Introduction

The need for respite and crisis care continues to grow. As the trend towards deinstitutionalization continues more and more families are caring for members with disabilities and chronic health care conditions at home. As the costs of long term care continue to rise, respite and crisis care services are increasingly recognized as a cost effective way to help preserve families and protect children and dependent adults at risk of abuse or neglect. At the same time that federal programs which could potentially provide funding to states for these services have grown, these federal funding sources have become more challenging for states and local programs to identify and access.

While these federal programs hold great potential for funding respite and crisis care services, little is known about the extent to which states and local programs are accessing these funding sources. The information available indicates that very few, if any, of these federal funds are currently being invested in respite and/or crisis care programs. This is probably due to several factors:

- lack of knowledge on the part of states and local programs about these federal programs and their potential for funding respite and crisis care services
- lack of awareness on the part of state level decision makers about respite and crisis care services and their value to children, dependent adults, and their families.

This fact sheet provides basic information about each of the federal programs that provide funding to states which they could, if they chose to, use to fund respite and/or crisis care programs. For more complete information about each of these federal programs, readers are encouraged to see the ARCH Guide to Federal Funding for Respite and Crisis Care Programs. For each of these funding sources, the ARCH Guide contains a description of the federal legislation, state use of funds, case studies, consumer issues, provider issues, current appropriation, and state contacts.

Most public funding for respite comes from the federal government. Potential funding for respite and crisis care services can be found in many federal statutes. There are two major categories of these funds:

- programs with a medical or health focus that serve people of all ages with medical needs
- programs that focus on human service, child welfare, or family preservation and serve only children who are at risk of abuse or neglect and their families.

Medicaid and Mental Health Programs

Medicaid is the largest source of federal funding for medical and health-related services for low-income children, children with special health care needs, and people of all ages with disabilities. Although respite care is not covered as a regular Medicaid benefit because it is considered a non-medical expense, special Medicaid waivers permit states to use Medicaid funds for respite services.

Contact State Medicaid directors.
Home & Community-Based Service (HCBS) Waivers

The only Medicaid program that pays for non-medical services in the home, HCBS waivers makes direct payments to respite providers and are believed to be the leading source of federal funds for respite care. The programs may serve clients of all ages who are physically disabled, developmentally disabled, mentally retarded, or mentally ill, and clients who have specific illnesses such as AIDS, or specific conditions, such as head injury. There are often long waiting lists for these programs. Providers are reimbursed on a fee-for-service basis and must follow the state’s reporting requirements. Medicaid’s billing system may also require programs to implement somewhat sophisticated cost accounting procedures. Questions should be directed to state contacts.

Personal Care Benefit

Personal care is an optional service which states may include in their Medicaid plans. It provides incidental respite for caregivers, because caregivers are able to take a break or even leave the home while the personal care is being provided. If the benefit is included in a state’s Medicaid plan, anyone who meets the state Medicaid eligibility guidelines is entitled to personal care, making the benefit available to many more people than could ever receive respite through HCBS waivers. Respite care providers may legitimately label themselves “personal care providers” and access this funding source as long as they comply with applicable state guidelines.

Children’s Health Insurance Program (CHIP)

This block grant provides health insurance to uninsured children, either by extending Medicaid eligibility or by creating a separate state insurance program. Children in families with incomes up to 200 percent of the federal poverty level are eligible, and all Medicaid services, including access to personal care through the state Medicaid plans, are available to them. These children also then become eligible for HCBS waiver services. Check the status and contact info for your state.

Freedom of Choice (Managed Care) Waivers

States may enroll Medicaid recipients in managed care plans in which providers are paid a certain amount per service period for each enrollee, based on anticipated costs. This gives providers an incentive to keep clients healthy through preventive services. Personal care, but not respite, is an allowable benefit under this program. Many states are requesting permission to merge HCBS waivers with managed care waivers, which could make respite more available, shortening clients’ waiting time for non-medical services and keeping them from being placed in expensive residential facilities.

Research and Demonstration Waivers

Also called "1115 waivers," these grant states broad exemptions and great flexibility to test new approaches to service that are outside standard Medicaid policies. Although these waivers are only incidentally related to providing respite, any state with a 1115 waiver may expand benefits to include respite care and expand eligibility to cover individuals and families who need respite. The waivers generally are granted to states for five years and may provide payments to respite care providers for direct services.

Community Mental Health Services Block Grant

This is a formula grant which provides funding to states for the purpose of infrastructure building, service integration, training, support for mental health planning councils, and provision of direct services (which may include respite and crisis care). Children must have, or be at risk of, serious emotional disturbance in order to qualify for services. Mental health planning councils must include consumers, advocacy groups, and providers.

Children’s Mental Health Services Demonstration Projects

Only states can apply for these competitive grants, which are to be used for the development of community based systems of care. The purpose of the program is to provide comprehensive community mental health services for children and adolescents with serious emotional disturbance and their families. These services
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(which may include respite and/or crisis care) are to help keep children with their families and in their communities, while adequately addressing their needs.

**Child Welfare & Family Preservation Programs**

The federal government provides funds for child welfare and family preservation programs. Some of those programs include funds which states may use for respite and crisis care for children and their families. Generally, eligibility is based not on financial need or disability but on the level of risk of abuse, neglect, or out-of-home placement faced by the child.

**Promoting Safe and Stable Families**

Formerly known as the Family Preservation and Support Services Program, this block grant program is the primary federal effort to preserve families by reducing child abuse and neglect. State grants are based on the number of children receiving food stamps, and a 25 percent state match is required. Funds can be used to pay respite and crisis care providers and to develop and maintain provider networks. Each state must develop a plan in consultation with child welfare service agencies to provide family support, preservation and reunification services, and services to promote and support adoption. The plan also must be coordinated with other similar federally assisted programs for at-risk populations. States may set their own eligibility requirements for consumers and providers and may subcontract with any provider of family preservation or family support services (including respite and crisis care providers).

**Child Welfare Services**

These block grants support improvements to the state child welfare system. Among other things, the funds pay for child abuse prevention and treatment efforts, which may include respite and crisis care. Child welfare demonstration projects waive certain federal requirements and allow states to support preventive services, which may include respite and crisis care service delivery networks.

**Social Services Block Grant (SSBG)**

The [program](http://www.archrespite.org/archfs52.htm) provides funds for social services to families with special needs. Its goals are to prevent neglect, abuse or exploitation of children and adults, and prevent or reduce inappropriate institutional care. Respite and crisis care are accepted SSBG services. States receive the funds with few strings attached. The annual allotments are non-competitive, there is no required match, and the funds may be used to support public agencies or to contract with private service providers. Client eligibility is not restricted, and service provider qualifications are flexible.

**Maternal and Child Health Service (MCHS) Block Grant**

This program provides grants to states which they may use to provide respite and other services for children with special health care needs. At least 30 percent of the funds must be used for services to children with disabilities. The conditions that qualify as special health care needs vary widely among states, but typically they are defined as congenital or acquired chronic disabling conditions. Income eligibility requirements usually are based on Medicaid guidelines. Some states use the funds as seed money for new programs, while others provide respite care for extended periods. Most states link Medicaid and MCHS and provide services through their state health departments, often subcontracting with regional or non-profit health agencies for specific services.

**Child Care and Development Block Grant (CCDBG)**

The Child Care and Development Block Grant as amended by Congress in Public Law 104-193 (Personal Responsibility and Work Opportunity Reconciliation Act) unified what was a fragmented child care system. Welfare reform repealed the welfare-connected child care programs (AFDC JOBS, At-Risk and Transitional Child Care), and placed new child care funding under the aegis of the lead state agency for the Child Care and Development Block Grant. The combined and increased funding therefore becomes part of a holistic and streamlined system for child care. The integrated funding sources consisting of both discretionary and mandatory Federal funds have a single, unified purpose. To reflect this integration of multiple funding sources, the Department of Health and Human Services has established a Child Care and Development Fund. This Fund (CCDF) supports all child care activities conducted across the country. CCDBG can provide funds
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which can be used to build capacity and improve quality of respite care programs. Some states have used CCDBG money to augment networks of respite care providers, but because of the lack of clear guidance regarding respite care in the legislation, only a few have included respite in their state plans.

Adoption Assistance

The Title IV-E Adoption Assistance program provides funds to States to assist in paying maintenance costs for adopted children (AFDC or SSI eligible) with special needs, e.g., children who are older or handicapped. Funds are also used for the administrative costs of managing the program and training staff. The goal of this program is to facilitate the placement of hard to place children in permanent adoptive homes and thus prevent long, inappropriate stays in foster care.

Adoption Opportunities Act

Discretionary grants are available to both public and private agencies for services that eliminate the barriers to adoption and promote the adoption of vulnerable children. Grants have been made to pay respite care providers after an adoption to help ensure a permanent placement. Federal regulations require only that children and families need the adoptive services provided by the grants. Only state or local government agencies or nonprofit organizations engaged in adoption services may apply for these grants.

Supplemental Security Income (SSI)

Direct monthly payments are available for unrestricted use for those with incomes and resources below certain levels and who are blind or disabled or over 65. To qualify as disabled, a person must have a permanent, medically proven physical or mental condition that results in marked and severe functional limitations. Although the Welfare Reform Law of 1996 disqualified many behavioral disabilities that formerly had been allowed, many of those canceled cases are now being reviewed. SSI income eligibility guidelines differ among states. SSI benefits may be used by family caregivers to pay for respite care, but most families raising a child with a disability have too many other expenses to have money left over for purchase of respite care services.

Community-Based Family Resource and Support (CBFRS)

In 1997, the one federal program that specifically funded the start-up of respite and crisis care services, the Temporary Child Care Act, was consolidated into the Community Based Family Resource and Support (CBFRS) Program. CBFRS encourages, but does not require, states to fund respite and crisis care services.

This block grant funds programs to prevent child abuse and neglect. States are directed to meet respite and crisis care needs to the extent practicable, but they have the authority to set their own funding priorities as long as certain basic needs are met. A lead agency identified by the state administers the funds, assesses needs, and plans a statewide prevention approach.

Funds have been used by states to develop and maintain statewide respite and crisis care coalitions and to make grants to local agencies to provide services, including respite and crisis care. Within certain limits states may establish their own eligibility requirements. The eligibility of local providers is not restricted. States with programs that leverage local funds can receive significant federal bonuses.

Individuals with Disabilities Education Act (IDEA)

The act provides formula grants to states for programs that ensure a free and appropriate education in the least restrictive environment possible for children who are disabled. IDEA consists of two parts: Part C, for infants and toddlers from birth to age three who have developmental delays or are at substantial risk of delays; and Part B, for children over three who are disabled. A separate Part B grant provides special education for preschoolers, ages three to five, with developmental disabilities. Depending on the state, children may be eligible for Part B benefits until age 22. Respite has sometimes been funded as an early intervention strategy under Part C but only as part of an Individual Family Service Plan and only as last resort on a case-by-case basis. In some Part C programs, respite care is provided on a sliding-fee scale according to a family’s income. Part B funds related services, such as parent counseling and training, to help families assist their children in their education. These services could result in incidental respite for the parents.
Developmental Disability (DD) Councils

State DD Councils develop plans to establish and improve services for individuals with developmental disabilities. They receive funds based on their population and other factors, such as relative per capita income, for basic support, and may apply separately for grants for specific projects. In many states the councils help develop and maintain provider networks, but they have only limited funds to pay respite providers. In some cases, councils have provided start-up funds to develop new respite programs, or temporary emergency funds to help respite providers stay in business.

Summary

Although respite and crisis care services are not specifically mandated by any of these federal statutes, respite and/or crisis care are among the services that are eligible for funding under all of these statutes. In most cases, the authority to decide whether or not to fund respite and/or crisis care services has been given to state, regional, or local governments.

Some of these federal programs can provide direct payments to respite or crisis care consumers or providers, while others fund program expenses through a competitive grant process.

Many of these federal programs are categorical, restricting their funds to certain populations defined by factors such as age, disability, or family circumstances. Respite, however, is needed for people of all ages, with all sorts of disabilities and in all sorts of situations. For this reason, states and local programs need to be diligent in their search for funds and look creatively at many of these federal funding sources.

References and Resources

This fact sheet is based on the ARCH Guide to Federal Funding for Respite and Crisis Care Programs. To order the guide, send $25, plus $6 shipping and handling, to ARCH National Resource Center for Respite and Crisis Care Services, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514

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