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## **Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite**

Lifespan Respite Programs are defined in recent 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 provide respite funding to states have grown somewhat, federal funding sources have become more challenging for states and local programs 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 of states and local programs about these federal programs and their potential for funding respite and crisis care services, competition for scarce resources, or limited knowledge about the benefits respite and crisis care programs can incur.

This issue brief provides basic information about each of the federal programs that provide funding, or could potentially provide respite funding, to states. Although respite and crisis care services are not specifically mandated by any of these federal statutes, respite and/or crisis care are among the services that are eligible for funding or support under all of these statutes. In most cases, the authority to decide whether or not 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 grant process. The list may not be all inclusive.

### ***Programs Administered by the Centers for Medicaid and Medicare Services***

**Medicaid Waiver Programs:** The Medicaid program permits States to offer respite to caregivers through the Home and Community-Based Waiver Program (section 1915(c) of the Social Security Act). A 50-state study on caregiving published by the Family Caregiver Alliance in November 2004 found that 44 out of 49 states with Medicaid waivers covered respite care for caregivers of frail elders or persons with disabilities. In the year studied, section 1915(c) waiver programs paid \$84.5 million for respite care. ***The Medicaid Aging and Disabled Waiver*** is the most common home and community based waiver for respite services for the elderly. The Aging and Disabled Waiver is available in all States but Arizona. Examples of other waivers are those for individuals with Autism, Developmental Disabilities, or Traumatic Brain Injury.

**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.

**Medicaid State Plan Option for Home and Community-Based Services:** Section 1915(i) of the Deficit Reduction Act (DRA) of 2005 enables States to provide home and community-based services as a State plan option. Under this option, States may provide some of the same services to caregivers that are available under 1915(c) waivers (see above).

**Medicare Demonstrations:** In 2006, CMS launched the Medical Adult Day Care Services Demonstration, a three-year Medicare demonstration that encourages Home Health Agencies (HHAs) to partner with Medical Adult Day Care Facilities (MADCFs) to provide medical adult day-care services to Medicare beneficiaries as a substitute for a portion of home health services otherwise provided in the home. The demonstration will provide caregivers with respite while their loved ones attend adult day care.

**Medicaid Demonstrations:** In the *Money Follows the Person (MFP) Demonstration*, CMS has awarded five-year grants to 30 States and the District of Columbia to transition eligible individuals from institutions into the community. The grants will pay for one year of community-based services for each person transitioned, which may include respite programs for caregivers. In the *Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration*, CMS has awarded five-year grants to 10 States to transition children from psychiatric residential treatment facilities into the community. States may also use the grant money from this demonstration to offer respite programs for caregivers.

**Cash and Counseling Program:** Participants receive a monthly allowance or budget based on what Medicaid would otherwise have paid to the regular service vendors. Participants may manage funds themselves or use an accounting service. They develop their own care plans and spend the allowance as they choose, as long as the services are related to the disability. Currently available in the following states: Arkansas, Florida, New Jersey, Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, West Virginia.

## **Children**

**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 demonstration projects that will prevent the abandonment of infants and young children, especially those impacted by substance abuse and HIV and who are at-risk of being or are currently abandoned. By providing respite care for families and caregivers, abandoned infants and children are able to reside with their natural families or in foster care.

**Children's Mental Health Services Demonstration Projects:** Only states 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. These services (which may include respite and/or crisis care) are to help keep children with their families and in their communities, while adequately addressing their needs.

**Family-to-Family Health Care Information and Education Centers:** CMS and the Health Resources and Services Administration (HRSA) have awarded 36 grants worth \$7 million since 2002 for States to establish Family-to-Family Health Care Information and Education Centers.

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 and could prove to be a useful Lifespan Respite partner.

**Promoting Safe and Stable Families:** 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. Funds can be used to pay respite and crisis care providers and to develop and maintain provider networks. 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. 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 Welfare Services:** These block grants support improvements to the state child welfare system. Among other things, the funds pay for child abuse prevention and treatment efforts, which may include respite and crisis care. Child welfare demonstration projects waive certain federal requirements and allow states to support preventive services, which may include respite and crisis care service delivery networks.

**Maternal and Child Health Services Block Grant:** This program provides grants to states which they may use to provide services for children with special health care needs. 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. Few states have taken advantage of the flexibility available under this block grant to provide or support respite.

**Adoption Assistance:** The Title IV-E Adoption Assistance program provides funds to States to assist in paying maintenance costs for adopted children (AFDC or SSI eligible) with special needs, e.g., children who are older or have disabilities. Funds are also used for the administrative costs of managing the program and training staff. The goal of the program is to facilitate placement of hard to place children in permanent adoptive homes and prevent long, inappropriate stays in foster care.

**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, the Temporary Child Care 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. States are directed to meet respite and crisis care needs to the extent practicable, but they have 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 possible for children who are disabled. IDEA consists of two parts: Part C, for infants and toddlers from birth to age three who have developmental delays or are at substantial risk of delays; and Part B, for children over three with disabilities. A separate Part B grant provides special education for preschoolers, ages three to five, with disabilities. Depending on the state, children may be eligible for Part B benefits until age 22. 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 care is provided on a sliding-fee scale according to a family's income. Part B funds related services, such as parent counseling and training, to help families assist their children in their education. These services could result in incidental respite for the parents, but respite is not funded as a discrete service under Part B.

**Family Support 360:** Family Support 360 is an initiative of the U.S. Department of Health and Human Services' 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 and works in partnership with the state's Developmental Disability Council, Protection and Advocacy System, and University Center on Developmental Disabilities, family members, policymakers, and others. Currently, there are 21 implementation grantees in 21 States and in U.S. Territories. Each state grantee is working with at least 50 targeted families a year in a variety of community settings to assist them in locating and navigating public human service agencies and private community organizations. Families participate in writing a family service plan (FSP), which describes the services they may receive, as well as the steps to be taken to secure the services. Through the FSP, families may be assisted with a broad range of needs, for example, accessing health care, childcare, early intervention, education, employment, marriage education, transportation, housing, respite care, and assistance in maintaining parental rights.

### ***Children and Adults***

**Community Mental Health Services Block Grant:** This is a formula grant which provides funding to states for the purpose of infrastructure building, service integration, training, support for mental health planning councils, and provision of direct services (which may include respite and crisis care). Children must have, or be at risk of, serious emotional disturbance in order to qualify for services. Mental health planning councils must include consumers, advocacy groups, and providers.

**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 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 Agencies 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:

- Information
- Assistance accessing support services
- Individual counseling, support groups, and caregiver training
- Respite care
- Limited supplemental services

Eligible individuals are family caregivers caring for anyone over the age of 60 and

- Family caregivers of a person with Alzheimer's disease or a related dementia regardless of the age of the person with dementia.
- Grandparents and other relative caregivers 55 years of age and older providing care to children (under age 18 years);
- Grandparent or relative caregivers, providing care for adult children with a disability, who are between 19 and 59 years of age, provided:
  - Caregivers are age 55 years and older;
  - Priority is given to caregivers providing care for an adult child with severe disabilities.

Services provided to these caregivers 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. Technical correction legislation has been proposed to allow parents age 55 of older who care for their own adult children with disabilities who are under age 60.

**Social Services Block Grant:** The program provides funds for social services to families with special needs. Among its goals are to prevent neglect, abuse or exploitation of children and adults, and prevent or reduce inappropriate institutional care. Respite and crisis care are accepted SSBG services. States receive the funds with few strings attached. The annual allotments are non-competitive, 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.

**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 or 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 care, but most families raising a child with a disability have too many other expenses to have money left over for purchase of respite care services.

### ***Adults/Aging***

**Alzheimer's Demonstration Program:** Although the funding for this program goes only to State government agencies on a competitive basis, half the funds must be spent on home health care, personal care, day care, companion services, short-term care in health facilities, and other respite

care for individuals with Alzheimer's disease and related dementia. The objectives are to create models of assistance for persons with Alzheimer's disease and their families and to improve the responsiveness of existing community-based systems to them.

**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 and should be explored by respite programs as resources for respite providers.

**Program of All-Inclusive Care for the Elderly (PACE):** PACE is a Federal-State program for the frail elderly that provides comprehensive services. It may be 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 program utilizes an interdisciplinary team that develops a plan of care with the participant that includes services in various settings including the home. A PACE program can incorporate caregiver services into the care plan and make respite services available to caregivers. As of 2007, there were 37 PACE programs that serve approximately 13,000 enrollees.

### ***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 payor.

**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. On September 1, 2005, TRICARE's Extended Care Health Option (ECHO) replaced TRICARE's Program for Persons with Disabilities (PFPWD). The ECHO program has a new respite care benefit. It 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 may be provided per month 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. **New provisions were included in the recently authorized "National Defense Authorization Act for Fiscal Year 2008" to ensure respite and other extended care benefits 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.

- **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. See revised Army Memorandum titled "[Guidelines for Use of FY 07 Global War on Terrorism \(GWOT\) Funds for Exceptional Family Member Program Respite Care](#)," dated 4 June 2007.
- **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.

***Information adapted from the following sources:***

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