

ARCH National Respite Network and Resource Center

# Federal Funding and Support Opportunities for Respite

Building Blocks for Lifespan Respite Systems

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## 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 AARP found that of the 65 million family caregivers nationwide, 89% 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

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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.

## 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. Congressional funding has continued 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.

***Federal funding agency:***

US Department of Health and Human Services, Administration on Aging.

***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 [Access to Respite Care and Help] 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/?s=program&mode=form&tab=step1&id=3f5d554c0aff224235606bfe82dda556>

ARCH National Respite Network and Resource Center.

[www.archrespite.org](http://www.archrespite.org)

Project summaries for the 2009 grantees can be found on the Administration on Aging website.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/LRCP/index.aspx#Grantees](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx#Grantees)

***References:***

Administration on Aging, DHHS. (2011). *Lifespan Respite Care*. Washington, DC: Author.

[http://www.aoa.gov/AoARoot/Press\\_Room/Products\\_Materials/fact/pdf/Lifespan\\_Respite\\_Care\\_Program.pdf](http://www.aoa.gov/AoARoot/Press_Room/Products_Materials/fact/pdf/Lifespan_Respite_Care_Program.pdf)

ARCH National Respite Network and Resource Center. (2010). *Webinar: Lifespan Respite 101* (and accompanying resource materials)

<http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences/webinar-lifespan-respite-101#Resources1>

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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](#), a service to help family caregivers and professionals locate respite services and funding sources in their community; the [National Respite Coalition](#), a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels; and the [Technical Assistance Centers for Caregiver Programs and](#)

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*\*ARCH stands for Access to Respite Care and Help*



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## Acronyms

AAAs	Area Agencies on Aging
ACA	Affordable Care Act
ACF	Administration for Children and Families
ADDGS	Alzheimer's Disease Demonstration Grants to the States
ADRC	Aging and Disability Resource Center
ADRD	Alzheimer's disease and related disorders
ADSSP	Alzheimer's Disease Supportive Services Program
AFAS	Air Force Aid Society
AFP	Adoption Family Preservation
AGR	Active Guard Reserve
AIA	Abandoned Infants Assistance (Program)
AoA	Administration on Aging
ARCH	Access to Respite Care and Help
ARRA	American Recovery and Reinvestment Act
CAPTA	Child Abuse Prevention and Treatment Act
CCDBG	Child Care and Development Block Grant
CCDF	Child Care and Development Fund
CDBG	Community Development Block Grant
CDC	child development center
CFC	Community First Choice
CFSIA	Child and Family Services Improvement Act
CFSP	Child and Family Services Plan
CHIP	Children's Health Insurance Program
CHIPRA	Children's Health Insurance Program Reauthorization Act
CILs	Centers for Independent Living
CISS	Community Integrated Service Systems
CLASS	Community Living Assistance Supports and Services
CMHI	Child Mental Health Initiative
CMS	Centers for Medicare and Medicaid Services
CNCS	Corporation for National and Community Services
CRC	Caregiver Resource Center
CSHCN	children with special health care needs
CYSHCN	children and youth with special health care needs
DD Act	Developmental Disabilities Assistance and Bill of Rights Act
DELTA	Domestic Violence Prevention Enhancement and Leadership Through Alliances
DFPS	Department of Family and Protective Services
DHHS	US Department of Health and Human Services
DoD	Department of Defense
DRA	Deficit Reduction Act

ECHO	extended care health option
EFM	exceptional family member
EFMP	Exceptional Family Member Program
EMA	eligible metropolitan area
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
F2F HIC	Family-to-Family Health Information Center
FACT	Families and Children Together
FGP	Foster Grandparent Program
FRIENDS	Family Resource, Information, Education and Network Development Services
FVPSA	Family Violence Prevention and Services Act
GAB	Give Me a Break (GAB)
HCBS	home and community-based services
HCD	Housing and Community Development
HUD	Department of Housing and Urban Development
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Educational Plan
IFSP	Individualized Family Service Plan
IL	independent living
IMH	infant mental health
LME	local management entity
LTC	long-term care
MCHS	Maternal and Child Health Services
MFP	Money Follows the Person
MIPPA	Medicare Improvements for Patients and Providers Act
MMA	Medicare Modernization Act
MOE	maintenance-of-effort
MR/DD	Mental Retardation/Developmental Disabilities
MSA	metropolitan statistical area
NACCRA	National Association of Child Care Resource & Referral Agencies
NASUAD	National Association of States United for Aging and Disabilities
NCCC	National Civilian Community Corps
NFCSP	National Family Caregiver Support Program
NRC	National Resource Center
OAA	Older Americans Act
OCAN	Office on Child Abuse and Neglect
OCC	Office of Care Coordination
OEF/OIF	Operation Enduring Freedom/Operation Iraqi Freedom
OKDHS	Oklahoma Department of Human Services
OMB	Office of Management and Budget
ORRN	Oklahoma Respite Resource Network
PACE	Programs of All-Inclusive Care for the Elderly
PFPWD	Program for Persons with Disabilities

PNS	Programs of National Significance
PPACA	Patient Protection and Affordable Care Act
PRTF	psychiatric residential treatment facility
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
RHHI	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
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	US 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 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 eight 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. An additional section describes provisions enacted in health care reform that have the potential to support respite. 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, newer initiatives made possible through recent enactment of the Affordable Care Act, such as the Community First Choice Option or State Balancing Incentive Payments Program, are financing methods that can be used by states to increase the federal share of Medicaid funding they receive for home and community-based services overall; indirectly, those initiatives could mean additional resources for respite.

The economic crises 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 more people in need. Medicaid sustainability is increasingly threatened in the face of serious state budget shortfalls. In 2009, all states reported using mechanisms to control costs in home and community-based service (HCBS) waivers such as restrictive financial and function eligibility standards, enrollment limits, and waiting lists.<sup>1</sup> Waiting lists for certain home and community-based Medicaid waivers are extremely high, and the waiting times on average are close to 2 years. Referring families to them may only result in disappointment when services are not immediately available. In addition, given serious state funding shortfalls, state match requirements for some federal grants may discourage states from seeking those grants 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<sup>2</sup>:

- **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.
- **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.

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<sup>1</sup> Kaiser Commission on Medicaid and the Uninsured. (2011). *Medicaid Home and Community-Based Service Programs: Data Update*. <http://www.kff.org/medicaid/upload/7720-04.pdf>

<sup>2</sup> Lind, C., Relave, N., Schmid, W., & Terzaghi, D. (2009). [Finding Funding: A Guide to Federal Sources for Asset-Building Initiatives](#). Washington, DC: The Finance Project.



## State Funding

This guide has not addressed state funding for respite. ARCH is in the process of identifying these programs, and the information will be available in a subsequent publication. 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 can be difficult to identify state government as a source of funding.

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 help, contact the ARCH National Respite Network at 703-256-2084 or by email at [jbkagan@verizon.net](mailto:jbkagan@verizon.net).

## 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. There was a slight increase in total participants in Medicaid HCBS programs, with more than 2.8 million individuals being served through these programs in 2007. Since 1999, the number of HCBS participants has increased by nearly 1 million people, but the number of participants has remained relatively flat since 2005. Most of the growth has occurred through waiver programs. Almost 1.2 million individuals were served through HCBS waivers, 813,848 individuals received care through the home health benefit, and 826,251 individuals received the personal care services benefit (see [Medicaid Personal Care Benefit](#) in this section).

Federal regulations limit the ability of states to cover the cost of respite care directly as a regular Medicaid benefit under the state plan because it is considered a nonmedical expense. The exception, begun in 1985, is the Medicaid Hospice option. However, there are a number of research, demonstration, and waiver programs under Medicaid that have allowed 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

- **Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities** demonstrations,
- **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**

Most recently, health care reform legislation 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]), a State Balancing Incentives Payment Program of enhanced funding for HCBS, and Community Living Assistance Supports and Services (CLASS), a voluntary insurance program to pay for long-term services and supports.

Each of these programs, demonstrations, and waivers is described in this and the following two sections.

## 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. This amount can change each year; for FY 2010, the approved amount is \$147.83, resulting in a daily co-payment of less than \$7.50 per day.

### *Federal funding agency:*

US 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 list of Regional Home Health Intermediaries (RHHIs) can be downloaded from the CMS website at <http://www.cms.gov/center/hha.asp> (scroll down to Contacts on the right side of the page); or call 1-800-MEDICARE (1-800-633-4227) for local telephone numbers. TTY users can call 1-877-486-2048.

A list of state hospice organizations can be found on the Hospice Directory website.

[http://www.hospicedirectory.org/cm/about/state\\_hospice](http://www.hospicedirectory.org/cm/about/state_hospice)

***Related links:***

US Department of Health and Human Services, Administration on Aging. Hospice Fact Sheet.

[http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Hospice\\_Care.aspx](http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Hospice_Care.aspx)

Medicare Hospice Benefits.

<http://www.medicare.gov/publications/pubs/pdf/02154.pdf>

***References:***

Considering Hospice Care.

[http://www.medicare.gov/caregivers/pdfs/Medicare\\_Basics/Considering\\_hospice\\_care.pdf](http://www.medicare.gov/caregivers/pdfs/Medicare_Basics/Considering_hospice_care.pdf)

## Medicare Advantage Special Needs Plans (SNPs)

### *Authorizing legislation:*

Title XIX 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; and
- Medicare Improvements for Patients and Providers Act (MIPPA) of 2008.

### *Currently authorized through:*

December 31, 2010.

### *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 precancer conditions),
  - certain cardiovascular disorders,
  - chronic heart failure,
  - dementia,
  - 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:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***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.

<http://www.medicare.gov/find-a-plan/questions/home.aspx>

HealthCare.gov.

<http://www.healthcare.gov/>

***References:***

Centers for Medicare & Medicaid Services. (2011). *Medicare & You*.

<http://www.medicare.gov/publications/pubs/pdf/10050.pdf>

Centers for Medicare & Medicaid Services. (2010). *Your Guide to Medicare Special Needs Plans (SNPs)*.

<http://www.medicare.gov/Publications/Pubs/pdf/11302.pdf>

The Commonwealth Fund. (2008). *Issue brief: Medicare Advantage Special Needs Plans for Dual Eligibles: A Primer*.

[http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2008/Feb/Medicare%20Advantage%20Special%20Needs%20Plans%20for%20Dual%20Eligibles%20%20A%20Primer/Milligan\\_MedicareAdvspecneedsprimer\\_1108\\_ib%20pdf.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2008/Feb/Medicare%20Advantage%20Special%20Needs%20Plans%20for%20Dual%20Eligibles%20%20A%20Primer/Milligan_MedicareAdvspecneedsprimer_1108_ib%20pdf.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. In 2008, federal and state spending on personal care totaled \$47.8 billion, or 42% of the \$114.8 billion spent for long-term care under Medicaid.<sup>3</sup>

### *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.”<sup>4</sup>

### *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. As of October 2010, 30 states and the District of Columbia included the personal care option in their state plan.

### *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.

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<sup>3</sup> Kaiser Commission on Medicaid and the Uninsured. (2010). *The Medicaid program at a glance*. <http://www.kff.org/medicaid/upload/7235-04.pdf>

<sup>4</sup> Section 1905(a)(24) of the Social Security Act, as amended.



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.

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:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Catalog of Federal Domestic Assistance: Medical Assistance Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=9a3cebadf7408ddc4777e05e6c6e2dda>

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>

***References:***

Summer, L.L., & Ihara, E.S. (2005). *The Medicaid Personal Care Services Benefit: Practices in states that offer the optional state plan benefit*. Washington, DC: Georgetown University Health Policy Institute.

[http://assets.aarp.org/rgcenter/health/2005\\_11\\_medicaid.pdf](http://assets.aarp.org/rgcenter/health/2005_11_medicaid.pdf)

## 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 began as a Section 1115 waiver (see [Section 1115, Research and Demonstration Projects, Medicaid Waivers](#), p. 37) 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](#), p. 36) or under other programs. There is considerable variation by and even within states.

### *Federal funding agency:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

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***Points of contact:***

Contact information for each state is available through an online interactive map.

[http://www.cashandcounseling.org/about/participating\\_states](http://www.cashandcounseling.org/about/participating_states)

***Related links:***

Cash & Counseling.

[http://www.bc.edu/schools/gssw/nrcpds/cash\\_and\\_counseling.html](http://www.bc.edu/schools/gssw/nrcpds/cash_and_counseling.html)

National Resource Center for Participant-Directed Services.

<http://www.bc.edu/schools/gssw/nrcpds/>

Paying for Senior Care: Receive Payment as a Caregiver: Cash & Counseling Program.

<http://www.payingforseniorcare.com/longtermcare/resources/cash-and-counseling-program.html>

***References***

Brown, R., Lepidus Carlson, B., Dale, S., Foster, L., Phillips, B., & Schore, J. (2007). *Cash & Counseling: Improving the lives of Medicaid beneficiaries who need personal care or home and community-based services*. Final report. Princeton, NJ: Mathematica Policy Research, Inc.

<http://www.rwjf.org/files/research/0807casfinalcrosscutting.pdf>

Doty, P., Mahoney, K.J., & Sciegaj, M. (2010). New state strategies to meet long-term care needs. *Health Affairs* 29:1, 49-56.

<http://www.rwjf.org/files/research/53890.pdf>

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

### *Authorizing legislation:*

Balanced Budget Act of 1997.

### *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.

### *Funding:*

PACE is a capitated benefit with integrated Medicare and Medicaid financing.

### *Activities supported by the funding:*

“An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants’ needs, develops care plans, and delivers all services (including acute care services and, when necessary, nursing facility services), which are integrated for seamless provision of total care. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant’s needs. The PACE service package must include all Medicare- and Medicaid-covered services and other services determined necessary by the interdisciplinary team for the care of the PACE participant.”<sup>5</sup> As of January 2011, there were more than 80 PACE programs in 30 states serving more than 19,000 enrollees.<sup>6</sup>

### *Respite connection:*

A PACE program can incorporate caregiver services into the care plan and make respite services available to caregivers.<sup>7</sup> 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.

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

PACE becomes the sole source of services for Medicare and Medicaid for eligible enrollees.

### *Federal funding agency:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

### *Points of contact:*

A list of PACE Provider Organizations is available from the Centers for Medicare & Medicaid Services at <https://www.cms.gov/PACE/LPPO/list.asp>

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<sup>5</sup> Centers for Medicare & Medicaid Services. Overview. [https://www.cms.gov/PACE/01\\_Overview.asp](https://www.cms.gov/PACE/01_Overview.asp)

<sup>6</sup> National PACE Association, *PACE in the States*: <http://www.npaonline.org/website/download.asp?id=1741>

<sup>7</sup> Centers for Medicare & Medicaid Services. [https://www.cms.gov/PACE/01\\_Overview.asp#TopOfPage](https://www.cms.gov/PACE/01_Overview.asp#TopOfPage)

***Related links:***

National PACE Association.

<http://www.npaonline.org/website/article.asp?id=4>

Kaiser Family Foundation Medicaid Benefits Online Database.

<http://medicaidbenefits.kff.org/service.jsp?gr=off&nt=on&so=0&tg=0&yr=5&cat=1&sv=42>

***References***

Centers for Medicare & Medicaid Services. (2008). *Quick Facts about the Programs of All-Inclusive Care for the Elderly (PACE)*.

<https://www.cms.gov/PACE/Downloads/externalfactsheet.pdf>

## 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.

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***Federal funding agency:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services. <http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Catalog of Federal Domestic Assistance: Medical Assistance Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=9a3cebadf7408ddc4777e05e6c6e2dda>

Health Resources and Services Administration: EPSDT and Title V Collaboration to Improve Child Health.

<http://www.hrsa.gov/epsdt/>

***References:***

Kaiser Commission on Medicaid and the Uninsured. (2007). *Aging out of EPSDT: Issues for young adults with disabilities*.

<http://www.kff.org/medicaid/upload/7491.pdf>

## 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 October 2010, 49 states (all but Oklahoma) plus the District of Columbia offer 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:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

### *Eligible entity:*

State Medicaid Agency.

### *Points of contact:*

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

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***Related links:***

Catalog of Federal Domestic Assistance: Medical Assistance Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=9a3cebadf7408ddc4777e05e6c6e2dda>

Kaiser Family Foundation Medicaid Benefits Online Database

<http://medicaidbenefits.kff.org/service.jsp?gr=off&nt=on&so=0&tg=0&yr=5&cat=1&sv=13>

***References:***

State Medicaid Director Letter SMD#10-018 - 9/9/10

<http://www.cms.gov/smdl/downloads/SMD10018.pdf>

## Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities

### *Authorizing legislation:*

Section 6063, Deficit Reduction Act of 2005 (DRA), P.L. 109-71.

### *Currently authorized through:*

September 30, 2011.

### *Program purpose:*

To enable states to provide home and community-based alternatives to care to youth with serious emotional disturbances requiring an institutional level of care. Psychiatric residential treatment facilities (PRTFs), the primary providers of care for these youth, have not been eligible providers for Section 1915(c) waivers.

### *Beneficiaries:*

Medicaid-eligible individuals who are under age 21 and require a PRTF, as defined in the state's Medicaid State Plan. States may elect to add additional criteria to carve out or target a specific subpopulation to receive home and community-based services.

### *Funding:*

DRA provided up to \$218 million to nine states to develop demonstration programs that provide home and community-based services to youth as alternatives to PRTFs. Grants range between \$5 million and \$60 million. The PRTF Demonstration is authorized for up to 5 years and is due to expire in 2012. At the conclusion of these demonstrations, states will have the option of continuing to provide home and community-based care alternatives for demonstration participants under a 1915(c) waiver. Programs must be budget neutral; unspent funds will be carried over to the following grant year.

### *Activities supported by the funding:*

Grants support funding for diagnosis, treatment planning, treatment, educational services, vocational services and activities, social skills training, and support to both the consumer and the family.

### *Respite connection:*

Respite care is specifically listed as a support service that may be funded under this program. Locations for respite service include (but are not limited to) the consumer's home; private residence of the respite care provider; foster home; Medicaid-certified hospital, nursing facility, or intermediate care facility for the mentally retarded; or group home, licensed respite care facility, or other approved community residential facility. Respite can be provided specifically for relieving a primary family caregiver.

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

States may limit availability of these services to specific geographic areas or populations.

States initially receiving these grants were Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia. Florida was initially awarded a grant but withdrew from the demonstration. States have enrolled close to 3,000 children and youth as of March 1, 2011. It is estimated that approximately 6,000 children and youth will be served by the end of the demonstration.

### *Federal funding agency:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency or State Mental Health Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

or <https://www.cms.gov/apps/contacts/>

***Related links:***

Catalog of Federal Domestic Assistance: Alternatives to Residential Treatment Facilities for Children.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=cba91bf034fc1551f498e3d71d2036c0>

***References***

IMPAQ International & Westat, Inc. (2010). National evaluation of Medicaid demonstration: Home and community-based alternatives to psychiatric residential treatment facilities Year 2 implementation status report.

[https://www.cms.gov/CommunityServices/Downloads/CBA\\_Implementation\\_Status\\_Report\\_2009.pdf](https://www.cms.gov/CommunityServices/Downloads/CBA_Implementation_Status_Report_2009.pdf)

## 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. There are currently four separate types of waivers 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 (c) Waivers.**

Medicaid Waivers are by far the largest source of federal funds for respite. However, in most states, long waiting lists for services prevail. In 2009, 39 states reported waiver wait lists totaling 365,553 individuals, including almost a quarter of a million persons waiting for Mental Retardation/Developmental Disabilities (MR/DD) waiver services, and more than 100,000 persons waiting for aged/disabled waivers. The average time on a waiting list for waiver services was almost 2 years, with wide variations among programs. The average length of time an individual spent on a waiting list ranged from 6 months for aged and HIV/AIDS waivers to 35 months for MR/DD waivers.<sup>8</sup>

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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<sup>8</sup> Kaiser Commission on Medicaid and the Uninsured. (2011). *Medicaid Home and Community-Based Service Programs: Data Update*. <http://www.kff.org/medicaid/upload/7720-04.pdf>

## 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](#) on p. 26) began as a Section 1115 waiver in 1998 in three states; it was expanded to include 15 states and will expand to an additional 20 states in 2011. Arizona and Vermont operate their Medicaid long-term care program under a Section 1115 demonstration waiver.

### *Respite connection:*

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

**Example:** Vermont's *Choices for Care* is a 1115 Long-Term Care Medicaid waiver program that covers care and support for elderly residents and those with physical disabilities. It provides assistance with everyday activities at home, in an enhanced residential care setting, or in a nursing facility. Personal care, respite, companion services, and adult day services are core activities covered by the program.<sup>9</sup>

**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

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<sup>9</sup> Vermont Division of Disability and Aging Services. (2010). *Choices for care (1115 long-term care Medicare waiver)*. <http://www.ddas.vermont.gov/ddas-programs/programs-cfc/programs-cfc-default-page#services>

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.<sup>10</sup>

***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 US 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:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Medicaid Waivers and Demonstrations List.

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

***References:***

Kitchener, M., Willmott, M., Wong, A., & Harrington, C. (2006). *Home and Community-Based Services: Medicaid Research and Demonstration Waivers*. Center for Personal Assistance Services.

[http://pascenter.org/demo\\_waivers/](http://pascenter.org/demo_waivers/)

Kaiser Commission on Medicaid and the Uninsured. (2003). *Section 1115 Medicaid and SCHIP waivers: Policy implications of recent activity*.

<http://www.kff.org/medicaid/upload/Section-1115-Medicaid-and-SCHIP-Waivers-Policy-Implications-of-Recent-Activities-Policy-Brief.pdf>

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<sup>10</sup> Tennessee. (2010). TennCare. <http://www.tn.gov/tenncare/>

## Section 1915(b) Managed Care/Freedom of Choice 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 of providers for services.

### *Respite connection:*

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

**Example:** North Carolina operates a waiver program for individuals needing mental health, developmental disabilities, and substance abuse services. Those services are delivered through local management entities (LMEs). Respite is a service specifically covered under the waiver, which is approved through March 31, 2013.<sup>11</sup>

### *Federal funding agency:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

### *Eligible entity:*

State Medicaid Agency.

### *Points of contact:*

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

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<sup>11</sup> North Carolina Department of Health and Human Services. (2010). *MH/DD/SAS Health Plan Waiver*. <http://www.ncdhhs.gov/dma/services/piedmont.htm>

*Related links:*

Medicaid Waivers and Demonstrations List.

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

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## 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 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 currently there are approximately 287 active HCBS waiver programs in operation throughout the country. All of these states include respite within one or more of their 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.

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. Providers are reimbursed on a fee-for-service basis and must follow the state’s reporting requirements. Medicaid’s billing system may also require programs to implement somewhat sophisticated cost accounting procedures.

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:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Medicaid Waivers and Demonstrations List.

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

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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 disabled and/or elderly populations. 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.

**Example:** Texas STAR+PLUS, approved in January 1998 for Harris County, was the first combined 1915(b)/(c) program to be implemented. It currently serves 29 counties and will expand to 13 more in 2011. This mandatory program serves Supplemental Security Income (SSI-) or Medicaid-eligible individuals with physical or mental disabilities, SSI recipients age 21 and older, and certain other individuals. It is voluntary for SSI recipients under age 21. It excludes residents of nursing facilities. Consumers have a choice of health plans, but if they fail to enroll, they are assigned to both a plan and a primary care provider. Plans are required to provide a range of medically necessary services, including home health care, personal attendant, day activity, and in- or out-of-home respite.<sup>12</sup>

### *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.

<sup>12</sup> Texas Health and Human Services Commission. (2010). *STAR+PLUS*. <http://www.hhsc.state.tx.us/starplus/Overview.htm>

***Federal funding agency:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Medicaid Waivers and Demonstrations List.

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

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## Additional Opportunities in Health Care Reform

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 programs were enacted under ACA:

- **Community Living Assistance Supports and Services (CLASS)**, a voluntary insurance program funded by payroll deduction to help adults with functional impairments remain independent, employed, and engaged in the community. Recipients receive a cash benefit expected to average around \$75 per day. Recipients have the flexibility to use cash benefits to pay for a range of long-term services and supports, including respite care. However, the US Department of Health and Human Services does not plan to implement the program because of questions about its potential solvency.
- **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.
- **State Balancing Incentives Payments Program** to provide states with additional funds to increase the portion of Medicaid long-term services and supports funding going toward HCBS.

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. 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.

<http://www.medicaid.gov/>

## Community Living Assistance Supports and Services (CLASS)

### *Authorizing legislation:*

Title VIII of the Patient Protection and Affordable Care Act of 2010 (ACA).<sup>13</sup>

### *Currently authorized through:*

Authorizing legislation requires that the program will be solvent for at least 75 years.

### *Program purpose:*

To help adults with functional impairments remain independent, employed, and engaged in the community.

### *Beneficiaries:*

To receive benefits, participants must be certified as having a functional limitation expected to last at least 90 days, consisting of

- a limitation in at least two or three activities of daily living (e.g., eating, bathing, dressing) or
- a cognitive impairment requiring substantial supervision or hands-on assistance to perform activities of daily living.

Participants will pay premiums for 5 years before they may receive a benefit. For 3 of those 5 years, they must earn enough to qualify for one quarter of Social Security coverage (in 2010, about \$1,100).

### *Funding:*

This is a voluntary insurance program funded by payroll deductions.

### *Activities supported by the funding:*

Recipients will receive a cash benefit provided through a debit card. Benefits, which will vary based on the level of impairment, are expected to average around \$75 per day. Recipients have the flexibility to use the benefit to meet their specific needs.

### *Respite connection:*

Cash benefits may be used to pay for respite care.

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

This program was to become effective January 1, 2011, but the Secretary Sebelius of the US Department of Health and Human Services transmitted a report and letter to Congress stating that the Department does not see a viable path forward for CLASS implementation at this time.<sup>14</sup> Components of the program are:

- Participants will pay premiums for 5 years before they may receive a benefit. For 3 of those 5 years they must earn enough to qualify for one quarter of Social Security coverage (in 2010, about \$1,100).

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<sup>13</sup> Patient Protection and Affordable Care Act of 2010 (PPACA) and the Affordable Care Act (ACA) are used interchangeably in this document and the acronym ACA used for the final health care reform law.

<sup>14</sup> US Department of Health and Human Services (2011). *A Report on the Actuarial, Marketing, and Legal Analyses of the CLASS Program*. <http://aspe.hhs.gov/daltcp/reports/2011/class/index.shtml>

- Premiums will vary by age, with older participants paying less.
- Premiums will not vary by income or medical condition.
- There will be no exclusions for pre-existing conditions; there will be no means-testing for benefits.
- CLASS benefits will offset some Medicaid costs; CLASS will be the primary payer for persons also eligible for Medicaid.

#### ***Related links:***

Healthcare.gov: What is Community Living Assistance Services and Supports (CLASS) Program?  
<http://www.healthcare.gov/using-insurance/medicare-long-term-care/long-term-care/#living>

#### ***References:***

Association of University Centers on Disabilities. (2010). *Patient Protection and Affordable Care Act. New Options for Long-Term Services and Supports*. Silver Spring, MD: Author.  
[https://www.aucd.org/docs/policy/health\\_care/Section%20by%20Section%20summary%20of%20LTSS%20in%20HCR%20law%205-5-10.pdf](https://www.aucd.org/docs/policy/health_care/Section%20by%20Section%20summary%20of%20LTSS%20in%20HCR%20law%205-5-10.pdf)

Henry J. Kaiser Family Foundation. (2009). *The Community Living Assistance Services and Supports (CLASS) Act*. Menlo Park, CA: Author.  
<http://www.kff.org/healthreform/upload/7996.pdf>

## 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 will also help consumers acquire, maintain, and enhance their daily living skills, will train the consumer on selecting, managing, and dismissing attendants, and will establish 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.

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.

***Federal funding agency:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Kaiser Family Foundation: Health Reform.

<http://www.kff.org/healthreform/7952.cfm>

***References:***

Walker, L. (2010). *Fact sheet 192: Health care reform improves access to Medicaid home and community-based services*. Washington, DC: AARP Public Policy Institute.

<http://assets.aarp.org/rgcenter/ppi/lrc/fs192-hcbs.pdf>

## State Balancing Incentive Payments Program

### *Authorizing legislation:*

Patient Protection and Affordable Care Act (ACA), P.L. 111-148.

### *Currently authorized through:*

Effective October 1, 2011, through September 30, 2015.

### *Program purpose:*

To provide states with additional funds to increase the portion of Medicaid long-term services and supports funding going toward home and community-based services (HCBS).

### *Funding:*

States spending less than half their total Medicaid long-term services and supports dollars on HCBS programs can receive an enhanced federal match. The law makes \$3 billion available over the 4 years of the program. The enhanced match will be

- a 5% increase for those states that spent less than 25% of their Medicaid long-term services and supports spending on HCBS in FY 2009, and
- a 2% increase for all other states that spent less than 50% of their Medicaid long-term services and supports spending on HCBS in FY 2009.

### *Activities supported by the funding:*

Enhanced match can be spent on all Medicaid HCBS programs including HCBS waivers, mandatory home health benefit, Personal Care Option, self-directed personal assistance services, and Program of All-Inclusive Care for the Elderly (PACE) programs.

### *Respite connection:*

The State Balancing Incentive Payments Program potentially increases funding for Medicaid HCBS services. Since respite may be funded under any of the Medicaid HCBS programs, additional funding for respite could be available as a result.

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

The state must apply for these funds and describe structural changes it plans to make to its delivery system within 6 months. It may not adopt more restrictive eligibility standards than those in place as of December 31, 2010.

### *Federal funding agency:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

### *Eligible entity:*

State Medicaid Agency.

### *Points of contact:*

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services. <http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

### *Related links:*

Kaiser Family Foundation: Health Reform.

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<http://www.kff.org/healthreform/7952.cfm>

**References:**

Walker, L. (2010). Fact sheet 192: *Health care reform improves access to Medicaid home and community-based services*. Washington, DC: AARP Public Policy Institute.

<http://assets.aarp.org/rgcenter/ppi/lrc/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.

### *Activities supported by the funding:*

As with 1915(c) HCBS waivers, states can provide services not previously covered by the 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 supported under this option.

**Example:** Iowa used this State Plan Option to create its HCBS Habilitation Services Program for individuals with functional impairments associated with mental illnesses. Allowable services—designed to assist consumers in the areas of self-help, socialization, and adaptive skills so they can reside successfully in home and community settings—include day habilitation services outside the home. While respite is not specifically discussed, these services would provide a break for family caregivers.<sup>15</sup>

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

This State Plan Option first became available under DRA effective in 2007, but only four states<sup>16</sup> pursued it because (1) states could place caps on the number of individuals served; (2) income limitations were more strict than those under 1915(c) waivers, which would have caused beneficiaries to lose eligibility; (3) states were not permitted to target services to specific populations, which they could do under 1915(c) waivers; and (4) only HCBS services specified in a 1915(c) waiver could be offered.

Effective October 1, 2010, ACA builds on the DRA authority by expanding eligibility under this option to individuals with incomes up to 300% of the maximum Supplemental Security Income (SSI) payment and by making a number of other changes to address state concerns. The ACA also eliminated the states' ability to cap enrollment or maintain a waiting list. Only four states (Colorado, Iowa, Nevada, and Washington) had the HCBS State Plan Option in place prior to FY 2010. Two states (Wisconsin and

<sup>15</sup> Iowa Department of Human Services. *HCBS Habilitation Services Program*. <http://www.ime.state.ia.us/HCBS/HabilitationServices/Info.html>

<sup>16</sup> Iowa, Colorado, Nevada, and Washington.

Washington) reported implementing the HCBS State Plan Option in FY 2010, and six states indicated plans to implement this option in FY 2011 (California, Georgia, New Jersey, North Carolina, Oregon, and Texas).<sup>17</sup>

***Federal funding agency:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***Points of contact:***

A list of state Medicaid program websites is available from the Centers for Medicare & Medicaid Services.

<http://www.cms.gov/MedicaidEligibility/downloads/ListStateMedicaidWebsites.pdf>

***Related links:***

Binder, C. (2008). Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act. Washington, DC: Congressional Research Service.

<http://aging.senate.gov/crs/medicaid17.pdf>

***References:***

Bazelon Center for Mental Health Law. (2007). *Medicaid State Plan Option for Home and Community-Based Services*. Washington, DC: Author

<http://www.bazelon.org/LinkClick.aspx?fileticket=dwpFNntcYBs%3D&tabid=242>

Enquist, G., Johnson, C., Lind, A., & Palmer Barnette, L. (2010). *Medicaid-funded long-term care: Toward more home and community-based options*. Hamilton, NJ: Center for Health Care Strategies, Inc.

[http://www.chcs.org/usr\\_doc/LTSS\\_Policy\\_Brief\\_.pdf](http://www.chcs.org/usr_doc/LTSS_Policy_Brief_.pdf)

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<sup>17</sup>Smith, Vernon K. Ph.D., Kathleen Gifford, Eileen Ellis, Robin Rudowitz and Laura Snyder. (2010). *Hoping for Economic Recovery, Preparing for Health Reform: A Look at Medicaid Spending, Coverage and Policy Trends -- Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2010 and 2011*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured Kaiser Family Foundation. <http://www.kff.org/medicaid/upload/8105.pdf>

## Money Follows the Person (MFP) Demonstration Grants

### *Authorization:*

Deficit Reduction Act of 2005, P.L. 109-171; Patient Protection and Affordable Care Act of 2010 (ACA).

### *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 extends funding for Medicaid Money Follows the Person Rebalancing Demonstration Programs through 2016 and reduces the length of time a person is required to reside in an institutional setting before becoming eligible to participate in this program (previously at least 6 months, but now at least 90 consecutive days).<sup>18</sup> 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:*

Grants pay for 1 year of community-based services for each person transitioned from an institution. The savings incurred by the state through the enhanced federal match are to be used to develop and/or sustain LTC HCBS systems.

### *Respite connection:*

Respite programs for family caregivers are included in covered 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.

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<sup>18</sup> *Medicaid Long-Term Services and Supports: Key Changes in the Health Reform Law*. Kaiser Family Foundation, June 2010. <http://www.kff.org/healthreform/upload/8079.pdf>

**Example:** Ohio's MFP program, HOME Choice, is managed by the Ohio Department of Job and Family Services, the State Medicaid Agency. Participants enroll in one of the state's home and community-based services (HCBS) waivers or receive services through Medicaid with HOME Choice demonstration services as a "wrap-around" for the first 365 days to ensure continuity of care and integration back into community living. Demonstration services include respite. Services are participant directed. Referrals to HOME Choice can come from any source via the completion of an Interest Form and/or the HOME Choice Application. Referrals come from nursing homes, long-term care ombudsmen, centers for independent living, and individuals themselves. If found eligible, the Medicaid beneficiary is preapproved for HOME Choice and chooses a transition coordinator. The transition coordinator works with the case manager to assist the consumer in discharge planning activities. Transition coordinators help specifically with finding housing, employment, and other services. Transition coordination ends when the consumer moves to a community setting and the 365-day demonstration period begins.

**Example:** The Roads to Community Living (RCL) is Washington State's Money Follows the Person Program. Respite services may be authorized on an hourly basis for eligible RCL participants and can be provided by the participant's paid individual provider, family provider, or agency provider in the participant's home. The services are authorized at the hourly rate for the provider up to a maximum of 60 hours over a 3-month period. Respite is billed at the provider's hourly rate. The services are authorized at the hourly rate for the provider up to a maximum of 60 hours over a 3-month period. To receive information on how to apply, go to <http://www.aasa.dshs.wa.gov/professional/roads/>

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

With the extension of the program through the ACA, additional states are able to start MFP demonstration projects, and the existing states will be able to seamlessly transition into the next 5 years. In February 2011, CMS awarded 13 MFP grants to another 13 states for a total of 44 grants. The extension of the program also changes 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:*

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

### *Eligible entity:*

State Medicaid Agency or State Mental Health Agency.

**Points of contact:**

MFP and Home and Community-Based Waiver state contacts.

<http://www.hud.gov/offices/pih/programs/hcv/pwd/state-agency-contacts.pdf>

**Related links:**

Catalog of Federal Domestic Assistance: Money Follows the Person Rebalancing Demonstration.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=4eead63e20828562d21e3675d1e78dc7>

**References:**

Lipson, D., Gruman, C., Schimmel, J., Colby, M., Denny-Brown, N., Peterson, S., et al. (2007). *Money Follows the Person Demonstration Grants: Summary of state MFP program applications*. Washington, DC: Mathematica Policy Research, Inc.

<https://www.cms.gov/CommunityServices/Downloads/StateMFPGrantSummaries-All.pdf>

Denny-Brown, Noelle, et al. (2011). *Money Follows the Person Demonstration: Overview of State Grantee Progress, July – December 2010*. Mathematica Policy Research, Inc. [http://www.mathematica-mpr.com/publications/pdfs/health/MFP\\_july-dec2010\\_progress.pdf](http://www.mathematica-mpr.com/publications/pdfs/health/MFP_july-dec2010_progress.pdf)

National Association of States United for Aging and Disabilities. (2011) *Money Follows the Person: Impediments to Implementation, A Fact Sheet on Program Start up, Capacity and Access*.

[http://www.nasuaad.org/documentation/nasuaad\\_materials/MFP%20Fact%20Sheet%20Final.pdf](http://www.nasuaad.org/documentation/nasuaad_materials/MFP%20Fact%20Sheet%20Final.pdf)



## 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.<sup>19</sup>

### *Currently authorized through:*

September 2015.

### *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.

### *Beneficiaries:*

Targeted low-income children who have been determined eligible by the state for child health assistance under their state plan are low-income children or 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. In general, children in families with incomes up to \$44,100/year (for a family of four) are likely to be eligible for coverage. In many states, families can have higher incomes, and their children can still qualify.

### *Funding:*

Each state's federal FY 2009 allotment was determined by formulas based on FY 2008 spending or allotment or projected FY 2009 spending. In 2010 and 2011, allotments will be automatically increased by an inflation factor. In 2011 and 2013, allotments will be redetermined ("rebased") on the basis of the amount each state actually used in the previous year. Unused amounts from those years will be redistributed to other states that demonstrate need. Beginning in FY 2016, states will receive an increase of 23% (up to 100%) in their Children's Health Insurance Program (CHIP) match rate.

### *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. The federal government provides a capped amount of funds to states on a matching basis. 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.

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<sup>19</sup> 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).

***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.”

**Example:** North Carolina CHIP, known as Health Choice, has a separate component for children with special health care needs, defined as those who have a condition lasting 12 months or more that interferes with the child’s daily routine and requires more medical care and family management than needed by most children. Eligibility is certified annually by a physician. Services under this additional coverage include emergency respite for “unplanned situations in which family members temporarily do not have the capacity to safely care for their child or when changes in their child’s health, behavior, or development require in-home or out-of-home temporary support.”<sup>20</sup> All services under this coverage require prior approval and documentation from a medical provider that the service is medically necessary.

***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:***

US Department of Health and Human Services, Centers for Medicare & Medicaid Services.

***Eligible entity:***

State Medicaid Agency.

***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>

***Related links:***

Catalog of Federal Domestic Assistance: Children’s Health Insurance Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=37f3aa6a3e750e44a9dc076fcdc edfce>

Georgetown University Health Policy Institute Center for Children and Families.

<http://ccf.georgetown.edu/index/chip-law>

Insure Kids Now.

<http://www.insurekidsnow.gov/>

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<sup>20</sup> North Carolina Department of Health and Human Services. (2008). Information for children with special health care needs and their families. [http://www.dhhs.state.nc.us/dma/healthchoice/sn\\_booklet.pdf](http://www.dhhs.state.nc.us/dma/healthchoice/sn_booklet.pdf)

**References:**

Georgetown University Health Policy Institute Center for Children and Families. (2009). *The Children's Health Insurance Reauthorization Act of 2009: Overview and Summary*.

<http://ccf.georgetown.edu/index/cms-fileSystem-action?file=ccf%20publications/federal%20schip%20policy/chip%20summary%2003-09.pdf>

Template for Child Health Plan under Title XXI of the Social Security Act Children's Health Insurance Program. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/Downloads/Title-XXI-State-Plan-Revised-091311-508final.pdf>

## 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 I, Family Connection Grants;
- 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 Abandoned Infants Assistance Act,
- 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 Program.

For more on federal child welfare funding, see: US Department of Health and Human Services. (2009). How Federal legislation impacts child welfare service delivery. Washington, DC: Child Welfare Information Gateway. <http://www.childwelfare.gov/pubs/impacts/impacts.pdf>

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

### *Authorizing legislation:*

Title I, Section 106 of the Child Abuse Prevention and Treatment Act of 1974 (CAPTA), P.L. 93-247, 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 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. Total funding has been steady at \$26.5 million since 2008.

### *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:***

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

#### ***Eligible entity:***

State child welfare agency.

#### ***Points of contact:***

Links to state agency websites are available at the Child Welfare Information Gateway.

[http://www.childwelfare.gov/pubs/reslist/rl\\_dsp\\_website.cfm?rs\\_ID=16&rate\\_chno=AZ-0004E](http://www.childwelfare.gov/pubs/reslist/rl_dsp_website.cfm?rs_ID=16&rate_chno=AZ-0004E)

#### ***Related links:***

Catalog of Federal Domestic Assistance, Child Abuse and Neglect State Grants.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=32edc51ae4eee193aaefbfebcc99e07a>

#### ***References:***

Stoltzfus, E., (2009). *The Child Abuse Prevention and Treatment Act (CAPTA): Background, programs and funding*. Washington, DC: Congressional Research Service.

<http://www.napcwa.org/Legislative/docs/CAPTACongressionalResearchReport.pdf>

US Dept of Health and Human Services, Administration for Children and Families, Children's Bureau (2011). *The Child Abuse Prevention and Treatment Act, Including Adoption Opportunities & The Abandoned Infants Assistance Act, as Amended by P.L. 111-320 The CAPTA Reauthorization Act of 2010*  
[http://www.acf.hhs.gov/programs/cb/laws\\_policies/cblaws/capta/capta2010.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/cblaws/capta/capta2010.pdf)

## 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 US 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,
- respite and crisis nursery programs provided by community-based organizations, and
- 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](http://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:***

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

***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>

US Dept of Health and Human Services, Administration for Children and Families, Children's Bureau (2011). *The Child Abuse Prevention and Treatment Act, Including Adoption Opportunities & The Abandoned Infants Assistance Act, as Amended by P.L. 111-320 The CAPTA Reauthorization Act of 2010.*

[http://www.acf.hhs.gov/programs/cb/laws\\_policies/cblaws/capta/capta2010.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/cblaws/capta/capta2010.pdf)

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## 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 Wisconsin, the Wisconsin Respite Care Association is working with the state Children’s Trust Fund to prevent initial occurrences of child abuse and neglect by targeting planned and/or emergency respite care to families exhibiting risk factors. The organization is currently working to establish regional partnerships to coordinate resources and deliver direct respite care services, establish guidelines and standards for programs and providers, establish evaluation protocol, and provide training and technical assistance.

**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 specifically 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:*

US 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:*

Children’s Bureau, Office on Child Abuse and Neglect.

### *Related links:*

Catalog of Federal Domestic Assistance, Community-Based Child Abuse Prevention Grants.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=2a9c96170a2c6b4a8aa962bfadcf426f>

FRIENDS National Resource Center for Community-Based Child Abuse Prevention.

<http://www.friendsnrc.org>

Regional and state:

FRIENDS National Resource Center for CBCAP website contains an interactive map of state lead agency contacts. <http://www.friendsnrc.org/state-lead-agency-contacts>

### *References:*

Kagan, J. (2006). *Respite in Community-Based Grants for the Prevention of Child Abuse and Neglect (CBCAP). Fact Sheet Number 10*. Chapel Hill, NC: FRIENDS National Resource Center for CBCAP Programs. <http://www.friendsnrc.org/print-materials>

US Dept of Health and Human Services, Administration for Children and Families, Children's Bureau (2011). The Child Abuse Prevention and Treatment Act, Including Adoption Opportunities & The Abandoned Infants Assistance Act, as Amended by P.L. 111-320 The CAPTA Reauthorization Act of 2010 [http://www.acf.hhs.gov/programs/cb/laws\\_policies/cblaws/capta/capta2010.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/cblaws/capta/capta2010.pdf)

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## 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 community-based agencies.

### *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 the proportion 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.

States must limit their use of these funds for foster care maintenance payments, adoption assistance, and day care related to employment or training for employment to no more than their 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:*

Child and family services programs that use community-based agencies and have the following goals:

- child protection;
- prevention of child abuse, neglect, and exploitation;
- family preservation services for at-risk families;
- promoting the child welfare outcomes of safety, permanency, and well-being of children in foster care and adoptive homes; and
- 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 four 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. Activities to be funded under this program are described in the plan.

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

***Eligible entity:***

State child welfare agency and federally recognized Indian Tribes.

***Points of contact:***

Links to state agency websites are available on the Child Welfare Information Gateway.

[http://www.childwelfare.gov/pubs/reslist/rl\\_dsp\\_website.cfm?rs\\_ID=16&rate\\_chno=AZ-0004E](http://www.childwelfare.gov/pubs/reslist/rl_dsp_website.cfm?rs_ID=16&rate_chno=AZ-0004E)

***Related links:***

Catalog of Federal Domestic Assistance, Child Welfare Services State Grants.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=713605eb24f0adb06748fb2d31cddf45>

***References***

Children's Bureau: Stephanie Tubbs Jones Child Welfare Services: Title IV-B, Subpart 1 of the Social Security Act.

[http://www.acf.hhs.gov/programs/cb/programs\\_fund/state\\_tribal/ss\\_act.htm](http://www.acf.hhs.gov/programs/cb/programs_fund/state_tribal/ss_act.htm)

CWLA. (2011). *Fact Sheet: Child and Family Services Improvement and Innovation Act*.

<http://www.cwla.org/advocacy/HR2883finalsummaryformattedforwebsite.pdf>

US House of Representatives. (2011). *House Report 112-210. Child and Family Services Improvement and Innovation Act*.

<http://www.gpo.gov/fdsys/pkg/CRPT-112hrpt210/pdf/CRPT-112hrpt210-pt1.pdf>

## Family Connection Grants

### *Authorizing legislation:*

Title IV-B, Subpart 1, Section 427 of the Social Security Act.

### *Currently authorized through:*

September 30, 2013.

### *Program purpose:*

To provide matching grants to state, local, or Tribal child welfare agencies and private nonprofit organizations that have experience working with foster children or children in kinship care arrangements for the purpose of helping children who are in or at risk of entering foster care to reconnect with family members.

### *Beneficiaries:*

Foster children or children in kinship care arrangements or children at risk of entering foster care to help the children reconnect with family members.

### *Funding:*

A guarantee for \$15 million a year for competitive, matching grants, with \$5 million set aside for Kinship Navigator Programs, 3% set aside for evaluation of grant activities, and 2% set aside to provide technical assistance to grant recipients. A grant can be no more than \$1 million a year and no less than \$450,000 a year. Grants are available for a maximum of 36 months and a minimum of 12 months. Renewal funding for multiple-year grants is dependent upon grantee performance and availability of funds. The required match must increase over the course of the grant period such that grantees must contribute 25% of the program costs for the first and second year of the grant and 50% of the program costs for the third year of the 3-year grant.

### *Activities supported by the funding:*

May include the following: (1) a Kinship Navigator Program to assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children they are raising and their own needs and to promote effective partnerships among public and private agencies to ensure that kinship caregiver families are served; (2) intensive family-finding efforts that use search technology to find biological family members for children in the child welfare system; (3) family group decision-making meetings for children in the child welfare system that enable families to make decisions and develop plans that nurture children and protect them from abuse and neglect; and (4) residential family treatment programs that enable parents and their children to live in a safe environment for a period of not less than 6 months, including residential family substance abuse treatment programs. One hundred percent of funds are used for discretionary activities.

### *Respite connection:*

At a minimum, Kinship Navigator Programs will assist grandparents and other relative caregivers to learn about, find, and use respite services. These programs are directed to link families to programs and services that help them meet the needs of the children they are raising and their own needs. Kinship Navigator Programs also promote effective partnerships among public and private agencies to ensure that kinship caregiver families are served, making them essential partners in Lifespan Respite systems. These programs can help link relatives who are caregivers, both in and out of foster care, and the children they are raising to a broad range of services and supports.

While respite is not specifically mentioned, a case could be made to provide or arrange for respite as a component of a residential family substance abuse treatment program.

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

The FY 2011 US Department of Health and Human Services (DHHS) Funding Announcements for Family Connection Grants were limited to “Using Family Group Decision-making to Build Protective Factors for Children and Families.” See HHS-2011-ACF-ACYF-CF-0181.

<http://www.acf.hhs.gov/grants/open/foa/view/HHS-2011-ACF-ACYF-CF-0181>

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families, Children’s Bureau.

***Eligible entity:***

State, local, or Tribal child welfare agencies and private nonprofit organizations that have experience in working with foster children or children in kinship care arrangements.

***Points of contact:***

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

A listing of the 24 Fostering Connections Grants is available at

[http://library.childwelfare.gov/cbgrants/ws/library/docs/cb\\_grants/GrantHome](http://library.childwelfare.gov/cbgrants/ws/library/docs/cb_grants/GrantHome)

***Related links:***

Catalog of Federal Domestic Assistance, Family Connection grants.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=6dca06485ba3322bde6379ebd8cd78d7>

Fostering Connections Resource Center.

<http://www.fosteringconnections.org/>

***References:***

Children’s Defense Fund. (2010). *Fostering Connections to Success and Increasing Adoptions Act*, Summary. Washington, DC: Author.

<http://www.childrendefense.org/child-research-data-publications/data/FCSIAA-detailed-summary.pdf>

Children’s Defense Fund and Generations United. *FAQs about Fostering Connections*. Washington, DC: Author.

<http://www.childrendefense.org/child-research-data-publications/data/questions-answers-family-connections-grant.pdf>

“Fostering Connections to Success and Increasing Adoptions Act of 2008.” P. L. 110-351.

[http://www.fosteringconnections.org/tools/assets/files/Public\\_Law\\_110-351.pdf](http://www.fosteringconnections.org/tools/assets/files/Public_Law_110-351.pdf)



## 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:*

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 appropriations by 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. Certain 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 are providing respite under PSSF.<sup>21</sup>

**Example:** The Elaine Clark Center, Inc., in Chamblee, GA, provides services to approximately 40 children per day at their center. The Center is also a Child Development Center. Fifty percent of its children have special needs such as autism, Down syndrome, or cerebral palsy. Under PSSF, respite is provided from 1 to 8 hours per day depending on the family's needs. They also have an after-school program, and Saturday respite time from 9:00 to 5:00. Unique to this program is the use of a therapeutic intervention team that provides structured treatment plans to children attending the Center. This is termed Therapeutic Respite and is funded through PSSF. Contact: Early Intervention Support Services, 770-458-3251.

**Example:** In Virginia, the State Department of Social Services grants PSSF Program funds to United Methodist Family Services (UMFS), Richmond, VA, for their Adoption Family Preservation Program (AFP). Families with open cases may submit a request for reimbursement of monies paid to respite providers. Families use in-home respite and use camp as respite. Families determine their own providers for in-home respite. Funding is limited to \$500/family/year. Contact: 804-353-4461 x1447.

**Example:** Since 1995, Arizona PSSF Family Support and Family Preservation Programs collectively served more than 112,000 families and their children. In state FY 2009, the state contracted with 16 non-tribal service providers and seven tribal nations to provide family support and family preservation services to families and children in both urban and rural settings. Biological, kinship, foster, adoptive, and non-English-speaking families accessed these voluntary programs directly or by referral. A broad array of free services was offered, including respite. Service providers were required to form collaboration partnerships for the provision of services and provide 25% in-kind matches to state funds.

**Example:** Safe Families, a collaborative project with Clemson University in South Carolina, was designed to serve as a resource for families not meeting criteria as substantiated cases of abuse or neglect but who would benefit from services as a preventive measure. Churches and other community volunteers support the program. Currently, there are 102 partner family volunteers available to support families under the Safe Families project. These volunteers have provided support to 71 families. The families receiving support have a level of need that would in all likelihood have resulted in reports of child neglect in the absence of support. Services have included in-home and respite care.

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<sup>21</sup> 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:*

US Department of Health and Human Services, Administration on Children, Youth and Families.

### *Eligible entity:*

(1) Formula Grants: States, territories and certain Indian Tribes are eligible applicants. For caseworker visit funds, only states and territories are eligible applicants. (2) 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.

[http://www.childwelfare.gov/pubs/reslist/rl\\_dsp.cfm?rs\\_ID=7&rate\\_chno=11-11272](http://www.childwelfare.gov/pubs/reslist/rl_dsp.cfm?rs_ID=7&rate_chno=11-11272)

### *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:*

CWLA. (2011). *Fact Sheet: Child and Family Services Improvement and Innovation Act*.

<http://www.cwla.org/advocacy/HR2883finalsummaryformattedforwebsite.pdf>

US House of Representatives. (2011). House Report 112-210. Child and Family Services Improvement and Innovation Act. <http://www.gpo.gov/fdsys/pkg/CRPT-112hrpt210/pdf/CRPT-112hrpt210-pt1.pdf>

Stoltzfus, E., & Spar, K. (2002). *Child Welfare: The Promoting Safe and Stable Families Program*. Washington, DC: Congressional Research Service.

[http://assets.opencrs.com/rpts/RL30894\\_20020124.pdf](http://assets.opencrs.com/rpts/RL30894_20020124.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. In 2007, \$35 million in 2008, \$30 million in 2009, and \$20 million each year for 2010 and 2011. States 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. Grant award may be for not less than two fiscal years, but not for more than five years. Grants may be extended for two years at 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,
  - 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:***

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

#### ***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:***

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

#### ***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>

National Center on Substance Abuse and Child Welfare Regional Partnership Grant Program.  
<http://www.ncsacw.samhsa.gov/technical/ta-rpg.aspx>

Grantee proposal abstracts are available at  
<http://www.ncsacw.samhsa.gov/files/RPG-Proposal-Abstracts-by-State.pdf>

#### ***References:***

CWLA. (2011). *Fact Sheet: Child and Family Services Improvement and Innovation Act*.  
<http://www.cwla.org/advocacy/HR2883finalsummaryformattedforwebsite.pdf>

US House of Representatives. (2011). *House Report 112-210. Child and Family Services Improvement and Innovation Act*.  
<http://www.gpo.gov/fdsys/pkg/CRPT-112hrpt210/pdf/CRPT-112hrpt210-pt1.pdf>

US Department of Health and Human Services. (2010). Targeted grants to increase the well-being of, and to improve the permanency outcomes for, children affected by methamphetamine or other substance abuse: First annual report to Congress. Washington, DC: Author.  
[http://www.acf.hhs.gov/programs/cb/pubs/targeted\\_grants/targeted\\_grants.pdf](http://www.acf.hhs.gov/programs/cb/pubs/targeted_grants/targeted_grants.pdf)

## Abandoned Infants Assistance (AIA) Program

### *Authorizing legislation:*

Abandoned Infants Assistance Act of 1988, P.L. 100-505, 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 prevent the abandonment in hospitals of infants and young children, identify their needs, develop a program of comprehensive support services, and recruit and train service providers to meet their needs.

### *Beneficiaries:*

Abandoned infants and young children, infants and children impacted by HIV/AIDS and/or substance abuse, or who have a life-threatening illness or other special medical need, along with their parents, families, and other caretakers.

### *Funding:*

Competitive project grants are made for periods of up to 4 years.

### *Activities supported by the funding:*

- Preventing the abandonment of infants and young children exposed to HIV/AIDS and drugs, including the provision of services to family members for any conditions that increased the probability of abandonment of an infant or young child.
- Identifying and addressing the needs of abandoned infants, especially those born with AIDS and those exposed to drugs.
- Assisting these children to reside with their natural families, if possible, or in foster care.
- Recruiting, training, and retaining foster parents for these children.
- Carrying out residential care programs for abandoned children and children with AIDS who are unable to reside with their families.
- Establishing programs of respite care for families and foster families.
- Recruiting and training health and social services personnel to work with families, foster families, and residential care staff.
- Preventing the abandonment of infants and young children by providing needed resources through model programs.

Applicants must give priority to infants and young children who are infected with or exposed to HIV, have a life-threatening illness or other special medical need, or have been perinatally exposed to a dangerous drug.

### *Respite connection:*

Respite is a core service of the program funding, although it is not a required component.

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**Example:** Families and Children Together (FACT), a Maine agency involved with the development of children with emotional and behavioral problems, received 4-year funding in 2004 to expand an existing program (Kids-Kin) serving rural relative caregivers. Respite was one of three focus areas they chose to address through broader community partnerships. Social workers assisted families in overcoming obstacles to accessing respite, including use of a community fund for that purpose.<sup>22</sup> The program, originated in 1993, continues to operate with funding from other state, national, and local partners.<sup>23</sup>

**Example:** Mission Inn in Grand Rapids, Michigan, is a voluntary, comprehensive, community-based wraparound model serving impoverished families in West Michigan with infants and young children, ages 0 to 5, who are affected by substance abuse or HIV/AIDS. A home-based model that combines both infant mental health (IMH) and gender-specific substance abuse therapy was recently instituted. This project also provides child-specific services, including developmental assessments and referrals to community agencies to address noted developmental delays. In addition, single-source case coordination with community services, respite services for children, individualized parent/caregiver training, guidance with a therapist or peer mentor, and community referrals are also offered.<sup>24</sup>

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

Grantees design and implement service programs to meet any of eight program goals, expressed as supported activities above. These may or may not include respite components. The number of projects funded varies from year to year; in 2010, there were 17 projects funded in 12 states and the District of Columbia.

### *Federal funding agency:*

US Department of Health and Human Services, Administration on Children, Youth and Families, Children's Bureau.

### *Eligible entity:*

Public and nonprofit private entities.

### *Points of Contact:*

National Abandoned Infants Assistance Resource Center.

<http://aia.berkeley.edu/>

A directory of current grantees can be found on the National Abandoned Infants Resource Center website.

[http://aia.berkeley.edu/direct\\_service\\_programs/directory.php](http://aia.berkeley.edu/direct_service_programs/directory.php)

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<sup>22</sup> National Abandoned Infants Assistance Resource Center. (2006). AIA Project Profiles. Berkeley, CA: Author. [http://aia.berkeley.edu/media/pdf/aia\\_project\\_profiles.pdf](http://aia.berkeley.edu/media/pdf/aia_project_profiles.pdf)

<sup>23</sup> Families and Children Together. Maine Kids-Kin. <http://www.mainekids-kin.org/>

<sup>24</sup> National Abandoned Infants Assistance Resource Center. (2011). AIA Project Profiles. Berkeley, CA: Author. [http://aia.berkeley.edu/media/pdf/AIAProjectProfiles2011\\_ver16\\_Color.pdf](http://aia.berkeley.edu/media/pdf/AIAProjectProfiles2011_ver16_Color.pdf)

***Related Links:***

Catalog of Federal Domestic Assistance, Abandoned Infants.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=07ca8dd91509335a57fa8f118fb14462>

***References:***

National Abandoned Infants Assistance Resource Center. (2010). AIA Project Profiles. Berkeley, CA:

Author

[http://aia.berkeley.edu/media/pdf/AIAProjectProfiles2010\\_Final.pdf](http://aia.berkeley.edu/media/pdf/AIAProjectProfiles2010_Final.pdf)

US Dept of Health and Human Services, Administration for Children and Families, Children's Bureau (2011). *The Child Abuse Prevention and Treatment Act, Including Adoption Opportunities & The Abandoned Infants Assistance Act, as Amended by P.L. 111-320 The CAPTA Reauthorization Act of 2010*

[http://www.acf.hhs.gov/programs/cb/laws\\_policies/cblaws/capta/capta2010.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/cblaws/capta/capta2010.pdf)

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## Adoptions Opportunities Act

### *Authorizing legislation:*

Child Abuse Prevention and Treatment and Adoption Reform Act of 1978, P.L. 95-266; 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 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:*

US Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

***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=step1&id=2b9c3a0ecea5889f0ca2f629c05ff90>

***References:***

US Department of Health and Human Services. (2005). *Post-legal adoption services for children with special needs and their families: Challenges and lessons learned*. Washington, DC: Author.

[http://www.childwelfare.gov/pubs/h\\_postlegal/h\\_postlegal.pdf](http://www.childwelfare.gov/pubs/h_postlegal/h_postlegal.pdf)

US Dept of Health and Human Services, Administration for Children and Families, Children's Bureau (2011). *The Child Abuse Prevention and Treatment Act, Including Adoption Opportunities & The Abandoned Infants Assistance Act, as Amended by P.L. 111-320 The CAPTA Reauthorization Act of 2010*.

[http://www.acf.hhs.gov/programs/cb/laws\\_policies/cblaws/capta/capta2010.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/cblaws/capta/capta2010.pdf)

## Family Violence Prevention and Services Act (FVPSA)

### *Authorizing legislation:*

Family Violence Prevention and Services Act (FVPSA), as extended by the US Department of Health and Human Services Appropriations Act, 2010 (P.L. 111-117; 42 U.S.C. 10401-10421), 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 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:*

- *Formula grants* to states and Tribal entities to provide shelter and supportive services through subgrants to local domestic violence programs. Local programs serve nearly 1 million adult and child victims annually.
- *Grants to State Domestic Violence Coalitions*, which act as information clearinghouses and coordinate state- and territory-wide domestic violence programs, outreach, and technical assistance.
- *Specialized Services for Abused Parents and their Children* program will be funded through a set-aside of 25% of any increase in funding over \$130 million (provided in the annual appropriations process).
- The formula for the other grants programs: state formula grants (70%); Tribal grants (10%); State and Territorial Domestic Violence Coalitions (10%); training and technical assistance (6%); and monitoring, evaluation, and administrative costs (2.5%). The remaining 1.5% is available to the Family Violence Prevention and Services Program office for discretionary projects.

### *Activities supported by the funding:*

The Act funds essential services that are at the core of ending domestic violence: emergency shelters, counselling and advocacy, and primary and secondary prevention. Also funded are national and specialized training and technical assistance resource centers, the National Domestic Violence Hotline, and in collaboration with the Centers for Disease Control and Prevention, the Domestic Violence Prevention Enhancement and Leadership Through Alliances (DELTA) prevention grants program.

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.

*Specialized Services for Abused Parents and Their Children* grantees must use the funds to provide direct counseling; advocacy, including coordinating services with services provided by the child welfare system; and services for nonabusing parents to support those parents' roles as caregivers and their roles in responding to the social, emotional, and developmental needs of their children. A grantee may use the funds made available through the grant to provide early childhood development and mental health services; to coordinate activities with and provide technical assistance to community-based organizations serving victims of family violence or children exposed to family violence; and to provide additional services and referrals to services for children, including child care, transportation, educational support, respite care, supervised visitation, or other necessary services.

#### **Respite connection:**

Advocacy, case management, and information and referral services related to respite services is one of the supportive services that must be provided by state subcontractors under formula grants to states using 25% of the available funds. This requirement could encourage partnerships between the subcontractors and Lifespan Respite Care Programs and/or community-based respite services.

Respite is an allowable funded service for grantees under The *Specialized Services for Abused Parents and Their Children* program.

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

The *Specialized Services for Abused Parents and Their Children* program will not be funded until overall appropriations for FVPSA exceed \$130 million.

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families.

***Eligible entity:***

States, Tribal entities; State Domestic Violence Coalitions; for *Specialized Services for Abused Parents and Their Children*, eligible entities are local agencies, nonprofit organizations, or Tribal organizations with a demonstrated record of serving victims of family violence, domestic violence, or dating violence and their children.

***Points of contact:***

Family and Youth Services Bureau  
1250 Maryland Ave., SW  
Washington, DC 20024  
Phone: 202-401-5756

***Related links:***

Catalog of Federal Domestic Assistance: Family Violence Prevention and Services Act.

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

National Network to End Domestic Violence.

<http://www.nnedv.org/policy/issues/fvpsa.html>

***References:***

National Network to End Domestic Violence. *Fact Sheet: The Family Violence Prevention and Services Act, 2010.*

[http://www.nnedv.org/docs/Policy/FVPSA\\_2010\\_Analysis.pdf](http://www.nnedv.org/docs/Policy/FVPSA_2010_Analysis.pdf)

## 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 five 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;
- **Maternal and Child Health Community Integrated Service Systems (CISS) Discretionary Grants**;
- **Maternal and Child Health Special Projects of Regional and National Significance (SPRANS)**;
- **Family-to-Family Health Information Centers**; and
- **Services to Individuals with a Postpartum Condition and Their Families (not yet funded)**.

**Children's Mental Health**, Title V 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.

### *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 six criteria: severity of the child's disability and needs; potential risk of out-of-home placement if respite is not provided; lack of access to informal supports; lack of access to other sources of respite; presence of family stress factors such as family size or multiple children with disabilities; and expressed level of need for respite services.<sup>25</sup> The US Department of Education agreed that New York's policy was consistent with Part C of IDEA.<sup>26</sup>

<sup>25</sup> Rules and Regulations of the State of New York. Subpart 69-4.18. [http://www.health.state.ny.us/regulations/nycrr/title\\_10/part\\_69/docs/subpart\\_69-4.pdf](http://www.health.state.ny.us/regulations/nycrr/title_10/part_69/docs/subpart_69-4.pdf)

<sup>26</sup> US Department of Education letter to Bradley Hutton. (2009, June 19). <http://www2.ed.gov/policy/speced/guid/idea/letters/2009-2/hutton061909eis2q2009.pdf>

**Example:** In North Carolina, the Part C Early Intervention program provides funds for a nonprofit agency for payment of invoices for respite care. The need for and the location of respite service provision is determined by the IFSP team, depending on the needs of the individual child and family. Any person living in the child's home cannot be paid for providing respite services. The IFSP team must explore all resources for meeting the need for respite and give consideration to the most cost-effective method. Part C Program funds for this service will be used only when there is no other resource for this service.

Once respite services have been determined by the IFSP team to be an appropriate resource for meeting an IFSP outcome, the service coordinator works with the family to identify appropriate respite providers. Reimbursement for respite services is limited to 32 hours per year per client. In FYs 2010-2011, a total of \$48,000 is budgeted for family support activities, which includes respite. The cost for respite is individualized for each child and family. The base reimbursement rate is \$5.00 per hour and the amount is limited to 32 hours per year. Respite is not to be provided to meet daily family needs, such as allowing the parent to work.<sup>27</sup>

#### *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.

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](#)).

#### *Federal funding agency:*

US Department of Education, Office of Special Education and Rehabilitative Services.

#### *Eligible entity:*

State educational agency.

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<sup>27</sup> Personal Communication with NC Part C Coordinator, June 2011.



**Points of contact:**

Contact information for IDEA Part C State Coordinators can be found on the website of the National Early Childhood Technical Assistance Center.

<http://www.nectac.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>

**References:**

US Department of Education. (2009). *28th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2006*. Vol. 1. Washington, DC: Author.

<http://www2.ed.gov/about/reports/annual/osep/2006/parts-b-c/index.html>

Child Welfare Information Gateway. (2007). *Addressing the Needs of Young Children in Child Welfare: Part C—Early Intervention Services*. Washington, DC: Author.

<http://www.childwelfare.gov/pubs/partc.pdf>

## Individuals with Disabilities Education Act, Part B: Special Education Preschool Grants

### *Authorizing legislation:*

Individuals with Disabilities Education Act of 2004, P.L. 108-446, Part B, Section 619.

### *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:*

US Department of Education, Office of Special Education and Rehabilitative Services.

### *Eligible entity:*

State educational agencies.

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***Points of contact:***

Contact information for IDEA State Section 619 (Preschool Grants) Coordinators can be found on the National Early Childhood Technical Assistance Center website.

<http://www.nectac.org/contact/619coord.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=b8f55d51156bceb8beae77de2a5f2fe0>

***References:***

Building the Legacy: IDEA 2004.

<http://idea.ed.gov/explore/home>

US General Accounting Office. (2002). *Special Education Grant Programs Designed to Serve Children Ages 0-5*. Washington, DC: Author.

<http://www.gao.gov/new.items/d02394.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 some of their 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.<sup>28</sup>

<sup>28</sup> Association of Maternal & Child Health Programs. (2010). Connecticut State Profile. <http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/2011PROFILES/Connecticut.pdf>

**Example:** Children with Special Health Needs Clinics within the Vermont Department of Health supports the Respite Care Program for Families, which provides limited funds to families to offer a rest from their caregiving experience. Eligibility for Respite Care funding is based on a family's income and the specific needs of individual children.<sup>29</sup>

**Example:** The Oklahoma CSHCN program contracts with a respite facility to provide respite to medically fragile children. Children can stay at the center for a total of 7 days one time per year. Children do not attend school or receive therapy while there, but they do participate in recreational activities. CSHCN also works closely with the Oklahoma Respite Resource Network (ORRN), the state's Lifespan Respite Program. The Respite Voucher Program, a component of the ORRN, provides funding assistance for the purchase of respite services. Requests and applications for services are made to the OASIS, the state's information and referral services for individuals with disabilities. The OASIS determines eligibility and makes referrals to the appropriate Oklahoma Department of Human (OKDHS) funding. CSHCN will fund vouchers through this effort for its eligible population, depending on the availability of funds.<sup>30</sup>

#### *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:*

US 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>

<sup>29</sup> Vermont Department of Health, CSHN Clinics. <http://healthvermont.gov/family/cshn/clinic.aspx>

<sup>30</sup> Maternal and Child Health Services Title V Block Grant State Narrative for Oklahoma, Application for 2012, Annual Report for 2010. <https://mchdata.hrsa.gov/TVISReports/NarrativeSearch/SearchBySectionResult.aspx?Type=NarrativeSearch&Action=R&Section=IIIB&State=OK&MeasureNo=&PMSection=&Text=respite#>

***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>

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

<https://mchdata.hrsa.gov/TVISReports/Default.aspx>

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>

Association of Maternal & Child Health Programs.

<http://www.amchp.org>

***References:***

US Department of Health and Human Services. (2009). *Understanding Title V of the Security Act*.

<http://www.eric.ed.gov/PDFS/ED450923.pdf>

US Department of Health and Human Services. (2009). *Maternal and Child Health Services Title V Block Grant Program: Guidance and Forms for the Title V Application/Annual Report*. Rockville, MD: Author.

<ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf>

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## Maternal and Child Health Community Integrated Service Systems (CISS) Discretionary Grants

### *Authorizing legislation:*

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

### *Program purpose:*

To improve the health of mothers and children through support for the development and expansion of public–private partnerships using community resources.

### *Beneficiaries:*

For training grants: (1) Trainees in the health professions related to maternal and child health (MCH), and (2) mothers and children who receive services through training programs. For research grants: public or private nonprofit agencies and organizations engaged in research in MCH or children with special health care needs (CSHCN) programs.

### *Funding:*

These are competitive grants. For funding appropriated in any fiscal year for Title V over \$600 million, 12.75% is set aside for six categories of projects. For 2010, \$662 million was appropriated for Title V, providing just over \$7.9 million for CISS projects.

### *Activities supported by the funding:*

These grants provide funding in six categories:

- maternal and infant health home visiting programs;
- increasing the participation of obstetricians and pediatricians for programs under Titles V and XIX;
- integrated maternal and child health service delivery systems;
- maternal and child health centers under the direction of not-for-profit hospitals;
- rural maternal and child projects; and
- outpatient and community-based services for CSHCN whose medical services are provided primarily through inpatient institutional care.

### *Respite connection:*

While respite is not a specified activity funded by these grants, funding announcements under some categories might provide the opportunity to include respite as a community-based service for CSHCN.

**Example:** A 3-year CISS grant to the Tennessee Department of Mental Health and Mental Retardation was used to build a respite coalition to coordinate respite activities, identify and work to fill gaps in respite services, and develop and advocate for a plan for a comprehensive system of respite services to parents of children with special needs.<sup>31</sup>

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<sup>31</sup> Maternal and Child Health Project Database: Tennessee Respite Coalition. <http://www.mchlibrary.info/databases/mchprojdetail.php?id=2988>

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

Availability of funds is usually announced biannually. Funding may be made available in any of the six categories listed above under

***Activities supported by the funding:******Federal funding agency:***

US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

***Eligible entity:***

Any public or private entity.

***Points of contact:***

Associate Administrator for Maternal and Child Health  
Health Resources and Services Administration  
US Department of Health and Human Services  
Room 18-05, 5600 Fishers Lane  
Rockville, MD 20857  
Telephone: 301-443-2170

***Related links:***

Catalog of Federal Domestic Assistance: Maternal and Child Health Federal Consolidated Programs.  
<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=d052aa6b501fc3cc0853b951fb49a799>

***References:***

US Department of Health and Human Services. (2009). *Understanding Title V of the Social Security Act*. Rockville, MD: Author.  
<http://www.eric.ed.gov/PDFS/ED450923.pdf>

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## Maternal and Child Health Special Projects of Regional and National Significance (SPRANS)

### *Authorizing legislation:*

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

### *Program purpose:*

To carry out special projects related to the health of mothers and children that are determined to have regional or national significance.

### *Beneficiaries:*

For training grants: (1) trainees in the health professions related to maternal and child health (MCH), and (2) mothers and children who receive services through training programs. For research grants: public or private nonprofit agencies and organizations engaged in research in MCH or children with special health care needs (CSHCN) programs.

### *Funding:*

These are competitive grants. For funding appropriated in any fiscal year for Title V, 15% of the first \$600 million is set aside for SPRANS. In addition, after 12.75% of any amount over \$600 million is set aside for Community Integrated Service Systems (CISS) projects, 15% of the remaining balance over \$600 million is also for SPRANS. For 2010, \$662 million was appropriated for Title V, providing just over \$17.1 million available for SPRANS projects.

### *Activities supported by the funding:*

SPRANS activities include

- maternal and child health research and training;
- testing, counseling, and information dissemination on genetic diseases;
- hemophilia diagnostic and treatment centers; and
- improvement projects supporting “a broad range of innovative strategies.”

### *Respite connection:*

While respite is not a specified activity funded by these grants, funding announcements under some categories might provide the opportunity to include respite in an “improvement project supporting a broad range of innovative strategies.”

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

No funding is set aside for any particular category of grant. Respite has not been a focus of any SPRANS funding in the past.

### *Federal funding agency:*

US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

### *Eligible entity:*

Any public or private entity.

***Points of contact:***

Associate Administrator for Maternal and Child Health  
Health Resources and Services Administration  
US Department of Health and Human Services  
Room 18-05, 5600 Fishers Lane  
Rockville, MD 20857  
Telephone: 301-443-2170

***Related links:***

Catalog of Federal Domestic Assistance: Maternal and Child Health Federal Consolidated Programs.  
<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=d052aa6b501fc3cc0853b951fb49a799>

***References:***

US Department of Health and Human Services. (2009). *Understanding Title V of the Social Security Act*. Rockville, MD: Author. <http://www.eric.ed.gov/PDFS/ED450923.pdf>

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## 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 to restore funding for Family-to-Family Health Information Centers.

### *Currently authorized through:*

September 20, 2012.

### *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:*

Previously funded through the Family Opportunity Act. Competitive grants. In 2010, 51 Centers received \$97,500 (a total of \$4.9 million in grants).

### *Activities supported by the funding:*

The primary activity of F2F HICs is providing information and guidance to families.

### *Respite connection:*

Some HICs have developed informational materials about respite to help families access respite in their state or community.

**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.<sup>32</sup>

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<sup>32</sup> Massachusetts Consortium for Children with Special Health Care Needs and Massachusetts Family-to-Family Health Information Center. (2008). Getting a break: A roadmap to respite care for Massachusetts families of children with special health care needs. <http://massfamilyvoices.org/Respite%20Brochure.pdf>

**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 will provide outreach, information, and screening for respite services and encourage use of and connect family caregivers with respite options as early as possible.<sup>33</sup>

#### *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:*

US Department of Health and Human Services, Health Resources and Services Administration.

#### *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/info/ncfpp/grantees.php>

#### *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=step1&id=5df89eec661e9b61d2ea0ee1cdf6132>

National Center for Family/Professional Partnerships.

<http://www.familyvoices.org/info/ncfpp/>

#### *References:*

Eiken, S., Galantowicz, S., & Stubbs, A. (2006). *Innovative strategies for strengthening Family-to-Family Health Information and Education Centers*. Cambridge, MA: Thomson Medstat.

[http://www.familyvoices.org/pub/ncfpp/F2F\\_PromPrac.pdf](http://www.familyvoices.org/pub/ncfpp/F2F_PromPrac.pdf)

Greene, A.M., Walsh, E.G., O'Keeffe, J., & Koetse, E. (2006). *Activities and accomplishments of the Family-to-Family Health Care Information and Education Center grantees*. Washington, DC: US Department of Health and Human Services.

<http://www.hcbs.org/files/91/4525/FTFPaper.pdf>

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<sup>33</sup> Lifespan Respite Program Summary for South Carolina. [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/LRCP/docs/SC\\_Program\\_Summary\\_2009.html](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/docs/SC_Program_Summary_2009.html)

## Services to Individuals with a Postpartum Condition and Their Families

### *Authorizing legislation:*

Title V of the Social Security Act, as amended by the Patient Protection and Affordable Care Act of 2010, P.L. 111-148, to establish a new section 512.

### *Currently authorized through:*

September 30, 2012 (not yet funded).

### *Program purpose:*

To establish, operate, and coordinate efficient and cost-effective systems of service delivery for individuals with or at risk of postpartum conditions and their families.

### *Funding:*

This legislation was enacted in March 2010 and became effective March 23, 2010. A total of \$3 million was authorized in FY 2010 and similar sums were authorized for FY 2011 and FY 2012. Congress has not yet appropriated funds.

### *Activities supported by the funding:*

Funded projects should provide education and services for the diagnosis and management of postpartum conditions, and may include

- outpatient and home-based health and support services, including case management and comprehensive treatment services;
- inpatient care management services that ensure the well-being of the mother and family and the future development of the infant;
- improvement in the quality, availability, and organization of health care and support services (including transportation services, attendant care, homemaker services, day or respite care, and counseling on financial assistance and insurance); and
- education about postpartum conditions to promote earlier diagnosis and treatment.

### *Respite connection:*

Respite care is included as a potential core service allowable under this program.

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

Congress must still appropriate the funds for this new program.

### *Federal funding agency:*

US Department of Health and Human Services, Health Resources and Services Administration.

### *Eligible entity:*

A state or local government, public-private partnership, recipient of a grant under Section 330H of the Public Health Service Act (relating to the Healthy Start Initiative), public or private nonprofit hospital, community-based organization, hospice, ambulatory care facility, community health center, migrant health center, public housing primary care center, or homeless health center.

### *Points of contact:*

Not yet available.

***Related links:***

Not yet available.

***References:***

Association of Maternal and Child Health Programs. (March 2010). *What Health Reform Means for Maternal and Child Health!*

[http://www.amchp.org/Policy-Advocacy/health-reform/Documents/Senate Bill - MCH Highlights 3 22 10.doc](http://www.amchp.org/Policy-Advocacy/health-reform/Documents/Senate%20Bill%20-%20MCH%20Highlights%203%2022%2010.doc)

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## Child Mental Health Initiative (CMHI)

### *Authorizing legislation:*

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

### *Program purpose:*

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” is an organizational philosophy and framework that involves collaboration across 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.

### *Beneficiaries:*

Children under age 22 with a diagnosed serious emotional disturbance, serious behavioral disorder, or serious mental disorder.

### *Funding:*

Competitive discretionary cooperative agreements are granted for periods of up to 6 years.

### *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, which must include (but are not limited to)

- diagnostic and evaluation services;
- 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 advocacy and peer support services.

### *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:***

US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

***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/>

***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=step1&id=32fa4da600f907afd7adc57f6184f3de>

***References:***

US Department of Health and Human Services. (2009). Cooperative Agreements for Comprehensive Community Mental Health Services for Children and Their Families Program: Request for Application (RFA) No. SM-10-005.

<http://www.samhsa.gov/Grants/2010/SM-10-005.pdf>

US Department of Health and Human Services. (2011). Planning Grants for Expansion of the Comprehensive Community Mental Health Services for Children and their Families (Short Title: System of Care Expansion Planning Grants) Request for Application (RFA) No. SM-11-008.

[http://www.samhsa.gov/grants/2011/sm\\_11\\_008.aspx](http://www.samhsa.gov/grants/2011/sm_11_008.aspx)

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## 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.

The **Services to Advocate for and Respond to Youth** program, while not solely targeted toward low-income young people, is mandated to include services for underserved populations, which may include homeless youth and those in low-income populations.

These three programs are described under this heading.

## Temporary Assistance for Needy Families (TANF) Program

### *Authorizing legislation:*

Title IV-A of the Social Security Act, as amended; the Deficit Reduction Act of 2005; and the American Recovery and Reinvestment Act of 2009.

### *Currently authorized through:*

September 30, 2010.

### *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:*

Needy families with children, as determined eligible by the state, territory, or Tribe in accordance with the state or Tribal plan submitted to the US Department of Health and Human Services (DHHS).

### *Funding:*

Under this block grant program, states receive \$16.5 billion each year, with the amount each state receives based on their peak expenditures for the period 1992 to 1995 (before enactment of TANF). Some states receive supplemental grants if they have experienced either high levels of population growth or historically low welfare grants relative to poverty in the state. For 2009 and 2010, an emergency fund of an additional \$5 billion was established for states experiencing elevated caseloads because of poor economic conditions, as well as an increase in expenditures in one of three categories: basic assistance, non-recurrent short-term benefits, or subsidized employment. No additional emergency funds were authorized after September 30, 2010.

State maintenance-of-effort (MOE) funds: 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 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 Block Grant 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:*

While respite is not specifically listed as an acceptable use of TANF funds, it is not prohibited and could be considered to meet one or more of the program purposes.

States can use TANF funds directly or through transfer to the Child Care and Development Fund (CCDF) to pay for child care. TANF can cover child care expenditures for unemployed parents who need such care to attend “other work activities such as job search, community service, education, or training, or for

respite purposes.”<sup>34</sup> TANF might also be used to provide funding, including respite care, to prevent placement in foster care.<sup>35</sup>

**Example:** The Oklahoma Respite Resource Network (ORRN), the state’s Lifespan Respite program, uses state MOE TANF funds to provide respite vouchers for TANF-eligible families when they don’t qualify for any other respite funding streams.<sup>36</sup>

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:*

US Department of Health and Human Services, Administration for Children and Families, Office of Family Assistance.

### *Eligible entity:*

States and federally recognized Tribes.

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<sup>34</sup>Center for the Study of Law and Social Policy. (nd.) Categories and definitions for TANF and MOE funds. <http://www.clasp.org/admin/site/publications/files/0523.pdf>

<sup>35</sup> US Department of Health and Human Services. (1999). Helping families achieve self-sufficiency: A guide on funding services for children and families through the TANF program. Washington, DC: Author. <http://www.acf.hhs.gov/programs/ofa/resources/funds2.pdf>

<sup>36</sup> Rose Ann Percival. Oklahoma Respite Resource Network. (2010). ARCH National Respite Network and Resource Center Webinar: Lifespan Respite 101 PowerPoint Presentation. March 2010. <http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences/webinar-lifespan-respite-101>

***Points of contact:***

For links to state agencies administering TANF programs, see the Office of Family Assistance website.

<http://www.acf.hhs.gov/programs/ofa/states/stlinks.htm>

***Related links:***

Catalog of Federal Domestic Assistance: Temporary Assistance for Needy Families.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=9482927922cf767f05dae8ae3503a068>

***References***

US Department of Health and Human Services Fact Sheet.

[http://www.acf.hhs.gov/opa/fact\\_sheets/tanf\\_factsheet.html](http://www.acf.hhs.gov/opa/fact_sheets/tanf_factsheet.html)

Falk, G. (2007). *The Temporary Assistance for Needy Families (TANF) Block Grant: A Primer on TANF Financing and Federal Requirements*. Washington, DC: Congressional Research Service.

<http://www.policyarchive.org/handle/10207/bitstreams/2326.pdf>

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## Child Care and Development Fund (CCDF)

### *Authorizing legislation:*

Child Care and Development Block Grant Act of 1990 (CCDBG); Consolidated Appropriations Act of 2010, P.L. 111-117; Title IV of the Social Security Act, as amended.

### *Currently authorized through:*

Discretionary Funds are subject to annual authorization. Mandatory Funds are authorized through September 30, 2010.

### *Program purpose:*

To increase the availability, affordability, and quality of child care for working families, especially low-income families and those moving from public assistance to work.

### *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 child care programs in certain years between 1992 and 1995.

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 use a minimum of 4% of 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:*

The US Department of Health and Human Services provided guidance indicating 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.”<sup>37</sup>

Further, 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.”<sup>38</sup>

In 2003, 18 states reported making respite child care available for children in protective services. In the 2008–2009 state child care plans, only a few states mentioned offering such services.

**Example:** The lead child care agency in Texas partners with the child welfare agency to provide services when

- A child is at risk of abuse or neglect in the immediate or short-term future and the child’s family cannot or will not protect the child without the intervention of the Child Protective Services Agency. These services include respite care provided to custodial parents of children in protective services.
- A child is in the managing conservatorship of the Department of Family and Protective Services (DFPS) and is residing with a relative or a foster parent.
- A child who has been provided with protective services by DFPS within the prior 6 months and requires services to ensure the stability of the family.<sup>39</sup>

**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.<sup>40</sup>

<sup>37</sup> Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), P.L. No. 104-193, Section 658P. The CCDF Final Rule, 45 CFR Parts 98 and 99, was promulgated in the Federal Register, July 24, 1998; Vol. 63, No. 142, pp. 39948-39949. <http://www.acf.hhs.gov/programs/ccb/law/finalrul/fr072498.pdf>

<sup>38</sup> Ibid.

<sup>39</sup> Texas CCDF State Plan FY 2012–2013. <http://www.twc.state.tx.us/twcinfo/ccdfstateplan13.doc>

<sup>40</sup> US Department of Health and Human Services, Administration for Children and Families, Office of Child Care. (2011). *Collaborative Partnerships Between EarlyCare & Education and Child Welfare: Supporting Infants, Toddlers, and Their Families Through Risk to Resilience*. Washington, DC: Authors. <http://www.acf.hhs.gov/programs/ccb/ta/pubs/nitcci/ChildWelfareECEBrief.pdf>

CCDF funds can also be used for training and professional development of early childhood and school age child care providers. In 2008, forty-one states offered training for providers to help them include children with special needs in their programs. 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.<sup>41</sup>

#### *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:*

US Department of Health and Human Services, Administration for Children and Families, Office of Child Care.

#### *Eligible entity:*

State child care agency.

#### *Points of contact:*

Links to state Child Care and Development Fund contacts can be found on the Office of Child Care website. [http://www.acf.hhs.gov/programs/ccb/ccdf/ccdf\\_state\\_territory\\_grantees.htm](http://www.acf.hhs.gov/programs/ccb/ccdf/ccdf_state_territory_grantees.htm)

#### *Related links:*

Catalog of Federal Domestic Assistance: Child Care and Development Block Grant.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=57d79fe17cd9d722f62940b7045f8da2>

#### *References:*

US Department of Health and Human Services. (2010). *Child Care and Development Fund Fact Sheet*. Washington, DC: Author.

<http://www.acf.hhs.gov/programs/ccb/ccdf/factsheet.htm>

Center for Law and Social Policy. (Update 2010). *CCDBG: What's in the Law?* Washington, DC: Author. <http://www.clasp.org/admin/site/publications/files/ccdbginlawrev.pdf>

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<sup>41</sup> Alabama CCDF State Plan FY 2010–2011. [http://dhr.alabama.gov/documents/2010-2011\\_CCDF\\_Plan.pdf](http://dhr.alabama.gov/documents/2010-2011_CCDF_Plan.pdf)

## Services to Advocate for and Respond to Youth

### *Authorizing legislation:*

Violence Against Women and Department of Justice Reauthorization Act of 2005, P.L. 109-162.

### *Currently authorized through:*

September 30, 2011.

### *Program purpose:*

To serve youth victims of domestic violence, dating violence, sexual assault, and stalking.

### *Beneficiaries:*

Teen and young adult victims affected by domestic violence, dating violence, sexual assault, and stalking.

### *Funding:*

Competitive discretionary grants totaling \$15 million for each fiscal year from 2007 through 2011.

### *Activities supported by the funding:*

Design, replication, and implementation of programs and services that

- provide direct counseling and advocacy services; and
- include linguistically, culturally, and community-relevant services for underserved populations.

Programs may include mental health services or legal advocacy efforts and may work with public agencies and officials to develop and implement policies, rules, and procedures aimed at reducing or eliminating domestic violence, dating violence, sexual assault, and stalking against youth and young adults. Not more than 25% of grant funds can be used to provide additional services and resources for youth, including childcare, transportation, educational support, and respite care.

### *Respite connection:*

Respite care is specifically included as an allowable service, but the amount of funds that can be used for that purpose is limited.

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

Appropriations from FY 2008 through FY 2010 were combined to make cooperative agreement awards in FY 2010. Hence, grants in FY 2010 may be larger than in subsequent awards.

### *Federal funding agency:*

US Department of Justice, Office on Violence Against Women.

### *Eligible entity:*

Nonprofit, nongovernmental entities, community-based organizations, and Tribes and Tribal organizations that provide services to the beneficiary population.

### *Points of contact:*

Office on Violence Against Women  
202-307-6026

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***Related links:***

Catalog of Federal Domestic Assistance: Services to Advocate for and Respond to Youth.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=c70ed432474606a05d42055447de4db8>

***References:***

US Department of Justice. (2011). *OVW Fiscal Year 2011 Services to Advocate for and Respond to Youth Program*.

<http://www.ovw.usdoj.gov/docs/youth-program-services-fy2011.pdf>

## Programs Serving All Ages

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 is 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,**
- **Social Services Block Grant (SSBG), and**
- **Community Development Block Grant (CDBG).**

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:

- Programs designed to provide assistance to individuals with developmental disabilities and their families, including programs under the **Developmental Disability Assistance and Bill of Rights Act (DD Act)** of 2000:
  - **Developmental Disability Councils,**
  - **Projects of National Significance: Family Support 360, and**
  - **Projects of National Significance: Family Support and Community Access Demonstration Projects;**
- **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
- Programs designed to provide assistance to individuals with HIV/AIDS:
  - **HIV Care Formula Grants and**
  - **HIV Emergency Relief Projects Grants.**

**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 Services have the potential to provide volunteers that may serve in a respite capacity for certain populations of family caregivers:

- **National Senior Service Corps:**
    - **Foster Grandparents Program (FGP),**
    - **Retired and Senior Volunteer Program (RSVP), and**
    - **Senior Companion Program (SCP); 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. Currently, the majority of ADRCs are serving only the aging population and adults with physical disabilities, but given their role in Lifespan Respite systems and the vision of Administration on Aging (AoA) and Centers for Medicare and Medicaid Services (CMS) that these programs serve all ages in the future, the program description is included in this section.

Finally, the **National Family Caregiver Support Program (NFCSP)** provides a source of direct respite funding that specifically addresses respite for caregivers 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. Another purpose of the program is to provide planned and emergency respite services to family caregivers.

## 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 entitlement program (Entitlement Cities and Urban Counties). 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.

**Example:** In summarizing its funding since 1999, the City of Missoula, Montana, Consolidated Plan for HUD-Funded Programs for Federal Fiscal Years 2009–2013 cited respite for at-risk children as one of the public services they have funded annually. They included in their 5-year plan a recommendation to fund respite for older citizens through Missoula Aging Services.<sup>42</sup>

**Example:** In 2008–2009, Give Me a Break (GAB) Community Respite, Inc., received \$25,000 from the City of Las Vegas CDBG program to support its respite services.<sup>43</sup> The City of Las Vegas is the lead agency for administering programs and projects covered under the Consolidated Plan for the HUD, CDBG, Home Investment Partnerships, Emergency Shelter Grants, and the Housing Opportunities Program for People with AIDS for the Five-Year Period July 1, 2010–June 30, 2015. GAB is a participating nonprofit organization covered by the 2010–2015 Consolidated Plan. GAB provides respite care provider training, a 24-hour statewide respite information toll-free line, community respite program days, community service, and technical assistance and outreach.<sup>44</sup>

### *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.

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<sup>42</sup> Missoula Office of Planning and Grants. (2009). City of Missoula Consolidated Plan for HUD-Funded Programs for Federal Fiscal Years 2009-2013.

<sup>43</sup> City of Las Vegas. (2009). The CPMP Consolidated Annual Performance and Evaluation Report. <http://www.lasvegasnevada.gov/files/CAPERReport.pdf>

<sup>44</sup> Give Me a Break, Inc. <http://www.givemeabreakinc.com/services.html>

***Federal funding agency:***

US Department of Housing and Urban Development, Office: 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:***

451 7th Street SW, Room 7282

Washington, DC 20410

Phone: 202-402-3416; fax: 202-401-2044

Information by state can be found at

[http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/comm\\_planning/communitydevelopment/programs/contacts](http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/communitydevelopment/programs/contacts)

***Related links:***

Catalog of Federal Domestic Assistance: Community Development Block Grants.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=8b305079dda233f9ad667682b814dee9>

US Department of Housing and Urban Development, Homes and Communities, Community Development Block Grants.

<http://www.hud.gov/offices/cpd/communitydevelopment/programs/index.cfm>

***References:***

US Department of Housing and Urban Development. *State Administered CDBG*.

[http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/comm\\_planning/communitydevelopment/programs/stateadmin](http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/communitydevelopment/programs/stateadmin)

## 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.

### *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
- any other social services found necessary by the state for its population.

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.

*Respite connection:*

Respite and crisis care are accepted Social Services Block Grant (SSBG) services and could be related to any of the five 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.<sup>45</sup>

During 2009, the last year in which states reported data on SSBG expenditures, 24 states reported more than \$315 million in SSBG funds for services for individuals with disabilities, down from \$375 million in 2008. However, between 2005 and 2009, expenditures for special services for individuals with disabilities still represented an increase of 24%. The number of recipients decreased by 29%; from 1.3 million in 2005 to 928,493 in 2009. Expenditures in this category accounted for approximately 18% of all SSBG expenditures. In fact, expenditures for individuals with disabilities were the third largest of all service categories in 2009.<sup>46</sup>

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 less than 1% to 67%. Five States used more than 20% of their total SSBG expenditures for special services for individuals with disabilities—Montana (67%), Georgia, (58%), Iowa (42%), Florida (40%), and California (32%).<sup>47</sup>

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<sup>45</sup> Administration for Children and Families, Office of Community Supports. DHHS. (2010). SSBG Focus Reports 2009: Special Services for Individuals with Disabilities. Washington, DC: Author.  
[http://www.acf.hhs.gov/programs/ocs/ssbg/reports/ssbg\\_focus\\_2008/services\\_older\\_adults.html](http://www.acf.hhs.gov/programs/ocs/ssbg/reports/ssbg_focus_2008/services_older_adults.html)

<sup>46</sup> *Ibid.*

<sup>47</sup> *Ibid.*



Although older adults received services from all of the 29 SSBG service categories, at least one-third of SSBG expenditures for each of eight service categories, several of which could include respite, was directed toward older adults:

- adult protective services,
- home-based services,
- adult foster care,
- adult day care,
- home-delivered meals,
- transportation services,
- congregate meals, and
- recreation services.

Most relevant to respite are home-based services which accounted for 31% of SSBG expenditures for older adult services in the eight service categories and adult day care (5.8%). Some states use a portion of their total expenditures on adult protective services category for crisis respite. Overall, states expend the largest percentage of their SSBG funds for adult services on adult protective services (46%).<sup>48</sup>

In 2009, 38 States reported spending an estimated \$299 million for the provision of services to older adults. Approximately 13% of all SSBG expenditures in 2009 were used for services for this population. Among the 38 States that reported SSBG expenditures for services for older adults, the percentage of their total SSBG expenditures used for this purpose varied from less than 1% to 45%. Twelve States reported using 20% or more of their total SSBG expenditures for services for older adults—Puerto Rico (45%), Texas (43%), Wisconsin (41%), District of Columbia (31%), South Carolina (25%), Tennessee (23%), Maryland (23%), Delaware (22%), Kansas (21%), Georgia (21%), North Carolina (21%) and New York (21%).<sup>49</sup>

**Example:** In Delaware, the Community Companion Respite Program is funded with SSBG funds and provides respite by facilitating access to community resources to meet individual needs and interests of care recipients. This service occurs outside the home. The goal is to provide opportunities to adults with physical disabilities for personal, social, and/or educational enrichment through access to community resources while simultaneously reducing stress and exhaustion for caregivers. A unit of service for this program is 1 hour of service provided by a respite worker to an eligible care recipient. The service can be provided in a variety of community locations, depending on the needs of individual program care recipients.

Eligible individuals must be age 18 to 60 and have a physical disability that is expected to last 12 months or more, that substantially affects his or her ability to independently carry out activities of daily living, and for which assistive technology or home

<sup>48</sup> Administration for Children and Families, Office of Community Supports. DHHS. (2010). SSBG Focus Reports 2009: Services for Older Adults. Washington, DC: Author.

[http://www.acf.hhs.gov/programs/ocs/ssbg/reports/ssbg\\_focus\\_2009/services\\_older\\_adults.html](http://www.acf.hhs.gov/programs/ocs/ssbg/reports/ssbg_focus_2009/services_older_adults.html)

<sup>49</sup> *Ibid.*

modification is not practical. Recipients can remain upon turning 60 if they are still able to access the community with the assistance of a respite care worker. They must also require substantial assistance from a caregiver to remain independent and be eligible for Medicaid. An average of 14-15 hours/month or an average of 168-180 hours/year is provided. The Aging Disability Resource Center and Delaware's Caregiver Resource Centers (CRCs) maintain respite provider contact information.

**Example:** In Nebraska, through the Department of Health and Human Services (DHHS), Medicaid Long-Term Care Division, SSBG funds respite for adults age 19 or older who have no access to any other source of respite funding and are receiving Supplemental Security Income (SSI) or State Supplemental benefits, or are on the low-income aged or disabled Medicaid waiver. The client and DHHS resource development staff locate respite providers who are willing to accept DHHS payment. There is no cost to the client. A maximum of 120 hours or 18 days (1 day = 6-24 hours) in 6 months is provided. For Adult Protective Service clients, clients can access a maximum of 31 days in situations of abuse or neglect.

**Example:** The Mississippi Department of Human Services, Division of Social Services Block Grant, provides SSBG funds (\$60,712) to the Division of Aging and Adult Services, which in turn subcontracts with the Area Agencies on Aging (AAAs) to provide SSBG supported respite services at the regional level. Most AAAs subcontract with respite vendors to provide the service locally. The family caregiver must be 60 years of age. A maximum of 32 hours of in-home respite can be provided. Caregivers of persons with special needs are also served. Southern Mississippi Area Agency on Aging (SMAAA) has served 43 clients to date, providing 2,875 hours of respite since October, 1, 2010. Services can be accessed by calling the Mississippi Department of Human Services, the Aging and Disability Resource Centers, or local home health provider agencies.

**Example:** In Missouri, respite services are provided at the Missouri Disability Resource Association (Center for Independent Living) using SSBG funding. Clients must be at least 60 years of age or at least 18 years of age with a disability. *Basic Respite Care* is intended to offer short-term periods of caregiver relief and cannot be authorized in lieu of other home and community-based services required on a regular basis, such as Personal Care and Homemaker services. *Basic Block Respite Care* is intended to offer caregiver relief for longer episodes. Those who are eligible for this respite have yet to complete the Medicaid eligibility process; have low income but don't qualify for Medicaid; or receive home and community-based services, but have a short-term need because of health complications or caregiver issues. Respite is provided on average for 10 hours per week.

### ***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:***

US 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 US Department of Health and Human Services website.

[http://www.acf.hhs.gov/programs/ocs/ssbg/grantees/Contact\\_08.html](http://www.acf.hhs.gov/programs/ocs/ssbg/grantees/Contact_08.html)

***Related links:***

Catalog of Federal Domestic Assistance: Social Services Block Grant.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=c57b733c35959542148940030bcc3f11>

US Department of Health and Human Services: Social Services Block Grant (SSBG) Program.

<http://www.acf.hhs.gov/programs/ocs/ssbg/about/factsheets.htm>

***References:***

Child Welfare Information Gateway: Social Services Block Grant (SSBG).

[http://www.childwelfare.gov/management/funding/program\\_areas/ssbg.cfm](http://www.childwelfare.gov/management/funding/program_areas/ssbg.cfm)

## Community Mental Health Services Block Grant

### *Authorizing legislation:*

Title XIX, Part B of the Public Health Service Act, as amended.

### *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:*

Respite and crisis care may be included in direct mental health services provided by community programs.

### *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.

### *Federal funding agency:*

US 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 can be found on the National Association of State Mental Health Program Directors website.

[http://nasmhpd.org/mental\\_health\\_resources.cfm#State](http://nasmhpd.org/mental_health_resources.cfm#State)

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***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:***

National Association of State Mental Health Program Directors Research Institute, Inc. (2007). *How state mental health agencies use community mental health services block grant to improve care and transform systems: 2007*. Rockville, MD: US Department of Health and Human Services.

<http://download.ncadi.samhsa.gov/ken/pdf/MHBGReportSection508-5-6-08.pdf>

## Developmental Disabilities Councils

### *Authorizing legislation:*

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), P.L. 106-402.

### *Currently authorized through:*

September 30, 2007. Congress appropriated funds for the DD Act for FY 2008–2011.

### *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 uses 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.<sup>50</sup>

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<sup>50</sup> Alabama Respite Receives ACDD Grant Award. <http://alabamarespite.org/index.php/component/content/article/6-news/39-mobile-county-will-host-an-open-meeting-to-introduce-a-sharing-the-care-committee-in-september.html>

***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:***

US Department of Health and Human Services, Administration for Children and Families, Administration on 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.

<http://www.nacdd.org/about-nacdd/council-listings-map.aspx>

***Related links:***

Catalog of Federal Domestic Assistance: Developmental Disabilities Basic Support and Advocacy Grants.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=f993f730ba7bb5c7ad636858f863f3e7>

National Association of Councils on Developmental Disabilities.

<http://www.nacdd.org>

The President's Committee for People with Intellectual Disabilities.

<http://www.acf.hhs.gov/programs/pcpid/index.html>

***References:***

US Department of Health and Human Services. (2011). FY 2011 DD Council final allotment table revised May 24, 2011.

<http://www.acf.hhs.gov/programs/add/adddocs/FY2011RevisedAllotmentTablesDDC.pdf>

## Projects of National Significance (PNS): Family Support 360 Demonstration

### *Authorizing legislation:*

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), P.L. 106-402.

### *Currently authorized through:*

September 30, 2007. Congress appropriated funds for the DD Act for FY 2008–2011. Projected grants for Family Support 360 projects run through September 30, 2014.

### *Program purpose:*

To plan and implement family support centers that connect families to services for the entire family of individuals with developmental disabilities.

### *Beneficiaries:*

Individuals with developmental disabilities and their families.

### *Funding:*

These are competitive project grants of \$200,000 per year over a 5-year grant period. Grantees must supply a 25% match.

### *Activities supported by the funding:*

Each state grantee assists at least 50 targeted families a year in a variety of community settings, helping them locate and navigate public and private agencies that provide services. Families receive individualized assessment and planning for services and supports that may focus on one or more areas, including

- health and mental health services;
- eligibility for personal assistance and supports, such as direct care workers, respite care, food stamps, and cash assistance;
- transportation;
- child care services;
- family strengthening programs, such as marriage and parenting education;
- early intervention;
- education;
- housing; and
- employment-related assistance.

Such planning and assessment must involve at least three services in the first year of the grant, with three additional services being made available each year in years 2 through 5 of the grant. The selection of services to be offered in any year should be those that the eligible targeted families will most likely need throughout the grant year.

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***Respite connection:***

Connecting families to needed respite care in the community is one of the core areas Family Support 360 Centers may focus on.

**Example:** The Wisconsin Family Support 360 program produced brochures connecting families to community respite services. The brochure identifies respite care providers and information about eligibility for each provider's services.<sup>51</sup>

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

PNS helps individuals with developmental disabilities to fully and directly contribute to and participate in all facets of community life through funding opportunities to public and private nonprofit institutions. Family Support 360 is one of five active PNS. The others are ongoing data collections; Youth Information, Training, and Resources Centers; a National Clearinghouse and Technical Assistance Center; and a web-based Medicaid Reference Desk for adults and children with developmental disabilities.

Twenty states and territories and the District of Columbia received Family Support 360 grants for FY 2004–2009: Alaska, Colorado, District of Columbia, Hawaii, Idaho, Maryland, Massachusetts, Michigan, Minnesota, Missouri, New Hampshire, New Mexico, North Carolina, Northern Mariana Islands, Oklahoma, Oregon, Rhode Island, South Dakota, Vermont, Wisconsin, and Utah.

For 2009–2014, state grantees are Georgia, Iowa, Mississippi, Nevada, New Jersey, Virginia, and Washington.

Additional projects are funded for Family Support 360 Military Projects (see [Programs for Military Families and Veterans](#) and [Family Support and Community Access Demonstration Projects](#)).

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities.

***Eligible entity:***

Public or private nonprofit entities.

***Points of contact:***

Contact information for current Family Support 360 grantees can be found on the Family Support 360 Resource Center website.

[http://www.addfamilysupport360.org/3\\_10/contact1.asp](http://www.addfamilysupport360.org/3_10/contact1.asp)

***Related links:***

Catalog of Federal Domestic Assistance: Developmental Disabilities Projects of National Significance.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=74d0f409e0f593861de25cc3d6ee91a0>

Family Support 360 Resource Center.

[http://www.addfamilysupport360.org/3\\_10/index.asp](http://www.addfamilysupport360.org/3_10/index.asp)

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<sup>51</sup> South Madison Health & Family Center-Harambee. (2009). Summary of Community Agencies: Respite Care and Personal Care. <http://www.waisman.wisc.edu/familysupport360/lc/l%20need%20a%20break/english/Summary%20of%20Community%20Agencies.pdf>

*References:*

US Department of Health and Human Services. (2010). Projects of National Significance.

<http://www.acf.hhs.gov/programs/add/pns/pns.html>

US Department of Health and Human Services. (2009). Funding Opportunity Number HHS-2009-ACF-ADD-DN-0046.

<http://www.acf.hhs.gov/grants/closed/HHS-2009-ACF-ADD-DN-0046.html>

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## Projects of National Significance (PNS): Family Support and Community Access Demonstration Projects

### *Authorizing legislation:*

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), P.L. 106-402.

### *Currently authorized through:*

September 30, 2007. Congress appropriated funds for the DD Act for FY 2008–2011. Projected grants for Family Support and Community Access Demonstration Projects run through 2015.

### *Program purpose:*

To support innovative family support demonstration projects that rely on collaborative efforts and community-based solutions to reach unserved and underserved families; to encourage systemic change and improved community capacity to support families of individuals with developmental disabilities.

### *Beneficiaries:*

Individuals with developmental disabilities and their families.

### *Funding:*

Five competitive grants for cooperative agreements to be awarded for 5-year periods, funded at \$200,000 to \$250,000 per year. The application period for this program closed on August 2, 2010.

### *Activities supported by the funding:*

Each grantee assists at least 50 targeted families from an unserved or underserved population per year. Using family-centered and/or person-centered planning to determine the needs, interests, preferences, and desires of the individual with a developmental disability and his or her family, the grantees will develop and implement methods and resources to

- make choices that empower the family member with a disability;
- support the family as caregivers;
- strengthen family unity in the family home; and
- access the resources, supports, and services the family needs.

Family support services is defined as “services, supports, and other assistance, provided to families with members who have developmental disabilities, that are designed to strengthen the family’s role as primary caregiver while respecting the need for self-determination and choice for the individual with developmental disabilities; prevent inappropriate out-of-the-home placement of the members and maintain family unity; and reunite families with members who have been placed out of the home whenever possible. It also includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses, associated with the needs of individuals with developmental disabilities.”

### *Respite connection:*

Respite care is included as a family support allowable under this funding.

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

PNS support the ability of individuals with developmental disabilities to fully and directly contribute to and participate in all facets of community life through funding opportunities to public and private nonprofit institutions.

Collaborations must include state Developmental Disabilities Networks and at least one community partner that does not focus on disability populations.

More than half of advisory committees formed to decide how federal funding will be spent on activities and outcomes must be made of families of individuals with developmental disabilities.

A developmental disability is defined in the DD Act as “severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments that are manifested before the individual attains age 22 and are likely to continue indefinitely.

Developmental disabilities result in substantial limitations in three or more of the following functional areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and capacity for economic self-sufficiency.”

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities.

***Eligible entity:***

Public or private nonprofit entities.

***Points of contact:***

Administration on Developmental Disabilities  
Administration for Children and Families  
US Department of Health and Human Services  
370 L' Enfant Promenade, SW  
Washington, DC 20447  
Phone: 202-690-7025

***Related links:***

Catalog of Federal Domestic Assistance: Developmental Disabilities Projects of National Significance.  
<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=74d0f409e0f593861de25cc3d6ee91a0>

***References:***

US Department of Health and Human Services. (2010). Projects of National Significance: Family Support and Community Access Demonstration Projects: Announcement.

<http://www.acf.hhs.gov/grants/open/foa/view/HHS-2010-ACF-ADD-DN-0031>

## Centers for Independent Living (CILs)

### *Authorizing legislation:*

Title VII, Part C of the Rehabilitation Act of 1973, as amended; American Recovery and Reinvestment Act of 2009 (ARRA), P.L. 111-5.

### *Currently authorized through:*

September 30, 2003. Congress has continued to appropriate funds for this program in each year.

### *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:*

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, and
- any other appropriate independent living services specified in Title II of the Rehabilitation Act.

### *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.<sup>52</sup> In some instances, CILs are important partners in providing access to respite.

**Example:** Missouri's Center for Independent Living provides respite services but offers them through the Consumer-Directed and In-Home Services programs using Medicaid waiver funds programs and Social Services Block Grant funds (see **Social Services Block Grant**). Clients must have an assessed nursing facility level of care or higher to receive respite under the waivers.

#### *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 are 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. In 2010, funds were available to fund two new centers in Maryland and one in American Samoa. In addition, the ARRA provided sufficient funds for new centers in 11 other states.

#### *Federal funding agency:*

US Department of Education, Rehabilitative Services 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.

<http://www.ilru.org/html/publications/directory/index.html>

US Department of Education  
400 Maryland Avenue, SW, Room 5016, PCP  
Washington, DC 20202-2800  
Phone: 202-245-7604  
TDD: Call toll free, at 1-800-877-8339

<sup>52</sup> US Department of Education. (2011). Section 704 Annual Performance Report for Centers for Independent Living Program, Part II Instructions. <http://www2.ed.gov/programs/cil/performance.html>

***Related links:***

Catalog of Federal Domestic Assistance: Centers for Independent Living.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=d92e36460e6f7040361f7f2a8db11224>

Catalog of Federal Domestic Assistance: Centers for Independent Living, Recovery Act.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=8f954aaa1084485ec31661ad95df493d>

US Department of Education: Centers for Independent Living.

<http://www2.ed.gov/programs/cil/index.html>

***References:***

National Council on Independent Living. (2010). *Legislative & Advocacy Priorities*. Washington, DC:

Author.

<http://www.ncil.org/news/PolicyPrioritiesJuly2010LowRes.pdf>

## HIV Care Formula Grants

### *Authorizing legislation:*

Title XXVI, Part B, of the Public Health Service Act, as amended by the Ryan White HIV/AIDS Treatment Modernization Act of 2006.

### *Currently authorized through:*

September 30, 2013.

### *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:*

An interactive map linking to each state's HIV/AIDS program grantee can be found on the Health Resources and Services Administration website.

<http://careacttarget.org/community.asp>

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**Related links:**

Catalog of Federal Domestic Assistance: HIV Care Formula Grants.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=f47cb3f11f9885c8ba2d953c6d76511a>

US Department of Health and Human Services, Health Resources and Services Administration, The HIV/AIDS Programs: Caring for the Underserved.

<http://hab.hrsa.gov/>

**References:**

US Department of Health and Human Services. (2008). *The Ryan White HIV/AIDS Program Part B: Grants to States and Territories*. Washington, DC: Author.

<ftp://ftp.hrsa.gov/hab/B.StatesTerr.final.pdf>

US Department of Health and Human Services, Health Resources and Services Administration. (2010). *Fact Sheet: The Ryan White HIV/AIDS Program*. Washington, DC: Author.

<http://hab.hrsa.gov/about/hab/files/programoverview2010.pdf>

## 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 Modernization Act of 2006.

### *Currently authorized through:*

September 30, 2013.

### *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.

### *Federal funding agency:*

US Department of Health and Human Services, Health Resources and Services Administration.

### *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 more than 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.

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***Points of contact:***

A list of EMAs and TGAs receiving this funding is on the Health Resources and Services Administration website.

<http://hab.hrsa.gov/gethelp/granteecontacts.html>

***Related links:***

Catalog of Federal Domestic Assistance: HIV Emergency Relief Project Grants.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=9709e4bf38e9c2a81e7b80a8dd23aa93>

***References:***

US Department of Health and Human Services. (2008). *The Ryan White HIV/AIDS Program Part A: Grants to Eligible Metropolitan Areas*. Washington, DC: Author.

<ftp://ftp.hrsa.gov/hab/A.EMAs.final.pdf>

## 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.

### *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.

### *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.

### *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 proven physical or mental condition that results 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.

Most families caring for a person with a disability have too many other expenses to have money left over for purchase of respite care services.

Most states<sup>53</sup> provide supplementary payments above the federal amount. In nine states (California, Hawaii, Massachusetts, Nevada, New Jersey, New York, 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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<sup>53</sup> States that do not provide any supplement are Arkansas, Kansas, Mississippi, Tennessee, and 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

Directions to local Social Security offices can be found on the Social Security Administration website.

<https://secure.ssa.gov/apps6z/FOLO/fo001.jsp>

Contact information for state assistance programs can be found on the Social Security Administration website.

[http://www.socialsecurity.gov/policy/docs/progdsc/ssi\\_st\\_asst/2009/index.html](http://www.socialsecurity.gov/policy/docs/progdsc/ssi_st_asst/2009/index.html)

***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](http://www.socialsecurity.gov/pgm/links_ssi.htm)

## Senior Companion Program (SCP)

### *Authorizing legislation:*

Title II, Part B of the Domestic Volunteer Service Act of 1973, as amended, P.L. 93-113.

### *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 US 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 and the frail elderly.

### *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. In FY 2010, more than 15,000 volunteers will contribute 11 million hours of service to 58,000 clients through 223 funded organizations.

### *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

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**Example:** In South Carolina, the Senior Companion Program of the Midlands is sponsored by Senior Resources, Inc., a Senior Corps grantee. Senior Resources follows guidelines as required by federal law for oversight of the program. The program is funded 90% through the Corporation for National and Community Services (CNCS). The remainder of the funding is local. Adults over the age of 21 who have special or exceptional needs are eligible for respite if it is necessary to enable them to live independently. Clients are primarily senior citizens who are homebound and require some assistance with activities of daily living. There are no income guidelines for clients, but the majority are low income. Respite volunteers are over the age of 55 and have income under 200% of the Federal Poverty Guidelines. Volunteer respite providers are placed with a client on the basis of availability and location. Volunteers work a set schedule, a minimum of 15 hours/week, and typically work with multiple clients. A typical client receives 2 days of service per week for 4 hours at a time for a total of 8 hours per week. There is no direct cost to the clients or the client's family. Donations are accepted but are not solicited. Volunteers do not provide weekend respite.

**Example:** In North Carolina, a joint effort of the Family Caregiver Support Program and Senior Companion Program (SCP), provides respite in four of the five counties served by the program. The SCP requested funds from the Family Caregiver Support Program (through the Area Agency on Aging) to provide respite by Senior Companion Volunteers. The care recipient's situation is assessed by the Family Caregiver Resource Specialist and the SCP Director to make sure the SCP is the appropriate service. The client service plan encourages outings not only for the caregiver but also for the care recipient to promote peer socialization and a sense of independence that may have been lost through mental or physical deterioration. The Family Caregiver Resource Specialist works closely with the SCP to keep the Project Director up-to-date on trainings, workshops, and retreats for caregivers. The SCP project participates in the trainings and provides on-site respite at caregiver retreats.

#### *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 may participate in a Performance Work Plan that measures respite outcomes using tools developed by the Senior Companion Working Group with assistance from Project Star.<sup>54</sup>

#### *Federal funding agency:*

Corporation for National and Community Service.

#### *Eligible entity:*

State and local government agencies, nonprofit organizations.

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<sup>54</sup> Senior Companion Performance Measurement Work Plan and Instruments (revised August 9, 2007).  
<http://www.nationalserviceresources.org/star/sc-workplan-optional>

***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/about/contact/stateoffices.asp>

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

<http://www.seniorcorps.gov/about/programs/sc.asp>

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

<http://www.seniorcorps.gov/about/programs/sc.asp>

***Related links:***

Catalog of Federal Domestic Assistance: Senior Companion Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=1d4f195229e2b56776890cd0cd8eea56>

***References:***

Corporation for National and Community Service. (2010). *Senior Corps Grant Application*.

[http://www.seniorcorps.gov/forms/sc\\_grant\\_app.pdf](http://www.seniorcorps.gov/forms/sc_grant_app.pdf)

Corporation for National and Community Service. (2008). *Senior Companions Make Independence a Reality: Get Involved*. Operations Handbook. Washington, DC: Author.

[http://www.seniorcorps.gov/pdf/scp\\_handbook.pdf](http://www.seniorcorps.gov/pdf/scp_handbook.pdf)

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## National Senior Service Corps

### *Authorizing legislation:*

Title II, Domestic Volunteer Service Act of 1973, as amended, P.L. 93-113; as amended through P.L. 111-13, 2009.

### *Currently authorized through:*

September 30, 2014.

### *Program purpose:*

The Corporation for National and Community Service oversees the National Senior Service Corps (Senior Corps). The Senior Corps includes 1) the Senior Companion Program (SCP; described under [Programs for the Aging](#)), 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 through service, enhancing the lives of those who serve and those whom they serve, and provide communities with valuable services. The specific purpose of the 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.

The most recent 2009 reauthorization specifies that at least 25% of grants under Programs of National Significance (PNS) must be to organizations not currently receiving Corporation assistance and, when possible, in locations where no Senior Corps projects operate. Respite Care was added to the list of programs that can be funded under PNS.

***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 Programs and volunteer opportunities can be found by state at

<http://www.seniorcorps.gov/about/programs/fg.asp>

RSVP programs and volunteer opportunities can be found at

<http://www.seniorcorps.gov/about/programs/rsvp.asp>

***Related links:***

Catalog of Federal Domestic Assistance: Retired and Senior Volunteer Program (RSVP).

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=b52d0679ef8b1ac732bd38fd8c63f7e9>

Catalog of Federal Domestic Assistance: Foster Grandparent Program.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=a0fda21bf0889ca53e169a532f903f1f>

Corporation for National and Community Service, Senior Corps.  
<http://www.seniorcorps.gov/Default.asp>

**References:**

Domestic Volunteer Act of 1973.  
[http://www.seniorcorps.gov/pdf/dvsa\\_dec99.pdf](http://www.seniorcorps.gov/pdf/dvsa_dec99.pdf)

The Edward M. Kennedy Serve America Act Summary Public Law 111-13, enacted April 21, 2009.  
[http://www.nationalservice.gov/pdf/09\\_0421\\_serveact\\_summary.pdf](http://www.nationalservice.gov/pdf/09_0421_serveact_summary.pdf)

Edward M. Kennedy Serve America Act Public Law 111-13, Side-by-Side comparison with current law.  
[http://www.nationalservice.gov/pdf/09\\_0519\\_serveact\\_sidebyside.pdf](http://www.nationalservice.gov/pdf/09_0519_serveact_sidebyside.pdf)

Corporation for National and Community Service. (2008). RSVP Operations Handbook. Washington, DC: Author.  
[http://www.seniorcorps.gov/pdf/rsvp\\_handbook.pdf](http://www.seniorcorps.gov/pdf/rsvp_handbook.pdf)

Corporation for National and Community Service. (2008). *Foster Care Grandparents Share Today. Shape Tomorrow. Get Involved.* Operations Handbook. Washington, DC: Author.  
[http://www.seniorcorps.gov/pdf/fgp\\_handbook.pdf](http://www.seniorcorps.gov/pdf/fgp_handbook.pdf)

## AmeriCorps

### *Authorizing legislation:*

National and Community Service Act of 1990 (as amended by the Serve America Act), codified as 42 U.S.C. 12501 *et seq.*, and 45 CFR 2510 *et seq.*; as amended by the Serve America Act, P.L. 111-13, 2009

### *Currently authorized through:*

September 30, 2014.

### *Program purpose:*

Begun 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; Perry Point, 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.<sup>55</sup>

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<sup>55</sup>Corporation for National and Community Service. (2011). AmeriCorps NCCC Project Service Application.

For funding guidance for the VISTA program, see the FY 12 AmeriCorps VISTA Program Guidance for Current and Potential Project Sponsors.<sup>56</sup>

#### *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 the most recent grant announcement, under the Healthy Futures priority, grants may support older adults, homebound individuals, and individuals with disabilities with activities such as food delivery, transportation, or other services that allow them to live independently, including evidence-based programs supported by other partner agencies such as the US Department of Health and Human Services and Veterans Affairs. Since respite is a funded service to allow individuals to live independently under these partner agencies, a case could be made to allow AmeriCorps volunteers to provide respite under this grant announcement.

#### *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 11* focused AmeriCorps grantmaking on six areas:

- disaster services,
- education,
- environmental stewardship,
- healthy futures,
- opportunity, and
- 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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[http://www.americorps.gov/pdf/nccc\\_project\\_app.pdf](http://www.americorps.gov/pdf/nccc_project_app.pdf)

<sup>56</sup> Corporation for National and Community Service. (2011). AmeriCorps VISTA Program Guidance for Current and Potential Project Sponsors, FY 12. [http://www.americorps.gov/pdf/2012\\_vista\\_pg.pdf](http://www.americorps.gov/pdf/2012_vista_pg.pdf)

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

***Points of contact:***

AmeriCorps Service in Your State.

<http://www.americorps.gov/>

***Related links:***

Catalog of Federal Domestic Assistance: AmeriCorps.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=b1b5343e62b34d5d666000a53426413c>

AmeriCorps Site.

<http://www.americorps.gov/Default.asp>

***References:***

The Edward M. Kennedy Serve America Act Summary P.L. 111-13, enacted April 21, 2009.

[http://www.nationalservice.gov/pdf/09\\_0421\\_serveact\\_summary.pdf](http://www.nationalservice.gov/pdf/09_0421_serveact_summary.pdf)

Edward M. Kennedy Serve America Act P.L. 111-13, Side-by-Side comparison with current law.

[http://www.nationalservice.gov/pdf/09\\_0519\\_serveact\\_sidebyside.pdf](http://www.nationalservice.gov/pdf/09_0519_serveact_sidebyside.pdf)

Corporation for National and Community Service (Amended Notice of Federal Funding Opportunity). October 25, 2010. AmeriCorps State and National Grants FY 2011. CFDA No. 94.006.

[http://www.americorps.gov/pdf/10\\_0831\\_ac\\_nofo.pdf](http://www.americorps.gov/pdf/10_0831_ac_nofo.pdf)

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## Aging and Disability Resource Centers (ADRCs)

### *Authorizing legislation:*

Patient Protection and Affordable Care Act , Title III, Part III, Section 2405, P.L. 111-111-148, III Stat. 930, 1395W U.S.C. 3306.

### *Currently authorized through:*

September 30, 2014

### *Program purpose:*

(A) 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; (B) to provide personalized and consumer-friendly assistance to empower people to make informed decisions about their care options; (C ) 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; (D) to help people plan ahead for their future long-term care needs; and (E) 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.

### *Beneficiaries:*

The aging population and persons with disabilities, including family caregivers in need of long-term services and supports information.

### *Funding:*

ADRCs are a joint effort between Administration on Aging (AoA) and Centers for Medicare & Medicaid Services (CMS). CMS's original funding for the ADRC program came from the Real Choice Systems Change Initiative. 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:*

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.

### *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:*

ADRCs now operate in at least one community in each of the 50 states and in four territories. There are currently more than 300 ADRC networks across the nation.

***Federal funding agency:***

US Department of Health and Human Services, Administration on Aging.

***Eligible entity:***

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

***Points of contact:***

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

<http://www.adrc-tae.org>

***Related links:***

Catalog of Domestic Federal Assistance: Affordable Care Act–Aging and Disability Resource Center.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=d1ae2c23f09db4f4550c45cbd28a2b1c>

***References:***

U.S Department of Health and Human Services, Administration on Aging. (2011) *Aging and Disability Resource Centers Fact Sheet*.

[http://www.aoa.gov/AoAroot/Press\\_Room/Products\\_Materials/fact/pdf/ADRC.pdf](http://www.aoa.gov/AoAroot/Press_Room/Products_Materials/fact/pdf/ADRC.pdf)

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## National Family Caregiver Support Program (NFCSP)

### *Authorizing legislation:*

Titles III-E (National Family Caregiver Support Program [NFCSP]) and VI-C (Native American Caregiver Support Program) of the Older Americans Act of 1965, P.L. 106-501 as amended.

### *Currently authorized through:*

September 30, 2011.

### *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 2008, the NFCSP provided respite care services to more than 73,000 caregivers, and the Native American Caregiver Support Program provided respite to 4,761 caregivers.<sup>57</sup>

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

Individuals eligible for respite care are

- family caregivers who provide care for individuals age 60 or older;

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<sup>57</sup> Administration on Aging. [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx)

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

US Department of Health and Human Services, 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/state\\_agency\\_website\\_links.html](http://www.nasuad.org/about_nasuad/state_agency_website_links.html)

Contact information for Area Agencies on Aging and Tribal Organizations that administer the NFCSP can be found at

[www.eldercare.gov](http://www.eldercare.gov)

American Indians can search for a Title VI program by state on the National Association of Area Agencies on Aging (n4a) website.

<http://www.n4a.org/about-n4a/?fa=aaa-title-VI>

***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=step1&id=d3fa738ec87226361395471c4b761d00>

Catalog of Federal Domestic Assistance: National Family Caregiver Support, Title VI, Part C, Native American Caregiver Support Program.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=171df19d7ab684066a12a4020c9f46b5>

US Department of Health and Human Services, Administration on Aging: National Family Caregiver Support Program.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx)

US Department of Health and Human Services, Administration on Aging: Services for Native Americans (OAA Title VI).

[http://www.aoa.gov/aoa\\_programs/hcltc/native\\_americans/index.aspx](http://www.aoa.gov/aoa_programs/hcltc/native_americans/index.aspx)

Administration on Aging Integrated Database.

<http://www.agidnet.org/>

### **References**

US Department of Health and Human Services. Administration on Aging. (2009). *Outline of 2006 Amendments to the Older Americans Act*.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/OAA/oa.aspx#t3](http://www.aoa.gov/AoARoot/AoA_Programs/OAA/oa.aspx#t3)

Link, G., Dize, V., Folkemer, D., & Curran, C. (2006). *Family Caregiver Support: State Facts at a Glance*. Washington, DC: National Association of State Units on Aging and Denver, CO: National Conference of State Legislatures. <http://www.ncsl.org/Portals/1/Documents/Health/forum/item0166605.pdf>

## Programs for the Aging

Some federal programs that provide for respite care are designed 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, and
  - Title IV—Community Living Program Grants.
- 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.

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## Supportive Services and Senior Centers

### *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 65 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:***

US Department of Health and Human Services, 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 website.

[http://www.nasua.org/about\\_nasua/sua\\_links.html](http://www.nasua.org/about_nasua/sua_links.html)

To locate home and community-based services, use the Eldercare Locator on the US Department of Health and Human Services website.

<http://www.eldercare.gov/Eldercare.NET/Public/Home.aspx>

***Related links:***

Catalog of Federal Domestic Assistance: Special Programs for the Aging.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=29426dfd8f7fea091d1ce25e35b2d97>

National Aging Information and Referral Support Center.

<http://www.nasuad.org/IR/index.html>

National Institute of Senior Centers.

<http://www.ncoa.org/strengthening-community-organizations/senior-centers/nisc/>

***References:***

US Department of Health and Human Services. Administration on Aging: Supportive Services and Senior Centers Program.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/supportive\\_services/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/supportive_services/index.aspx)

## Community Living Program Grants

### *Authorizing legislation:*

Title IV of the Older Americans Act,<sup>58</sup> as amended.

### *Currently authorized through:*

September 30, 2011.

### *Program purpose:*

To assist individuals who are at risk of placement in a nursing home and at risk of spending down their financial assets to receive home and community-based services that will enable them to continue living in the community.

### *Beneficiaries:*

Individuals at risk of placement in a nursing home or at risk of spending down their financial assets to receive home and community-based services

### *Funding:*

Two-year competitive grants; funding for the second year is dependent on availability of funds. The percentage of grant funds that can be used for direct provision of home and community-based services and supports to individuals and their families is limited. Since 2007, 28 states have received \$23.4 million in grants. Grantees must provide a 25% match.

### *Activities supported by the funding:*

The program supports the Aging Services Network to transform the funding they receive under the Older Americans Act or other non-Medicaid sources into flexible, consumer-directed service dollars to enable individuals to live in home and community-based settings.

Grant funds may be used for

- providing home and community-based services and supports, including personal care, homemaker/chore services, transportation, meal preparation, home-delivered meals, home modifications, respite, assistive devices, and other goods and services that support the individual's ability to remain at home;
- supporting nursing home diversion operations of a single point of entry program;
- training and technical assistance activities;
- evaluation and quality assurance; and
- project administration.

### *Respite connection:*

Respite is a core service supported by the funding.

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<sup>58</sup> Formerly known as Nursing Home Diversion Grants.

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

By the end of the first year of the program, grantees are required to provide a full range of service options, including consumer-directed models giving individuals control over the types of services they receive and the manner in which they are provided.

These grants also provided the infrastructure to initiate a program made available by the Veterans Health Administration for the Aging Network to provide home and community-based services to veterans and their family caregivers. See the section on Programs for Military Families and Veterans for more information.

***Federal funding agency:***

US Department of Health and Human Services, Administration on Aging.

***Eligible entity:***

State Units on Aging.

***Points of contact:***

Information on grantees, including contact information, is available on the Aging & Disability Resource Center Technical Assistance Exchange website.

<http://www.adrc-tae.org/tiki-index.php?page=NHDmap>

***Related links:***

Catalog of Federal Domestic Assistance: Special Programs for the Aging, Title IV and Title II Discretionary Projects.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=6533303e41b932efaac83bbf3d953554>

US Administration on Aging, Community Living Program Grants.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/NHD/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/NHD/index.aspx)

***References:***

US Department of Health and Human Services. (2009). *The Community Living Program: Supporting Independence and Choice in the Community*. Program Announcement and Grant Application Instructions. Washington, DC: Author.

<http://www.aoa.gov/AoARoot/Grants/Funding/2009.aspx>

US Department of Health and Human Services. (2009). *FY 2009 Community Living Program Cooperative Agreements*. Questions and Answers Document.

[http://www.aoa.gov/AoARoot/Grants/Funding/docs/2009/Community\\_Living\\_FAQs.doc](http://www.aoa.gov/AoARoot/Grants/Funding/docs/2009/Community_Living_FAQs.doc)



## Alzheimer's Disease Supportive Services Program (ADSSP)

### *Authorizing legislation:*

Title III, Subpart II, Section 398 of the Public Health Service Act, P.L. 78-410, as amended by the Home Health Care and Alzheimer's Disease Amendments of 1990, P.L. 101-557, and the Health Professions Education Partnership Act of 1998, P.L. 105-392.

### *Currently authorized through:*

September 30, 2002. Congress has continued to appropriate funds for the Alzheimer's Disease Supportive Services Program (formerly known as the Alzheimer's Disease Demonstration Grants to the States [ADDGS]).

### *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. The program focuses on serving hard-to-reach and underserved persons with ADRD and their family caregivers by using evidence-based and innovative models.

### *Beneficiaries:*

(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 1- to 3-year projects. Grantees must provide a 25% match in the first year, a 35% match in the second year, and a 45% match in the third year.

### *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."

### *Respite connection:*

Respite is a core activity of this funding. Respite is defined in the 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."

***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.

Under the most recent program announcement (2011), respite is defined as an interval of rest or relief OR the result of a direct service or support intervention that generates rest or relief for the person with ADRD 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 will be considered to have generated respite for the participants, and therefore this intervention may be considered part of the direct service requirement. Additionally, states are not allowed to make payments with grant funds under this program announcement for any items or services to the extent that payment has been made, or can reasonably be expected to be made, with respect to such item or service under any state compensation program, under an insurance policy, or under any state or federal health benefits program, such as Medicare and Medicaid, or an entity that provides health services on a prepaid basis.

Thirty states, the District of Columbia, and Puerto Rico are currently operating programs.

***Federal funding agency:***

US Department of Health and Human Services, Administration on Aging.

***Eligible entity:***

State Units on Aging

***Points of contact:***

Information about currently operating programs, along with state contact information for each, is available on the Aging & Disability Resource Center website.

<http://www.adrc-tae.org/tiki-index.php?page=adsspmap>

***Related links:***

Catalog of Federal Domestic Assistance: Alzheimer's Disease Demonstration Grants to States.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=aa2715dd3da78f43d192806023712404>

Administration on Aging: Alzheimer's Disease Supportive Services Program.

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/index.aspx)

***References***

US Department of Health and Human Services. (2011). *Creating Dementia Capable, Sustainable Service Systems For Persons With Dementia And Their Family Caregivers*. Program Announcement and Grant Application Instructions. Washington, DC: Author.

[http://www.aoa.gov/Grants/Funding/docs/2011/FY11\\_CompProgAnn\\_PrtsAB\\_071211.pdf](http://www.aoa.gov/Grants/Funding/docs/2011/FY11_CompProgAnn_PrtsAB_071211.pdf)

US Department of Health and Human Services. (2010). *Alzheimer's Disease Supportive Services Program: Innovation Programs to Better Serve People with Alzheimer's Disease and Related Disorders*. Program Announcement and Grant Application Instructions. Washington, DC: Author.

[http://www.aoa.gov/Grants/Funding/docs/2010/addsp\\_inovative\\_programs\\_3\\_15.pdf](http://www.aoa.gov/Grants/Funding/docs/2010/addsp_inovative_programs_3_15.pdf)

US Department of Health and Human Services. (2010). Alzheimer's Disease Supportive Services Program: Evidence-Based Programs to Better Serve People with Alzheimer's Disease and Related Disorders. Program Announcement and Grant Application Instructions. Washington, DC: Author.  
[http://www.aoa.gov/Grants/Funding/docs/2010/ADSSP\\_Evidence\\_Based\\_3\\_15.pdf](http://www.aoa.gov/Grants/Funding/docs/2010/ADSSP_Evidence_Based_3_15.pdf)

## 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

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- 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:*

Indian Child Welfare Act, P.L. 95-608.

### *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. 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:*

US 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:***

Catalog of Federal Domestic Assistance: Indian Child Welfare Act Title II Grants.

<https://www.cfda.gov/?s=program&mode=form&tab=step1&id=d550bfa7c5938e31b09ea79a9bbc0daf>

Bureau of Indian Affairs.

<http://www.bia.gov/>

***References:***

Native American Rights Fund. (n.d.). *A Practical Guide to the Indian Child Welfare Act*. Boulder, CO.

Author.

<http://www.narf.org/icwa/index.htm>

## Social and Economic Development Strategies (SEDS) Program for American Indians

### *Authorizing legislation:*

Native American Programs Act of 1974.

### *Currently authorized through:*

September 30, 2002. Congress has continued to allocate 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:***

US 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////grants/grant\\_awards.html](http://www.acf.hhs.gov/programs/ana////grants/grant_awards.html)

***Related links:***

Catalog of Federal Domestic Assistance: Native American Programs.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=5be32de128a12c74cdda1c6f6ad19661>

Administration for Native Americans: Program Information.

[http://www.acf.hhs.gov/programs/ana///programs/program\\_information.html](http://www.acf.hhs.gov/programs/ana///programs/program_information.html)

***References:***

US Department of Health and Human Services. (2010). *Social and Economic Development Strategies*.

<http://www.acf.hhs.gov/grants/open/foa/view/HHS-2010-ACF-ANA-NA-0040/pdf>

US Department of Health and Human Services. (n.d.). *Fiscal Year 2006 Report to Congress on the Impact and Effectiveness of Administration for Native American Projects*. Washington, DC: Author.

[http://www.acf.hhs.gov/programs/ana///archive/congressional\\_reports/2006.html](http://www.acf.hhs.gov/programs/ana///archive/congressional_reports/2006.html)

US Department of Health and Human Services. Administration for Native Americans. (2010). *Social and Economic Development Strategies (SEDS)*.

<http://www.acf.hhs.gov/programs/ana///relevant/Documents/FastFactsSEDS.pdf>

## 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:***

US Department of Health and Human Services, 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:***

For information about grants for supportive services made in years 2002–2008, use the Administration on Aging Integrated Database custom tables.

<http://www.agidnet.org/CustomTables/NA/Year/>

***Related links:***

Catalog of Federal Domestic Assistance, Special Programs for the Aging.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=edbb9deea50cc01e5d4457b04a9bf51d>

***References:***

Administration on Aging: Services for Native Americans (OAA Title VI).

[http://www.aoa.gov/aoa\\_programs/hcltc/native\\_americans/index.aspx](http://www.aoa.gov/aoa_programs/hcltc/native_americans/index.aspx)

## 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.
- A competitive grant program under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 funds the implementation of family support centers for military families whose children have developmental disabilities.
- 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.

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## 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 (PPPWD).

### *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

<http://www.military.com/benefits/tricare/tricare-extended-care-health-option#4>

*Related links:*

Military.com: TRICARE Extended Care Health Option.

<http://www.military.com/benefits/tricare/tricare-extended-care-health-option>

*References:*

TRICARE Extended Care Health Option brochure.

[http://www.tricare.mil/tricaresmartfiles/Prod\\_294/ECHO\\_Br\\_Lo\\_Res.pdf](http://www.tricare.mil/tricaresmartfiles/Prod_294/ECHO_Br_Lo_Res.pdf)

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## Respite for Injured Service Members

### *Authorizing legislation:*

National Defense Authorization Act for FY 2008, P.L. 110-181, Subtitle C, Sec. 1633.

### *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 Military Medical Support Office, 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/contacts/>

***Related links:***

Injured while on Active Duty.

<http://tricare.mil/mybenefit/home/LifeEvents/InjuredActiveDuty>

***References:***

Respite for Injured Active Duty Service Members.

<http://tricare.mil/mybenefit/home/LifeEvents/SpecialNeeds/RespiteCare?>

Compensation and Benefits Handbook For Seriously Ill and Injured Members of the Armed Forces.

<http://tricare.mil/mybenefit/Download/Forms/Compensation-Benefits-Handbook.pdf>



## 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<sup>59</sup> 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 past 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;

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<sup>59</sup> Department of Defense Instruction Number 1315.19. (2005). Identifying a Family Member with Special Needs. Enclosure 4, page 12. <http://www.dtic.mil/whs/directives/corres/pdf/1315.19p.pdf>

- 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.
- 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:***

US Department of Defense.

***Related links:***

Military Homefront: Special Needs/EFMP.

[http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF\\_DETAIL\\_1?section\\_id=20.40.500.570.0.0.0.0&current\\_id=20.40.500.570.500.20.0.0.0](http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_DETAIL_1?section_id=20.40.500.570.0.0.0.0&current_id=20.40.500.570.500.20.0.0.0)

***References:***

Department of Defense Instruction Number 1342.22. (1992). *Family Centers*.

<http://www.dtic.mil/whs/directives/corres/pdf/134222p.pdf>

## 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).

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

Soldiers with EFMs must enroll in one of the EFMPs:

- Active Army,
- US 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:***

Army OneSource: Respite Care Program.

<https://www.myarmyonesource.com/FamilyProgramsandServices/FamilyPrograms/ExceptionalFamilyMemberProgram/RespiteCareProgram/default.aspx>

Army OneSource: EFMP Respite Care Frequently Asked Questions.

<https://www.myarmyonesource.com/FamilyProgramsandServices/FamilyPrograms/ExceptionalFamilyMemberProgram/RespiteCareProgram/FAQs/default.aspx#15>

US Army Medical Department, Exceptional Family Member Program.

<http://efmp.amedd.army.mil>

***References:***

US Army Regulation 608-75. (2006). Personal Affairs. Exceptional Family Member Program; Rapid Action Revision (RAR) Issue Date: 24 February 2011.

[http://www.army.mil/usapa/epubs/pdf/r608\\_75.pdf](http://www.army.mil/usapa/epubs/pdf/r608_75.pdf)

US Department of the Army Release #0981. (2009). *Army Exceptional Family Member Program (EFMP) Respite care offers families some valuable rest.*

<https://www.myarmyonesource.com/cmsresources/Army%20OneSource/Media/PDFs/Family%20Programs%20and%20Services/Family%20Programs/Exceptional%20Family%20Member%20Program/Respite%20Care%20Program/ATT1051015.pdf>

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## Marine Corps Exceptional Family Member Program (EFMP) Respite Care

### *Funding:*

Qualified families may receive up to 40 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.

Respite programs funded by non-military state and local agencies are not counted against the allotted 40 hours per month.

There are four levels of care, 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 may also receive respite at no more than the CDC rate.

### *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/efmp/index.cfm?sid=fl&smid=1>

NACCRRRA Exceptional Family Member Program (EFMP) Respite Care.

<http://www.naccrra.org/MilitaryPrograms/EFMP/#2>

### *References:*

US Marine Corps. (2010). Procedural Changes to Exceptional Family Member Program (EFMP).

<http://www.usmc.mil/news/messages/Pages/MARADMIN308-10.aspx>

## Navy Exceptional Family Member Program (EFMP) Respite Care

### *Funding:*

Qualified families may receive up to 40 hours of respite care per month.

### *Respite connection:*

Respite is provided through the National Association of Child Care Resource & Referral Agencies (NACCRRA).

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

Navy families are eligible for respite care if

- the family is enrolled in the Navy's EFMP;
- the child is age 18 or younger;
- the level of enrollment is
  - Level IV—the family member's needs require an assignment near a major military or civilian medical facility; or
  - Level V—the family member is severely disabled **and** is housebound, and
- the sailor is stationed at one of the following bases:
  - Bremerton, Washington,
  - Washington, DC,
  - Jacksonville, Florida,
  - Norfolk, Virginia, or
  - San Diego, California.

Those stationed at other bases may be approved on a case-by-case basis.

### *Points of contact:*

Families should call Child Care Aware at 1-800-424-2246. Once eligibility is confirmed, the family will be connected with the local agency administering the program.

### *Related links:*

Navy Exceptional Family Member Program (EFMP).

[http://www.cnic.navy.mil/CNIC\\_HQ\\_Site/WhatWeDo/FleetandFamilyReadiness/FamilyReadiness/FleetAndFamilySupportProgram/CNICD\\_A065893](http://www.cnic.navy.mil/CNIC_HQ_Site/WhatWeDo/FleetandFamilyReadiness/FamilyReadiness/FleetAndFamilySupportProgram/CNICD_A065893)

National Association of Child Care Resource & Referral Agencies: Navy Exceptional Family Member Program (EFMP) Respite Care.

<http://www.naccrra.org/MilitaryPrograms/NavyEFMP/>

### *References:*

Navy Personnel Command: Navy Exceptional Family Member Program.

<http://www.npc.navy.mil/CommandSupport/ExceptionalFamilyMember/>

## Air Force Exceptional Family Member Program (EFMP) Respite Care

### *Funding:*

Qualified families may receive 8 to 20 hours 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 EFMP;
- the child is age 18 or younger;
- 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 at (or near) one of the following bases:
  - Tacoma, Washington,
  - Washington, DC,
  - Hampton Roads, Virginia,
  - Charleston, South Carolina,
  - San Antonio, Texas,
  - Colorado Springs, Colorado, or
  - 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:*

National Association for Child Care Resource & Referral Agencies (NACCRRA) at 1-800-424-2246.

Information may also be obtained from the local Airman & Family Readiness Center.

### *Related links:*

National Association for Child Care Resource & Referral Agencies (NACCRRA), Air Force Exceptional Family Member Program Respite Care.

<http://www.naccrra.org/militaryprograms/air-force/EFMP/>

### *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.

Air Force Aid Society: Respite Care.

<http://www.afas.org/Community/RespiteCareProgram.cfm>

## Coast Guard Mutual Assistance Respite Care

### *Funding:*

Respite is based on need (financial need and need for a break from care giving) 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 (2) is enrolled in the Coast Guard Special Needs Program.<sup>60</sup>

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 representatives can be found on the Coast Guard Mutual Assistance website.

<http://www.cgmahq.org/Map/repMembers.html>

### *Related links:*

US Coast Guard: Office of Work-Life Programs—Special Needs Program.

[http://www.uscg.mil/worklife/special\\_needs.asp](http://www.uscg.mil/worklife/special_needs.asp)

### *References:*

Coast Guard Mutual Assistance Respite Care Program. (2006).

<http://uscg.mil/bsuAlameda/WLS/cgma-respite-care-program.pdf>

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<sup>60</sup> 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 of active duty service members, deployed guard and reserve personnel, and those assigned to a Community Based Warrior in Transition Unit

### *Activities supported by the funding:*

The Department of Defense has contracted with the Young Men's Christian Association (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 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 Military OneSource website.

<http://www.militaryonesource.com/Portals/0/Content/Web%20Pages/YMCA/YMCARespiteCare.pdf>

### *Related links:*

Military OneSource: Respite Child Care.

<http://www.militaryonesource.com/MOS/Tools/MilitaryRecreationMWR/YMCAProgramMWR/YMCARespiteChildCare.aspx>

### *References:*

DoD/YMCA Respite Care Eligibility Form.

[http://www.militaryonesource.com/Portals/0/Content/Web%20Pages/YMCA/Respite\\_Care\\_Eligibility\\_Form\\_Oct09.pdf](http://www.militaryonesource.com/Portals/0/Content/Web%20Pages/YMCA/Respite_Care_Eligibility_Form_Oct09.pdf)

## Projects of National Significance: Family Support 360 for Military Families

### *Authorizing legislation:*

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), P.L. 106-402.

### *Currently authorized through:*

The DD Act is authorized through September 30, 2007. Congress appropriated funds for the DD Act for FY 2008–2010. Projected grants for Family Support 360 for Military Families projects run through September 30, 2014.

### *Program purpose:*

To plan and implement family support centers that connect military families with children (birth to age 25) with developmental disabilities to services for the entire family.

### *Beneficiaries:*

Military families with children (birth to age 25) with developmental disabilities

### *Funding:*

These are competitive project grants of \$200,000 per year over a 5-year grant period.

### *Activities supported by the funding:*

Each state grantee assists at least 20 families in the first year and 40 families in years 2 through 5. Families receive individualized assessment and planning for services and supports and access to a navigator (guide and advocate) to help them learn about and access the military and civilian services contained in their plan.

Individualized planning and assessment must involve at least three of the following services in the first year of the grant, with three additional services being made available each year in years 2 through 5:

- health and mental health services;
- eligibility for personal assistance and supports, such as direct care workers, respite care, food stamps, and cash assistance;
- transportation;
- child care services;
- family strengthening programs such as marriage and parenting education;
- early intervention;
- education;
- housing; and
- employment-related assistance.

The selection of services to be offered in any year should be those that the eligible targeted families will most likely need throughout the grant year.

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***Respite connection:***

Connecting families to needed respite care in the community is one of the core areas Family Support 360 Military Centers may focus on.

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

Projects must be conducted in partnership with the commander of a military installation and the state Developmental Disabilities Network.

Four states and/or territories received Family Support 360 Military Project grants for FY 2008–2013: California, Guam, Texas, and Washington.

For FY 2009–2014, state grantees are Alaska, Florida, Mississippi, New Jersey, North Carolina, and Utah.

***Federal funding agency:***

US Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities.

***Points of contact:***

Contact information for current Family Support 360 Military grantees can be found on the Family Support 360 Resource Center website.

[http://www.addfamilysupport360.org/3\\_10/contact1.asp](http://www.addfamilysupport360.org/3_10/contact1.asp)

***Eligible entity:***

Public or private nonprofit entities.

***Related links:***

Catalog of Federal Domestic Assistance: Developmental Disabilities Projects of National Significance.

<https://www.cfda.gov/index?s=program&mode=form&tab=step1&id=74d0f409e0f593861de25cc3d6ee91a0>

Family Support 360 Resource Center.

[http://www.addfamilysupport360.org/3\\_10/index.asp](http://www.addfamilysupport360.org/3_10/index.asp)

***References:***

US Department of Health and Human Services. (2010). *Family Support 360 for Military Families Fact Sheet*.

[http://www.acf.hhs.gov/programs/add/pns/fs360\\_militaryfactsheet.html](http://www.acf.hhs.gov/programs/add/pns/fs360_militaryfactsheet.html)

US Department of Health and Human Services. (2008). Funding Opportunity Number HHS-2009-ACF-ADD-DN-0047.

<http://www.acf.hhs.gov/grants/closed/HHS-2009-ACF-ADD-DN-0047.html>

## Army Respite Child Care

### *Program purpose:*

Respite child care for certain military families.

### *Beneficiaries:*

Families of Army service members, Mission Levels 1 and 2, in one of the following categories:

- deployed (for 30 days prior to and 90 days after return),
- Temporary Change of Station,
- Unaccompanied Permanent Change of Station,
- TDY (90–179 days),
- Wounded, Ill, and Injured Soldiers, or
- Survivors of Fallen Soldiers.

A similar program, the *Army Give Parents a Break* program is for families of:

- geographically dispersed Accessions Command Army Recruiters,
- ROTC Cadet Cadres (trainer), or
- Deployed and in the Army National Guard or deployed Army Reserve soldiers.

### *Funding:*

The Army contracts with the National Association of Child Care Resource and Referral Agencies (NACCRRA) to reimburse the respite provider for eligible care at the Army-approved hourly rate. Eligible child care providers will be reimbursed at a maximum of \$10/hour for the first child and \$5/hour for each additional child, not to exceed \$20/hour per family.

### *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 family with a specified number of free child care each month for each eligible child. Child does not need to have any special need.

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

Respite Child Care is not a substitute for regularly scheduled child care. Therefore, it cannot be used during the hours the family uses regularly scheduled child care. It may be used at the discretion of the parent. Respite cannot be used in conjunction with installation respite to exceed authorized monthly hours, and parents must sign an agreement to this effect. Respite must be used in at least 2-hour increments, and monthly attendance sheets need to be verified by parent and provider.

Spouse does not have to be working, looking for work, or in school to qualify. If a family is currently receiving assistance through NACCRRA and intends to use their current provider for respite care, orders must be submitted. If parents are not currently receiving financial assistance through NACCRRA, they

must submit the following documents: Parent Child Care Respite Application, Soldier's Orders, Parent Self-Certification Statement, or copy of child's birth certificate.

Providers must be state-licensed and annually inspected child care home or center. If not currently enrolled with NACCRRA, providers must submit a Child Care Provider Respite Application, W-9 form, and direct deposit enrollment form (preferred method).

***Points of contact:***

To find a provider who meets the requirements, contact NACCRRA's Child Care Aware® at 1-800-424-2246 for a personal consultation or [search online](#) for providers already pre-qualified to serve Army families in your area.

Army Respite Child Care  
1515 N. Courthouse Rd. 11th Floor  
Arlington, VA 22201

***References:***

National Association of Child Care Resource and Referral Agencies. *What Programs are Available*.  
<http://www.naccrra.org/about-us/military-families/army/what-programs-are-available>

## Veterans Affairs Health Care

### *Authorizing legislation:*

Millennium Health Care and Benefits Act of 1999, P.L. 106-117.

### *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 US 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:*

US Department of Veterans Affairs, Veterans Health Administration.

### *Points of contact:*

Veterans can access information about their health benefits on the Department of Veterans Affairs website.

<http://www.myhealth.va.gov/>

Contact information for VA offices and facilities can be found on the Department of Veterans Affairs website.

[http://www.va.gov/landing2\\_locations.htm](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](http://www.caregiver.va.gov/help_landing.asp) for help finding a local Caregiver Support Coordinator.

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***Related links:***

US Department of Veterans Affairs. VA Caregiver Support and Respite Care.

<http://www.caregiver.va.gov/>

[http://www.va.gov/GERIATRICS/Respite\\_Care.asp](http://www.va.gov/GERIATRICS/Respite_Care.asp)

***References:***

US Department of Veterans Affairs. (2008). VHA Handbook 1140.02. Respite Care.

[http://www1.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=1802](http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=1802)

## 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 or surviving spouses

### *Funding:*

The Department of Veterans Affairs (VA) pays a maximum of \$1,949/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:*

US Department of Veterans Affairs.

### *Points of contact:*

Contact information for the appropriate VA Regional Office is available on the Department of Veterans Affairs website.

<http://www.vba.va.gov/bln/21/ro/rocontacts.htm>

### *Related links:*

US Department of Veterans Affairs: Veterans Pension Program.

<http://www.vba.va.gov/bln/21/pension/vetpen.htm#7>

### *References:*

US Department of Veterans Affairs: Improved Disability Benefits Pension Rate Table.

<http://www.vba.va.gov/bln/21/Rates/pen01.htm>

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## 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 ill, injured, or disabled veterans in their homes.

### *Beneficiaries:*

Family caregivers of seriously injured veterans with polytrauma, traumatic brain injury (TBI), and/or spinal cord injury (SCI)

### *Funding:*

In February 2008, the US 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 at 12 sites through the local VA Health Center (see the **Twelve Pilot Sites** list below).

### *Activities supported by the funding:*

The Department of Veterans Affairs Voluntary Service (VAVS) has formed the Caregiver Support Network to recruit and provide volunteers to provide in-home respite and other supports to family caregivers of veterans from all eras. The pilot programs are training small groups of volunteers and matching them with veterans living in their neighborhoods.

### *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:*

US Department of Veterans Affairs, Veterans Health Administration.

### *Points of contact:*

Interested volunteers should contact the Voluntary Service Department at the local VA facility.

**Twelve Pilot Sites**

Augusta, GA  
Home Respite Program  
706-731-7208

San Francisco, CA  
Respite Care Program  
415-221-4810 x6331

Baltimore, MD  
Volunteer Home Respite Program  
410-605-7000 x7102

Seattle, WA  
Volunteer Respite Program  
206-277-3884

Lexington, KY  
Volunteer Home Respite Program  
859-233-4511 x3564

St. Louis, MO  
Volunteer Respite Program  
314-289-6530

Los Angeles, CA  
Respite/Telehealth Program  
310-268-3048

Syracuse, NY  
Voluntary Service Home Respite Program  
315-425-4315

Minneapolis, MN  
Volunteer Caregiver Support Program  
612-725-2050 x3203

Temple, TX  
VAVS Respite Care Program  
254-743-0740

Richmond, VA  
Volunteer Visitation Program  
804-675-5107

Tucson, AZ  
Volunteer Respite Program  
520-792-1450 x6020

***Related links:***

Voluntary Service, US Department of Veterans Affairs. (2010). Volunteer with VA Caregiver Support Network (Brochure).

[http://www.volunteer.va.gov/docs/2010\\_Caregiver\\_Recruitment.pdf](http://www.volunteer.va.gov/docs/2010_Caregiver_Recruitment.pdf)

***References:***

Statement of Mahdulika Agarwal, MD, MPH, Chief Officer, Patient Care Services, Veterans Health Administration, US Department of Veterans Affairs before the Committee on Veterans Affairs, Subcommittee on Oversight and Investigations, US House of Representatives, March 13, 2008.

<http://www.va.gov/OCA/testimony/hvac/soi/080313MA.asp>

## Veteran Directed Home and Community Based Services (VD-HCBS) Program

### *Authorizing legislation:*

Title IV of the Older Americans Act, as amended.

### *Currently authorized through:*

September 30, 2011.

### *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 VD-HCBS Program offered through the Aging Network (e.g., State Unit on Aging, Area Agencies on Aging) provides veterans with a person-centered alternative to traditional home care services and programs.

Participating US Department of Veterans Affairs (VA) Medical Centers (VAMCs) refer eligible veterans to the Aging Network to enroll in the VD-HCBS Program. VAMCs authorize a flexible spending budget based on the veteran's assessed needs. The Aging Network works with the veteran to arrange and secure the needed goods and services within the budget and is also responsible for ensuring that the veteran's needs are met so that he or she can 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 VA program coordinator to oversee quality, satisfaction, and service delivery; an options counselor from the Aging Network to assist in finding and training workers and securing needed goods and services within the allocated budget; and a financial management service to pay the bills and payroll taxes and ensure the integrity of the budget.

### *Respite connection:*

Respite is a core service supported by the funding.

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

Veterans of all ages are eligible for services under this program.

### *Federal funding agency:*

US Department of Veterans Affairs, Veterans Health Administration.

### *Eligible entity:*

State Units on Aging, Area Agencies on Aging.

***Points of contact:***

Information on states participating in the VD-HCBS Program, including contact information, is available on the Aging & Disability Resource Center website.

<http://www.adrc-tae.org/tiki-index.php?page=NHDmap>

***Related links:***

Veteran Directed Home and Community Based Services Program.

<http://www.adrc-tae.org/tiki-index.php?page=NewVDHCBS>

***References:***

US Department of Health and Human Services Press Release (2008). September 29.

[http://www.aoa.gov/AoAroot/Press\\_Room/For\\_The\\_Press/pr/archive/2008/September/9\\_29\\_08.aspx](http://www.aoa.gov/AoAroot/Press_Room/For_The_Press/pr/archive/2008/September/9_29_08.aspx)

US Department of Health and Human Services. (2009). *The Community Living Program: Supporting Independence and Choice in the Community. Frequently Asked Questions*. Washington, DC: Author.

<http://www.aoa.gov/AoAroot/Grants/Funding/2009.aspx>

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## Program of Comprehensive Assistance for Family Caregivers

### *Authorizing legislation:*

Caregivers and Veterans Omnibus Health Services Act of 2010, P.L. 111-163.

### *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.

### *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;
- medical care; and
- 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/>

Caregiver Support Line: 1-855-260-3274.

***Related Links:***

US Department of Veterans Affairs. VA Caregiver Support.

<http://www.caregiver.va.gov/>

US Department of Veteran's Affairs. *FACT SHEET: Caregiver Support Program Interim Rule Implementation of the Program of Comprehensive Assistance for Family Caregivers*. (2011).

[http://www.caregiver.va.gov/pdfs/CaregiverFactSheet\\_Apply.pdf](http://www.caregiver.va.gov/pdfs/CaregiverFactSheet_Apply.pdf)

***References:***

P.L. 111-163 Caregivers and Veterans Omnibus Health Services Act of 2010.

<http://www.gpo.gov/fdsys/pkg/PLAW-111publ163/html/PLAW-111publ163.htm>

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## Appendix 1: Federal Programs That May Be Potentially Accessed by States, Local Agencies, or Individuals for Respite Services, Support, or Funding

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
<b>Medicare and Medicaid Programs</b>				
Medicare Hospice Benefit	Fee for service entitlement to individuals	Social Security Act, Title XVIII, Section 1861(dd)	Medicare-eligible aged and disabled individuals with terminal illnesses	Payments to hospice care facilities
Medicare Advantage Special Needs Plans	Managed care health insurance plan to individuals	Social Security Act, Title XIX,	Medicare-eligible individuals who are dually eligible, institutionalized, or have certain conditions	Payments to respite care providers
Medicaid Personal Care Benefit	Formula grant to states at state option	Social Security Act, Title XIX, Section	Medicaid-eligible individuals in states including this option in their state plan	Payments to providers of services that result in “indirect” respite care
Self-Directed Assistance Services	Formula grant to states at state option	Social Security Act, Title XIX, Section 1915(j)	Frail elders, adults with disabilities, and some children with developmental disabilities	Consumer-directed budgets can be used to pay respite providers
Programs of All-Inclusive Care for the Elderly (PACE)	Capitated benefit with integrated Medicare and Medicaid financing	Balanced Budget Act of 1997	Individuals age 55 or older certified as eligible for nursing home care	Payments to providers of services that result in “indirect” respite care; payments to respite care providers
Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)	Formula grant to states Entitlement	Social Security Act, Title XIX	Medicaid-eligible children	Payments to providers of services that result in “indirect” respite care
Medicaid Hospice Benefit	Formula grant to states State option	Social Security Act, Title XIX	Medicaid-eligible individuals with terminal illnesses	Payments to hospice care facilities

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities	Discretionary grant to states	Deficit Reduction Act of 2005, Section 6063	Youth with serious emotional disturbance	Payments to respite care providers
<b>Medicaid Waiver Programs</b>				
Medicaid Research & Demonstration Projects	Discretionary grant to states	Social Security Act, Title XXI, Section 1115	Medicaid-eligible individuals	Payments to respite care providers
Medicaid Managed Care/Freedom of Choice Waivers	Waiver of Medicaid regulations	Social Security Act, Title XIX, Section 1915(b)	Medicaid-eligible individuals	Payments to respite care providers
Home and Community-Based Services Waivers	Waiver of Medicaid regulations	Social Security Act, Title XIX, Section 1915(c)	Medicaid-eligible individuals	Payments to respite care providers or consumer-directed
Combined Waivers	Waiver of Medicaid regulations	Social Security Act, Title XIX, Sections 1915(b) and (c)	Medicaid-eligible individuals	Payments to respite care providers or consumer-directed
<b>Additional Opportunities in Health Care Reform</b>				
Community Living Assistance Supports and Services (CLASS) <sup>61</sup>	Voluntary insurance program funded by payroll deduction	Title VIII of the Patient Protection and Affordable Care Act of 2010	Individuals with functional impairments who have paid premiums for five years	Unrestricted payments to consumers; could be used for respite
Community First Choice Option	Formula grant to states State option	Social Security Act, Section 1915(k)	Medicaid-eligible individuals requiring an institutional level of care	Payments to providers of services that result in “indirect” respite care

<sup>61</sup> Because of governmental concerns about potential solvency issues, the program will not be implemented at this time. See US Department of Health and Human Services (2011). A Report on the Actuarial, Marketing, and Legal Analyses of the CLASS Program. <http://aspe.hhs.gov/daltcp/reports/2011/class/index.shtml>



Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
State Balancing Incentive Payments Program	Discretionary grant to states State Option	Patient Protection and Affordable Care Act	Medicaid-eligible individuals	Payments to respite providers or to providers of services that result in “indirect” respite care
Medicaid State Plan Option for Home and Community-Based Services	Formula grant to states State option	Social Security Act, Title XIX, Section 1915(j)	Medicaid-eligible individuals	Payments to respite care providers
Money Follows the Person	Discretionary grant to states	Deficit Reduction Act of 2005	Medicaid-eligible individuals transitioning out of institutional settings	Payments to respite care providers or consumer directed
Children’s Health Insurance Program (CHIP)	Formula grant to states	Social Security Act, Title XXI	Low-income children	Payments to respite care providers
<b>Programs for Children Only: Child Welfare and Child Abuse Prevention Programs</b>				
CAPTA Basic State Grants	Formula grant to states	Child Abuse Prevention and Treatment Act, Title I, Section 106 extended by CAPTA Reauthorization Act of 2010	Children identified as abused or neglected and their families	Support of community respite and crisis nursery programs
CAPTA Discretionary Activities	Discretionary grants or contracts to states, local government, tribes, tribal organizations, public or private agencies	Child Abuse Prevention and Treatment Act, Title I, Section 105 extended by CAPTA Reauthorization Act of 2010	Children identified as abused or neglected or at risk of abuse or neglect and their families	Support of community respite and crisis nursery programs

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Child Abuse Community-Based Prevention Grants (CBCAP)	Formula grant to states	Child Abuse Prevention and Treatment Act, Title II extended by CAPTA Reauthorization Act of 2010	Children at risk of child abuse or neglect and their families	Support of community respite and crisis nursery programs
Stephanie Tubbs Jones Child Welfare Services	Formula grant to states	Social Security Act, Title IV-B, Subpart 1	Families and children in need of child welfare benefits	Payments to respite care providers
Family Connection Grants	State, local or tribal child welfare agencies and private nonprofit organizations	Social Security Act, Title IV-B, Subpart 1	Foster children or children in kinship care or children at risk of entering foster care	Funds information centers to connect families to respite.
Promoting Safe and Stable Families	Formula grant to states	Social Security Act, Title IV-B, Subpart 2	Families and children in need of child welfare and family strengthening services	Payments to respite care providers and crisis nursery programs
Targeted Grants to Increase Well-Being of, and to Improve Permanency Outcomes for, Children Affected by Substance Abuse	Competitive grant to state partnerships serving children at risk of out-of-home placement	Social Security Act, Title IV-B, Subpart 2	Children at risk of out-of-home placement due to parent or caregiver's substance abuse	Payments to providers of services that result in "indirect" respite care
Abandoned Infants Assistance	Discretionary grant to projects	Abandoned Infants Assistance Act as extended by the CAPTA Reauthorization Act of 2010	Infants and young children with HIV/AIDS or substance abuse, who might otherwise be abandoned in hospitals	Payments to respite care providers; support of respite care programs

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Adoptions Opportunities	Discretionary grant to projects	Child Abuse Prevention and Treatment and Adoption Reform Act as extended by the CAPTA Reauthorization Act of 2010	Children in foster care with a goal of adoption	Grants to programs that may be use to pay providers of respite care
Family Violence Prevention and Services Act	States, Tribal entities; State Domestic Violence Coalitions; for <i>Specialized Services for Abused Parents and Their Children</i> , local agencies, nonprofit or Tribal Organizations	Family Violence Prevention and Services Act, as extended by the CAPTA Reauthorization Act of 2010	Victims of domestic violence, their children and other dependents, their families, and the public.	Assistance in accessing and providing information and referral to respite services; payment to respite providers under <i>Specialized Services for Abused Parents and Their Children</i>
<b>Programs for Children Only: Child Education/Health/Mental Health</b>				
Early Intervention for Infants and Toddlers	Formula grant to states	Individuals with Disabilities Education Act, Part C	Children ages 0 to 2 with developmental disabilities and their families	Payments to respite care providers
Special Education Preschool	Formula grant to states	Individuals with Disabilities Education Act, Part B	Children ages 3 to 5 with developmental disabilities	Payments to respite care providers
Maternal and Child Health Block Grant	Formula grant to states	Social Security Act, Title V, Section 501	Mothers, infants and children, including children with special health care needs, particularly low-income	Payments to respite care providers
Maternal and Child Health Community Integrated Service Systems	Discretionary grant to projects	Social Security Act, Title V, Section 502	Mothers, infants and children, including children with special health care needs, particularly low-income	Funds development of community systems that may include respite activities

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Maternal and Child Health Special Projects of Regional and National Significance	Discretionary grant to projects	Social Security Act, Title V, Section 501	Mothers, infants and children, including children with special health care needs, particularly low-income	None to date
Family to Family Health Information Centers	Discretionary grant to projects	Social Security Act, Title V, Section 501(c)(1)(A)	Children and families receiving services from organizations engaged in activities for children and youth with special health care needs	Funds information centers to connect families to respite. No direct funding for respite care
Services to Individuals with a Postpartum Condition and Their Families	Discretionary grant to projects	Social Security Act, Title V, Section 512	Individuals at with or at risk for postpartum conditions and their families	Not yet funded
Child Mental Health Initiative	Discretionary grant to states	Public Health Services Act, Title V, Section 561	Children under age 22 with a diagnosed serious emotional disturbance, serious behavioral disorder, or serious mental disorder	Payments to respite care providers
<b>Programs for Children Only: Child and Family Low-Income Assistance</b>				
Temporary Assistance for Needy Families (TANF)	Formula grant to states	Social Security Act, Title IV-A	Low-income families with children	Payments to respite care providers or consumer directed
Child Care and Development Block Grant	Formula grant to states	Social Security Act, Title IV	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	Payments to respite care providers if family receiving protective services; development and support of provider networks

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Services to Advocate for and Respond to Youth	Discretionary grant to projects	Violence Against Women and Department of Justice Reauthorization Act, Title III	Youth who have experience domestic violence, dating violence, sexual assault or stalking	Payments to respite care providers
Programs Serving All Ages				
Community Development Block Grant	Entitlement grants to principal cities of Metropolitan Statistical Areas (MSAs) and qualified urban counties; Non-entitlement grants to states	Housing and Community Development Act of 1974, Title I	Low- and moderate-income persons	Grants to respite care providers
Social Services Block Grant	Formula grant to states	Social Security Act, Title XX	No restrictions	Grants to respite care providers
Community Mental Health Services Block Grant	Formula grant to states	Public Health Service Act, Title XIX, part B	Adults with serious mental illness; children with serious emotional disturbance	Payments to respite care providers
Developmental Disability Basic Support and Advocacy Grants	Formula grant to states	Developmental Disabilities Assistance and Bill of Rights Act	Individuals with developmental disabilities	Funds development and maintenance of provider networks. Limited payments to respite care providers
Family Support 360/Family Support and Community Access	Discretionary grant to projects	Developmental Disabilities Assistance and Bill of Rights Act, Title I	Families of individuals with developmental disabilities	Funds information services connecting families to respite care providers

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Centers for Independent Living	Discretionary grant to projects	Rehabilitation Act, Title VII, Part C; Recovery Act	Individuals with significant disabilities	Payments to respite care providers or linkages to respite using other funding sources for payment
HIV Care Formula Grants	Formula grant to states	Public Health Service Act, Title XXVI, Part B	Individuals with HIV/AIDS and their families	Payments to respite care providers
HIV Emergency Relief Project Grants	Formula grant to states	Public Health Service Act, Title XXVI, Part A	Individual with HIV/AIDS and their families	Payments to respite care providers
Supplemental Security Income	Entitlement to individuals	Social Security Act, Title XVI	Individuals who are disabled, blind, or over 64 and low income	Unrestricted payments to individuals; can be used for respite
Senior Companion	Discretionary grant to projects	Domestic Volunteer Service Act, Title II, Part B	Individuals age 21 and over with special needs; frail elderly	Payments in the form of stipends to volunteer companions who in turn provide no cost services to consumers
National Senior Service Corps	Grants to national and local nonprofits, schools, government agencies, faith-based and other community organizations	Title II, Domestic Volunteer Service Act of 1973, as amended, P.L. 93-113; as amended through P.L. 111-13, 2009	Older volunteers serve children, adults, and the aging population	No-cost volunteer services provided to consumers
AmeriCorps	Formula grants when applicable to Governor-appointed State Service Commissions	National and Community Service Act of 1990; as amended through P.L. 111-13, 2009	Beneficiaries identified with an application for assistance	No-cost volunteer services provided to consumers

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Aging and Disability Resource Centers	Competitive grants to State Agency or instrumentality of the State	Affordable Care Act , Title III, Part III, Section 2405	Aging population and persons with disabilities, including family caregivers	ADRCs play a central role in Lifespan Respite systems as mandated primary stakeholders.
National Family Caregiver Support Program	Formula grant to states, Indian Tribal Organizations; public or nonprofit Native Hawaiian organizations	Older Americans Act, Title III-E and VI-C (Native American Caregiver Support Program)	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	Payments to respite care providers or consumer direction
<b>Programs for the Aging</b>				
Supportive Services and Senior Centers	Formula grant to states	Older Americans Act, Title III, Part B	Individuals age 60 and over with economic and social need	Payments to providers of services that result in “indirect” respite care
Community Living Program	Discretionary grant to projects	Older Americans Act, Title IV	Individuals age 60 and over at risk of placement in a nursing home and spending down financial assets	Payments to respite care providers. Program expired but grants finishing last year
Alzheimer’s Disease Supportive Services Program	Discretionary grant to states	Public Health Service Act, Title III, Section 398	Individuals with Alzheimer’s Disease and their family caregivers	Payments to respite care providers
<b>Programs for American Indians</b>				
Indian Child Welfare Act Grants	Discretionary grant to Tribes	Indian Child Welfare Act	American Indian children and families	Payments to respite care providers
Social and Economic Development Strategies	Discretionary grant to Tribes	Native American Programs Act	American Indians, Alaska Natives, Native Hawaiians, Native American Pacific Islanders	Payments to providers of services that result in “indirect” respite care
Special Program for the Aging	Discretionary grant to projects	Older Americans Act, Title VI	Older American Indians, Alaska Natives, and Native Hawaiians	Payments to providers of services that result in “indirect” respite care

Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Programs for Military Families				
TRICARE ECHO	Supplemental health insurance	—	Military families with an exceptional family member	Payments to respite care providers
Respite for Injured Service Members	Extended TRICARE respite benefits	National Defense Authorization Act for FY 2008, P.L. 110-181, Subtitle C, Sec. 1633.	Injured active duty service members, including National Guard/Reserve who have a serious injury	Payments to respite providers at no cost to family and no cap
Exceptional Family Member Program	Entitlement to individuals	—	Military families with an exceptional family member	Payments to respite care providers; varies by service
Armed Services YMCA Respite Child Care	Entitlement to individuals	—	Military families at participating YMCAs	Free membership and respite child care
Family Support 360 for Military Families	Discretionary grant to projects	Developmental Disabilities Assistance and Bill of Rights Act	Military families with children (birth to age 25) with developmental disabilities	Funds information services connecting families to respite care providers
Army Respite Child Care (and Give Parents a Break)	Entitlement to individuals	—	Families of Deployed; Wounded, Ill, and Injured Soldiers; and Survivors of Fallen Soldiers; or geographically dispersed Accessions Command Army Recruiters, ROTC Cadet Cadres (trainer), or Deployed and in the Army National Guard or deployed Army Reserve soldiers	Payments to respite providers at no cost to family
Programs for Veterans				
Veterans Affairs Health Care	Entitlement to individuals	Millennium Health Care and Benefits Act	Veterans of all eras	Provides respite care through VA medical centers, community settings, or in-home



Program	Type of Assistance & Eligible Entity	Authorizing Legislation	Beneficiaries (may vary by state)	Payments to or Support for Respite Services
Aid-and-Attendance and Housebound Benefit	Entitlement to individuals	—	Veterans with medical needs or mental or physical disability or surviving spouses	Unrestricted payments to individuals; can be used for respite
Volunteer Caregiver Support Network	Funding to twelve pilot sites	—	Family caregivers of seriously injured veterans with polytrauma, traumatic brain injury (TBI), and/or spinal cord injury (SCI)	Voluntary respite services
Veteran-Directed Home and Community Based Services	Discretionary grant to State Units on Aging or Area Agencies on Aging	Older Americans Act, Title IV	Veterans at risk of placement in a nursing home	Payments to respite care providers or consumer directed
VA Programs of Comprehensive Assistance for Family Caregivers	Stipends to family caregivers, mental health services, health coverage and respite	Caregivers and Veterans Omnibus Health Services Act	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	Respite must be medically and age-appropriate, and include in-home care.