GUIDE

Self-Directed Respite Voucher Guide

Applied Self-Direction

ARCH National Respite Network And Resource Center

Developed by Applied Self-Direction in Partnership with the ARCH National Respite Network and Resource Center

Applied Self-Direction staff bring decades of experience as consultants, federal and state administrators, people with lived experience self-directing, family members of people with disabilities, and Medicaid providers. Together, we work with self-direction programs to maximize the level of choice and control that participants can exercise over their services and supports. We help make self-direction programs more flexible, accessible, compliant, and person-centered.

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 in the United States; 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 includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service 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 in the U.S. Department of Health and Human Services.

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Introduction

Self-direction is a model of long-term services and supports (LTSS) that helps people of all ages, with all types of disabilities, maintain their independence at home. The use of self-directed services, which provides individuals and their families the option to direct and manage their own services and supports, has grown steadily across the United States for the past several decades. Self-direction provides a greater degree of control and choice than is found in traditional models of care.

An important, but often overlooked, aspect of LTSS for people with disabilities and older adults is ensuring that family caregivers receive regular, short-term breaks from the difficult job of continuously caring for their loved one. Respite is a means for caregivers to take breaks from the daily care routine and is invaluable to the health and wellbeing of the family caregiver. Traditional programs that offer respite do so via agency staff that are trained as respite providers while self-directed respite allows the family caregiver to hire a respite worker of their choosing, including other family members, friends, or neighbors who already know the person receiving care. In self-directed respite, the family caregiver can hire, train, and supervise the respite provider.

This is often accomplished through a voucher system[1], which empowers the family caregiver by giving them control and recognizing their decision-making capacity. Payments can also be made directly to the respite provider or the primary support. Overall, self-direction in respite provides the care recipient and their primary family caregiver control of who provides services and how that is achieved. Choice and control help to ensure that services are person and family-centered and result in satisfaction with services received.

The following guidebook is a resource for programs that provide respite and are interested in developing and implementing self-directed respite. This guidebook was originally developed collaboratively in 2011 by the ARCH National Respite Network and Resource Center and the National Resource Center for Participant-Directed Services. In 2022, ARCH partnered with Applied Self-Direction (the successor organization to the National Resource Center for Participant-Directed Services) to update this guidebook to reflect the latest changes and lessons learned over the past decade.

1 Depending on the state, terms such as stipend, grant, or reimbursement may be used instead of the term 'voucher' to describe the mode of payment in respite programs.

How to Use the Guidebook

This guidebook is organized into sections following the different elements of self-direction programs. At the end of each section, we have included relevant excerpts from three case studies that Applied Self-Direction conducted during the summer of 2022. Each section also includes additional resources on the topic. The full case studies, including lessons learned, can be found in Appendix I. For more information, we have also included links to useful self-direction resources. The guidebook includes the following:

- **Overview of Self-Direction**
- **Overview of Respite**
- **Stakeholder Involvement in the Program –** How to involve all stakeholders in all aspects of the self-directed respite program.
- **Program Structure –** Includes various administrative roles, financial considerations, determining how the allocation can be used, setting time limits and rate setting.
- **Quality and Risk Management –** Information on the elements of a good quality management system.
- **Appendix I: Case Studies and Additional State Examples –** Complete case studies conducted of the Oklahoma Lifespan Respite Program, the Alabama Lifespan Respite Resource Network, and Lifespan Respite Washington. Each of these programs have well-established self-directed services and share successes, challenges, and lessons learned. Additional examples from self-directed respite programs across the country are also provided.
- **Appendix II: Building Support, Dealing with Opposition, and Dissemination of Information –** Information on how to build support and combat opposition to self-directed respite services.
- **Appendix III: Potential for Other Funding Sources –** Additional funding sources in which to fund your self-directed respite program.

Definition of Terms

With the change to self-direction, many of the terms used in traditional programs may also shift to reflect different roles. We have defined several key terms here to promote consistency and clarity throughout the guidebook.

Respite – Planned or emergency care provided to a child or adult with a special need[2] in order to provide temporary relief to the family caregiver of that child or adult (Lifespan Respite Care Act, 2006).

Family Caregiver – Sometimes referred to as a primary support, unpaid caregiver, or paid caregiver.[3] This may be a family member, foster parent, or another adult who provides in-home monitoring, management, supervision, or treatment of a child or adult with a disability (Lifespan Respite Care Act, 2006). States are increasingly allowing family caregivers to be paid for providing care, which may actually increase respite needs. In terms of respite, the "participant" is considered to be the family caregiver. Although, as a best practice, any decisions made about the respite provider and services should be made by the caregiver and the care recipient together if possible.

Respite Provider – An individual or agency selected by a family or caregiver to provide respite to an individual with disabilities (Baker and Edgar, 2004).

Care Recipient – Sometimes referred to as a person with a disability or client. This is the person to whom the provider delivers services. The person can be any age with any type(s) of disability, chronic illness, or functional limitation. The Lifespan Respite Care Program Act includes the following terminology and definitions: An adult with a special need is defined broadly as a person 18 years of age or older who requires care or supervision to meet the person's basic needs, to prevent physical self-injury or injury to others, or to avoid placement in an institutional facility. A child with a special need is a person less than 18 years of age who requires care or supervision beyond that required of children generally to meet the child's basic needs or prevent physical self-injury or injury to others (Lifespan Respite Care Act, 2006).

Self-Direction – Self-directed services are home and community-based services that help people of all ages across all types of disabilities maintain their independence and determine for themselves what mix of personal assistance supports and services work best for them. Self-direction is sometimes referred to as consumer direction or participant direction.

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2 Please note that many advocates oppose the use of the terms 'adult with a special need' or 'child with a special need' and prefer the terms 'disabled person' or 'person with a disability.' While the Lifespan Respite Care Act uses the 'special needs' terminology, this guidebook refrains from using these terms unless directly quoting the legislation. For more background on terminology, review the article *Disability advocates, experts implore you to stop saying 'special needs'*

3 According to the Lifespan Respite Care Act of 2006, "Also, ''unpaid family caregivers'' means family caregivers who do not receive funds to provide care as their primary means of income (i.e., nonprofessional family caregivers). The language is not meant to exclude family caregivers who receive minimal payments from State or Federal sources from receiving lifespan respite information or services. Such sources include funds received under Home and Community-Based Services (HCBS) Waiver developmental disability programs, Independence Plus and 1115 Waivers (Cash and Counseling programs included), and other State or Federal family support programs, to help assist with the person in their care, but this source of income is not what they rely on as primary income."

Overview of Self-Direction

Self-direction is a model of LTSS that helps people with disabilities maintain their independence at home. When a person self-directs, they decide how, when, and from whom their services and supports will be delivered. In typical self-direction programs, the individual receiving the personal care services (or their appointed representative) is the primary decision maker. The Lifespan Respite program differs from the typical self-direction approach in that the family caregiver is defined as the "participant" (the person receiving respite services) and is therefore directing the respite services. As a best practice, any decision about which respite provider is selected and how they deliver services should be made between the family caregiver and the care recipient if possible. In the case of disabled children, the decision might involve the whole family, or for persons with advanced dementia or otherwise not able to provide input, the decision may lie with the family caregiver.

In the traditional service delivery model, decision making, and managerial authority is vested in professionals who may be either program employees or service providers. Self-direction transfers much of this authority to the care recipient and their representative (if applicable).

There are many benefits of self-direction and research has documented the success of the model. Some of the greatest benefits include:

- Self-direction allows people to hire who they want to be providers, expanding the pool of available workers (Feinberg, Wolkwitz, and Goldstein, 2006). Many of the workers in self-direction are people who would not have typically entered this field. These workers are able to provide customized and, often, culturally sensitive services to the individual.
- The model can be cost effective. In self-directed respite, the family caregiver takes on more responsibilities, including the role of employer. This can lead to reduced administrative costs (Feinberg, Wolkwitz, and Goldstein, 2006). In addition, the support of the program may lead to reduced institutional placements (Yuan et al., 2021). These measures may have positive results on costs (Brown, et al., 2007).
- Self-direction has a positive impact on satisfaction and involvement in the community (Brown, et al., 2007). Family caregivers are more likely to choose self-direction because they "retain control, choice, and flexibility. They also report greater well-being and higher satisfaction rates than do family caregivers receiving agency-based or 'traditional' services" (Brown, et al., 2007). If caregivers are more likely to utilize self-directed services, it may have a greater impact on relieving caregiver burnout.
- The benefits of self-direction for people who live in rural settings and/or living with high care needs have been found to be especially pronounced (Yuan et al., 2021).

Choice is the hallmark of self-direction and includes the choice to direct to the extent desired, or not at all. Program designs should permit individuals to elect the traditional service model if self-direction does not work for them or to direct some of their services while receiving others from agency providers.

Overview of Respite

In 2020, it was estimated that more than one in five Americans serve as a family caregiver, with 53 million people providing care. These caregivers provided an average of 24 hours of care per week (National Alliance for Caregiving and AARP, 2020). Respite is defined as planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult (Lifespan Respite Care Act, 2006). While family members mostly choose to and enjoy caring for their loved ones, the continual strain of providing ongoing care can often cause physical, emotional, and financial hardship. Respite can help tremendously in these situations. It has shown to be effective in reducing or delaying more costly out-of-home placements, improving caregiver's health and well-being, preventing abuse or neglect, and helping to sustain marriages (ARCH National Respite Network and Resource Center, 2020; Avison, et al., 2018).

Respite may be provided in a variety of settings, including the home, adult day services centers, hospitals, community-based programs, or residential care facilities. Additionally, types of respite vary, including skilled or unskilled care, and the use of formal providers who are hired and trained by an agency, or informal providers who are available through parent or caregiver cooperatives, faith-communities, volunteer programs, or family and friends. There are, however, many barriers to respite, including confusing and restrictive eligibility criteria, affordability issues, limited providers, reluctance to identify as a caregiver or ask for help, and a bureaucratic maze of funding streams and services (Kagan, n.d.).

In order to minimize some of these barriers, a majority of Lifespan Respite Care grantees have implemented self-directed respite services, primarily using a voucher system. (In addition to the three case studies presented, a sample of publicly and privately administered self-directed respite programs is included in Appendix I on page 53). While traditional programs that offer respite do so via agency staff that are trained as respite providers, self-directed respite allows greater choice, including the ability to hire, train, pay, and supervise the respite provider. Vouchers offer families greater flexibility to use respite when they really need it and allow them to hire friends and family members who are familiar with the needs of the care recipient.

Nationally, Medicaid supplies the majority of public funding to support self-direction through State Plan services and Medicaid waiver services, although the Veterans Health Administration also funds self-directed care to disabled Veterans. State programs may develop specific respite services under various waiver authorities using two different service delivery models: traditional agency respite services and self-directed respite (see Appendix III on page 59 for more detail). Many states require that providers meet basic minimum qualifications, for example requiring a criminal background check or training certification. These requirements may apply to self-directed providers at the discretion of the state. Other models of self-direction with varying degrees of participant/caregiver autonomy include individual budgets and agency-with-choice models (Edwards-Orr and Sciegaj, 2015). This guidebook will focus on voucher respite.

Self-directed respite empowers caregivers and families, giving them greater control over their respite experience.

Self-Directed Respite Provider Eligibility Examples

Alabama Lifespan Respite Resource Network (Alabama Respite) – Caregivers are able to direct their respite services with the use of vouchers. Caregivers are able to select, hire, set the pay rate (varies per funding stream) and train the respite provider of their choice, whether that is a formal or informal provider, or a skilled or unskilled respite provider. The only two requirements include: 1) the provider must be at least 18 years old; and 2) the respite provider cannot live in the same household as the person with a special need.

Oklahoma Lifespan Respite Program – Caregivers who receive a voucher can hire anyone they choose, with two limitations: 1) the provider must be 18 years old or older; and 2) have a social security number and social security card. This can include informal providers, such as family, friends and co-workers, as well as formal providers, such as childcare centers, adult day service centers, nursing facilities, or hospitals. Caregivers are responsible for interviewing and selecting their respite provider, setting an hourly rate, training the provider, ensuring proper payment for services, keeping track of the number of hours or days of respite used, and tracking the total amount claimed against the voucher. Caregivers can use the voucher for respite either in the home or in an adult day service center, childcare center, or recreational program setting.

Lifespan Respite Washington (LRW) – Caregivers may choose their respite provider from a database of registered provider agencies via the online registry. The caregiver support team offers one-on-one support by phone, email, or text to assist family caregivers with their selection, checking in with every single family with an active voucher. Caregivers may request a particular program or agency not included in the registry, in which case LRW PAVE staff will contact the preferred agency and provide customer service so they will become a registered respite provider. Most do opt to join, and the online registry includes many caregiver requested providers.

Additional Resources on Self-Direction Overview

- Self-Directed Services, Medicaid.gov
- "What is Self-Direction?" Video
- Self-Direction in Action: Participant Stories
- 2019 National Inventory of Self-Direction Programs
- Taking It to the Next Level: Using Innovative Strategies to Expand Options for Self-Direction
- Self-Direction Toolkit
- Financial Assistance for Family Caregivers

Stakeholder Involvement in the Program

Research on programs' efforts to change their LTSS systems – including those to initiate or expand self-direction programs – has found that their success depends to a significant extent on early and sustained stakeholder involvement and buy-in. People with disabilities, people with chronic conditions, and older adults, along with their family caregivers, are the essential stakeholders. In order to ensure their buy-in, they need to be involved in program development, design, implementation, and evaluation. Additional stakeholders include respite coalitions, Aging and Disability Resource Centers (ADRCs)/No Wrong Door systems and state agencies.

There are many areas to develop and increase involvement:

- **Design, Implementation, Evaluation, and Continuous Quality Improvement –** There are many phases during which it is important to involve and seek participants' input and feedback: the program design and pre-testing phase; program implementation; program evaluation; and continuous quality improvement. Programs should make it a priority from the outset to identify strategies for ensuring involvement in each phase and sustaining it for the long term. Experience of the family caregiver and the care recipient provides essential information about what does and does not work, what types of outreach and enrollment strategies will be most effective, and how best to meet the needs of all.
- **Formal Advisory Groups –** The most common method programs use to involve stakeholders in program design and implementation is through membership in an advisory group or on a task force. Programs may expand the scope of work of an existing group (for example, an advisory group from a state agency) or create a new group.
- **Focus Groups, Surveys, and Telephone Response Lines –** In addition to informal consultation, these methods provide an opportunity for programs to obtain input from a greater number of stakeholders than those who can serve on advisory groups. These additional methods of involving stakeholders can complement, but should not replace, the input provided by a formal advisory group. An advantage of focus groups is that they can be conducted on a relatively small budget if programs partner with Centers for Independent Living (CILs), Area Agencies on Aging (AAA), and state advocacy networks to gain access to stakeholders.
- **Peer Support and Mentoring –** Support groups or family caregiver coalitions that bring together individuals with similar experiences provide a forum in which people can share the problems that they are confronting and identify potential solutions to those problems. Local chapters of the Alzheimer's Association, the National Multiple Sclerosis Society, Family

Voices and other organizations concerned with chronic conditions host support groups for or connect individuals with disabilities or their family caregivers.

- **Involving Additional Agencies –** Involving respite coalitions, ADRCs and state agencies throughout program development and implementation is an important step in collecting stakeholder feedback and support. For Lifespan Respite grantees, a mandate requires the involvement of ADRCs and state respite coalitions. These groups are an important start for the process of collaboration, but it should extend well beyond that mandated minimum. For more information, see What's the Key Ingredient for a Successful, Sustainable Coalition from the ARCH National Respite Network.

Stakeholder Involvement Case Study Examples

Alabama Lifespan Respite Resource Network (Alabama Respite) – Participants have been involved in Alabama Respite since its inception. Participants were actively involved in the initial taskforce to gather respite resources and increase availability and access across the state. Currently, participants contribute to the Alabama Lifespan Respite Coalition and the quarterly Caregiver and Agency Resource Exchange (CARE), a community of practice forum for collaborative partners to share resource information with caregivers and, in turn, for caregivers to help agencies identify and potentially reduce gaps in service.

Essentially, participants are involved in planning and development of respite programs throughout the state.

Oklahoma Lifespan Respite Program – The Oklahoma Caregiver Coalition (OCC) is a partnership of over 100 public and private agencies who have voluntarily come together to develop and sustain various areas of support for primary caregivers including respite services. With Lifespan Respite Grant funding from the Administration for Community Living (ACL), the OCC was formed at the end of 2016 by Aging Services within the Oklahoma Department of Human Services. The mission of the OCC is to improve the supports and experiences over the lifespan of family caregivers through education, advocacy, and access to resources. Their Executive Team includes Sooner SUCCESS, AARP Oklahoma, Healthy Living OKC, WovenLife, and Oklahoma Human Services (OKDHS). The OCC meets on a quarterly basis and is composed of nine subcommittees, including a respite subcommittee chaired by Nadine Walter, the Lifespan Respite Grant Manager. The OCC hosts OKCares.org to bridge the gap between state services and local community resources and features a 'Respite Locator' making it easy for caregivers to identify the best respite program to meet their needs.

Family caregivers are regularly engaged for feedback regarding the respite program primarily via regular surveys.

Lifespan Respite Washington (LRW) – The LRW Coalition includes family caregivers, public and private agency staff, and advocates from across the state and meets at least twice a year. This group serves as an important avenue for stakeholder engagement which aims to support individuals with disabilities from a cross-section of ages, cultural or ethnic backgrounds, and needs or disabilities of the individuals needing care. Occasionally the group hosts training

sessions on respite-related topics. They also meet to share information, updates, best practices, and to learn from one another.

Beyond the LRW Coalition, the team conducts regular surveys with both caregivers and respite providers. The first year of the program focused on gathering feedback on specific and overall respite service systems with five surveys targeted to: survivors of traumatic brain injury (TBI) and their caregivers, American Indian/Alaska Native caregivers, caregivers of individuals with Developmental Disabilities, and previous Lifespan Respite voucher recipients along with respite providers.

Caregivers are also empowered to request or recommend new providers to be included in the LRW program.

Additional Resources on Stakeholder Involvement

- The Alliance for Citizen-Directed Support
- What's the Key Ingredient for a Successful, Sustainable Coalition
- Webinar: Sustaining Lifespan Respite and Strengthening Stakeholder Engagement
- Tools for Collaboration: Building and Sustaining Partnerships for Lifespan Respite Care Programs
- Toolkit for Stakeholder Asset Mapping, Collective Insight and NCAPPS
- Engaging People Who Receive Services: A Best Practice Guide, NCAPPS
- Authentic Stakeholder Engagement: A Discussion with Colorado's Participant Direction Programs Policy Collaborative
- Teaching Public Speaking Skills and Creating Opportunities for Self-Advocates
- The Alliance for Citizen-Directed Support: Growing Self-Direction from the Ground Up

Program Structure

There are structural systems that should be in place in order to create a functional self-directed program. Clear roles and responsibilities for administrative and financial functions are the essential components of structure. Each is described in more detail in this section.

Administrative Roles

Administration of the program has been addressed in different ways. Some programs have dedicated program staff, while others rely on volunteers or a combination of both. Essential roles and responsibilities, independent of the type of staff, include performing outreach, tracking enrollment, and providing information and assistance.

Administrative Roles Case Study Examples

Alabama Lifespan Respite Resource Network – Alabama Respite started with a full-time program manager and a part-time director. Since that time, it has grown to a staff of five, including: 1) the Director, who oversees administration of program staff and activities, program development, grant and contract management, respite provider training, technical assistance to community-based respite services, legislative communication, and Coalition activities; 2) the Project Coordinator, who creates, schedules, and conducts respite education trainings, lunch and learns, respite clinics, caregiver support groups, and public awareness opportunities for caregivers statewide, as well as coordinates a caregiver mental health counseling program; 3) a training specialist, who conducts respite education and public awareness opportunities specifically in the southernmost counties of Alabama; 4) the Caregiver Resource Coordinator, who coordinates the Area Agency on Aging (AAA) voucher respite programs; and 5) the Respite Resource Assistant, who coordinates the Department of Mental Health (DMH), Universal (for caregivers across the lifespan who do not qualify for other voucher respite programs funded through the Lifespan Respite Care Program), and Emergency voucher respite programs, and education stipends. Alabama Respite charges an administrative fee between 10% -12.5%, depending on the funding source. This helps to cover the costs of running the voucher program.

Funding sources for Alabama Respite include: the Administration on Community Living (ACL)/ Administration on Aging Federal Lifespan Respite Grants (two grants running concurrently in 2022), Alabama Department of Rehabilitation Services; Alabama Department of Mental Health (DMH); all 13 Alabama Area Agencies on Aging (AAAs); and various grant opportunities.

Funding specifically for the voucher programs comes from DMH, Children's Trust Fund (CTF), AAAs, and ACL. The budget for the voucher program in FY22 was $1,273,675.

Oklahoma's Lifespan Respite Program – Families interested in the Lifespan Respite Grant Voucher Program are directed to contact Sooner SUCCESS, a nonprofit agency that contracts with OKDHS to coordinate the program. Sooner SUCCESS is the entry point for applications and information regarding respite services. Once approved, vouchers are sent to families, which they then use to hire a respite care provider of their choice. Another partner is WovenLife, which acts as the fiscal intermediary.

Lifespan Respite Washington – The Respite and Crisis Care Coalition of Washington launched as a statewide coalition in 2002. Later renamed Lifespan Respite Washington (LRW), the group received their first federal Lifespan Respite Grant in 2010 and has continued since then to receive funding through the U.S. Administration on Aging, Administration for Community Living. LRW is administered by their host agency, PAVE (Partnerships for Action, Voices for Empowerment), in partnership with the state's Aging and Long-Term Support Administration within the Department of Social and Health Services. The PAVE team administers the Lifespan Respite Voucher program for unpaid and under-served family caregivers of all ages across Washington State. There is a total of six LRW staff, two with the Aging and Long-Term Support Administration and four with PAVE. The PAVE staff provide caregiver support, respite provider customer service, website maintenance, both content and technology. They also research, create information, and post new caregiver resources; conduct social media outreach; facilitate Coalition meetings; execute all data and evaluations; coordinate with finance team staff internally and with the Aging and Long-Term Support Administration; offer trainings and presentations; and coordinate with the WA TBI Council who hosts and provides in-kind support of the statewide Caregiver Support Group. The Caregiver Support Group is a free, online/virtual support group with a trained facilitator who utilizes the topics and resources produced by the PAVE LRW staff.

Awarded vouchers are held in the caregiver's name with the LRW program accounts and paid out directly to the caregiver's selected provider upon delivery of services. The respite provider bills LRW directly, freeing up the caregiver from having to file for reimbursements.

Marketing and Outreach

Outreach is needed to ensure that all potentially eligible individuals know about the new self-directed program and have the information that they need to decide if it is right for them. Individuals may learn about the new program through formal channels designed by the program, but they may also hear about it from agency case managers, current workers, consumer advocacy organizations, friends and family, and other sources.

In addition to planning and carrying out outreach, program administrators must be prepared to both counter misinformation from other sources and to take advantage of opportunities for "free" marketing. Forming and maintaining relationships with partner organizations, advocacy organizations and local news outlets can be helpful.

Programs must first decide how much information they will provide directly and how much will be provided by other sources they enlist. It is essential that programs identify sources that can provide accurate information about the new self-direction program. Most programs have information about their new programs on websites, from which individuals can obtain accurate information. However, many potential participants may not have easy access to a computer or may not know how to find information on the Internet.

To determine which sources to enlist, programs must first determine which sources potential applicants trust and tend to rely upon most when seeking information about LTSS.

To ensure that all potential participants have information about the program, several programs have translated outreach and enrollment materials into commonly spoken foreign languages or engaged in other culturally relevant outreach strategies, such as piloting programs with tribal communities in Washington state. Other programs have made videos about the program and distributed them.

It is important to recognize that much of what people hear about a new program will not come directly, or even indirectly, from the program. Some of what they hear will be favorable and some unfavorable; some will be accurate, and some will be inaccurate. As news of the new program spreads and enrollment increases, programs may be able to reduce outreach activities. However, programs need to recognize that due to participant and staff turnover, some level of outreach needs to be ongoing. Experience with outreach and the enrollment process can provide valuable information for fine-tuning activities in these areas to be both effective and efficient. Collaboration with the state or local Aging and Disability Resource Centers, which are charged with outreach and enrollment experience, could prove to be beneficial.

Find more information on building support, dealing with opposition, and dissemination of information in Appendix II on page 56.

Marketing and Outreach Case Study Examples

Alabama Lifespan Respite Resource Network – Caregivers learn about the voucher programs through a variety of sources, including: 1) presentations, including lunch and learns, in the community to service coordinators, caregivers, agency partners, support groups, churches, and other stakeholders; 2) media outreach via social media, internet, television, radio, podcasts, community news magazines, and agency newsletters; 3) membership in the Alabama Respite Coalition; 4) state agency referrals; and 5) word-of-mouth in the community. The caregiver can enroll in the program by calling or emailing Alabama Respite for an enrollment packet or downloading it from the website. Lifespan Respite is included in the Universal Intake Form screening door used by Aging and Disability Resource Center (ADRC) staff, and by the 13 state Areas Agencies on Aging (AAAs), creating seamless access to respite services for clients. After completing an application form, including demographic data verification, and proof of the care recipient's diagnosis is attached, the packet is returned to Alabama Respite. The Alabama Respite team determines eligibility and approves the application, working with the family as needed to assist in the process. Demographic data requested, and tracked, includes gender, age, race, ethnicity, military status, household income, county of residence, caregiver's relationship to the care recipient, how many hours

of care per week the caregiver provides, caregiver stress level, enrollment with other respite services, and information regarding the care recipient's diagnosis. Caregivers may also indicate on the application if they are interested in receiving information about Alabama's Respite caregiver mental health counseling program. Alabama Respite goes to great lengths to ensure that families in need of respite know about the programs and are able to access vouchers from this service.

Oklahoma Lifespan Respite Program – The Oklahoma Caregiver Coalition (OCC) plays a critical role in outreach with over 100 partners who each play their part in spreading the word and sharing about respite options with their clients. Other outreach includes OKcares.org, email campaigns, radio advertisements, and social media. Across social media platforms, Twitter and LinkedIn have been especially helpful. LinkedIn has particularly helped to attract potential respite providers.

To enroll in the program, families and caregivers simply have to contact Sooner SUCCESS to determine if they qualify, and subsequently receive an application. The basic application is designed to meet federal partner reporting requirements. Sooner SUCCESS processes the applications and onboards caregivers.

Lifespan Respite Washington – The vast majority of family caregivers (70%) find LRW through online search or a direct link from another website. Other caregivers find LRW through referral from social service or health care programs (15%) or social media (10%). LRW maintains a web page with detailed information about the program benefits and limitations, eligibility requirements, and a link to the online application.

LRW has developed online respite tools and other training materials/modules which are placed on key partners' websites to raise awareness about LRW. Each of the online modules was designed by Washington Aging and Long-Term Support Administration Instructional Developers to provide information on what respite is, ways it could be used, how both the caregiver and recipient can plan to get the most out of the respite opportunity, along with what services are available.

Factors that Influence the Participation in a Self-Direction Respite Program

Several factors influence whether a family caregiver or care recipient is interested in utilizing a self-directed respite program.

Perhaps the most important factor that will affect the interest of people currently receiving services is their satisfaction with their available service options. Individuals in the traditional system who are satisfied with their current arrangements will likely have little incentive to enroll in a new program that entails the assumption of additional responsibilities. Conversely, those who are dissatisfied with current service options will likely be very interested in enrolling.

For all program participants, the manner in which the self-directed respite option is first presented to an eligible individual can make a significant impact. If the increased responsibilities of self-direction are emphasized, then it may be perceived as overly burdensome. However, participants

and family caregivers may be more attracted to the program when the high degree of choice and control afforded by these programs are emphasized. Program administrators may benefit from referencing the LifeCourse Tools for Respite for in-depth guidance on how to ensure respite services are highly person- and family-centered.

Individuals' willingness to enroll in self-direction programs will be greatly influenced by how difficult they think it will be to recruit respite providers that they will want to hire. This in turn will be highly influenced by whether or not they have family members, friends, or neighbors whom they know and trust and think they might employ.

Administrators can also provide information on resources available, like worker registries, to help increase participation in the program. As of 2022, the ARCH National Respite Network and Resource Center partnered with the National Academy for State Health Policy and the Respite Care Association of Wisconsin to field test a new competency-based training program for respite providers in 11 states. The purpose of this new initiative is to increase the supply of trained respite providers which will in turn increase caregiver confidence in self-directed respite programs by having a larger array of potential trained providers available to hire. States will be listing the trained providers on respite worker registries to help caregivers find them.

Determining Eligibility

Eligibility for respite services is dependent on the funding stream. However, there are consistently two essential components of eligibility across funding sources:

1. Assessment of need
2. Financial and resource checks. Sometimes applied to the family, caregiver, or person with a disability or older adult.

See 'How Can the Allocation Be Used' section for additional information.

Eligibility Case Study Examples

Alabama Lifespan Respite Resource Network (Alabama Respite) – Eligibility for the voucher program is dependent on specific funding streams, with criteria set by the funder. Alabama Respite relies on multiple funding streams for its self-directed voucher program. All funders require proof of age and disability or direct referral from the funding source to receive a voucher. DMH funding is for children and adults who have a diagnosis that includes an intellectual disability, while CTF funding is only for caregivers of children with any disability under the age of nineteen. AAAs have income guidelines and age requirements. The ACL Lifespan Respite grant funds respite for caregivers who have no access to other funds for respite.

Oklahoma's Lifespan Respite Program – Eligibility is largely determined by the care recipient. The care recipient must be 59 or younger and need assistance with activities of daily living in order to stay at home. Qualifying disabilities include:

- Cognitive impairment/dementia
- Intellectual disabilities

- Developmental disabilities
- Mental health/behavioral issues
- Physical disabilities
- Traumatic brain injury
- Other special health care needs

Additionally, the care recipient must not qualify for respite services or payment through any other program including but not limited to foster care, Family Support Assistance Payment, Older Americans Act (OAA) Title III-E or Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS) Systems of Care funding. The caregiver must also meet certain requirements, including be age 18 or older and serve as a full-time, unpaid caregiver or be a grandparent or other relative age 54 or younger raising a child, and not receive respite services from any of the aforementioned programs or otherwise.

Lifespan Respite Washington – Eligible applicants must reside in WA State and provide 40 or more hours per week of care or support to someone with a special need or condition (the person can be any age), and the 40 or more hours must include supervision of the person receiving care. Care recipients must have a special need or condition (the person can be any age), and the 40 or more hours per week must include supervision of the person receiving care. Caregivers must be unable to afford respite care on their own and not be enrolled in any program that provides respite services, unless on a waitlist and not scheduled to receive services within 30 days of application.

Tracking Enrollment

Program administrators should consider their information needs for managing outreach and enrollment and improving these processes. Programs have tracked enrollment by month and compared the numbers with outreach activities performed during the same time period in order to determine which outreach activities were more effective. A number of programs have kept track of reasons for not enrolling after initial interest was expressed and used this data for continuous quality improvement.

Because a series of detailed steps are sometimes needed to enroll in public programs, it is critical to track applicants' experiences. Program managers are often surprised to learn how long some of their processes take or how cumbersome the process is to complete.

To identify important types of tracking information, it is useful to begin by documenting the program's processes for outreach, enrollment, service plan development, and ongoing support. For example, what steps do applicants have to take to obtain information, to find out if they are eligible, to enroll, find a provider, and to receive services and supports? Once a program has documented these processes, it is then possible to make decisions about which aspects should be tracked. Information from tracking systems can inform continuous quality improvement.

Offering Information and Assistance

Providing information and assistance to individuals in self-directed programs can be a key administrative service. The goal is to offer flexible and personalized support to ensure that self-direction works for those who choose it.

This role consists of two broad activities – providing information about self-direction and providing assistance and training as needed with self-directed tasks. These activities are accomplished within a person-centered framework.

Administrators can provide individuals with detailed information to enable them to make informed decisions about whether self-direction is right for them, and if it is, about how to obtain and manage their services.

Administrators can assist individuals with a wide range of self-directed activities. The extent and type of assistance provided varies. Specific types of assistance can include:

- defining needs, preferences, and goals
- developing a backup plan if a scheduled worker fails to show
- developing a backup plan for emergency situations
- identifying and obtaining services, supports, and resources
- recruiting, hiring, and managing workers
- navigating employer responsibilities and related tax requirements

Please note that information and assistance will likely include providing guidance on provider qualifications and training approaches. Families who are self-directing respite will benefit from this type of support, but ultimately should be empowered to make key decisions on these issues independently after soliciting advice. Individual choice and control is a hallmark of self-directed respite.

Offering Information and Assistance Case Study Examples

Alabama Lifespan Respite Resource Network – The provision of respite services has been limited in Alabama; however, the awareness and need for respite for family caregivers have increased through the efforts and support provided by Alabama Respite and collaborative partners. Alabama Respite supports caregivers by providing up to eight caregiver education opportunities, both onsite in community settings and online, each month. Approximately 70 trainings are available, and topics include: caregiver stress, grief, emotional and mental health; diagnosis-specific caregiving; building caregiving support systems; resources; disaster preparedness; working while caregiving; and writing a care plan. Virtual reality empathy training is also available to caregivers, care providers, first responders, and universities, and experiences include Parkinson's/Dementia, Alzheimer's Disease, Vision and Hearing Loss, End of Life Conversations, Elder Safety and Well-Being, Trans Health and LGBT Aging, and Social Isolation. Respite clinics are offered quarterly in collaboration with statewide agency partners, including the Alabama Department of Rehabilitation Services/Children's Rehabilitation Services and Aging and Disability Resource Centers (ADRCs) located in all 13 AAA regional

offices, to teach caregivers about: 1) the need to take respite; 2) where respite is available in the state; and 3) how to access it. Alabama Respite distributes a monthly newsletter to inform caregivers of upcoming events and maintains an online calendar of caregiver education opportunities hosted by both Alabama Respite and collaborative partners statewide.

Once caregivers are connected with respite vouchers, Alabama Respite provides access to a twenty-page manual with detailed information on hiring a respite provider, which is available on the website for download. Included in this manual is information on relationship roles, recordkeeping, telephone screening, interview strategies, background checks, locating respite providers, creating a good work environment, training a respite provider and terminating an employee. Samples of a job description, employment application, recordkeeping sheet, agreement contract and advertisement for a respite provider are provided in the manual. Caregivers may also apply to Alabama Respite for a reimbursement stipend to assist in conducting a criminal background check of a respite provider if they so choose.

Oklahoma Lifespan Respite Program – Sooner SUCCESS has been a strong partner to the Oklahoma Caregiver Coalition (OCC) and serves as the primary resource for information and assistance for families utilizing Lifespan Respite. All staff involved also provide essential encouragement to family caregivers, including the critical reminder not to feel guilty for taking respite time. As part of the program, a card is sent out to caregivers explaining that by prioritizing their own health, caregivers are better able to support the health of the care recipient. The card also lists ideas for how caregivers may wish to spend their respite time.

The OCC is currently developing a respite registry which will include any eligible providers who are certified from an 8-hour training. This training will be modeled after the Respite Care Provider Training used in Wisconsin with support from the Respite Care Association of Wisconsin. Oklahoma is one of 11 pilot sites participating in the ARCH/NASHP Respite Provider Recruitment and Training field test.

Lifespan Respite Washington – The LRW website includes robust resources and guidance for family caregivers on how to use their respite voucher, how to find providers, and other tips for success. Staff check-in on families regularly regarding the status of their voucher and provide guidance and support when caregivers encounter challenges due to widespread workforce shortages.

LRW utilizes a HIPAA compliant database of all respite applicants and recipients. Staff can easily reference the system to determine the status of each family caregiver's voucher usage and they have protocols in place for when follow-up is needed.

To assist in the availability of providers, LRW regularly recruits among home care agencies, organizations offering programs for people with special health needs or disabilities, and organizations selected by caregivers that meet their needs for respite. LRW also encourages all respite provider organizations to join the LRW Coalition and take part in the meetings to learn more about respite best practices.

Employment Financial Considerations

When determining an individual's voucher allocation, it is important to keep in mind both the Internal Revenue Service (IRS) and Department of Labor (DOL) have specific regulations guiding who is an employer, and thresholds for when taxes should be withheld and deposited. It is important to classify workers appropriately, as both the IRS and DOL will impose hefty penalties if workers are misclassified.

Workers who provide personal-care services for a set hourly rate are most likely to be considered employees. If respite is being provided by an individual personal respite provider (rather than an agency or adult day care provider), then that provider will be considered an employee and not an independent contractor. The person directing and paying the provider via voucher, be it the person with a special need or the family caregiver, is by extension the employer. This is because the employer has a high level of control over how the worker does his or her job- the employer "has the right to direct and control the performance of the services. This control refers not only to the result to be accomplished by the work but also the means and details by which that result is accomplished" (IRS, 2003). Employees generally have income tax, Medicare, and Social Security taxes withheld from their pay, and are subject to the Fair Labor Standards Act minimum wage and overtime requirements. Employers pay a share of Medicare and Social Security, and also pay Federal and State Unemployment Insurance contributions on top of the wages paid. At year-end, employers issue Form W-2 to each employee showing wages paid and taxes withheld.

Workers who are licensed professionals, such as a nurse or therapist and have their own business working for more than one client, generally need less instruction on how to perform a given task and are more likely to be considered independent contractors. Independent contractors generally do not have taxes withheld from their pay, and instead pay self-employment taxes on their own. Independent contractors must be issued a Form 1099-NEC if they received $600 or more in payments in a calendar year.

Federal Guidance: Employee vs. Independent Contractor

If an individual chooses to direct their own care and hire their own workers, rather than use an agency or adult day service provider, the staff they hire are considered employees. The IRS uses the Common Law test to determine if a worker is considered an employee or independent contractor, which takes into account the amount of control for the following three areas from IRS Topic Number 762:

- *Behavioral Control – Who has a right to control what work is accomplished, how it is accomplished, the instructions and training?*
- *Financial Control – Is there an opportunity for the worker to have a profit/loss based on the work? Who controls business expenses? Who provides the tools? Is this work done in other locations for other parties?*
- *Relationship of the Parties – To what extent are the services performed by the worker a key aspect of the business? How permanent is the relationship? Are there any written agreements which describe the relationship?*

If a worker is considered an employee by the IRS, taxes must be withheld from the worker's paycheck and deposited with the IRS and your state's Department of Revenue. If there are questions about the worker's classification, the worker and the participant can complete an *IRS Form SS-8 Determination of Worker Status* for an official determination. Please note, this determination would only apply to IRS classification, and would not apply to the Department of Labor.

DOL compliance requirements also depend on whether a worker is an employee or independent contractor for Fair Labor Standards Act (FLSA) purposes. FLSA requires employees to be paid minimum wage and overtime, in contrast to independent contractors who are not bound by the FLSA. DOL has different criteria for determining if someone is an employee or an independent contractor. DOL Fact Sheet 13: Employment Relationship Under the Fair Labor Standards Act (FLSA) explains this in more detail:

The U.S. Supreme Court has on a number of occasions indicated that there is no single rule or test for determining whether an individual is an independent contractor or an employee for purposes of the FLSA. The Court has held that it is the total activity or situation which controls. Among the factors which the Court has considered significant are:

1. *The extent to which the services rendered are an integral part of the principal's business.*
2. *The permanency of the relationship.*
3. *The amount of the alleged contractor's investment in facilities and equipment.*
4. *The nature and degree of control by the principal.*
5. *The alleged contractor's opportunities for profit and loss.*
6. *The amount of initiative, judgment, or foresight in open market competition with others required for the success of the claimed independent contractor.*
7. *The degree of independent business organization and operation.*

In general, DOL criteria focus more on the degree of economic dependence the worker has on the employer, the length of the working relationship, and the degree of control the employer has over the work. Additionally, DOL recognizes more than one employer, otherwise known as joint-employment relationships. This commonly occurs when an agency and individual "jointly-employ" a worker when that worker performs services for an individual in their home, but an agency hires the worker and pays the wages. If the worker completes work for multiple individuals, the agency would be required to tally all hours worked to comply with FLSA minimum wage and overtime requirements. Since the individual is directing the day-to-day work inside their home, they would also be considered an employer.

Employees must be paid at least federal or state minimum wage (whichever is higher, depending on the state). The hourly rate can be determined for per-diem payments by dividing the per-diem rate by the hours actually worked each day. The rate must be inclusive of any employee expenses, such as mileage expenses for job-related driving. Employees must be paid "time and a half" for each hour worked above 40 in a workweek, i.e., an employee whose normal wage is $10 per hour must be paid $15 per hour for every hour they work over 40 each week. Minimum wage and overtime compliance is typically assessed on a per-week basis, not a per-day basis.

Tax Considerations

Home Care Service Recipients are *individuals participating in an in-home domestic services program administered by a state or local agency and all or part of the services received are paid for with funds supplied by the Federal, state or local government*. (IRS, 2003). The procedures for withholding and depositing of taxes by a third-party on behalf of a Home Care Service Recipient is detailed in IRS Revenue Procedure 2013-39 and fall under Section 3504 of the IRS Code.

If a domestic employee earns $2400 or more in calendar year 2022 then both the employee and employer are liable for Federal Insurance Contributions Act (FICA) tax. The FICA threshold for domestic employees is often updated annually and can be found in Publication 926, Table 1.

If an employer pays more than $1000 in wages in a given quarter then they will be responsible for paying Federal Unemployment Tax Act (FUTA) taxes, and likely, state unemployment taxes for all quarters in the current tax year and future tax years.

In some cases, an employee may provide respite for more than one family. As long as the individual employer (each family caregiver) pays this employee less than thresholds for FICA and FUTA, they are not responsible for paying for either. Although there will be employers who are far from those thresholds, there are others who will need to withhold income tax, FICA and pay both SUTA and FUTA.

In addition to SUTA, some states have additional compliance requirements which should be considered, including workers' compensation, and less-often time-off requirements or a domestic workers' bill of rights. For example, some states require domestic employers to furnish a workers' compensation policy, while other states exempt domestic employers from workers' compensation requirements completely, and still others vary the requirements based on the number of employees, hours or days worked. Similarly, if a specific state has passed a domestic workers' bill of rights, additional requirements related to working hours or time off requirements might come into effect.

Income Reclassifications and Tax Exemptions

There are several family relationship exemptions that are relevant when considering taxes, and are listed in IRS Publication 926, Table 1 Do You Need to Pay Employment Taxes? A summary of this table includes:

Parent/Representative Employer is:	And Employee is their:	Then, Employer and Employee
Child (adult or minor)	Parent	FICA, FUTA, SUTA
Parent	Child under 21	FICA, FUTA
Spouse	Spouse	FICA, FUTA, SUTA

IRS Notice 2014-7 reclassifies payments for providing care under a 1915(c) waiver for federal income tax purposes, meaning these payments are not considered gross wages, when individuals live together full-time. The application of Notice 2014-7 does not necessarily mean someone would also be exempt from FICA and/or FUTA; payment of FICA and/or FUTA would depend on

the individual family relationship listed above. The IRS has compiled a list of frequently asked questions related to Notice 2014-7 that can be used as additional reference.

Additionally, individuals/families who hire workers directly might be eligible for certain Fair Labor Standards Act exemptions. It is important to keep in mind these exemptions are only possible if there is no joint-employment with an agency or other professional organization. If the employee is employed by a third-party, such as an agency or other professional organization, the agency/third-party must always pay minimum wage and overtime. Additionally, some states have laws prohibiting the use of these exemptions, so it is important to review individual state guidelines, which are generally available on a state Department of Labor website.

- **Live-In Worker Exemption –** Employees who live full-time with their employer and have no other permanent address are not required to be paid for overtime hours worked over 40 hours. These employees still must be paid at least minimum wage.

Financial Management Services

In order to minimize the level of complication for program participants around paying taxes, many participant-directed programs use a fiscal intermediary or Financial Management Services (FMS) provider. The primary duties of an FMS provider are to:

- Provide protections and safeguards for participants, their representatives and program administrative agencies.
- Complete financial transactions on behalf of participants in accordance with spending plans, authorizations and/or program rules. (This could include paying workers, agencies or other goods and services vendors.)
- Generate reports for individuals and program administrative agencies showing financial transactions, spending plan data and other information applicable to the program.
- File all tax and labor reports on behalf of the participant/employer.

If your program exceeds tax thresholds described above, an FMS provider may be able to provide important support for the program and employers/family caregivers. With most models of FMS, the family caregiver is still classified as the managing employer. As a result, the tax thresholds described above still apply to the family caregiver serving as the employer and not the FMS provider. Additional financial resources are listed at the end of this section.

Financial Roles Case Study Examples

Alabama Lifespan Respite Resource Network – Alabama Respite does not utilize a fiscal intermediary, but instead handles everything within its own team. As a cost of doing this, they charge an administrative fee of 10-12.5%, depending on the funding source.

Oklahoma Lifespan Respite Program – Sooner SUCCESS utilizes WovenLife as a fiscal intermediary. WovenLife issues and mails the vouchers to the family or caregiver, receives the completed vouchers and sends the payment directly to respite care providers. OKDHS previously served as the fiscal agent, but as the program grew larger, subcontracting this role was more appropriate.

Lifespan Respite Washington – Awarded vouchers are held in the caregiver's name with the LRW program accounts and paid out directly to the caregiver's selected provider upon delivery of services. The respite provider bills LRW directly, freeing up the caregiver from having to file for reimbursements.

Spending Limits

Voucher programs have a spending cap, with a maximum usable amount within a given period of time. This cap varies both across and within programs, with the main determinant being the funding source. In the cases examined for this guidebook, the yearly limit was more a result of budgetary restrictions than ideological ones.

Spending Limits Case Study Examples

Alabama Lifespan Respite Resource Network – The caregiver is allowed to set the payment rate with some restrictions, depending on funding stream, but Alabama's minimum wage rate ($7.25 per hour) is a standard minimum across funding streams. It is not uncommon for a provider to be paid a set amount for an extended period of time (for example, $200 to provide care for a weekend).

Oklahoma Lifespan Respite Program – Vouchers are $400 for a four-month period. Previously, the funding limit was $300 for every three months, but shifting the time requirement has helped to reduce administrative costs without impacting the funding amount provided to families. The general yearly limit is $1,200, but funders are able to make exceptions to this rule. Such scenarios are examined and funding amount determined on a case-by-case basis by program staff. Voucher renewal is not automatic nor are families reminded to re-apply. Caregivers must take the initiative to reach out and re-enroll in the program for each four-month period.

Educational vouchers are also available to help caregivers attend a training that assists with their responsibilities. Eligible caregivers may receive $100 for a full day training event or $50 for a half day. They must be registered for an educational event and complete a respite application prior to the training. Emergency vouchers are also available on a case-by-case basis for full-time, unpaid caregivers who encounter an unexpected need for respite due to surgery, hospitalization, death in the family, or other unforeseen emergency. This is a one-time voucher of $300.

Lifespan Respite Washington – Caregivers are eligible for one voucher per year that are typically $1000 and are encouraged to use them within 90 days. If extenuating circumstances arise after being awarded, caregivers can receive extensions as was the norm during the height of COVID. The main reason use is encouraged is because other caregivers are waiting to be awarded. Any portion of a voucher that is not used by a caregiver is recycled back into the amount available to be awarded. Respite providers bill LRW and receive an additional $100 over the $1000 voucher limit for any intake and/or administrative costs incurred in serving the caregiver. Therefore, LRW sets aside $1100 per awarded voucher. Exceptions have been provided in terms of the total amount awarded and/or the amount of time to use the voucher, on a case-by-case basis to assist caregivers with unusual circumstances.

Time Limits

Another common voucher characteristic is the imposition of a time limit in which it must be used. The main reason for this time limit is that it prevents unforeseeable accounting shocks in future time periods. For instance, if a large number of caregivers all happened to save up their vouchers and then used them during the same period, the program would suddenly face a dramatic spike in costs, potentially resulting in significant budgetary issues. Holding funds specifically earmarked to all outstanding vouchers is not an efficient way to mitigate this risk because it is also common for families to under-spend. This can result in a large amount of idle funds that could instead be used to provide vouchers to other caregivers. Vouchers expire within a set time period, without the ability to roll over funds to future vouchers, in Alabama, Oklahoma, and Washington.

Rate Setting

The Live-In Worker Exemption in the Fair Labor Standards Act (FLSA) allows household workers who live full-time with their employer and have no other residence not to be paid overtime for hours worked in excess of 40 per week. These workers still must be paid at least minimum wage for all hours. This is important because in states that recognize this exemption, employers have more flexibility in the rates that they can set due to lower total wage costs.

The rates that participating caregiver employers are allowed to pay their respite providers varies from program to program.

Rate Setting Case Study Examples

> In both Alabama Respite and Oklahoma Respite, the caregiver is allowed to set the rate, maximizing their choice and control and adhering to the principles of self-direction. In Washington, the rate is determined by the provider agency.

Additional Resources on Program Structure

- State Lifespan Respite Voucher Tools
- LifeCourse Tools for Respite
- Building Respite Registries to Meet the Needs of Families
- Sustaining Lifespan Respite Systems: Lessons Learned and Practical Applications with a Checklist for Success
- Core Standards for Information and Assistance in Self-Direction
- What Employers Need to Know
- Fair Labor Standards Act Toolkit
- IRS Notice 2013-39

Quality and Risk Management

Whether a self-directed program is funded by the federal government or the state, by Medicaid or the Older Americans Act, quality has the same meaning: it is the degree to which services and supports for individuals increase the likelihood of attaining desired health and quality of life outcomes. Many have assumed that ensuring quality is more difficult in self-directed programs because agencies will not be supervising home care or respite workers or protecting participants from fraud, abuse, and neglect.

The Cash and Counseling Demonstration and Evaluation showed that participants and their families care deeply about quality and that the self-directed programs had the same or higher quality as those using agency-delivered services, and that quality management strategies were successful because participants directed their own services (Brown, et al., 2007). More recent research affirms that rates of fraud in self-directed programs are very low (Applied Self-Direction, 2021). Successful quality and risk management strategies in self-directed programs view caregivers and care recipients as the experts on their services, respect the need for accountability in publicly funded programs, and place a strong emphasis on quality improvement.

Key lessons learned from existing self-directed programs are that quality assurance requires programs to: (1) design quality management strategies as part of program operations, (2) provide support for participants to obtain high-quality services, and (3) use data to continually improve the program.

Elements of a Good Quality Management System

Regardless of size and funding source, all programs require quality considerations to ensure intended results are achieved. Experience teaches us to separate quality into two broad sections: the individual and the system. From the individual perspective, quality can be approached from six domains. In these instances, individual refers to the person receiving care and/or the family caregiver. These include:

- Is the individual satisfied with services and supports?
- Are individual rights, desires and preferences acknowledged as key?
- Is individual well-being appropriately safeguarded?
- Is there a plan to meet individual/personal goals?
- Are services and supports accessible and available?

- Are outcomes positive?

From the system perspective:

- Is the program operating as intended?
- Is the program effectively meeting goals?
- Is the program financially responsible?
- Are overall program goals being met?
- Do performance indicators tell us how the program is doing?

The first step in developing a quality system is to determine which program processes and outcomes need to be monitored. Since resources are limited, it is often necessary to identify only a few key elements and focus on monitoring them well rather than trying to do too much and thus doing none of it well. As noted, program funders may have a say in what needs to be monitored.

A second essential part of quality is to observe how the program is doing. This means developing and implementing data collection methods that allow program staff to know what is going on at ground level. This may be surveys of all participants or interviews with selected participants. Routine operating data, such as information contained on voucher claims, may also be useful. In the real world, these efforts may be modest, but they need to be consistent and ongoing.

Third, if problems are identified during a review/observation process, how can a program correct these? Typically, this is referred to as the remediation phase of a quality system. Information about persistent problems and their solutions can inform system-wide quality improvement efforts.

Improvement, the final phase of quality management, is the process of using the information collected to enhance overall program operations. Rather than focusing on one specific individual or situation, the objective of quality improvement is to modify overall program performance to ensure that system changes are made that will help to prevent recurrences of problems.

A Few Quality Tips

Establish Operational Policies, Procedures, and Practices – Policies, procedures, and practices specific to self-direction should be clearly specified to set realistic expectations and provide clear direction. These should be consistently applied throughout the program. Self-direction works best in an environment where the rights, roles and responsibilities of participants, family members, and representatives, providers of services and supports, and program staff are clearly defined. In particular, attention should be paid to the policies around financial aspects including threshold limits for employees and who serves as the employer (please see financial considerations section above for more information). Programs need to educate participants, representatives, and families about their rights and responsibilities in all aspects of the program.

Conduct Criminal Background Checks, if Required – Typically, self-direction programs provide a mechanism for participants to obtain criminal record checks on potential workers. Many programs do not require criminal background checks when participants hire relatives or family members, but their use depends on state laws and specific program requirements. If background checks are not

required for workers in the traditional system, programs must decide whether or not to mandate their use in self-direction programs.

Monitor the Program Using Existing Resources – Monitoring can take many different forms. Programs can and do use their existing monitoring staff – as long as training is conducted on self-direction – to oversee the performance of providers unique to self-direction, such as respite workers and Financial Management Services providers (if an FMS is used, see financial considerations section for more information). They also may identify other staff or techniques to conduct monitoring activities. Programs also may require counselors or traditional case managers to assume quality oversight responsibilities to ensure that participants are receiving authorized services and that these services adequately meet their needs.

Collect Data – The systematic collection and review of data are important to assess the quality of a program. The crucial first step is not just in the discovery process, but also in the improvement process because a program cannot be improved without knowing where improvements are needed. Data is essential for understanding a program's problems, issues, and patterns, and for targeting areas where changes would be beneficial. While anecdotal information can be illuminating, effective quality improvement relies on a well-established mechanism for obtaining data on participants' experiences and integrating these data with other information collected, such as results of participant experience surveys or assessments of participant under- or overspending.

The ability to use data to improve a program is a critical quality principle. While programs have progressed in their ability to collect data needed for quality activities, many do not have the means to integrate, analyze, and use data to actually improve program performance. In order to use data, programs need a mechanism for entering and analyzing the information collected. Although data entry is not difficult, it requires a routine method for recording information.

A Note on Electronic Visit Verification

The 21st Century Cures Act, signed into law on December 13, 2016, includes requirements for the use of electronic visit verification (EVV) systems for Medicaid personal care services programs. While EVV systems can be an important tool in quality management, they are only required if your self-directed respite program meets certain criteria, including receiving Medicaid funding. If you have not received guidance from your state Medicaid agency requiring the utilization of EVV, it is likely not a required feature in your program. Further guidance on EVV requirements is available from Medicaid.gov.

Quality and Risk Management Case Study Examples

Alabama Lifespan Respite Resource Network – In terms of risk management, the voucher system allows for a paper trail of where and when the money was spent. Additionally, the risk of fraud is minimized because both the respite provider and the family caregiver are required to sign the voucher. An annual Yellow Book Audit is conducted by an independent auditor.

Alabama Respite has done satisfaction surveys over the years with CTF grants focusing mainly on addressing the effectiveness of respite as a prevention technique for child abuse and neglect. For example, CTF requires that an evaluation survey be sent to all recipients

of respite vouchers annually, which includes questions regarding whether they received information that helped them to make better choices to reduce stress in their lives, and whether they know where to access resources for their children with disabilities. Results have overwhelmingly shown that respite is valuable to families and that most wish they could receive more money in vouchers. Caregivers using DMH and Universal vouchers are given an opportunity annually to complete a satisfaction survey.

Data Collection

Alabama Respite's ACL grant oversight is provided by the Alabama Department of Senior Services (ADSS), which shares the united goal to enhance and expand the delivery of existing planned and emergency respite services and supports to family caregivers across the lifespan in Alabama. Progress and achievement of program objectives are evaluated by an in-house ADSS independent evaluator whose specialized skills allow ADSS to develop procedures for, as well as oversee data collection, analysis, and promote the significant impact of utilizing effective data collection. Mixed methods of evaluations, surveys, standardized tools, telephone follow-up, or face-to-face interviews, with measurable outcomes are gathered, evaluated bi-annually, are made available for utilization annually by the Coalition, policy leaders, agency personnel, collaborative partners, and other stakeholders when addressing caregiver outcomes and satisfaction in the provision of respite and support services. The evaluation process includes developmental procedures and transitional steps, as well as a collective summary review of measurable program outcomes. The developmental evaluation process addresses effectiveness in community outreach and program performance, including evaluations of service providers, caregivers, care recipients, and community benefactors. The summary review focuses on those indicators in place needed to support success. Results demonstrate to decision makers the continued need for enhanced respite and caregiver supports, and the outstanding work Alabama Lifespan Respite produces. This is a critical part of sustaining Alabama Respite's current respite care initiatives for all caregivers. The most recent data summary review, A Voice That Matters: The Impact of Family Caregiving in Alabama (White Paper: Volume 2), was distributed in 2021.

Oklahoma Lifespan Respite Program – OKDHS uses a few different methods to manage risk and ensure a quality program. First, by having one point of entry – Sooner SUCCESS– they can minimize duplication across agencies. Additionally, OKDHS maintains an electronic referral record which documents why no other respite programs are suitable and ensures appropriate eligibility for Lifespan Respite. The voucher system also allows for a paper trail of where and when the money was spent. The risk of fraud is minimized because both the respite provider and the family caregiver are required to sign the voucher. As the fiscal intermediary, WovenLife regularly verifies addresses to ensure that funds are being sent to the appropriate person. As a policy, they will not issue checks to a P.O. box.

Prior to receiving a voucher, caregivers must complete a pre-survey in order to receive funding. Then, six to 12 months later caregivers are encouraged to respond to a post-survey regarding their experience. In 2017, OKDHS completed a detailed survey with caregivers across the Lifespan Respite Program which affirmed that respire was a continuing top need, even among caregivers who already received respite care.

Data Collection

As mentioned above, OKDHS does regularly collect some information via survey. The survey asks about the type of person providing respite, demographics of the caregiver and care recipient (e.g., age, race/ethnicity, marital status, and number of children), how long they have received respite vouchers, and their feelings about the receipt of respite vouchers and Lifespan Respite as a program. Additionally, OKDHS collects and tracks some information that is provided on the Respite Voucher Program application, including annual income, age, gender, relationship between caregiver and care recipient, number of household members, marital status, race/ethnicity, and type of disability/need. Data regarding outreach is also obtained via website and social media metrics.

Lifespan Respite Washington – All respite provider agencies submit an application that outlines essential organization information, certificate(s) of insurance naming PAVE and WA State DSHS as additional named insureds, and sign and submit an Interagency Agreement. LRW can efficiently vet and onboard new agencies with the help of their robust database. After a respite provider completes the process to be a registered provider, LRW staff reviews and ensures all required documentation has been submitted. Once approved, with one click LRW staff can approve the agency and their contact information is automatically available online in the searchable respite registry. With contracted vendors in place, LRW meets the State's requirements and offers caregivers staff within agencies who assure background checks, training, are knowledgeable, and protected from liability. In working with a vulnerable population, seniors and persons with significant disabilities, the vetting and care of those assisting caregivers is a priority.

Data Collection

Data collection begins with both online applications, voucher applicants and respite providers producing cumulative information around optional and required questions. Data such as demographics, including Washington county, amount of time since receiving a break, barriers in receiving respite, age of their care recipient, the primary and secondary disability of the person in their care, etc. County-level locations help LRW determine if vouchers are being equitably distributed across the state and help with respite provider outreach. Demographics help ensure LRW is reaching out to and serving the many population groups in WA. Identified conditions help show the needs caregivers are providing, and can assist with additional funding sources dedicated to certain conditions such as TBI, paralysis, Parkinson's disease, etc. Identified conditions also help the caregiver support team direct voucher applicants and awardees to agencies or programs with condition-specific capacity.

Finally, data captured from respite provider applications is also posted on the online interactive provider registry, where voucher applicants and recipients can search providers by areas served, ages and conditions served and types of services.

Additional Resources on Quality and Risk Management

- State Lifespan Respite Performance Measurement and Data Tools
- Measuring Systems Change and Consumer Outcomes: Recommendations for Developing Performance Metrics for State Lifespan Respite Programs
- Expanding Self-Direction and Its Impact on Quality
- Risk Management and Participant Direction
- Fraud in Self-Directed Personal Care Programs: What Does the Data Tell Us?
- Safe at Home? Developing Effective Criminal Background Checks and Other Screening Policies for Home Care Workers

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Appendix I: Case Studies and Additional State Examples

Alabama Lifespan Respite Resource Network

The Alabama Lifespan Respite Resource Network (Alabama Respite) is a statewide respite program whose mission is "to increase access to and availability of high-quality respite resources for all caregivers in Alabama" (Alabama Lifespan Respite Resource Network, 2022). The primary goal of Alabama Respite is to provide planned and emergency self-directed respite reimbursement services, caregiver education, respite awareness, caregiver mental health counseling, free respite provider training, diagnosis-specific virtual reality empathy training for public and private agencies, respite resource information and referrals, a statewide calendar of caregiver events, monthly newsletter, technical assistance and funding for startup or expansion of community-based respite services, advocacy, and to support the statewide Alabama Lifespan Respite Coalition.

The Alabama Respite voucher program began in 1994 with funding from Alabama Department of Child Abuse/Neglect Prevention - the Children's Trust Fund (CTF) for caregivers of children with disabilities up to age 19 being served through United Cerebral Palsy (UCP) of Huntsville and Tennessee Valley, Inc. The Alabama Respite Network began six years later, in 2000, when they received a grant from the Alabama Council for Developmental Disabilities (ACDD) to develop a directory of respite services in Alabama for primary providers to easily access. With this three-year grant, they formed a task force of over 45 interested stakeholders, including caregivers, disability organizations, state agencies and nonprofits. The taskforce produced a statewide strategic plan that provided for the development of a website that included a database of all known respite resources in the state (www.alabamarespite.org). Alabama Respite also purchased a toll-free number for caregivers to call to receive information and referral services. Additionally, Alabama Respite successfully replicated and implemented the CTF voucher programs with the five other UCP affiliates in the state.

- In 2007, the Alabama Department of Mental Health (DMH) asked Alabama Respite to manage a voucher program for their caregivers of adults with intellectual disabilities; this was expanded to include caregivers of children with intellectual disabilities in 2008. Piloted in 2011, Alabama Respite currently contracts with each of Alabama's thirteen Area Agencies on Aging (AAAs) to administer voucher respite funding for caregivers who choose self-directed respite with AAAs. Administration on Community Living (ACL) Federal Lifespan Respite grants

have enabled Alabama Respite to manage its own Universal and Emergency Respite voucher programs since 2014 for caregivers across the lifespan who do not qualify for other voucher respite programs. Alabama Respite receives an annual state appropriation, administered by the Alabama Department of Rehabilitation Services, to serve as a state match to federal grant funds and to provide respite education and awareness.

DMH, Universal, and Emergency voucher reimbursement programs are run with similar policies and procedures. Families requesting respite call or email the Alabama Respite office, or go on the Alabama Respite website, in order to complete an enrollment application. After Alabama Respite staff approves the respite request, the family is mailed or emailed the voucher, along with resources for hiring and managing respite providers. Caregivers are responsible for paying their respite providers and Alabama Respite reimburses the caregiver. AAAs enroll caregivers, approve funding, and send individual caregiver referrals to Alabama Respite to process vouchers. After Alabama Respite staff receives the referral, the caregiver is mailed or emailed the voucher, along with resources for hiring and managing respite providers.

Staff at Alabama Respite have worked hard to develop the self-directed voucher respite program over time, making changes with input from participants. In 2022, Alabama Respite served 132 families with CTF voucher respite, 237 families with DMH voucher respite, 342 families with Universal/Emergency voucher respite, and 1035 families with AAA voucher respite. Alabama Respite staff are also active across the state, advocating for respite to secure further funding, and educating caregivers and organizations regarding the benefits of respite, particularly self-directed respite programs.

Participant Involvement

Participants have been involved in Alabama Respite since its inception. Participants were actively involved in the initial taskforce to gather respite resources and increase availability and access across the state. Currently, participants contribute to the Alabama Lifespan Respite Coalition and the quarterly Caregiver and Agency Resource Exchange (CARE), a community of practice forum for collaborative partners to share resource information with caregivers and, in turn, for caregivers to help agencies identify and potentially reduce gaps in service. Essentially, participants are involved in planning and development of respite programs throughout the state.

Provider Eligibility

Caregivers are able to direct their respite services with the use of vouchers. Caregivers are able to select, hire, set the pay rate (varies per funding stream) and train the respite provider of their choice, whether that is a formal or informal provider, or a skilled or unskilled respite provider. The only two requirements include: 1) the provider must be at least 18 years old; and 2) the respite provider cannot live in the same household as the person with a special need.

How the Alabama Respite Voucher Works

Once a caregiver has been approved for respite, they receive information about Alabama Respite, a guide for hiring and training a respite provider, and the respite voucher. The respite voucher states the amount for which a primary provider is approved, and the primary provider

> is required to use the voucher within certain dates as indicated on the voucher. The family arranges respite and payment with their selected provider. Once respite has been provided, the caregiver submits a reimbursement form to Alabama Respite with the caregiver's and provider's signatures on the voucher form. This voucher form also includes the date of respite services, the number of hours of respite provided, the rate of pay and the total amount paid. The amount of the respite vouchers that a caregiver receives is determined by the funder and may be issued quarterly or annually. The caregiver may use all of their allotment at one time, or many periods of respite provision. Staff at Alabama Respite process the returned voucher paperwork and approve expenditures for respite services. Alabama Respite submits monthly invoices to funding agencies; the family is mailed a check for the amount owed once Alabama Respite is reimbursed by the funding agency. The caregiver is responsible for payment to the respite provider, and reimbursement for respite services to the caregiver may take 30-60 days.

Marketing and Outreach

Caregivers learn about the voucher programs through a variety of sources, including: 1) presentations, including lunch and learns, in the community to service coordinators, caregivers, agency partners, support groups, churches, and other stakeholders; 2) media outreach via social media, internet, television, radio, podcasts, community news magazines, and agency newsletters; 3) membership in the Alabama Respite Coalition; 4) state agency referrals; and 5) word-of-mouth in the community. The caregiver can enroll in the program by calling or emailing Alabama Respite for an enrollment packet or downloading it from the website. After completing an application form, including demographic data verification and proof of the care recipient's diagnosis are attached, the packet is returned to Alabama Respite. The Alabama Respite team determines eligibility and approves the application, working with the family as needed to assist in the process. Demographic data requested, and tracked, includes gender, age, race, ethnicity, military status, household income, county of residence, caregiver's relationship to the care recipient, how many hours of care per week the caregiver provides, caregiver stress level, enrollment with other respite services, and information regarding the care recipient's diagnosis. Caregivers may also indicate on the application if they are interested in receiving information about Alabama's Respite caregiver mental health counseling program. Alabama Respite goes to great lengths to ensure that families in need of respite know about the programs and are able to access vouchers from this service.

Alabama Respite started with a full-time program manager and a part-time director. Since that time, it has grown to a staff of five, including: 1) the Director, who oversees administration of program staff and activities, program development, grant and contract management, respite provider training, technical assistance to community-based respite services, legislative communication, and Coalition activities; 2) the Project Coordinator, who creates, schedules, and conducts respite education trainings, lunch and learns, respite clinics, caregiver support groups, and public awareness opportunities for caregivers statewide, as well as coordinates a caregiver mental health counseling program; 3) a training specialist, who conducts respite education and public awareness opportunities specifically in the southernmost counties of Alabama; 4) the Caregiver Resource Coordinator, who coordinates the AAA voucher respite programs; and 5) the Respite Resource Assistant, who coordinates the DMH, Universal, and Emergency voucher respite

programs and education stipends. Alabama Respite charges an administrative fee between 10% -12.5%, depending on the funding source. This helps to cover the costs of running the voucher program.

Eligibility and Budgeting

Eligibility for the voucher program is dependent on specific funding streams, with criteria set by the funder. Funding sources for Alabama Respite include: the Administration on Community Living/ Administration on Aging Federal Lifespan Respite Grants (two grants running concurrently in 2022), Alabama Department of Rehabilitation Services; Alabama Department of Mental Health; all 13 Alabama Area Agencies on Aging; and various grant opportunities. Funding specifically for the voucher programs comes from DMH, CTF, AAAs, and ACL. The budget for the voucher program in FY22 was $1,273,675.

All funders require proof of age and disability or direct referral from the funding source to receive a voucher. DMH funding is for children and adults who have a diagnosis that includes an intellectual disability, while CTF funding is only for caregivers of children with any disability under the age of nineteen. AAAs have income guidelines and age requirements. The ACL grant funds respite for caregivers who have no access to other funds for respite.

Alabama Respite does keep a waitlist for their programs, although they make every effort to keep this list as short as possible. Currently, they have approximately 10 caregivers on the waitlist who will be added to the program as soon as the next quarterly voucher is distributed. Quarterly DMH, CTS, and Universal voucher funding amounts depend on the number of program participants and available funding per funding stream. Vouchers expire in three months, without the ability to roll over remaining funds to future vouchers. AAA vouchers are issued annually, and amounts are determined by individual AAA partners. Some, but not all, AAA partners allow rollover of available funds; annual re-enrollment is also determined by individual AAA partners.

The caregiver is allowed to set the payment rate with some restrictions, depending on funding stream, but Alabama's minimum wage rate ($7.25 per hour) is a standard minimum across funding streams. It is not uncommon for a provider to be paid a set amount for an extended period of time (for example, $200 to provide care for a weekend). Alabama Respite does not utilize a fiscal intermediary, but instead handles everything within its own team. As a cost of doing this, they charge an administrative fee of 10-12.5%, depending on the funding source.

Supporting Provision of Respite Services

The provision of respite services has been limited in Alabama; however, the awareness and need for respite for family caregivers have increased through the efforts and support provided by Alabama Respite and collaborative partners. Alabama Respite supports caregivers by providing up to eight caregiver education opportunities, both onsite in community settings and online, each month. Approximately 70 trainings are available, and topics include: caregiver stress, grief, emotional and mental health; diagnosis-specific caregiving; building caregiving support systems; resources; disaster preparedness; working while caregiving; and writing a care plan. Virtual reality empathy training is also available to caregivers, care providers, first responders, and universities, and experiences include Parkinson's/Dementia, Alzheimer's Disease, Vision and Hearing Loss,

End of Life Conversations, Elder Safety and Well-Being, Trans Health and LGBT Aging, and Social Isolation. Respite clinics are offered quarterly in collaboration with statewide agency partners, including the Alabama Department of Rehabilitation Services/Children's Rehabilitation Services and Aging and Disability Resource Centers (ADRCs) located in all 13 AAA regional offices, to teach caregivers about: 1) the need to take respite; 2) where respite is available in the state; and 3) how to access it. Alabama Respite distributes a monthly newsletter to inform caregivers of upcoming events and maintains an online calendar of caregiver education opportunities hosted by both Alabama Respite and collaborative partners statewide.

Once caregivers are connected with respite vouchers, Alabama Respite provides access to a twenty-page manual with detailed information on hiring a respite provider which is available on the website for download. Included in this manual is information on relationship roles, recordkeeping, telephone screening, interview strategies, background checks, locating respite providers, creating a good work environment, training a respite provider and terminating an employee. Samples of a job description, employment application, recordkeeping sheet, agreement contract and advertisement for a respite provider are provided in the manual. Caregivers may also apply to Alabama Respite for a reimbursement stipend to assist in conducting a criminal background check of a respite provider if they so choose.

Additionally, Alabama Respite began offering a free basic respite provider training opportunity in FY22 through CareAcademy for unskilled, in-home respite providers to be better prepared to deliver planned and emergency respite services to the families they serve. Alabama Lifespan Respite offers eight hours of free basic care provider training for up to 25 individuals (Alabama residents only) per month, which includes the opportunity to earn class completion certificates. Mobile-friendly classes, designed by industry experts and offered through an easy-to-use video training platform, are available with Closed Captioning in English and Spanish through CareAcademy. Participants can use earned certificates to reassure caregivers and care recipients that they have completed training and are ready to provide quality care. Topics include: Working with an Aging Population; Communicating with Older Adults; Maintaining a Clean and Healthy Environment (Infection Control/Universal Precautions); Performing Basic First Aid During Medical Emergencies and Non-Emergencies; Safety Precautions and Fall Prevention; Assisting with Personal Care Through ADLs; Assisting with Independent Living Through IADLs; and Basic Housekeeping Techniques. Classes begin on the first day of each month and end on the last day of each month, so participants have up to 31 days to complete classes at their own pace. Information and applications are distributed by Alabama Respite and collaborative partners, including AAAs, via email and social media monthly. The State of Alabama does not have specific training requirements for self-employed, unskilled in-home respite providers. It is the belief of Alabama Respite, the Alabama Lifespan Respite Coalition, and collaborative partners that these training efforts have the potential to greatly expand and strengthen the respite care workforce statewide and serve as a model for the need for and importance of respite provider training and minimum standard requirements in Alabama.

Quality and Risk Management

In terms of risk management, the voucher system allows for a paper trail of where and when the money was spent. Additionally, the risk of fraud is minimized because both the respite provider

and the family caregiver are required to sign the voucher. An annual Yellow Book Audit is conducted by an independent auditor.

Alabama Respite has done satisfaction surveys over the years with CTF grants focusing mainly on addressing the effectiveness of respite as a prevention technique for child abuse and neglect. For example, CTF requires that an evaluation survey be sent to all recipients of respite vouchers annually, which includes questions regarding whether they received information that helped them to make better choices to reduce stress in their lives, and whether they know where to access resources for their children with disabilities. Results have overwhelmingly shown that respite is valuable to families and that most wish they could receive more money in vouchers. Caregivers using DMH and Universal vouchers are given an opportunity annually to complete a satisfaction survey.

Data Collection

Alabama Respite's ACL grant oversight is provided by the Alabama Department of Senior Services (ADSS), which shares the united goal to enhance and expand the delivery of existing planned and emergency respite services and supports to family caregivers across the lifespan in Alabama. Progress and achievement of program objectives are evaluated by an in-house ADSS independent evaluator whose specialized skills allow ADSS to develop procedures for, as well as oversee data collection, analysis, and promote the significant impact of utilizing effective data collection. Mixed methods of evaluations, surveys, standardized tools, telephone follow-up, or face-to-face interviews, with measurable outcomes are gathered, evaluated bi-annually, are made available for utilization annually by the Coalition, policy leaders, agency personnel, collaborative partners, and other stakeholders when addressing caregiver outcomes and satisfaction in the provision of respite and support services. The evaluation process includes developmental procedures and transitional steps, as well as a collective summary review of measurable program outcomes. The developmental evaluation process addresses effectiveness in community outreach and program performance, including evaluations of service providers, caregivers, care recipients, and community benefactors. The summary review focuses on those indicators in place needed to support success. Results demonstrate to decision makers the continued need for enhanced respite and caregiver supports, and the outstanding work Alabama Lifespan Respite produces. This is a critical part of sustaining Alabama Respite's current respite care initiatives for all caregivers. The most recent data summary review, *A Voice That Matters: The Impact of Family Caregiving in Alabama (White Paper: Volume 2)*, was distributed in 2021.

Alabama Respite does collect some information regarding how respite vouchers are used and the value of services through annual surveys sent to families receiving respite vouchers with CTF funding. Caregivers using DMH and Universal vouchers are given an opportunity annually to complete a satisfaction survey. Data is also collected through existing grant and contract reporting, including sign-in sheets, pre/post education tests, education stipend delivery, public awareness, and website statistics.

Building Support for the Program

In addition to personal-choice option respite reimbursement programs, caregivers have benefited from Alabama Respite's public awareness efforts to educate employers, local government bodies,

and the community at large about caregiver challenges and the mutual benefits of respite, as well as from technical assistance and grant awards to expand and enhance community respite options statewide. It is crucial to continue educating public policy makers about the growing number of Alabama caregivers, caregiving challenges, the importance of respite to caregivers, the financial benefits of respite to the state, and the work Alabama Respite does to support these caregivers statewide.

ADSS, AARP of Alabama, and Alabama Respite worked in partnership to gain passage of Senate Joint Resolution 73 in 2015 establishing the Alabama Lifespan Respite Coalition for the purpose of proactively working together with partners to address these daily caregiver challenges while providing services and supports to caregivers statewide. To advise the Alabama Legislature on the challenges of caregiving, the Alabama Lifespan Respite Coalition, after completing extensive research into the statistics of Alabama caregivers and the challenges they face, was charged with creating a white paper on caregiving in Alabama to identify policies, resources, and potential solutions to improve caregiving challenges for Alabamians. "A Voice That Matters: The Impact of Family Caregiving in Alabama" was completed and distributed in 2017 by ADSS and Alabama Respite to the Alabama Legislature, thus increasing the exposure of public policy makers to the valuable contributions of caregivers and proposing actionable solutions. Building upon that momentum, an updated white paper was completed in 2020 and distributed again to public policy makers to: provide an update on the status of Alabama Respite and the Coalition's work from identified action items of the 2017 white paper; provide a current "state of the state" regarding respite and support services for family caregivers; and to educate the lawmakers on where Alabama is headed in terms of workforce shortages and increased demand over the next five years. In response to past and present successes of Alabama Respite's programs and services, the Alabama Legislature has increased its annual allocation of funding from $175,000 to $315,000 in support of Alabama Respite caregiver programs and services.

Alabama Respite currently collaborates with more than 50 agencies to build support for its program and to increase respite for caregivers statewide, including the Alabama Department of Veteran Affairs, Governor's Office on Disability, Alabama Department of Medicaid, Alabama Department of Human Resources/Adult Protective Services, Alabama Department of Public Health, Alabama Council on Developmental Disabilities, Alabama Head Injury Foundation, Family Voices of Alabama, Autism Society of Alabama, respite and hospice direct service providers, universities, and diagnosis-specific support groups.

Successes, Challenges, and Lessons Learned

As caregiver needs evolve, so do Alabama Respite's efforts to support them. The Alabama Lifespan Respite Resource Network has had many successes, challenges and lessons learned over years of running several respite voucher programs. Some of these are shared here in the hopes that respite programs interested in developing and implementing a participant-directed voucher system can learn from Alabama Respite's experiences.

Successes: Created year-round, consistent, planned respite to increase caregiver well-being and decrease the need for emergency respite through additional grant support. The amount of planned respite has increased annually from an average of 42 hours (FY20) to at least 84 hours (FY22) per caregiver served through the Universal respite reimbursement program.

Challenges: Establishment of a statewide database for caregivers to identify available, individual, self-employed respite providers who have completed basic provider training and have passed a criminal background check.

Lessons Learned: Flexibility is key. Building in flexibility has enabled Alabama respite to respond and adapt quickly to changing caregiver needs.

Program Changes During the COVID-19 Pandemic

- Newly provided online training for caregivers was a major success. Alabama respite was able to reach new audiences and provide an online forum for caregivers to connect with one another, many hailing from rural areas. Relationships have developed that now extend far beyond the training group. Online education is now a critical component of the program.
- Using new grant funding, Alabama Respite was able to support caregivers with internet costs and technology access to enable their participation in online training and events while most families were confined to the home during the pandemic.
- Alabama Respite conducted daily check-in phone calls with caregivers during the pandemic, ultimately reaching over 800 people. Through these one-on-one interactions, the team recognized a need for mental health services and subsequently launched a 'Care Chat' program. Through Care Chat, social workers were made available to provide support during thirty-minute chats. The program also created seasonal care packages for over 300 caregivers living in rural areas. For instance, a summer respite care package included seeds, sunscreen, and insect repellent. The team also sent cards with Starbucks gift cards to caregivers living in urban areas. These outreach efforts helped the team to connect in a new way and received great positive feedback.
- In recognition of the mental health needs of caregivers arising from the pandemic, the Alabama Respite team successfully secured grant funding for a new Caregiver Wellness Program. Through the program, caregivers will be reimbursed for up to three sessions with a mental health professional of the caregiver's choice. The team also maintains a list of mental health professionals familiar with caregiving issues as a resource.

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Oklahoma Lifespan Respite Program

The Oklahoma Caregiver Coalition (OCC) is a partnership of over 100 public and private agencies who have voluntarily come together to develop and sustain various areas of support for primary caregivers including respite services. With Lifespan Respite Grant funding from the Administration for Community Living (ACL), the OCC was formed at the end of 2016 by Aging Services within the Oklahoma Department of Human Services. The mission of the OCC is to improve the supports and experiences over the lifespan of family caregivers through education, advocacy, and access to

resources. Their Executive Team includes Sooner SUCCESS, AARP Oklahoma, Healthy Living OKC, WovenLife, and Oklahoma Human Services (OKDHS). The OCC meets on a quarterly basis and is composed of nine subcommittees, including a respite subcommittee chaired by Nadine Walter, the Lifespan Respite Grant Manager. The OCC hosts OKCares.org to bridge the gap between state services and local community resources and features a 'Respite Locator' making it easy for caregivers to identify the best respite program to meet their needs.

The OKCares.org Respite Locator is extremely family friendly. It gives families one place to find information and connect with the appropriate respite service, regardless of the funding source. The Lifespan Respite Grant Voucher Program is one of thirteen different respite programs listed on the Respite Locator.

Families interested in the Lifespan Respite Grant Voucher Program are directed to contact Sooner SUCCESS, a nonprofit agency that contracts with OKDHS to coordinate the program. Sooner SUCCESS is the entry point for applications and information regarding respite services. Once approved, vouchers are sent to families, which they then use to hire a respite care provider of their choice. Another partner is WovenLife, which acts as the fiscal intermediary.

Stakeholder Involvement

The Oklahoma Lifespan Respite program is highly self-directed allowing maximal choice and control for families. The main goal in the beginning, and still today, is to increase the availability of respite for families and caregivers and decrease the barriers to accessing these needed services. By having a single-entry point and giving families and caregivers flexibility and control in hiring their own respite care providers, respite care is accessible and widely used. Family caregivers are regularly engaged for feedback regarding the respite program primarily via regular surveys.

Provider Eligibility

Caregivers who receive a voucher can hire anyone they choose, with two limitations: 1) the provider must be 18 years old or older; and 2) have a social security number and social security card. This can include informal providers, such as family, friends and co-workers, as well as formal providers, such as childcare centers, adult day service centers, nursing facilities, or hospitals. Caregivers are responsible for interviewing and selecting their respite provider, setting an hourly rate, training the provider, ensuring proper payment for services, keeping track of the number of hours or days of respite used, and tracking the total amount claimed against the voucher. Caregivers can use the voucher for respite either in the home or in an adult day service center, childcare center, or recreational program setting.

How the Oklahoma Respite Voucher Works

Once a caregiver is approved for respite, they may receive up to $400 worth of respite vouchers to be used within a 4-month period. Caregivers have full discretion on how to use their respite funding, whether all at once or allocated throughout the 4-month period. They can also determine the reimbursement rate for respite providers. Respite care can be provided in the caregiver's home, someone else's home, a center-based program or care center, such as an adult day services center or nursing facility, as long as agreed to by the

> caregiver and respite care provider. Once the respite is provided, both the provider and caregiver fill out a voucher, which includes the amount claimed, and the provider's address and social security number. The caregiver and provider each sign the voucher and the caregiver sends it to Sooner SUCCESS. Given that these are already encumbered funds, a check is sent to the provider. After four months, given the availability of funds, the caregiver is eligible for additional vouchers, and the process repeats.

Marketing and Outreach

The OCC plays a critical role in outreach with over 100 partners who each play their part in spreading the word and sharing about respite options with their clients. Other outreach includes OKcares.org, email campaigns, radio advertisements, and social media. Across social media platforms, Twitter and LinkedIn have been especially helpful. LinkedIn has particularly helped to attract potential respite providers.

To enroll in the program, families and caregivers simply must contact Sooner SUCCESS to determine if they qualify, and subsequently receive an application. The basic application is designed to meet federal partner reporting requirements. Sooner SUCCESS processes the applications and onboards caregivers.

Eligibility and Budgeting

Eligibility is largely determined by the care recipient. The care recipient must be 59 or younger and need assistance with activities of daily living in order to stay at home. Qualifying disabilities include:

- Cognitive impairment/dementia
- Intellectual disabilities
- Developmental disabilities
- Mental health/behavioral issues
- Physical disabilities
- Traumatic brain injury
- Other special health care needs

Additionally, the care recipient must not qualify for respite services or payment through any other program including but not limited to foster care, Family Support Assistance Payment, Older Americans Act (OAA) Title III-E or Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS) Systems of Care funding. The caregiver must also meet certain requirements, including be age 18 or older and serve as a full-time, unpaid caregiver or be a grandparent or other relative age 54 or younger raising a child, and not receive respite services from any of the aforementioned programs or otherwise.

Vouchers are $400 for a four-month period. Previously, the funding limit was $300 for every three months, but shifting the time requirement has helped to reduce administrative costs without impacting the funding amount provided to families. The general yearly limit is $1,200, but funders

are able to make exceptions to this rule. Such scenarios are examined and funding amount determined on a case-by-case basis by program staff. Voucher renewal is not automatic nor are families reminded to re-apply. Caregivers must take the initiative to reach out and re-enroll in the program for each four-month period.

Educational vouchers are also available to help caregivers attend a training that assists with their responsibilities. Eligible caregivers may receive $100 for a full day training event or $50 for a half day. They must be registered for an educational event and complete a respite application prior to the training. Emergency vouchers are also available on a case-by-case basis for full-time, unpaid caregivers who encounter an unexpected need for respite due to surgery, hospitalization, death in the family, or other unforeseen emergency. This is a one-time voucher of $300.

Sooner SUCCESS utilizes WovenLife as a fiscal intermediary. WovenLife issues and mails the vouchers to the family or caregiver, receives the completed vouchers and sends the payment directly to respite care providers. OKDHS previously served as the fiscal agent, but as the program grew larger, subcontracting this role was more appropriate.

In recent years, there has been no need to maintain a waitlist. Due to the diverse array of additional respite programs, typically it is possible to utilize other programs to free up Lifespan Respite funding for those families that are not eligible for any other respite.

Supporting Provision of Respite Services

Sooner SUCCESS has been a strong partner to the OCC and serves as the primary resource for information and assistance for families utilizing Lifespan Respite. All staff involved also provide essential encouragement to family caregivers, including the critical reminder not to feel guilty for taking respite time. As part of the program, a card is sent out to caregivers explaining that by prioritizing their own health, caregivers are better able to support the health of the care recipient. The card also lists ideas for how caregivers may wish to spend their respite time.

The OCC is currently developing a respite registry which will include any eligible providers who are certified from an 8-hour training. This training will be modeled after the Respite Care Provider Training used in Wisconsin with support from the Respite Care Association of Wisconsin.

Quality and Risk Management

OKDHS uses a few different methods to manage risk and ensure a quality program. First, by having one point of entry – Sooner SUCCESS – they can minimize duplication across agencies. Additionally, OKDHS maintains an electronic referral record which documents why no other respite programs are suitable and ensures appropriate eligibility for Lifespan Respite. The voucher system also allows for a paper trail of where and when the money was spent. The risk of fraud is minimized because both the respite provider and the family caregiver are required to sign the voucher. As the fiscal intermediary, WovenLife regularly verifies addresses to ensure that funds are being sent to the appropriate person. As a policy, they will not issue checks to a P.O. box.

Prior to receiving a voucher, caregivers must complete a pre-survey in order to receive funding. Then, six to 12 months later caregivers are encouraged to respond to a post-survey regarding their experience. In 2017, OKDHS completed a detailed survey with caregivers across the Lifespan

Respite Program which affirmed that respire was a continuing top need, even among caregivers who already received respite care.

Data Collection

As mentioned above, OKDHS does regularly collect some information via surveys. The survey asks about the type of person providing respite, demographics of the caregiver and care recipient (e.g., age, race/ethnicity, marital status, and number of children), how long they have received respite vouchers, and their feelings about the receipt of respite vouchers and Lifespan Respite as a program. Additionally, OKDHS collects and tracks some information that is provided on the Respite Voucher Program application, including annual income, age, gender, relationship between caregiver and care recipient, number of household members, marital status, race/ethnicity, and type of disability/need. Data regarding outreach is also obtained via website and social media metrics.

Building Support for the Program

The original founders of respite services in Oklahoma decades ago knew that these services were much needed, yet unavailable in the state; it took them about two and a half years to convince different public agencies, legislators, and others that families could be trusted to use a voucher and hire their own respite providers. For varying reasons, some parties were in support of the voucher program; in particular, having caregivers hire their own respite providers removes the liability from the agency, bringing with it additional benefits. While several options were offered along the way that would have included requirements that may have been more difficult for families to meet, the original founders persisted with the type of self-directed program that they envisioned. Their persistence developed into a model program that has assisted many families with meeting their respite needs.

Successes, Challenges, and Lessons Learned

OKDHS, OCC, and Sooner SUCCESS have had many successes, challenges and lessons learned. Some of these are shared here in the hopes that respite programs interested in developing and implementing a self-directed voucher system can learn from their experiences.

Successes:

- In the Oklahoma Lifespan Respite Program, the self-directing caregiver is given significant autonomy and control. The program does not micromanage caregivers but empowers them to make their own decisions. All supporting partners believe that caregivers know best what they need, and their role is limited to making a path available to get respite.
- The partnership between OKDHS and Sooner SUCCESS has been highly effective. Every person who works for Sooner SUCCESS has experience as a parent of a child with special needs which informs their effectiveness with caregivers seeking respite.
- OKDHS has been successful in obtaining numerous grants, currently nine active grants, that are able to function interdependently. Nadine Walter, as the OKDHS grants manager, has been highly successful building connections across funding sources.

- Members of the OCC are required to commit to one topic-specific subcommittee. Therefore, the respite subcommittee is composed of a network of Oklahomans with robust expertise in this specific area. This has facilitated incredible connections and collaborations within the Lifespan Respite program.

Challenges:

- Expanding the availability of respite, especially for families without immediate family in the area has been a challenge. There are many caregivers interested in self-directed respite care, yet they do not have informal supports to provide that care. This is particularly a salient issue in Oklahoma, where there are many military families. It is always a challenge to work with these families to locate appropriate respite providers.
- Oklahoma has especially high incarceration rates, resulting in family members unexpectedly taking on significant caregiving responsibilities with no built-in respite. In response, OKDHS has developed a 'relative safety plan' which makes newly minted caregivers eligible for respite vouchers after care recipients have been residing in their home for at least 10 days.
- Unlike other programs in the state, the Lifespan Respite Program has no built-in opportunities to showcase program outcomes and successes to state legislators. However, the program is saving a significant amount of tax dollars which is important for state legislators to understand.

Lessons Learned:

- Putting a time limit on the use of vouchers was a lesson learned early. As explained above, respite vouchers expire at the end of four months. OCC learned that some families do not use all the money offered in a voucher. At the end of the year, if the money was not used, it was lost. Therefore, the four-month time limit allows Sooner SUCCESS to recover the unused money and provide it to their families needing respite.
- If you subcontract out program operations, that subcontractor will make or break your program. Sooner SUCCESS has made Lifespan Respite a success.
- Caregivers should be afforded as much choice and control as possible, as they are best able to meet their own unique needs.

The Oklahoma Lifespan Respite Program is one of the longest running self-directed respite programs in the country and was used as a model when the Lifespan Respite Care Act was first developed. They are continually evaluating their program with input from participants to make changes and evolve over time. OKDHS, OCC, and Sooner SUCCESS provide an invaluable service in Oklahoma by increasing the availability and accessibility of respite services for many families and caregivers.

Program Changes During the COVID-19 Pandemic

- ▶ Family caregivers 18 years old or older living in the same household as the care recipient were allowed for the first time to be hired to provide respite services.
- ▶ The income cap on eligibility for respite was removed.

- The voucher allotment was raised from $300 every three months to $400 every four months which helped reduce administrative costs, while benefiting families.
- Previously enrollment in the Lifespan Respite program was managed via phone, but during the pandemic, the option was added to complete an online application.
- As of 2022, all these programmatic changes were expected to remain in place following the end of the public health emergency

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Lifespan Respite Washington

The Respite and Crisis Care Coalition of Washington launched as a statewide coalition in 2002. Later renamed Lifespan Respite Washington (LRW), the group received their first federal Lifespan Respite Grant in 2010 and has continued since then to receive funding through the U.S. Administration on Aging, Administration for Community Living. LRW is administered by their host agency, PAVE (Partnerships for Action, Voices for Empowerment), in partnership with the state's Aging and Long-Term Support Administration within the Department of Social and Health Services. The PAVE team administers the Lifespan Respite Voucher program for unpaid and under-served family caregivers of all ages across Washington State. LRW staff includes a total of six (staff), two with the Aging and Long-Term Support Administration and four with PAVE. The PAVE staff provide caregiver support, respite provider customer service, website maintenance, both content and technology. They also research, create information, and post new caregiver resources; conduct social media outreach; facilitate Coalition meetings; execute all data and evaluations; coordinate with finance team staff internally and with the Aging and Long-Term Support Administration; offer trainings and presentations; and coordinate with the Washington TBI Council who hosts and provides in-kind support of the statewide Caregiver Support Group. The Caregiver Support Group is a free, online/virtual support group with a trained facilitator who utilizes the topics and resources produced by the PAVE LRW staff.

LRW is also supported by a Lifespan Respite Coalition composed of family caregivers, public and private agency staff, and advocates from across the state. The LRW Coalition meets at least twice a year, and during COVID, exceeded that number. The Coalition supports various respite related initiatives and works to educate the public and policymakers about the importance of respite and how to access these critical services.

Families seeking respite can access all the information they need via the LRW website. Through the website, family caregivers may apply for respite, search for respite providers via the online registry, obtain vital resources and information, and learn about the policies of the program.

Stakeholder Involvement

The LRW Coalition includes family caregivers, public and private agency staff, and advocates from across the state and meets at least twice a year. This group serves as an important avenue for stakeholder engagement which aims to support individuals with disabilities from a cross-section of ages, cultural or ethnic backgrounds, and needs or disabilities of the individuals needing care. Occasionally the group hosts training sessions on respite-related topics. They also meet to share information, updates, best practices, and to learn from one another.

Beyond the LRW Coalition, the team conducts regular surveys with both caregivers and respite providers. The first year of the program focused on gathering feedback on specific and overall respite service systems with five surveys targeted to: survivors of traumatic brain injury (TBI) and their caregivers, American Indian/Alaska Native (AI/AN) caregivers, caregivers of individuals with Developmental Disabilities, and previous Lifespan Respite voucher recipients along with respite providers.

Provider Eligibility

Caregivers may choose their respite provider from a database of registered provider agencies via the online registry. The caregiver support team offers one on one support by phone, email, or text to assist family caregivers with their selection, checking in with every single family with an active voucher. Caregivers are also empowered to request or recommend new providers to be included in the LRW program. They may request a particular program or agency not included in the registry, in which case LRW PAVE staff will contact the preferred agency and provide customer service so they will become a registered respite provider. Most do opt to join and the online registry includes many caregiver requested providers.

How the Washington Respite Voucher Works

Caregivers apply via an online application for mini grants in the form of vouchers for respite services. The online registry is highly accessible and interactive, allowing caregivers to search within specific criteria (for instance within their county). Family caregivers awarded a voucher use the registry to select, ask questions of, and arrange with agencies and organizations for services. They can download their search results to use a tool in ongoing information gathering, to contact, and assess what's best for their family. Awarded vouchers are held in the caregiver's name with the LRW program accounts and paid out directly to the caregiver's selected provider on delivery of services. The respite provider bills LRW directly, freeing up the caregiver from filing for reimbursements. Caregivers receive $1000 vouchers (per family) which they are typically required to use within 90 days. Vouchers may be used with more than one provider either sequentially or simultaneously. In Washington, LRW can pay registered providers and cannot pay friends and/or family members of a voucher recipient. Caregivers do have a choice in their respite provider agency, the staff, and manage the range of service options they receive.

Marketing and Outreach

Most family caregivers (70%) find LRW through online search or a direct link from another website. Other caregivers find LRW through referral from social service or health care programs (15%)

or social media (10%). LRW maintains a web page with detailed information about the program benefits and limitations, eligibility requirements, and a link to the online application.

LRW has developed online respite tools and other training materials/modules which are placed on key partners' websites to raise awareness about LRW. Each of the online modules was designed by Washington Aging and Long-Term Support Administration Instructional Developers to provide information on what respite is, ways it could be used, how both the caregiver and recipient can plan to get the most out of the respite opportunity, along with what services are available.

Eligibility and Budgeting

Eligible applicants must reside in Washington State and provide 40 or more hours per week of care or support to someone with a special need or condition (the person can be any age), and the 40 or more hours must include supervision of the person receiving care. Care recipients must have a special need or condition (the person can be any age), and the 40 or more hours per week must include supervision of the person receiving care. Caregivers must be unable to afford respite care on their own and not be enrolled in any program that provides respite services, unless on a waitlist and not scheduled to receive services within 30 days of application.

Caregivers are eligible for one voucher per year that are typically $1000 and are encouraged to use them within 90 days. If extenuating circumstances arise after being awarded, caregivers can receive extensions as was the norm during the height of COVID. The main reason use is encouraged is because other caregivers are waiting to be awarded. Any portion of a voucher that is not used by a caregiver is recycled back into the amount available to be awarded. Respite providers bill LRW and receive an additional $100 over the $1000 voucher limit for any intake and/or administrative costs incurred in serving the caregiver. Therefore, LRW sets aside $1100 per awarded voucher. Exceptions have been provided in terms of the total amount awarded and/or the amount of time to use the voucher, on a case-by-case basis to assist caregivers with unusual circumstances.

In July 2022, there were 43 family caregivers currently utilizing vouchers with 146 caregivers on a waitlist. There was no waitlist during the pandemic. LRW program funding is very limited and any additional future funding would go towards meeting the demand and reducing the waitlist. Respite vouchers are awarded equitably across the state regions, ensuring that rural and urban communities are given equal access. There is no preferential treatment for caregivers who have previously received a voucher. Once eligible again, eligible voucher recipients are awarded based on a first in, first served with available funding.

Supporting Provision of Respite Services

The LRW website includes robust resources and guidance for family caregivers on how to use their respite voucher, how to find providers, and other tips for success. Staff check-in on families regularly regarding the status of their voucher and provide guidance and support when caregivers encounter challenges due to widespread workforce shortages.

LRW utilizes a HIPAA compliant database of all respite applicants and recipients. Staff can easily reference the system to determine the status of each family caregiver's voucher usage and they have protocols in place for when follow-up is needed.

To assist in the availability of providers, LRW regularly recruits among home care agencies, organizations offering programs for people with special health needs or disabilities, and organizations selected by caregivers that meet their needs for respite. LRW also encourages all respite provider organizations to join the LRW Coalition and take part in the meetings to learn more about respite best practices.

Quality and Risk Management

All respite provider agencies submit an application that outlines essential organization information, certificate(s) of insurance naming PAVE and WA State DSHS as additional named insureds, and sign and submit an Interagency Agreement. LRW can efficiently vet and onboard new agencies with the help of their robust database. After a respite provider completes the process to be a registered provider, LRW staff reviews and ensures all required documentation has been submitted. Once approved, with one click LRW staff can approve the agency and their contact information is automatically available online in the searchable respite registry. With contracted vendors in place, LRW meets the State's requirements and offers caregivers staff within agencies that assure background checks, training, are knowledgeable, and protected from liability. In working with a vulnerable population, seniors and persons with significant disabilities, the vetting and care of those assisting caregivers is a priority.

Data Collection

Data collection begins with both online applications, voucher applicants and respite providers producing cumulative information around optional and required questions. Data such as demographics, including Washington county, amount of time since receiving a break, barriers in receiving respite, age of their care recipient, the primary and secondary disability of the person in their care, etc. County-level locations help LRW determine if vouchers are being equitably distributed across the state and help with respite provider outreach. Demographics help ensure LRW is reaching out to and serving the many population groups in WA. Identified conditions help show the needs caregivers are providing, and can assist with additional funding sources dedicated to certain conditions such as TBI, paralysis, Parkinson's disease, etc. Identified conditions also help the caregiver support team direct voucher applicants and awardees to agencies or programs with condition-specific capacity.

Finally, data captured from respite provider applications is also posted on the online interactive provider registry, where voucher applicants and recipients can search providers by areas served, ages and conditions served and types of services.

Building Support for the Program

During the initial year of funding, LRW and the Aging and Long-Term Support Administration advanced efforts to increase respite service options tailored to the needs of individuals with TBI and their caregivers, and American Indian/Alaska Native populations, including making a presentation at the Washington State Traumatic Brain Injury Council Conference in May 2018, and using a Tribal specific lifespan respite survey to better understand the needs of Tribal caregivers. In addition, LRW staff made dedicated presentations during multiple Tribal specific conferences over many years.

LRW routinely connects and partners with organizations to provide information, education, and network to expand the awareness of the value of short breaks for caregivers. An important component in training has been the dedicated TBI efforts across the state in identifying, supporting, and offering certificates in working with someone with a TBI. Home care agency workers will be trained in TBI basics to increase use of paid caregivers in the TBI community. A pilot project has begun in three Washington tribal home care agencies to train tribal staff members on respite services so they in turn can educate tribal members about the importance of short breaks for caregivers and assist tribal members to apply for vouchers and choose care providers.

Successes, Challenges, and Lessons Learned

LRW has had many successes, challenges and lessons learned. Some of these are shared here in the hopes that respite programs interested in developing and implementing a self-directed voucher system can learn from their experiences.

Successes:

- The HIPPA compliant database enables LRW to process caregiver and provider applications expeditiously and with minimal effort. This database feeds information directly into the searchable, online respite provider directory, which is user-friendly, and accessible.
- LRW has been successful in providing person-to-person individualized family caregiver support throughout the respite delivery process.
- The LRW Coalition model is also self-directed with meetings where members share many resources for families and for providers.

Challenges:

- Other self-directed programs offer more flexibility in the choice of provider, often including the option to hire friends and family.
- Obtaining funding beyond ACL has been a major challenge and despite a documented need, new funding sources are very limited and not readily available.
- Meeting the needs of rural communities has been difficult, particularly for those populations that do not utilize formal programs or services. LRW is seeking to find better ways to adapt program rules to the needs of tribal populations.
- Meeting the needs of care recipients related to their condition, culture, and/or trust factors is a challenge. When layered with a rural residence this can increase the degree of difficulty. LRW is actively engaged with identifying and adapting whenever possible to serve the needs of Tribal members, TBI, and military care recipients and their caregivers.

Lessons Learned:

- Caregivers benefit greatly from one-to-one, personalized contacts from LRW staff through the application process and voucher period whether by phone or email.
- Recycling revenue of any portion of a voucher that is unused significantly extends the amount of funding and caregivers who can select providers and receive a much-needed break.

- The value of respite in the lives of its caregivers, their care recipients and communities across Washington, and the dire need for funding across all 50 States and US Territories, were important lessons learned.

Program Changes During the COVID-19 Pandemic

- LRW increased their capacity to provide more individualized support to family caregivers beyond their existing approach to information and assistance. They also increased their collaboration and coordination statewide.
- Family caregivers were supported to utilize their voucher funds immediately with minimal stalls or lapses in respite service delivery. LRW proactively reached out to caregivers who had only partially utilized their voucher funds and helped families determine the best way to spend remaining funds.
- During an extensive time during the pandemic, family caregivers could take far longer than the traditional goal of 90 days to use their voucher funds to accommodate disruptions, change, and uncertainty.
- The impact of the pandemic on the LRW voucher program was explored in depth via a case study conducted by the ARCH National Respite Network.

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State Examples

There are many programs implementing self-directed respite services in addition to the three Lifespan Respite grantees presented in the case studies for this guidebook. The following chart provides a snapshot of a few respite programs across the country working to include self-direction.

State	Brief Description	For Additional Information
Colorado	The Colorado Respite Care Program's Family Respite Voucher Program provides funds for respite care to family caregivers across the state of Colorado, serving all ages and special health care needs. This program offers a resource for unserved and underserved family caregivers who have limited access to respite care and/or other supports through current systems. This program is intended to act as a Payer of Last Resorts. Family caregivers can receive financial assistance to access respite care. Providers can partner with the CRC to provide respite services as funded by the voucher program. The program is partially funded by a Lifespan Respite Care Program grant.	**Colorado Respite Care Program** https://www.coloradorespitecoalition.org
Maryland	The MD Dept. of Human Resources, Office of Adult Services, serves families caring for adults with functional or developmental disabilities. This program is over 30 years old and is the only state-funded program for Respite Care in the state. Family caregivers identify whether they want to use professional, licensed care or their own individual respite provider. Families may choose a neighbor, friend or other family member (not living in their home) to be their provider and they train them specifically around the needs of their family member. The rate is determined between the family and the person they choose. Depending on which entity is implementing the program at the local level, the family may pay the provider out-of-pocket and the agency reimburses them or the agency pays the family-identified provider directly. Money can be used for a broad range of respite services including paying for camp. The hourly rate for skilled care is capped at $25/hour.	**Respite Program, MD Office of Adult Services** https://dhs.maryland.gov/office-of-adult-services/respite-care-program/
Nebraska	The state-funded Lifespan Respite Subsidy Program provides respite for the caregiver who is providing continuous ongoing care. Individuals who receive continuous ongoing care from an unpaid caregiver and who are not eligible for other governmental programs are eligible to receive respite subsidy if they meet income guidelines (312% of Poverty). Participants are allowed to hire whomever they want to provide respite. Once respite has been provided, the participant and provider sign and submit a billing document. The participant/parent may choose	**Nebraska Lifespan Respite Network** https://respite.ne.gov/

State	Brief Description	For Additional Information
Nebraska (cont.)	to have the respite program pay the provider directly or reimburse them directly. Each participant is allowed up to $125.00 per month and may request to bank respite for up to 3 months to use at one time.	
Nevada	Nevada designed a self-directed respite option, Respite Rx, as a pilot program that included a person-centered philosophy model into the service delivery of respite, with the focus on the caregivers instead of the care recipients. Care recipients were still important within the program, but not the primary focus. The design of the new pilot program took a year of preparation, working to remove as many known barriers to caregiver participation as possible. As outlined in the Lifespan Respite grant, the self-directed program was targeted to fill certain "gaps" in the social service delivery system, specifically rural communities and caregivers caring for individuals aged 18-59. Eligible caregivers for Respite Rx also included those unable to qualify for other respite programs due to limited eligibility criteria, waitlists, or program reach that did not deliver care after-hours, weekends, overnights, etc. Nevada was able to see higher usage in the self-directed program when caregivers were empowered to decide who, what, when, where, and how they could use respite to best fit their respite goals.	**Nevada's Respite Rx** *Final Report of the Caregiver Respite Self-Directed Pilot*
Tennessee	In the TN Respite Coalition (TRC)'s Family Directed Respite program, caregivers are given control over who they hire to provide respite (individual, program, camp, etc.). They are allotted a bank of funds to access through vouchers. They can use their "bank" all in one month or make the amount stretch over an entire year. Eligibility criteria depend on the funding source requirements. The program is partially funded by a Lifespan Respite Care program grant. The TRC covers the entire state. They have two program staff operating out of the main office in Nashville and three program staff around the state covering different regions. Each program staff operates the voucher programs for their regions.	**Tennessee Respite Coalition's Family Directed Respite Program** https://tnrespite.org/
Texas	Respite voucher services in the TX Consumer-Directed Services Option are the provision of vouchers to a program participant to allow the program participant to select a respite provider, establish a work schedule and payment rate, and provide the respite provider information and training on the program participant's needs. This program is available to people who serve as an informal provider of in-home and community care for an older adult. Texas also has a state funded Lifespan Respite Program that is partially funded by a federal Lifespan Respite Care Grant. Respite	**Take Time Texas** https://apps.hhs.texas.gov/taketimetexas

State	Brief Description	For Additional Information
Texas (cont.)	vouchers are available through local Aging and Disability Resource Centers.	
Wisconsin	Under the Wisconsin Lifespan Respite Care Program, administered by the Respite Care Association of Wisconsin, the Caregiver Respite Grant Program provides financial support for family caregivers for up to 5 days of respite care within 30 days of application approval. This grant allows approved applicants to hire the respite care provider of their choice for their loved one living with disabilities or special needs. The Supplemental Respite Grant Program supports primary caregivers by providing funding for supplemental respite services. This grant allows you to hire the person of your choice to help you with housekeeping, meal prep, laundry, lawn care, snow removal, transportation, and technology. The Wisconsin Lifespan Respite Care Program is funded by the WI Department of Health Services and a federal Lifespan Respite Care Program grant.	**Respite Care Association of Wisconsin** https://respitecarewi.org/

Appendix II: Building Support, Dealing with Opposition, and Dissemination of Information

Building Support and Adoption of the Program

As with any program, a new self-directed program will have its supporters, opponents and those who fall somewhere in between. The primary goal of any communications strategy is to convince stakeholders that self-direction is a valuable and desirable addition to the LTSS options currently available.

The ultimate goal – beyond designing and implementing a new program – is to attract and enroll sufficient eligible individuals to sustain the program, providing the base for future expansion. Creating a strategic communications plan for the new program will help to achieve this goal.

Building Support and Advocates

Among the first steps in any formal or informal communications plan is a "stakeholder analysis" – identifying key stakeholders and determining their needs. Stakeholders are those people who are in a position to influence the new program and whose support and participation are essential to its success. Inviting stakeholders to serve on a program's advisory panel not only engages them in its planning and implementation, but also creates a group of knowledgeable individuals who can provide valuable insights, such as the best channels to reach various target audiences or the most effective messages for particular groups. Communicating with potential participants, for example, requires a very different approach than does communicating with state legislators or representatives of provider organizations. Having advisory panel members who represent all the major stakeholders will help program staff target communications efforts more effectively. Stakeholders who are invested in the success of a new program can also help counter opposition and eliminate challenges to the program by carrying a positive message about the program to many different audiences.

Dealing with Opposition

Not everyone is supportive of self-direction programs, particularly some providers who express doubts about participants' abilities to manage the responsibilities of the program or who worry about losing their clients or staff. Some opposition may be powerful and well-organized. Many self-direction programs have experienced some opposition to the program.

Lessons learned from states about countering provider resistance:

- Take an active approach rather than reacting to problems. To communicate messages effectively, do not rely on phone calls or letters. Seek out and meet with provider groups in person before any issues arise.
- Enlist providers who see the benefits of self-direction to help deliver information about the new program to other providers. Recruit these providers as early as possible, for example, as soon as the stakeholder analysis is completed.
- Educate providers about the positive outcomes of self-direction. Many are genuinely concerned about the safety and well-being of their clients.
- Provide accurate information to provider organizations. Get on their meeting agendas and make clear and compelling presentations about the benefits of self-direction. Take ample amounts of informational materials for audience members.
- Tell stories and show photos or videos of participants who have benefited from self-direction. Help providers see for themselves that the program can work.
- Address health and welfare concerns directly. Stakeholders want to know how the program will ensure health and welfare and control fraud and abuse. Answer these questions immediately.

Dissemination of Program Information

One of the most frequent questions program staff will hear when talking to others about the new program is: "Do you have any materials on the program?" Developing and providing information in multiple formats helps stakeholders and other audiences to better understand the program. Here is a list of useful materials and tips for creating them.

- **Program name and logo –** These items will help establish a unique identity for the new program. They will help target audience members differentiate the new program from already existing LTSS options. A catchy, easily recalled name and/or logo are particularly helpful for potential participants and their families, who can be overwhelmed by the variety of similarly named (and heavily acronymed) government programs available to them.
- **Fact sheets and frequently asked questions (FAQs) –** One-page info sheets and FAQs with answers about the new program are extremely helpful and relatively easy and inexpensive documents to produce. Fact sheets should explain the program's primary features in easy-to-read language on a single page in bullet form. An FAQ can be longer and should include the questions that readers are most likely to ask with succinct answers.
- **Letters and postcards –** These are important documents to develop, particularly to promote the self-direction program to potential participants and their families.
- **Brochures –** An easy-to-read, visually interesting, versatile brochure that explains the new program clearly and answers the most important questions will be very useful to program staff. It is the document that will be used the most and should be developed with multiple audiences in mind. It should present information about the program in clear, conversational language; include quotes from influential opinion leaders and/or participants; and feature

engaging photographs of the types of people and their families who could benefit from the program.

- **Websites –** An easy-to-navigate website is essential for any new program. While some potential participants and their families may not have access to a computer, a website is an effective and efficient method for providing current information to those who do and all other audiences, including state government officials and their staff, media, providers, and consumer advocates.
- **Videos –** An effective supplement or alternative to written material, videos make information about the program "come alive." Videos can be made available through program websites and/or distributed with written materials.
- **Social Media –** An active presence on major social media platforms, including Facebook, Twitter, and LinkedIn, can help in reaching new audiences. To have a meaningful impact social media requires frequent, ongoing use with relevant updates and content.

Appendix III: Funding for Respite Services

Highlights of Funding Respite

Nationally, Medicaid supplies the majority of public funding to support home and community living through State Plan services and Medicaid waiver services with the largest vehicle being the 1915(c) waiver. State programs may develop specific respite services under this authority using two different service delivery models: traditional agency respite services and self-directed respite. Both models use the same definition: Respite services are provided to participants unable to care for themselves that are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the participant. With traditional agency services, qualified provider organizations enrolled in the State's Medicaid program are selected by the individual or representative to provide the services. With self-directed respite, the service definition remains the same, but individuals have the right to hire whomever they want providing the person meets basic minimum qualifications. Services can be a distinct service (as in California's Self-Determination Program) but typically, with self-direction we see similar services bundled into one service category. For example, North Dakota's 1915(c) waiver for persons with disability (including older adults) offers self-directed services entitled Community Supports. This service combines personal attendant, homemaker, chore, transportation and respite into one service. The individual or caregiver may use their budget to purchase any of these bundled services so great flexibility is provided to obtain respite services.

For a full description of Medicaid and non-Medicaid funding options, please see the reports on federal funding listed at the end of this section.

Additional Resources on Funding

- Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems
- Medicaid Waivers for Respite Support: State-by-State Summaries of Medicaid Waiver Information

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