Toolkit: Lifespan Respite “101”

Fact Sheet 2: 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). 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. Moreover, at the same time that the number of federal programs which could potentially fund respite has grown somewhat, federal funding sources have become more challenging 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, especially in these times of serious budgetary challenges, or limited knowledge about the benefits respite and crisis care programs can incur.

This fact sheet highlights select federal programs that provide funding, or could potentially provide respite funding. Although respite and crisis care services are not specifically mandated by most of these federal statutes that govern program implementation, 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 program expenses 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. http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide

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

Medicaid is the nation’s primary payer for long-term care (LTC), 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. A recent 50-state survey suggests that this trend is continuing, but at a slightly slower pace than previously. Most states already have limits in place for their community-based services such as coverage limits, enrollment caps, and waiting lists for services. In 2010, more states began implementing utilization controls and other reductions on LTC services to contain costs.¹

Medicaid Waiver Programs: The Medicaid program permits States to fund respite for family caregivers of individuals with specific conditions through the Home and Community-Based Waiver Program (section
1915(c) of the Social Security Act). Virtually all of the states, but none of the territories, has at least one Section 1915(c) HCBS waiver. Arizona, Rhode Island, Tennessee and Vermont provide home and community-based services through their comprehensive Section 1115 Medicaid waivers. Medicaid home and community-based waivers for the aging, for individuals with intellectual or developmental disabilities, or individuals with physical disabilities are the most common. Examples of other home and community-based waivers are those for individuals with Autism, Mental Illness, HIV/Aids, or Traumatic Brain Injury, or for those who are Medically Fragile or Technology Dependent. For the most recent information on Medicaid waivers by state, visit The Kaiser Family Foundation’s Medicaid Benefits: Online Database (2010): http://medicaidbenefits.kff.org/service.jsp?yr=5&cat=1&nt=on&sv=41&so=0&tg=0

Medicare-and Medicaid-covered Hospice: The hospice benefit is designed to enable the beneficiary to remain in the home and to support the family. The beneficiary may be placed in an inpatient facility for up to five consecutive days to provide respite for the caregiver.

Section 1915(j) Self-Directed Personal Assistance Services: Originally established as Cash & Counseling demonstrations through Section 1115 Medicaid waivers, this program is now a state option available under the Medicaid State Plan. The provision gives frail elders and adults with disabilities the option to manage a flexible budget and decide what mix of goods and services, including respite, will best meet their personal care needs. In some states, children with developmental disabilities are served also.

Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities (PRTFs) Demonstration: In 2007, CMS awarded five-year grants to 10 States to transition children from psychiatric residential treatment facilities into the community (Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia. Florida was initially awarded a grant, but withdrew from the demonstration). Grants support funding of diagnosis, treatment, educational, vocational services, social skills training, and support to both the consumer and the family. Respite is specifically listed as a support service which may be funded. At the conclusion of these demonstrations, states will have the option of continuing to provide home and community-based care alternatives for demonstration participants, under a 1915(c) waiver.

Program of All-Inclusive Care for the Elderly (PACE): PACE is a Federal-State 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, determined by the State to need nursing home level of care, and reside in the PACE programs’ service area. The PACE service package must include all Medicare and Medicaid covered services, and other services determined necessary by the interdisciplinary team for the care of the PACE participant. A PACE program can incorporate caregiver services into the care plan and make respite services available to caregivers. As of January 2010, there were 80 PACE programs in 30 states serving more than 19,000 enrollees.

Health Care Reform Changes to Long-Term Services and Supports under the Affordable Care Act (ACA)

Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services: The Deficit Reduction Act of 2005 gave states the option to offer home and community-based services through a Medicaid State Plan Amendment rather than through a 1915(c) waiver. Under this option, States may provide some of the same services to caregivers that are available under 1915(c) waivers (see above). Effective October 1, 2010, eligibility was expanded under this option to individuals with incomes up to 300% of the maximum SSI payment. The states’ ability to cap enrollment or maintain a waiting list was
also eliminated. Only four states (Colorado, Iowa, Nevada and Maine) reported having the HCBS State Plan option in place prior to FY 2010. According to the most recent 50 state survey in 2010, two states (Wisconsin and Washington) reported implementing the HCBS State Plan Option in FY 2010, and six states had indicated plans to implement this option in FY 2011 (California, Georgia, New Jersey, North Carolina, Oregon, and Texas). Severe economic conditions in many states due to the severity of the ongoing recession, as well as provider shortages, may have prevented these states from moving forward.

Money Follows the Person (MFP): In 2007, CMS awarded five-year grants totaling $1.4 billion to 30 States and the District of Columbia to transition eligible individuals from institutions into the community. The grants pay for one year of community-based services for each person transitioned, which may include respite programs for caregivers. The savings incurred by the state through the enhanced federal match are to be used to develop and/or sustain LTC HCBS systems. ACA extends funding for Medicaid Money Follows the Person Rebalancing Demonstration Programs through 2016, and also reduces the length of time a person is required to reside in an institutional setting before they are eligible to participate in this program (previously at least six months, but now at least 90 consecutive days). In February 2011, CMS awarded 13 MFP grants to another 13 states for a total of 44 grants.

State Balancing Incentive Payments Program: Beginning in October 2011, the program made additional Medicaid matching funds available to states that meet certain requirements for expanding the percentage of long-term care spending for HCBS (and reducing the percentage of long-term care spending for institutional services). To qualify, a state must explain how it will expand and diversify HCBS and be approved for funding by CMS.

Section 1915 (k) Community First Choice (CFC) Option: Beginning in October 2011, states electing this state plan option to provide Medicaid-funded home and community-based attendant services and supports will receive an FMAP increase of six percentage points for CFC services.

Community Living Assistance Supports and Services (CLASS) program is a voluntary insurance program funded by payroll deductions to help adults with functional impairments remain independent, employed, and engaged in the community. Recipients would receive a cash benefit expected to average around $50-$75 per day, and would have the flexibility to use cash benefits to pay for a range of long-term services and supports, including respite care. However, the US Department of Health and Human Services does not plan to implement the program at the current time because of questions about its potential solvency.

Initiatives to Build Workforce Capacity: ACA allocates $10 million for new training opportunities for direct care workers who provide long-term services and supports; and allocates $5 million for demonstration projects to develop training and certification for personal and home care aids.

Aging and Disability Resource Center (ADRC): ADRCs are primary stakeholders in Lifespan Respite systems. The ADRC program, a collaborative effort of the AoA and CMS, is designed to streamline access to long-term services and supports. ADRCs 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 the responsiveness of State and local systems of care. ADRCs now operate in at least one community in each of the 50 States and in four Territories. There are currently over 300 ADRC networks across the nation. The ACA extended funding for ADRCs across the states.
Respite Funding for Children Only

Abandoned Infants Assistance Program: This program provides grants to public and private nonprofit agencies, State and county child welfare agencies, universities, and community-based organizations to develop, implement, and operate projects to prevent the abandonment of infants and young children, especially those affected by substance abuse and HIV and who are at-risk of being or are currently abandoned. The 2003 reauthorization extended priority for services to abandoned infants and young children who have life threatening illness or other special needs. Funded activities may include recruitment and training of foster families for abandoned children, and health and social services personnel to work with abandoned children; residential care for infants and young children who cannot live with their families or be placed in family foster care; and respite for families and foster families.\(^{12}\)

Promoting Safe and Stable Families (PSSF): This program is a primary federal effort to preserve families by reducing child abuse and neglect. State grants are based on the number of children receiving food stamps, and a 25 percent state match is required. 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): Only states, local government entities, and Tribal Organizations can apply for these competitive grants, which are to be used for the development of community-based “systems of care”. The purpose of the program is to provide comprehensive community mental health services for children and adolescents with serious emotional disturbance and their families. 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.\(^{13,14}\)

Family-to-Family Health Care Information and Education Centers (F2F HICs): Between 2002 and 2010, CMS and the Health Resources and Services Administration (HRSA) awarded 36 grants worth $7 million for States to establish F2F HICs. These centers provide information to families of children with special health care needs to help them navigate the health care system and make informed health care choices for their children. One aspect of the model is that families give information to and mentor other families, a model that could prove useful as a Lifespan Respite partner. Funding for F2F Health Information Centers was extended by the AFA to fund F2F HICs in the District of Columbia (DC) and 40 states in 2010.\(^{15}\)

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). At least 30 percent of the funds must be used for services to children with disabilities. The conditions that qualify as special health care needs vary widely among states, but typically they are defined as congenital or acquired chronic disabling conditions. Income eligibility requirements usually are based on Medicaid guidelines. Most states link Medicaid and MCHS and provide services through their state health departments, often subcontracting with regional or non-profit health agencies for specific services.\(^{16}\) A few states (CT, OK, and VT) have taken advantage of the flexibility available under this block grant to provide or support respite.\(^{17}\)
Adoption Opportunities Act: Discretionary grants are available to both public and private agencies for services that eliminate the barriers to adoption and promote the adoption of vulnerable children. Grants have been made to pay respite care providers after an adoption to help ensure a permanent placement. Federal regulations require only that children and families need the adoptive services provided by the grants. Only state or local government agencies or nonprofit organizations engaged in adoption services may apply for these grants.

Community-Based Child Abuse and Neglect Prevention Program (CBCAP): In 1997, the one federal program that specifically funded the start-up of respite and crisis care services for children, the Temporary Child Care and Crisis Nurseries Act, was consolidated into the Community Based Family Resource and Support (CBFRS) Program, Title II of the Child Abuse Prevention and Treatment Act. The 2003 reauthorization changed the name of this Title II program to the Community-Based Child Abuse and Neglect Prevention Program (CBCAP). CBCAP is focused on supporting community-based efforts to prevent child abuse and neglect. In the most recent reauthorization, States are directed to treat 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 develop and maintain statewide respite and crisis care coalitions and to make grants to local agencies to provide services, including respite and crisis care. Within certain limits states may establish their own eligibility requirements. The eligibility of local providers is not restricted. States with programs that leverage local funds can receive significant federal bonuses.

Individuals with Disabilities Education Act (IDEA): The act provides formula grants to states for programs that ensure a free and appropriate education in the least restrictive environment 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 as an early intervention strategy under Part C but only as part of an Individual Family Service Plan and only as last resort on a case-by-case basis. In some Part C programs, respite is provided on a sliding-fee scale according to a family's income.

Family Support 360: Family Support 360 is an initiative of the U.S. Administration on Developmental Disabilities (ADD) to provide state grants for the creation of one-stop centers to assist families of individuals with developmental disabilities (DD). The lead entity is designated by the Governor. In FY 2009, 7 entities were funded to plan and implement Family Support 360 Centers. These grantees are working with families in a variety of community settings to assist them in locating and navigating public human service agencies, as well as connecting to private community organizations. In 2008, four sites were funded to provide Family Support 360 Military Projects and in 2009, an additional six sites were funded. These projects focus on assisting military families who have a child with a developmental disability and must navigate two systems – civilian and military.18

Respite Funding for All Ages

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

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18 Referenced sources or further reading on the specific initiatives mentioned in the text.
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
- grandparents and other relative caregivers (not parents) 55 years of age or older providing care to adults age 18-59, with disabilities, to whom they are related by blood, marriage, or adoption.

For the last category, priority is given to caregivers providing care for an adult child with severe disabilities; services are not counted against the 10% ceiling for grandparents and other caregivers providing care to children under the age of 18 years. Older caregivers providing care to their own adult children with disabilities can be served in the NFCSP if the adult children are 60 years of age and older.\(^{19}\) Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services.

**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.\(^{20}\)

**Supplemental Security Income (SSI):** Direct monthly payments are available for unrestricted use for those with incomes and resources below certain levels and who are blind, disabled or over 65. To qualify as disabled, a person must have a permanent, medically proven physical or mental condition that results in marked and severe functional limitations. SSI income eligibility guidelines differ among states. SSI benefits may be used by family caregivers to pay for respite.\(^{21}\)

**Senior Companion Program:** The Senior Companion Program has two purposes: to engage persons 60 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.\(^{22}\)
Respite Funding for Military Families/Veterans

Veterans Millennium Health Care and Benefits Act: 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. The services can be contracted or provided directly by the staff of the Veterans Health Administration (VHA) or by another provider or payer.

VA Volunteer Support In-Home Respite Program: The Office of Care Management (OCM) and the Department of Veterans Affairs Volunteer Service formed a partnership to form the Caregiver Support Network to recruit and provide volunteers to provide in-home respite and other supports to family caregivers of veterans from all eras. Twelve pilot sites were established throughout the United States. The pilot programs are training small groups of volunteers and matching them with veterans age 18 and over living in their neighborhoods. The volunteer support caregiver provides respite to a Veteran’s family caregiver. The sites are in Augusta, GA; Baltimore, MD; Lexington, KY; Los Angeles and San Francisco, CA; Richmond, VA; Minneapolis, MN; Seattle, WA; St. Louis, MO; Syracuse, NY; Temple, TX; Tucson, AZ.23

Aid-and-Attendance and Housebound Benefit: The Department of Veterans Affairs pays a maximum of $1,949 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. Funds may be used in any way, including paying for respite care.24

Veteran-Directed Home and Community Based Services (VDHCBS) Program: The VD-HCBS Program offered through the Aging Network (e.g., State Unit on Aging, Area Agencies on Aging) provides veterans with a person-centered alternative to traditional home care services and programs. Veterans of any age at risk of placement in a nursing home are eligible. Participating US Department of Veterans Affairs (VA) Medical Centers (VAMCs) refer eligible veterans to the Aging Network to enroll in the VD-HCBS Program. VAMCs authorize a flexible spending budget based on the veteran’s assessed needs. The Aging Network works with the veteran to arrange and secure the needed goods and services within the budget and is also responsible for ensuring that the veteran’s needs are met so that he or she can safely remain independent in the community. Respite is among the home and community-based services supported by the funding.25, 26

Program of Comprehensive Assistance for Family Caregivers: This effort was enacted under the Caregivers and Veterans Omnibus Health Services Act of 2010. Primary family caregivers of veterans seriously injured in the line of duty on or after September 11, 2001, may be eligible to receive a monthly stipend; health care coverage; mental health services; travel, lodging and subsistence, expanded respite services, and education and training. The program took effect in May 2011.27 Some services, such as respite and family caregiver education are available to caregivers of eligible veterans from all eras.

Veterans Health Administration (VHA) Home and Community-Based Respite Services (HCBS-Respite): As a result of expanded eligibility categories in the Caregivers and Veterans Omnibus Health Services Act, the VHA is working on improving all respite options for family caregivers of veterans. HCBS-Respite will incorporate person-centered planning to meet the age specific health care needs of the Veteran, while providing relief to the caregiver. VHA will use multiple agencies to provide HCBS-Respite: National Family Caregiver Programs offered by Area Agencies on Aging and ADRCs; home care agencies; adult day care
services; and respite options as provided by state agencies with approval from the VA’s Office of Geriatrics and Extended Care. VHA will also be implementing a participant-directed model.28

TRICARE’s Extended Care Health Option (ECHO) Respite Care: 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. In addition to standard TRICARE benefits there is an additional benefit program for the dependents of active duty members who have a disability. TRICARE’s Extended Care Health Option (ECHO) has a respite care benefit, which provides short-term care for a patient in order to relieve those who have been caring for him/her at home, usually the family. A maximum of 16 hours of respite care per month may be provided for any month a family member is receiving ECHO benefits. However, unused hours may not be banked for future use. This benefit is not meant to be a relief for parents to be deployed, be employed, seek employment, or pursue education. ECHO respite care services are provided by TRICARE-authorized home health agencies. The National Defense Authorization Act of 2008 expanded eligibility to ensure that respite and other extended care benefits be available for members of the uniformed services who incur a serious injury or illness on active duty (Title XVI. Sec. 1633—Wounded Warrior Matters; PL 110-181).

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.29

- **Marine Corps EFMP Respite Care Program**: The Marine Corps EFMP Respite Care is a program that provides temporary rest periods for family members responsible for the regular care of persons with disabilities. The Marine Corps EFMP Respite Care program provides up to 40 hours of respite care monthly for EFMP enrolled families. Respite Care may be provided by the installation CDC, FCC Home, Visiting Nursing Service, Family Member, or Neighbor.
- **Army EFMP Respite Care Program**: Eligibility for the Army’s Respite Care Program is based on EFMP enrollment status, the exceptional family member’s medical or educational condition and deployment needs. Families can receive up to 40 hours of respite per month for each certified exceptional family member.
- **Similar programs exist for Marines, Navy and Coast Guard.**30

Additional Resources:


Endnotes


3 Ibid.


8 Ibid.


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