Introduction

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

- could be the building blocks for 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 family caregivers or those who assist them in helping to identify sources of funding that could be used to pay for respite. Having numerous potential funding sources for respite certainly does not suggest that funding is even close to sufficient to meet the need, but it does suggest the need to coordinate such efforts to maximize their benefits.

This guide is divided into 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 the Aging. The last two sections describe respite funding sources for American Indians and Military Families and Veterans. Each program is summarized in a table in the Appendix.

Understanding Federal Funding

The more than 70 federal programs listed in this guide have wide-ranging purposes and uses, and certainly not every funding source will be useful or appropriate in every state or beneficial to every family caregiver in meeting their particular respite needs. Some federal funding sources will not be directly available to family caregivers or local programs because they are limited to certain grantees, such as state governmental agencies. Other funding sources place limitations on the populations that are eligible to receive the benefits. Eligibility may be based on restrictive criteria, such as household income, legal status, personal characteristics, and family circumstances.

Some of the federal programs discussed in this guide provide general support for home and community-based services, which indirectly could support respite capacity building or service delivery. For example, 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, however, also make it much more challenging to use flexible funding sources such as the Social Services, Maternal and Child Health Services, or Community Development Block Grants, which are already being stretched very thin by increasing demands on these sources to finance health and social services for people in need. Medicaid expansion allowable under the Affordable Care Act has been advancing only slowly for political reasons, but also due to a slow economic recovery. In 2014, all states reported using mechanisms to control costs in home and community-based service (HCBS) waivers such as restrictive financial and functional eligibility standards, enrollment limits, or waiting lists.\(^1\) 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 in fact to maximize use of existing resources and be positioned to leverage new public or private funding sources.

The following is a brief guide to understanding how different funding streams operate so users can select the appropriate strategy when trying to access various funding sources:\(^2\)

- **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.

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• 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.

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 your family needs to do to access these funds more easily. Some funds are for use solely by government agencies or local public or private entities, or solely for families or family caregivers; some funds are available to both. Funding will usually be discussed in these subsections under each federal program: 1) Activities supported by the funding; 2) Issues for consumers, providers, and advocates; or 3) Eligible entity.

• If your state is not currently using this funding source for respite, work with others in your state, including your state Lifespan Respite Care Program and partners and the State Respite Coalition, to educate state policy-makers and decision-makers about the need for respite, the cost-benefits, and about the potential of using funds from this source.

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