Federal Funding and Support Opportunities for Respite
Building Blocks for Lifespan Respite Systems
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 older 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 Impact of the Pandemic on Respite Services

During the pandemic, we have had to shift how we perceive and offer respite. While many families continued to take advantage of in-home respite supported by Lifespan Respite Care grantees, Medicaid home and community-based waivers, and other state and federal programs when available, many more caregivers lost respite and other caregiver supports. In addition, the number of family members increased when adult day or other community-based programs closed or because they chose to remove loved ones from facility-based care to provide care at home.

Many providers and grantees in the Lifespan Respite network, and among other aging and disability service organizations, pivoted to providing virtual support and education programs, phone check-ins, care packages, delivery services, curb-side visits and other innovative approaches to reaching and supporting family caregivers and their loved ones. Federal programs, including Medicaid waivers and Lifespan Respite, offered new flexibilities in how funds could be used for respite by modifying eligibility, expanding who could be a respite provider and where services could be offered, or by extending the timeline for use of vouchers and raising the amount of the voucher. Some states, like New Jersey, even offered free respite, as did a special program of the Elizabeth Dole Foundation to provide free in-home respite to military and Veteran caregivers. ARCH issued National Voluntary Guidelines for Providing and Using Respite during the COVID-19 Pandemic to guide both providers and family caregivers during this challenging time.
Importance of Federal Funding for Respite

Despite the significant changes to respite service delivery in 2020, the role of federal funding for respite remains critical for current services, and for future service planning. The aim of this guide is to help grantees, partners and all who work in the caregiving arena to better understand the role of federal funding and the role that the Lifespan Respite Care Program can play in coordinating and making better use of these funding streams at the state level.

The *Lifespan Respite Care Program* provides the roadmap to efficient statewide delivery of respite services and information. The program provides federal 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 many of these statutes, it may be listed as one of the many family caregiver support services that are eligible for funding. In some cases, support for respite is only implied under the larger headings of home and community-based services or family support. In most cases, the authority to decide whether to fund respite and/or crisis care services with these federal resources has been given to state, regional, or local governments. No national data exist regarding how much federal funding is actually being spent on all respite and crisis care services for all ages. *In fact, given the limited availability of respite services, long waiting lists for respite, and small percentages of family caregivers who use respite, it is believed that a relatively small proportion of federal funds is invested in respite and crisis care.* The most recent survey of family caregivers conducted by the National Alliance for Caregiving and the AARP Policy Institute found that of the more than 50 million family caregivers of adults nationwide, 86% were not receiving respite. The proportion is similar for parents and other caregivers of children with special health care needs. Inadequate use of these potential funding sources could be due to lack of awareness about these federal programs and their potential for funding respite and crisis care services, competition for scarce resources, especially in these times of serious budgetary challenges, or limited knowledge about the benefits that investments in respite and crisis care programs can bestow.

Lifespan Respite systems are meant to help states identify existing or potential respite funding sources within their own states, better coordinate these funding streams and maximize their use, and reduce the state’s administrative expenditures, while also reducing the bureaucratic, cost, and social barriers family caregivers face while trying to access respite. All of the actual and potential sources of funding identified in this guide can be perceived as building blocks for Lifespan Respite systems. As states build, enhance or embed these coordinated systems of respite care, Lifespan Respite Care grantees are increasingly becoming a source of service delivery dollars, especially for the countless number of family caregivers and those they care for who currently are not eligible for any existing source of public funding for respite or are on waiting lists for services. 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 professionals guide family caregivers as respite consumers, and to assist 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; as amended by the Lifespan Respite Care Program Reauthorization Act, P.L. 116-324.

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/No Wrong Door 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:
Grants are competitive and not every state has received a federal Lifespan Respite Care grant. Each state 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.

As a result, Lifespan Respite activities will vary from state to state, depending on family caregiver needs, other available resources, and state capacity.
Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living (ACL), 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 National Respite Network and Resource Center website. http://www.archrespite.org/lifespan-programs

Related links:
General Services Administration Assistance Listings: Lifespan Respite Care Program. https://beta.sam.gov/fal/4311baea36eb48028a1387299560d5d9/view?index=cfda&sort=-relevance&page=1&keywords=Lifespan%20Respite%20Care%20Program&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

ARCH National Respite Network and Resource Center. archrespite.org

Administration for Community Living, Administration on Aging Lifespan Respite Care. https://acl.gov/programs/support-caregivers/lifespan-respite-care-program

References:

Acknowledgments

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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 Service to help family caregivers and professionals locate respite services and funding sources in their community; the National Respite Coalition, the policy division of ARCH, that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels; and the Lifespan Respite Technical Assistance and Resource Center, which is funded by the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services. The Lifespan Respite TA Center provides training and technical assistance to state Lifespan Respite grantees and their stakeholders, including State Respite Coalitions, Aging and Disability Resource Center (ADRC)/No Wrong Door (NWD) representatives, and others interested in building such systems at the state and local levels.

ARCH* National Respite Network and Resource Center
archrespite.org

*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
ACL  Administration for Community Living
ADDGS  Alzheimer’s Disease Demonstration Grants to the States
ADRC  Aging and Disability Resource Center
ADRD  Alzheimer’s disease and related disorders
ADPI  Alzheimer’s Disease Program Initiative
AFAS  Air Force Aid Society
AFP  Adoption Family Preservation
AoA  Administration on Aging
ARCH  Access to Respite Care and Help
ARRA  American Recovery and Reinvestment Act
CAPTA  Child Abuse Prevention and Treatment Act
CFC  Community First Choice
CFSIA  Child and Family Services Improvement Act
CFSP  Child and Family Services Plan
CISS  Community Integrated Service Systems
CLASS  Community Living Assistance Supports and Services
CMHI  Children’s 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  U.S. 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
F2F HIC Family-to-Family Health Information Center
FACT  Families and Children Together
FFPSA Families First Prevention Services Act
FRIENDS Family Resource, Information, Education and Network Development
HIC   Family-to-Family Health Information Center
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
LTSS  Long-term services and supports
MCHS  Maternal and Child Health Services
MFP   Money Follows the Person
MIPPA Medicare Improvements for Patients and Providers Act
MLTSS Managed Long-Term Services and Support
MMA   Medicare Modernization Act
MOE   maintenance-of-effort
MSA   metropolitan statistical area
NCCC  National Civilian Community Corps
NFCSP National Family Caregiver Support Program
NRC   National Resource Center
NWD   No Wrong Door
OAA   Older Americans Act
OCAN  Office on Child Abuse and Neglect
OMB   Office of Management and Budget
PACE  Programs of All-Inclusive Care for the Elderly
PCAFC Program of Comprehensive Assistance for Family Caregivers
PGCSS Program of General Caregiver Support Services
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<th>Abbreviation</th>
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<td>PNS</td>
<td>Programs of National Significance</td>
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<td>RFA</td>
<td>Request for Application</td>
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<td>RHII</td>
<td>Regional Home Health Intermediaries</td>
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<td>SCI</td>
<td>spinal cord injury</td>
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<td>SCP</td>
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<td>technical assistance</td>
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<td>Temporary Assistance for Needy Families Program</td>
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<td>TBI</td>
<td>traumatic brain injury</td>
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<td>VA</td>
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Introduction

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

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

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

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

Understanding Federal Funding

The more than 40 federal programs listed in this guide have wide-ranging purposes and uses, and certainly not every funding source will be useful or appropriate in every state or beneficial to every family caregiver in meeting their particular respite needs. Some federal funding sources will not be directly available to family caregivers or local programs because they are limited to certain grantees, such as state governmental agencies. Other funding sources place limitations on the populations that are eligible to receive the benefits. Eligibility may be based on restrictive criteria, such as household income, legal status, personal characteristics, and family circumstances.

Some of the federal programs discussed in this guide provide general support for home and community-based services, which indirectly could support respite capacity building or service delivery. For example, the Community First Choice Option is a financing method that can be used by states to increase the federal share of Medicaid funding they receive for home and community-based services overall; indirectly, initiatives such as this one, could mean additional resources for respite.

Economic difficulties in many states, most recently resulting from the COVID-19 pandemic, make it much more challenging to use flexible funding sources such as the Social Services or Maternal and Child Health Services Block Grant, which are already being stretched very thin by increasing demands on these sources.
to finance health and social services for people in need. Waiting lists for certain home and community-based Medicaid waivers remain high in many states, with average waiting times exceeding two years. Referring families to these waivers may only result in disappointment when services are not immediately available. In addition, state funding shortfalls may discourage some states from pursuing federal grants with state match requirements for fear of not being able to meet the match requirement.

Yet knowledge of the full array of potential resources for supporting respite is important because Lifespan Respite Care Programs or other programs may be able to access these resources through strategic partnerships with other state agencies or other eligible entities. One of the goals of Lifespan Respite Care Programs is 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:1

- **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.

**State Funding**

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

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

- Decide which funding source(s) you would like to access. Determine who the eligible entities are in your state.
- Get to know the contact person in your state for this funding source. If available, an Internet address or other contact information is included in this guide to help you identify this person.
- If your state currently uses this funding source for respite, find out what your state Lifespan Respite Care Program, local program, or family caregivers need to do to access these funds more easily. Some funds are for use solely by government agencies or local public or private entities, or solely for families or family caregivers; some funds are available to both. Funding will usually be discussed in these subsections under each federal program: 1) Activities supported by the funding; 2) Issues for consumers, providers, and advocates; or 3) Eligible entity.
- If your state is not currently using this funding source for respite, work with others in your state, including your state Lifespan Respite Care Program and partners and the State Respite Coalition, to educate state policy-makers and decision-makers about the need for respite, the cost-benefits, and about the potential of using funds from this source.

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

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

Medicare covers individuals age 65 and older, people under age 65 with certain disabilities, and individuals with end-stage renal disease. Coverage of respite care is limited to Medicare Hospice Benefits and Medicare Advantage 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.

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

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

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

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

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

The Affordable Care Act made improvements to several of the options listed above and authorized a new Medicaid state plan option to provide home and community-based attendant services and supports.
Federal Funding and Support Opportunities for Respite (known as Community First Choice [CFC]). In addition, during the most recent pandemic, many states requested and received approval for changes to waiver programs to enhance program flexibilities to expedite or expand access to long-term services and supports (LTSS) for beneficiaries by easing financial and clinical eligibility requirements for LTSS and removing barriers that could jeopardize beneficiaries’ eligibility for services.² Read more about these changes by state at Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19 published by the Kaiser Family Foundation.³ Historically, federal regulations limited the ability of states to cover the cost of respite care directly as a regular Medicaid benefit under the state plan because it was considered a nonmedical expense. However, since 2005, states can choose to pay for HCBS (including respite) through their state plan under Section1915(i) as well as through Medicaid waivers. In 2018, four main Medicaid HCBS programs provided access to long-term services and supports for close to 4 million people. Total enrollment is about 4.7 million; however, some individuals are enrolled in multiple programs. Most of the growth in enrollment over the last several years has occurred through waiver programs. More than 1.8 million individuals (38%) were served through Section 1915(c) waivers in 47 states and DC and 698,500 individuals (15%) received care through Section 1115 waivers in 12 States. In addition, 616,800 (13%) individuals received care through the home health state plan benefit in 50 states and DC, and close to 1.2 million (25%) individuals received the personal care state plan services benefit in 34 states.⁴ Fewer individuals receive HCBS through Section 1915 (i) and Community First Choice.⁵

HCBS can be provided through either a provider managed or self-directed service delivery model. Increasingly, states are electing to offer services through the self-direction model. This model typically includes initiatives to allow the participants to choose how to allocate their own budgets for services and/or allow them to select, train, supervise and dismiss their HCBS providers. All 50 states and D.C. allow some type of self-directed personal care assistance. In 2018, 49 states and the District of Columbia with HCBS waivers permitted or required self-direction in at least one waiver, 20 states permitted self-direction in personal care state plans, and 3 states allowed self-direction in home health state plan services.⁶ Under these various types of Medicaid programs, many states allow participants to hire friends and relatives, who do not have legal authority over the participant, to provide the needed assistance. Thirty states allow certain legally responsible relatives (e.g. spouse, parent) to be paid providers.⁷

Each of the Medicaid benefits, state options, demonstrations, and waivers is described in this and the following section.

⁵Ibid., 2020.
⁷Ibid., 2020
Medicare Hospice Benefits

Authorizing legislation:
Title XVIII of the Social Security Act.

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

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

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

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

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

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

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

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

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

Points of contact:
A map of Regional Home Health Intermediaries (RHHIs) can be downloaded from page three of this CMS website:
A list of state hospice organizations can be found on the Hospice Foundation of America website. 
https://hospicefoundation.org/Hospice-Directory

Related links:
https://eldercare.acl.gov/Public/Resources/Factsheets/Hospice_Care.aspx

References:
Medicare Advantage

Authorizing legislation:
Title XVIII of the Social Security Act, as amended by Bipartisan Budget Act of 2018 which included provisions of the CHRONIC Care Act (Public Law No: 115-123).

Program purpose:
Medicare Advantage Plans, sometimes called "Part C" or "MA Plans," are an “all in one” alternative to Original Medicare. They are offered by private companies approved by Medicare. These "bundled" plans include Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance), and usually Medicare prescription drug (Part D).

Beneficiaries:
Individuals who qualify for original Medicare, also qualify for Medicare Advantage.

Activities supported by the funding:
Medicare Advantage Plans cover all Medicare services. Some Medicare Advantage Plans also offer extra coverage, like vision, hearing and dental coverage. Increasingly, plans are offering benefits that address social determinants of health, such as care in the home, transportation to appointments, meal delivery, and home modifications.

Respite connection:
Most recently, with passage of the Bipartisan Budget Act of 2018 that included provisions from the Chronic Care Act, Medicare Advantage Plans were given the option of covering additional benefits, such as caregiver support, adult day services and respite.

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

Federal funding agency:

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

Related links:
Medicare Plan Finder.
https://www.medicare.gov/find-a-plan/questions/home.aspx

References:
Centers for Medicare & Medicaid Services. Medicare Advantage
https://www.medicare.gov/sign-up-change-plans/types-of-medicare-health-plans/medicare-advantage-plans


*Understanding Medicare Advantage Plans*

*Medicare & You*
https://www.medicare.gov/medicare-and-you
Medicare Advantage Special Needs Plans (SNPs)

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

- Section 206 of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) extended the SNP program through December 31, 2018.
- Bipartisan Budget Act of 2018 which included provisions of the CHRONIC Care Act (Public Law No: 115-123)

Currently authorized through:
Permanently authorized with restrictions.

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

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

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

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

- chronic alcohol and other drug dependence,
- certain autoimmune disorders,
- cancer (excluding pre-cancer conditions),
- certain cardiovascular disorders,
- chronic heart failure,
- dementia,
- diabetes mellitus,
- end-stage liver disease,
- end-stage renal disease requiring dialysis,
- certain hematologic disorders,
- HIV/AIDS,
- certain chronic lung disorders,
- certain mental health disorders,
- certain neurologic disorders, and
- stroke.
**Respite connection:**
Plans may offer respite for family caregivers of patients who do not live in institutions.

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

**Federal funding agency:**

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

**Related links:**
Medicare Plan Finder.
https://www.medicare.gov/find-a-plan/questions/home.aspx

**References:**

Medicare & You
https://www.medicare.gov/medicare-and-you

Medicaid Personal Care Benefit

Authorizing legislation:
Title XIX of the Social Security Act.

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

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

Funding:
When a state elects an optional service, it is obliged to provide that benefit to its entire eligible population, as needed, and to pay its share of the cost of the service. As of 2018, 33 states and the District of Columbia included this optional benefit in their state plan.

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.”

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

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

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

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).

8 Section 1905(a)(24) of the Social Security Act, as amended.
**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

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

**Related links:**
Kaiser Family Foundation Medicaid Benefits Online Database.
[https://www.kff.org/medicaid/state-indicator/personal-care-services](https://www.kff.org/medicaid/state-indicator/personal-care-services)

**References:**

Section 1915(j) Self-Directed Personal Assistance Services

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

**Program purpose:**
To give frail elders and adults with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs. In some states, children with developmental disabilities are also served. This option allows states to include such services under their Medicaid state plans or through Section 1915(c) waivers. This concept is now referred to as “consumer direction”, “participant direction”, “self-directed care”, and a variety of other state-specific names.

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

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

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

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

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

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

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

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

**Federal funding agency:**

**Points of contact:**
Contact information for each state’s self-directed programs is available through an online interactive map at Applied Self-Direction. [https://www.appliedselfdirection.com/self-direction-programs](https://www.appliedselfdirection.com/self-direction-programs)

**Related links:**

Applied Self-Direction  
[https://www.appliedselfdirection.com/](https://www.appliedselfdirection.com/)

The American Elder Care Resource Organization (2019). *Paying for Senior Care: Receive Payment as a Caregiver: Cash & Counseling and Other Options.*  

**References:**


Centers for Medicare & Medicaid Services. *Self-directed Personal Assistance Services 1915(j).*  

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

**Authorizing legislation:**

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

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

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

**Activities supported by the funding:**
The PACE program offers a comprehensive medical and social service delivery system using an interdisciplinary team approach in an adult day health center, supplemented by in-home and referrals services, based on participants’ needs. PACE programs must be provided by a not-for-profit or public entity and include all Medicaid and Medicare covered services plus all other services determined necessary by the health professionals team to improve and maintain an individual’s health. As of 2019, there were 130 PACE programs in 31 states serving 51,055 individuals.

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

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

**Federal funding agency:**

**Points of contact:**
A list of PACE Provider Organizations is available at [https://www.npaonline.org/pace-you/pacefinder-find-pace-program-your-neighborhood](https://www.npaonline.org/pace-you/pacefinder-find-pace-program-your-neighborhood)

**Related links:**
National PACE Association.
[https://www.npaonline.org/](https://www.npaonline.org/)
Kaiser Family Foundation Medicaid Benefits Online Database: Program for All Inclusive Care for the Elderly.

References:
Centers for Medicare & Medicaid Services. PACE.
https://www.medicaid.gov/medicaid/ltss/pace/index.html

Centers for Medicare & Medicaid Services. Programs of All Inclusive Care for the Elderly Benefits.

National PACE Association. PACE in the States.
https://www.npaonline.org/sites/default/files/PACE%20in%20the%20States%20September%202019.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 2018, 46 states offered hospice care as a covered Medicaid benefit.

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

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

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. [https://medicaiddirectors.org/about/medicaid-directors/](https://medicaiddirectors.org/about/medicaid-directors/)
Related links:
Kaiser Family Foundation Medicaid Benefits Online Database
https://www.kff.org/medicaid/state-indicator/hospice-care

References:
Center for Medicare and Medicaid Services. Hospice Benefits.
https://www.medicaid.gov/medicaid/benefits/hospice/index.html

Center for Medicare and Medicaid Services. State Medicaid Director Letter SMD#10-018 - 9/9/10 Re Hospice Benefits for Children in Medicaid and CHIP.
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. These optional programs are called waivers because they give states the authority to “waive” specific Medicaid requirements governing services included in the Medicaid state plan, including those related to eligibility and to offer services beyond those typically offered through Medicaid for all eligible populations or in all parts of the State. Each state determines the income, age, and disability eligibility criteria, the services included in each waiver as well as the geographical areas to be served.

When included, respite is usually paid for through one or more of the following four types of Medicaid waivers:

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

Medicaid waivers are by far the largest source of federal funds for respite. In 2018, 47 states and the District of Columbia had Section 1915(c) HCBS waivers. Among states with these waivers, most have waivers focused on beneficiaries who are older adults, adults with physical disabilities, or beneficiaries of any age with an intellectual or developmental disability. Some states have waivers for HCBS for beneficiaries with other disabilities, such as traumatic brain injury/spinal cord injury, people with mental or behavioral conditions, medically fragile or technologically dependent children, and people with HIV/AIDS. Three states (Arizona, Rhode Island and Vermont) had transitioned all of their Section 1915(c) waivers and operate long-term care programs under broader Section 1115 research and demonstration waivers. Nine states (CA, DE, HI, NJ, NM, NY, TN, TX, and WA) serve some HCBS populations under a Section 1115 waiver and other HCBS populations through Section 1915(c) waivers.

Waivers are subject to federal approval and are approved for between 2 and 5 years, depending on the authority. To continue to operate waivers, states must submit applications to renew or extend each one. States also may submit amendments to make changes to waivers, when needed, during an approval period. In FY2020, nearly all states (47) are expanding the number of people served in home and community-based settings.

However, depending on the waiver authority used, states may set caps on enrollment in the waiver programs, resulting in long waiting lists for services in most states. In 2018, 41 states reported approximately 820,000 people on waiting lists for HCBS waiver services. People with I/DD comprise over 70 percent (about 590,000 in 37 states) of total waiver waiting lists, while older adults and adults with physical disabilities account for about one-quarter (about 199,000 in 20 states) of total waiting lists. The remaining four percent of waiver waiting lists is spread among other populations, including children who are medically fragile or technology dependent, people with traumatic brain or spinal cord injuries,

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people with mental illness, and people with HIV/AIDS. The national average time an individual was on a Section 1915(c) waiting list was 39 months, with the average ranging from one month for people with HIV/AIDS to 71 months for intellectual/developmental disabilities waivers.11

Many states have recently made changes to their Medicaid waivers by moving toward capitated managed care for long-term services and supports (MLTSS). Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities at the discretion of the state and as approved by CMS, including Section 1915(a), Section 1915(b), and Section 1115.12 The majority of states are implementing Medicaid MLTSS through Section 1115 global demonstration waivers or combinations of Section 1115 and Section 1915(c) or Section 1915(b)/(c) waivers.13 As of 2017, several states established separate programs for people dually eligible for Medicare and Medicaid as part of the CMS Financial Alignment initiative, and total enrollment in these MLTSS programs was 1.8 million.14 As of July 2019, 25 states covered long-term services and supports through one or more managed care arrangements. Another two states operated managed fee-for-service LTSS models. In FY2019 and FY2020, will expand their MTLSS programs either through geographic or population expansions.15

For a full list of current state Section 1115 and Section 1915(c) waiver programs, see the State Waivers List on the Centers for Medicare & Medicaid Services website: https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html

Detailed information on each state’s Medicaid waivers can be found in ARCH’s Medicaid Waivers for Respite Support: State-by-State Summaries at https://archrespite.org/images/docs/Guides_Compendiums/Medicaid_Waivers_for_Respite_2019.pdf

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11 Ibid., 2020.
Section 1115 Research and Demonstration Projects

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

Program purpose:
To test, 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 can be extended for an additional three to five years. Demonstrations must be budget neutral, not costing the federal government more than they would without the waiver.

Activities supported by the funding:
Initiatives under this authority are intended to demonstrate a wide variety of new health care services delivery methods. Successful demonstrations may lead to broader implementation of innovations. For example, the Medicaid Cash & Counseling Option (described above in Section 1915(j) Self-Directed Personal Assistance Services) began as a Section 1115 waiver in 1998 in three states. Increasingly, states are using Section 1115 waivers to implement capitated Medicaid managed care for long-term services and supports. Three states (Arizona, Rhode Island and Vermont) had transitioned all of their Section 1915(c) waivers and operate long-term care programs under broader Section 1115 research and demonstration waivers. Nine states (CA, DE, HI, NJ, NM, NY, TN, TX, and WA) serve some HCBS populations under a Section 1115 waiver and other HCBS populations through Section 1915(c) waivers.

Respite connection:
Many State Section 1115 waivers include respite services, while others could expand services to include respite and/or eligibility to individuals and families in need of that service.

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

Federal funding agency:

Eligible entity:
State Medicaid Agency.

Points of contact:
A list of state Medicaid program websites is available from the National Medicaid Directors Association website. https://medicaiddirectors.org/about/medicaid-directors/
Related links:
Center for Medicare and Medicaid Services. State Waivers List.

References:
Centers for Medicare & Medicaid Services (CMS). About Section 1115 Waivers.
Section 1915(b) Managed Care Waivers

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

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

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

Activities supported by the funding:
States may:

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

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

Federal funding agency:

Eligible entity:
State Medicaid Agency.

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

Related links:
State Waivers List
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 in a nursing facility, Intermediate Care facility for Individuals with Intellectual Disabilities (ICF/IID), hospital or psychiatric hospital.

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 can be grouped into nine categories: (1) case management; (2) home-based services (including personal care, companion services, home health, respite, chore/homemaker services, and home-delivered meals); (3) day services (including day habilitation and adult day health services); (4) nursing/other health/therapeutic services; (5) round-the-clock services (including in-home residential habilitation, supported living, and group living); (6) supported employment/training; (7) other mental health and behavioral services (including mental health assessment, crisis intervention, counseling, peer specialist); (8) equipment/technology/modifications (such as personal emergency response systems, home and/or vehicle accessibility adaptions); and (9) other services (including non-medical transportation, community transition services, payments to managed care, and goods and services).

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. Exceptions are temporary amendments to many waivers during the COVID-10 pandemic that allowed for payments to family members to provide respite services.

Respite connection:
Respite is specifically supported by this waiver authority and most states include respite within one or more of their Section 1915 (c) Medicaid waiver programs. It is the leading source of federal funds for respite care for those who are eligible.

In 2018, 47 states and the District of Columbia had Section 1915(c) HCBS waivers. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time, and in 2018, there were 265 1915 (c) HCBS waiver programs in operation throughout the country with a state average of six and ranging from one to eleven. Only three states (AZ, RI, and VT) use a Section 1115 waiver to provide HCBS to all covered populations and do not offer any Section 1915 (c) waivers.

While states have some flexibility in defining respite included in their HCBS waivers, the types of respite funded in Medicaid HCBS waivers include:

• **Respite** is intermittent or regularly scheduled temporary medical care and/or supervision of the participant. It typically includes support to assist family so participant can stay at home; provide appropriate care and supervision to protect person’s safety in the absence of a family member; relieve family from constant demanding responsibility of providing care; and attend to basic self-help needs and other activities that would ordinarily be performed by the family.

• **In-Home Respite Services** are provided in the home of the participant. States may require that the participant be homebound due to physical or mental impairments and normally unable to leave the home unassisted, require 24 hour assistance of the caregiver, and unable to be left alone and unattended for any period of time.

• **Out of Home, Facility or Institutional Respite** services are provided in licensed residential facilities.

• **Group Respite** is provided in a group setting to encourage socialization and may be provided in a licensed facility, camp, or other appropriate community setting.

• **Skilled Respite** Care must be provided by either a licensed RN/LPN or CNA. Skilled respite is required for ongoing medical needs that can only be provided by an RN/LPN or CAN, (i.e., suctioning).

• **Unskilled Respite** is for individuals who will not have any medical needs requiring skilled care, such as a G-tube feeding. This includes the possibility of the need for skilled/medical intervention.

• **Maintenance Respite** is planned or scheduled. It is provided: (1) when families or the usual caretakers need additional support or relief or (2) when the consumer needs relief or a break from the caretaker.

• **Emergency Respite** is a short term service for a waiver participant who requires a period of structured support, or respite is necessitated by unavoidable circumstances, such as a family emergency.

Other services that may provide a break for family caregivers and can be provided through Medicaid waivers include companion services, personal care, attendant care, medical day care, and adult day care.

**Issues for consumers, providers, and advocates:**
Depending on how individual waivers are written by the state, waiver programs generally are targeted to individuals of specific ages and/or 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 older adults.

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

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17 Centers for Medicare & Medicaid Services. *Fact Sheet: Summary of Key Provisions of the 1915(c) Home and Community-Based Services (HCBS) Waivers Final Rule (CMS 2249-F/2296-F).*

establishes requirements for home and community-based settings under the 1915(c), 1915(i) and 1915(k) Medicaid authorities, and person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i).

Because Medicaid 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. To be eligible for an HCBS waiver, participants also must meet the specific age, disability, and level of care criteria set for that waiver. HCBS waiver programs often have long waiting lists because HCBS waivers are granted only for a limited number of slots at one time. If all slots are filled, even if a person meets all the eligibility criteria, they will not receive services until a slot opens up.

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.

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

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

Other state agencies with responsibility for specific populations (e.g. aging, individuals with intellectual and/or developmental disabilities) may operate specific waivers. See the ARCH publication, *Medicaid Waivers for Respite Support* and the state summaries for specific contacts for 1915(c) waivers in each state and the District of Columbia. [https://archrespite.org/images/docs/Guides_Compendiums/Medicaid_Waivers_for_Respite_2019.pdf](https://archrespite.org/images/docs/Guides_Compendiums/Medicaid_Waivers_for_Respite_2019.pdf)

**Related links:**

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References:
Centers for Medicare & Medicaid Services. Home & Community Based Services Authorities. 
https://www.medicaid.gov/medicaid/hcbs/authorities/index.html


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 older adults or to people with disabilities. States use the Section 1915(b) authority to mandate managed care enrollment or limit provider contracting and 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 Section 1915(b) and Section 1915(c) programs must be met. States must submit separate applications for each waiver type. For example, states must demonstrate cost neutrality in the Section 1915(c) waiver and cost-effectiveness in the Section 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 Section1915(b) and Section1915(c) waiver programs may be included.

Respite connection:
As discussed in the section on section 1915(b) waivers, these waivers may expand services to include respite; respite is specifically included under the Section1915(c) authority.

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

Section 1915(b) waivers are renewed at 2-year intervals; Section1915(c) waivers are approved for 5 years. Therefore, renewal requests on combined waivers must be prepared and submitted separately. For participants to access HCBS, they must enroll with a state-contracted managed care plan.

Federal funding agency:

Eligible entity:
State Medicaid Agency.

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

Related links:
## Additional Medicaid Opportunities

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

The following program was enacted under ACA:

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

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

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

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

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.

[https://www.medicaid.gov/](https://www.medicaid.gov/)
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 receive an enhanced federal match of 6% for included services.

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

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

Issues for consumers, providers, and advocates:
This state plan option became effective October 1, 2011. As of 2018, eight states (California, Connecticut, Maryland, Montana, New York, Oregon, Texas, and Washington State) continued to offer attendant services and supports through the CFC option.

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

“Activities of daily living” includes tasks such as eating, toileting, grooming, dressing, bathing, and transferring.

“Health-related tasks” means specific tasks related to the needs of an individual, which can be delegated or assigned by licensed health care professionals under state law to be performed by an attendant.

“Instrumental activities of daily living” includes (but is not limited to) meal planning and preparation; managing finances; shopping for food, clothing, and other essential items; performing essential household chores; communicating by phone or other media; and traveling around and participating in the community.

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

In 2014, CMS issued a final rule that establishes requirements for home and community-based settings under the 1915(c), 1915(i) and 1915(k) Medicaid authorities.¹⁹

Federal funding agency:

Eligible entity:
State Medicaid Agency.

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

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

References:


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 the Patient Protection and Affordable Care Act of 2010 (ACA).

Program purpose:
To allow states to cover home and community-based services (HCBS) for Medicaid beneficiaries without a special waiver and, thus, without having to demonstrate budget neutrality (compared to institutional care). People with mental illness and those with I/DD are the populations most commonly served under Section 1915(i) programs.

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

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

Issues for consumers, providers, and advocates:
Eligibility is determined by states. However, effective October 1, 2010, eligibility under this option was expanded to individuals with incomes up to 300% of the maximum Supplemental Security Income (SSI) payment. Unlike the HCBS waivers, under this option states cannot cap enrollment or maintain a waiting list. In 2014, CMS issued a final rule that requires Section 1915(i) services be provided in a home and community-based setting, similar to Community First Choice state plan option services.

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

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As of FY 2019, 12 states (AR, CA, CT, DE, ID, IN, IA, MI, MS, OH, NV, and TX) and the District of Columbia offered Section 1915(i) state plan benefits.

**Federal funding agency:**

**Eligible entity:**
State Medicaid Agency.

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

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

**References:**
Centers for Medicare & Medicaid Services. *Home & Community Based Services.*

[http://www.chcs.org/media/LTSS_Policy_Brief_.pdf](http://www.chcs.org/media/LTSS_Policy_Brief_.pdf)

Money Follows the Person (MFP) Program

Authorization:

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. ACA extended and expanded funding for Medicaid Money Follows the Person Rebalancing Demonstration Programs through 2016. States receive an enhanced federal match for each Medicaid beneficiary transitioned to the community from an institution during the demonstration period. A series of short extensions has transpired over the last year. The most recent extension of the program, through November 2020, was included as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act (P.L. 16-136).

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

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

**Issues for consumers, providers, and advocates:**
With the extension of the program through the ACA, additional states were able to start MFP demonstration projects, and the existing states were able to seamlessly transition into the next 5 years. As a result, by 2018, 44 States and the District of Columbia were receiving MFP grants. Additionally, CMS awarded funding for the Money Follows the Person (MFP) Tribal Initiative (TI) to five state grantees. The extension of the program also changed the definition of individuals eligible to participate in MFP. Individuals are now eligible for MFP after residing in an institution for more than 90 days instead of for more than 6 months (as was formerly the case).

Since the program began in 2007, over 93,000 people with chronic conditions and disabilities transitioned from institutions back into the community through MFP programs. The program is now operating in 43 states, but with reauthorization uncertain, states have begun to curtail some services.

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. An additional extension of the program could present an opportunity for Lifespan Respite Programs or respite providers to partner with MFP programs to meet an anticipated increased respite demand.

**Federal funding agency:**

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

**Points of contact:**
MFP state contacts.

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

General Services Administration Assistance Listings: Money Follows the Person Rebalancing Demonstration.
https://beta.sam.gov/fal/a51250cabbaa471e878922d5e97699bd/view?index=cfda&sort=relevance&page=1&keywords=Money%20Follows%20the%20Person&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

**References:**
Programs for Children

Individuals and families experiencing changes in family situations or job- and income-related challenges may be eligible to access respite services through child abuse prevention and child welfare programs authorized by the Child Abuse Prevention and Treatment Act (CAPTA) or Title IV of the Social Security Act provisions modified or established through the Family First Prevention Services Act of 2018 (FFPSA). Certain child-focused education, health, or mental health programs such as the Maternal and Child Health Services Block Grant, as described in the sections that follow, also hold potential for states to fund respite services for families. 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.
Child Welfare and Child Abuse Prevention Programs

The focus of the **Community-Based Child Abuse Prevention (CBCAP) Grants**, Title I of the Child Abuse Prevention and Treatment Act (CAPTA), is on primary prevention of child abuse and neglect and strengthening families. Provision of respite services has been core to the CBCAP program from its inception in 1995.

A shift to prevention has also been occurring in child welfare policy. 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. The **Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123)** reformed federal funding for child welfare systems to place a greater emphasis on preventing children’s separation from their families and foster care placement. The Act authorized new funding to provide services to families who are at risk of entering the child welfare system.

Two key provisions of the Family First Prevention Services Act that amended Title IV-E of the Social Security Act law authorized the following new prevention funding which can include some level of support for respite care programs for those who care for children at risk of foster care placement.

- **Title IV-E Prevention Program** provides federal matching funds, at State option, for providing prevention services to keep identified children at risk of foster care placement safely at home. The services can be provided to the child, parent or kin caregiver.

- **Title IV-E Payments for Evidence-based Kinship Navigator Programs** allows States and some Tribes to receive federal reimbursement for up to 50 percent of their expenditures for kinship navigator programs that are qualified evidence-based programs (i.e. that are promising, supported or well-supported by research evidence).

The FFPSA also reauthorized the Promoting Safe and Stable Families Program, under Title IV-B, Subpart 2 of the Social Security Act through FY 2021 and renamed it the MaryLee Allen Promoting Safe And Stable Families Program.

Adoption Assistance is an additional related federal program whose funds can be used for respite care.

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

For more on federal child welfare funding, see:

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).

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.

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

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

**Eligible entity:**
The state’s Children’s Trust Fund is the lead entity in about half the states. In other states, lead entities include state offices of child abuse prevention, child and family services, health, and self-sufficiency. In a few states, other private agencies are designated.
**Points of contact:**
FRIENDS National Resource Center for CBCAP website contains an interactive map of state lead agency contacts.  [http://www.friendsnrc.org/state-lead-agency-contacts](http://www.friendsnrc.org/state-lead-agency-contacts)

**Related links:**
General Services Administration Assistance Listings: Community-Based Child Abuse Prevention Grants.  [https://beta.sam.gov/fal/1479b7927feb42b884d7e02583b4feca/view?keywords=Community%20Based%20Child%20Abuse%20Prevention%20grants&sort=relevance&index=&is_active=true&page=1](https://beta.sam.gov/fal/1479b7927feb42b884d7e02583b4feca/view?keywords=Community%20Based%20Child%20Abuse%20Prevention%20grants&sort=relevance&index=&is_active=true&page=1)

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

**References:**

Title IV-E Foster Care Prevention Services and Programs

Authorizing legislation:
Title IV-E of the Social Security Act authorizes foster care prevention services and programs. The Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123), amended Title IV-E of the Social Security Act and among other provisions allows states to receive Title IV-E entitlement funding to provide services to families who are at risk of entering the child welfare system.

Program purpose:
The new program seeks to support States in providing services to prevent children from entering foster care, when feasible.

Beneficiaries:
Federal support for these services and program are available for any child a state determines is at “imminent risk” of entering foster care; to the child’s parents or kin caregivers; and pregnant or parenting youth in foster care. States cannot limit eligibility for federal reimbursement for these services to children whose parents would have been eligible for Title IV Temporary Assistance to Needy Families.

Funding:
Title IV-E is a federal entitlement program. States and tribes that elect to provide Title IV-E prevention services and programs are required to submit a Prevention Services and Programs five-year plan to the federal Children’s Bureau as part of the Title IV-E state plan. Through October 1, 2026 these states receive 50 percent of the amount spent for prevention services and programs. In addition, states must not use these funds to replace existing family preservation services. That is, they cannot spend less on prevention than they did in a particular prior fiscal year. Beginning in FY 2021, HHS will publicly report on the prevention services’ expenditures and outcomes.

Activities supported by the funding:
Allowable services under the Title IV-E Prevention Program are time limited (up to 12 months) mental health services, substance use treatment, and in-home parenting skill training that include parenting skills training, parent education, and individual and family counseling. For each child recipient of services, the state or tribe must have a specific plan for the child, outlining the services to be provided to prevent foster placement. The services provided must be trauma-informed and provided in accordance with general practice requirements. Services must meet one of the following three thresholds:

- Promising Practice: Created from an independently reviewed study that uses a control group and shows statistically significant results.
- Supported Practice: Uses a random-controlled trial or rigorous quasi-experimental design. Must have sustained success for at least six months after the end of treatment.
- Well-supported treatment: Shows success beyond a year after treatment.

Respite connection:
While respite is not explicitly mentioned as a fundable service, some advocates have asserted that respite and crisis care could potentially be funded under the broad category of in-home skill training if other service requirements are met.

Issues for consumers, providers, and advocates:
Respite and crisis care services must meet a certain threshold of service before being deemed allowable for funding. Not all states will be choosing to provide respite or crisis care under this program.
Federal funding agency:  

Eligible entity:  
State child welfare agency.

Points of contact:  
Links to state agency websites are available at the Child Welfare Information Gateway.  
https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspList&rolType=Custom&RS_ID=158&rList=RCL

Related links:  
https://www.acf.hhs.gov/cb/policy-guidance/im-18-02

References:  
First Focus Campaign for Children (2018). Family First Prevention Services Act: Section by Section.  

https://fas.org/sgp/crs/misc/IN10858.pdf
Title IV-E Kinship Navigator Care Program

Authorizing legislation:
As an amendment to Title IV-E of the Social Security Act, the Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123) created a new provision that allows states to use Title IV-E entitlement funding to offer evidence-based kinship navigator programs that include promising, supported or well-supported practices to support kinship caregivers in meeting their needs and the needs of the children they care for. It also authorized for the first time, under Title IV-B, subpart 2 of the Social Security Act, grants to states to help them prepare for the changes in Title IV-E funding by developing, enhancing or evaluate kinship navigator programs.

Program purpose:
The purpose of the kinship navigator grants are 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. The programs help connect caregivers with supports to ensure they are able to meet the needs of the children they are caring for.

Beneficiaries:
Children at risk of foster care placement and their relatives who receive preventive services and supports to prevent placement in non-kinship foster care or other out of home placements.

Funding:
The federal reimbursement for kinship navigator programs is 50 percent of the state’s total cost. It is not required, but encouraged, that a state or tribe that opts for this funding operate the programs in all locations in the state/tribe.

In FY 2018 and FY 2019, discretionary grant funding was available to State and tribal IV-E agencies for the development, enhancement or evaluation of kinship navigator programs under two-year grants to States and Territories (with funding allocated based on each their average monthly number of children receiving Supplemental Nutrition Assistance Program (SNAP) benefits). Those funds had a minimum award of $200,000 and no matching requirement. Tribal allocations are based on their child populations with a minimum award of $25,000 per tribe.

Activities supported by the funding:
The Title IV-E Kinship Navigator Care program helps states and tribes that also operate the title IV-E foster care and adoption assistance programs operate kinship navigator programs. The allowed activities included establishing (and coordinating with existing) information and referral systems that link kinship caregivers to each other, to eligibility and enrollment information for benefits, training in caregiving and obtained needed benefits and services, and relevant help in obtaining legal services. These programs also promote partnerships among public and private agencies to ensure kinship caregiver families are served. The programs must meet evidence-based requirements of promising, supported or well-supported practices. Qualifying evidence-based programs to be identified by a national evidence-based clearinghouse.

The previous Kinship Navigator grants funded States to develop, enhance or evaluate a program to assist kinship caregivers in learning about, finding and using programs and services to meet the need of the children they are raising and their own needs.
**Respite connection**
While referral to respite services are not specifically mentioned as a covered activity, a cross site evaluation of the family navigator programs documented that these kind of programs included referrals to respite care as a key component of their information and referrals services for kinship caregivers.

**Issues for consumers, providers, and advocates:**
With prevention and support of kinship care and specifically kinship navigator programming now a priority for state Title IV system enhancement, there is an opportunity to work with Title IV agencies to incorporate respite care programming into their Title IV-E outreach and information and referral services targeted to kinship caregivers.

**Federal funding agency:**

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

**Points of contact:**
Links to state agency websites are available at the Child Welfare Information Gateway.
https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspList&rolType=Custom&RS_ID=158&rList=RCL

**Related links:**
General Services Administration Assistance Listings: Kinship Navigator Care Program.
https://beta.sam.gov/fal/aa891730384f42f884e13d689c4896d6/view?keywords=Kinship%20Navigator%20Programs&sort=-relevance&index=&is_active=true&page=1

https://www.childwelfare.gov/pubPDFs/kinshipnavigator.pdf

**References:**
Casey Family Programs (2018). What are Kinship Navigator Programs?
https://www.casey.org/what-are-kinship-navigators


https://www.acf.hhs.gov/cb/policy-guidance/pi-18-05
MaryLee Allen Promoting Safe and Stable Families (PSSF)

Authorizing legislation:
Title IV-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 reauthorized for five years under the Family First Prevention Services Act (FFPSA) in February 2018, P.L. 115-123.

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. The Family First Prevention Services Act removed time limits on how long states could use funds for family reunification services, regardless of how long the child has been in care. The law also allows family reunification services to be funded for up to 15 months after a child returns home. And, the funds can be used to support foster families so that children do not have to move unnecessarily.

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:
Allocations to States range from almost $33 million (California) to just over $243,500 (Wyoming). Almost 140 Tribes received funds in FY 2019. In FY 2019, the program was funded at approximately $423 million. Funds are distributed to states and territories on the basis of the number of children receiving Supplemental Nutrition Assistance Program benefits (three-year average). States are required to match their funding allotments with at least 25% in state funds and are restricted from spending more than 10% of the total funds on administrative costs. States may in turn fund community-based organizations to provide direct services. Indian Tribes and Alaska Native organizations are also eligible for funding.

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

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

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

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

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

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

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

**Points of contact:**
Contact information for state agencies receiving PSSF grants is available on the Child Welfare Information Gateway Library website.

https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspList&rolType=Custom&RS_ID=158&rlList=RCL

**Related links:**
General Services Administration Assistance Listings: Promoting Safe and Stable Families

**References:**
https://www.casey.org/promoting-safe-stable-families-program/

Adoption Assistance

Authorizing legislation:
The Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123), reauthorized Title IV-E of the Social Security Act, including the entitlement program known as the adoption assistance program.

Program purpose:
Title IV-E Adoption Assistance provides funds to States to facilitate timely placement of children, whose special needs or circumstances would otherwise make it difficult to place them with adoptive families.

Beneficiaries:
To be eligible for federal Title IV-E Adoption Assistance, the child being adopted must qualify as a child with special needs. To be considered a child with special needs, the state has to have determined that the child cannot or should not be returned to the parents’ birth home and made a reasonable, but unsuccessful, effort to place the child without financial adoption assistance. Each state sets its own special needs definition, which may include the child’s ethnic background, age, sibling group status, medical condition, or physical, mental or emotional disabilities. Ninety percent of children adopted from foster care are eligible for adoption assistance, including children who are in kinship foster care with relatives who adopt them. In FY 2017, the average monthly number of children receiving IV-E Adoption Assistance was approximately 469,000.

Like the new Title IV-E prevention services authorized by the FFPSA, eligibility for federally funded adoption assistance is in most cases not linked to the income guidelines for the Title IV-E foster care program. However, in 2018, the FFPSA temporarily relinked eligibility for federal IV-E adoption assistance to the birth parent income for a subset of children—those who are under age two and whose adoptions are finalized between January 1, 2018 and June 30, 2024. After that date, eligibility for adoption assistance will again not be linked to the income-eligibility provisions for Title IV-E foster care.

Funding:
Federal funds for the Adoption Assistance Program are available to the 50 States, the District of Columbia and Puerto Rico. The federal government reimburses States for at least one-half of their adoption assistance program expenses under Title IV-E and at a higher rate up to 83 percent, depending on the state’s per capita income.

Activities supported by the funding:
Adoption subsidy benefits are negotiation on a case-by-case basis, differ from each child, and vary among states, but may include the following:

- Nonrecurring adoption expense payments: Parents who adopt children with special needs are often eligible for a one-time reimbursement to cover expenses directly related to the legal adoption of a child with special needs. The maximum allowable reimbursement rate in 2017 was $2,000, but each state sets its own maximum rate which can be lower than the federal maximum.

- Monthly payments: Adoptive parents may receive monthly of any amount up to the amount the state would have paid for the child in family foster care, and higher rates for children with more significant needs.

- Medical assistance: Children eligible for Title IV-E adoption assistance are categorically eligible for Medicaid. In some States, programs may pay for medical services not covered by a family’s other health insurance provider.
Post-adoption services: Many states provide post-adoption services to families who adopt children with special needs. These services vary from state to state and are determined on an individual basis as part of the adoption assistance agreement. Examples of post-adoption services provided with Title IV-E funding include child care, respite care, in-home supportive services, referral to community services, and other child welfare services.

**Respite connection:**
Respite is a post-adoption service that States may fund with Title IV-E for parents who adopt children with special needs. While some States do not directly fund respite care with Title IV-E funding, many do provide referrals to respite care organizations for the adoptive parents who are receiving adoptive assistance through their categorical eligibility for Medicaid. These children may also be eligible for available Medicaid funded respite services.

**Federal funding agency:**

**Eligible entity:**
State agencies that administer the adoption assistance program receive federal reimbursement for eligible subsidies and services. These are usually the same agency that administers other child welfare related programs.

**Points of contact:**
Contact information and description of State adoption assistance programs as well as other program in each state that provide support to adoptive parents are available on the Child Welfare Information Gateway Library website at [https://www.childwelfare.gov/topics/adoption/adopt-assistance/](https://www.childwelfare.gov/topics/adoption/adopt-assistance/)

**Related links:**
Links and summaries of State Adoption Assistance programs can be found at the North American Council for Adoptable Children on the State Adoption Assistance Programs page at: [https://www.nacac.org/help/adoption-assistance/adoption-assistance-us/state-programs/](https://www.nacac.org/help/adoption-assistance/adoption-assistance-us/state-programs/)

Links to States’ adoption assistance agencies’ contacts and websites are also available at: [https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main dspList&rolType=Custom &RS_ID=156&rList=RCL](https://www.childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main dspList&rolType=Custom &RS_ID=156&rList=RCL)

**References:**
General Services Administration Assistance Listings: Adoption Assistance. [https://beta.sam.gov/fal/3bbdaef82d134d38b9ef2a360036a0a3/view?keywords=93.652&sort=- relevance&index=cfda&is_active=true&page=1](https://beta.sam.gov/fal/3bbdaef82d134d38b9ef2a360036a0a3/view?keywords=93.652&sort=-relevance&index=cfda&is_active=true&page=1)


Child Education/Health/Mental Health/Low-Income Assistance

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. Part C, **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, is used by some states to provide respite care.

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

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

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

**Temporary Assistance for Needy Families Program (TANF)**. States utilize TANF to provide financial and other assistance to families with children.

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. IDEA stipulates that children must have either a developmental delay or a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. States are able to develop their own criteria for determining the presence of developmental delays and what physical or mental conditions qualify a child for eligibility. States also have the option to serve children under 3 years who would be at risk of experiencing a substantial developmental delay if Early Intervention (EI) services were not provided. This could include children who are at risk of experiencing developmental delays because of biological or environmental factors that can be identified, including a history of maltreatment. In addition, the Keeping Children and Families Safe Act of 2003 (P.L. 108-36) requires States to develop “provisions and procedures for referral of a child under age 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under Part C.” The 2004 reauthorization of IDEA contains language parallel to this.

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

Activities supported by the funding:
Early intervention services must be provided as part of an Individualized Family Service Plan (IFSP) and as defined in the legislation. These include a variety of therapies, training, and medical services, as well as

- family training, counseling, and home visits;
- social work services; and
- transportation and related costs needed to enable the child and family to benefit from other listed services.

Respite connection:
Respite may be funded as an early intervention strategy under Part C as part of an Individualized Family Service Plan (IFSP) on a case-by-case basis. Respite can be authorized as a support that assists parents in meeting the outcomes on the IFSP Individualized Family Service Plan (IFSP). According to a 2018 survey of expenditures of states’ Part C programs, ten states were using Part C funds to provide direct respite care services for the children’s IFSP, and eight States were using Medicaid funding to finance respite for these children. In some states’ Part C programs, respite care is provided on a sliding-fee scale according to a family’s income.

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.

In 2018, ten states funded respite with Part C funds and others funded respite for an IFSP under a child’s Medicaid coverage. 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:**

**Eligible entity:**
State agencies receive and administer the federal funding, often through regional entities. The two most common types of agencies administering Part C are state health departments and state education agencies.

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

http://ectacenter.org/contact/ptccoord.asp

**Related links:**
General Services Administration Assistance Listings: Special Education Grants for Infants and Families.

https://beta.sam.gov/fal/06c95c3a77b1467c994f798d3025afc2/view?keywords=Special%20education%20for%20infants%20and%20families&sort=-relevance&index=&is_active=true&page=1&organization_id=100001616

Early Childhood Technical Assistance Center.

http://ectacenter.org/

**References:**


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 to States in the form of a block grant. Individual state allotments are determined based on a statutory formula which considers the proportion of low-income children in each state compared to the total number of low-income children in the U.S. 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 match every $4 of federal Title V money they receive with at least $3 of non-federal dollars.

Activities supported by the funding:
States use 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.”

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. Only a few states, including Connecticut and Vermont, have taken advantage of the flexibility available under this block grant to provide or support respite. Both Arizona and Washington Lifespan Respite grantees ran short-term pilot programs to partner with Title V CSHCN to provide respite vouchers.
Federal funding agency:
U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

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

Points of contact:
Title V block grants are administered by state departments of health. Contact information for each state’s Title V program is on the HRSA website at https://mchb.tvisdata.hrsa.gov/Home/StateContacts

Related links:
General Services Administration Assistance Listings: Maternal and Child Health Services Block Grant to the States.
https://beta.sam.gov/fal/7abf1e3357434b1990791a9815d1779f/view?index=cfda&page=2&organization_id=100004222&sort=-relevance&keywords=Maternal%20and%20Child%20Health%20services%20block%20grant%20to%20states&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

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

The federal Maternal and Child Health Bureau provides a searchable online Title V Information System. A complete copy of each state’s most recent annual report, describing needs, services, priorities, expenditures, and performance measures can be found at:
https://mchb.tvisdata.hrsa.gov/Home/StateApplicationOrAnnualReport


References:
U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Title V Maternal and Child Health Services Block Grant Program.

http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf

Family-to-Family Health Information Centers

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

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

**Funding:**
F2Fs are funded through competitive federal grants to states from the Health Resources and Services Administration (HRSA). In 2018, HRSA added new funding for F2Fs in American Samoa, Guam, Puerto Rico, Northern Mariana Islands, U.S. Virgin Islands, as well as for three F2Fs serving American Indians and Alaskan Natives. This federal funding is blended in some states with other federal or state specific funding to support F2F activities.

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

**Respite connection:**
Some F2F HICs have developed informational materials about respite to help families access respite in their state or community. In 2018, 45% of F2Fs were involved with respite initiatives in their states.

**Issues for consumers, providers, and advocates:**
The entities funded focus on advocacy and training families of children with special health care needs to access the services and care and supports they need. Technical assistance to the Centers is provided by the National Center for Family/Professional Partnerships at Family Voices.

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

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

**Points of contact:**
Contact information for the state F2F HICs and highlights of the grantee’s activities are available on the Family Voices website. [https://familyvoices.org/](https://familyvoices.org/)
Related links
General Services Administration Assistance Listings: Family-to-Family Health Information Centers.
https://beta.sam.gov/fal/b3cae1d1a25a4e82b563697ff23845f4/view?index=cfda&sort=-relevance&page=1&keywords=Family%20to%20Family%20Health%20Information%20Centers&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

References:


Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances (SED) (also known as the Children’s Mental Health Initiative)

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

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

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

Funding:
Competitive discretionary cooperative agreements are granted to states, territories, political subdivisions of a State, such as county or local governments, and Indian tribal governments.

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

- diagnostic and evaluation services;
- medication management;
- cross-system care management processes;
- development of individualized service plans that include participation of caregivers;
- provision of community-based counseling, consultation, and medication services;
- availability of emergency services;
- availability of intensive in-home services to prevent out-of-home placement;
- intensive day treatment services;
- respite care;
- therapeutic foster care and group homes;
- services for transition to adulthood; and
- family and youth advocacy and peer support services.
Like the previous expansion cooperative agreements, new cooperative agreements are intended to help awardees focus on building sustainable SOCs through sustainable financing, cross-agency collaboration, the creation of policy and infrastructure, and the development and implementation of evidence-based and evidence-informed services and supports.

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

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

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

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

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

**Related links:**
General Services Administration Assistance Listings: Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances.
https://beta.sam.gov/fal/ae7bc0ede8bc40f7954967670b936fe/view?keywords=Comprehensive%20Community%20Mental%20Health%20Services%20for%20Children%20with%20Serious%20Emotional%20Disturbances%20(SED)%20%E2%80%93%20CMHS%20Child%20Mental%20Health%20Service%20Initiative%20&sort=-relevance&index=cfda&is_active=true&page=1

National Technical Assistance Center for Child, Youth and Family Mental Health
https://www.samhsa.gov/nttac

**References:**
Centers for Medicare and Medicaid Services [CMS] and Substance Abuse and Mental Health Services Administration [SAMHSA], U.S. Department of Health and Human Services. (May 2013). *Joint CMS and SAMHSA Informational Bulletin. Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions.* Rockville, MD

https://drive.google.com/file/d/0B7p3xcafvE8nQmLYZEpWUVdFcUk/view

U.S. Department of Health and Human Services (2019). *Grants for Expansion and Sustainability of the Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances (Funding opportunity announcement SM-19-009)*
Temporary Assistance for Needy Families (TANF) Program

Authorizing legislation:

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

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

Funding:
Created in 1996, TANF is a federal block grant. Under this block grant program, states receive $16.5 billion each year, with the amount each state receives based on a formula determined by their peak expenditures for the period 1992 to 1995 (before enactment of TANF). States must spend 80% of their historic level of spending (FY 1994)—or 75% if they meet work participation requirements—on “qualified State expenditures” to meet the basic maintenance-of-effort (MOE) requirement. Under the law’s maintenance of effort (MOE) requirement states must maintain a certain level of state TANF spending, based on state spending for AFDC and related program before enactment of TANF, which was 410.3 billion. In 2017, states’ TANF MOE funds totaled an additional $14.7. Up to 30% of TANF funds can be transferred to the Child Care and Development Fund and the Social Services Block Grant combined; those funds become subject to the rules of the receiving grants and are not subject to TANF rules.

Activities supported by the funding:
States have broad flexibility to use the funds in any manner “reasonably calculated” to achieve TANF’s above states purposes. 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.

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.

Respite connection:
States can use TANF funds directly or through transfer to the Child Care and Development Fund (CCDF) to pay for child care. TANF can also directly cover child care expenditures for unemployed parents who need care to attend “other work activities such as job search, community service, education, or training, or for respite purposes.” In 2018 states spent $5.3 billion (17 percent) of their federal and state TANF funds on child care; 15 states spent less than 5 percent.
In State FY 2016, child welfare agencies in 42 states reported spending a total of $2.7 billion in federal TANF funds. 18 States reported using TANF funds for “family preservation services,” which include counseling, parenting skills classes, and respite care.

**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.
- Using Federal TANF funds for cash benefits to families 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. However there is no work participation or tie limit applied to families receiving benefits and services, including activities to help families that have experienced or are “at risk” of child abuse and neglect.
- Single parents with a child under age 6 cannot be penalized if they cannot find adequate child care.

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

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

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

**Points of contact:**
Links to state agencies administering TANF programs are available at the Office of Family Assistance website. [https://www.acf.hhs.gov/ofa/programs/temporary-assistance-needy-families-tanf](https://www.acf.hhs.gov/ofa/programs/temporary-assistance-needy-families-tanf)

**Related links:**
General Services Administration Assistance Listings: Temporary Assistance for Needy Families. [https://beta.sam.gov/fal/4168af581e644557b1b6a419d8a97ba2/view?keywords=TANF&sort=relevance&index=cfda&is_active=true&page=1](https://beta.sam.gov/fal/4168af581e644557b1b6a419d8a97ba2/view?keywords=TANF&sort=relevance&index=cfda&is_active=true&page=1)


**References**


Programs Serving All Age Groups

This section describes federal funding sources that support the use of respite care for both children (generally under the age of 18) and adults, including older adults.

- **Social Services Block Grant (SSBG).** The SSBG Block Grant furnishes social services best suited for meeting the needs of the individuals residing within each state. States have a great deal of flexibility in administering block grants. The SSBG Block grant focuses on providing services for low-income and vulnerable populations, but few other restrictions apply.

- **Developmental Disability Councils Programs** is authorized by the Developmental Disability Assistance and Bill of Rights Act (DD Act) of 2000. It is a discretionary grant program focused on a specific disability population, which may span across ages.

- **Aging and Disability Resource Centers (ADRCs)/No Wrong Door Systems** are required partners in Lifespan Respite Programs and support respite in various capacities in partnership with Lifespan Respite systems. Aging and Disability Resource Centers provide information and counseling to help individuals make informed decisions about long-term services and supports and help accessing programs. They are important components of states’ No Wrong Door Systems.

- The **National Family Caregiver Support Program (NFCSP)** provides respite funding that specifically addresses respite for caregivers (age 55 or 60 and older) primarily of older adults age 60 and older, but also for some groups of children and adults.

- **The Lifespan Respite Care Program**, described in detail in the preface, has as its primary purpose the coordination of community-based respite services that are funded by various federal and state respite funding streams in order to improve access to respite for family caregivers regardless of the age or disability of the care recipient.

Several programs rely on volunteers to provide respite and caregiver support for certain populations of family caregivers who provide care across age groups:

- **AmeriCorps.** In November 2020, the Corporation for National and Community Service (CNCS) released a new brand strategy, announcing it will operate as “AmeriCorps.”.

- **AmeriCorps Senior Companion Program.** AmeriCorps’ three programs that cater exclusively to volunteers 55 years and older under the Senior Corps name – Foster Grandparents, Senior Companions, and RSVP – will now operate and be promoted under the banner of AmeriCorps Seniors. Among these, the Senior Companion Program has the potential to provide volunteers who may provide respite for certain populations of family caregivers.

- **National Community Care Corps** provides grants to local community and faith-based entities to support volunteer services to family caregivers.
Social Services Block Grant (SSBG)

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

Program purpose:
To furnish social services best suited for meeting the needs of the individuals residing within each state. Services funded are directed at one or more of five goals:

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

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

Funding:
This is a block grant. Funding is authorized as “such sums as necessary” and in recent years the annual appropriations have remain level funded at $1.7 billion. A state may transfer up to 10 percent of its annual TANF block grant allocation into its SSBG program. Funds transferred from TANF to SSBG are to be used only for programs or services to children or their families whose income is less than 200 percent of the federal income poverty guideline applicable to a family of the size involved.

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

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

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

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

States also use funds for adult day services for older adults who require care and supervision in a protective setting for a portion of a 24-hour day.

Respite may also be provided to children or adults through prevention and intervention services to support families and prevent or ameliorate the consequences of abuse, neglect, or family violence. Component services and activities may include investigation; assessment and/or evaluation of the extent of the problem; counseling, including mental health counseling or therapy as needed; developmental and parenting skills training; respite care; and other services including supervision, case management, and transportation.

A significant number of states use SSBG funds for home-based services, which include in-home services or activities provided to individuals or families to assist with household or personal care activities that improve or maintain adequate family well-being. These services may be provided for reasons of illness, incapacity, frailty, absence of a caretaker relative, or to prevent abuse and neglect of a child or adult. Component services or activities may include protective supervision of adults and/or children to help prevent abuse, temporary non-medical personal care, house-cleaning, essential shopping, simple household repairs, yard maintenance, teaching of homemaking skills, training in self-help and self-care skills, assistance with meal planning and preparation, sanitation, budgeting, and general household management.

Issues for consumers, providers, and advocates:
States receive these funds with few strings attached and have broad flexibility in how they spend the funds. 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:

Eligible entity:
States.

Points of contact:
A list of SSBG state officials and program contacts can be found on the U.S. Department of Health and Human Services website.
https://www.acf.hhs.gov/ocs/programs/ssbg

Related links:
General Services Administration Assistance Listings: Social Services Block Grant.
https://beta.sam.gov/fal/419e8a07a2a24d16aa3b0431b48bf7d9/view?index=cfda&sort=-relevance&page=1&keywords=Social%20services%20block%20grant&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

U.S. Department of Health and Human Services: Social Services Block Grant (SSBG) Program.
https://www.acf.hhs.gov/ocs/programs/ssbg

References:
U.S. Department of Health and Human Services, Administration for Children and Families, Office of Community Services (2018). Social Services Block Grant Fact Sheet

Developmental Disabilities Councils

Authorizing legislation:

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.

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. To implement the state plans, Councils work with different groups in many ways, including educating communities to welcome people with developmental disabilities; funding projects; and seeking information from the public as well as state and national sources.

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

Federal funding agency:
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Disabilities, Office of Intellectual and Developmental Disabilities Programs
**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](https://nacdd.org/councils/) website.

**Related links:**

General Services Administration Assistance Listings: Developmental Disabilities Basic Support and Advocacy Grants.
https://beta.sam.gov/fal/3c01353ebe5c48459990835c953e4342/view?index=cfda&sort=-relevance&page=1&keywords=Developmental%20Disabilities%20Councils&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

**References:**

https://acl.gov/about-acl/tool-kit
Federal Funding and Support Opportunities for Respite

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

Authorizing legislation:

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

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

No Wrong Door (NWD) Systems were established jointly by the Administration for Community Living and the Centers for Medicare and Medicaid Services in collaboration with the Veterans Health Administration (VHA) to make it easy for people of all ages, disabilities and income levels to learn about and access long-term services and supports (LTSS) (see Activities supported by the funding). Aging and Disability Resource Centers (ADRCs) may serve as the state’s No Wrong Door System or are important partners in states’ NWD systems.

Transforming the existing publicly supported LTSS access programs and functions into a single statewide NWD System helps states create more efficient, effective, and person-centered ways of administering their long-term services and support (LTSS) programs. Individuals can turn to a NWD partner, including Aging and Disability Resource Centers, for objective information on long-term services and support options. 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, the Veterans Health Administration and state revenue programs.

Beneficiaries:
All populations in need of LTSS regardless of age, income or disability, including family caregivers in need of long-term services and supports information.
Funding:
The Aging and Disability Resource Center Program (ADRC), a collaborative effort of the Administration for Community Living (ACL), the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration (VHA), was first launched in the fall of 2003 to support state efforts to develop streamlined systems of access to Long Term Services and Supports (LTSS). In 2006, Congress reauthorized the Older Americans Act with the inclusion of language supporting the development of ADRC efforts in every state.

Continued funding for ADRCs was authorized in the Affordable Care Act from FY 2010–2014 for $10 million each year, and reauthorized in the Supporting Older Americans Act of 2020 at $8.7 million in FY 2020 rising to $10.9 million in FY 2024. Congress has appropriated about $8 million annually for ADRCs. In FY 2020, ACL provided $50 million in emergency funding in response to the outbreak of Coronavirus Infections Disease (COVID-19) to state Aging and Disability Resource Center/No Wrong Door Systems.

Activities supported by the funding:
ADRCs are important partners of a state’s NWD system and may even serve as the entry point for the system. These efforts have been supported over time by a variety of additional programs, including the Real Choice Systems Change grants, the Balancing Incentive Program, Money Follows the Person (MFP), and Veteran Directed Care.

Key characteristics of a No Wrong Door approach are:

- One-stop coordinated system
- Single standard process
- Objective and neural
- Person-centered
- Seamless & Person Friendly
- Use of Private & Public Programs (i.e., streamed access to LTSS from all payers)

The four primary functions of a NWD System, as outlined in the ACL’S No Wrong Door National Key Elements document (reference link below) are:

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

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. There are many ways that Lifespan Respite programs can collaborate and coordinate with their States’ ADRCs/No Wrong Door Systems including through outreach and information systems, training (e.g. of caregivers and personal care coordinators), expanding administrative claiming for Medicaid eligible individuals, incorporation of respite education and access in caregiver support programs and systems, expanding volunteer capacity, and embedding person-centered approaches in all aspects of LTSS policies and workforce practices.
Issues for consumers, providers, and advocates:
Currently, 56 states and territories have NWD activity, with an estimated 1,322 local agencies within the NWD systems actively serving older adults and people with disabilities.

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

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

Points of contact:
Local ADRC locations and contact information by state can be found on the ACL’s Eldercare Locator website.  https://eldercare.acl.gov

Related links:


References:


U.S Department of Health and Human Services, Administration for Community Living. *Aging and Disability Resource Centers.*

U.S Department of Health and Human Services, Administration for Community Living. *Key Elements of a NWD System of Access to LTSS for All Populations and Payers.*

https://acl.gov/sites/default/files/about-acl/2020-06/FY21%20ACL_Budget%20Justification_8%20Jun%202020.pdf
National Family Caregiver Support Program (NFCSP)

**Authorizing legislation:**

**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. In FY 2018, the program served nearly 800,000 caregivers. Individuals eligible for respite care and other family caregiver support services are:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer’s disease and related disorders;
- Older relatives (not parents) age 55 and older providing care to children under the age of 18; and
- Older relatives, including parents, age 55 and older providing care to adults ages 18-59 with disabilities.

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.

**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 and a significant majority of those served by the program receive respite. In FY 2018, the NFCSP provided over 58,500 caregivers with nearly 6.2 million hours of temporary relief, at home or in an adult day care or nursing home setting. The national evaluation of the NFSCP program found that among caregivers who used NFCSP respite care, as the respite hours per week increased so did the probability of caregivers saying that the service allowed them to provide care longer.

An additional $100 million in emergency funding was provided by Congress in FY 2020 for the National Family Caregiver Support Program to expand a range of services that help family and informal caregivers provide support for their loved ones at home during the COVID-19 pandemic. These include counseling, respite care, training, and connecting people to information.

**Issues for consumers, providers, and advocates:**
The most recent reauthorization of the Older Americans Act added a definition of caregiver assessment to ensure that required services take into consideration information received from such assessments. Also, while the priority for services is still focused on support services for older individuals, the ten percent funding cap for serving older relative caregivers of adults with disabilities and grandchildren was removed.

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

**Eligible entity:**
States; Indian Tribal Organizations representing at least 50 individuals age 60 or older; public or nonprofit Native Hawaiian organizations serving at least 50 individuals age 60 or older. In most states, funds are distributed to Area Agencies on Aging which administer the program locally.

**Points of contact:**
Contact information and links to each State Unit on Aging, Area Agencies on Aging, and Tribal Organizations that administer the NFCSP can be found on the Eldercare Locator.
[https://eldercare.acl.gov](https://eldercare.acl.gov)

Links to Title VI programs for Native Americans can be found by state on the National Resource Center on Native American Aging website. [https://www.nrcaa.org/service-locator](https://www.nrcaa.org/service-locator)

**Related links:**

General Services Administration Assistance Listings: National Family Caregiver Support, Title VI, Part C, Grants to Indian Tribes and Native Americans. [https://beta.sam.gov/fal/ce6771050dff4eb3a3325d1b8083b8ea/view?index=cfda&sort=-relevance&page=1&keywords=National%20Family%20Caregivers%20Support%20Program&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false](https://beta.sam.gov/fal/ce6771050dff4eb3a3325d1b8083b8ea/view?index=cfda&sort=-relevance&page=1&keywords=National%20Family%20Caregivers%20Support%20Program&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false)
Federal Funding and Support Opportunities for Respite

https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program

U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. *Services for Native Americans (OAA Title VI).*
https://acl.gov/programs/services-native-americans-oaa-title-vi


References


https://www.everycrsreport.com/files/2020-07-01_R46439_d3f0a880b0bd560371669f0ec4761b50211c15bd.pdf


https://acl.gov/sites/default/files/about-acl/2020-06/FY21%20ACL_Budget%20Justification_8%20Jun%202020.pdf

AmeriCorps

Authorizing legislation:

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. For FY 2019 applicants, the four priority program areas were: economic opportunity, healthy futures, veterans and military families, and education.

- AmeriCorps NCCC (National Civilian Community Corps) is a full-time, team-based, residential program for men and women ages 18–24. Members live on one of five campuses, located in Denver, Colorado; Sacramento, California; Baltimore, Maryland; Vicksburg, Mississippi; and Vinton, Iowa.

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

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

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

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 some past grant announcements, under the Healthy Futures or Veterans and military families priority areas, grants may support increasing seniors’ or Veterans’ ability to remain in their own homes with the same or improved quality of life for as long as possible. Since respite has been shown to have this outcome, a case could be made to allow AmeriCorps volunteers to provide respite. Also, some state coalitions have used AmeriCorps volunteers to support administrative tasks of the coalition.

**Issues for consumers, providers, and advocates:**
AmeriCorps has six core areas of service (areas of focus may change):

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

**Federal funding agency:**
Although the Corporation for National and Community Service (CNCS) remains its legal name, CNCS now operates under the working name of AmeriCorps.

**Eligible entity:**
Governor-appointed State Service Commissions. The State Service Commissions accept applications from state and local nonprofit organizations; community and faith-based organizations; state, local, and higher education institutions; state and local governments; and U.S. territories.

**Points of contact:**
AmeriCorps Advanced Listing Search and Application Portal
https://www.nationalservice.gov/programs/americorps/join-americorps

**Related links:**
General Services Administration Assistance Listings: AmeriCorps State and National.
https://beta.sam.gov/fal/42a1c14d142ddfe4bd5c017f7c006f73/view?index=cfda&sort=-relevance&page=1&keywords=Americorps&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false

AmeriCorps. *Be the Greater Good.*

**References:**
AmeriCorps. *Categories of AmeriCorps Grants Presentation.*
https://www.nationalservice.gov/documents/grants/2013/categories-americorps-grants

AmeriCorps. *AmeriCorps State and National Focus Areas.*
https://www.nationalservice.gov/focus-areas

AmeriCorps Senior Companion Program (SCP)

**Authorizing legislation:**

**Program purpose:**
The Senior Companion Program provides grants to qualified agencies and organizations for the dual purpose of engaging persons 55 and older, particularly those with limited incomes, in volunteer service to meet critical community needs; and to provide a high quality experience that will enrich the lives of the volunteers. While program priorities may shift over time, program funds are used to support Senior Companions in providing supportive, individualized services to help older adults with special needs maintain their dignity and independence.

**Beneficiaries:**
Senior companions must be 55 years of age or older, with an income of up to 200% of poverty, based on the U.S. Department of Health and Human Services Poverty Guidelines; interested in serving special-needs adults, especially older adults; 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 adults, primarily older adults, who have one or more physical, emotional, or mental health limitations and are in need of assistance to achieve and maintain their highest level of independent living, and their informal caregivers.

**Funding:**
Competitive project grants are awarded, when available, to public agencies, including Indian tribes, and private, non-profit organizations, both secular and faith-based, that have authority to accept and the capability to administer a Senior Companion project.

**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 older adults in need of assistance to live independently.

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

**Issues for consumers, providers, and advocates:**
Volunteers must serve 260 to 2080 hours annually, or 5 to 40 hours per week in person-to-person relationships with the individuals served. Updated program regulations went into effect in January 2019 reducing the minimum requirement of ongoing in-service training annually from 40 hours to 24 hours. Respite programs funded through this initiative participate in national performance measurement using Performance Measurement framework.

Federal Funding Agency
Although the Corporation for National and Community Service (CNCS) remains its legal name, CNCS now operates under the working name of AmeriCorps, and Senior Corps is now referred to as AmeriCorps Seniors. The Senior Companion Program is a branch of AmeriCorps Seniors.

Eligible entity:
State and local government agencies, including Indian tribes, and private, non-profit organizations, both secular and faith-based, that have authority to accept and the capability to administer an SCP.

Points of contact:
Organizations interested in exploring the possibility of developing a local SCP should contact the state service commission about applying. Contact information for those offices and profiles of the state programs are available on the AmeriCorps website.

Individuals interested in volunteering or wanting to receive services from an SCP in their state can find a list of the senior corps programs on the website at:
https://www.nationalservice.gov/programs/senior-corps/get-involved/senior-corps-pathfinder

Individuals wanting to receive services from an SCP can locate a program in their state on the AmeriCorps website. https://www.nationalservice.gov/impact-our-nation/state-profiles

Related links:
General Services Administration Assistance Listings: Senior Companion Program.
https://beta.sam.gov/fal/6813ee5323d04e3c8116608b7c9466e7/view?index=cfda&sort=-relevance&page=1&keywords=Senior%20Companion%20Program&date_filter_index=0&date_rad_selection=date&inactive_filter_values=false


References:
Federal regulations for Senior Companion Program (CFR Title 45, Subtitle B, Chapter XXV, Part 2551) https://www.ecfr.gov/cgi-bin/text-id?c=ecfr&sid=99f8e15d953a2684bc6267b117b9713a&rgn=div5&view=text&node=45:4.1.9.11.33&iddo=45


National Community Care Corps

Authorizing legislation:
None. However, funds were set aside in the Department of Defense and Labor, Health and Human Services, and Education Appropriations Act, 2019 and Continuing Appropriations Act, 2019 (P.L. 115-245) from funding for the Aging Network Support Activities authorized by the Older Americans Act, and in the Continuing Appropriations Act of 2021 (P.L. 116-260).

Program purpose:
In September 2019, the U.S. Department of Health and Human Services’ Administration for Community Living awarded a five-year cooperative agreement to the Oasis Institute, in partnership with the Caregiver Action Network, the National Association of Area Agencies on Aging, and the Altarum Institute to establish a National Volunteer Care Corps (renamed Community Care Corps). This team launched a national program to foster innovative models in which local volunteers assist family caregivers, older adults, or persons with disabilities with nonmedical care in their own homes in order to maintain their independence. The initiative was required to establish a Steering Committee comprised of a diverse group of stakeholders.

Beneficiaries:
Family caregivers, older adults and persons with disabilities.

Funding:
The Administration for Community Living was directed in the FY 2019 Continuing Appropriations Act (P.L. 115-245) to provide $5 million in FY 2019 for Care Corps grants as described in House Report 115-862, Departments of Labor, Health And Human Services, and Education, and Related Agencies Appropriations Bill, 2019. No funds were appropriated in FY 2020. However, in the Consolidated Appropriations Act of 2021 (P.L. 116-260), Congress again set aside funding for the program in FY 2021, even though no authorizing legislation exists.

The amount available funds in its first year was $3.8 million, of which $2.44 million was awarded by Oasis and partners through a competitive process to local organizations across the country to establish, enhance, or grow model volunteer programs serving caregivers. Twenty-three local grants ranging from $30,000 to $250,000 were awarded in July 2020.

Activities supported by the funding:
Primarily, funds will be used to support local volunteer caregiver supports. The national initiative is specifically tasked with providing technical assistance and resources to help guide communities and organizations in establishing or expanding volunteer care programs. Resources and tools provided by the initiative can support:

- Effective recruitment, selection and management of volunteers;
- Screening and placement of volunteers;
- Training of volunteers specific to identified community needs;
- Training of volunteers on person-centered approaches that support a volunteer recipient’s strengths, goals, preferences, needs, and desired outcomes;
- Implementing evidence based programming;
- Establishing community partnerships and collaborations; and
- Administration of local programs, including compensation options for volunteers.
In addition to expanding or enhancing local care support volunteer programs, the national initiative will evaluate the effectiveness of models funded in different communities, assist funded projects to create sustainability plans, and disseminate project findings, new solutions, and best practices that emerge from the project.

**Respite connection:**
Volunteer services offered by the local grantees include transportation, respite care, shopping, errands, and home maintenance. Many of the organizations also provide support with technology, empowering individuals to stay connected to family, friends, medical providers, and other community and faith-based organizations.

**Issues for consumers, providers, and advocates:**
Without authorizing legislation, future funding remains uncertain. The pandemic also has limited the range of in-person volunteer activities.

**Federal funding agency:**
U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. Oasis Institute received a cooperative agreement from the U.S. Administration for Community Living/Administration on Aging (ACL/AoA) to implement Community Care Corps

**Eligible entity:**
In its funding opportunity announcement, ACL stipulated a range of eligible entities to be funded as local programs, including but not limited to local aging services organizations, centers for independent livening, time-banking or volunteer agencies with expertise in the delivery of home and community-based services to older adults and people with disabilities, state, county or local government, or Tribes.

**Points of contact:**
For more information about grant awards, contact Community Care Corps at info@communitycarecorps.org or visit the website at https://www.communitycarecorps.org/

2020 Community Care Corps Grantees
https://www.communitycarecorps.org/grantees

**Related links:**
Altarum
https://altarum.org

Caregiver Action Network
https://caregiveraction.org

National Association of Area Agencies on Aging (n4a)
https://www.n4a.org

Oasis Institute
https://www.oasisnet.org

**References:**
[https://d54c4c32-0c64-46dc-9327-6d8087c2d5fd.filesusr.com/ugd/dd1ada_64ffda39cad645d084423b4df6129d7a.pdf](https://d54c4c32-0c64-46dc-9327-6d8087c2d5fd.filesusr.com/ugd/dd1ada_64ffda39cad645d084423b4df6129d7a.pdf)


Programs for Adults

Some federal programs that provide for respite care are designed solely for adults who have some special need or who have attained a particular age.

The following programs support grants for adults that have the potential or may be supporting respite and related services:

- **Older Americans Act: Title III-B —Supportive Services (Home and Community-Based Supportive Services) and Senior Centers Program**
- **Alzheimer’s Disease Program Initiative** consolidates the Alzheimer’s Disease Supportive Services Program (ADSSP), the Alzheimer’s Disease Initiative - Specialized Services Program (ADI-SSS), the ADI – Communications Campaign, and the Alzheimer’s Call Center (previously funded from the ANSA).

Each of these programs is described in this section.
Supportive Services and Senior Center Program (Home and Community-Based Supportive Services)

Authorizing legislation:
Title III, Part B (Section 321) of the Older Americans Act. Most recent authorizing legislation was P.L. 116-131, the Supporting Older Americans Act of 2020.

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

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

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

Activities supported by the funding:
Approved state grants may include, but are not limited to, services that support the older individual and their caregiver, such as:

- health, mental health, education and training, welfare, information, recreation, homemaker, counseling, referral services, chronic condition self-care management, or falls prevention;
- 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.”
Allows services that promote social connectedness and reduce the negative health effects associated with social isolation to be included as supportive services.

**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. In FY 2018, services that could provide respite to family caregivers funded by this program included personal care, homemaker, and chore services (provided more than 47.8 million hours of assistance to seniors unable to perform activities of daily living or instrumental activities of daily living; and Adult Day Care/Day Health (provided over 11.7 million hours of care for dependent adults in a supervised, protective group setting during some portion of the day).

**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.

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

**Eligible entity:**
State Agencies on Aging

**Points of contact:**
Contact information and links to each state’s Agency on Aging can be found on the Eldercare Locator on the U.S. Department of Health and Human Services website.
[https://eldercare.acl.gov](https://eldercare.acl.gov)

To locate home and community-based services, use the Eldercare Locator on the U.S. Department of Health and Human Services website.
[https://eldercare.acl.gov](https://eldercare.acl.gov)

**Related links:**
General Services Administration Assistance Listings: Special Programs for the Aging, Title III, Part B, Grants for Supportive Services and Senior Centers
[https://beta.sam.gov/fal/9ebb97149b144b689cdd26ca12b09e06/view?keywords=%22Supportive%20services%20and%20senior%20centers%22&sort=-relevance&index=cfda&is_active=true&page=1&cfda_published_date_filter_model=%7B%22startdate%22:%22%22%22%22%22%22%7D%7D&cfda_modified_date_filter_model=%7B%22startdate%22:%22%22%22%22%22%22%7D%7D&date_filter_index=0&inactive_filter_values=false]

National Aging Information and Referral Support Center.
References:


Alzheimer’s Disease Program Initiative (ADPI)

Authorizing legislation:
Older Americans Act, Title IV. Most recent authorizing legislation was P.L. 116-131, the Supporting Older Americans Act of 2020.

Program purpose:
In FY 2018, ACL consolidated all of its Alzheimer’s disease and related dementias (ADRD) programs into a single, more flexible, program. The Alzheimer’s Disease Supportive Services Program (ADSSP), the Alzheimer’s Disease Initiative - Specialized Services Program (ADI-SSS), the ADI – Communications Campaign, and the Alzheimer’s Call Center were all consolidated into the Alzheimer’s Disease Programs Initiative (ADPI).

State grants. These go to states who want to improve or develop their dementia systems capability with two objectives:

1. Create and sustain a dementia-capable HCBS system that includes Single Entry Point/No Wrong Door (SEP/NWD) access for people with ADRD and their caregivers, in which people with ADRD and their family caregivers have streamlined access to the full array of dementia-capable person-centered, public and private sector HCBS that promote community living and independence
2. Ensure access to a comprehensive, sustainable set of quality services/interventions that are dementia-capable and provide innovative services to the population with dementia and their family caregivers.

Community grants. These grants go to existing public and private community-based organizations already working in a system of home and community-based care for persons with dementia to address identified service gaps through expansion of on-going activities.

Together these two consolidated grants see to achieve the following objectives:

- Create state-wide, person-centered, dementia capable home and community-based service systems;
- Translate and implement evidence-based supportive services for persons with ADRD and their caregivers at the community level;
- Work with public and private entities to identify and address the special needs of persons with ADRD and their caregivers; and
- Offer direct services and support to thousands of persons with ADRD and their caregivers.

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

Funding:
Competitive cooperative agreements are usually for 3-years. Some grants may be 18-month expansion grants. Grantees must provide a 25% match and can apply for waivers to reduce the match requirement.
Activities supported by the funding:
As described in the most recent funding opportunity announcement issued by ACL in FY 2020, ADPI programs include dementia-capable direct person-centered services and supports, translation and implementation of evidence based interventions designed to improve the lives of persons with dementia and their caregivers, as well as dementia specific training for formal and informal caregivers. All funded initiatives also are required to include robust, third-party outcome-based evaluations designed to demonstrate program impact and support future translation successful program components.

At least one-half of federal funding must be applied to direct services to individuals and their families. There are six categories of allowable direct services, including adult day care, companion services, home health care, personal care, respite, and short-term care in a health facility.

Respite connection:
Respite is an allowed category of funded direct services. Respite was defined in the 2020 program announcement as “an interval of rest or relief OR the result of a direct dementia-specific service or intervention that generates rest or relief for the caregivers and/or care recipient.” Short-term care in a health facility may also provide respite as it is defined as “services provided on a short/long-term basis in a residential or assisted living facility, nursing home, or other long-term care institution because of the absence/need for relief of the regular 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.

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

Eligible entity:
Eligible entities for state grants include state government agencies designated to serve as the State Units on Aging. Eligible entities for community grants include community-based public and/or private home and community-based providers that are operating within an existing dementia-capable systems.

Funding eligibility is limited to public and/or private entities that are able to 1) demonstrate the existence of and their operation within a dementia-capable home and community-based system dedicated to the population that they serve, and 2) articulate opportunities and additional services that would enhance and strengthen the existing system. Community program applicants are not eligible to apply for or receive more than one grant through the ADPI program. States may only hold a single grant at any one time.

Points of contact:
Project officer in the U.S. Department of Health and Human Services, Administration for community Living, Office of Supportive and Caregiver Services.
**Related links:**
General Services Administration Listings: Alzheimer’s Disease Program Initiative (ADPI)
https://beta.sam.gov/fal/bc5614232de14630a6ecddbfaf197c29/view?keywords=%22Alzheimer%27s%20Disease%22&sort=-relevance&index=cfda&is_active=true&page=1


General Services Administration Assistance Listings: Alzheimer’s Disease Program Initiative.
https://beta.sam.gov/fal/d7b1977dc78f44a6b7e48ee6785d1df8/view

National Alzheimer’s and Dementia Resource Center.
https://nadrc.acl.gov/

**References**

https://acl.gov/sites/default/files/about-acl/2020-06/FY21%20ACL_Budget%20Justification_8%20Jun%202020.pdf
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.
- TRICARE 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.
- Coast Guard Mutual Assistance (CMGA) Respite Care, similar to the EFMP, is provided by a private, nonprofit entity. CMGA provides respite grants to eligible Coast Guard families.
- Armed Services YMCA Respite Child Care

For Veterans:

- The Veterans Health Administration in the U.S. Department of Veterans Affairs provides health care benefits to qualified Veterans; respite is included in the benefits package of Geriatric and Extended Care for Veterans.
- 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 Care for Veterans.
- The Program of Comprehensive Assistance for Family Caregivers began in May 2011 and is authorized under the Caregivers and Veterans Omnibus Health Services Act of 2010. Using a phase-in approach, the program was expanded to serve more Veterans in the 2018 by the MISSION Act of 2018.

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

**Authorizing legislation:**
Section 701(g) of the National Defense Authorization Act for FY 2002 (P.L. 107-107); codified in law in 10 U.S.C. 1079 (d) through (g); National Defense Authorization Act (NDAA) for fiscal year 2021.

**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 up to 32 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 and specifically includes respite services as a benefit.
Family members must have a qualifying condition such as

- Autism spectrum disorder
- Moderate or severe intellectual disability
- Serious physical disability
- Extraordinary physical or psychological condition that keeps the beneficiary homebound
- Diagnosis of a neuromuscular developmental condition or other condition in an infant or toddler (under age 3) that is expected to precede a diagnosis of moderate or severe intellectual disability or a serious physical disability
- Multiple disabilities, which may qualify if there are two or more disabilities affecting separate body systems

Family members must register for TRICARE ECHO and be enrolled in the Exceptional Family Member Program (EFMP) though the sponsor’s branch of service. Sometimes enrollment in EFMP may be waived, for example when the beneficiary resides with the custodial parent who isn’t the active duty sponsor.

Points of contact:
Military families contact their local Beneficiary Counseling and Assistance Coordinator, TRICARE Service Center, or their regional contractor. Regional contractors are listed at the TRICARE website. https://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx

Related links:

References:
TRICARE. Extended Care Health Option. https://www.tricare.mil/Plans/SpecialPrograms/ECHO.aspx
TRICARE Respite Benefit for Injured Service Members

Authorizing legislation:

Program is authorized through:
Began January 1, 2008. This program was established without a time limitation.

Program purpose:
To extend the TRICARE respite benefit to family caregivers of injured active duty service members.

Beneficiaries:
Injured active duty service members injured in the line of duty, and active duty service members, including National Guard/Reserve members who have a serious injury or an injury that has resulted in or may result in a physical disability or an extraordinary physical or psychological condition, qualify for the respite care benefit. In many cases, the condition may be so severe that the service member is left homebound.

Funding:
Service members pay nothing out of pocket for these services and there is no benefit cap.

Activities supported by the funding:
Injured active duty service members, including National Guard/Reserve members injured in the line of duty, are eligible for comprehensive health care services beyond basic TRICARE coverage, including respite care for the primary caregiver (of the injured service member).

Special benefits for injured active duty service members are similar to those available to family members of active duty service members under the TRICARE Extended Care Health Option (ECHO). However, active duty service members are not required to enroll in ECHO to receive these benefits, which include:

- diagnosis;
- inpatient, outpatient, and comprehensive home health care supplies and services;
- training, rehabilitation, special education, and assistive technology devices;
- institutional care in private nonprofit, public, and state institutions and facilities and transportation to and from such institutions and facilities (when appropriate); and
- custodial care in conjunction with authorized home health service.

Respite connection:
Respite benefits are limited to:

- a maximum of 40 respite hours in a calendar week,
- no more than 5 days per calendar week, and
- no more than 8 hours per calendar day.

The care must be provided by a TRICARE-authorized home health agency. Contact your regional contractor or TRICARE Area Office for help finding an authorized Home Health Agency. Authorized respite care does not cover care provided by family members or others who may reside with or visit the qualified active duty service member.
Issues for consumers, providers, and advocates:
Although the primary caregiver is usually a member of the patient’s family, he or she may be a relative or friend who assists the service member with the activities of daily living. Respite care services are provided exclusively to the active duty service member. The active duty service member respite benefit is intended to mirror the benefits provided under the TRICARE Extended Care Health Option (ECHO) Home Health Care benefit.

The service member’s case manager or other approving authority* may approve respite care when the care plan includes frequent primary caregiver interventions (more than two during the 8-hour period per day that the primary caregiver would normally be sleeping); respite care may be included in the care plan.

*Other approving authorities include Defense Health Agency-Great Lakes, Service Point of Contact, referring military treatment facility, or the TRICARE Area Office.

Points of contact:
The service member’s case manager.
TRICARE regional and program contractors.
https://www.tricare.mil/ContactUs/CallUs.aspx

Related links:

References:
TRICARE. Respite Care. https://www.tricare.mil/respite
Exceptional Family Member Program (EFMP)

Authorizing Legislation:

Program purpose:
The EFMP helps service members who have a spouse, child, or other dependent family member in need of ongoing medical or educational services by making sure special needs are considered during assignments and relocations, and providing family support.

Beneficiaries:
A service member who had a family member with special medical or educational needs – a spouse, child or dependent adult – who:

- Requires special medical services for a chronic condition such as asthma, attention deficit disorder, diabetes, multiple sclerosis, etc.
- Receives ongoing services from a medical specialist
- Has significant behavioral health concerns
- Receives early intervention or special education services through an individual family service plan or individualized education program.

Activities supported by the funding:
Department of Defense policy permits, but does not require, each service to offer family support services to exceptional family members through their Family Centers.

Respite Connection
All branches provide respite, but the services and eligibility categories may vary among the services (Army, Navy, Air Force, and Marines). For example, respite services for the Navy are provided through Child Care Aware EFMP Respite Program at https://www.childcareaware.org/fee-assistancerespite/exceptional-family-member-program-efmp-respite-care/.

The National Defense Authorization Act for Fiscal Year 2021 that became law on January 1, 2021, requires, within six months of enactment, that the Secretary of Defense standardize the respite care benefit across the covered Armed Forces, including the number of hours available under such benefit to military families enrolled in the EFMP. https://www.congress.gov/116/bills/hr6395/BILLS-116hr6395enr.pdf

Issues for consumers, providers, and advocates:
Currently, each branch of military service offers different amounts and types of respite services. The respite benefit is expected to be standardized across military branches in 2021.

- ARMY Exceptional Family Member Program https://www.myarmyonesource.com/familyprogramsandservices/familyprograms/exceptionalfamilymemberprogram/default.aspx
• Navy Exceptional Family Member Program  https://www.public.navy.mil/BUPERS-NPC/SUPPORT/EFM/Pages/default.aspx
• Marine Corps Exceptional Family Member Program  https://usmc-mccs.org/services/family/exceptional-family-member
• Air Force Exceptional Family Member Program  https://www.afpc.af.mil/Benefits-and-Entitlements/Exceptional-Family-Member-Program

**Federal funding agency:**
U.S. Department of Defense Office of Special Needs Exceptional Family Member Program

**Points of Contact:**
The Army, Navy, Marine Corps and Air Force each have EFMP resources. To find your service and installation EFMP office, check the Installation Program Directory at Military OneSource website.  
https://www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/the-exceptional-family-member-program-for-families-with-special-needs?inheritRedirect=true

EFMP & Me Online Tool  https://efmpandme.militaryonesource.mil/

Families can also call Military OneSource at 800.342.9647 and ask for a referral to a special needs consultant.

**Related links:**
Military One Source, *Exceptional Family Member*  
https://www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member

http://www.militaryfamily.org/info-resources/efmp-special-needs.html

**References:**


Coast Guard Mutual Assistance (CMGA) Respite Care

**Program Purpose:**
The Coast Guard’s Special Needs Program provides a comprehensive, coordinated, multidisciplinary approach to community support, housing, medical, educational, and personnel services for Coast Guard families with special needs.

**Beneficiaries:**
Eligible families are those in which a family member of a member of the U.S. Coast Guard (spouse, dependent child, or dependent parent) has been diagnosed with a profound disability or a serious or terminal illness requiring ongoing care, and is enrolled in the Coast Guard Special Needs Program. Eligibility is verified by the local command.

**Funding:**
Coast Guard Mutual Assistance (CMGA) Respite Care, a private, nonprofit entity, provides respite grants to eligible Coast Guard families. 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. Respite is based on need (financial need and need for a break from care giving when supported by a statement from a doctor or other medical authority and when no other sources will authorize assistance) and is given as a grant.

**Issues for consumers, providers, and advocates:**
Not all enrollees in the Coast Guard’s 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.

**Federal funding agency:**
While the U.S. Coast Guard is a federal entity, the agency that provides respite for members of the Coast Guard and their families is a private non-profit organization that is established and operated by . Coast Guard Mutual Assistance (CGMA) is the official relief society of the U.S. Coast Guard. While CGMA works closely with the Coast Guard, it is an independent non-profit charitable organization, established and operated by members of the Coast Guard.

**Points of contact:**
A list of local CGMA representatives can be found on the Coast Guard Mutual Assistance website. https://cgmahq.org/locations.html

**Related links:**
U.S. Coast Guard, Coast Guard Mutual Assistance, Special Needs Support. https://cgmahq.org/programs/special.html

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22 Equivalent to Exceptional Family Member Programs in other services.
References:
Coast Guard Mutual Assistance Respite Care Program.
https://www.dcms.uscg.mil/Portals/10/DOL/BaseSeattle/HSWL/CGMAREspiteCareProgram.pdf?ver=2017-06-12-164016-907

U.S. Coast Guard: Office of Work-Life Programs–Special Needs Program.
Armed Services YMCA Respite Child Care

Program purpose:
To provide respite for armed forces families.

Funding:
There is no cost to the family for this program.

Beneficiaries:
Families with children up to age 12 who are Title 10 personnel are eligible for a Y membership and respite care, including: Family members of deployed National Guard and Reservists, Active Duty Independent Duty personnel, relocated spouses/dependent children of deployed Active Duty personnel, and families of deployed Active Duty personnel residing 30 miles from a military installation.

Activities supported by the funding:
The Department of Defense has contracted with the YMCA to provide free family memberships at participating YMCAs.

Respite connection:
Participating YMCAs will provide up to 16 hours of respite child care per month per child for children age 12 and younger.

Issues for consumers, providers, and advocates:
A military ID card and copy of deployment orders or Independent Duty approval form are required for enrollment.

Points of contact:
Armed Services YMCA
https://www.asymca.org/

Find participating YMCAs on the YMCA website.
http://www.ymca.net/military-outreach/childcare.html

Related links:
YMCA, Military Outreach: About Respite Care.
http://www.ymca.net/military-outreach/childcare.html

References:
DoD/YMCA Respite Care Eligibility Form.
Geriatric and Extended Care for Veterans

Authorizing legislation:

Program purpose:
To establish a program of extended care services for Veterans.

Beneficiaries:
Family caregivers of Veterans from all eras.

Funding:
This program was established without a need for further fiscal appropriations. Services can be contracted or provided directly by the staff of the U.S. Department of Veterans Affairs (VA) or by another provider or payer.

Activities supported by the funding:
Geriatric and extended care services authorized by the Millennium Health Care and Benefits Act 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 a VA Community Living Center, a VA-contracted Community Residential Care Facility, or an Adult Day Health Care Center, 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. In addition to planned respite services, respite care may also be provided in response to a family caregiver’s unexpected hospitalization, a need to go out of town, or a family emergency.

Federal funding agency:
U.S. Department of Veterans Affairs, Veterans Health Administration, Geriatrics and Extended Care.

Points of contact:
Veterans can access information about their health benefits on the U.S. Department of Veterans Affairs website. https://www.va.gov/health-care/

Contact information for VA offices and facilities and state and local resources can be found on the U.S. Department of Veterans Affairs website.
https://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 https://www.caregiver.va.gov/help_landing.asp for help finding a local Caregiver Support Coordinator.
Related links:
U.S. Department of Veterans Affairs. VA Caregiver Support and Respite Care.
http://www.caregiver.va.gov/

References:
https://fas.org/sgp/crs/misc/R44697.pdf


Aid and Attendance and Housebound Benefits

Program purpose:
To provide financial assistance to Veterans with special needs.

Beneficiaries:
Veterans with medical needs or mental or physical disability who are at least 65 years old or permanently and totally disabled. Younger, single Veterans, and their surviving spouses may also qualify. This includes Veterans who are blind or confined to the bed.

Funding:
In 2021, the Department of Veterans Affairs (VA) pays a Maximum Annual Pension Rate (MAPR) of $27,549 to a Veteran with a spouse who qualifies for Aid and Attendance. If the Veteran has more than one dependent, add $2,382 to the MAPR amount for each additional dependent. Single Veterans and surviving spouses may be eligible for smaller payments. The MAPR for a Veteran with a spouse who qualifies for Housebound Benefits is $21,337.

Activities supported by the funding:
Aid and Attendance and Housebound benefits provide additional support above a regular 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.

An individual cannot receive Aid and Attendance benefits and Housebound benefits at the same time.

Federal funding agency:
U.S. Department of Veterans Affairs.

Points of contact:
Contact information for the appropriate VA Regional Office is available on the U.S. Department of Veterans Affairs website.
https://www.va.gov/landing2_locations.htm

Related links:
U.S. Department of Veterans Affairs: Improved Disability Benefits Pension Rate Table.
https://www.va.gov/pension/veterans-pension-rates/

References:

U.S. Department of Veterans Affairs, Veterans Health Administration, Geriatrics and Extended Care. Paying for Long-Term Care. [https://www.va.gov/GERIATRICS/pages/Paying_for_Long_Term_Care.asp](https://www.va.gov/GERIATRICS/pages/Paying_for_Long_Term_Care.asp)
Veteran Directed Care

Authorizing legislation:
No specific authorizing legislation for Veteran Directed Care.

Program purpose:
The Veteran Directed Care (VDC) Program, previously called the Veterans Directed Home and Community-Based Services (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 of any age who are at risk of nursing home admission. Their family caregivers may be served as well.

Funding:
The program is a collaboration between the Veteran’s Health Administration, Office of Geriatrics and Extended Care Services and the Administration for Community Living. As of 2020, the 69 participating U.S. Department of Veterans Affairs (VA) Medical Centers (VAMCs) in collaboration with over 115 Aging/Disability Network providers is serving 3,239 veterans with complex needs and those transitioning back to the community from hospitals and nursing home stays. As of 20, the program is serving Veterans across 37 States and the District of Columbia and Puerto Rico.

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 VDC Program 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. Veterans receive a flexible service budget they use to hire family, friends, and neighbors to provide long term services and supports. Veterans also receive facilitation services from a Person Centered Counselor (Options Counselor) and financial management support from a Financial Management Services (FMS) organization.

VDC providers may be Aging and Disability Network Agencies (ADNAs), including Aging and Disability Resource Centers (ADRC), Area Agencies on Aging (AAA), Centers for Independent Living (CIL), and State Units on Aging (SUA); 231 Aging and Disability Network Agencies are delivering VDC.

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. Veterans may use their budgets to purchase respite for their family caregivers.

Federal funding agency:
U.S. Department of Veterans Affairs, Veterans Health Administration, Chief Business Office.
**Eligible entities:**
State Units on Aging, Area Agencies on Aging, Aging & Disability Resource Centers and Centers for Independent Living

**Points of contact:**
Information on ADNA’s that have completed VA Readiness Reviews and have been approved as qualified providers for VDC is available on the Administration for Community Living website.  

**Related links:**

**References:**
http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/Veterans/AARP195_PP_NWDandVeterans_WEB.PDF


U.S. Department of Health and Human Services, Administration for Community Living Veterans Health Administration Opportunity for ADRCs: Special Opportunity To Expand HCBS Access for Veterans  

Program of Comprehensive Assistance for Family Caregivers (PCAFC)

Authorizing legislation:

Program purpose:
To provide comprehensive assistance to family caregivers of Veterans.

Beneficiaries:
Veterans may be eligible for this program if they sustained or aggravated a serious injury serious injury (now includes serious illness) in the line of duty on or before May 7, 1975, or on or after September 11, 2001; and meet both of the following criteria. Among other applicable eligibility criteria, the Veteran must:

- Have a single or combined service-connected disability rating by the Department of Veterans Affairs (VA) of 70% or more. This requirement is included in the definition of “serious injury;” and
- Be in need of personal care services (requiring in-person personal care services) for a minimum of six continuous months based on any one of the following:
  - an inability to perform an activity of daily living (ADL)
  - a need for supervision, protection, or instruction.

In 2020, not only were services expanded to pre-1975 era Veterans, the enhanced PCAFC eliminates the need for a connection between personal care services and the qualifying serious injury. It also redefines serious injury to now include any service-connected disability — regardless of whether it resulted from an injury, illness or disease. Both these changes greatly expand program eligibility. In the second phase, due to begin in 2022, the program will expand to eligible Veterans who incurred or aggravated a serious injury in the line of duty after May 7, 1975 and before September 11, 2001.

Activities supported by the funding:
Approved family caregivers may receive

- Education and training;
- Access to healthcare insurance if the caregiver is otherwise uninsured;
- Mental health counseling;
- Financial stipend;
- Wellness contact;
- Travel and per diem compensation when traveling for a Veteran’s healthcare appointment; and
- Up to 30 days per year of respite care, including 24-hour care of the Veteran.

Respite connection:
Respite is a core service of the program. Respite must be medically and age appropriate and include in-home care. A family caregiver must be at least 18 years of age and be either the eligible Veteran’s spouse, son, daughter, parent, stepfamily member, or extended family member; or someone who lives with the eligible Veteran full-time or will do so if designated as a family caregiver. The family caregiver must also be assessed by the VA as being able to complete caregiver education and training and
demonstrate the ability to carry out the specific personal care services, core competencies, and additional care requirements. In addition, there must be no determination by the VA of abuse or neglect of the eligible Veteran by the caregiver.

**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.

The first phase of a significant expansion began in 2020. In addition to expanding the program to a much larger group of caregivers, the VA MISSION Act of 2018 also requires the Department of Veterans Affairs to develop a new IT system to assess and improve the program, including specifically participating caregivers’ use of “support services under the Program such as respite care.”

If a Veteran is not eligible for the Program of Comprehensive Assistance, they and their caregivers can access the **Program of General Caregiver Support Services (PGCSS)**, which provides resources, education and support to caregivers of Veterans. The Veteran does not need to have a service-connected condition for which the caregiver is needed, and may have served during any era. No formal application is required. See Program of General Caregiver Support Services Fact Sheet at [https://www.caregiver.va.gov/docs/PGCSS_Fact_Sheet.pdf](https://www.caregiver.va.gov/docs/PGCSS_Fact_Sheet.pdf)

**Federal funding agency:**
Department of Veterans Affairs, Veterans Health Administration.

**Points of contact:**

Caregiver Support Coordinators are available at each VA Medical Center to help caregivers find the right support to meet their needs and to enroll in caregiver programs and services. To find Caregiver Support Coordinators, visit [https://www.caregiver.va.gov/support/New_CSC_Page.asp](https://www.caregiver.va.gov/support/New_CSC_Page.asp)

To apply for the PCAFC online, visit [https://www.va.gov/family-member-benefits/apply-for-caregiver-assistance-form-10-10cg/introduction](https://www.va.gov/family-member-benefits/apply-for-caregiver-assistance-form-10-10cg/introduction)

**Related Links:**

U.S. Department of Veteran’s Affairs. *MISSION Act Strengthens VA Care.* [https://missionact.va.gov/#caregivers](https://missionact.va.gov/#caregivers)

**References:**
U.S Department of Veterans Affairs. Veterans Affairs Program of Comprehensive Assistance for Family Caregivers Eligibility Criteria Fact Sheet.
https://www.caregiver.va.gov/pdfs/MIssionAct/EligibilityCriteriaFactsheet_Chapter2_Launch_Approved_Final_100120.pdf#

U.S Department of Veterans Affairs. Veterans Affairs Program of Comprehensive Assistance for Family Caregivers Expansion Fact Sheet.
https://www.caregiver.va.gov/pdfs/MIssionAct/ExpansionFactsheet_Chapter2_Launch_Approved_Final_100120.pdf#

https://www.blogs.va.gov/VAntage/66762/va-strengthens-caregiver-support-program/?fbclid=IwAR23alyijap_Dwc8qVwwmiNDDMM4_aF0wwVsau_rJeSOQqh5g0BAmbKE2X8

## Appendix: Summary Table of Federal Programs

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<td>Medicare-eligible aged and disabled individuals with terminal illnesses</td>
<td>Payments to hospice care facilities</td>
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<td>Medicare Advantage</td>
<td>Managed care health insurance plan to individuals</td>
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<td>Self-Directed Assistance Services</td>
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<td>Programs of All-Inclusive Care for the Elderly (PACE)</td>
<td>Capitated benefit with integrated Medicare and Medicaid financing</td>
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<tr>
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<td>Formula grant to states State option</td>
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<td>Medicaid State Plan Option for Home and Community-Based Services</td>
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<tr>
<td>Money Follows the Person</td>
<td>Discretionary grant to states</td>
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<td>Child Abuse Community-Based Prevention Grants (CBCAP)</td>
<td>Formula grant to states</td>
<td>Child Abuse Prevention and Treatment Act, Title II</td>
<td>Children at risk of child abuse or neglect and their families</td>
<td>Support of community respite and crisis nursery programs</td>
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<tr>
<td>Foster Care Prevention Services and Programs</td>
<td>Entitlement program with funding to states</td>
<td>Title IV-E of the Social Security Act, as amended by the Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123)</td>
<td>Children at imminent risk of entering foster care; child’s parents or kin caregivers; and pregnant or parenting youth in foster care</td>
<td>Payments to prevention programs and providers</td>
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<tr>
<td>Kinship Navigator Program</td>
<td>Formula grant to states</td>
<td>Title IV-E of the Social Security Act, as amended by the Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123)</td>
<td>Children at risk of foster care placement and their relatives</td>
<td>Navigator programs funded to link families to services, including respite. No direct funds for respite.</td>
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<tr>
<td>MaryLee Allen Promoting Safe and Stable Families</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title IV-B, Subpart 2</td>
<td>Families and children in need of child welfare and family strengthening services</td>
<td>Payments to respite care providers and crisis nursery programs</td>
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<tr>
<td>Adoption Assistance</td>
<td>Reimbursement to States for adoption assistance expenses.</td>
<td>Title IV-E of the Social Security Act, as amended by the Family First Prevention Services Act of 2018 (FFPSA) (P.L. 115-123)</td>
<td>Adopted children with special needs and their families.</td>
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<tr>
<td>Early Intervention for Infants and Toddlers</td>
<td>Formula grant to states</td>
<td>Individuals with Disabilities Education Act, Part C</td>
<td>Children ages 0 to 2 with developmental disabilities and their families</td>
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<tr>
<td>Maternal and Child Health Block Grant</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title V, Section 501</td>
<td>Mothers, infants and children, including children with special health care needs, particularly low-income</td>
<td>Payments to respite care providers</td>
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<tr>
<td>Family to Family Health Information Centers</td>
<td>Discretionary grant to projects</td>
<td>Social Security Act, Title V, Section 501(c)(1)(A)</td>
<td>Children and families receiving services from organizations engaged in activities for children and youth with special health care needs</td>
<td>Funds information centers to connect families to respite. No direct funding for respite care</td>
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<tr>
<td>Child Mental Health Initiative</td>
<td>Discretionary grant to states</td>
<td>Public Health Service Act, Title V, Section 561</td>
<td>Children under age 22 with a diagnosed serious emotional disturbance, serious behavioral disorder, or serious mental disorder</td>
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<tr>
<td>Temporary Assistance for Needy Families (TANF)</td>
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<td>Low-income families with children</td>
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<tr>
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<tr>
<td>Social Services Block Grant</td>
<td>Formula grant to states</td>
<td>Social Security Act, Title XX</td>
<td>No restrictions</td>
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<tr>
<td>Developmental Disabilities Councils</td>
<td>Formula grant to states</td>
<td>Developmental Disabilities Assistance and Bill of Rights Act</td>
<td>Individuals with developmental disabilities</td>
<td>Funds development and maintenance of provider networks. Limited payments to respite care providers</td>
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<tr>
<td>Aging and Disability Resource Centers/No Wrong Door Systems</td>
<td>Competitive grants to State Agency or instrumentality of the State</td>
<td>Titles II and IV of the Older Americans Act, as amended by Supporting Older Americans Act of 2020, P.L. 116-131, and Patient Protection and Affordable Care Act, P.L. 111-111-148.</td>
<td>Older adults and persons with disabilities, including family caregivers</td>
<td>ADRCs are mandated partners in the Lifespan Respite Care program, and an important part of a state’s No Wrong Door system. Information and referral to LTSS. No specific funds for respite</td>
</tr>
<tr>
<td>National Family Caregiver Support Program</td>
<td>Formula grant to states, Indian Tribal Organizations; public or nonprofit Native Hawaiian organizations</td>
<td>Older Americans Act, Title III-E and VI-C (Native American Caregiver Support Program) as amended by Supporting Older Americans Act of 2020, P.L. 116-131</td>
<td>Family caregivers; grandparents and relative caregivers of children; and older parents and relative caregivers of adults with disabilities; American Indian and Native Hawaiian family caregivers.</td>
<td>Payments to respite care providers or consumer direction</td>
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<tr>
<td>Lifespan Respite Care Program</td>
<td>Competitive grants to states</td>
<td>Public Health Service Act, Title XXIX, as amended by the Lifespan Respite Care Program Reauthorization Act, P.L. 116-324.</td>
<td>Family caregivers of children and adults with special needs</td>
<td>Payments to states for respite systems; training; information and referral; payments to respite providers and to individuals for respite.</td>
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<td>Program</td>
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<tr>
<td>AmeriCorps</td>
<td>Formula grants when applicable to Governor-appointed State Service Commissions</td>
<td>National and Community Service Act of 1990; as amended by Edward M. Kennedy Serve America Act, P.L. 111-13.</td>
<td>Beneficiaries identified with an application for assistance</td>
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<td>AmeriCorps Senior Companion Program</td>
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<td>Individuals age 21 and over with special needs; frail elderly</td>
<td>Payments in the form of stipends to volunteer companions who in turn provide no cost services to consumers</td>
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<tr>
<td>National Community Care Corps</td>
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<td>Family caregivers of children and adults with special needs</td>
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<tr>
<td>Supportive Services and Senior Centers</td>
<td>Formula grant to states</td>
<td>Older Americans Act, Title III, Part B; as amended by the Supporting Older Americans Act of 2020, P.L. 116-131</td>
<td>Individuals age 60 and over with economic and social need</td>
<td>Payments to providers of services that result in “indirect” respite care</td>
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<td>Alzheimer’s Program Initiative</td>
<td>Discretionary grant to States and communities.</td>
<td>Older Americans Act, Title IV; as amended by Supporting Older Americans Act of 2020, P.L. 116-131</td>
<td>Individuals with Alzheimer’s Disease and their family caregivers as well as professional care providers.</td>
<td>Payments to respite care providers to support caregiver participation in program</td>
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<td>Respite for Injured Service Members</td>
<td>Extended TRICARE respite benefits</td>
<td>National Defense Authorization Act for FY 2008, P.L. 110-181, Subtitle C, Sec. 1633.</td>
<td>Injured active duty service members, including National Guard/Reserve who have a serious injury</td>
<td>Payments to respite providers at no cost to family and no cap</td>
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<td>Exceptional Family Member Program</td>
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<td>Veterans Affairs Health Care – Geriatrics and Extended Care</td>
<td>Entitlement to individuals</td>
<td>Millennium Health Care and Benefits Act</td>
<td>Veterans of all eras</td>
<td>Provides respite care through VA medical centers, community settings, or in-home</td>
</tr>
<tr>
<td>Aid-and- Attendance &amp; Housebound Benefit</td>
<td>Entitlement to individuals</td>
<td></td>
<td>Veterans with medical needs or mental or physical disability or surviving spouses</td>
<td>Unrestricted payments to individuals; can be used for respite</td>
</tr>
<tr>
<td>Program</td>
<td>Type of Assistance &amp; Eligible Entity</td>
<td>Authorizing Legislation</td>
<td>Beneficiaries (may vary by state)</td>
<td>Payments to or Support for Respite Services</td>
</tr>
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</tr>
<tr>
<td>Veteran-Directed Care</td>
<td>Discretionary grant to Aging and Disability networks, including Centers on Independent Living</td>
<td>Collaborative initiative between the Veterans Health Administration and the Administration for Community Living.</td>
<td>Veterans at risk of placement in a nursing home</td>
<td>Payments to respite care providers or consumer directed</td>
</tr>
<tr>
<td>VA Program of Comprehensive Assistance for Family Caregivers</td>
<td>Stipends to family caregivers, mental health services, health coverage and respite</td>
<td>Caregivers and Veterans Omnibus Health Services Act as amended by the VA MISSION Act of 2018, P.L. 115-82.</td>
<td>Veterans with sustained or aggravated serious injury (now includes serious illness) in the line of duty on or before May 7, 1975, or on or after September 11, 2001. Veterans from all eras will be included in 2022.</td>
<td>Respite must be medically and age-appropriate, and include in-home care.</td>
</tr>
</tbody>
</table>