Federal Funding and Support Opportunities for Respite
Building Blocks for Lifespan Respite Systems
November 2015
Preface

Respite services were first created more than 40 years ago. As the trend toward home and community-based services continues and more and more families are caring for an aging family member or a family member with a disability or chronic condition in their homes, the nation also has begun to shift its strategy for long-term services and supports away from facilities and toward the home and community. Home and community-based services are preferred by most families, and many of these services, such as respite, are less expensive than facility-based living. However, if family caregivers are to continue to assume the responsibility for providing the bulk of long-term services and supports, they must receive support. When asked what kind of help they need, family caregivers frequently say, “I need a break.”

During this same period, there has been an increasing awareness of families who are experiencing a crisis or whose children or dependent adult family members are at risk of abuse or neglect. When the child or dependent adult who is at risk can be cared for temporarily by a trusted adult outside the family, often the family’s situation can be stabilized so the person at risk can safely return to the family’s care. This kind of temporary care is known as crisis care or emergency respite.

Respite can help family caregivers provide the care and nurturing that dependent family members need, meet the needs of other family members, ensure their own health and well-being, and participate normally in community life. When the need for a break from continuous care goes unmet, stress may build, potentially leading to adverse consequences, such as poor family caregiver health and well-being, abuse, neglect, divorce, or out-of-home placements.

The Lifespan Respite Care Program provides grants to states to establish or enhance Lifespan Respite systems, which are defined by law as “coordinated systems of community-based respite for family caregivers of children or adults with special needs.” Such systems are, to a large extent, dependent on existing state and federal funding streams for respite, which are often limited by restrictive age or disability eligibility criteria, family income, or circumstance. These disparate funding streams may result in programs with long waiting lists or create a bureaucratic maze difficult for families to navigate. The purpose of the Lifespan Respite Care Program is to expand and enhance respite care services; to improve statewide dissemination and coordination of respite care; and to provide, supplement, or improve access to and quality of respite care services.

Potential funding authorization for respite services can be found in many federal statutes or program directives. However, this should in no way be interpreted as providing enough support for respite for the nation’s family caregivers. The emphasis should be on the word “potential.” Although respite is not specifically mandated by any of these statutes, it may be listed as one of the many family caregiver support services that are eligible for funding. In some cases, support for respite is only implied under the larger headings of home and community-based services or family support. In most cases, the authority to decide whether to fund respite and/or crisis care services with these federal resources has been given to state, regional, or local governments. No national data exist regarding how much federal funding is actually being spent on all respite and crisis care services for all ages. In fact, given the limited availability of respite services, long waiting lists for respite, and small percentages of family caregivers who use respite, it is believed that a relatively small proportion of federal funds is invested in respite and crisis care. The most recent survey of family caregivers conducted by the National...
Alliance for Caregiving and the AARP Policy Institute found that of the 43 million family caregivers nationwide, 85% were not receiving respite. Inadequate use of these potential funding sources could be due to lack of awareness about these federal programs and their potential for funding respite and crisis care services, competition for scarce resources, especially in these times of serious budgetary challenges, or limited knowledge about the benefits that investments in respite and crisis care programs can bestow.

Lifespan Respite systems are meant to help states identify existing or potential respite funding sources within their own states, better coordinate these funding streams and maximize their use, and reduce the state’s administrative expenditures, while also reducing the bureaucratic, cost, and social barriers family caregivers face while trying to access respite. All of the real and potential sources of funding identified in this guide can be perceived as building blocks for Lifespan Respite systems. In time, once Lifespan Respite grants have allowed states to build or enhance these coordinated systems of respite care, Lifespan Respite Care Programs will increasingly become a source of service delivery dollars, especially for the countless number of family caregivers who currently are not eligible for any existing source of federal or state funding for respite. While Lifespan Respite Care Programs are intended to maximize and more efficiently use existing funding sources, given current fiscal challenges, the success of the program is dependent on increased state and federal investments in the Lifespan Respite Care Program as well.

This guide outlines the major sources of federal funding that states are using or could potentially use for some aspect of respite service improvement or delivery through their Lifespan Respite systems. It is intended to help family caregivers as respite consumers and respite providers obtain federal funds for which they qualify, help state government and state Lifespan Respite grantees and partners become more knowledgeable about securing respite funds and maximizing their use, and help state and federal policymakers become more aware of the importance and interconnectedness of these funding sources. The Lifespan Respite Care Program is described in the text box below. It is presented here to emphasize the overarching systems-building role that Lifespan Respite Care Programs are intended to have and to illustrate that the goal of Lifespan Respite Care Programs is to use the federal programs described in this guide as the building blocks for statewide coordinated systems for respite services, programs, and resources.

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Lifespan Respite Care Program

Authorizing legislation:
Lifespan Respite Care Act of 2006, Title XXIX of the Public Health Service Act, P.L. 109-442.

Currently authorized through:
September 30, 2011. Appropriations have continued annually past this date.

Program purpose:
To expand and enhance respite care services; to improve statewide dissemination and coordination of respite care; and to provide, supplement, or improve access to and quality of respite care services.

Funding:
Competitive grants are awarded to states that show the greatest likelihood of implementing or enhancing their Lifespan Respite systems statewide. State governors designate a lead agency to receive the funding. That entity must involve an Aging and Disability Resource Center and work in collaboration with a State Respite Coalition or organization. Recipients may subcontract with public or private entities to carry out the mandatory and optional activities described below in Activities supported by the funding. States must provide a 25% match, which may be cash or in-kind.

Activities supported by the funding:
Funds must be used for

- developing or enhancing lifespan respite programs at the state and local levels,
- providing respite care services for family caregivers who care for children or adults,
- recruiting and training respite workers and volunteers,
- providing information to caregivers about available respite services, and
- assisting caregivers in gaining access to such services.

Respite connection:
Respite is the primary activity to be undertaken under this funding authority. By building or enhancing Lifespan Respite Care Programs, defined as “coordinated systems of community-based respite for family caregivers of adults or children with special needs,” family caregivers are provided with improved access to quality respite services.

Issues for consumers, providers, and advocates:
Each Governor submits an application with descriptions of the eligible state agency; family caregivers to be served and eligibility criteria; existing respite services; methods for coordinating respite services and information; training programs; plans for administration, collaboration, and coordination with other related services; how family caregivers and others will participate in planning and implementation; how other federal, state, and local funds, programs, and other resources will be maximized; unmet needs; quality and safety monitoring procedures; expected results; and evaluation plans.

The first Lifespan Respite grants were awarded in 2009 to 11 states and the District of Columbia: Alabama, Arizona, Connecticut, District of Columbia, Illinois, Nevada, New Hampshire, North
Carolina, Rhode Island, South Carolina, Tennessee, and Texas. An additional 12 states were funded in 2010: Delaware, Kansas, Louisiana, Massachusetts, Minnesota, Nebraska, New York, Oklahoma, Pennsylvania, Utah, Washington, and Wisconsin. In 2011, the following states received Lifespan Respite grants: Colorado, Hawaii, Montana, New Jersey, Ohio, and Virginia. In 2012, seven of the original 2009 states received new grants to build upon and expand efforts begun during their previous three years of work. These grants required states to provide gap-filling respite services to family caregivers and work with the Administration for Community Living (ACL) to develop program performance and outcome measures. In 2013 and 14, additional states received these Integration and Sustainability grants to complete the work they had begun. New states, Arkansas and Florida, were awarded Lifespan Respite grants in 2014 and 2015 respectively. As of 2015, a total of 33 states and DC had been awarded initial implementation grants.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Community Living (ACL), Center for Integrated Programs (CIP), Office of Consumer Access and Self Determination

**Eligible entity:**
State agency administering the Older Americans Act, the state’s Medicaid program, or another agency designated by the governor.

**Points of contact:**
Contact information and project updates for the Lifespan Respite Care Program grantees can be found on the ARCH National Respite Network and Resource Center website.
http://www.archrespite.org/lifespan-programs

**Related links:**
Catalog of Federal Domestic Assistance: Lifespan Respite Care Program.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=3a56cd68b41063d2050ab1d50a55259a


Administration for Community Living, Administration on Aging, Office of Integrated Programs. Lifespan Respite Care. http://acl.gov/Programs/CIP/OCASD/LifespanRespite

**References:**
http://www.arch.memberlodge.org/2014ConfProgram#LifespanPanel

U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging (2014). The Lifespan Respite Care Program. Washington, DC.

Acknowledgments

ARCH wishes to acknowledge the work of Vivian Gabor, of Gabor Consultants, as the principal author of the 2015 update of the document.

ARCH also wants to thank the following reviewers for their very helpful, thoughtful, and thorough comments of the original 2012 document: Greg Link, Joseph Lugo, Linda Velgouse, and Jane Tilly, U.S. Department of Health and Human Services, Administration on Aging; Marybeth P. Ribar, Camille Dobson, Kathy Poisal, Carrie Smith, Barbara Dailey, and Richard Jensen, Centers for Medicare and Medicaid Services; Kim Musheno, Association of University Centers on Disabilities; Treeby Brown and Brent Ewig, Association of Maternal and Child Health Programs; Dan Schoeps, U.S. Department of Veterans Affairs, Veterans Health Administration; and Kathy McHugh, U.S. Department of Health and Human Services, Administration for Children and Families (ACF). Joan Lombardi, formerly with ACF, Office of the Assistant Secretary, and Melissa Lim Brodowski, Office on Child Abuse and Neglect (OCAN) helped solicit and coordinate additional comments from OCAN and from ACF where relevant in the original document. Rebecca Posante, Office of the Secretary of Defense, Office on Special Needs, U.S. Department of Defense, for coordinating responses from the Exceptional Family Member Programs in each branch of the military.

For review of the 2015 update, ARCH would like to express thanks to John Sciamanna with the National Child Abuse Coalition for providing guidance on child welfare programs; Bonnie Storm with Child Care Aware of America for reviewing sections related to respite for families in the U.S. Navy and U.S. Air Force; and Patrick O’Keefe, formerly with, Geriatrics & Extended Care Services, Veterans Health Administration, U.S. Department of Veterans Affairs and Meg Kabat with the Veterans Health Administration for reviewing respite services for caregivers of Veterans. Appreciation is extended to Susie Butler, Director, Partner Relations Group, Office of Communications, Centers for Medicare & Medicaid Services for coordinating review of the Medicaid and Medicare sections. ARCH also thanks Greg Link, Joseph Lugo, Kevin Foley and Andrew Morris with the Administration for Community Living for reviewing relevant sections in this 2015 update.
The mission of the **ARCH National Respite Network and Resource Center** is to assist and promote the development of quality respite and crisis care programs, to help families locate respite and crisis care services in their communities, and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network and Resource Center consists of the **ARCH National Respite Resource Center**, the training and technical assistance (TA) division, which provides support to service providers and families through consultation, training, evaluation, and research. The ARCH National Respite Network also includes the **National Respite Locator Service** to help family caregivers and professionals locate respite services and funding sources in their community; the **National Respite Coalition**, the policy division of ARCH, that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels; and the **Lifespan Respite Technical Assistance Center**, which is funded by the **Administration for Community Living (ACL)** in the U.S. Department of Health and Human Services. The Lifespan Respite TA Center provides training and technical assistance to state Lifespan Respite grantees and their stakeholders, including State Respite Coalitions, Aging and Disability Resource Center (ADRC) representatives, and others interested in building such systems at the state and local levels.

**ARCH* National Respite Network and Resource Center**
Annandale, VA
703-256-2084
http://archrespite.org/home

*ARCH stands for Access to Respite Care and Help*

This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration for Community Living. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services, and endorsement by the Federal Government should not be assumed.
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<td>Administration for Children and Families</td>
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<td>Administration for Community Living</td>
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<td>CSHCN</td>
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<td>CYSHCN</td>
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<td>DD Act</td>
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<td>DELTA</td>
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<td>Department of Defense</td>
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<td>DRA</td>
<td>Deficit Reduction Act</td>
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<td>Description</td>
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<tr>
<td>ECHO</td>
<td>extended care health option</td>
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<td>exceptional family member</td>
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<td>EMA</td>
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<td>EPSDT</td>
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<td>F2F HIC</td>
<td>Family-to-Family Health Information Center</td>
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<td>FACT</td>
<td>Families and Children Together</td>
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<td>FGP</td>
<td>Foster Grandparent Program</td>
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<tr>
<td>FRIENDS</td>
<td>Family Resource, Information, Education and Network Development</td>
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<td>FVPSA</td>
<td>Family Violence Prevention and Services Act</td>
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<td>GAB</td>
<td>Give Me a Break (GAB)</td>
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<td>HCBS</td>
<td>home and community-based services</td>
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<td>HCD</td>
<td>Housing and Community Development</td>
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<td>Department of Housing and Urban Development</td>
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<td>Individualized Educational Plan</td>
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<td>IFSP</td>
<td>Individualized Family Service Plan</td>
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<tr>
<td>IL</td>
<td>independent living</td>
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<td>IMH</td>
<td>infant mental health</td>
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<td>LME</td>
<td>local management entity</td>
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<td>LTC</td>
<td>long-term care</td>
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<td>MCHS</td>
<td>Maternal and Child Health Services</td>
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<td>MFP</td>
<td>Money Follows the Person</td>
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<td>Medicare Improvements for Patients and Providers Act</td>
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<td>MMA</td>
<td>Medicare Modernization Act</td>
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<td>MOE</td>
<td>maintenance-of-effort</td>
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<tr>
<td>MR/DD</td>
<td>Mental Retardation/Developmental Disabilities</td>
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<td>MSA</td>
<td>metropolitan statistical area</td>
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<td>NACCRRA</td>
<td>National Association of Child Care Resource &amp; Referral Agencies</td>
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<td>NASUAD</td>
<td>National Association of States United for Aging and Disabilities</td>
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<td>NCCC</td>
<td>National Civilian Community Corps</td>
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<td>National Family Caregiver Support Program</td>
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<td>National Resource Center</td>
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<td>Older Americans Act</td>
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<td>Office on Child Abuse and Neglect</td>
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<td>Office of Care Coordination</td>
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<td>Operation Enduring Freedom/Operation Iraqi Freedom</td>
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<td>Office of Management and Budget</td>
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<td>Oklahoma Respite Resource Network</td>
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<td>PFPWD</td>
<td>Program for Persons with Disabilities</td>
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</table>
PNS  Programs of National Significance
PPACA  Patient Protection and Affordable Care Act
PRWORA  Personal Responsibility and Work Opportunity Reconciliation Act
PSSF  Promoting Safe and Stable Families
RAR  Rapid Action Revision
RCL  Roads to Community Living
RFA  Request for Application
RHII  Regional Home Health Intermediaries
RSVP  Retired and Senior Volunteer Program
SCHIP  State Children’s Health Insurance Program
SCI  spinal cord injury
SCP  Senior Companion Program
SEDS  Social and Economic Development Strategies
SMAAA  Southern Mississippi Area Agency on Aging
SNP  Special Needs Plan
SOC  Systems of Care
SPIL  State Plan for Independent Living
SPRANS  Special Projects of Regional and National Significance
SSBG  Social Services Block Grant
SSI  Supplemental Security Income
TA  technical assistance
TANF  Temporary Assistance for Needy Families Program
TBI  traumatic brain injury
TGA  Transitional Grant Area
UMFS  United Methodist Family Services
USAR  U.S. Army Reserve
VA  Veterans Administration
VAMC  VA Medical Center
VAVS  Department of Veterans Affairs Voluntary Service
VDHCBS  Veteran-Directed Home and Community-Based Services
VHA  Veterans Health Administration
YMCA  Young Men’s Christian Association
**Introduction**

This guide provides basic information about each of the federal programs that provide or could potentially provide respite funding or support. It is meant to be used by state Lifespan Respite Care Programs and their partners to help identify the funding sources that

- could be the building blocks for sustainability of the state’s Lifespan Respite systems;
- could help serve the underserved;
- could help build respite capacity and quality and help recruit and retain respite workers; and
- would identify the individuals who administer these funds for future collaboration and partnerships.

This guide can also be useful to community- and faith-based programs and other local public and private entities that are looking for potential sources of funding to help build new respite programs or expand or sustain current efforts to fund training opportunities for respite providers or to enhance quality in other ways. It can also be useful to family caregivers or those who assist them in helping to identify sources of funding that could be used to pay for respite. Having numerous potential funding sources for respite certainly does not suggest that funding is even close to sufficient to meet the need, but it does suggest the need to coordinate such efforts to maximize their benefits.

This guide is divided into seven major sections. One of the sections focuses on Medicaid and Medicare programs. The second section, Medicaid Waiver Programs, describes the largest source of federal funding for respite that serves all age groups and individuals with various disabling and chronic conditions. Three of the remaining sections describe respite funding sources specific to the age and/or special need of the care recipient: Programs for Children Only, Programs Serving All Ages, and Programs for the Aging. The last two sections describe respite funding sources for American Indians and Military Families and Veterans. Each program is summarized in a table in the Appendix.

**Understanding Federal Funding**

The more than 70 federal programs listed in this guide have wide-ranging purposes and uses, and certainly not every funding source will be useful or appropriate in every state or beneficial to every family caregiver in meeting their particular respite needs. Some federal funding sources will not be directly available to family caregivers or local programs because they are limited to certain grantees, such as state governmental agencies. Other funding sources place limitations on the populations that are eligible to receive the benefits. Eligibility may be based on restrictive criteria, such as household income, legal status, personal characteristics, and family circumstances.

Some of the federal programs discussed in this guide provide general support for home and community-based services, which indirectly could support respite capacity building or service delivery. For example, the Community First Choice Option is a financing method that can be used by states to increase the federal share of Medicaid funding they receive for home and community-based services overall; indirectly, initiatives such as this one, could mean additional resources for respite.
Economic difficulties in many states, however, also make it much more challenging to use flexible funding sources such as the Social Services, Maternal and Child Health Services, or Community Development Block Grants, which are already being stretched very thin by increasing demands on these sources to finance health and social services for people in need. Medicaid expansion allowable under the Affordable Care Act has been advancing only slowly for political reasons, but also due to a slow economic recovery. In 2014, all states reported using mechanisms to control costs in home and community-based service (HCBS) waivers such as restrictive financial and functional eligibility standards, enrollment limits, or waiting lists.\(^2\) Waiting lists for certain home and community-based Medicaid waivers remain high in many states, with average waiting times exceeding two years. Referring families to these waivers may only result in disappointment when services are not immediately available. In addition, state funding shortfalls may discourage some states from pursuing federal grants with state match requirements for fear of not being able to meet the match requirement.

Yet knowledge of the full array of potential resources for supporting respite is important, because Lifespan Respite Care Programs or other programs may be able to access these resources through strategic partnerships with other state agencies or other eligible entities. One of the goals of Lifespan Respite Care Programs is in fact to maximize use of existing resources and be positioned to leverage new public or private funding sources.

The following is a brief guide to understanding how different funding streams operate so users can select the appropriate strategy when trying to access various funding sources: \(^3\)

- **Formula or Block Grants** provide funds to states by using a formula that is tied to a measure of need (e.g., the poverty rate or the state’s population) and are used to address broad areas such as housing, health care, poverty, employment, and community development. States usually have flexibility in designing and implementing activities and services to meet program goals. Although specific state agencies are the primary grantees under this funding mechanism, funds can be reallocated to localities and other eligible grantees through subgrants and contracts.

- **Discretionary or project grants**—the most common federal funding mechanism—support a wide range of targeted efforts. Depending on the program requirements, state and local governments, community-based organizations, or coalitions of community groups can apply directly to the sponsoring federal agency for these funds through a competitive bidding process. Unlike formula or block grants, the amount received by grantees is not predetermined by a formula, and the uses of funds are typically not as flexible.

- **Direct payments** are funds paid by the federal government directly to individual beneficiaries who satisfy specific eligibility requirements. These programs may, however, be administered by an intermediate state agency or other organization.

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• **Federal Entitlement Programs** serve all individuals who meet the prescribed eligibility criteria, such as Foster Care (Title IV-E), Medicaid, Medicare, and Supplemental Security Income.

**State Funding**
This guide has not addressed state funding for respite. However, it is worth noting that many of the federal programs discussed in this guide require a cash or in-kind match. State funding to meet these specific match requirements can also be a source of funding or support for respite. State funding is sometimes merged with federal funding and it can be difficult to identify state government as a source of funding.

**How to Use this Guide**
The following are tips on how to use this guide for Lifespan Respite Care Programs, stakeholders, consumers, and providers of respite and crisis care services:

• Decide which funding source(s) you would like to access. Determine who the eligible entities are in your state.

• Get to know the contact person in your state for this funding source. If available, an Internet address or other contact information is included in this guide to help you identify this person.

• If your state currently uses this funding source for respite, find out what your state Lifespan Respite Care Program, local program, or your family needs to do to access these funds more easily. Some funds are for use solely by government agencies or local public or private entities, or solely for families or family caregivers; some funds are available to both. Funding will usually be discussed in these subsections under each federal program: 1) **Activities supported by the funding**; 2) **Issues for consumers, providers, and advocates**; or 3) **Eligible entity**.

• If your state is not currently using this funding source for respite, work with others in your state, including your state Lifespan Respite Care Program and partners and the State Respite Coalition, to educate state policy-makers and decision-makers about the need for respite, the cost-benefits, and about the potential of using funds from this source.

If you need further assistance, please contact the ARCH National Respite Network at 703-256-2084 or by email at jkagan@archrespite.org.
Medicare and Medicaid Programs

Medicare. Title XVIII of the Social Security Act, designated “Health Insurance for the Aged and Disabled,” is commonly known as Medicare. As part of the Social Security Amendments of 1965, the Medicare legislation established a health insurance program for aged persons to complement the retirement, survivors, and disability insurance benefits under Title II of the Social Security Act.

Medicare covers individuals age 65 and older, people under age 65 with certain disabilities, and individuals with end-stage renal disease. Coverage of respite care is limited to Medicare Hospice Benefits and Medicare Advantage Special Needs Plans. Both of these programs are described in detail following this introduction.

Medicaid. Title XIX of the Social Security Act is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. This program, known as Medicaid, became law in 1965 as a cooperative venture jointly funded by the federal and state governments (including the District of Columbia and the Territories) to assist states in furnishing medical assistance to eligible needy persons. Medicaid is the largest source of funding for medical and health-related services for America’s poorest people.

Each state submits a plan that describes how it intends to administer its Medicaid program. Included in the plan is a list of services to be funded. States are required to cover inpatient hospital services, some outpatient hospital services, laboratory and x-ray services, nursing facilities, and some physician’s care services, as well as services provided by authorized midwives and pediatric nurses. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is mandatory for eligible children up to age 21. The legislation also contains an extensive list of other services that states may choose to include in their plans.

Medicaid will pay for home and community-based services (HCBS) through the state plan as well as through Medicaid waivers. In 2012, three main Medicaid HCBS programs provided access to long-term services and supports for more than 3.2 million people. Most of the growth has occurred through waiver programs. Almost 1.5 million individuals were served through §1915(c) waivers in 47 states and DC, 764,487 individuals received care through the home health state plan benefit in 50 states and DC, and 944,507 individuals received the personal care state plan services benefit in 32 states (see Medicaid Personal Care Benefit in this section).

Increasingly, states are electing to offer services through the self-direction model, which includes initiatives to allow the beneficiary to choose how to allocate their own budgets for services and/or allow them to select and dismiss their providers. In 2014, 42 states with §1915(c) waivers permitted or required self-direction in at least one waiver, 24 states permitted self-direction in personal care state plans, and 9 states allowed self-direction in home health state plan services.

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5 Ibid., 2015.
Historically, federal regulations limited the ability of states to cover the cost of respite care directly as a regular Medicaid benefit under the state plan because it was considered a nonmedical expense. One exception, begun in 1985, was the Medicaid Hospice option.

A number of research, demonstration, and waiver programs under Medicaid continue to allow states to provide respite as one of the home and community-based services offered as a lower-cost alternative to treatment in a medical facility. These include

- **Section 1115 Research and Demonstration Projects,**
- **Section 1915(b) Managed Care/Freedom of Choice Waivers,**
- **Section 1915(c) Home and Community-Based Services Waivers,** and
- **Money Follows the Person (MFP) Demonstration Grants.**

In addition, Medicaid has made available several state options that pay for personal care services for consumers and provide an opportunity for family caregivers to receive a break from their duties:

- **Medicaid Personal Care Benefit,**
- **Section 1915(j) Self-Directed Personal Assistance Services,**
- **Programs of All-Inclusive Care for the Elderly (PACE),** and
- **Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services**

The Affordable Care Act made improvements to several of the options listed above and authorized a new Medicaid state plan option to provide home and community-based attendant services and supports (known as Community First Choice [CFC]).

Each of these programs, demonstrations, and waivers is described in this and the following section.
Medicare Hospice Benefits

Authorizing legislation:
Title XVIII of the Social Security Act.

Program purpose:
Hospice care is a program of support and care for individuals who are terminally ill and their families. Hospice is chosen to provide comfort rather than cure at the end of life.

Funding:
Medicare pays for covered services using daily capitated rates.

Activities supported by the funding:
Medicare covers a range of hospice services, generally at home, from a team that may include doctors, nurses, counselors, other medical professionals, social workers, aides, homemakers, and volunteers. In addition, inpatient respite care from a hospice in a Medicare-approved facility is available when the patient’s usual family caregiver needs a rest.

Respite connection:
Respite for family caregivers is a core service of the program. Individuals receive hospice care in a Medicare-approved facility to give family caregivers a break. Such respite stays can last up to 5 days at a time, and there is no limit to the number of times respite can be used. There is a co-payment for respite services, which is 5% of the Medicare-approved amount for inpatient respite care.

Issues for consumers, providers, and advocates:
The hospice benefit is available only to individuals who

- are eligible for Medicare Part A (Hospital Insurance),
- have been certified by a doctor and hospice medical director to be terminally ill with 6 months or less to live if the illness runs its normal course,
- have signed a statement choosing hospice care instead of other Medicare-covered benefits that would treat the illness, and
- receive care from a Medicare-approved hospice program.

A co-payment of 5% of the Medicare-approved amount for inpatient respite care is required.

Federal funding agency:
U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS).

Eligibility:
Individuals eligible for Medicare who meet the hospice requirements.

Points of contact:
A map of Regional Home Health Intermediaries (RHHIs) can be downloaded from page three of this CMS website:
A list of state hospice organizations can be found on the Hospice Directory website.
http://www.hospicedirectory.org/cm/about/state_hospice

**Related links:**
http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Hospice_Care.aspx

**References:**
Medicare Advantage Special Needs Plans (SNPs)

Authorizing legislation:
Title XVIII of the Social Security Act, as amended by

- Medicare Modernization Act (MMA) of 2003;
- Medicare, Medicaid, and SCHIP [State Children's Health Insurance Program] Extension Act of 2007;
- Medicare Improvements for Patients and Providers Act (MIPPA) of 2008;
- Patient Protection and Affordable Care Act (the ACA);
- Section 607 of the American Taxpayer Relief Act of 2012 (ATRA); and

Currently authorized through:
December 31, 2015.

Program purpose:
To improve care for certain vulnerable groups of Medicare beneficiaries.

Beneficiaries:
Medicare beneficiaries who are institutionalized, those who are dually eligible (covered by both Medicare and Medicaid), and those with certain disabling or chronic conditions (limited to 15 specific conditions at the present time). These beneficiaries are typically older with multiple conditions and are therefore more challenging and costly to treat.

Funding:
SNPs are a specialized Medicare Advantage (Part C) program.

Activities supported by the funding:
Plans must cover all of the medically necessary services and preventive services covered under Medicare Parts A and B and prescription drug coverage under Part D. They may cover additional services tailored to the special groups being served. Chronic conditions currently approved for SNPs are

- chronic alcohol and other drug dependence,
- certain autoimmune disorders,
- cancer (excluding pre-cancer conditions),
- certain cardiovascular disorders,
- chronic heart failure,
- dementia,

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6 Medicare Managed Care Manual Chapter 16b: Special Needs Plans. Table of Contents. (Rev, 100, Issued 01-17-2014; Rev101, Re-issued 02-28-2014)  
- diabetes mellitus,
- end-stage liver disease,
- end-stage renal disease requiring dialysis,
- certain hematologic disorders,
- HIV/AIDS,
- certain chronic lung disorders,
- certain mental health disorders,
- certain neurologic disorders, and
- stroke.

**Respite connection:**
Plans may offer respite for family caregivers of patients who do not live in institutions.

**Issues for consumers, providers, and advocates:**
Not all SNPs provide the same coverage for the same individuals; consumers should find out specific information about any plan (use the Medicare Plan Finder below under **Related links**).

**Federal funding agency:**

**Points of contact:**
Use the Medicare Plan Finder (see below under **Related links**) or call 1-800-MEDICARE (1-800-633-4227) to find an SNP in your area. TTY users can call 1-877-486-2048.

**Related links:**
- Medicare Plan Finder.
  https://www.medicare.gov/find-a-plan/questions/home.aspx
- HealthCare.gov.
  http://www.healthcare.gov/
  http://www.medicare.gov/Publications/Pubs/pdf/11302.pdf
Medicaid Personal Care Benefit

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide coverage of personal care services to some individuals eligible for Medicaid. States may choose to include this option in their state Medicaid plan for adults over age 21 but must provide these services to individuals under age 21.

Beneficiaries:
Low-income persons who are over age 65, blind, or disabled; members of families with dependent children; low-income children and pregnant women; and certain Medicare beneficiaries. In many states, medically needy individuals may apply to a state or local welfare agency for medical assistance. Eligibility is determined by the state in accordance with federal regulations.

Funding:
When a state elects an optional service, it is obliged to provide that benefit to its entire eligible population, as needed, and to pay its share of the cost of the service. As of October 1, 2012, 30 states and the District of Columbia included this optional benefit in their state plan.7

Activities supported by the funding:
“Personal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such services and who is not a member of the individual’s family, and (C) furnished in a home or other location.”8

Respite connection:
Although the personal care benefit does not specifically include respite, while the consumer is receiving personal care services, other family caregivers can take a break from caregiving. States therefore have the option of providing respite to their entire eligible population indirectly through the personal care benefit.

Issues for consumers, providers, and advocates:
Federal rules require states to provide equal access for all eligible Medicaid recipients to all services in a state Medicaid plan. If a state includes personal care as part of its plan, then any individual who meets the state Medicaid eligibility guidelines must have access to personal care.

Respite care providers may legitimately label themselves “personal care providers” as long as they comply with applicable state guidelines. For information about how providers can apply for recognition as a provider of Medicaid personal care, contact the director of Medicaid for your state.

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8 Section 1905(a)(24) of the Social Security Act, as amended.
For information about whether the Personal Care Option is part of a state’s Medicaid Plan, visit the state Medicaid website (see Points of contact below) or check the Kaiser Family Foundation Online Database (see Related links below).

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A map with links to state Medicaid program websites is available from the National Medicaid Directors Association. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Catalog of Federal Domestic Assistance: Medical Assistance Program. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49b41](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49b41)

Kaiser Family Foundation Medicaid Benefits Online Database. [http://medicaidbenefits.kff.org/service.jsp?yr=5&so=0&cat=1&sv=28&gr=off&x=53&y=12](http://medicaidbenefits.kff.org/service.jsp?yr=5&so=0&cat=1&sv=28&gr=off&x=53&y=12)

**References:**
Section 1915(j) Self-Directed Personal Assistance Services

Authorizing legislation:
Title XIX of the Social Security Act, as amended by the Deficit Reduction Act of 2005.

Program purpose:
To give frail elders and adults with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs. In some states, children with developmental disabilities are also served. This option allows states to include such services under their Medicaid state plans rather than through Section 1915(c) waivers.

Beneficiaries:
Medicaid-eligible frail elders, children, and adults with disabilities, depending on the state.

Funding:
At the state’s option, funds are allocated directly to consumers (via budgets), who are then free to decide how they wish to spend their personal care dollars. Participants receive a monthly allowance or budget based on what Medicaid would otherwise have paid to the regular service vendors. States can also choose to require Financial Management Entities to conduct all activities related to cash disbursement, payroll functions, tax functions, and so on.

Activities supported by the funding:
Self-directed personal assistance services (other than room and board) may be considered to be “medical assistance” for eligible individuals. This can include help with everyday needs such as bathing, dressing, grooming, cooking, and housekeeping.

Respite connection:
Consumers can hire personal caregivers of their choice in order to provide respite for their regular family caregivers.

Issues for consumers, providers, and advocates:
Cash & Counseling, now more commonly known as participant-directed services, began as a Section 1115 waiver (see Section 1115, Research and Demonstration Projects, Medicaid Waivers) and is now a state option available under the Medicaid State Plan.

§1915(j) programs include both “budget authority,” meaning the consumer or family directs a personal budget and has flexibility to purchase goods and services other than attendant care, and “employer authority,” which conveys to the consumer/family the authority of hiring, firing, and supervising individual aides or attendants of their choosing.

Consumers may use their budgets to hire anyone they choose, including a relative, to provide that care. However, some states do not permit payment to persons legally responsible for the participant’s care; this would generally exclude spouses. Some states do permit such payments.

Participant-directed programs may be operating under Medicaid home and community-based services (HCBSs) waivers, other demonstration or waiver programs (see Medicaid Waivers) or under other programs. There is considerable variation by and even within states.

Federal funding agency:
**Points of contact:**
Contact information for each state is available through an online interactive map.
[https://nrcpds.bc.edu/insights-publications.php](https://nrcpds.bc.edu/insights-publications.php)

**Related links:**
National Resource Center for Participant-Directed Services, Cash & Counseling.
[http://www.bc.edu/schools/gssw/nrcpds/cash_and_counseling.html](http://www.bc.edu/schools/gssw/nrcpds/cash_and_counseling.html)


**References:**

Programs of All-Inclusive Care for the Elderly (PACE)

Authorizing legislation:

Program purpose:
To enable individuals needing nursing home care to remain in the community; to provide flexible service delivery to those individuals.

Beneficiaries:
Participants must be age 55 or older, live in the PACE service area, and be certified as eligible for nursing home care by the state. The PACE Innovation Act of 2015, which was enacted in November 2015, allows the Centers for Medicare & Medicaid Services (CMS) to develop pilots using the PACE Model of Care to serve individuals under age 55 and those at risk of needing a nursing home (Public Law 114-85).  

Funding:
PACE is a capitated benefit with integrated Medicare and Medicaid financing. PACE providers receive monthly Medicare and Medicaid payments for each enrollee. Medicare enrollees who are not eligible for Medicaid pay monthly premiums equal to the Medicaid capitation amount. The PACE program is a unique capitated managed care benefit for the frail elderly provided by a not-for-profit or public entity.

Activities supported by the funding:
The PACE program offers a comprehensive medical and social service delivery system using an interdisciplinary team approach in an adult day health center, supplemented by in-home and referrals services, based on participants’ needs. PACE programs must be provided by a not-for-profit or public entity and include all Medicaid and Medicare covered services plus “all other services determined necessary by the health professionals team to improve and maintain an individual’s health.”  

As of 2015, there were 114 PACE programs in 32 states  serving more than 34,413 enrollees.

Respite connection:
A PACE program can incorporate caregiver services, including caregiver training and support groups, into the care plan and make respite services available to caregivers. In addition to breaks available to family caregivers during the provision of services at an adult day health center, respite may be available as a service determined to be necessary by the consumer’s interdisciplinary team.

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12 National PACE Association, PACE Census and Capitation Rate Survey, January 2015 (information obtained over the telephone on June 2, 2015)

**Issues for consumers, providers, and advocates:**
PACE becomes the sole source of services for Medicare and Medicaid for eligible enrollees.

**Federal funding agency:**

**Points of contact:**
A list of PACE Provider Organizations is available at
http://www.npaonline.org/pace-you/find-pace-program-your-neighborhood

**Related links:**
National PACE Association.
http://www.npaonline.org/website/article.asp?id=5&title=About_NPA

Kaiser Family Foundation Medicaid Benefits Online Database: Program for All Inclusive Care for the Elderly.

**References:**
Centers for Medicare & Medicaid Services. *PACE Fact Sheet.*
Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide a comprehensive and preventive child health care program for individuals under the age of 21.

Beneficiaries:
Medicaid-eligible children under age 21.

Funding:
EPSDT is a required program for all state Medicaid plans.

Activities supported by the funding:
EPSDT must include

- comprehensive health and developmental history and physical examination,
- appropriate immunizations,
- state-identified laboratory tests for specific ages or populations,
- lead toxicity screening,
- health education and counseling for parents and children,
- vision diagnosis and treatment,
- dental examination and some treatments,
- hearing diagnosis and treatment, and
- “Other necessary health care, diagnosis services, treatment, and other measures...to correct or ameliorate defects, and physical and mental illnesses and conditions discovered by the screening services.”

Respite connection:
Even if personal care benefits are not included in a state's Medicaid plan, children and young people up to age 21 can receive personal care benefits under the EPSDT provision. When a Medicaid-eligible child has a diagnosis indicating a “medical necessity” for any required or optional Medicaid service, the state is obligated to provide the service. As with the personal care option, while the consumer is receiving personal care services, other family members can take a break from caregiving if they are permitted to leave the home.

Issues for consumers, providers, and advocates:
When consumers reach age 21, they are no longer eligible for EPSDT. Availability of personal care services for adults may differ from those provided under EPSDT, depending on the individual’s eligibility as well as services provided in the state.
**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Catalog of Federal Domestic Assistance: Medical Assistance Program. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41)


**References:**
Medicaid Hospice Benefits

Authorizing legislation:
Title XIX of the Social Security Act.

Program purpose:
To provide palliative care for individuals with terminal illnesses.

Beneficiaries:
Medicaid-eligible individuals with terminal illnesses.

Funding:
States may choose to include this option in their state Medicaid plan to adults over age 21 but must provide this service to individuals under age 21. When a state elects an optional service, it is obliged to provide that benefit to its entire eligible population, as needed, and to pay its share of the cost of the service.

Activities supported by the funding:
In general, Medicaid hospice benefits parallel the Medicare hospice benefit (see Medicare Hospice Benefits) although there may be some variations in certain states. As of 2012, 42 states offered hospice care as a covered Medicaid benefit.

Respite connection:
For Medicaid-eligible individuals, hospice care is an optional benefit that may be available if chosen by the state. Patients who reside in a nursing facility may receive hospice care in that setting. Respite is available to family caregivers who are caring for the patient at home on an occasional basis and for no more than 5 consecutive days at a time. Respite is not available if the patient is a resident of a nursing facility.

Issues for consumers, providers, and advocates:
As with the Medicare Hospice Benefit, the consumer must be terminally ill, elect to receive palliative care (rather than treatment) for that illness, and receive care from an approved program. Section 2302 of the Affordable Care Act amended the Medicaid hospice benefit to implement a concurrent care provision for children. Individuals under age 21 are no longer required to forgo curative treatment of the terminal illness upon election of Medicaid hospice.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website.  http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Catalog of Federal Domestic Assistance: Medical Assistance Program.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c095abf249685c0320745b57ad49ba41

Kaiser Family Foundation Medicaid Benefits Online Database
http://kff.org/medicaid/state-indicator/hospice-care/
References:
Center for Medicare and Medicaid Services, Hospice Benefits.  
http://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/hospice-benefits.html

Medicaid Waiver Programs

The Social Security Act authorizes several different waiver and demonstration opportunities for states to operate their Medicaid programs with some flexibility. Each authority has its own purpose and requirements. States have used a variety of waivers to expand Medicaid eligibility and to adopt new models of coverage and care delivery.

Four separate types of waivers are available to states:

- **Section 1115, Research and Demonstration Projects,**
- **Section 1915(b), Managed Care/Freedom of Choice Waivers,**
- **Section 1915(c), Home and Community-Based Services Waivers,** and
- **Combined Sections 1915(b) and 1915(c) Waivers.**

Medicaid Waivers are by far the largest source of federal funds for respite. All states have §1915(c) HCBS waivers except Arizona, Rhode Island and Vermont, which operate their long-term care programs under Section 1115 demonstration waivers. However, in most states, long waiting lists for services prevail. In 2014, 39 states reported a total of 582,066 people on waiting lists across 154 §1915(c) waivers. This included 349,511 individuals with intellectual/developmental disabilities and 155,000 persons waiting for aged/disabled waiver services. The national average time an individual was on a §1915(c) waiting list was 29 months, with the average ranging from 4 months for mental health waivers (available only in 5 states in 2012) to 47 months for intellectual/developmental disabilities waivers.  

Many states are currently making changes to their Medicaid waivers, by moving toward capitated managed care for long-term services and supports (MLTSS). Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities at the discretion of the state and as approved by CMS, including §1915(a), §1915(b), and §1115. The majority of states are implementing Medicaid MLTSS through §1115 demonstrations or §1915(b)/(c) waivers. As of September 2015, 26 states were providing long-term services and supports through managed care.

For a full list of current state waiver programs, see the Medicaid Waivers and Demonstrations List on the Centers for Medicare & Medicaid Services website.

http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp

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Section 1115 Research and Demonstration Projects

**Authorizing legislation:**
Title XXI, Section 1115 of the Social Security Act.

**Program purpose:**
To demonstrate and evaluate policies or approaches that have not been widely implemented, including expanded eligibility guidelines, coverage of services not typically provided, or innovation in service delivery systems.

**Funding:**
State Medicaid agencies submit applications, often working with the Centers for Medicare & Medicaid Services to develop the proposal. Demonstrations typically run 5 years and may include continuations beyond that time. Demonstrations must be budget neutral, not costing the federal government more than they would without the waiver.

**Activities supported by the funding:**
Initiatives under this authority are intended to demonstrate a wide variety of new health care services delivery methods. Successful demonstrations may lead to broader implementation of innovations. For example, the Medicaid Cash & Counseling Option (described above in Section 1915(j) Self-Directed Personal Assistance Services) began as a Section 1115 waiver in 1998 in three states. Increasingly, states are using 1115 waivers to implement Medicaid managed care for long-term services and supports. As of 2012, three states (Arizona, Rhode Island, and Vermont) use §1115 waivers exclusively to administer statewide Medicaid managed care programs that include all covered HCBS for all populations. Another five states (Delaware, Hawaii, New York, Tennessee, and Texas) use §1115 waivers for Medicaid managed care programs that include HCBS for at least some geographic areas and/or populations as well as §1915(c) waivers for HCBS services in other geographic areas and/or populations.18

**Respite connection:**
State waivers could expand services to include respite and/or eligibility to individuals and families in need of that service.

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**Example:** Tennessee has been operating its Section 1115 waiver, TennCare, since 1994. It has received multiple extensions and is currently approved through June 30, 2013. TennCare provides coverage statewide to many populations, including children under 21, pregnant women, some low-income families with children, Supplemental Security Income recipients, and some other low-income adults. There are several packages within TennCare that provide different coverage of services such as home health services when medically necessary. In 2010, home and community-based services have been folded into TennCare’s CHOICES program for long-term care for individuals in nursing homes as well as adults age 65 or older and younger adults who have physical disabilities who receive home care. CHOICES includes coverage for personal care visits, attendant care, adult day care, and both in-home and inpatient respite care. **Source:** Tennessee. (2010). TennCare. [http://www.tn.gov/tenncare/](http://www.tn.gov/tenncare/)

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**Issues for consumers, providers, and advocates:**
Proposals are subject to approval by the Centers for Medicare & Medicaid Services (CMS), Office of Management and Budget (OMB), and U.S. Department of Health and Human Services (DHHS) and may be subject to additional requirements such as site visits before implementation. CMS does not have a specific timeframe to approve, deny, or request additional information on the proposal. Additionally, CMS usually develops terms and conditions that outline the operation of the demonstration project when it is approved.

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Center for Medicare and Medicaid Services, Section 1115 Demonstrations [http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp](http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp)

**References:**
Section 1915(b) Managed Care Waivers

Authorizing legislation:
Title XIX, Section 1915(b) of the Social Security Act.

Program purpose:
To allow states to implement managed care delivery systems or otherwise limit choice of providers under Medicaid.

Funding:
The Centers for Medicare & Medicaid Services has 90 days to act on applications submitted by state Medicaid agencies, with a second 90-day review period if necessary, after which the application is deemed approved. Programs must be “cost-effective,” which means that the state’s actual expenditures under a waiver are less than the state’s projected budget for the program. Waivers are approved for 2-year periods, which may be extended indefinitely through renewal applications.

Activities supported by the funding:
States may

- mandate enrollment in managed care programs,
- allow local governments to act as an enrollment broker,
- use cost savings to provide additional services, or
- limit the number or type of providers for services.

Respite connection:
States can use the authority to provide additional services to specify respite as one of those additional services.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website.  http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Section 1915(c) Home and Community-Based Services Waivers

Authorizing legislation:
Title XIX, Section 1915(c) of the Social Security Act.

Program purpose:
To allow states to provide home and community-based services (HCBS) to individuals who would otherwise require institutional nursing care.

Funding:
States apply to Centers for Medicare and Medicaid Services (CMS) for an initial HCBS waiver for a 3-year period; renewals are at 5-year intervals. Applications must show that providing these services to the target population will not exceed the cost of institutional care.

Activities supported by the funding:
In addition to traditional medical services, states can also provide services not usually covered by the Medicaid program as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care. Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general, spouses and parents of minor children cannot be paid providers of waiver services.

Respite connection:
Respite is specifically supported by this waiver authority. It is the leading source of federal funds for respite care for those who are eligible.

All states have HCBS waivers except Arizona, Rhode Island and Vermont, which operate their long-term care programs under Section 1115 demonstration waivers. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time, and in 2014, there were 293 HCBS waiver programs in operation throughout the country. Most states include respite within one or more of their Section 1915(c) Medicaid Waiver Programs.

Issues for consumers, providers, and advocates:
Depending on how individual waivers are written by the state, waiver programs generally are narrowly targeted to individuals of specific ages with specific disabilities, illnesses (such as AIDS), or conditions (such as head injury). The “Aging and Disabled Waiver” is the most common waiver for respite services for the aging population.

However, in 2014, CMS published a final rule that permits, but does not require, states to combine target groups within one HCBS waiver. Prior to that change, a single section 1915(c) HCBS waiver could only serve one of the following three target groups: older adults, individuals with disabilities, or both; individuals with intellectual disabilities, developmental disabilities, or both; or individuals with mental illness. This change allows states to design a waiver that meets the needs of more than one target population. If a state chooses the option of more than one target group under a single waiver, the state “must assure CMS that it is able to meet the unique service needs of individuals in each target group, and that each individual in the waiver has equal access to all needed services.”19 The rule also establishes requirements for home and community-based settings under the 1915(c), 1915(i) and

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1915(k) Medicaid authorities, and person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i).20

Because HCBS waivers are granted only for a limited number of slots at one time, waiver programs, by their nature, often have waiting lists. Because eligibility is based on the income of the consumer and not the family, most children and adults with disabilities meet income eligibility guidelines for the HCBS waiver, even if their families have income and resources.

Medicaid operates as a vendor payment program, which means that states pay providers, or vendors, directly. Although vendors must agree to accept Medicaid payment rates, payment for services such as respite can vary among states up to a maximum set by CMS. Respite care is the only service for which Medicaid will reimburse vendors for room and board expenses. While states may establish co-payments or deductibles for services, these charges cannot be levied on services provided to children under age 18.

In some but certainly not all states, HCBS providers may face stringent reporting requirements. To continue receiving a waiver, state Medicaid administrators must show CMS that waiver services cost no more than placement in a medical facility. States may also require vendors to show that without the services they provide, their clients would qualify for placement in a medical facility. Finally, the process of establishing rates for services can require significant cost accounting.

**Federal funding agency:**

** Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Medicaid Waivers and Demonstrations List. [http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp](http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp)

**References:**


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Combined 1915(b)/(c) Waivers

Authorizing legislation:
Title XIX, Sections 1915(b) and (c) of the Social Security Act.

Program purpose:
To enable states to provide a continuum of services to the aging or to people with disabilities. States use the §1915(b) authority to mandate managed care enrollment or limit provider contracting and §1915(c) authority to target eligibility for the program and provide home and community-based services. Thus, states can provide long-term care services in a managed care environment or use a limited pool of providers.

Funding:
All federal requirements for both §1915(b) and §1915(c) programs must be met. States must submit separate applications for each waiver type. For example, states must demonstrate cost neutrality in the §1915(c) waiver and cost-effectiveness in the §1915(b) waiver. States must also comply with the separate reporting requirements for each waiver. Renewal requests must be prepared separately and submitted at different points in time.

Activities supported by the funding:
All activities allowable under both §1915(b) and §1915(c) waiver programs may be included.

Respite connection:
As discussed in the section on §1915(b) waivers, these waivers may expand services to include respite; respite is specifically included under the §1915(c) authority.

Issues for consumers, providers, and advocates:
Combined waivers give states the option to propose inclusion of both traditional long-term care state plan services (e.g., home health, personal care, and institutional services) and nontraditional home and community-based services (e.g., homemaker and adult day health services and respite care) in their managed care programs.

§1915(b) waivers are renewed at 2-year intervals; §1915(c) waivers are approved for 5 years. Therefore, renewal requests on combined waivers must be prepared and submitted separately.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Association of Medicaid Directors website. http://medicaiddirectors.org/about/medicaid-directors/

Related links:
Additional Medicaid and Children’s Health Insurance Program Opportunities

The Patient Protection and Affordable Care Act, P.L. 111-148, enacted March 23, 2010, and the Health Care and Education Reconciliation Act of 2010, P.L. 111-152, enacted March 30, 2010, are together referred to as the Affordable Care Act (ACA). ACA included some important provisions that could potentially fund or support respite services for eligible individuals.

The following program was enacted under ACA:

- **Community First Choice (CFC) Medicaid State Plan Option** to enable individuals requiring an institutional level of care to receive attendant services and supports at home or in the community.

Other programs were originally enacted as part of the Deficit Reduction Act of 2005 and modified by ACA:

- **Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services** to allow states to cover home and community-based services for Medicaid beneficiaries without a special waiver.

- **Money Follows the Person (MFP)** to help states increase home and community-based long-term care services by transitioning individuals out of institutions and reducing the reliance on institutional care for the elderly and individuals with disabilities by using savings from enhanced federal match for long-term care home and community based service systems development and sustainability.

The **Children’s Health Insurance Program (CHIP)** was first signed into law during the Clinton Administration. It was reauthorized by the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), which was signed into law by President Barack Obama on February 4, 2009, and additional changes were made by ACA. The program was most recently reauthorized as part of the Medicare Access and CHIP Reauthorization Act of 2015. CHIP provides health care coverage for low-income children who do not qualify for Medicaid and who would otherwise be uninsured. States may elect to provide coverage to qualifying children by expanding their Medicaid programs or through a state program separate from Medicaid.

Each of these programs, demonstrations, or state plan options is described in this section.

For more information, visit the Medicaid.gov, Keeping America Healthy website.

Community First Choice (CFC) State Plan Option

**Authorizing legislation:**
Section 1915(k) of the Social Security Act, as amended by Section 2401 of the Patient Protection and Affordable Care Act, P.L. 111-148.

**Program purpose:**
To enable individuals requiring an institutional level of care to receive attendant services and supports at home or in the community.

**Funding:**
States will receive an enhanced federal match of 6% for included services.

**Activities supported by the funding:**
This option provides home and community-based attendant services and supports to assist the consumer in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks. This option helps consumers acquire, maintain, and enhance their daily living skills, trains the consumer on selecting, managing, and dismissing attendants, and establishes a backup system to ensure continuity of services.

**Respite connection:**
While respite is not specifically covered, family caregivers can receive breaks from caregiving while attendants are providing services.

**Issues for consumers, providers, and advocates:**
This state plan option became effective October 1, 2011. As of September 2015, five states have CMS approved 1915(k) State Plan Amendments (CA, MD, MT, OR, and TX).

Activities supported under this State Plan Option are more restricted than those allowed under the 1915(i) Home and Community-Based Services option. The following are definitions from Title XIX specific to this option:

- “Activities of daily living” includes tasks such as eating, toileting, grooming, dressing, bathing, and transferring.
- “Health-related tasks” means specific tasks related to the needs of an individual, which can be delegated or assigned by licensed health care professionals under state law to be performed by an attendant.
- “Instrumental activities of daily living” includes (but is not limited to) meal planning and preparation; managing finances; shopping for food, clothing, and other essential items; performing essential household chores; communicating by phone or other media; and traveling around and participating in the community.

States must develop and implement this option in collaboration with a Development and Implementation Council that includes “a majority of members with disabilities, elderly individuals, and their representatives.”
Services must be offered on a statewide basis, without regard to the individual’s age or to the type, severity, or nature of the disability or the form of services required for the individual to lead an independent life. Services can be provided under an agency-provider model (within which individuals must maintain the ability to have a significant role in the selection and dismissal of providers of their choice), a self-directed model, or other models approved by CMS.

In 2014, CMS issued a final rule that establishes requirements for home and community-based settings under the 1915(c), 1915(i) and 1915(k) Medicaid authorities.\(^{21}\)

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available from the National Association of Medicaid Directors website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**
Centers for Medicare & Medicaid Services, *Community First Choice 1915(k)*


**References:**
Centers for Medicare & Medicaid Services. *Home & Community Based Services.*
[http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html)


[http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf](http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf)

Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services

Authorizing legislation:
Section 1915(i) of the Social Security Act, as amended by

- Section 6086 of the Deficit Reduction Act of 2005 (DRA); and
- Patient Protection and Affordable Care Act of 2010 (ACA).

Program purpose:
To allow states to cover home and community-based services (HCBS) for Medicaid beneficiaries without a special waiver and, thus, without having to demonstrate budget neutrality (compared to institutional care).

Activities supported by the funding:
As with §1915(c) HCBS waivers, states who take this option can offer a variety of medical and long-term services not previously covered by the state Medicaid program as long as these services are required to keep a person from being institutionalized. Services covered include case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care.

Respite connection:
Respite is specifically mentioned as a covered service in the federal regulations for this option [CFR 44.182 (c) (7)]. States are required to conduct an individual assessment of the needs of each individual determined to be eligible for the state option benefits.

Example: The purpose of Montana’s 1915(i) HCBS State Plan program is to provide mental health services to qualifying youth in the community setting. Services are provided through a wraparound service model that includes the youth and family and structured to provide the supports needed to maintain youth safely in their home and community. The state plan program defines respite care as the provision of supportive care to the youth when the unpaid persons normally providing day to day care for the youth will not be available to provide care. Respite care services may be provided only on a short term basis, such as part of a day, weekends, or vacation periods. Respite services may be provided in the youth’s home, another private residence or other community setting, excluding psychiatric residential treatment facilities. The provider of respite care must ensure that its employees providing respite care services meet specific qualifications.

Source: Montana Department of Public Health and Human Services, Children’s Mental Health Bureau. 1915(i) Home and Community Based Services State Plan Program for Youth with Serious Emotional Disturbance (SED) Policy Manual – Effective (July 1, 2014).

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**Issues for consumers, providers, and advocates:**
Eligibility is determined by states. However, effective October 1, 2010, eligibility under this option was expanded to individuals with incomes up to 300% of the maximum Supplemental Security Income (SSI) payment. Unlike the HCBS waivers, under this option states cannot cap enrollment or maintain a waiting list.

In 2014, CMS issued a final rule that requires Section 1915(i) services be provided in a home and community-based setting, similar to Community First Choice state plan option services.23 The rule also establishes person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i). CMS specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. This process must be directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen. The person-centered planning requirements under 1915(i) also stipulate that “if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan” then a caregiver assessment must be conducted.

As of July 2015, 16 states (California, Colorado, Connecticut, Delaware, Florida, Idaho, Indiana, Iowa, Louisiana, Maryland, Michigan, Mississippi, Montana, Nevada, Oregon and Wisconsin) and the District of Columbia offered Section 1915(i) state plan benefits.24

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

**Points of contact:**
A list of state Medicaid program websites is available National Association of Medicaid Directors website. [http://medicaiddirectors.org/about/medicaid-directors/](http://medicaiddirectors.org/about/medicaid-directors/)

**Related links:**

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Centers for Medicare and Medicaid Services, *Home and Community Based Services 1915(i).*

**References:**
Centers for Medicare & Medicaid Services. *Home & Community Based Services.*
http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

http://www.chcs.org/media/LTSS_Policy_Brief_.pdf
Money Follows the Person (MFP) Demonstration Grants

Authorization:

Currently authorized through:
September 30, 2016.

Program purpose:
To help states increase home and community-based long-term care services by transitioning individuals out of institutions and reducing the reliance on institutional care for the elderly and individuals with disabilities. MFP uses savings from an enhanced federal match for long-term care (LTC) home and community-based services (HCBS) systems development and sustainability.

Beneficiaries:
Individuals in the state who, immediately before beginning participation in the MFP demonstration project, resided in an inpatient facility for at least 3 months; are receiving Medicaid benefits; and for whom a determination has been made that, but for the provision of home and community-based long-term care services, the individual would continue to require the level of care provided in an inpatient facility.

Funding:
In 2007, Centers for Medicare and Medicaid Services (CMS) awarded almost $1.5 billion in MFP competitive grants, with states proposing to transition more than 34,000 individuals out of institutional settings over the 5-year demonstration period. ACA extended and expanded funding for Medicaid Money Follows the Person Rebalancing Demonstration Programs through 2016. States receive an enhanced federal match for each Medicaid beneficiary transitioned to the community from an institution during the demonstration period.

Activities supported by the funding:
MFP demonstration grants pay for 1 year of community-based services for each person transitioned from an institution. Services that qualify for the MFP enhanced federal matching rate during a beneficiary’s MFP participation year are those waiver and state plan services that will continue once the individual’s MFP demonstration transition period has ended. The savings incurred by the state through the enhanced federal match, known as rebalancing funds, can be used to develop and/or sustain LTC HCBS systems and services.

Respite connection:
Respite programs for family caregivers are included in covered home and community-based services. Respite care means services provided to individuals unable to care for themselves, furnished on a short-term basis because of the absence of or need for relief for those persons normally providing care. MFP may not be claimed for the cost of room and board except when provided as part of respite care furnished in a facility approved by the state. Once individuals are living in the community, they can continue to access respite and other home and community-based services through waiver or state plan services.

In addition, rebalancing funds can be used to serve family caregivers of individuals who have been transitioned back into the community by providing respite and other caregiver supports.
**Issues for consumers, providers, and advocates:**
With the extension of the program through the ACA, additional states were able to start MFP demonstration projects, and the existing states were able to seamlessly transition into the next 5 years. As a result, by 2015, 44 States and the District of Columbia were receiving MFP grants. Additionally, CMS awarded funding for the Money Follows the Person (MFP) Tribal Initiative (TI) to five state grantees. The extension of the program also changed the definition of individuals eligible to participate in MFP. Individuals are now eligible for MFP after residing in an institution for more than 90 days instead of for more than 6 months (as was formerly the case).

The limits in the supply and availability of a range of home and community-based services and supports, including respite, could impede the ability of some states to implement MFP. When states began to implement MFP, many grantees reported the need to increase the capacity of HCBS waiver programs in their state in order to meet the anticipated demand of MFP participants. This could present an opportunity for Lifespan Respite Programs or respite providers to partner with MFP programs to meet an anticipated increased respite demand.

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency or State Mental Health Agency.

**Points of contact:**
MFP and Home and Community-Based Waiver state contacts.

**Related links:**
Centers for Medicare and Medicaid, *Money Follows the Person*  

Catalog of Federal Domestic Assistance: Money Follows the Person Rebalancing Demonstration.  
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=608884168116eecaef45984edbb48594

**References:**
Kaiser Family Foundation (April 2014). *Money Follows the Person: A 2013 Survey of Transitions, Services and Costs*  

Children’s Health Insurance Program

Authorizing legislation:
Title XXI of the Social Security Act, as amended by

- Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), P.L. 111-3, and
- Patient Protection and Affordable Care Act of 2010 (ACA), P.L. 111-148.

Currently authorized through:
September 2019, but funded only through September 30, 2017.

Program purpose:
To provide health care coverage for low-income children who do not qualify for Medicaid and would otherwise be uninsured. States may elect to provide coverage to qualifying children by expanding their Medicaid programs or through a state program separate from Medicaid. States may elect to cover pregnant women and currently five states offer this coverage.

Beneficiaries:
Targeted uninsured low-income children up to age 19 who have been determined eligible by the state for child health assistance under their state plan are children whose family income exceeds the Medicaid-applicable income level but does not exceed 50 percentage points above the Medicaid-applicable income level and are not found to be eligible for medical assistance under Title XIX or covered under a group health plan or under health insurance coverage. States have broad flexibility to set their CHIP income eligibility levels. Most states cover children in families up to or above 200 percent of the federal poverty level. In federal FY 2013, 8 million children were enrolled in coverage funded by CHIP.

Funding:
Federal and state governments jointly finance the CHIP, although the federal government assumes a larger share of the financing with a matching rate ranging from 65 to 81 percent. Unlike Medicaid, CHIP funds are capped for each state. This capped funding is distributed through state-specific allotments determined by a formula to account for the state’s actual use of CHIP funds, adjusted for health care inflation and child population growth.

Activities supported by the funding:
Within broad federal guidelines, each state determines the design of its program, eligibility groups, benefit packages, payment levels for coverage, and administrative and operating procedures. Categories of basic services include inpatient and outpatient hospital care, doctor’s care, laboratory and x-ray services, and well-child pediatric care, including immunizations. Plans may also cover prescription drugs and mental health, vision, and hearing services. States can choose health benefits coverage, but it must be equivalent to those offered under: (1) the standard Blue cross/Blue Shield preferred provider option service plan offered to federal employees; (2) a health plan available to a state’s public employees; or (3) the HMO within the state that has the highest commercial enrollment (excluding Medicaid enrollment).

Respite connection:
The original statute specifically states that nothing prevents a state “from providing coverage of benefits that are not within a category of services.”
**Issues for consumers, providers, and advocates:**
Both eligibility for CHIP and covered services are determined by each state, within broad federal guidelines. States are required to cover medically necessary services but rarely have expanded CHIP coverage to personal care, family support, or respite.

**Federal funding agency:**

**Eligible entity:**
State CHIP programs can be run by a State Medicaid Agency or by another state entity as a separate child health insurance program.

**Points of contact:**
Links to state CHIP websites are available on the federal government’s Connecting Kids to Coverage website. [http://www.insurekidsnow.gov/state/index.html](http://www.insurekidsnow.gov/state/index.html)

**Related links:**
Catalog of Federal Domestic Assistance: Children’s Health Insurance Program.
[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=6a755cd785c483b5b892708adaecf998](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=6a755cd785c483b5b892708adaecf998)


**References:**
Programs for Children Only

Child Welfare and Child Abuse Prevention Programs

The federal government started providing grants to states for child welfare services under the Social Security Act in 1935. Over time, various social policy goals have been addressed by federal legislation and funding. At the present time, child welfare programs, which can include some level of support for respite care programs for those who care for children, are contained in two major Acts, which have been amended by a number of pieces of legislation.

The Child Abuse Prevention and Treatment Act (CAPTA) contains provisions for

- Title I, Section 106, State Grants;
- Title I, Section 105, Discretionary Activities; and
- Title II, Community-Based Grants for the Prevention of Child Abuse and Neglect.

The Social Security Act provides opportunities for respite funding in several of its titles:

- Title IV-B, Subpart I, Stephanie Tubbs Jones Child Welfare Services;
- Title IV-B, Subpart 2, Promoting Safe and Stable Families; and
- Title IV-B, Subpart 2, Targeted Grants to Increase the Well-Being of, and to Improve the Permanency Outcomes for, Children Affected by Methamphetamine or Other Substance Abuse.

Additional federal legislation supporting respite services includes

- the Adoption Opportunities Act, and
- the Family Violence Prevention and Services Act.

Each of these programs, demonstrations, and waivers is described in this section on Child Welfare and Child Abuse Prevention Programs.

For more on federal child welfare funding, see:

Child Abuse Prevention and Treatment Act (CAPTA), Basic State Grants

Authorizing legislation:

Currently authorized through:
September 30, 2015.

Program purpose:
To improve state child abuse prevention and treatment programs.

Beneficiaries:
Abused and neglected children and their families and at-risk children and families who receive prevention services.

Funding:
Formula grants; the amount is determined by the ratio of children under age 18 in each state to the total number of children in the nation.

Activities supported by the funding:
Flexible funding is to be used to improve aspects of the state’s child protective services program in the areas of

- abuse and neglect intake, screening, and investigation;
- use of multidisciplinary teams and interagency protocols for investigation;
- legal preparation and representation;
- case management, including ongoing case monitoring and delivery of services and treatment;
- safety and risk assessment instruments;
- technology;
- caseworker training;
- workforce recruitment, development, and retention;
- mandated reporter training;
- programs to obtain or coordinate “necessary services for families of disabled infants with life-threatening conditions, including existing social and health services, financial assistance, and services necessary to facilitate adoptive placement of any such infants who have been relinquished for adoption”;
- public education on child abuse and neglect;
- shared leadership strategies between professionals and parents in community-based prevention programs;
- collaboration between the child protection and juvenile justice systems; and
• collaboration between the child protection and public health systems and community-based prevention and treatment programs.

**Respite connection:**
While respite is not specifically mentioned as a covered activity, a state could include respite in its CAPTA State Plan under the areas of the delivery of services and treatment and/or as a service to families of infants with life-threatening conditions. For FY 2008, states planned to spend 48% of their grant funding on prevention and support services, which could include respite care.

**Issues for consumers, providers, and advocates:**
States submit 5-year plans that outline which of the activities listed above they intend to fund under the grant. To receive funding, states must make a number of assurances to the federal government about the way they operate their child abuse and neglect programs.

Currently, all 50 states, the District of Columbia, and several territories receive these grants.

**Federal funding agency:**

**Eligible entity:**
State child welfare agency.

**Points of contact:**

**Related links:**
Catalog of Federal Domestic Assistance: Child Abuse and Neglect State Grants. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=9dfc03d2ef426cd54f123da07e631b87

**References:**

Child Abuse Prevention and Treatment Act (CAPTA), Discretionary Activities

**Authorizing legislation:**
Title I of the Child Abuse Prevention and Treatment Act (CAPTA), Section 105, most recently amended and reauthorized on December 20, 2010, by the CAPTA Reauthorization Act of 2010 (P.L. 111-320).

**Currently authorized through:**
September 30, 2015.

**Program purpose:**
To support a variety of activities related to the causes, prevention, identification, assessment, and treatment of child abuse and neglect.

**Beneficiaries:**
Abused and neglected children and their families and at-risk children and families who receive prevention services.

**Funding:**
CAPTA requires that the U.S. Department of Health and Human Services (DHHS) must make 30% of the total appropriation for Title I programs available for “discretionary activities.” However, Congress generally appropriates two separate funds: one for CAPTA State Grants (see Child Abuse Prevention and Treatment Act (CAPTA), Title I, Section 106, State Grants) and a separate fund for Discretionary Activities.

**Activities supported by the funding:**
DHHS may use funds under this section for a variety of research, demonstration, or contracted activities in areas including cross-systems collaboration, training, safety and risk assessment tools, workforce development, visitation centers, kinship placement procedures, mutual parent support and self-help programs, and “other innovative and promising programs related to preventing and treating child abuse and neglect.” In addition, the following activities are specified but have never been funded under this authority:

- respite and crisis nursery programs provided by community-based organizations under the direction and supervision of hospitals,
- programs based within children’s hospitals or other pediatric and adolescent care facilities that provide model approaches for improving medical diagnosis of child abuse and neglect and for health evaluations of children for whom a report of maltreatment has been substantiated.

**Respite connection:**
Support of respite and crisis nursery programs is one of the primary activities that DHHS could choose to fund by these grants. In addition, a case could be made for including respite under several other areas, such as kinship placement and “other innovative...programs.”
**Issues for consumers, provider, and advocates:**
Program announcements published at [grants.gov](https://grants.gov) provide specifics of activities to be funded in each grant cycle. Announcements regarding funding for the respite-related activities (discussed in [Respite connection](#) above) have not been made to date. Applications are evaluated on the basis of the degree to which proposals meet specific objectives defined in the annual announcement, including the relevance of the proposal to the stated areas of emphasis for the grant cycle. Grants are generally for 1 to 5 years.

All grants under this section must be evaluated for effectiveness; funding for evaluation may be a portion of the grant or a separate grant or contract.

**Federal funding agency:**

**Eligible entity:**
Individual grant announcements list eligible entities. Grants or contracts can be made to states, local governments, Tribes, Tribal organizations, public agencies, or private agencies or organizations (or combinations of such agencies or organizations) engaged in activities related to the prevention, identification, and treatment of child abuse and neglect.

**Points of contact:**
Research and Innovation Division, Children’s Bureau
1250 Maryland Ave, SW
Washington, DC 20024
Phone: 202-205-8172

**Related links:**
Catalog of Federal Domestic Assistance: Child Abuse and Neglect Discretionary Activities. [https://www.cfda.gov/?s=program&mode=form&tab=step1&id=869b1c2e79e85c33ba21801987516583](https://www.cfda.gov/?s=program&mode=form&tab=step1&id=869b1c2e79e85c33ba21801987516583)

**References**
Child Abuse Prevention and Treatment Act (CAPTA), Community-Based Child Abuse Prevention (CBCAP) Grants

Authorizing legislation:
Title II of the Child Abuse Prevention and Treatment Act (CAPTA), most recently amended and reauthorized on December 20, 2010, by the CAPTA Reauthorization Act of 2010 (P.L. 111-320).

Currently authorized through:
September 30, 2015.

Program purpose:
To support community-based, prevention-focused programs and activities that strengthen and support families in order to prevent child abuse and neglect.

Beneficiaries:
Children and their families and organizations dealing with community-based, prevention-focused programs and activities designed to prevent child abuse and neglect.

Funding:
Funds are distributed to the states under a formula grant. Seventy percent of funds are distributed based on the number of children under age 18 in the state; the remaining 30% is allotted based on the amount of other aid the current lead agency leveraged and directed during the preceding fiscal year. States must provide a 20% cash match.

One percent of appropriated funds is reserved for allotments to Indian Tribes and organizations and migrant programs.

Each state governor designates a lead agency to administer CBCAP funds. Lead agencies must then submit annual applications for funding. The instructions for this application are included in a program instruction released in the spring of each year. States in turn subcontract with community-based agencies to fund direct services.

This program also supports a national resource center, Family Resource, Information, Education and Network Development Services (FRIENDS), to assist CBCAP lead agencies with the development and evaluation of their programs and activities.

Activities supported by the funding:
The lead agency identified by the state administers the funds, assesses needs, and plans a statewide prevention approach. Local community-based grants are awarded to provide core services such as:

- parent education, mutual support and self-help, and parent leadership services;
- respite care services;
- outreach and follow-up services, which may include voluntary home visiting services; and
- community and social service referrals.
And access to optional services, including:

- referral to and counseling for adoption services for individuals interested in adopting a child or relinquishing their child for adoption;
- child care, early childhood education and care, and intervention services;
- referral to services and supports to meet the additional needs of families with children with disabilities and parents who are individuals with disabilities;
- referral to job readiness services;
- referral to educational services, such as academic tutoring, literacy training, and General Educational Degree services;
- self-sufficiency and life management skills training;
- community referral services, including early developmental screening of children;
- peer counseling; and
- domestic violence service programs that provide services and treatment to children and their non-abusing caregivers

**Respite connection:**

Respite is a core service of the program, defined as “short term care services, including the services of crisis nurseries, provided in the temporary absence of the regular caregiver (parent, other relative, foster parent, adoptive parent, or guardian) to children who are in danger of child abuse or neglect; have experienced child abuse or neglect; or have disabilities or chronic or terminal illnesses.

As the only federal source of funding to actually start up, implement, and help sustain respite and crisis care programs, CBCAP is critical to building and ensuring respite availability and affordability as an abuse and neglect prevention program. CBCAP funds can be used to help existing respite agencies and programs expand services and reduce waiting lists, build new capacity and programming to serve underserved or unserved populations, especially for families in isolated or rural areas or for families who don’t meet eligibility criteria for existing programs, and help support agency efforts to recruit and train new providers. CBCAP funds can also be used to support respite vouchers or subsidies to help families pay for respite of their choosing. CBCAP lead agencies can help improve timely access, availability, and affordability for critical respite and crisis care services by working in collaboration with disability organizations, state respite coalitions, other child abuse and neglect prevention programs, family resource centers, community- and faith-based organizations, Part C of the Individuals with Disabilities Act (IDEA) Early Intervention Services, and state and local Developmental Disabilities and Mental Health agencies.

**Example:** In Alabama, the Children’s Trust Fund contracts with United Cerebral Palsy-Huntsville to provide respite vouchers or home health respite in six counties through the Alabama Lifespan Respite Resource Network. CBCAP funds one of these projects in Huntsville. Under the voucher program, families of children with disabilities or chronic conditions up to age 19 are eligible for quarterly vouchers and may hire and train anyone they choose as long as the respite provider is 18 or older and does not reside in the home.

**Issues for consumers, providers, and advocates:**
CBCAP requires states to include provisions for children with disabilities and to give high priority to community-based, prevention-focused programs for low-income neighborhoods and programs that provide services to young parents or parents with young children. States are also required to consider the special needs of parents with disabilities in program design and implementation. States may establish their own eligibility requirements for clients, on the basis of their approach to meeting the particular needs of communities. Families served with CBCAP funds are typically those that meet some “at risk” definition but—in keeping with the prevention focus—usually are not linked to Child Protective Services.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration on Children, Youth and Families, Children’s Bureau, Office on Child Abuse and Neglect.

**Eligible entity:**
The state’s Children’s Trust Fund is the lead entity in about half the states. In other states, lead entities include state offices of child abuse prevention, child and family services, health, and self-sufficiency. In a few states, other private agencies are designated.

**Points of contact:**
FRIENDS National Resource Center for CBCAP website contains an interactive map of state lead agency contacts. [http://www.friendsnrc.org/state-lead-agency-contacts](http://www.friendsnrc.org/state-lead-agency-contacts)

**Related links:**
Catalog of Federal Domestic Assistance: Community-Based Child Abuse Prevention Grants. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c40ae1c761d5a9550c1805af991e4372](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=c40ae1c761d5a9550c1805af991e4372)

FRIENDS National Resource Center for Community-Based Child Abuse Prevention. [http://www.friendsnrc.org](http://www.friendsnrc.org)

**References:**

Stephanie Tubbs Jones Child Welfare Services

Authorizing legislation:
Title IV-B, Subpart 1 of the Social Security Act; amended by the Child and Family Services Improvement and Innovation Act, P.L. 112-34.

Currently authorized through:
September 30, 2016.

Program purpose:
To provide states and Tribes flexibility in developing child and family services programs using a range of services and programs.

Beneficiaries:
Families and children in need of child welfare services.

Funding:
Each state receives $70,000 and additional funds determined by a formula based on their relative share of the population of children under age 21 times the complement of the state’s average per capita income. Eligible Tribes receive funding based on the allotment for the state in which they are located, the state population under age 21, and the number of children in the Tribal population. States and Tribes must provide a 25% match. States, in turn, fund community-based organizations to provide direct services.

Some states are allowed to use a portion of these funds for foster care maintenance payments, adoption assistance based on earlier history, and day care related to employment or training for employment to no more than their Federal FY 2005 level and must limit spending for administrative costs to a maximum of 10%. Beginning in 2008, states may also have their funding decreased if they do not meet certain goals related to caseworker visits to children in foster care in the preceding year.

Activities supported by the funding:
States use the funding in varying ways. In FY 2014, they collectively reported planning to spend the program funds primarily on the following types of activities (in descending order based on percentage of federal funds planned to be used for each activity type).

- child protection;
- family preservation services for at-risk families;
- family support or prevention services;
- foster care maintenance payments;
- promoting and supporting adoption (including through provision of adoption subsidies); and
- other activities, including developing and supporting a well-qualified child welfare workforce.
Respite connection:
Respite services could be part of a plan that addresses any of the first five activities listed above.

Issues for consumers, providers, and advocates:
States and Tribes submit 5-year state Child and Family Services Plans that outline the goals they will work toward to improve safety, permanency, and well-being of children and their families. The plan must be written after consultation with appropriate public and nonprofit private agencies and community-based organizations. Activities to be funded under this program are described in the plan.

Federal funding agency:

Eligible entity:
State child welfare agency and federally recognized Indian Tribes.

Points of contact:
Links to state agency contacts are available on the Child Welfare Information Gateway website. https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main dsp ROL & rol Type=Custom & RS_ID=45

Related links:
Catalog of Federal Domestic Assistance: Stephanie Tubbs Jones Child Welfare Services Program https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e8f5b25b58b9eda59b63656f629fea0e

References:


Promoting Safe and Stable Families (PSSF)

Authorizing legislation:
Title IV, Part B, Subpart 2 of the Social Security Act, as amended by the Child and Family Services Improvement Act of 2006 (CFSIA), P.L. 109-288; and the Child and Family Services Improvement and Innovation Act, P.L. 112-34.

Currently authorized through:
September 30, 2016.

Program purpose:
To reduce child abuse and neglect, thereby preserving families; to promote flexibility in the ways states develop and expand child and family services programs that coordinate with community-based agencies.

Beneficiaries:
Families and children who need services to help them stabilize their lives, strengthen family functioning, prevent out-of-home placement of children, enhance child development, increase competence in parenting abilities, facilitate timely reunification of the child, and promote appropriate adoptions.

Funding:
For Federal FY 2015, the program was funded for a total of $379.6 million ($319.8 million in formula grants to states, tribes, and territories and $59.8 million for discretionary grants). Funds are distributed to states and territories on the basis of the number of children receiving Supplemental Nutrition Assistance Program benefits. States are required to match their funding allotments with at least 25% in state funds and are restricted from spending more than 10% of the total funds on administrative costs. States may in turn fund community-based organizations to provide direct services. Indian Tribes and Alaska Native organizations are also eligible for funding.

Activities supported by the funding:
States are required to spend at least 20% of their funding on each of four categories of services:

- Family support services, which help prevent family crisis by enhancing family functioning and child development. Such services could include, but are not limited to, respite and crisis care, counseling, parent training, and conflict resolution.
- Family preservation services, which focus on families at risk or in crisis and could include respite and crisis care, child abuse treatment and prevention, and domestic violence treatment.
- Family reunification services, which bring separated families back together and are time-limited. Suggested services include respite and crisis care, counseling, substance abuse treatment, mental health services, and services to address domestic violence.
- Adoption promotion and support services, which advance the successful placement of children in safe, permanent families. These services could also include respite and crisis care and family counseling.

States are required to provide an annual report on planned child and family services expenditures for the following year, in addition to their 5-year Child and Family Services Plan (CFSP). For most states, one or both of these documents can be found on the state’s website.

**Respite connection:**
Respite care can be included in each of the four required categories of services. According to the National Resource Center for In-Home Services (a service of the Children’s Bureau’s National Child Welfare Training and Technical Assistance Network), 36 states were providing respite under PSSF in 2011.26

**Example:** Tennessee began a statewide Adoption Support and Preservation program (ASAP) in 2004, prompted by the settlement of a lawsuit, Brian A. v. State of Tennessee. (Section 8 of the settlement agreement dealt with adoption and post-adoption support to families.) Services are provided through a contract with Harmony Adoption Services in Maryville and Knoxville, TN, that serves eastern Tennessee. A service of the ASAP program involves helping the families develop a relief team to provide a natural support network for all family members, and stipends are available to assist families in obtaining respite. In addition, the Department of Children’s Services may serve the family through non-custodial crisis intervention services and directly purchase respite services if warranted.


**Example:** In Iowa, each child receiving adoption subsidy through PSSF is eligible for five days of paid respite each fiscal year, administered through the Iowa Foster and Adoptive Parents Association (IFAPA). Adoptive parents select their own respite provider and, after the care has been provided, submit a form directly to IFAPA, which pays the provider. Families may receive additional respite days if there are extraordinary circumstances and funds are available. Also, Iowa KidsNet support staff help connect families to respite resources if they are unable to find their own.


**Example:** The South Carolina Department of Social Services designates funds from PSSF for its Health Support Service, which includes reimbursement for Respite Care for adoptive parents in order to enable them to cope with the stress of caring for a child with special needs. Adoptive families are allowed to be reimbursed up to $500 annually to pay for respite care.


26 Personal communication, May 2011.
Issues for consumers, providers, and advocates:

- Federal law does not limit the eligibility of beneficiaries; states are free to set their own eligibility requirements based on income level, disability, age, or level of risk.
- Federal law does not place limits or restrictions on providers; states may set their own eligibility guidelines for providers and may subcontract with any provider of family preservation or family support services.
- States may plan an array of services to best serve the specific needs of their residents, choosing from among those allowed by the law. The legislation requires states to coordinate both the delivery and funding of services, seeking input from practitioners to define the types of benefits provided. The state agency that writes the plan must consult with public and not-for-profit agencies that provide child welfare services, and the plan must show that the funded services have been coordinated with other federally assisted programs serving the same populations. Many states have given local networks authority to set policy for their particular areas, which might be a town, a county, a region, or some combination. Therefore, advocates for policy changes may need to address policymakers at the state, regional, county, or local levels.

Federal funding agency:
U.S. Department of Health and Human Services, Administration on Children, Youth and Families.

Eligible entity:
Formula Grants: States, territories and certain Indian Tribes are eligible applicants. For caseworker visit funds, only states/territories are eligible applicants. Discretionary Grants: States, local governments, Tribes, and public agencies or private agencies or organizations (or combinations of such agencies or organizations) with expertise in providing and evaluating technical assistance related to family preservation, family support, time-limited family reunification, and adoption promotion and support.

Points of contact:
Contact information for state agencies receiving PSSF grants is available on the Child Welfare Information Gateway Library website.
https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspROL&rolType=Custom&RS_ID=45

Related links:
Catalog of Federal Domestic Assistance: Promoting Safe and Stable Families.
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=847d62c1906f9bb547a53c00408b99fa

References:
Casey Foundation (2011). The Promoting Safe and Stable Families Program.
http://www.casey.org/media/PromotingSafeandStableFamilies.pdf


Targeted Grants to Increase the Well-Being of, and to Improve the Permanency Outcomes for, Children Affected by Substance Abuse

Authorizing legislation:
Title IV, Part B, Subpart 2 of the Social Security Act, as amended by the Child and Family Services Improvement Act of 2006 (CFSIA), P.L. 109-288; and Child and Family Services Improvement and Innovation Act, P.L. 112-34.

Currently authorized through:
September 30, 2016.

Program purpose:
To improve the well-being and permanency outcomes for children affected by substance abuse. These funds can be used for a variety of services and activities in five main areas:
- systems collaboration and improvements,
- substance abuse treatment linkages and services,
- services for children and youth,
- support services for parents and families, and
- expanded capacity to provide treatment and services to families.

The most recent reauthorization of the program eliminated the priority for serving children affected by methamphetamine use.

Beneficiaries:
Agencies or organizations serving children and families who have experienced or are at risk of experiencing an out-of-home placement as a result of a parent’s or caregiver’s substance abuse.

Funding:
Funding for this competitive grant program was set at $20 million for each of fiscal years 2012 through 2016. On September 30, 2012, 17 new Round II five-year grants were awarded and 8 Round I grantees received two-year extensions. In FY 2014, four new Round III (2014-2019) regional grants were awarded.27 Grantees must provide matching funds of 15% for the first and second fiscal years of the grant award, 20% for the third and fourth fiscal years of the grant award, and 25% for the fifth fiscal year of the grant award. Grants may be extended for two years at a matching rate of 30% for year six and 45% for year seven.

Activities supported by the funding:
Funds can be used for services and activities “consistent with the purpose” of the grants, and “may include” services for
- family-based comprehensive long-term substance abuse treatment,
- prevention and early intervention,

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Federal Funding and Support Opportunities for Respite

- child and family counseling,
- mental health,
- parenting skills training, and
- replication of successful models of treatment.

**Respite connection:**
Respite is not mentioned in the legislation, grant announcement, or abstracts of any of the grantees. Nonetheless, a case could be made for funding respite as a component of family-based treatment or of prevention and early intervention.

**Issues for consumers, providers, and advocates:**
Grants are expected to support regional partnerships aimed at establishing or enhancing a collaborative infrastructure intended to meet a broad range of needs of families who have both substance abuse and child welfare involvement.

**Federal funding agency:**

**Eligible entity:**
Regional partnerships, which must include either the state child welfare agency or an Indian Tribe. There is great latitude in the identity of the other partner(s).

**Points of contact:**

**Related links:**
Catalog of Federal Domestic Assistance: Enhance the Safety of Children Affected by Substance Abuse. [https://www.cfda.gov/?s=program&mode=form&tab=core&id=c6982a75030dfced7917258ff006ca77](https://www.cfda.gov/?s=program&mode=form&tab=core&id=c6982a75030dfced7917258ff006ca77)


Children and Family Futures

**References:**
Adoption Opportunities

Authorizing legislation:

Currently authorized through:
September 30, 2015.

Program purpose:
To eliminate barriers to adoption and help find permanent families for children, particularly those with special needs.

Beneficiaries:
Children who are in foster care.

Funding:
Competitive discretionary grants are made to state or local entities, public or private agencies, or adoptive family groups for 3 to 5 years.

Activities supported by the funding:
The legislation requires activities in 11 major areas, including the following areas specifically related to adoption practices:

- support for permanency for children through kinship and adoption;
- increase in the number of minority children placed for adoption, with emphasis on recruitment of minority families; and
- increase in the number of older children adopted from foster care.

In addition, the Act calls for the provision of post-adoption services for families who adopt children with special needs, including counseling; case management; training; adoptive parent organizations; support groups for parents, children, and siblings; day treatment; and respite care.

Respite connection:
Respite is a core service that may be funded under this legislation.

Issues for consumers, providers, and advocates:
Grants, which may not be awarded each year, are generally solicited in specific program areas. For example, in 2002, grant areas were Developing Projects for Increasing Adoptive Placement of Minority Children, Developing Projects for Post-Legal Adoption Services, and Developing Projects of Respite Care as a Service for Families who Adopt Children with Special Needs. This was the most recent year in which respite was a focus of funding. In 2010, applications were solicited for programs on the Diligent Recruitment of Families for Children in the Foster Care System.

Federal funding agency:
**Eligible entity:**
State and local government entities, public or private licensed child welfare or adoption agencies, other community-based organizations, adoptive family groups, minority groups, or sectarian institutions.

**Points of contact:**
Children’s Bureau, Administration for Children and Families
1250 Maryland Ave, SW
8th Floor
Washington, DC 20024
Phone: 202-260-7794

**Related links:**
Catalog of Federal Domestic Assistance: Adoption Opportunities.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=5ad836479cd62aeb05c5ffbfdfc98985

**References:**

Family Violence Prevention and Services Act (FVPSA)

Authorizing legislation: 

Currently authorized through: 
September 30, 2015.

Program purpose: 
To support 2,000 local domestic violence agencies that provide essential services, including emergency shelters, hotlines, counseling and advocacy, and primary and secondary prevention.

Beneficiaries: 
Victims of domestic violence, their children and other dependents, their families, and other persons affected by such violence, including friends, relatives, and the general public.

Funding: 
The program is authorized at $175 million for each of Federal FYs 2011-2015. The authorization specifies the following programs that have received funding to date:

• Formula Grants to States, Territories and Tribes for Shelter and Support. At least 70% of the FVPSA appropriations must go to states and territories and 10% must go to Indian Tribes to fund: programs and projects that seek to prevent family/domestic/dating violence, provide immediate shelter and supportive services for victims and provide specialized services for children, underserved populations, and victims who are members of racial and ethnic minority populations.

• Grants to State Domestic Violence Coalitions. At least 10 percent must go statewide nongovernmental, non-profit domestic violence coalitions, which act as information clearinghouses and coordinate state- and territory-wide domestic violence programs, outreach, and technical assistance.

• National Resource Centers. At least 6 percent of FVPSA appropriations goes to support national resource centers.

• Domestic Violence Prevention enhancement and Leadership through Alliance (DELTA). $6 million is authorized each year for the Centers for Disease Control and Prevention administered program that supports selected state domestic violence coalitions to work on prevention of family/domestic/dating violence. This program was funded for the first time in FY 2013 and will support grantees for five years.

• National Domestic Violence Hotline. A $3.5 million annual authorization supports a 24-hour national, toll-free hotline.

**Activities supported by the funding:**
The Act funds essential services that are at the core of ending domestic violence: emergency shelters, counseling and advocacy, and primary and secondary prevention.

The states must subgrant 95% of their funding to local domestic violence organizations or community-based organizations to provide shelter and supportive services. The law further maintains that 70% of these funds must be provided to eligible entities for the primary purpose of providing immediate shelter and supportive services to victims of domestic violence. Not less than 25% of the funds must be used for supportive services and prevention services, including:

- assistance in developing safety plans;
- individual and group counseling, peer support groups, and referral to community-based services;
- services, training, technical assistance, and outreach to increase awareness of family violence, domestic violence, and dating violence;
- culturally and linguistically appropriate services;
- services for children exposed to family violence, domestic violence, or dating violence;
- prevention services, including outreach to underserved populations; and
- advocacy, case management, and information and referral services concerning issues related to family violence, domestic violence, or dating violence intervention and prevention, including—
  - assistance in accessing related federal and state financial assistance programs;
  - legal advocacy to assist victims and their dependents;
  - medical advocacy, including provision of referrals for appropriate health care services (including mental health and alcohol and drug abuse treatment);
  - assistance locating and securing safe and affordable permanent housing and homelessness prevention services;
  - transportation, child care, respite care, job training and employment services, financial literacy services and education, financial planning, and related economic empowerment services; and;
  - parenting and other educational services for victims and their dependents.

**Respite connection:**
Advocacy, case management, and information and referral services related to respite services are among the supportive services that must be provided by state subcontractors under formula grants to states using 25% of the available funds.

**Issues for consumers, providers, and advocates:**
The requirement that advocacy, case management, and information and referral services related to respite must be provided by state formula grant subcontractors could encourage partnerships between the subcontractors and Lifespan Respite Care Programs and/or community-based respite services.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Children and Families.

**Eligible entity:**
States, Tribal entities; State Domestic Violence Coalitions.
Points of contact:
Family and Youth Services Bureau
1250 Maryland Ave., SW
Washington, DC 20024
Phone: 202-401-5756

Related links:
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=86e6ac3fc2bc5ff4c373357b22a86054

Futures without Violence.
http://www.futureswithoutviolence.org/

National Network to End Domestic Violence.
http://www.nnedv.org/policy/issues/fvpsa.html

References:

Child Education/Health/Mental Health

Federal funding for programs that could include respite services for caregivers of children with health or mental health needs or who have or are at risk of developmental delays is available potentially under several legislative authorizations.

The Individuals with Disabilities Education Act (IDEA) provides formula grants to states for programs that ensure a free and appropriate education in the least restrictive environment possible for children with disabilities. First passed in 1975 as the Education for All Handicapped Children Act, it was reauthorized in 2004. It consists of two parts:

- **Part C**, the Early Intervention Program for infants and toddlers from birth to 3 years who have developmental delays or are at substantial risk of delays; and
- **Part B**, for children over age 3 with disabilities, which funds related services to help families assist their children in their education. In addition, Part B includes preschool grants for children 3 to 5 years old.

Maternal and Child Health Programs, Title V of the Social Security Act, has provided grants to states for maternal and child welfare since the inception of the Act in 1935. Currently, there are two programs within Title V, which can potentially provide funding for respite or respite support programs:

- **Maternal and Child Health Services Block Grant**, including the Children with Special Health Care Needs Program; and
- **Family-to-Family Health Information Centers**.

Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances (Children’s Mental Health Initiative) Title V, Part E, Section 561 of the Public Health Services Act, establishes grants for comprehensive community-based systems of care for children and adolescents with serious emotional disturbances and their families.

Each of these programs is described in this section.
Individuals with Disabilities Education Act (IDEA), Part C: State Grants

**Authorizing legislation:**
Individuals with Disabilities Education Act of 2004 (IDEA), P.L. 108-446, Part C.

**Program purpose:**
To maximize the potential of infants and toddlers with disabilities by enhancing their development through early intervention services.

**Beneficiaries:**
Infants and toddlers with developmental delays, physical or mental disabilities and, in some states, those who are at-risk of substantial developmental delays age birth through 2 years. In addition, the Keeping Children and Families Safe Act of 2003 (P.L. 108-36) requires States to develop “provisions and procedures for referral of a child under age 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under Part C. The 2004 reauthorization of IDEA contains language parallel to this.

**Funding:**
States receive annual formula grants based on their proportional share of children up to age 2 years in the general population.

**Activities supported by the funding:**
Early intervention services must be provided as part of an Individualized Family Service Plan (IFSP) and as defined in the legislation. These include a variety of therapies, training, and medical services, as well as
- family training, counseling, and home visits;
- social work services; and
- transportation and related costs needed to enable the child and family to benefit from other listed services.

**Respite connection:**
Respite may be funded as an early intervention strategy under Part C as part of an IFSP 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.

**Example:** New York State regulations on early intervention services provide for the discussion of respite services with parents at the individualized family service plan meeting. Respite services may be provided on an individual basis, with consideration given to the following criteria: severity of the child’s disability and needs; child’s risk of out-of-home placement; lack of access to informal supports; stressful family situations; and the need for respite expressed by the parents.

**Source:** New York State Department of Health, *The Early Intervention Program.*
Federal Funding and Support Opportunities for Respite

Example: In North Carolina, through the Part C Early Intervention program, respite services must be listed on the Individualized Family Service Plan and linked to a specific outcome for the child or family. As with all Infant-Toddler Program services, the Individualized Family Service Plan team must consider the use of natural supports to meet the respite needs of the child and family. Reimbursement for respite is limited to thirty-two (32) hours per year. Families choose the type of respite that best meets their family’s needs as well as provider of the service. Respite providers may charge for this service at their usual rate; parents pay the provider directly for services rendered. Infant-Toddler Program will reimburse the family a portion of the cost.


Issues for consumers, providers, and advocates:
When the family of a child with a disability applies for services under Part C, an assessment of the needs of the child and the family is conducted by certified child development practitioners from at least two disciplines, such as a nurse, an occupational therapist, or a social worker. Then a service coordinator (or case manager) assembles a team to review the assessment. In addition to the parents, the service coordinator, and at least two of the people who made the initial assessment, the team may include a family advocate and anyone providing services to the child and family.

The team drafts an IFSP based on the evaluation and needs assessment and the stated needs and priorities of the family. The completed plan is reviewed every 6 months, or more often if necessary, by the team, which revises it at least annually.

States are required to serve children who are experiencing developmental delays and children with certain diagnosed physical or mental developmental disabilities, such as autism and cerebral palsy that have a high probability of causing developmental delays. States also have the option of serving children at risk of substantial developmental delays.

IDEA state lead agencies may contract with public or private providers for services indicated in the IFSP of Part C clients.

A limited number of states fund respite with Part C funds. To see which states currently cover respite, see the ARCH State Funding Streams for Respite across the Lifespan, 2013 Update at http://archrespite.org/images/docs/2013_Reports/State_Funding_Streams_for_Respite_Across_the_Lifespan_August_2013.pdf. For information about how consumers or providers may apply for IDEA funding for respite, contact the IDEA Part C coordinator in your state (see below under Points of contact).

http://archrespite.org/images/docs/2013_Reports/State_Funding_Streams_for_Respite_Across_the_Lifespan_August_2013.pdf
Federal funding agency:

Eligible entity:
State educational agency.

Points of contact:
Contact information for IDEA Part C State Coordinators can be found on the website of the Early Childhood Technical Assistance Center.
http://ectacenter.org/contact/ptccoord.asp

Related links:
Catalog of Federal Domestic Assistance: Special Education Grants for Infants and Families.
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=4ce6f0cd35c3b46d3e8cdcb8de68abe3

Early Childhood Technical Assistance Center.
http://ectacenter.org/

References:


http://www2.ed.gov/about/reports/annual/osep/2014/parts-b-c/36th-idea-arc.pdf
Individuals with Disabilities Education Act, Part B: Special Education Preschool Grants

**Authorizing legislation:**

**Program purpose:**
To provide incentives to states to help prepare preschoolers with disabilities to enter school ready to learn.

**Beneficiaries:**
Children ages 3 through 5 with disabilities, and (at the state’s option) 2-year-olds who will reach age 3 during the school year who require special education and related services.

**Funding:**
States receive annual formula grants based on previous funding, the relative number of children ages 3 to 5, and the relative number of those children living in poverty. Most of the funds are distributed to local education agencies that directly serve children.

**Activities supported by the funding:**
Funds are used by states to
- provide a free appropriate public education to children with disabilities ages 3 through 5 (which the state may extend to children who will reach age 3 during the next school year);
- cover administrative, support, and other costs; and
- provide early intervention services to children ages 3 through 5 who previously received services under Part C until they are eligible to enter kindergarten.

**Respite connection:**
Respite may be covered under early intervention services for those children who previously received Part C services as part of an Individualized Family Service Plan (see Individuals with Disabilities Education Act (IDEA), Part C: State Grants above).

**Issues for consumers, providers, and advocates:**
The goal of each Part B state grant is in helping states provide access to high-quality education and related services for preschool students with disabilities.

States are eligible to receive preschool grant funds if the state education agency establishes eligibility by submitting an application as described under Part B State Grants Funding section.

**Federal funding agency:**

**Eligible entity:**
State educational agencies.
Points of contact:
Contact information for IDEA State Section 619 (Preschool Grants) Coordinators can be found on the Early Childhood Technical Assistance Center website.
http://ectacenter.org/contact/619coord.asp

Related links:
Catalog of Federal Domestic Assistance: Preschool Grants.
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=b8f55d51156bceb8beae77de2a5f2fe0


Early Childhood Technical Assistance Center
http://ectacenter.org/

References:
http://www2.ed.gov/about/reports/annual/osep/2014/parts-b-c/36th-idea-arc.pdf
Maternal and Child Health Services Block Grant

Authorizing legislation:
Title V of the Social Security Act, as amended by the Omnibus Budget Reconciliation Act of 1981.

Program purpose:
To promote and improve the health of pregnant women, mothers, infants, children, and children with special health care needs (CSHCN).

Beneficiaries:
Mothers, infants, children, including CSHCN and their families, particularly those of low income.

Funding:
Funds are awarded each year according to a statutory formula, with 85% of the appropriation going to state health agencies for block grants. States must use at least 30% of their funding for preventive primary care services for children and at least 30% for services for CSHCN. States must contribute a 75% match to federal funding.

Activities supported by the funding:
States use their funds to improve health services for mothers and children through four levels of services:

- direct health care services, including those for CSHCN;
- enabling services, which include transportation; translation; outreach; respite; health education; family support; health insurance; case management; and coordination with Medicaid, the Women, Infants & Children (WIC) nutrition program and education;
- population-based services, such as newborn screening, lead screening, immunization, sudden infant death syndrome counseling, oral health, injury prevention, nutrition, and outreach; and
- infrastructure-building services, such as needs assessment, evaluation, planning, policy, coordination, quality assurance, development of standards, monitoring, training, research, systems of care, and information systems.

Respite connection:
Respite is specifically identified as an “enabling service.”

Example: Connecticut uses Title V funds to support community-based care coordination through the Medical Home Initiative for Children and Youth with Special Health Care Needs. Care coordinators co-located in pediatric primary care settings coordinate care with specialists and promote medical homes with primary care providers. They work with a statewide respite and extended services provider and family outreach and education contractor to promote and support medical homes.

Example: Children with Special Health Needs, Vermont Department of Health, serves Vermont children and youth ages birth to 21 who have a chronic physical or developmental condition, and who also require health and related services of a type or amount beyond that required by children generally. Respite is a planned break for parents or caregivers to allow them time to spend with other children, schedule necessary appointments, or rest and recharge. Respite provides limited funding for short-term support and relief to families who earn at or less than 500% of the Federal Poverty Level.


Example: The Arizona Office of Children with Special Health Care Needs (OCSHCN) funds the AZ Department of Economic Security’s Lifespan Respite voucher program to enable families/caregivers of children and youth with special health care needs to receive short-term respite.


Issues for consumers, providers, and advocates:
States complete a needs assessment every 5 years; they complete an application for a block grant annually. Applications must include a plan for responding to needs identified in the assessment and a description of how funds will be used.

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 are usually based on Medicaid guidelines. Most states link Medicaid and Maternal and Child Health Services (MCHS) and provide services through their state health departments, often subcontracting with regional or nonprofit health agencies for specific services. Few states have taken advantage of the flexibility available under this block grant to provide or support respite.

Federal funding agency:
U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

Eligible entity:
State Health Agency (a small number of CSHCN programs are located in other state agencies, usually universities, because the Title V legislation “grandfathered” existing programs).

Points of contact:
Title V block grants are administered by state departments of health. Links to those agencies can be found through an interactive map on the Centers for Disease Control and Prevention website. http://www.cdc.gov/mmwr/international/relres.html
**Related links:**
Catalog of Federal Domestic Assistance: Maternal and Child Health Services Block Grant to the States.
[https://www.cfda.gov/?s=program&mode=form&tab=step1&id=71c60388ca2673697c96e4be166b7b54](https://www.cfda.gov/?s=program&mode=form&tab=step1&id=71c60388ca2673697c96e4be166b7b54)

The Maternal and Child Health Bureau provides a searchable online Title V information system at

Profiles of each state’s use of Title V funds for the most recent fiscal year are available on the Association of Maternal & Child Health Programs website.
[http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages-StateProfiles.aspx](http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages-StateProfiles.aspx)

Association of Maternal & Child Health Programs. [http://www.amchp.org](http://www.amchp.org)

**References:**
[http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf](http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf)

Family-to-Family Health Information Centers

Authorizing legislation:
Title V, Section 501 of the Social Security Act, as amended by the Patient Protection and Affordable Care Act of 2010, and the Access to Medicaid and CHIP Reauthorization Act of 2015

Currently authorized through:
September 30, 2017.

Program purpose:
To develop and support Family-to-Family Health Information Centers (F2F HICs), which help families of children with disabilities to make informed health care choices by providing information, identifying successful health delivery models, and developing models of collaboration between families and health professionals. Centers also provide training and guidance and conduct outreach activities. Centers are staffed by families and health professionals.

Beneficiaries:
Projects will benefit (1) public or private agencies, organizations, and institutions engaged in activities for children and youth with special health care needs (CYSHCN); (2) family members and children who receive services through the program; and (3) professionals and trainees who provide services to CYSHCN.

Funding:
F2Fs are funded through competitive grants to states. Up to $95,700 is available per year to fund a center in each state and the District of Columbia. This federal funding is blended in some states with other federal or state specific funding to support F2F activities.

Activities supported by the funding:
The primary activity of F2F HICs is providing information and guidance to families.

Respite connection:
Some F2F HICs have developed informational materials about respite to help families access respite in their state or community. In 2013-14, more than 50% of F2Fs were involved with respite initiatives in their states.  

Example: The Massachusetts Family-to-Family Health Information Center collaborated with other organizations in the state to produce a brochure providing both general information about respite and a chart to help families determine whether they are eligible for publicly funded respite services.


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Example: Family Connection of South Carolina is the Family-to-Family Health Information and Education Center that is serving as a primary stakeholder in implementing the state’s Lifespan Respite Program. Along with the state’s Aging and Disability Resource Center, the F2F HIC provided outreach, information, and screening for respite services, encouraged use of and connected family caregivers with respite options as early as possible.


Issues for consumers, providers, and advocates:
The emphasis on partnerships between families and professionals is intended to ensure that the needs of the families of children with special health care needs are served by these F2F HICs.

Technical assistance to the Centers is provided by the National Center for Family/Professional Partnerships at Family Voices.

Federal funding agency:
U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

Eligible entity:
Any public or private entity or faith-based or community organization that is staffed by families.

Points of contact:
Contact information for F2F HICs is available on the Family Voices website. http://www.familyvoices.org/page?id=0052

Related links:
Catalog of Domestic Federal Assistance: Affordable Care Act – Family-to-Family Health Information Centers. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=09d59d5911e90d5cb7d850b86c1ec883


References:

Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances (SED) – CMHS Child Mental Health Service Initiative

Authorizing legislation:
Title V, Part E of the Public Health Services Act, Section 561, P.L. 102-321.

Program purpose:
Beginning in 1993, the Substance Abuse and Mental Health Services Administration (SAMHSA) funded states, tribal agencies and localities to provide integrated home and community-based services and supports for children and youth with serious emotional disturbances and their families by encouraging the development and expansion of systems of care. A “system of care” (SOC) is an organizational philosophy and framework that involves collaboration across child-serving agencies, families, and youth for the purpose of improving access and expanding the array of coordinated community-based, culturally and linguistically competent services and supports for children and youth with a serious emotional disturbance and their families. Each child or adolescent served through the program receives an individualized service plan developed with the participation of the family (and where appropriate the child).

After an extensive evaluation documented the effectiveness of the CMHS SOC, in 2011, SAMHSA funded widespread expansion of the SOC approach. For FY 2015, the awards to states are called grants for “Expansion and Sustainability of the Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances” and SAMHSA is planning to make 15-45 multi-year awards.

Beneficiaries:
Children under age 22 with a diagnosed serious emotional disturbance, and those with early signs and symptoms of serious mental illness including first episode of psychosis, and their families.

Funding:
Competitive discretionary cooperative agreements are granted to states, territories, political subdivisions of a State, such as county or local governments, and Indian tribal governments. The most recent round of cooperative agreements was awarded by the end of Federal FY 2015 for four years for up to $3 million each for states and $1 million for local governments and tribes and territories. Awardees of these cooperative agreements must provide at least a 33% match in the first three years and at least a 100% match for the fourth year.

Activities supported by the funding:
Cooperative agreements require grantees to implement certain key cross-agency administrative structures and procedures as well as an array of mental health and support services, in the least restrictive environment, which must include (but are not limited to):

- diagnostic and evaluation services;

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Federal Funding and Support Opportunities for Respite

- medication management;
- cross-system care management processes;
- development of individualized service plans that include participation of caregivers;
- provision of community-based counseling, consultation, and medication services;
- availability of emergency services;
- availability of intensive in-home services to prevent out-of-home placement;
- intensive day treatment services;
- respite care;
- therapeutic foster care and group homes;
- services for transition to adulthood; and
- family and youth advocacy and peer support services.

The new cooperative agreements are intended to help awardees focus on building sustainable SOCs through sustainable financing, cross-agency collaboration, the creation of policy and infrastructure, and the development and implementation of evidence-based and evidence-informed services and supports. In addition, this program encourages the implementation of strategies to decrease the difference in access, service use and outcomes among the racial and ethnic minority populations served. 32

Respite connection:
Respite is a core required service under this program.

Issues for consumers, providers, and advocates:
Children served under this program must have certain diagnosable emotional, socio-emotional, behavioral, or mental disorders and must have a reduced level of functioning in the family, school, or community.

Federal funding agency:
U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, Child, Adolescent and Family Branch.

Eligible entity:
States, political subdivisions within states, the District of Columbia, territories, Native American Tribes, and Tribal organizations.

Points of contact:
The Substance Abuse and Mental Health Services Administration website contains archived lists of previous years’ grantees. http://www.samhsa.gov/grants/awards

Related links:
Catalog of Federal Domestic Assistance: Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e5a8cc5eb2e47ce257e94b4be85d252e

References:


Child and Family Low-Income Assistance

Individuals and families experiencing job- and income-related challenges may be eligible to access respite services through child welfare and/or education, health, or mental health programs as described in the section Child Welfare and Child Abuse Prevention Programs. Additional sources of federal funding may be found through the Temporary Assistance for Needy Families Program (TANF), which provides financial and other assistance to families with children, and/or the Child Care and Development Fund (CCDF), designed to provide child care for low-income families.

These two programs are described under this heading.
Temporary Assistance for Needy Families (TANF) Program

Authorizing legislation:

Currently authorized through:
September 30, 2014.

Program purpose:
To assist families in need so that children can be cared for in their own home; to promote job preparation, work, and marriage in order to reduce dependency by needy parents; to prevent out-of-wedlock pregnancies; and to encourage the formation and maintenance of two-parent families.

Beneficiaries:
Families must be financially needy and have a minor child to qualify for assistance; states and tribal organizations determine the financial eligibility rules and benefit amounts. Some families have eligible children but the adults who care for their children are ineligible for aid. These are termed “child only” families because benefits are paid only on behalf of the children.

Funding:
Under this block grant program, states receive $16.5 billion each year, with the amount each state receives based on a formula determined by their peak expenditures for the period 1992 to 1995 (before enactment of TANF). States must spend 80% of their historic level of spending (FY 1994)—or 75% if they meet work participation requirements—on “qualified State expenditures” to meet the basic maintenance-of-effort (MOE) requirement. All MOE funds must be spent on TANF-eligible families.

Up to 30% of TANF funds can be transferred to the Child Care and Development Fund and the Social Services Block Grant combined; those funds become subject to the rules of the receiving grants and are not subject to TANF rules.

Activities supported by the funding:
States have broad flexibility to use the funds “in any manner that meets the purposes of the program.” States provide “assistance” in the form of direct payments to families that pay for basic needs such as food, clothing, shelter, utilities, household goods, personal care items, and other personal expenses. States can also provide “non-assistance” to families in the form of non-recurrent, short-term benefits, subsidized employment, and other ways.

Respite connection:
States can use TANF funds directly or through transfer to the Child Care and Development Fund (CCDF) to pay for child care. TANF can also directly cover child care expenditures for unemployed parents who need care to attend “other work activities such as job search, community service, education, or training, or for respite purposes.”33 In 2013, states spent 16 percent of total TANF and MOE funds on child care; 13 states spent less than 5 percent.34 TANF might also be used to provide funding for services, including

respite care, to prevent placement in foster care.  

Some families receive child-only TANF assistance, where aid is provided only to the child. These are generally families in which the child is eligible for aid, but living with a grandparent, parent, or other relative who is not. States may support respite care for these caregivers.

**Issues for consumers, providers, and advocates:**

- Families must include a resident minor child.
- Teenage parents must complete or be on the road to completing high school and must generally be living in an adult-supervised setting.
- Federal TANF funds cannot be used to provide medical services except for pre-pregnancy family planning.
- Recipients must work as soon as they are ready.
- Federal TANF assistance is limited to a maximum of 5 years (with exceptions related to domestic violence and living in Tribal areas). Up to 20% of a state’s caseload can receive assistance beyond the 5 years.
- Single parents with a child under age 6 cannot be penalized if they cannot find adequate child care.

Each state determines its own income eligibility standards and can set other conditions for eligibility as well as benefit amounts.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Children and Families, Office of Family Assistance.

**Eligible entity:**
States and federally recognized Tribes.

**Points of contact:**
Links to state agencies administering TANF programs are available at the Office of Family Assistance website.  [http://www.acf.hhs.gov/programs/ofa/help](http://www.acf.hhs.gov/programs/ofa/help)

**Related links:**
Catalog of Federal Domestic Assistance: Temporary Assistance for Needy Families. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e60f4dc146270477ed90dc979194282f](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e60f4dc146270477ed90dc979194282f)


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References

Child Care and Development Fund (CCDF)

Authorizing legislation:
Child Care and Development Block Grant Act of 1990 (CCDBG); Child Care and Development Block Grant Act of 2014, P.L. 113-186, Title IV of the Social Security Act, as amended.

Currently authorized through:

Program purpose:
The following program purposes were outlined in the 2014 reauthorization of CCDBG:

- to allow each State maximum flexibility in developing child care programs and policies that best suit the needs of children and parents within that State;
- to promote parental choice regarding the child care services that best suit their family’s needs;
- encourage States to provide consumer education information to help parents make informed choices about child care services and to promote involvement by parents and family members in the development of their children in child care settings;
- to assist States in delivering high-quality, coordinated early childhood care and education services to maximize parents’ options and support parents trying to achieve independence from public assistance;
- to assist States in improving the overall quality of child care services and programs;
- to improve child care and development of participating children; and
- to increase the number and percentage of low-income children in high-quality child care settings.36

Beneficiaries:
Children under age 13 (or, at the option of the grantee, up to age 19, if physically or mentally incapable of self-care or under court supervision) who reside with a family whose income does not exceed 85% of the state median income for a family of the same size, who reside with a parent (or parents) who is working or attending job training or an educational program, or who are in need of or are receiving protective services.

Funding:
The CCDBG authorizes Discretionary Fund formula grants that are subject to annual appropriation. States receive an amount calculated based on (1) the ratio of children under age 5 in the state to children under age 5 in the country, (2) the ratio of children in the state receiving free or reduced price lunches to the number of such children in the country, and (3) a factor determined by dividing the 3-year average national per capita income by the 3-year average state per capita income.

In addition, the Deficit Reduction Act of 2005 appropriated Mandatory Funds for FY 2006–2010 under the Social Security Act. States receive an amount based on federal share of expenditures in State IV-A

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After amounts are allocated to the states for the Mandatory Fund, the remaining appropriation is distributed on the basis of the number of children under age 13 in each state compared with the total number of children under age 13 in the country. States must match this amount by their applicable Medical Assistance Percentage rate.

**Activities supported by the funding:**
Funds are used to subsidize the cost of child care for children under the age of 13 (or, at the option of the grantee, up to age 19 if disabled or under court supervision). Subsidized child care services are available to eligible families through certificates or contracts with providers. A state must set aside a certain percentage CCDF funds to improve child care quality and availability through comprehensive consumer education, activities to increase parental choice, and other activities such as resource and referral services, provider grants and loans, monitoring and enforcement of requirements, training and technical assistance, and improved compensation for child care.

**Respite connection:**
New rules pursuant to the 2014 reauthorization of the program have not yet been promulgated. However, previous guidance from the U.S. Department of Health and Human Services indicated that “respite child care is allowable for only brief, occasional periods in excess of the normal ‘less than 24-hour period’ in instances where parent(s) of children in protective services—including foster parents where the Lead Agency has defined families in protective services to include foster care families—need relief from caretaking responsibilities . . . . If a State or Tribe uses CCDF funds to provide respite child care service (i.e., for more than 24 consecutive hours) to families receiving protective services . . . the CCDF Plan must include a statement to that effect in the definition of protective services.”

Further, this guidance states that “since respite care is provided to give parents time off from parenting, rather than care to allow the parent to participate in work or in education or training, the CCDF cannot be used for respite care for children with disabilities unless the child also needs or is receiving protective services.”

**Example:** Louisiana’s CCDF lead agency partners with the child welfare agency to provide respite services to children in protective care. Protective care is defined under these circumstances as services offered to individuals under 13 years of age who are in danger of or threatened with abuse, neglect, or exploitation, or who are without proper custody or guardianship, and for whom the need for child care services has been determined by the State agency responsible for the provision of abuse and neglect complaint investigations. Children in foster care are also considered to be in protective services.


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38 Ibid.
CCDF funds can also be used for training and professional development of early childhood and school age child care providers. The 2014 reauthorization requires the inclusion of a focus on children with disabilities in all training and professional development supported by the CCDF. States may extend professional development opportunities to other providers, including respite providers.

Example: Using CCDF quality improvement funds, the Alabama Child Care and Education Professional Development System widely disseminated its Alabama Pathways to Quality Care and Education plan brochure to nontraditional caregivers such as homeschoolers, nannies, and respite providers.


Issues for consumers, providers, and advocates:

- These discretionary funds must be used to supplement, not supplant, state general revenue funds for child care assistance for low-income families.
- Grantees must give parents the option of receiving vouchers or certificates to allow parents the choice of faith-based or community child care providers.
- Discretionary funds cannot be used for students in grades 1 through 12 during the regular school day; for any services for which such students receive academic credit toward graduation; or for any instructional services that supplant or duplicate the academic program of any public or private school.
- States must use all allocated funds within prescribed time limits.

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Care.

Eligible entity:
State child care agency.

Points of contact:
**Related Links:**
Catalog of Federal Domestic Assistance: Child Care and Development Block Grant.  
[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=9386203db5577233ae9ce36e9f90e5](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=9386203db5577233ae9ce36e9f90e5)

Resources related to the 2014 reauthorization of the Child Care Development Fund can be found on the Office of Child Care website.  

**References:**
[https://www.acf.hhs.gov/sites/default/files/occ/occ_reauthorization_webinar.pdf](https://www.acf.hhs.gov/sites/default/files/occ/occ_reauthorization_webinar.pdf)


Federal Funding and Support Opportunities for Respite

Programs Serving Multiple Age Groups

Some federal funding sources support the use of respite care for both children (generally under the age of 18) and adults, including the aging population. The aging population may not be explicitly stated as eligible, but they are not excluded from eligibility in the programs included in this section.

Several federal block grants may be a source of funding for respite for children or adults:

- **Community Mental Health Services Block Grant**,
- **Community Development Block Grant (CDBG)**,
- **Social Services Block Grant (SSBG)**.

States have a great deal of flexibility in administering block grants. The last two programs—the Social Services and Community Development Block Grants—focus on providing services for low-income and vulnerable populations, but few other restrictions apply.

The Community Mental Health Services Block Grant is restricted to serving individuals with mental health conditions. In addition, the following discretionary grant programs are focused on a specific disability population, which may span across ages:

- **Developmental Disability Councils Programs** under the Developmental Disability Assistance and Bill of Rights Act (DD Act) of 2000;
- **Centers for Independent Living (CIL)** under the Rehabilitation Act of 1973 for individuals with significant disabilities who need assistance to live independently in the family or community; and
- **HIV Care Formula Grants** and **HIV Emergency Relief Projects Grants** designed to provide assistance to individuals with HIV/AIDS.

**Supplemental Security Income (SSI)**, administered by the Social Security Administration, provides direct cash assistance to the aging population as well as children and adults who have severe visual impairments or other disabilities. Individuals or families may use this cash assistance to pay for respite.

Several programs administered by the Corporation for National and Community Service have the potential to provide volunteers who may provide respite for certain populations of family caregivers:

- **National Senior Service Corps:***
  - **Senior Companion Program (SCP),**
  - **Foster Grandparent Program (FGP),**
  - **Retired and Senior Volunteer Program (RSVP),** and

- **AmeriCorps**

**Aging and Disability Resource Centers (ADRCs)** are required partners in Lifespan Respite Programs and support respite in various capacities in partnership with Lifespan Respite systems.

The **National Family Caregiver Support Program (NFCSP)** provides respite funding that specifically addresses respite for caregivers (55 or 60 and older) of children, adults, and the aging population.

**The Lifespan Respite Care Program**, described in detail in the preface, has as its primary purpose the coordination of all federal and state respite funding streams in order to improve access to respite for all family caregivers regardless of the age or disability of the care recipient.
Community Development Block Grant (CDBG)

**Authorizing legislation:**
Title 1 of the Housing and Community Development Act of 1974, P.L. 93-383, as amended.

**Program purpose:**
To enable local governments to undertake a wide range of activities intended to create suitable living environments, provide decent affordable housing, and create economic opportunities, primarily for persons with low and moderate income.

**Beneficiaries:**
The principal beneficiaries of CDBG funds are low- and moderate-income persons (generally defined as a member of a family having an income equal to or less than the Section 8 low-income limit established by the Department of Housing and Urban Development [HUD]). The recipient must certify that at least 70% of the grant funds received during a 1-, 2-, or 3-year period, which it designates, are expended for activities that will principally benefit low- and moderate-income persons.

**Funding:**
HUD, which administers the block grant, determines the amount of each grant by using a formula that includes several measures of community need—the extent of poverty, population, housing overcrowding, age of housing, and population growth lag in relationship to that of other metropolitan areas. CDBG Entitlement Communities Grants provide annual grants on a formula basis to entitled cities and counties. To receive its annual CDBG entitlement grant, a grantee must develop and submit its Consolidated Plan to HUD.

Congress amended the Housing and Community Development Act of 1974 (HCD Act) in 1981 to give each state the opportunity to administer CDBG funds for non-entitlement areas. Non-entitlement areas include those units of general local government that do not receive CDBG funds directly from HUD as part of the CDBG Entitlement Program (Entitlement Communities). Non-entitlement areas are cities with populations of less than 50,000 (except cities that are designated principal cities of metropolitan statistical areas) and counties with populations of less than 200,000.

**Activities supported by the funding:**
CDBG funds may be used for activities that include, but are not limited to

- acquisition of real property;
- relocation and demolition;
- rehabilitation of residential and nonresidential structures;
- construction of public facilities and improvements, such as water and sewer facilities, streets, neighborhood centers, and the conversion of school buildings for eligible purposes;
- public services, within certain limits;
- activities relating to energy conservation and renewable energy resources; and
- provision of assistance to profit-motivated businesses to carry out economic development and job creation and job retention activities.

**Respite connection:**
Respite is not specifically mentioned, but funding is allowable as a public service.
Issues for consumers, providers, and advocates:
A grantee must develop and follow a detailed plan that provides for and encourages citizen participation and that emphasizes participation by persons of low or moderate income, particularly residents of predominantly low- and moderate-income neighborhoods, slum or blighted areas, and areas in which the grantee proposes to use CDBG funds. The plan must

- provide citizens with reasonable and timely access to local meetings, information, and records related to the grantee’s proposed and actual use of funds;
- provide for public hearings to obtain citizen views and to respond to proposals and questions at all stages of the community development program, including at least the development of needs, review of proposed activities, and review of program performance;
- provide for timely written answers to written complaints and grievances; and
- identify how the needs of non–English-speaking residents will be met in the case of public hearings in which a significant number of non–English-speaking residents can be reasonably expected to participate.

Federal funding agency:
U.S. Department of Housing and Urban Development, Office of Community Planning and Development

Eligible entity:
For entitlement grants, entities eligible for annual grants are

- principal cities of metropolitan statistical areas (MSAs).
- other metropolitan cities with populations of at least 50,000, and
- qualified urban counties with populations of at least 200,000 (excluding the population of entitled cities).

For non-entitlement grants, the eligible agency is the state.

Points of contact:
U.S. Department of Housing and Urban Development (HUD)
Office of Community Planning and Development
451 7th Street SW, Room 7282
Washington, DC 20410
Phone: 202-402-3416; fax: 202-401-2044

HUD Regional Field Offices can be found at:
https://www.hudexchange.info/manage-a-program/cpd-field-office-directory

CDBG contacts by state can be found at:

Related links:
Catalog of Federal Domestic Assistance: Community Development Block Grants.
https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=5db773b6a126bff84884a423f66e9576
U.S. Department of Housing and Urban Development, *State Community Development Block Grant Program*.  

*References:*  
https://www.hudexchange.info/community-development/cdbg-laws-and-regulations
Social Services Block Grant (SSBG)

Authorizing legislation:
Title XX of the Social Security Act, as amended.

Program purpose:
To furnish social services best suited for meeting the needs of the individuals residing within each state.

Services funded are directed at one or more of five goals:

- achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency;
- achieving or maintaining self-sufficiency, including reduction or prevention of dependency;
- preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating, or reuniting families;
- preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care; and/or
- securing referral or admission for institutional care when other forms of care are not appropriate or providing services to individuals in institutions.

Beneficiaries:
Under Title XX, each eligible jurisdiction determines the services that will be provided and the individuals who will be eligible to receive services.

Funding:
This is a block grant. Funding is authorized in the amount of $1.7 billion per fiscal year.

Activities supported by the funding:
Services provided may include, but are not limited to,

- daycare for children or adults,
- protective services for children or adults,
- special services for persons with disabilities,
- adoption,
- case management,
- health-related services,
- transportation,
- foster care for children or adults,
- substance abuse treatment,
- housing, home-delivered meals,
- independent/transitional living,
- employment services, or
- other social services found necessary by the state for its population.
Respite connection:
Respite and crisis care are accepted Social Services Block Grant (SSBG) services and could be related to any of the five program goals listed above.

Specifically for individuals with disabilities, the SSBG program provides flexible funds that states can use to maximize the potential of persons with disabilities; help alleviate the effects of physical, mental, or emotional disabilities; and enable people to live in the least restrictive environment possible. Component services or activities include:

- personal and family counseling,
- respite care,
- family support,
- recreation,
- transportation,
- assistance with independent functioning in the community,
- training in mobility and communication skills,
- training in the use of special aids and appliances, and
- self-sufficiency skills development.  

During Federal FY 2012, 21 states reported spending approximately $308 million in SSBG funds (11% of all SSBG expenditures) for services for individuals with disabilities, down from $375 million in 2008. The number of recipients of these services decreased from 1.3 million in 2005 to 891,800 individuals (31% children, 69% adults) in FY 2012. At the same time, expenditures for individuals with disabilities remained the third largest of all service categories in Federal FY 2012.

Great variability exists among States that reported any SSBG expenditures for services for individuals with disabilities. As a percentage of their total SSBG expenditures used for this purpose, the range was from zero to 62%. Four states used more than 25% of their total SSBG expenditures for special services for individuals with disabilities—Montana (62%), Georgia, (53%), California (45%), and Iowa (42%).

SSBG expenditures accounted for 66% of the total expenditures for adult day care services, 49% of the total expenditures for special services for youth at risk, and 46% of the total expenditures for adult protective services.

Most relevant to respite are home-based services which accounted for $155 million in SSBG expenditures by 31 states. Four States reported using more than 25% of their SSBG expenditures for this service—Illinois (49%), New Hampshire (34%), South Dakota (27%), and Texas (26%). Approximately 255,000 individuals (29% children, 71% adults) benefited from home-based services funded by the SSBG program.

40 Ibid.
41 Ibid.
**Federal Funding and Support Opportunities for Respite**

**Example:** The Indiana Family and Social Services Administration (FSSA), Division of Aging uses the Social Services Block Grant (SSBG) to fund a number of different in-home, community-based, and facility-oriented services targeted for low-income older adults and persons with disabilities, including adult day services and respite. Respite can include in-home respite (personal care, homemaker, and others), respite provided by attendance of the client at a senior center or other non-residential program and institutional respite which is provided by placing the resident in a non-institutional setting such as a nursing facility for a short period of time as a respite service for the caregiver, or a summer camp in the case grandparents caring for children.

*Source:* Indiana Family and Social Services Administration, *Social Services Block Grant.*
[http://www.in.gov/fssa/da/3471.htm](http://www.in.gov/fssa/da/3471.htm)

**Example:** The two major funding streams used for in-home respite services in Missouri are Medicaid and the Social Services Block Grant/General Revenue. Respite is defined as providing temporary relief for the caregiver of a dependent adult and includes 1) Basic – provided to participants with non-skilled needs; 2) Advanced - provided to participants with special care needs requiring a higher level of oversight; and 3) Nurse - provided to participants with skilled nursing needs.


**Issues for consumers, providers, and advocates:**
States receive these funds with few strings attached. The annual allotments are noncompetitive, 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.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Children and Families.

**Eligible entity:**
States.

**Points of contact:**
A list of SSBG state officials and program contacts can be found on the U.S. Department of Health and Human Services website.

**Related links:**
Catalog of Federal Domestic Assistance: Social Services Block Grant.
[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e6579a9c07c3fc07fc67f39e649c4a17](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=e6579a9c07c3fc07fc67f39e649c4a17)

U.S. Department of Health and Human Services: *Social Services Block Grant (SSBG) Program.*

**References:**
Community Mental Health Services Block Grant

Authorizing legislation:
Title XIX, Part B, Subpart I and III of the Public Health Service Act, as amended by The Children’s Health Act of 2000, P.L. 106-310.

Currently authorized through:
September 30, 2003. Congress has continued to appropriate funds annually for this program.

Program purpose:
To assist states in carrying out a plan for providing comprehensive community mental health services to adults with a serious mental illness and to children with a serious emotional disturbance.

Beneficiaries:
Adults with a serious mental illness and children with a serious emotional disturbance.

Funding:
These grants are awarded under a complex formula, with a minimum allocation based on 1998 funding levels.

Activities supported by the funding:
• Mental health services, which must be provided only through appropriate, qualified community programs.
• Up to 5% of grant funds may be used for administering the funds.
• Funds may not be used for inpatient services, for cash payments to intended recipients of health services, or for provision of financial assistance to any entity other than a public or nonprofit private entity.

Respite connection:
Funding for respite and crisis care may be included as support services for children’s mental health services, crisis prevention and early intervention services, and crisis intervention services as part of state’s comprehensive mental health service plan.

Issues for consumers, providers, and advocates:
States are required to submit an application that contains a state plan that describes comprehensive community mental health services for adults with a serious mental illness and children with a serious emotional disturbance, an implementation report that describes state progress in implementing the plan for the preceding year, recommendations from the State Mental Health Planning Council, a report on expenditures of the preceding fiscal year’s block grant funds, a report on maintenance of effort, and agreements signed by the chief executive officer of the state. Consumers and family members must comprise at least 51% of this Planning Council.

Federal funding agency:
U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Eligible entity:
State mental health agencies.
Points of contact:
Contact information for each state’s mental health agency.
http://www.samhsa.gov/grants/block-grants/contacts

Related links:
Catalog of Federal Domestic Assistance: Block Grants for Community Mental Health Services.
https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=d6d364841a352bedfcef4a4e2030f08a

References:

http://www.mentalhealthamerica.net/sites/default/files/How_State_Mental_Health_Agencies_Use_the_Community_Mental_Health_Services_Block_Grant_to_Improve_Care_and_Transform_Systems.pdf

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. Community Mental Health Services Block Grant.
http://www.samhsa.gov/grants/block-grants/mhbg

Developmental Disabilities Councils

Authorizing legislation:

Currently authorized through:
September 30, 2007. Congress has continued to appropriate funds annually for the DD Act.

Program purpose:
To develop plans to establish and improve services for individuals with developmental disabilities through systems change.

Beneficiaries:
Basic program benefits individuals with developmental disabilities. Developmental disability is defined as a severe chronic disability of an individual that is attributable to mental, physical, or a combination of impairments; that is manifested before age 22; that is likely to continue indefinitely; that results in substantial functional limitations in three or more major life activities (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency); and that reflects an individual’s lifelong need for services. Infants and children from birth to age 9 inclusive are included if they have a developmental delay or condition with a high probability of resulting in developmental disabilities if services are not provided.

Funding:
State councils receive formula grants based on state population, the extent of needs for services for individuals with developmental disabilities, and the financial need of the state.

Activities supported by the funding:
The focus is on changing systems rather than on providing direct services.

Respite connection:
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, temporary emergency funds to help respite providers stay in business, or support for state respite coalitions and their activities.

Example: The Alabama Lifespan Respite Network used grant funds from the Alabama Developmental Disabilities Council to expand its Sharing the Care respite initiative into four areas of Alabama: Mobile, Montgomery, Selma, and Dothan. Sharing the Care is a proven grassroots effort to expand Alabama Lifespan Respite’s mission “to increase access to and availability of quality respite services for caregivers in Alabama.” The project brings together an advisory council of volunteers in localized areas who are interested in working together to expand the community’s respite resources.

Source: Alabama Lifespan Respite Network, Sharing the Care.
http://alabamarespite.org/index.php/get-involved/sharing-the-care
**Issues for consumers, providers, and advocates:**
States submit 5-year plans describing other federally funded programs that provide services to individuals with developmental disabilities; the extent to which such individuals are helped by existing programs; and plans for advocacy, capacity building, and systemic change related to unmet needs of those individuals.

At least 60% of the Council must consist of individuals with developmental disabilities, parents or guardians of children with developmental disabilities, or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disabilities, Administration on Intellectual and Developmental Disabilities

**Eligible entity:**
Designated state agency.

**Points of contact:**
An interactive map providing links to each state’s Council can be found on the National Association of Councils on Developmental Disabilities website.

**Related links:**
Catalog of Federal Domestic Assistance: Developmental Disabilities Basic Support and Advocacy Grants.
[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=d70981b6defbb7f6755f92a5aa8f9c89](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=d70981b6defbb7f6755f92a5aa8f9c89)

**References:**

Centers for Independent Living (CILs)

**Authorizing legislation:**

**Currently authorized through:**
September 30, 2020

**Program purpose:**
To provide independent living (IL) services to individuals with significant disabilities to help them function more independently in family and community settings by developing and supporting a statewide network of Centers for Independent Living (CILs).

**Beneficiaries:**
Individuals with significant disabilities, as defined in Section 7 of the Rehabilitation Act and 34 CFR 364.4 of the IL program regulations. This refers to an individual with a severe physical, mental, cognitive, or sensory impairment whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of IL services will improve the ability to function, continue functioning, or move toward functioning independently in the family or community or to continue in employment.

**Funding:**
Competitive, discretionary grants are awarded on a formula based on population and availability of funds.

**Activities supported by the funding:**
At a minimum, centers funded by the program are required to provide the following five IL core services: information and referral; skills training; peer counseling; Individual and systems advocacy; and services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life. Centers also may provide other services necessary to improve the ability of individuals with significant disabilities to function independently in the family or community and/or to continue in employment.

Establishment and operation of CILs that offer a combination of services, including independent living core services such as:

- information and referral services,
- training in independent living skills,
- peer counseling,
- individual and systems advocacy,
- services that facilitate transition from nursing homes and institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life, and
- other appropriate independent living services.
Respite connection:
Respite is not specifically mentioned as an allowable activity under this legislation. However, Title II of the Act includes in its discussion of “covered activities” demonstration and other projects that “maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities.” Respite is often included in the category of family support in federally funded programs.

Instructions for completion of an annual performance report required of CILs specifically state that family services necessary for improving an individual’s ability to live and function more independently or to engage or continue in employment may include respite care.\(^2\) In some instances, CILs are important partners in providing access to respite.

Issues for consumers, providers, and advocates:
States submit a State Plan for Independent Living (SPIL) every 3 years. The SPIL details the activities the state plans to achieve. Eligible entities for CIL funding must be consistent with the design for establishing a statewide network of centers in the most recently approved state plan in their states.

A CIL is defined as a “consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services.”

Each center must have a governing board composed of a majority of persons with significant disabilities. The majority of the staff and individuals in decision-making positions must be individuals with disabilities.

All CILs funded by the end of FY 1997 were grandfathered in to continuing funding for as long as they continue to meet program and fiscal standards and assurances. New CILs are funded when sufficient funds are appropriated to do so.

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disabilities, Independent Living Administration

Eligible entity:
Nonprofit organizations. Consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies are eligible to apply. Only eligible agencies from states and territories holding competitions may apply.

Points of contact:
An interactive map linking to each state’s CILs can be found on the Independent Living Research Utilization website.

Related links:
Catalog of Federal Domestic Assistance: Centers for Independent Living.
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=8c3d48298040ae301601bc6fface93da

National Council on Independent Living
http://www.ncil.org/

References:

HIV Care Formula Grants

**Authorizing legislation:**

**Currently authorized through:**
September 30, 2013. Congress has continued to appropriate funds annually for this program.

**Program purpose:**
To improve the quality, availability, and organization of health care and support services for individuals with HIV and their families.

**Beneficiaries:**
Individuals and families with HIV disease.

**Funding:**
Grants, which include a base grant, a drug assistance program award, a drug assistance supplemental grant, and grants to states for Emerging Communities, are made under a formula involving the number of cases of AIDS.

**Activities supported by the funding:**
Seventy-five percent of the base grant funds are to be used for core medical services and 25% for support services. Support services are intended to facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services for individuals with HIV and their families. This includes respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referral for health care and support services.

This funding also covers the establishment and operation of HIV care consortia, health insurance coverage, and outreach activities.

**Respite connection:**
Respite is a core service covered by this funding.

**Issues for consumers, providers, and advocates:**
Providers of services may include both public and nonprofit entities. For-profit entities may receive funding only if they are the sole area providers of quality HIV care. States may provide services directly or subcontract with HIV care consortia.

**Federal funding agency:**
US Department of Health and Human Services, Health Resources and Services Administration.

**Eligible entity:**
State public health agency.

**Points of contact:**
A link to each state’s HIV/AIDS program grantee can be found on the Health Resources and Services Administration, HIV/AIDS Bureau website, [https://careacttarget.org/grants/59](https://careacttarget.org/grants/59)
Related links:
Catalog of Federal Domestic Assistance: HIV Care Formula Grants.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=0b51831d19acdfed5f622ba0e5d763af

U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau,
http://hab.hrsa.gov/

References:
U.S. Department of Health and Human Services, Health Resources and Service Administration, HIV/AIDS Bureau. Ryan White Part B.
http://hab.hrsa.gov/abouthab/partbdrug.html

HIV Emergency Relief Projects Grants

Authorizing legislation:
Title XXVI, Part A, of the Public Health Service Act; Title XXVI, Part A, as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 11-87)

Currently authorized through:
September 30, 2013. Congress has continued to appropriate funds annually for this program.

Program purpose:
To help areas most severely affected by HIV develop, organize, and operate programs that provide an efficient, appropriate, and cost-effective continuum of health care and support services for individuals and families with HIV disease.

Beneficiaries:
Individuals and families with HIV disease.

Funding:
Grants are made under a formula involving the number of cases of AIDS.

Activities supported by the funding:
Seventy-five percent of grant funds are to be used for core medical services and 25% for support services. Support services are intended to facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services for individuals with HIV and their families. This includes respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referral for health care and support services.

Respite connection:
Respite is a core service covered by this funding.

Issues for consumers, providers, and advocates:
Eligible Metropolitan Areas (EMAs) must have reported more than 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. Transitional Grant Areas (TGAs) must have reported at least 1,000 but fewer than 2,000 new AIDS cases in the most recent 5 years. Currently, 22 EMAs and 34 TGAs are receiving funding. Each EMA must have an HIV/AIDS Planning Council whose membership must reflect the local epidemic demographically and include members with specific expertise in health-care planning, housing for the homeless, health care for incarcerated populations, and substance abuse and mental health treatment or members who represent other Ryan White and Federal programs. The Planning Council works with the local elected official to develop the needs assessment and plan allocation of Part A resources.

Federal funding agency:
U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau.

Eligible entity:
EMAs with a population of 50,000 or more individuals for which the Centers for Disease Control and Prevention has reported a cumulative total of at least 2,000 HIV/AIDS cases for the most recent 5-year period. TGAs with a population of 50,000 or more individuals for which the Centers for Disease
Control and Prevention has reported a cumulative total of at least 1,000 but not more than 1,999 HIV/AIDS cases for the most recent 5-year period. Grants are awarded to the chief elected official (CEO) of the city or county that provides health care services to the greatest number of people living with AIDS in the EMA or TGA.

**Points of contact:**
A list of Part A EMAs and TGAs receiving this funding is on the Health Resources and Services Administration, HIV/AIDS Bureau website.

**Related links:**
Catalog of Federal Domestic Assistance: HIV Emergency Relief Project Grants.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=3cd8495bc4ddacc07fe6e692dda9a25e

**References:**
http://hab.hrsa.gov/abouthab/parta.html

Supplemental Security Income (SSI)

Authorizing legislation:
Title XVI of the Social Security Act, as amended.

Program purpose:
To supplement the income of needy individuals who are 65 or older, blind, or disabled. The Supplemental Security Income (SSI) for Children provides SSI for children under age 18 or under age 22 and is a student regularly attending school.

Beneficiaries:
Individuals who have attained age 65 or are blind or disabled, who continue to meet the income and resources tests, citizenship/qualified alien status, residence in the United States, and certain other requirements. Eligibility may continue for beneficiaries who engage in substantial gainful activity despite disabling physical or mental impairments. For a child to be eligible for SSI, they must be either blind or disabled and meets the SSI income and resource requirements after deductions are made from deemed income for parents and other children living in the home.

Funding:
This is a cash benefit program. The benefit amount increases automatically when the Consumer Price Index rises; generally the amount increases each year. There was no increase in 2010. The 2010 federal benefit is $674 for an individual and $1,011 for a couple.

Activities supported by the funding:
Direct monthly payments are available for unrestricted use for those with incomes and resources below certain levels who are blind, disabled, or age 65 or older or are eligible for the SSI Program for Children.

Respite connection:
SSI benefits may be used by family caregivers to pay for respite care.

Issues for consumers, providers, and advocates:
Proof of age, marital status, income, and resources; establishment of blindness or disability; and proof of residence in the United States and U.S. citizenship or alien status are required.

To qualify as having a disability, a person under age 18 must have a medically determinable physical or mental condition or other conditions that result in marked and severe functional limitations and can either be expected to result in death or which has lasted or can be expected to last at least 1 year. A person age 18 or older is considered to have a disability if he or she has a medically proven physical or mental condition that results in the inability to do any substantial gainful activity and can either be expected to result in death or which has lasted or can be expected to last at least 1 year.

Because of their limited income, most families caring for a person with a disability who qualify for SSI have too many other expenses to have money left over for purchase of respite care services.

Most states43 provide supplementary payments above the federal amount. In ten states (California, Delaware, Hawaii, Iowa, Montana, Nevada, New Jersey, Pennsylvania, Rhode Island, and Vermont) and the District of Columbia, state supplements are administered by the Social Security Administration. In other states, a separate application must be made to the state agency. 

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43 States or territories that do not provide any supplement are Arizona, Mississippi, North Dakota, Northern Mariana Islands, West Virginia.
Federal funding agency:
Social Security Administration.

Eligible entity:
Individuals who are aged, blind, or have a disability and who meet the income, resource, citizenship, and residency requirements of the law.

Points of contact:
Social Security Administration
Toll-free telephone number: 1-800-772-1213 TTY number: 1-800-325-0778

Locations of Social Security offices can be found on the Social Security Administration website.
https://secure.ssa.gov/apps6z/FOLO/fo001.jsp

Related links:
Catalog of Federal Domestic Assistance: Supplemental Security Income.
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=9022644a6b91ac724ab063c420d504de

References:
Social Security Administration: Supplemental Security Income (SSI).
http://www.socialsecurity.gov/pgm/links_ssi.htm

National Senior Service Corps - Senior Companion Program (SCP)

Authorizing legislation:

Currently authorized through:
September 30, 2014. Congress has continued to appropriate funds for this program.

Program purpose:
To give older volunteers opportunities to provide critical support services and companionship to adults at risk of institutionalization and who are struggling to maintain a dignified independent life.

Beneficiaries:
Senior companions must be 55 years of age or older, with an income of up to 200% of poverty, based on the U.S. Department of Health and Human Services Poverty Guidelines; interested in serving special-needs adults, especially the frail elderly; and must be physically, mentally, and emotionally capable and willing to serve on a person-to-person basis. However, individuals who are not eligible because of their income may serve as non-stipended volunteers under certain conditions. Recipients are individuals with special needs age 21 and older, the frail elderly, and their informal caregivers.

Funding:
Competitive project grants are awarded, when available, to eligible entities for the support of SCPs. Grants are generally funded for 3 years in 1-year increments. The most recent annual statistical highlights from FY 2010-11: With annual federal funding of $46 million, 13,600 volunteers provided 12.2 million hours of service in 220 projects. Nearly 8000 family caregivers received respite from Senior Companion Program volunteers.

Activities supported by the funding:
Funds may be used for volunteer stipends, transportation, physical examinations, insurance, and meals. They may also be used for staff salaries and fringe benefits, travel, equipment, and space costs. Volunteers are engaged in providing companionship services to special-needs individuals age 21 or older and especially to the frail elderly.

Respite connection:
A volunteer may provide respite services to the caregiver of an adult with special needs by taking over companionship services to allow the caregiver to have a break. Respite care is listed as an appropriate activity in the Senior Companion Program Operations Handbook.

Issues for consumers, providers, and advocates:
Volunteers must serve from 15 to 40 hours per week in person-to-person relationships with the individuals served. Respite programs funded through this initiative participate in national performance measurement using CNCS’ Performance Measurement framework. CNCS has a focused set of agency-wide Priority Measures derived from the 2011-2015 Strategic Plan.

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**Federal funding agency:**
Corporation for National and Community Service.

**Eligible entity:**
State and local government agencies, nonprofit organizations.

**Points of contact:**
Organizations interested in exploring the possibility of developing a local Senior Companion project should contact the Corporation for National and Community Service State Program Office serving their state. Contact information for those offices is available on the Corporation for National and Community Service website.

[http://www.nationalservice.gov/stateoffices](http://www.nationalservice.gov/stateoffices)

Individuals interested in volunteering can search for an SCP in their state on the Corporation for National and Community Service website.

[http://www.nationalservice.gov/programs/senior-corps/senior-companions](http://www.nationalservice.gov/programs/senior-corps/senior-companions); or


Individuals wanting to receive services from an SCP can locate a program in their state on the Corporation for National and Community Service website.


**Related links:**
Catalog of Federal Domestic Assistance: Senior Companion Program.

[https://www.cfda.gov/index?s=program&mode=form&tab=core&id=a5f093223e2978055632946fe669b8c1](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=a5f093223e2978055632946fe669b8c1)

**References:**
Federal regulations for Senior Companion Program (Title 25, Subpart B, Chapter XXV, Part 2551)

[http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&sid=99f8e15d953a2684bc6267b117b9713a&rgn=div5&view=text&node=45:4.1.9.11.33&iddo=45](http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&sid=99f8e15d953a2684bc6267b117b9713a&rgn=div5&view=text&node=45:4.1.9.11.33&iddo=45)


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*Example: The Tennessee Respite Coalition (TRC) is the sponsor organization for the Senior Companion Program in Davidson County, TN. It is one of the smaller grants of the Corporation for National and Community Service (CNCS) program supporting 12 Volunteer Service Years (VSY) with $48,276 annually. The TRC also has secured funding to support additional program costs from a local foundation. CNCS established new performance measures for the Senior Companion Program in 2013 that specifically include respite for caregivers. Through this initiative, the individual with the disability receives companionship, the family caregiver receives a well-deserved break from the stress of caregiving, and the volunteer reaps the benefits and satisfaction of being of service to their community as well as a monetary stipend.

Source: Personal communication (October 2015) with Jennifer Abernathy, Executive Director, Tennessee Respite Coalition (www.tnrespite.org).*
National Senior Service Corps - Retired and Senior Volunteer Program (RSVP) and the Foster Grandparent Programs

Authorizing legislation:

Currently authorized through:
September 30, 2014. Congress has continued to appropriate funds for these programs.

Program purpose:
The Corporation for National and Community Service (CNCS) oversees the National Senior Service Corps. The Senior Service Corps includes: 1) the Senior Companion Program (SCP; described above), 2) the Retired and Senior Volunteer Program (RSVP), and 3) the Foster Grandparent Program (FGP). The purpose of all three programs is to provide opportunities for senior service to meet unmet needs, to empower people 55 years or older to contribute to their communities, enhancing the lives of those who serve and those whom they serve, and provide communities with valuable services. The specific purpose of RSVP is to provide opportunities for older volunteers to share their knowledge, experiences, abilities, and skills for the betterment of their communities and themselves. The specific purpose of the FGP is to provide opportunities for older volunteers to have a positive impact on the lives of children in need.

Beneficiaries:
Older volunteers serve children, adults, and the aging population in volunteer service.

Funding:
Grant awards are generally for 3 years, with funding provided in 1-year increments. SCP, RSVP, and FGP have separate funding streams, and existing projects receive a one-third set-aside from any funding increases under Programs of National Significance.

Activities supported by the funding:
FGP grants may be used for low-income foster grandparent stipends, transportation, physical examinations, and meals. They may also be used for staff salaries, fringe benefits, staff travel, equipment, and space costs. Foster grandparents may be assigned to children and youth in residential and nonresidential facilities, including schools and preschools, and to children living in their own homes.

RSVP grants may be used to assist all volunteers age 55 or older who want to find challenging, rewarding, and significant service opportunities in their local communities.

Respite connection:
A particular focus of the Corporation’s Baby Boomer initiative is to increase the number of frail elderly people and people with disabilities who receive assistance from the community who are able to live independently. All of the programs under the Corporation’s authority are being encouraged to increase the capacity of their communities to provide services, such as respite, that will reduce the need for expensive professional in-home care or nursing home care.

FGP is authorized to provide supportive, person-to-person services to children “having special or exceptional needs or with conditions or circumstances identified as limiting their academic, social, or economic development.” The Foster Grandparent’s Handbook addresses respite specifically. On rare occasions, it may be in the best interest of the child for a foster grandparent to provide in-home respite care without the primary caregiver being present. The volunteer station’s professional staff and the sponsor should jointly make this determination. Respite assignments should be carefully and frequently
monitored to ensure the safety and well-being of the child and the volunteer. Project staff should ensure that respite care is consistent with the purposes of the FGP.

RSVP volunteers serve through nonprofit and public organizations. They organize neighborhood watch programs, tutor children and teenagers, renovate homes, teach English to immigrants, teach computer software applications, help people recover from natural disasters, serve as museum docents, and do whatever else their skills and interests lead them to do to meet the needs of their community. Such services could include providing respite for family caregivers.

**Issues for consumers, providers, and advocates:**
Foster grandparents must be 55 years of age or older, with an income of up to 200% of poverty, and must be interested in serving infants, children, and youth with special or exceptional needs. (However, individuals who are not income eligible may serve as non-stipended volunteers under certain conditions.) Foster grandparents must be physically, mentally, and emotionally capable and willing to serve selected infants, children, or youth on a person-to-person basis.

**Federal funding agency:**
Corporation for National and Community Service.

**Eligible entity:**
National and local nonprofits, schools, government agencies, and faith-based and other community organizations and other groups committed to strengthening their communities through volunteering. Qualified agencies and organizations with the capacity to operate direct community service programs, experience and interest in the needs of older adults, and the ability to develop strong community financial and programmatic support.

**Points of contact:**
Foster Grandparent and RSVP programs and volunteer opportunities can be found by state at:
http://www.nationalservice.gov/impact-our-nation/state-profiles

**Related links:**
Catalog of Federal Domestic Assistance: Retired and Senior Volunteer Program (RSVP).
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=7d77bd00266a5c14bf13c06a488cf49e

Catalog of Federal Domestic Assistance: Foster Grandparent Program.
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=025f63bc5308acb4d7b87491083bdeed

Corporation for National and Community Service, RSVP
http://www.nationalservice.gov/programs/senior-corps/rsvp

Corporation for National and Community Service, Foster Grandparent Program
http://www.nationalservice.gov/programs/senior-corps/foster-grandparents

**References:**

AmeriCorps

Authorizing legislation:

Currently authorized through:
September 30, 2014. Congress has continued to appropriate funds annually for this program.

Program purpose:
Began in 1994, the AmeriCorps programs provide opportunities for Americans to make an intensive commitment to service. Members serve their communities through three programs:

- AmeriCorps*State and National, is the broadest network of AmeriCorps programs. It provides financial support through grants to public and nonprofit organizations that sponsor service programs around the country, including hundreds of faith-based and other community organizations, higher education institutions, Indian Tribes, and public agencies.
- AmeriCorps*VISTA (Volunteers in Service to America) provides full-time members to nonprofit, faith-based and other community organizations, and public agencies to create and expand programs that bring low-income individuals and communities out of poverty.
- AmeriCorps*NCCC (National Civilian Community Corps) is a full-time, team-based, residential program for men and women ages 18–24. Members live on one of five campuses, located in Denver, Colorado; Sacramento, California; Baltimore, Maryland; Vicksburg, Mississippi; and Vinton, Iowa.

Beneficiaries:
Beneficiaries must be identified with an application for assistance.

Funding:
AmeriCorps grant funding is distributed to Governor-appointed State Commissions and multi-state grantees. State Commissions award subgrants to organizations in their states, and the multi-state grantees work through operating sites in more than one state. These organizations recruit AmeriCorps members to respond to local needs.

AmeriCorps State and National Direct grants, the AmeriCorps program most likely to support the provision of respite services, cover a 3-year period, but funds are provided 1 year at a time. Continued funding during the course of the 3 years is contingent upon satisfactory performance, compliance, the availability of funds, and other criteria established in the award agreement. The minimum State formula grant is $600K, or 0.5% of the amount allocated for the State formula portfolio, whichever is greater.

For funding under the AmeriCorps NCCC program, sponsoring organizations request the assistance of AmeriCorps NCCC teams by submitting a project application to the regional campus that covers that organization’s state. The campuses provide assistance in completing the application, developing a work plan, and preparing the project sponsor for the arrival of the AmeriCorps NCCC team.46

Activities supported by the funding:
The AmeriCorps network of local, state, and national service programs engages more than 70,000 Americans in intensive service each year. AmeriCorps members serve through more than 3,000 nonprofits, public agencies, and faith-based and other community organizations, helping meet critical needs in education, public safety, health, and the environment. The variety of service opportunities is almost unlimited. Members may tutor and mentor youth, build affordable housing, teach computer skills, clean parks and streams, run after-school programs, or help communities respond to disasters.

Respite connection:
In recent grant announcements, under the Healthy Futures priority, grants may support increasing seniors’ ability to remain in their own homes with the same or improved quality of life for as long as possible. Since respite has been shown to have this outcome, a case could be made to allow AmeriCorps volunteers to provide respite.

Issues for consumers, providers, and advocates:
In alignment with the Serve America Act, the AmeriCorps State and National Notice of Federal Funding Opportunity for FY 16 focused AmeriCorps grant making on six core areas (additional areas of focus exist that may change annually):

- disaster services,
- education,
- environmental stewardship,
- healthy futures,
- economic opportunity,
- Veterans and military families.

Federal funding agency:
Corporation for National and Community Service.

Eligible entity:
Governor-appointed State Service Commissions. The State Service Commissions accept applications from

- state and local nonprofit organizations;
- community and faith-based organizations;

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Federal Funding and Support Opportunities for Respite

- state, local, and higher education institutions;
- state and local governments; and
- U.S. territories.

**Points of contact:**

**Related links:**
Catalog of Federal Domestic Assistance: AmeriCorps. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=b1b5343e62b34d5d666000a53426413c](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=b1b5343e62b34d5d666000a53426413c)


**References:**
Aging and Disability Resource Centers (ADRCs)/No Wrong Door (NWD) Systems

Authorizing legislation:

Program purpose:
Title II Section 202(b) of the Older Americans Act specifically authorizes the Assistant Secretary for Aging to work with the Administrator of the Centers for Medicare and Medicaid Services to: “implement in all States’ Aging and Disability Resource Centers –

- to serve as visible and trusted sources of information on the full range of long-term care options that are available in the community, including both institutional and home and community-based care;
- to provide personalized and consumer friendly assistance to empower people to make informed decisions about their care options;
- to provide coordinated and streamlined access to all publicly supported long-term care options so that consumers can obtain the care they need through a single intake, assessment and eligibility determination process;
- to help people to plan ahead for their future long-term care needs; and
- to assist, in coordination with the State Health Insurance Assistance Program, Medicare beneficiaries in understanding and accessing the Prescription Drug Coverage and prevention health benefits available under the Medicare Modernization Act”.

The ADRC/NWD System’s primary purpose is to make it easy for people of all ages, disabilities and income levels to learn about and access the Long Term Services and Supports (LTSS) they need (see explanation of NWD systems on the following page under Activities supported by the funding). People in need of LTSS often need more than one service and will use a mix of programs to fulfill their LTSS needs. Each publicly supported LTSS program has an application and enrollment process. LTSS access programs and functions are funded with public money and are often duplicative and overlapping, creating inefficiencies for both the consumer and the government. Transforming the existing publicly supported LTSS access programs and functions into a single statewide NWD System will give states a vehicle for creating more efficient and effective ways of administering their LTSS programs. States will also be able to use their NWD Systems to make their overall LTSS systems more consumer-driven and more cost-effective. ADRCs are designed to serve as visible and trusted sources that people can turn to for objective information on their long-term services and support options and their Medicare benefits. These programs also provide one-on-one counseling and advice to help consumers, including private pay individuals, to fully understand how available options relate to their particular needs; they also provide streamlined access to all publicly supported long-term services and support programs, including those funded under Medicaid, the Older Americans Act, and state revenue programs.

Beneficiaries:
All populations in need of LTSS regardless of age, income or disability, including family caregivers in need of long-term services and supports information.


**Funding:**
The Aging and Disability Resource Center Program (ADRC), a collaborative effort of the Administration for Community Living (ACL), the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration (VHA), was launched in the fall of 2003 to support state efforts to develop streamlined systems of access to Long Term Services and Supports (LTSS).

In 2006, Congress reauthorized the Older Americans Act with the inclusion of language supporting the development of ADRC efforts in every state. Continued funding for ADRCs was authorized in the Affordable Care Act from FY 2010–2014 for $10 million each year.

**Activities supported by the funding:**
ACL, CMS and VHA have partnered for several years to support states’ efforts to develop coordinated systems of access to make it easier for consumers to learn about and access LTSS. These efforts have been supported by a variety of programs, including the Aging and Disability Resource Center (ADRC) program, Real Choice Systems Change grants, the Balancing Incentive Program, Money Follows the Person (MFP), and Veteran Directed Home and Community-Based Services (VD-HCBS).

In 2014, building on the work of eight original state grantees of the 2012 Part A: The Enhanced ADRC Options Counseling Program, the Administration for Community Living, in partnership with CMS and the Veterans Health Administration, awarded 25 states and territories one year planning grants to develop single statewide No Wrong Door Systems (NWD), a single statewide system of access to LTSS for all populations and all payers. In 2015, ACL, CMS and VHA announced three year awards to five of these states to identify No Wrong Door promising practices.49

The four primary functions of a NWD System that are reflected in these Elements include:

1. State Governance and Administration
2. Public Outreach and Coordination with Key Referral Sources
3. Person-Centered Counseling (PCC)
4. Streamlined Eligibility for Public Programs

A further description of each of these functions can be found in the Key Elements of a NWD System of Access to LTSS for All Populations and Payers located at http://acl.gov/Programs/CIP/OCASD/ADRC/docs/NWD-National-Elements.pdf

**Respite connection:**
ADRCs play a central role in Lifespan Respite systems as mandated primary stakeholders. They provide a variety of functions, including respite services in their databases and assisting with family caregiver outreach and public education.

**Issues for consumers, providers, and advocates:**
To date, ACL has funded 54 out of 56 states and territories to implement ADRC/NWD System activities. Nationwide, 530 local ADRC networks are in place actively serving older adults and persons with disabilities.

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49 Descriptions of 2015 Identifying No Wrong Door Promising Practices grantee activities can be found at http://acl.gov/Programs/CIP/OCASD/ADRC/2015-Grantee-Summaries.aspx
Federal Funding Agency:
U.S. Department of Health and Human Services, Administration for Community Living, Center for Integrated Programs (CIP), Office of Consumer Access and Self Determination

Eligible entity:
State Agency or instrumentality of the State (e.g., State Unit on Aging, State Medicaid Agency, State Disability Agencies).

Points of contact:
Local ADRC locations and contact information by state can be found on the Technical Assistance Exchange website.

Related links:
Catalog of Domestic Federal Assistance: Affordable Care Act–Aging and Disability Resource Center. https://www.cfsda.gov/index?s=program&mode=form&tab=core&id=983b4b660ccbaac2653ff78fe7aaf87b3

References:
U.S Department of Health and Human Services, Administration for Community Living, Center for Integrated Programs, Aging & Disability Resource Centers Program/No Wrong Door System. http://acl.gov/Programs/CIP/OCASD/ADRC/
National Family Caregiver Support Program (NFCSP)

Authorizing legislation:

Currently authorized through:
September 30, 2011. Congress has continued to appropriate funds annually for this program.

Program purpose:
To assist states and Tribal Organizations in providing systems of support services for family caregivers and grandparents or older individuals who are relative caregivers.

Beneficiaries:
Family caregivers, grandparents, and older individuals who are relative caregivers will benefit. More detail regarding eligibility is available under Issues for consumers, providers, and advocates below.

Funding:
For states, Title III-E formula grants are based on the percentage of the population age 70 and older in the state. For Tribal and Native Hawaiian Organizations, grants are available to Tribes with approved applications under Parts A and B, and they assist in funding the delivery of supportive services to eligible older individuals.

Activities supported by the funding:
State Agencies on Aging work with regional Area Agencies on Aging, local community-service providers, and Tribal Organizations under Title VI, Part C, to offer five basic services for family caregivers:

- information;
- assistance with accessing support services;
- individual counseling, support groups, and caregiver training;
- respite care; and
- limited supplemental services.

Respite connection:
Respite is a core activity funded by this program. In FY 2013, the most recent year for which service data are available, the NFCSP provided respite care services to nearly 60,000 caregivers, and in FY 2013 the Native American Caregiver Support Program provided nearly 97,000 units of respite services to more than 9,000 caregivers.50

Issues for consumers, providers, and advocates:
Individuals eligible for respite care and other family caregiver support services are

- family caregivers who provide care for individuals age 60 or older;
- family caregivers who provide care for individuals with Alzheimer’s disease and related disorders, regardless of age;

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50 Personal communication with Greg Link, Administration for Community Living (ACL), October 23, 2015. Data was elicited from the ACL Aging Integrated Database (AGID): http://www.agid.acl.gov/CustomTables/.
• grandparents and other relative caregivers (not parents) 55 years of age or older providing care to children under age 18; or
• grandparents and other relative caregivers (not parents) 55 years of age or older providing care to adults age 18-59, with disabilities, to whom they are related by blood, marriage, or adoption.

Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services.

Priority is given to

• caregivers age 60 or older with the greatest social or economic need;
• caregivers age 60 or older providing care to individuals, including children, with severe disabilities; and
• caregivers of older individuals with Alzheimer’s disease.

State programs can use only up to 10% of their funding to provide services to grandparents and other relative caregivers who are providing care to children under age 18. Most of the services are targeted to family caregivers caring for the aging population. (This does not pertain to Title VI, Part C grantees).

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging.

Eligible entity:
States; Indian Tribal Organizations representing at least 50 individuals age 60 or older; public or nonprofit Native Hawaiian organizations serving at least 50 individuals age 60 or older.

Points of contact:
Contact information and links to each state’s Agency on Aging and Disabilities can be found on the National Association of States United for Aging and Disabilities (NASUAD) website. http://www.nasuad.org/about-nasuad/about-state-agencies/list-members

Contact information for Area Agencies on Aging and Tribal Organizations that administer the NFCSP can be found at http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx

Links to Title VI programs for Native Americans can be found by state on the National Resource Center on Native American Aging website. http://olderindians.aoa.gov/directors.html

Related links:
Catalog of Federal Domestic Assistance: National Family Caregiver Support, Title III, Part E. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=7e9bf741672386dea8f7a1eea16d0239

http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/index.aspx

U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging, Services for Native Americans (OAA Title VI). 
http://www.aoa.acl.gov/AoA_Programs/HCLTC/Native_Americans/index.aspx#Resources

Administration on Aging Integrated Database. http://www.agidnet.org/

References
Programs for the Aging

Some federal programs that provide for respite care are designed solely for those in the aging population who have some special need or who have attained a particular age.

The following legislation supports grants for aging services:

- Older Americans Act: Title III—Supportive Services and Senior Centers Program
- Public Health Service Act (Grants for Supportive Services to Serve People with Alzheimer’s Disease and Related Disorders).

Each of these programs is described in this section.
Supportive Services and Senior Centers Program

Authorizing legislation:
Title III, Part B of the Older Americans Act.

Currently authorized through:
September 30, 2011.

Program purpose:
To maximize informal supports to older Americans so that they can stay in their homes and communities by developing and implementing comprehensive and community-based systems of service.

Beneficiaries:
Individuals age 60 and older, targeting those older individuals with the greatest economic needs, the greatest social needs, and those residing in rural areas.

Funding:
One-year noncompetitive formula grants are awarded on the basis of the proportion of individuals age 60 or older in the state in relation to the number in the nation, after approval of a 2-, 3-, or 4-year state plan. States must supply a 15% match.

Activities supported by the funding:
Approved state grants may include

- health, mental health, education and training, welfare, information, recreation, homemaker, counseling, or referral services;
- services to help older individuals avoid institutionalization and return to their communities, through
  - client assessment, case management, and development and coordination of community services;
  - supportive activities to meet the needs of caregivers; and
  - in-home and community services, including home health, homemaker, shopping, escort, reader, and letter-writing;
- maintenance of physical and mental well-being through physical activity, music, art, and dance-movement therapy;
- a coordinated system of support services designed to enable mentally impaired older individuals attain and maintain emotional well-being and independence;
- services designed to support family members and other persons providing voluntary care to older individuals who need long-term care;
- services to encourage and facilitate regular interaction between students and older individuals;
- in-home services for frail older individuals, including those with Alzheimer’s disease or related neurological and organic brain dysfunction, and their families; and
- “any other services necessary for the general welfare of older individuals, if such services meet standards prescribed by the Assistant Secretary and are necessary for the general welfare of older individuals.”
Respite connection:
While respite care is not specifically listed in the authorizing legislation, a case could be made for including respite services under any of the services listed above.

Issues for consumers, providers, and advocates:
The term “family caregiver” means an adult family member or another individual who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer’s disease or a related neurological or organic brain dysfunction.

For a comparable program for American Indians and Hawaiian Natives, see Special Programs for Aging American Indians.

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging.

Eligible entity:
States that have Agencies on Aging designated by their governors.

Points of contact:
Contact information and links to each state’s Agency on Aging can be found on the National Association of State Units on Aging and Disability website.
http://www.nasuad.org/about-nasuad/about-state-agencies/list-members

To locate home and community-based services, use the Eldercare Locator on the U.S. Department of Health and Human Services website.
http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx

Related links:
Catalog of Federal Domestic Assistance: Special Programs for the Aging, Title III, Part B, Grants for Supportive Services and Senior Centers
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=59f3a8cfe2d1a5f92844aebada9bcc

National Aging Information and Referral Support Center.
http://www.nasuad.org/initiatives/national-information-referral-support-center

National Council on Aging, National Institute of Senior Centers.
http://www.ncoa.org/national-institute-of-senior-centers/

References:
U.S. Department of Health and Human Services. Administration for Community Living, Administration on Aging. Supportive Services and Senior Centers Program.
http://www.aoa.acl.gov/AoA_Programs/HCLTC/supportive_services/index.aspx

Alzheimer's Disease Supportive Services Program (ADSSP)

**Authorizing legislation:**

**Currently authorized through:**
September 30, 2002. Congress has continued to appropriate funds for this program.

**Program purpose:**
To expand the availability of diagnostic and support services for persons with Alzheimer's disease and related disorders (ADRD), their families, and their caregivers and to improve the responsiveness of the home and community-based care system to persons with dementia. There are three types of ADSSP grants that have been funded over the life of the program:

- **Evidence-Based Cooperative Agreements to Better Serve People with Alzheimer’s Disease and Related Disorders.** Funds states to implement evidence-based supportive service programs at the community level, including: Resources for Enhancing Alzheimer’s Caregiver Health (REACH) II, Savvy Caregiver, Star-Caregiver, Reducing Disability in Alzheimer’s Disease (R-DAD), the New York University Caregiver Intervention (NYUCI) and Coping with Caregiving.

- **Innovation Cooperative Agreements to Better Serve People with Alzheimer’s Disease and Related Disorders.** Funds states and partner organizations to explore innovative approaches to improving the delivery of supportive services at the community-level to people with ADRD and their family caregivers.

- **Dementia Capability Grants.** Fund states to help ensure Systems Integration Programs to Create Dementia Capable, Sustainable Service Systems to help ensure that people with dementia and their family caregivers have access to a home and community-based services system that identifies those with dementia, ensures that program staff have appropriate dementia care training, and assures delivery of quality services.

In 2011, the ADSSP expanded its scope to focus on ensuring the availability of dementia-capable community-based social and health care services through the coordination and incorporation of ADRD into broader home and community-based service systems. Fifteen states initially were awarded grants dedicated to the implementation of dementia-capable services and through FY 2015, additional states have been awarded these grants to expand dementia capable systems.

**Beneficiaries:**
Services are targeted to 1) individuals with Alzheimer’s disease and related disorders; (2) families and other informal caregivers of those individuals; and (3) professional care providers of those individuals.

**Funding:**
Competitive cooperative agreements for usually 3-years. Grantees must provide a 25% match in the first year, a 35% match in the second year, and a 45% match in the third and future years.
Activities supported by the funding:
At least half of federal funding must be applied to direct services to individuals and their families. Direct services are listed as

- home health care,
- personal care,
- adult day care,
- companion services,
- short-term care in health facilities, and
- “other respite care to individuals with Alzheimer’s disease or related disorders who are living in single-family homes or congregate settings.”

These ADSSP initiative with a focus on promoting dementia capable systems have had a broad reach, but in an effort to fill existing gaps, the Alzheimer’s Disease Initiative – Specialized Supportive Services (ADI-SSS) project, funded with public health funds, was promoted by ACL in 2015. Successful applicants will be expected to engage in a minimum of 3f the following activities in support of individuals with ADRD.

- Provision of effective supportive services to persons living alone with ADRD in the community.
- Provision of effective care/supportive services to persons living with moderate to severe impairment from ADRD and their caregivers
- Improvement of the quality and effectiveness of programs and services dedicated to individuals aging with intellectual and developmental disabilities with ADRD or those at high risk of developing ADRD.
- Delivery of behavioral symptom management training and expert consultation for family caregivers.

Respite connection:
Respite is a core activity of this funding. Respite was defined in the 2015 program announcement as “an interval of rest or relief or the result of a direct service intervention that generates rest or relief for the person with dementia and/or their family caregiver.” For example, if people with dementia and/or their family caregivers receive counseling or training through an intervention, the intervention was be considered to have generated respite for the participants, and therefore this intervention may be considered part of the direct service requirement.51

Issues for consumers, providers, and advocates:
There are no age restrictions on either the individuals with dementia to be served or their family caregivers. Individuals served do not need to have a diagnosis of Alzheimer’s disease, but they must have evidence of progressive cognitive and functional decline due to a degenerative brain disease and require assistance with adult day care, companion services, home health care, personal care, respite, or short-term care in a health facility.

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging.

Eligible entity:
State Units on Aging

Points of contact:
Information about current and past grantees, along with state contact information for each, is available on the Aging & Disability Resource Center website.

Related links:
Catalog of Federal Domestic Assistance: Alzheimer’s Disease Demonstration Grants to States. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=a4b92ad5ae30f7709548cf10e839e795


References


Programs for American Indians

Block and formula grants to states for funding major programs that include American Indians, Native Alaskans, and Native Hawaiians as state beneficiaries of services include

- Medicare and Medicaid programs,
- Child Abuse and Prevention and Treatment Act (CAPTA) State Grants,
- Community-Based Child Abuse Prevention Grants,
- Title XX Social Services Block Grants,
- Block Grants for Community Mental Health Services,
- Developmental Disabilities Councils,
- HIV Care Formula Grants,
- Supplemental Security Income, and
- Supportive Services to Better Serve People with Alzheimer’s Disease and Related Disorders.

Most other grant programs that cover respite care that list state agencies as the eligible entity are also open to federally recognized Tribes, and some are open to Tribes that are not federally recognized, including the following programs discussed previously in this Guide:

- Child Abuse Prevention and Treatment Act Discretionary Activities Grants;
- Title IV-B Child Welfare Services Grants;
- Title IV-E Adoption Assistance;
- Promoting Safe and Stable Families;
- Targeted Grants to Increase the Well-Being of, and to Improve the Permanency Outcomes for, Children Affected by Methamphetamine or Other Substance Abuse;
- Abandoned Infants Assistance;
- Adoptions Opportunities;
- Developmental Disabilities Projects of National Significance;
- Centers for Independent Living;
- HIV Emergency Relief Project Grants;
- National Family Caregiver Support Program (under separate authorizing legislation; see National Family Caregiver Support Program);
- Senior Companion Program; and
- Community Living Program Grants.

In addition, several programs are funded solely for individuals who are American Indians, Native Alaskans, Native Hawaiians, and other Native American Pacific Islanders. These programs, which are discussed in this section, are

- Indian Child Welfare Act Title II Grants,
- Native American Programs Act Social and Economic Development Strategies Programs, and
- Grants for Native Americans under Title VI of the Older Americans Act.
Indian Child Welfare Act Grants

Authorizing legislation:

Program purpose:
To support safe and stable American Indian Tribes and families through providing child protection, preventing the separation of families, and assisting in the operation of child and family service programs.

Beneficiaries:
American Indian children and families.

Funding:
Project grants are awarded on approval of application by the Tribe. Grants may be renewed indefinitely upon satisfactory performance by the grantee. The amount of a grant depends on the amount prioritized by the Indian Tribe through the budget formulation process.

Activities supported by the funding:
Uses of the funding, for both on- and off-reservation programs, include

- counseling facilities;
- family assistance, including homemaker and home counselors, day care and after school care, recreational activities, respite care, and employment;
- employment of professionals to assist Tribal courts personnel;
- education and training;
- foster care subsidy programs;
- legal advice and representation;
- home improvement programs with the primary emphasis of upgrading unsafe home environments;
- preparation and implementation of child welfare codes; and
- providing matching shares for other federal programs.

Respite connection:
Respite is a core service of the funding.

Federal funding agency:
U.S. Department of the Interior, Bureau of Indian Affairs

Eligible entity:
Federally recognized Indian Tribal governments

Points of contact:
A list of Tribal entities eligible to receive services can be found on the Bureau of Indian Affairs website. http://www.bia.gov/WhoWeAre/BIA/OIS/TribalGovernmentServices/TribalDirectory/index.htm
**Related links:**
https://www.cfda.gov/?s=program&mode=form&tab=step1&id=d550bfa7c5938e31b09ea79a9bbc0daf

Bureau of Indian Affairs.  
http://www.bia.gov/

**References:**
Social and Economic Development Strategies (SEDS) Program for American Indians

Authorizing legislation:

Currently authorized through:
September 30, 2002. Congress has continued to appropriate funding for this program.

Program purpose:
To promote economic and social self-sufficiency, support the interests of children and families, and strengthen communities for American Indians, Native Alaskans, Native Hawaiians, and other Native American Pacific Islanders from American Samoa, Guam, and the Commonwealth of the Northern Mariana Islands.

Beneficiaries:
American Indians, Native Alaskans, Native Hawaiians, and Native American Pacific Islanders.

Funding:
Competitive project grants of 1 to 3 years are awarded directly to the grantee. Grantees must supply a 20% match.

Activities supported by the funding:
Grants are made in four general program areas:

- Tribal governance projects,
- Economic development projects,
- Strengthening families projects, and
- Social development projects.

Grant announcements may be very general in nature, with little limitation on allowable activities.

Respite connection:
While respite care is not specifically identified as a service under this program, it could be considered in one of several identified areas, including

- improving the delivery of social services,
- developing and implementing projects that enlist community members in volunteer capacities to support community goals,
- developing and coordinating services to people with disabilities so they can live independently within the community,
- supporting early childhood programs to address the needs of young children and families;
- offering culturally relevant family preservation activities, and
- providing resources for grandparents raising grandchildren.
Federal funding agency:
U.S. Department of Health and Human Services, Administration for Children and Families, Administration for Native Americans.

Eligible entity:
Public and private nonprofit agencies serving American Indians, Native Alaskans, Native Hawaiians, and Native American Pacific Islanders.

Points of contact:
Information about current grants is available on the Administration for Native Americans website. http://www.acf.hhs.gov/programs/ana/current-grantees

Related links:
Catalog of Federal Domestic Assistance: Native American Programs. https://www.cfda.gov/index?s=program&mode=form&tab=core&id=0080278b35623bbd776b8497a2a22f11


References:
Special Programs for Aging American Indians

Authorizing legislation:
Title VI of the Older Americans Act of 1965.

Currently authorized through:
September 30, 2011.

Program purpose:
To promote the delivery of supportive services (comparable to those provided under Title III of the Older Americans Act) to older Indians, Native Alaskans, and Native Hawaiians.

Beneficiaries:
Indians who are 60 or older, and in the case of nutrition services, their spouses. Tribes also have the authority to define Indians under age 60 as “older Indians” making them eligible for services.

Funding:
One-year noncompetitive project grants, awarded on the basis of a formula that considers the number of eligible individuals age 60 or older represented by the Tribal Organization.

Activities supported by the funding:
Supportive services comparable to those provided under Title III of the Older Americans Act include

- health, mental health, education and training, welfare, information, recreation, homemaker, counseling, or referral services;
- services that help older individuals avoid institutionalization and return to their communities, through
  - client assessment, case management, and development and coordination of community services;
  - supportive activities to meet the needs of caregivers;
  - in-home and community services, including home health, homemaker, shopping, escort, reader and letter-writing services;
- maintenance of physical and mental well-being through physical activity, music, art, and dance-movement therapy;
- a coordinated system of support services designed to enable mentally impaired older individuals attain and maintain emotional well-being and independence;
- services designed to support family members and other persons providing voluntary care to older individuals who need long-term care;
- services to encourage and facilitate regular interaction between students and older individuals;
- in-home services for frail older individuals, including individuals with Alzheimer’s disease and related neurological and organic brain dysfunction, and their families; and
- “any other services necessary for the general welfare of older individuals; if such services meet standards prescribed by the Assistant Secretary and are necessary for the general welfare of older individuals.”
**Respite connection:**
While respite care is not specifically listed in the authorizing legislation, a case could be made for including respite services under any of the services listed above.

**Issues for consumers, providers, and advocates:**
Tribes have the authority to define Indians under age 60 as “older Indians” thus making them eligible for benefits.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging.

**Eligible entity:**
Tribal organizations and public or nonprofit private organizations that serve Native Hawaiian elders, which represent at least 50 individuals age 60 or older.

**Points of contact:**
Links to Title VI programs for Native Americans can be found by state on the National Resource Center on Native American Aging website. [http://olderindians.aoa.gov/directors.html](http://olderindians.aoa.gov/directors.html)

**Related links:**
Catalog of Federal Domestic Assistance: Special Programs for the Aging. [https://www.cfda.gov/index?s=program&mode=form&tab=core&id=7b3b8abe5929b14bcb79787f3d043bf3](https://www.cfda.gov/index?s=program&mode=form&tab=core&id=7b3b8abe5929b14bcb79787f3d043bf3)

**References:**
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging, Services for Native Americans (OAA Title VI). [http://www.aoa.acl.gov/AoA_Programs/HCLTC/Native_Americans/index.aspx#data](http://www.aoa.acl.gov/AoA_Programs/HCLTC/Native_Americans/index.aspx#data)

Programs for Military Families and Veterans

Military families of active duty service members and women as well as Veterans are often in need of respite care to provide a break from caregiving. Spouses of service members may have children or parents with special needs who need ongoing supervised care. Veterans return from deployments with physical and mental challenges that may require special care. Funding respite is approached in several different ways to assist these families with the needs of family caregivers.

For active duty military:

- Members receive health care through the TRICARE plan; a supplemental extended care health option (ECHO) is available to those who have family members with special needs, including respite care.
- Respite Care for Injured Service Members.
- The Exceptional Family Member Program (EFMP) in each branch of the military offers support to families that have members with special needs.
- The Department of Defense contracts with the Young Men’s Christian Association (YMCA) to provide free memberships and respite for families.
- Respite child care for families of deployed; wounded, ill, and injured soldiers; and survivors of fallen soldiers.

For Veterans:

- The Millennium Health Care and Benefits Act of 1999 provides health care benefits; respite is included in the benefits package.
- Aid and Attendance and Housebound Benefits are two benefit programs that provide supplemental financial support to Veterans with special needs who are receiving general Veterans Benefits.
- Title IV of the Older Americans Act created an opportunity for the Veterans Administration to partner with the Administration on Aging to fund Veteran Directed Home and Community Based Services for Veterans through Community Living Program grants.
- A new Program of Comprehensive Assistance for Family Caregivers began in May 2011 and is administered under the Caregivers and Veterans Omnibus Health Services Act of 2010.

Each of these programs is described in this section.
TRICARE’s Extended Care Health Option (ECHO)

Authorizing legislation:
Section 701(g) of the National Defense Authorization Act for FY 2002 (P.L. 107-107); codified in law in 10 U.S.C. 1079 (d) through (g). Department of Defense regulations for the Extended Care Health Option (ECHO) program are found at 32 CFR 199.5.

Currently authorized through:
On September 1, 2005, TRICARE’s ECHO replaced TRICARE’s Program for Persons with Disabilities (PFPWD).

Program purpose:
To supplement health insurance for military families who have family members with special needs.

Beneficiaries:
Retired and active duty military and their families (see issues for consumers, providers, and advocates below for more detail).

Funding:
Military members pay a monthly cost share of $25 to $250, depending on their pay grade.

Activities supported by the funding:
Benefits available under TRICARE ECHO may include

- medical and rehabilitative services,
- training to use assistive technology devices,
- special education,
- institutional care if needed,
- some transportation,
- assistive services,
- durable equipment,
- expanded in-home medical services, and
- respite care.

Respite connection:
Respite is available as a covered benefit in two categories:

- Respite care of 16 hours per month while receiving other authorized ECHO benefits, and
- Home Health Care Respite of up to 40 hours per week (8 hours/day, 5 days/week) if homebound.

Only one of these respite benefits can be used in a calendar month.
**Issues for consumers, providers, and advocates:**
TRICARE is the military health insurance plan for eligible family members of active duty service members, military retirees and their eligible family members, surviving eligible family members of deceased active duty or retired service members, and some former spouses of active or retired service members. TRICARE ECHO, for eligible active duty military families only, supplements TRICARE benefits.

Family members must have a qualifying condition such as
- moderate or severe mental retardation,
- serious physical disability, or
- extraordinary physical or psychological condition that keeps the beneficiary homebound.

Family members must register for TRICARE ECHO and enroll in the service’s Exceptional Family Member Program (EFMP). Service branches determine eligibility.

**Points of contact:**
Military families contact their local Beneficiary Counseling and Assistance Coordinator, TRICARE Service Center, or their regional contractor. Regional contractors are listed at the TRICARE website.
http://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx

**Related links:**

U.S. Military Health System, Defense Health Agency, TRICARE, Special Programs, Extended Care Health Option [http://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx](http://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx)

**References:**
TRICARE. Extended Care Health Option. [http://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx](http://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx)
**Respite for Injured Service Members**

*Authorizing legislation:*

*Program is authorized through:*
Began January 1, 2008. This program was established without a time limitation.

*Program purpose:*
To extend the TRICARE respite benefit to family caregivers of injured active duty service members.

*Beneficiaries:*
Injured active duty service members injured in the line of duty, and active duty service members, including National Guard/Reserve members who have a serious injury or an injury that has resulted in or may result in a physical disability or an extraordinary physical or psychological condition, qualify for the respite care benefit. In many cases, the condition may be so severe that the service member is left homebound.

*Funding:*
Service members pay nothing out of pocket for these services and there is no benefit cap.

*Activities supported by the funding:*
Injured active duty service members, including National Guard/Reserve members injured in the line of duty, are eligible for comprehensive health care services beyond basic TRICARE coverage, including respite care for the primary caregiver (of the injured service member).

Special benefits for injured active duty service members are similar to those available to family members of active duty service members under the TRICARE Extended Care Health Option (ECHO). However, active duty service members are not required to enroll in ECHO to receive these benefits, which include:

- diagnosis;
- inpatient, outpatient, and comprehensive home health care supplies and services;
- training, rehabilitation, special education, and assistive technology devices;
- institutional care in private nonprofit, public, and state institutions and facilities and transportation to and from such institutions and facilities (when appropriate); and
- custodial care in conjunction with authorized home health service.

*Respite connection:*
Respite benefits are limited to:

- a maximum of 40 respite hours in a calendar week,
- no more than 5 days per calendar week, and
- no more than 8 hours per calendar day.
The care must be provided by a TRICARE-authorized Home Health Agency. Contact your regional contractor or TRICARE Area Office for help finding an authorized Home Health Agency. Authorized respite care does not cover care provided by family members or others who may reside with or visit the qualified active duty service member.

Issues for consumers, providers, and advocates:
Although the primary caregiver is usually a member of the patient’s family, he or she may be a relative or friend who assists the service member with the activities of daily living. Respite care services are provided exclusively to the active duty service member. The active duty service member respite benefit is intended to mirror the benefits provided under the TRICARE Extended Care Health Option (ECHO) Home Health Care benefit.

The service member’s case manager or other approving authority* may approve respite care when the care plan includes frequent primary caregiver interventions (more than two during the 8-hour period per day that the primary caregiver would normally be sleeping); respite care may be included in the care plan.

*Other approving authorities include Defense Health Agency-Great Lakes, Service Point of Contact, referring military treatment facility, or the TRICARE Area Office.

Points of contact:
The service member’s case manager.

TRICARE regional and program contractors.  
http://www.tricare.mil/ContactUs/CallUs.aspx

Related links:

References:
Exceptional Family Member Program (EFMP)

Program purpose:
To give family support services to family members with special needs.

Beneficiaries:
See Issues for consumers, providers, and advocates below.

Activities supported by the funding:
Department of Defense policy permits, but does not require, each service to offer support to exceptional family members through their Family Centers. This program varies among the services (Army, Navy, Air Force, Marines, Coast Guard); each of these programs is covered separately below.

Issues for consumers, providers, and advocates:
The Department of Defense defines exceptional family members as family members of active duty service members and civilian employees appointed to an overseas position who meet one or more of the following criteria:

- Potentially life-threatening conditions and/or chronic medical/physical conditions (such as high-risk newborns, patients with a diagnosis of cancer within the last 5 years, sickle cell disease, insulin-dependent diabetes) requiring follow-up support more than once a year or specialty care.
- Current and chronic (duration of 6 months or longer) mental health condition (such as bipolar, conduct, major affective, or thought/personality disorders); inpatient or intensive outpatient mental health service within the last 5 years; or intensive (greater than one visit monthly for more than 6 months) mental health services required at the present time. This includes medical care from any provider, including a primary health care provider.
- A diagnosis of asthma or other respiratory-related diagnosis with chronic recurring wheezing which meets one of the following criteria:
  - scheduled use of inhaled anti-inflammatory agents and/or bronchodilators,
  - history of emergency room use or clinic visits for acute asthma exacerbations within the last year,
  - history of one or more hospitalizations for asthma within the last 5 years, or
  - history of intensive care unit admissions for asthma within the past 5 years.
- A diagnosis of attention deficit disorder or attention deficit hyperactivity disorder that meets one of the following criteria:
  - has a co-morbid psychological diagnosis;
  - requires multiple medications, psycho-pharmaceuticals (other than stimulants) or does not respond to normal doses of medication;
  - Requires management and treatment by mental health provider (e.g., psychiatrist, psychologist, or social worker);
  - requires a specialty consultant, other than a family practice physician or general medical officer, more than twice a year on a chronic basis; or
- requires modifications of the educational curriculum or the use of behavioral management staff.

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- requires adaptive equipment (e.g., an apnea home monitor, home nebulizer, wheelchair, splints, braces, orthotics, hearing aids, home oxygen therapy, or home ventilator),
- requires assistive technology devices (such as communication devices) or services;
- requires environmental/architectural considerations (such as a limited numbers of steps, wheelchair accessibility/housing modifications, or air conditioning);
- has or requires an Individualized Family Service Plan (IFSP); or
- has or requires an Individualized Educational Plan (IEP).

**Federal funding agency:**
U.S. Department of Defense.

**Points of Contact:**
To find your installation EFMP office, check the Installation Program Directory at Military OneSource website. [http://www.militaryonesource.mil/efmp](http://www.militaryonesource.mil/efmp). Families can also call Military OneSource at 800.342.9647 and ask for a referral to a special needs consultant.

**Related links:**
Military One Source, *Exceptional Family Member Program*

[http://www.militaryfamily.org/info-resources/efmp-special-needs.html](http://www.militaryfamily.org/info-resources/efmp-special-needs.html)

**References:**
U.S. Department of Defense Instruction Number 1342.22. (July 3, 2012). *Military Family Readiness (page 18, Exceptional Family Member Services).*
Army Exceptional Family Member Program (EFMP) Respite Care

**Funding:**
Qualified families may receive up to 40 hours of funded EFMP respite care per month for each certified family member.

**Respite connection:**
EFMP respite care eligibility is based on EFMP enrollment and severe chronic medical condition or significant medical needs of an exceptional family member (EFM). Strategic Resources Inc, (SRI) holds the contract with the Department of Defense to provide the respite services. SRI’s 700+ Respite Care Providers provide services for up to 1,650 Exceptional Family Members at 37 military installations and 50+ remote locations nationwide.

**Issues for consumers, providers, and advocates:**
Soldiers with EFMs must enroll in one of the EFMPs:
- Active Army,
- U.S. Army Reserve (USAR) in the USAR Active Guard Reserve (AGR) Program, or
- Army National Guard AGR serving under authority of 10 U.S.C. and 32 U.S.C.

Participants in EFMPs are enrolled permanently unless the medical or special education needs warrant case closure or the soldier is separated from the Army.

EFMP respite care is not an entitlement or a guaranteed benefit.

The Family Services Needs Matrix is used to determine EFMP respite care hours per month. The family must revalidate information in the matrix as the EFM condition changes or at least annually, whichever comes first.

EFMP respite care provides a temporary rest period for family members responsible for regular care of persons with disabilities. Care is provided in the respite care user’s home or other setting such as special needs camps and enrichment programs. Any Army EFMP respite care is subject to available funding.

Relatives or friends living in the home with the EFM are not authorized to be paid as respite care providers.

EFMP respite care payments are not authorized for live-in nannies, au pairs, babysitters, or services provided by agencies that provide any form of therapy.

Respite care providers must meet background, license/certification, and training requirements. The requirements can be waived for respite care providers who are adult family members of the EFM’s family.

**Points of contact:**
Families enrolled in EFMPs apply for EFMP respite care at the local Army Community Service EFMP Office.
Related links:
U.S. Army Medical Department, Exceptional Family Member Program. [http://efmp.amedd.army.mil](http://efmp.amedd.army.mil)


References:

Marine Corps Wounded and Fallen Marine Respite Care

**Funding:**
Qualified families may receive up to 20 hours of funded respite per month, per family, at authorized reimbursement rates.

**Respite connection:**
Respite provides temporary breaks for family members responsible for the regular care of individuals with disabilities. Respite may be provided by the installation child development center (CDC), fleet command center, a visiting nurse service, a family member, or a neighbor.

**Issues for consumers, providers, and advocates:**
Respite is available for all Marine Corps families enrolled in the EFMP; enrollment is mandatory for all active duty personnel and active reservists. The exceptional family member must reside full time with the sponsoring Marine.

From 2008 to 2013, there were four levels of need (LoN) with separate reimbursement rates:

- Level one: children age 12 or younger with mild special needs; rate cannot exceed the CDC rate.
- Level two: children age 12 or younger with mild special needs who could qualify for a higher level through an evaluation process; rate cannot exceed two times the CDC rate.
- Level three: family members with moderate special needs who require trained support; rate cannot exceed three times the CDC rate.
- Level four: family members with severe special needs who require nursing care services; rate cannot exceed nine times the CDC rate, or $45 per hour.

Siblings of EFMP children, and children of adults with disabilities age 12 or younger were also eligible to receive respite at no more than the CDC rate. However, beginning October 2013, the following new changes took effect:

- EFMP respite care reimbursement remained available to EFMs identified as LoN 3, or LoN 4 but family members identified as LoN 1 and LoN 2 were no longer eligible for respite care reimbursement.
- Age typical sibling reimbursement was no longer provided.
- Adult EFMs are no longer eligible for age typical reimbursement for their children.
- The maximum number of respite hours per month, per family, to be reimbursed at authorized rates is 20 hours.

**Points of contact:**
Respite care services can be accessed through the local installation EFMP coordinator.
Related links:
Marine Corps Community Services. Exceptional Family Member Program (EFMP). http://www.usmc-mccs.org/index.cfm/services/family/exceptional-family-member/

References:
Navy Exceptional Family Member Program (EFMP) Respite Care

**Funding:**
Qualified families may receive up to 40 hours of respite care per month at no cost to the family.

**Respite connection:**
Respite is provided through Child Care Aware® of America (formerly NACCRRA) and local partner agencies.

**Issues for consumers, providers, and advocates:**
Navy families are eligible for respite care if
- the family is enrolled in the Navy’s Exceptional Family Member Program;
- the EFM child is younger than 19; typical siblings are younger than 13;
- age 18 or younger;
- the level of enrollment is Level IV or V — the exceptional family member’s needs require an assignment near a major military or civilian medical facility
- the sailor is stationed within the United States.

**Points of contact:**
Child Care Aware® of America (formerly NACCRRA) at 1-800-424-2246. Once eligibility is confirmed, the family will be connected with the local agency administering the program.

**Related links:**
Child Care Aware® of America. Apply for Navy Exceptional Family Member Program (EFMP) Respite Care.

Navy Personnel Command (NPC) customer service center at 1-866-U-ASK-NPC, visit the NPC website at [http://www.public.navy.mil/bupers-npc/Pages/default.aspx](http://www.public.navy.mil/bupers-npc/Pages/default.aspx)

**References:**
U.S. Navy, Navy Personnel Command. *Navy Exceptional Family Member Program (EFMP).*
Air Force Exceptional Family Member Program (EFMP) Respite Care

**Funding:**
Qualified families are eligible for 12 hours of respite care per month.

**Respite connection:**
Respite is available to families of active duty members of the Air Force with a child enrolled in the EFMP.

**Issues for consumers, providers, and advocates:**
Air Force families are eligible for respite care if
- the family is enrolled in the Air Force’s Exceptional Family Member Program;
- the EFM child is younger than 19; typical siblings are younger than 13;
- the child resides with the Airman;
- the airman is on active duty (including guard and reserve activated for 30 days or more);
- the airman is stationed in the United States, including Alaska and Hawaii;
- the amount of respite care is based on the severity of the special need and deployment status (between 8 and 20 hours per month); or
- choice of care in an approved location—in child’s home, in a licensed family child care home, or in a child care center.

**Points of contact:**
Child Care Aware® of America (formerly NACCRRA) at 1-800-424-2246. Information may also be obtained from the local Airman & Family Readiness Center.

**Related links:**
Child Care Aware® of America. *Air Force Exceptional Family Member Program Respite Child Care.*
[http://usa.childcareaware.org/military-programs/](http://usa.childcareaware.org/military-programs/)


**Also available:**
Air Force Aid Society (AFAS) provides up to 20 hours of respite care per month. The amount of assistance is based on need—the need for respite time as well as financial need. Families may be referred to AFAS by the Airman and Family Readiness Center EFMP family support coordinator.

Coast Guard Mutual Assistance (CMGA) Respite Care

**Funding:**
Respite is based on need (financial need and need for a break from care giving when supported by a statement from a doctor or other medical authority and when no other sources will authorize assistance) and is given as a grant. The family locates a provider and agrees on an hourly rate, not to exceed $10 per hour. The grant may not be used to pay for care provided by a relative or an individual who is also receiving a respite care grant.

**Respite connection:**
Respite is available to eligible Coast Guard clients who have 24-hour responsibility for an ill or disabled family member living in the same household. Respite may not exceed 40 hours per month. Respite may be provided in the family’s home or out of the home.

**Issues for consumers, providers, and advocates:**
Eligible families are those in which a family member (spouse, dependent child, or dependent parent) (1) has been diagnosed with a profound disability or a serious or terminal illness requiring ongoing care, and is enrolled in the Coast Guard Special Needs Program.\(^{53}\) Eligibility is verified by the local command.

Not all enrollees in the Special Needs Program will qualify; the family member with special needs must be determined to be at high risk because of multiple stresses in the family.

Approval is given for one 3-month period and may be renewed for one additional 3-month period.

**Points of contact:**
A list of local CGMA representatives can be found on the Coast Guard Mutual Assistance website. [http://www.cgmahq.org/Map/repMembers.html](http://www.cgmahq.org/Map/repMembers.html)

**Related links:**
U.S. Coast Guard, Coast Guard Mutual Assistance, Medical and Dental Program. [http://www.cgmahq.org/Assistance/Programs/med.html](http://www.cgmahq.org/Assistance/Programs/med.html)

**References:**


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\(^{53}\) Equivalent to Exceptional Family Member Programs in other services.
Armed Services YMCA Respite Child Care

*Program purpose:*  
To provide respite for armed forces families.

*Funding:*  
There is no cost to the family for this program.

*Beneficiaries:*  
Families with children up to age 12 who are Title 10 personnel are eligible for a Y membership and respite care, including: Family members of deployed National Guard and Reservists, Active Duty Independent Duty personnel, relocated spouses/dependent children of deployed Active Duty personnel, and families of deployed Active Duty personnel residing 30 miles from a military installation.

*Activities supported by the funding:*  
The Department of Defense has contracted with the YMCA to provide free family memberships at participating YMCAs.

*Respite connection:*  
Participating YMCAs will provide up to 16 hours of respite child care per month per child for children age 12 and younger.

*Issues for consumers, providers, and advocates:*  
A military ID card and copy of deployment orders or Independent Duty approval form are required for enrollment.

*Points of contact:*  
A list of participating YMCAs is located on the YMCA website.  
[http://www.ymca.net/military-outreach/childcare.html](http://www.ymca.net/military-outreach/childcare.html)

*Related links:*  
YMCA, Military Outreach: About Respite Care.  
[http://www.ymca.net/military-outreach/childcare.html](http://www.ymca.net/military-outreach/childcare.html)

*References:*  
DoD/YMCA Respite Care Eligibility Form.  
[http://www.asymca.org/assets/Respite-Care-DoD-Eligibility-Form-Updated.pdf](http://www.asymca.org/assets/Respite-Care-DoD-Eligibility-Form-Updated.pdf)
Army Fee Assistance (AFA) for Respite Care

*Program purpose:*
Respite child care for certain military families.

*Beneficiaries:*
Army service members and their spouses in one of the following categories:

- Deployed (for 30 days prior to and 90 days after return),
- Geographically dispersed Army Recruiters
- ROTC Cadet Cadre (eligible during the months of May-September)
- Wounded Warriors
- Survivors of Fallen Warriors.
- Memorial Service Attendance for Fallen Soldiers (on site only)

The Army spouse is not required to be working or enrolled in school to qualify. Eligible hours will vary depending on status.

*Funding:*
The Army administers the program through the General Services Administration to reimburse the respite provider for eligible care at the Army-approved hourly rate.

*Activities supported by the funding:*
Free temporary child care for each eligible child to allow the parent or caregiver time to run errands, attend appointments, or just take time out for themselves.

*Respite connection:*
Respite Child Care provides each eligible family with up to five hours of no-cost child care for each child up to and including age 12 during an assignment period. Child does not need to have any special need.

*Issues for consumers, providers, and advocates:*
The Army Fee Assistance Program will be transitioning to a new contractor. The timeline for that transition has not yet been finalized at the time this document was prepared.

Spouse does not have to be working, looking for work, or in school to qualify.

Respite providers must be state-licensed and/or nationally accredited.

*Points of contact:*
All questions on eligibility and application for the AFA should be addressed to the GSA Subsidy Administration Section. Phone: (866) 508-0371 Fax: (816) 823-5410 or by email: armychildcare.newapplications@gsa.gov  Address: GSA/BCED Attention: Subsidy Administration Section 1500 East Bannister Road, #1061 Kansas City, MO 64131

*Related Links:*
U.S. General Services Administration (GSA), Army Fee Assistance. http://www.gsa.gov/portal/category/107359
References:
U.S. General Services Administration (GSA), Subsidy Administration Section. Army Fee Assistance – Family Handbook.
http://www.gsa.gov/portal/mediald/235863/fileName/Army_Fee_Assistance_(AFA)_Family_Handbook2.action

Veterans Affairs Health Care

Authorizing legislation:

Currently authorized through:
This program was established without a time limitation.

Program purpose:
To establish a program of extended care services for Veterans.

Beneficiaries:
Family caregivers of Veterans from all eras.

Funding:
This program was established without a need for further fiscal appropriations. Services can be contracted or provided directly by the staff of the U.S. Department of Veterans Affairs (VA) or by another provider or payer.

Activities supported by the funding:
Care services in this legislation include geriatric evaluation, nursing home care in Veterans Health Administration (VHA) and community-based facilities, domiciliary services, adult day health care, noninstitutional alternatives to nursing home care, and respite care.

Respite connection:
Respite care is part of the Veteran’s Medical Benefits Package. VA medical centers may provide respite care for up to 30 days per calendar year to eligible Veterans. Additional care days may be permitted with the approval of the medical center director for unexpected situations such as the death of the caregiver. Respite may be provided at the VA medical center, a community setting, or in the Veteran’s home.

Issues for consumers, providers, and advocates:
Respite is a covered benefit for all Veterans enrolled in the VA health care system or who are eligible for VA health care without the need to enroll for such care.

Federal funding agency:
U.S. Department of Veterans Affairs, Veterans Health Administration.

Points of contact:
Veterans can access information about their health benefits on the U.S. Department of Veterans Affairs website.
http://www.myhealth.va.gov/

Contact information for VA offices and facilities can be found on the U.S. Department of Veterans Affairs website.
http://www.va.gov/landing2_locations.htm

For questions about VA Caregiver Support Services, contact VA’s Caregiver Support Line at 1-855-260-3274 or see http://www.caregiver.va.gov/help_landing.asp for help finding a local Caregiver Support Coordinator.
Federal Funding and Support Opportunities for Respite

Related links:


References:
Aid and Attendance and Housebound Benefits

Program purpose:
To provide assistance to Veterans with special needs.

Beneficiaries:
Veterans with medical needs or mental or physical disability who are at least 65 years old or permanently and totally disabled if they are younger. This includes Veterans who are blind or confined to the bed.

Funding:
The Department of Veterans Affairs (VA) pays a maximum of $2,900/month to qualified married Veterans. Single Veterans and surviving spouses may be eligible for smaller payments.

Activities supported by the funding:
This is a benefit paid in addition to a monthly VA pension.

Respite connection:
Funds may be used in any way, including paying for respite care.

Issues for consumers, providers, and advocates:
Veterans must be receiving a regular VA pension. Qualifying Veterans must be at least 65 years old or permanently and totally disabled.

To qualify for the Aid and Attendance Benefits, Veterans must have medical needs—requiring assistance with activities of daily living, being blind, being bedridden, or having a mental or physical disability—that require care in an assisted-living facility or nursing home.

To qualify for Housebound Benefits, Veterans must have a 100% disabling conditions that substantially confines them to home or one 100% disabling condition and another disability or disabilities evaluated as being 60% or more disabling.

Federal funding agency:
U.S. Department of Veterans Affairs.

Points of contact:
Contact information for the appropriate VA Regional Office is available on the U.S. Department of Veterans Affairs website.
http://www.va.gov/directory/guide/home.asp?isflash=1

Related links:

U.S. Department of Veterans Affairs, Veterans Health Administration, Geriatrics and Extended Care. Paying for Long-Term Care. http://www.va.gov/GERIATRICS/Guide/LongTermCare/Paying_for_Long_Term_Care.asp#

References:
Volunteer Caregiver Support Network

Program purpose:
Developed to meet the growing need to support those outside the medical community who have the daily responsibility of caring for Veterans, who are ill, injured, or have disabilities, in their homes.

Beneficiaries:
Family caregivers of seriously injured Veterans with multiple injuries, traumatic brain injury (TBI), and/or spinal cord injury (SCI)

Funding:
In February 2008, the U.S. Department of Veterans Affairs’ (VA’s) Under Secretary for Health approved funding for programs to facilitate the transition and support of seriously injured Veterans with polytrauma, traumatic brain injury (TBI), and/or spinal cord injury (SCI) by providing specialized support and care in their homes and communities. The Veterans Health Administration’s (VHA’s) Office of Voluntary Service, in conjunction with other VHA offices, established Caregiver Support Network Services free to Veterans.

Activities supported by the funding:
The Department of Veterans Affairs Voluntary Service (VAVS) and the VA Office of Care Coordination (OCC) together formed the Caregiver Support Network. The program, available through local VA Health Centers, is comprised of trained volunteers from the community where the Veterans reside who provide up to 8 hours per week of free respite care for primary caregivers.

Respite connection:
Respite volunteers provide companionship and compassionate support for homebound Veterans, allowing their primary caregivers to take time off to complete necessary errands or enjoy a period of rest and relaxation.

Issues for consumers, providers, and advocates:
This program will aid both Veterans living in their homes and those who are no longer able to live independently but prefer an in-home alternative within their community. The Caregiver Support Network helps create access to needed home respite services for family caregivers, while giving members of the community an opportunity to volunteer with VA closer to home, regardless of distance from a VA facility. VAVS recruits, trains, and coordinates community volunteers to provide respite care in the homes of Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) Veterans. Volunteers must have their own source of transportation.

Federal funding agency:
U.S. Department of Veterans Affairs, Veterans Health Administration, VA Voluntary Service.

Points of contact:
Interested volunteers should contact the Voluntary Service Department at the local VA facility.

For questions about VA Caregiver Support Services or help finding a local Caregiver Support Coordinator, contact VA’s Caregiver Support Line at 1-855-260-3274 or search at http://www.caregiver.va.gov/help_landing.asp.
Related links:
U.S. Department of Veterans Affairs, Veterans Health Administration, VA Voluntary Service.
http://www.volunteer.va.gov/index.asp

References:

U.S. Department of Veterans Affairs, Veterans Health Administration, Voluntary Service. Volunteer with VA Caregiver Support Network (Brochure).
http://www.volunteer.va.gov/docs/Caregiver_Brochure.pdf
Veteran Directed Home and Community Based Services (VD-HCBS) Program

Authorizing legislation:
No specific authorizing legislation for VD-HCBS program.

Program purpose:
The VD-HCBS Program empowers veterans who are at risk of placement in a nursing home and their caregivers by giving them the ability to have direct control over the goods and services they receive.

Beneficiaries:
Veterans at risk of placement in a nursing home.

Funding:
The program is a collaboration between the Veterans Administration and the Administration for Community Living. The 57 participating U.S. Department of Veterans Affairs (VA) Medical Centers (VAMCs) in collaboration with over 115 Aging/Disability Network providers serve veterans with complex needs and those transitioning back to the community from hospitals and nursing home stays. VAMCs authorize a flexible spending budget based on the veteran’s assessed needs. The Aging & Disability Network provider works with the Veteran to develop a spending plan and assists them in securing the necessary goods and services that allow him or her to safely remain independent in the community.

Activities supported by the funding:
This consumer-directed approach empowers the veteran to actively participate in making informed decisions about accessing health and long-term care options. Veterans in the VD-HCBS Program are then able to select the services and goods that will best meet their long-term care needs to prevent an avoidable hospital admission or premature nursing home placement. The veteran in the VD-HCBS Program is supported by a person-centered counselor employed at an Area Agency on Aging, State Unit on Aging, Aging and Disability Resource Center or a Center for Independent Living to ensure the quality, satisfaction, and service delivery and to assist in finding and training workers and securing needed goods and services within the allocated budget. A financial management service ensures timely payment of the veteran’s employees.

Respite connection:
Respite is a core service supported by the funding. The VA is looking to expand a pilot program that focuses solely on self-directed respite.\(^\text{54}\)

Issues for consumers, providers, and advocates:
Veterans of all ages are eligible for services under this program. To date this program has served over 3200 Veterans including both older and younger Veterans with complex needs and those transitioning back to the community from hospitals and nursing home stays.

**Federal funding agency:**
U.S. Department of Veterans Affairs, Veterans Health Administration, Chief Business Office.

**Eligible entities:**
State Units on Aging, Area Agencies on Aging, Aging & Disability Resource Centers and Centers for Independent Living

**Points of contact:**
Information on states participating in the VD-HCBS Program, including contact information, is available on the Administration for Community Living website at [http://acl.gov/Programs/CIP/OCASD/VDHCBS/index.aspx#Status](http://acl.gov/Programs/CIP/OCASD/VDHCBS/index.aspx#Status)

**Related links:**


**References:**


Program of Comprehensive Assistance for Family Caregivers

Authorizing legislation:

Currently authorized through:
September 30, 2015.

Program purpose:
To provide assistance to family caregivers of Veterans.

Beneficiaries:
Veterans eligible for the program are those who are undergoing medical discharge from the Armed Forces for a serious injury (including traumatic brain injury, psychological trauma, or other mental disorder) incurred or aggravated in the line of duty on or after September 11, 2001, and their family caregivers. To be eligible the Veteran’s injury must require personal care services for at least six months.

Activities supported by the funding:
Approved family caregivers will receive

- instruction, preparation, and training to provide personal care services to the Veteran;
- ongoing technical support;
- counseling; and
- lodging and subsistence.

Family caregivers who are designated as primary providers of personal care services will also receive

- appropriate mental health services;
- respite care of at least 30 days per year, including 24-hour care of the Veteran;
- access to health insurance;
- travel expenses;
- a monthly stipend.

Respite connection:
Respite is a core service of the program. Respite must be medically and age appropriate and include in-home care.

Issues for consumers, providers, and advocates:
Eligible Veterans must be in need of personal care services because of an inability to perform one or more activities of daily living or is in need for supervision or protection on the basis of symptoms or impairment.

This program took effect in May 2011.

Federal funding agency:
Department of Veterans Affairs, Veterans Health Administration.
Points of contact:
Find Your Local Caregiver Coordinator at http://www.caregiver.va.gov/

Related Links:
U.S. Department of Veterans Affairs. Veterans Health Administration. VA Caregiver Support.
http://www.caregiver.va.gov/

http://www.caregiver.va.gov/pdfs/CaregiverFactSheet_Apply.pdf

References:
P.L. 111-163 Caregivers and Veterans Omnibus Health Services Act of 2010 (Title I, Caregiver Support).

### Appendix: Summary Table of Federal Programs That May Be Potentially Accessed by States, Local Agencies, or Individuals for Respite Services, Support, or Funding

<table>
<thead>
<tr>
<th>Program</th>
<th>Type of Assistance &amp; Eligible Entity</th>
<th>Authorizing Legislation</th>
<th>Beneficiaries (may vary by state)</th>
<th>Payments to or Support for Respite Services</th>
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</thead>
<tbody>
<tr>
<td>Medicare Hospice Benefit</td>
<td>Fee for service entitlement to individuals</td>
<td>Social Security Act, Title XVIII, Section 1861</td>
<td>Medicare-eligible aged and disabled individuals with terminal illnesses</td>
<td>Payments to hospice care facilities</td>
</tr>
<tr>
<td>Medicare Advantage Special Needs Plans</td>
<td>Managed care health insurance plan to individuals</td>
<td>Social Security Act, Title XVII, Section 1859; Medicare Modernization Act of 2003</td>
<td>Medicare-eligible individuals who are institutionalized, dually eligible, or have certain conditions</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Medicaid Personal Care Benefit</td>
<td>Formula grant to states at state option</td>
<td>Social Security Act, Title XIX</td>
<td>Medicaid-eligible individuals in states including this option in their state plan</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Self-Directed Assistance Services</td>
<td>Formula grant to states at state option</td>
<td>Social Security Act, Title XIX, Section 1915(j)</td>
<td>Frail elders, adults with disabilities, and some children with developmental disabilities</td>
<td>Consumer-directed budgets can be used to pay respite providers</td>
</tr>
<tr>
<td>Programs of All-Inclusive Care for the Elderly (PACE)</td>
<td>Capitated benefit with integrated Medicare and Medicaid financing</td>
<td>Balanced Budget Act of 1997</td>
<td>Individuals age 55 or older certified as eligible for nursing home care</td>
<td>Payments to providers of services that result in “indirect” respite care; payments to respite care providers</td>
</tr>
<tr>
<td>Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)</td>
<td>Formula grant to states Entitlement</td>
<td>Social Security Act, Title XIX</td>
<td>Medicaid-eligible children</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Medicaid Hospice Benefit</td>
<td>Formula grant to states State option</td>
<td>Social Security Act, Title XIX</td>
<td>Medicaid-eligible individuals with terminal illnesses</td>
<td>Payments to hospice care Facilities</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
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<td>Beneficiaries (may vary by state)</td>
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<tr>
<td>Medicaid Research &amp; Demonstration Projects</td>
<td>Discretionary grant to states</td>
<td>Social Security Act, Title XXI, Section 1115</td>
<td>Medicaid-eligible individuals</td>
<td>Payments to respite care providers or consumer-directed</td>
</tr>
<tr>
<td>Medicaid Managed Care/Freedom of Choice Waivers</td>
<td>Waiver of Medicaid regulations</td>
<td>Social Security Act, Title XIX, Section 1915(b)</td>
<td>Medicaid-eligible individuals</td>
<td>Payments to respite care providers or consumer-directed</td>
</tr>
<tr>
<td>Home and Community-Based Services Waivers</td>
<td>Waiver of Medicaid regulations</td>
<td>Social Security Act, Title XIX, Section 1915(c)</td>
<td>Medicaid-eligible individuals</td>
<td>Payments to respite care providers or consumer-directed</td>
</tr>
<tr>
<td>Combined Waivers</td>
<td>Waiver of Medicaid regulations</td>
<td>Social Security Act, Title XIX, Sections 1915(b) and (c)</td>
<td>Medicaid-eligible individuals</td>
<td>Payments to respite care providers or consumer-directed</td>
</tr>
<tr>
<td>Community First Choice Option</td>
<td>Formula grant to states State option</td>
<td>Social Security Act, Section 1915(k)</td>
<td>Medicaid-eligible individuals requiring an institutional level of care</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Medicaid State Plan Option for Home and Community-Based Services</td>
<td>Formula grant to states State option</td>
<td>Social Security Act, Title XIX, Section 1915(i)</td>
<td>Medicaid-eligible individuals</td>
<td>Payments to respite care providers or consumer-directed</td>
</tr>
<tr>
<td>Money Follows the Person</td>
<td>Discretionary grant to states</td>
<td>Deficit Reduction Act of 2005 and Affordable Care Act</td>
<td>Medicaid-eligible individuals transitioning out of institutional settings</td>
<td>Payments to respite care providers or consumer directed</td>
</tr>
<tr>
<td>Children’s Health Insurance Program (CHIP)</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title XXI</td>
<td>Low-income children</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
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<tr>
<td><strong>Programs for Children Only: Child Welfare and Child Abuse Prevention Programs</strong></td>
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<tr>
<td>CAPTA Basic State Grants</td>
<td>Formula grant to states</td>
<td>Child Abuse Prevention and Treatment Act, Title I</td>
<td>Children identified as abused or neglected and their families</td>
<td>Support of community respite and crisis nursery programs</td>
</tr>
<tr>
<td>CAPTA Discretionary Activities</td>
<td>Discretionary grants or contracts to states, local government, tribes, tribal organizations, public or private agencies</td>
<td>Child Abuse Prevention and Treatment Act, Title I</td>
<td>Children identified as abused or neglected or at risk of abuse or neglect and their families</td>
<td>Support of community respite and crisis nursery programs</td>
</tr>
<tr>
<td>Child Abuse Community-Based Prevention Grants (CBCAP)</td>
<td>Formula grant to states</td>
<td>Child Abuse Prevention and Treatment Act, Title II</td>
<td>Children at risk of child abuse or neglect and their families</td>
<td>Support of community respite and crisis nursery programs</td>
</tr>
<tr>
<td>Stephanie Tubbs Jones Child Welfare Services</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title IV-B, Subpart 1</td>
<td>Families and children in need of child welfare benefits</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Promoting Safe and Stable Families</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title IV-B, Subpart 2</td>
<td>Families and children in need of child welfare and family strengthening services</td>
<td>Payments to respite care providers and crisis nursery programs</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
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<tr>
<td>Targeted Grants to Increase Well-Being of, and to Improve Permanency Outcomes for, Children Affected by Substance Abuse</td>
<td>Competitive grant to state partnerships serving children at risk of out-of-home placement</td>
<td>Social Security Act, Title IV-B, Subpart 2</td>
<td>Children at risk of out-of-home placement due to parent or caregiver’s substance abuse</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Adoption Opportunities</td>
<td>Discretionary grant to projects</td>
<td>Child Abuse Prevention and Treatment and Adoption Reform Act</td>
<td>Children in foster care with a goal of adoption</td>
<td>Grants to programs that may be used to pay providers of respite care</td>
</tr>
<tr>
<td>Family Violence Prevention and Services Act</td>
<td>States, Tribal entities; State Domestic Violence Coalitions</td>
<td>Family Violence Prevention and Services Act</td>
<td>Victims of domestic violence, their children and other dependents, their families, and the public</td>
<td>Assistance in accessing and providing information and referral to respite services</td>
</tr>
</tbody>
</table>

**Programs for Children Only: Child Education/Health/Mental Health**

<table>
<thead>
<tr>
<th>Program</th>
<th>Type of Assistance &amp; Eligible Entity</th>
<th>Authorizing Legislation</th>
<th>Beneficiaries (may vary by state)</th>
<th>Payments to or Support for Respite Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Intervention for Infants and Toddlers</td>
<td>Formula grant to states</td>
<td>Individuals with Disabilities Education Act, Part C</td>
<td>Children ages 0 to 2 with developmental disabilities and their families</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
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<tr>
<td>Special Education Preschool</td>
<td>Formula grant to states</td>
<td>Individuals with Disabilities Education Act, Part B</td>
<td>Children ages 3 to 5 with developmental disabilities</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Maternal and Child Health Block Grant</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title V, Section 501</td>
<td>Mothers, infants and children, including children with special health</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Family to Family Health Information Centers</td>
<td>Discretionary grant to projects</td>
<td>Social Security Act, Title V, Section 501(c)(1)(A)</td>
<td>Children and families receiving services from organizations engaged in activities for children and youth with special health care needs</td>
<td>Funds information centers to connect families to respite. No direct funding for respite care</td>
</tr>
<tr>
<td>Child Mental Health Initiative</td>
<td>Discretionary grant to states</td>
<td>Public Health Service Act, Title V, Section 561</td>
<td>Children under age 22 with a diagnosed serious emotional disturbance, serious behavioral disorder, or serious mental disorder</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
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<tr>
<td><strong>Programs for Children Only: Child and Family Low-Income Assistance</strong></td>
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<tr>
<td>Temporary Assistance for Needy Families (TANF)</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title IV-A</td>
<td>Low-income families with children</td>
<td>Payments to respite care providers or consumer directed</td>
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<tr>
<td>Child Care and Development Fund</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title IV</td>
<td>Children under age 13 (option to 19 if disabled or under court supervision) with working parents under 85% of state median income, or receiving protective services</td>
<td>Payments to respite care providers if family receiving protective services; development and support of provider</td>
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<tr>
<td><strong>Programs Serving All Ages</strong></td>
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<tr>
<td>Community Development Block Grant</td>
<td>Entitlement grants to principal cities of Metropolitan Statistical Areas (MSAs) and qualified urban counties; Non-entitlement grants to states</td>
<td>Housing and Community Development Act of 1974, Title I</td>
<td>Low- and moderate-income persons</td>
<td>Grants to respite care providers</td>
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<tr>
<td>Social Services Block Grant</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title XX</td>
<td>No restrictions</td>
<td>Grants to respite care providers</td>
</tr>
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<tr>
<td>Community Mental Health Services Block Grant</td>
<td>Formula grant to states</td>
<td>Public Health Service Act, Title XIX, part B</td>
<td>Adults with serious mental illness; children with serious emotional disturbance</td>
<td>Payments to respite care providers</td>
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<tr>
<td>Developmental Disability Basic Support and Advocacy Grants</td>
<td>Formula grant to states</td>
<td>Developmental Disabilities Assistance and Bill of Rights Act</td>
<td>Individuals with developmental disabilities</td>
<td>Funds development and maintenance of provider networks. Limited payments to respite care providers</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
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<tr>
<td>Lifespan Respite Care Program</td>
<td>Competitive grants to states</td>
<td>Public Health Service Act, Title XXIX</td>
<td>Family caregivers of children and adults with special needs</td>
<td>Payments to states for respite systems; provider training and recruitment; information for family caregivers; payments to respite providers and to individuals for planned and emergency respite.</td>
</tr>
<tr>
<td>Centers for Independent Living</td>
<td>Discretionary grant to projects</td>
<td>Rehabilitation Act, Title VII, Part C; Recovery Act</td>
<td>Individuals with significant disabilities</td>
<td>Payments to respite care providers or linkages to respite using other funding sources for payment</td>
</tr>
<tr>
<td>HIV Care Formula Grants</td>
<td>Formula grant to states</td>
<td>Public Health Service Act, Title XXVI, Part B</td>
<td>Individuals with HIV/AIDS and their families</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>HIV Emergency Relief Project Grants</td>
<td>Formula grant to states</td>
<td>Public Health Service Act, Title XXVI, Part A</td>
<td>Individual with HIV/AIDS and their families</td>
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<td>Supplemental Security Income</td>
<td>Entitlement to individuals</td>
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<td>Individuals who are disabled, blind, or over 64 and low income</td>
<td>Unrestricted payments to individuals; can be used for respite</td>
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<tr>
<td>National Senior Service Corps - Senior Companion</td>
<td>Discretionary grant to projects</td>
<td>Domestic Volunteer Service Act, Title II, Part B</td>
<td>Individuals age 21 and over with special needs; frail elderly</td>
<td>Payments in the form of stipends to volunteer companions who in turn provide no cost services to consumers</td>
</tr>
</tbody>
</table>

Programs Serving Multiple Age Groups
<table>
<thead>
<tr>
<th>Program</th>
<th>Type of Assistance &amp; Eligible Entity</th>
<th>Authorizing Legislation</th>
<th>Beneficiaries (may vary by state)</th>
<th>Payments to or Support for Respite Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Senior Service Corps – RSVP and Foster Grandparent Programs</td>
<td>Grants to national and local nonprofits, schools, government agencies, faith-based and other community organizations</td>
<td>Title II, Domestic Volunteer Service Act of 1973, as amended, P.L. 93-113; as amended through P.L. 111-13, 2009</td>
<td>Older volunteers serve children, adults, and the aging population</td>
<td>No-cost volunteer services provided to consumers</td>
</tr>
<tr>
<td>AmeriCorps</td>
<td>Formula grants when applicable to Governor-appointed State Service Commissions</td>
<td>National and Community Service Act of 1990; as amended through P.L. 111-13, 2009</td>
<td>Beneficiaries identified with an application for assistance</td>
<td>No-cost volunteer services provided to consumers</td>
</tr>
<tr>
<td>Aging and Disability Resource Centers</td>
<td>Competitive grants to State Agency or instrumentality of the State</td>
<td>Titles II and IV of the Older Americans Act (OAA), as amended by the Older Americans Act Amendments of 2006, P.L. 109-365.</td>
<td>Aging population and persons with disabilities, including family caregivers</td>
<td>ADRCs play a central role in Lifespan Respite systems as mandated primary stakeholders. Information and referral to LTSS. No specific funds for respite</td>
</tr>
<tr>
<td>National Family Caregiver Support Program</td>
<td>Formula grant to states, Indian Tribal Organizations; public or nonprofit Native Hawaiian organizations</td>
<td>Older Americans Act, Title III-E and VI-C (Native American Caregiver Support Program)</td>
<td>Family caregivers; grandparents and older individuals who are relative caregivers; American Indian and Native Hawaiian family caregivers; grandparents and older individuals who are relative caregivers</td>
<td>Payments to respite care providers or consumer direction</td>
</tr>
</tbody>
</table>

### Programs for the Aging

<table>
<thead>
<tr>
<th>Program</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Supportive Services and Senior Centers</td>
<td>Formula grant to states</td>
<td>Older Americans Act, Title III, Part B</td>
<td>Individuals age 60 and over with economic and social need</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Alzheimer’s Disease Supportive Services Program</td>
<td>Discretionary grant to states</td>
<td>Public Health Service Act, Title III, Section 398</td>
<td>Individuals with Alzheimer’s Disease and their family caregivers</td>
<td>Payments to respite care Providers to support caregiver participation in program</td>
</tr>
<tr>
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<tr>
<td><strong>Programs for American Indians</strong></td>
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<tr>
<td>Indian Child Welfare Act Grants</td>
<td>Discretionary grant to Tribes</td>
<td>Indian Child Welfare Act</td>
<td>American Indian children and families</td>
<td>Payments to respite care providers</td>
</tr>
<tr>
<td>Social and Economic Development Strategies</td>
<td>Discretionary grant to Tribes</td>
<td>Native American Programs Act</td>
<td>American Indians, Alaska Natives, Native Hawaiian, and Native American Pacific Islanders</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td>Special Program for Aging American Indians</td>
<td>Discretionary grant to projects</td>
<td>Older Americans Act, Title VI</td>
<td>Older American Indians, Alaska Natives, and Native Hawaiians</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
</tr>
<tr>
<td><strong>Programs for Military Families</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite for Injured Service Members</td>
<td>Extended TRICARE respite benefits</td>
<td>National Defense Authorization Act for FY 2008, P.L. 110-181, Subtitle C, Sec. 1633.</td>
<td>Injured active duty service members, including National Guard/Reserve who have a serious injury</td>
<td>Payments to respite providers at no cost to family and no cap</td>
</tr>
<tr>
<td>Exceptional Family Member Program</td>
<td>Entitlement to individuals</td>
<td></td>
<td>Military families with a family member who has special needs/disabilities</td>
<td>Payments to respite care providers; varies by branch of military service</td>
</tr>
<tr>
<td>Armed Services YMCA Respite Child Care</td>
<td>Entitlement to individuals</td>
<td></td>
<td>Military families at participating YMCAs</td>
<td>Free membership and respite child care</td>
</tr>
<tr>
<td>Army Fee Assistance for Respite Care</td>
<td>Entitlement to individuals</td>
<td></td>
<td>Families of Deployed; Wounded, Ill, and Injured Soldiers; and Survivors of Fallen Soldiers; or geographically dispersed Accessions Command Army Recruiters, ROTC Cadet Cadres</td>
<td>Payments to respite providers at no cost to family</td>
</tr>
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<tr>
<td>Veterans Affairs Health Care – Geriatrics and Extended Care</td>
<td>Entitlement to individuals</td>
<td>Millennium Health Care and Benefits Act</td>
<td>Veterans of all eras</td>
<td>Provides respite care through VA medical centers, community settings, or in-home</td>
</tr>
<tr>
<td>Aid-and-Attendance and Housebound Benefit</td>
<td>Entitlement to individuals</td>
<td></td>
<td>Veterans with medical needs or mental or physical disability or surviving spouses</td>
<td>Unrestricted payments to individuals; can be used for respite</td>
</tr>
<tr>
<td>Volunteer Caregiver Support Network</td>
<td></td>
<td></td>
<td>Family caregivers of seriously injured veterans with polytrauma, traumatic brain injury (TBI), and/or spinal cord injury (SCI)</td>
<td>Voluntary respite services</td>
</tr>
<tr>
<td>Veteran-Directed Home and Community Based Services</td>
<td>Discretionary grant to Aging and Disability networks, including Centers on Independent Living</td>
<td></td>
<td>Veterans at risk of placement in a nursing home</td>
<td>Payments to respite care providers or consumer directed</td>
</tr>
<tr>
<td>VA Program of Comprehensive Assistance for Family Caregivers</td>
<td>Stipends to family caregivers, mental health services, health coverage and respite</td>
<td>Caregivers and Veterans Omnibus Health Services Act</td>
<td>Family caregivers of veterans receiving medical discharge for a serious injury incurred or aggravated in the line of duty on or after September 11, 2001</td>
<td>Respite must be medically and age-appropriate, and include in-home care.</td>
</tr>
</tbody>
</table>