 70 million Americans. It is the only national organization advocating for the mutual well-being of children, youth, and older adults. 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 U.S. Census Bureau (2002). American Community Survey Summary Tables. PCT014. Grandparents Responsible for Own Grandchildren Under 18 Years by Sex of Grandparents in Households.
- ³ Public Law 106-501. Section 316.
- ⁴ Generations United (2003). *A Guide to the National Family Caregiver Support Program and Its Inclusion of Grandparents and Other Relatives Raising Children* (Revised, September 2003). Available through Generations United. 202-638-1263 or www.gu.org
- ⁵ Public Law 106-501. Section 373(g)(2)(C).
- ⁶ Public Law 106-501. Section 373(c)(1).
- ⁷ U.S. Department of Health and Human Services, Administration on Aging (2003). Available on the Internet. Accessed September 8, 2003. <http://www.aoa.gov/oa/status/faq-caregiving.html>