Building Blocks for Lifespan Respite: Federal Funding for Respite for All Ages

Background: Lifespan Respite Programs are defined in public law as “coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs” (PL 109-442). Existing state and federal funding streams for respite are often not available to most families because of 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. Moreover, federal funding sources may be challenging even for Lifespan Respite grantees and others to identify and access. While these federal programs hold potential for funding respite and crisis care services, and can serve as the fundamental building blocks of a state Lifespan Respite Care Program, not enough is known about the extent to which states and local programs are accessing these funding sources. 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, or limited knowledge about the benefits of respite and crisis care programs.

This fact sheet highlights select federal programs that provide funding or could potentially provide respite funding. Although respite and crisis care services may not specifically be mandated by the federal statutes that govern implementation of many of the programs listed here, respite and/or crisis care are among the services that are eligible for funding or support. In most cases, the authority to decide whether to fund respite and/or crisis care services has been given to state, regional, or local governments. Some of these federal programs can provide direct payments to respite or crisis care consumers or providers, while others fund programs through a competitive or formula grant process to state or local public or private entities. The list is not inclusive. For more detailed information, including state contact information, see ARCH’s comprehensive guide to Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems [https://lifespanrespite.wildapricot.org/Federal_Funding_Guide/].

Programs Administered by the Centers for Medicare and Medicaid Services (CMS)

Medicaid is the nation’s primary payer for home and community-based services (HCBS) that allow persons to live independently in their own homes or in the community. Over the last two decades, states have steadily increased the amount of resources directed at HCBS options. Medicaid waivers are by far the largest source of federal funds for respite.

Medicaid Waiver Programs: The Social Security Act authorizes several different waiver and demonstration opportunities for states to operate their Medicaid programs with some
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flexibility to adopt new models of coverage and care delivery. Four separate types of waivers are available to states:

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

As of 2016, 44 states and the District of Columbia have §1915(c) HCBS waivers. Six states, including Arizona, Delaware, New Jersey, Oregon, Rhode Island and Vermont, have transitioned all of their §1915(c) HCBS waivers and now operate their long-term care programs under a broader §1115 demonstration waiver. Other states, like New York and Virginia, are only moving some of their HCBS waivers into a broader §1115 demonstration.¹ Most states include respite in one or more of their §1915(c) Medicaid Waiver Programs or §1115 waivers. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time.

Receipt of services through a state Medicaid waiver is not an automatic entitlement, as are services under the Medicaid State Plan program. Long waiting lists in most states delay access to needed waiver services. In 2014, 39 states reported having waiting lists for §1915(c) waivers, with a national average wait time of 29 months.²

Many states are currently making changes to their Medicaid waivers, by moving toward capitated managed care for long-term services and supports (MLTSS). The majority of states are implementing Medicaid managed long-term services and supports (MLTSS) through §1115 global demonstration waivers or combinations of §1115(a)/§1915(c), or §1915(b)/(c) waivers.³ As of February 2017, 19 states were providing Medicaid long-term services and supports through managed care.⁴


**Section 1915(j) Self-Directed Personal Assistance Services:** Originally established as Cash & Counseling demonstrations through §1115 Medicaid waivers, this program is now a state option available under the Medicaid State Plan. Medicaid eligible frail elders and adults with disabilities may be eligible, depending on the state. States that choose this option provide consumers with a flexible budget to obtain a combination of goods and services, including respite, which will best meet their personal care needs. Participants receive a monthly budget or the state has a Financial Management Entity that conducts all activities for the consumer related to cash disbursement and payroll functions. In some states, children with developmental disabilities are also served.

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Program of All-Inclusive Care for the Elderly (PACE): PACE is a Medicaid program for the frail elderly that provides comprehensive services. It is available in States that have chosen it as an optional Medicaid benefit. PACE participants are 55 years of age or older who are determined by the State to need nursing home level of care, and reside in the PACE programs’ service area. The PACE Innovation Act of 2015, 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. PACE services must be provided by a not-for-profit entity and include all Medicare and Medicaid covered services, and other services determined necessary by the interdisciplinary team for the care of the PACE participant. Services are provided in an adult day health center, supplemented by in-home and referral services, based on participants’ needs. A PACE program can incorporate caregiver services into the care plan and make respite services available to caregivers. As of 2016, there were 121 PACE programs in 31 states serving 38,072 participants.

Medicare and Medicaid-covered Hospice: Individuals eligible for Part A Medicare services who 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, can obtain coverage for a program of support and comfort rather than cure at the end of life. 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. Inpatient respite care for up to five consecutive days, in a Medicare-approved facility, is available when the patient’s usual family caregiver needs a rest. The hospice benefit is designed to enable the beneficiary to remain in the home and to support the family. The Medicaid Hospice benefit, similar to the Medicare benefit, is available to Medicaid beneficiaries.

Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services: States may choose to offer home and community-based services through a Medicaid State Plan option rather than through a §1915(c) waiver. Under this option, states may provide a variety of medical and long-term services not otherwise covered by the state Medicaid program that keep a person from being institutionalized. Services covered include case management, homemaker, home health, personal care, adult day health, habilitation, and respite care. Effective October 1, 2010, eligibility was expanded under this option to individuals with incomes up to 300% of the maximum SSI payment. States cannot cap enrollment or maintain a waiting list if they cover these services under the Medicaid State Plan. Service planning for participants must use a person-centered process that addresses health and long-term service and support needs in a manner that reflects individual preferences and goals. The person-centered planning requirements under 1915(i) also stipulate that “if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan” then a caregiver assessment must be conducted. As of December 2015, 16 States (CA, CO, CT, DE, FL, ID, IN, IA, LA, MD, MI, MS, MT, NV, OR, and WI) and the District of Columbia offered these optional Medicaid State Plan benefits.

Respite Funding for Children Only

Promoting Safe and Stable Families (PSSF): The goal of this program is to preserve families by reducing child abuse and neglect. State grants are based on the number of
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children receiving Supplemental Nutrition Assistance Program (SNAP), and a 25% state match is required. Each state must develop a plan in consultation with child welfare service agencies to provide family support, family preservation, time-limited reunification services, and services to promote and support adoption. Respite is an allowable expense under each of these four categories of service. The plan also must be coordinated with other similar federally assisted programs for at-risk populations. States may set their own eligibility requirements for consumers and providers and may subcontract with any provider of family preservation or family support services (including respite and crisis care providers).

**Child Mental Health Initiative (CMHI):** The federal Substance Abuse and Mental Health Services Administration (SAMHSA) awards cooperative agreements to states, local government entities, and Tribal Organizations for the development of community-based “systems of care”. The purpose of the program is to provide comprehensive community mental health services for children and adolescents with serious emotional disturbance and their families. Cooperative agreements require grantees to implement certain key cross-agency administrative structures and procedures as well as an array of mental health and support services which must include respite. These services are to help keep children with their families and in their communities, while adequately addressing their needs.9

**Family-to-Family Health Care Information and Education Centers (F2F HICs):** The Health Resources and Services Administration (HRSA) provides competitive grants to states 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, guidance and conduct outreach activities. Through F2Fs, families give information to and mentor other families, a model that could prove useful as a Lifespan Respite partner.10

**Maternal and Child Health Services Block Grant (MCHBG):** This program provides grants to states to promote and improve the health of pregnant women, mothers, infants, children, and children with special health care needs (CSHCN). States must contribute a 75% match to federal funding. At least 30% of the funds must be used for services to CSHCN. State MCHBG funds support an array of programs for CSHCN to facilitate the development of family-centered, community-based, coordinated systems of care. 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.11 A few states (e.g., CT, VT, and AZ) have taken advantage of the flexibility available under this block grant to provide or support respite.12

**Community-Based Child Abuse and Neglect Prevention Program (CBCAP):** CBCAP is focused on supporting community-based efforts to prevent child abuse and neglect. The law identifies respite and crisis care as core prevention services, but states retain the authority to set their own funding priorities as long as certain basic needs are met. A lead agency identified by the state administers the funds, assesses needs, and plans a statewide prevention approach. Funds have been used by states to maintain statewide respite and crisis care coalitions and to make grants to local agencies to provide services, including
respite and crisis care. Within certain limits, states may establish their own eligibility requirements. States that leverage local funds can receive significant federal bonuses.  

**Individuals with Disabilities Education Act (IDEA):** IDEA provides formula grants to states for programs that ensure a free and appropriate education in the least restrictive environment for children who have a disability. Part C of IDEA provides early intervention services for infants and toddlers from birth to age three who have developmental delays or are at substantial risk of delays. Respite has sometimes been funded under Part C, but only if it is part of an Individual Family Service Plan (an individualized assessment of the child and family’s needs) and there are no other resources available for respite. In some Part C programs, respite is provided on a sliding-fee scale according to a family’s income (NY) or the program funds part of the respite cost (NC).  

**Respite Funding for Multiple Age Groups**

**Developmental Disability (DD) Councils:** State DD Councils develop plans to establish and improve services for individuals with developmental disabilities. In many states the councils help develop and maintain provider networks, but they have only limited funds for services. 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.

**National Family Caregiver Support Program:** Authorized under the Older Americans Act, the program calls for State Units on Aging to work with regional Area Agencies on Aging, local community-service providers, and Tribal Organizations to offer five basic services for family caregivers: 1) information; 2) assistance accessing support services; 3) individual counseling, support groups, and caregiver training; 4) respite; and 5) limited supplemental services. Eligible individuals are:

- family caregivers who provide care for individuals age 60 or older;
- family caregivers who provide care for individuals with Alzheimer’s disease and related disorders, regardless of age;
- grandparents and other relative caregivers (not parents) 55 years of age or older providing care to children under age 18; or
- parents, grandparents and other relative caregivers 55 years of age or older providing care to adults ages 18-59, with disabilities, to whom they are related by blood, marriage, or adoption.

State programs can use up to 10% of their funding to provide services to grandparents and other relative caregivers who are providing care to children under age 18. Most of the services are targeted to family caregivers caring for the aging population. Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services.

**Aging and Disability Resource Centers (ADRC)/No Wrong Door Systems (NWD):** Aging and Disability Resource Centers are required partners in Lifespan Respite grants. The
ADRC/NWD system, a collaborative effort of the Administration for Community Living (ACL), CMS, and the Veterans Health Administration (VHA), is designed to streamline access to long-term services and supports. NWDs play a critical role in supporting health and long-term care reform by improving the ability of state and local governments to effectively manage the system, monitor program quality, and measure responsiveness of state and local systems of care. To date, ACL has funded 54 out of 56 states and territories to implement ADRC/NWD System activities. Nationwide, 530 local ADRC networks are in place actively serving older adults and persons with disabilities. In 2014, building on the work of eight original state grantees of the 2012 Part A: The Enhanced ADRC Options Counseling Program, 25 states and territories were awarded one-year planning grants to develop single statewide NWDs. In 2015, ACL, CMS and VHA announced three-year awards to five of these states to identify No Wrong Door promising practices.16

**Social Services Block Grant (SSBG):** The program provides funds for social services to families with special needs, adults with disabilities, and the aging population. Among its goals are to prevent neglect, abuse or exploitation of children and adults, and prevent or reduce inappropriate institutional care. Adult daycare, respite and crisis care are accepted SSBG services. States receive the funds with few strings attached. The annual allotments are noncompetitive, there is no required match, and the funds may be used to support public agencies or to contract with private service providers. Client eligibility is not restricted, and service provider qualifications are flexible.17

**National Senior Service Corps - Senior Companion Program:** The Senior Companion Program has two purposes: to engage persons 55 years of age and older, particularly those with limited incomes, in volunteer service to meet critical community needs, and to help adults with special needs maintain their dignity and independence. Senior Companions provide predominantly in-home services to frail, often elderly, adults. Although funding is through competitive grants to qualified agencies and nonprofit organizations to start or continue Senior Companion Programs, this resource—as well as the Foster Grandparent Program and the Retired Senior Volunteer Program, also federally funded—could be explored by respite programs as resources for volunteer respite providers.18

**Respite Funding for Military Families/Veterans**

**Veterans Affairs Health Care.** Veterans eligible for outpatient medical services can also receive non-institutional respite, outpatient geriatric evaluation and management services, and therapeutically oriented outpatient day care. Respite care may be provided in a home or other non-institutional setting, such as a community nursing home. Ordinarily, respite care is limited to no more than 30 days per year. With the approval of the medical center, additional care days may be permitted under certain circumstances, such as for the death of the caregiver. Services can be contracted or provided directly by Veterans Health Administration (VHA) or by another provider or payer.

**Program of Comprehensive Assistance for Family Caregivers:** Primary family caregivers of Veterans who were seriously injured in the line of duty on or after September 11, 2001, and whose injury requires personal care services for at least six months, may be eligible to receive a monthly stipend; health care coverage; mental health services; travel, lodging and subsistence; respite services for at least 30 days per year, including 24-hour
care; and education and training. To be eligible, the injured Veteran must be in need of personal care services because of an inability to perform one or more activities of daily living, or be in need of supervision or protection on the basis of symptoms of impairment.\textsuperscript{19}

**Aid-and-Attendance and Housebound Benefit:** The U.S. Department of Veterans Affairs pays a maximum of $2,900 a month to qualified married Veterans. Single Veterans and surviving spouses may be eligible for smaller payments. This is a benefit paid in addition to a monthly VA pension for Veterans with medical needs or mental or physical disability who are at least 65 years old or permanently and totally disabled if they are younger. Funds may be used in any way, including paying for respite care.\textsuperscript{20}

**Veteran-Directed Home and Community-Based Services (VDHCBS) Program:** The VD-HCBS Program is a collaboration between the U.S. Department of Veterans Affairs (VA) and the Administration for Community Living (ACL). The 57 participating VA Medical Centers (VAMCs) together with over 115 Aging/Disability Network providers serve Veterans with complex needs and those transitioning back to the community from hospitals and nursing home stays, as an alternative to traditional home care services and programs. Veterans of any age at risk of placement in a nursing home are eligible. VAMCs authorize a flexible spending budget based on the Veteran’s assessed needs. An Area Agency on Aging, State Unit on Aging, Aging and Disability Resource Center or a Center for Independent Living ensures the quality, satisfaction, and service delivery and assists in finding and training workers and securing needed goods and services within the allocated budget. A financial management service ensures timely payment of the Veteran’s employees.\textsuperscript{21}

**Exceptional Family Member Program (EFMP):** The Military Exceptional Family Member Program (EFMP) offers respite care to anyone in the military who is enrolled in the EFMP and meets the criteria. Whenever a family member (either a spouse or a child) of an active duty Navy, Marine Corps, Air Force, or Army member is identified with an ongoing medical or educational need, the Exceptional Family Member Program (EFMP) enrollment process MUST be initiated.\textsuperscript{22} The amount of respite available may vary among branches of the military.

**Information adapted from:**


**Endnotes**


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