

Participant-Directed Respite Guidebook

Developed by the
National Resource Center for Participant-Directed Services for the
ARCH National Respite Network and Resource Center

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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; 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 and Resource Center consists of the [ARCH National Respite Resource Center](#), the training and technical assistance division, which provides support to service providers and families through consultation, training, evaluation, and research. The ARCH National Respite Network also includes the [National Respite Locator](#), a service to help family caregivers and professionals locate respite services and funding sources 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 [Technical Assistance Centers for Caregiver Programs and Lifespan Respite](#), a joint venture with the [Family Caregiver Alliance](#) of San Francisco, which is funded by the [Administration on Aging](#) in the US Department of Health and Human Services. The TA Center for Lifespan Respite provides training and technical assistance to State Lifespan Respite grantees and their stakeholders, including State Respite coalitions, ADRC representatives, and others interested in building such systems at the state and local levels.

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INTRODUCTION

The use of participant-directed services, which provide options for individuals and their families to direct and manage their own services and supports, is growing across the United States in a variety of areas. Most common has been the use of participant-directed models in programs for people with disabilities, as well as long-term care for older adults. These models empower individuals and their families by allowing them a greater degree of control and choice than is found in traditional models of care.

Another important piece of long-term care for people with disabilities and older adults is ensuring that caregivers receive regular and short-term breaks from the often difficult job of continuously caring for their loved one. Respite is a means for the caregiver to take these breaks, and is invaluable to the family. While traditional programs that offer respite do so via agency staff that are trained as respite providers, participant-directed respite allows greater choice for caregivers, including the ability to hire, train, pay, and supervise their respite provider. This is often accomplished through a voucher system, which empowers caregivers 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, participant direction in respite provides the person with a special need and their primary support control of who provides services and how that is achieved. Choice and control helps to ensure satisfaction with services received.

The following guidebook is offered as a resource for programs that provide respite and are interested in developing and implementing participant-directed respite. Included are: overview materials that provide content information regarding participant direction, examples from two states that currently implement participant-directed respite programs using a voucher system, and resources for additional materials.¹ This guidebook is a collaborative effort between ARCH National Respite Network and Resource Center, which provides training and technical assistance services to Lifespan Respite grantees, partners and the general national respite network, and the National Resource Center for Participant-Directed Services (NRCPPDS), a center assisting states, agencies and organizations in offering participant-directed services to people with disabilities.

How to Use the Guidebook

This guidebook is organized into sections following the different elements of participant-directed programs. At the end of each section, we have included relevant excerpts from two case studies that were conducted. 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 the NRCPPDS Handbook on Participant Direction and other useful resources. The

¹ The two state case studies consisted of a short email survey to the Lifespan Respite Care programs in each state that provided an overview and basic information about their participant-directed respite care program, an hour-long telephone interview with key staff members of the Lifespan Respite Care program in each state, brief follow-up emails, and a review of relevant literature.

guidebook is organized into sections following the different elements of participant-directed programs, and includes the following:

- **Involvement in the Program** – how to involve *all* stakeholders in *all* aspects of the participant-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 & 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 Respite Resource Network and the Alabama Lifespan Respite Resource Network. Both programs have well-established participant-directed services and share successes, challenges, and lessons learned. Additional examples from participant-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 participant-directed respite services.
- **Appendix III: Potential for Other Funding Sources** – additional funding sources in which to fund your participant-directed respite program.

Definition of Terms

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

Respite – 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).

Family Caregiver – Sometimes referred to as a primary support, unpaid caregiver, or paid caregiver. 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 special need (Lifespan Respite Care Act, 2006). 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 person with a special need together.

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

Person with a Special Need – Sometimes referred to as a care recipient or person with a disability. This is the person to whom the provider delivers services. The person can be any age with any type(s) of disability. The Lifespan Respite Act includes the following definition: 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).

Participant Direction – Participant-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. Participant direction is sometimes referred to as consumer direction or self direction.

OVERVIEW OF PARTICIPANT DIRECTION

Participant direction (PD) is a service delivery model that empowers people with disabilities and their families by expanding their degree of choice and control over the long-term services and supports they need to live at home. In typical PD programs, the individual receiving the personal care services is the primary decision maker. Often times, he or she selects a representative to assist with decisions. The Lifespan Respite program differs from the typical PD approach in that the family caregiver is defined as the participant (person receiving respite services) and is therefore directing services. As a best practice, any decision about which provider is selected and how they deliver services should be made between the caregiver and the person with a special need. In the case of children with special needs, the decision might involve the whole family.

Participant direction represents a major paradigm shift in the delivery of funded home and community-based services (HCBS). In the traditional service delivery model, decision making and managerial authority is vested in professionals who may be either program employees or service providers. Participant direction transfers much (though not all) of this authority to people with disabilities and their families (when chosen or required to represent them).

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

- Providing a source for providers at times of worker shortages. Participant direction allows people to hire who they want to be providers, expanding the pool of available workers (Feinberg, Wolkwitz, & Goldstein, *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*, 2006). Many of the providers/workers 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 participant-directed respite, the family caregiver takes on more responsibilities, including the role of employer. This can lead to reduced administrative costs (Feinberg, Wolkwitz, & Goldstein, *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*, 2006). In addition, the support of the

program may lead to reduced institutional placements (Caldwell, 2007). These measures may have positive results on costs. For more cost information for participant direction, please see the [Cash & Counseling Final Report](#).

- Families, caregivers and individuals prefer to direct their own services and participant direction has an impact on satisfaction and involvement in the community (Heller, 2003). Family caregivers are more likely to choose participant 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” (Feinberg & Whitlatch, Family Caregivers and Consumer Choice: Options for In-Home Respite, Final Report, 1996). If caregivers are more likely to utilize participant-directed services, it may have greater impact on relieving caregiver burnout.

Choice is the hallmark of participant 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 participant direction does not work for them or to direct some of their services while receiving others from agency providers.

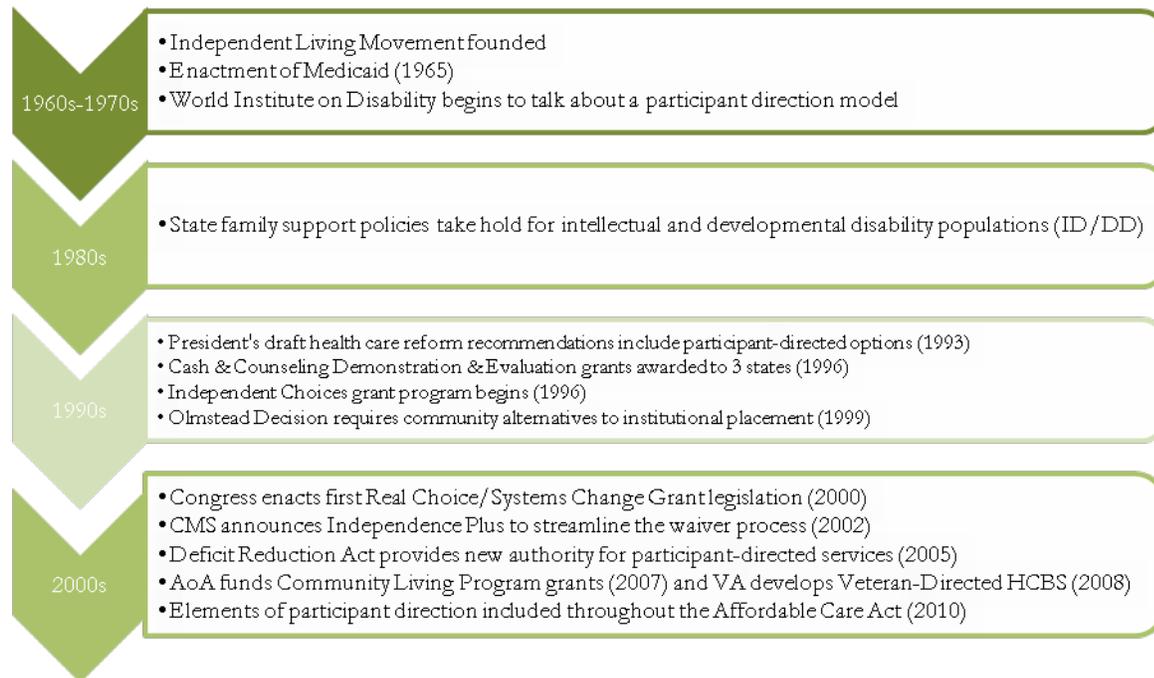
History of Participant Direction

The origins of participant-directed personal assistance services can be traced back more than 50 years. State officials saw what are now characterized as participant-directed services as a way to support and sustain the traditional role of family, friends, and neighbors in providing care to low-income older persons and individuals with disabilities. It was recognized that many family caregivers could not leave their relatives with severe disabilities alone and needed some “respite.”

The desire to reduce dependency on informal caregivers and alleviate caregiver stress led to the creation of some state-funded programs that provided cash allowances to caregivers. These funds could be used to purchase respite or for a variety of other purposes, such as reimbursement for out-of-pocket costs associated with caregiving and making home modifications.

The Lifespan Respite Care Act was enacted in 2006 in order to build the capacity for respite across the U.S., and help ensure that respite services are available to all families who need them. Lifespan Respite Programs have been in existence since 1997 when Oregon became the first state to create such a program. Since that time, other states have developed Lifespan Respite Programs; all are unique in their approaches, but have as a single goal to create a coordinated system of accessible, community-based respite services for all family caregivers regardless of age or special need. In 2009, the U.S. Administration on Aging (AoA) was given responsibility for program implementation and administration, and subsequently funded 12 competitive state grants for Lifespan Respite programs. Congress has appropriated \$2.5 million in 2009, 2010, and 2011 for these three-year Lifespan Respite Care grants and there are now thirty states with Lifespan Respite grants. Recently, several grantees have established participant direction for their programs.

Key Developments in Participant Direction



Overview of Respite

In 2009, it was estimated that 28.5% of the US population reported being a caregiver, with 65.7 million people as unpaid family caregivers to children and adults, including the aging population, with special needs. These caregivers provided an average of 20 hours of care per week (National Alliance for Caregiving & AARP, 2009). 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 and enjoy providing this care to 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 (Baker & Edgar, 2004).

Respite may be provided in a variety of settings, including the home, adult day care 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 that are available through parent or caregiver cooperatives, churches, 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, several Lifespan Respite Care grantees have implemented participant-directed respite services, primarily using a voucher system (In addition to the two case studies presented, a sample of publicly and privately administered participant-directed respite programs is included in Appendix I). While traditional programs that offer respite do so via agency staff that are trained as respite providers, participant-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 individual with the disability or special need.

Nationally, Medicaid supplies the majority of public funding to support participant direction through State Plan services and Medicaid waiver services. State programs may develop specific respite services under the 1915(c) authority using two different service delivery models: traditional agency respite services and participant-directed respite (See Appendix III for more detail). Many states require that providers meet basic minimum qualifications, for example requiring a criminal background check or training certification, which will in turn impact Medicaid participant-directed respite providers as well. Other models of participant direction with varying degrees of consumer/caregiver autonomy include individual budgets and agency-with-choice models (See Handbook Chapter 1 listed below for in depth descriptions). This guidebook will focus on voucher respite.

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

Additional Resources on Participant Direction Overview & History:

[Participant Direction Handbook, Chapter 1](#)

[Participant Direction Handbook, Chapter 3](#)

[State Approaches to Consumer Direction in Medicaid](#)

[How Can Consumer Direction Really Be Right For Everyone?](#)

[Family Caregivers and Consumer Choice: Options for In-Home Respite Care](#)

INVOLVEMENT IN THE PROGRAM

Research on programs' efforts to change their long-term services and supports systems—including those to initiate or expand participant direction programs—has found that their success depends to a significant extent on early and sustained stakeholder involvement and buy-in. People with disabilities or special needs and 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) 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 person with a special need 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, Area Agencies on Aging, the Arc, and other state advocacy networks to gain access to stakeholders.
- **Peer Support and Mentoring** – Support groups 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, and other organizations concerned with chronic conditions host support groups for individuals with disabilities or for 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 important for the process of collaboration.

Participant 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 Task Force to gather respite resources and increase availability and access across the state. Currently, participants contribute to the Alabama Respite Coalition, the local Sharing the Care initiatives, and a statewide faith-based coalition where respite programs are developed*. Essentially, participants are involved in the planning and development of respite programs throughout the state. Alabama Respite even offers stipends for caregivers to attend respite planning and organizational meetings.

Of course, caregivers are also able to direct their respite care services with the use of vouchers. Caregivers are able to select, hire, set the pay rate (up to \$10.00 per hour), and train the respite provider of their choice, whether that is a formal or informal provider, or a skilled or unskilled respite services. 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 care recipient.

Oklahoma’s Respite Resource Network (ORRN) - Not only are participants involved in the actual selection and direction of their respite care providers, but they are also members of ORRN. As members, many families and caregivers participate in planning and strategy sessions to sustain, improve, and build ORRN’s Voucher Program. As Rose Ann Percival, the Program Manager of ORRN, who has been with the program since its inception stated, “we never considered anything but a program that families and caregivers directed” (personal communication, 2011).

* Sharing the Care is a new volunteer initiative that was piloted in 2005, and has grown to other counties since 2009, with help from a Federal Lifespan Respite Care grant and a grant from Alabama Council for Developmental Disabilities. Each county or region participating brings together local stakeholders to increase access to respite, do public awareness regarding the need for respite, and find ways to increase respite resources by identifying faith-based organizations or other funding streams that might be specific to that community, such as community foundations or corporations.

Additional Resources on Involvement:

[Participant Direction Handbook, Chapter 3](#)
[National Participant Network Information & Resources](#)

PROGRAM STRUCTURE

There are structural systems that should be in place in order to create a functional participant-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 four, including: 1) the Director of Respite Services, who works out of United Cerebral Palsy of Huntsville & Tennessee Valley, Inc. (UCP); 2) the Alabama Respite Program Manager, housed in Anniston; 3) an Administrative Assistant who coordinates

the voucher program; and 4) and the coordinator of the Sharing the Care initiative, working from Montgomery, Alabama. 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.

Oklahoma’s Respite Resource Network - ORRN is unique in that it has no administrative costs, and all funds go directly towards respite vouchers to families. Oklahoma Developmental Disability Services Division (DDSD) and Aging Services Division within the Oklahoma Department of Human Services (DHS), each fund a portion of a full-time and part-time position at the Oklahoma Area-Wide Services Information System (OASIS) to deal solely with respite care. All other administrative costs are in-kind from DHS. Additional volunteers in both public and private agencies throughout the state serve as members of ORRN.

Marketing & Outreach

Outreach -providing information about the new program- is needed to ensure that all eligible and potentially eligible individuals know about the new participant-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 determined 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 participant 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 long-term services and supports.

To ensure that all potential participants have information about the program, several programs have translated outreach and enrollment materials into commonly spoken foreign languages. 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.

Marketing and Outreach Case Study Examples:

Alabama Lifespan Respite Resource Network - Alabama Respite goes to great lengths to ensure that families in need of respite know about the programs and are able to access vouchers to benefit from this service. Caregivers learn about the voucher programs through a variety of sources, including: 1) presentations in the community to service coordinators, caregivers, and other stakeholders; 2) media outreach via the television, radio, billboards, community news magazines, agency newsletters, and the internet; 3) membership in the Alabama Respite Coalition, Sharing the Care, and the faith-based 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, a demographic data sheet, and attaching proof of the care recipient's diagnosis, 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, ethnicity, educational level, household income, county of residence, and information regarding the care recipient's diagnosis.

Most of the Alabama Respite voucher programs developed because an agency approached Alabama Respite after hearing of the success of the original Children's Trust Fund (CTF) respite voucher program started in 1994. The remaining five UCP affiliates, the Department of Mental Health (DMH), and the South Alabama Regional Council on Aging (SARCOA), an Area Agency on Aging, have all asked Alabama Respite to replicate and manage a similar respite voucher program. Therefore, most support for the program has grown through previous successes and word-of-mouth.

On the other hand, Alabama Respite has found that some state agencies that have respite funding for family caregivers are reluctant to consider using their respite funding for something other than agency administered respite. Although they educate the state agencies to the cost-savings of using a voucher program, many are still resistant to the idea of offering participant direction in addition to agency provided respite to assure that primary supports and people with a special need have choices (i.e. instead of spending \$25-\$35 per hour to use agency provided care for everyone, they could be offering another option of spending \$10.00 per hour for participant-directed care). Alabama Respite continues to conduct outreach and training in the community regarding the benefits of offering alternatives and choice to primary supports through the use of participant-directed respite programs.

Oklahoma's Respite Resource Network - Although the founders of ORRN knew that respite was a much-needed yet unavailable service in Oklahoma, 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. Although Rose Ann Percival admits that you can never ensure 100% that the vouchers

will be spent in the way in which they say they are spent, for the most part, families need the service and will therefore use the vouchers appropriately (Percival, 2011).

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, ORRN members persisted with the type of participant-directed program that they envisioned. Their persistence developed into a model program that has assisted many families with meeting their respite care needs.

The system that is set up by ORRN is extremely family-friendly. It gives families one place to call to find information and obtain an application for respite services, regardless of the funding source. Staff at OASIS and DHS are knowledgeable about the various eligibility criteria set up by each individual funding source, and are able to easily and directly inform families and caregivers as to whether they are eligible and if funding is available. (More info on “marketing and outreach” in Appendix I).

Factors That Influence the Participation in a PD Respite Program

Several factors influence whether a family caregiver or person with a special need is interested in utilizing a participant-directed respite program.

Perhaps the most important factor that will affect individuals’ interest is their satisfaction or dissatisfaction with the service options currently available. Individuals in the traditional system who are satisfied with these 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.

Individuals’ willingness to enroll in participant 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.

Program administrators can provide information on the highlights of a new program. Administrators can also provide information on resources available, like worker registries, to help increase participation in the program.

Determining Eligibility

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

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

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

Eligibility Case Study Examples:

Alabama Lifespan Respite Resource Network - Eligibility for the voucher program is dependent on specific funding streams, with criteria set by the funder. Funding sources for Alabama Respite include: the Lifespan Respite Care grant, United Cerebral Palsy of Huntsville and Tennessee Valley, Federal stimulus funds, Department of Mental Health, Council for Development Disabilities, and various grant programs (Alabama Lifespan Respite Resource Network, 2010). Funding specifically for the voucher program comes from Alabama Department of Mental Health (DMH), Children's Trust Fund (CTF), Area Agency on Aging (AAA) of South Alabama, and a small community foundation grant in one county. The budget for the voucher program in FY2011 was \$334,882.

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. AAA of South Alabama has income guidelines and age requirements, and also serves grandparents of grandchildren with special needs. The community foundation grant is able to fund respite for caregivers who have no access to other funds for respite and live in a specific county.

Alabama Respite does keep a waitlist for their programs, although they make every effort to keep this list as small as possible. Currently, they have about 20 adults and 10 children on their waitlist; however, this does not account for a list that Alabama Respite maintains of families that do not qualify for any known statewide or local programs

Oklahoma's Respite Resource Network - Eligibility for respite vouchers is dependent on the funding stream, which includes federal, state, and private dollars. ORRN receives funding from the following: DDS, Aging Services Division, Maternal Child Health (Title V), Older Americans Act, Adoptions (Title IV-E), Child with Special Health Care Needs (Title V), SSI-Disabled Children's Programs, Temporary Cash Assistance for Needy Families (TANF) and Mental Health Systems of Care. Additionally, in partnership with several OK agencies, they received a three-year federal Lifespan Respite Care grant in FY2010. The program budget has grown from \$65,000 in 2000, to \$1.8 million in 2009 (Salehezadeh & Nguyen, 2009).

While most categories have no financial eligibility and are dependent only on eligibility related to the funding source, a few require that families earn less than \$60,000 per year to qualify (i.e. DDS, Maternal Child Health, and TANF). Subsequently, the following categories of people qualify for respite care vouchers in Oklahoma:

- families who are being served through the Oklahoma State Department of Health's Children First and Healthy Families programs;
- adoptive parents of a child who was formerly in the custody of the Department of Human Services (DHS) and who needs health and behavioral supports;
- parents of a child participating in the DHS SSI-Disabled Children's Program;
- caregivers providing care for a person with a developmental disability who is not receiving DHS Developmental Disabilities Services Division waiver services or the Family Support Assistance payment;
- caregivers with a family member age 60 or older who is not receiving Advantage waiver services;
- grandparents raising a grandchild;

- families with children being served through a mental health center that is contracted with the Department of Mental Health Substance Abuse Services; and
- two-parent families with children under the age of 18 who have any disability – physical, mental or chronic illness.

Oklahoma is now also able to serve those that do not meet any of the above criteria with Lifespan Respite Care grant dollars. In addition, they have an “emergency clause”, whereby ORRN will step in and help the family with additional money in extreme situations. As Rose Ann Percival stated, “Sometimes you just get a family that is collapsing and getting ready to explode, and you just need a little bit of money to keep that family together” (personal communication, 2011). The amount of money that a family may receive in vouchers is sometimes also dependent on the situation or need of the family, such as the number of children in the family or if the caregiver is taking care of a spouse in advanced stages of Alzheimer’s. ORRN often negotiates with funders, combines multiple funding sources, or finds flexible dollars to assist these families. They have found that it is often the “sandwich generations” that need additional funding (i.e. those family members taking care of a child with a disability as well as an aging parent).

Although ORRN does not keep a waitlist because of limited time and resources, they often review denied applications to better understand those that are not getting served or are underserved. Before receiving the Lifespan Respite Care grant, ORRN was turning away about 200-250 people each year simply because they did not qualify under one of the funding categories. Over the years, they have found that those groups not being served include those with a chronic illness, a neurological disease, and those between the ages of 18-55 years old without a developmental disability. The Lifespan Respite Care grant is used to help “plug these holes.”

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

This role is comprised of two broad activities—providing information about participant direction and providing assistance and training as needed with participant-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 participant 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 participant-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

Offering Information and Assistance Case Study Examples:

Alabama Lifespan Respite Resource Network - Alabama Respite supports caregivers by providing multiple caregiver training sessions through the Alabama Cooperative Extension Services program and statewide and local caregiver support groups, which teach caregivers about: 1) the need to take respite; 2) where respite is available in the state; and 3) how to access it. Once caregivers are connected with respite vouchers, Alabama Respite provides several documents that support the family in the provision of respite services. Specifically, a brochure is provided, entitled “Give Me a Break,” which provides brief information on finding and keeping respite providers, writing an agreement, and keeping records. Additionally, Alabama Respite has a twenty-page manual with detailed information regarding hiring a respite care provider available on the website for download and printing. Included in this manual is information on relationship roles, record keeping, 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, record keeping sheet, agreement contract, and advertisement for a respite provider are provided in the manual.

Oklahoma Respite Resource Network - ORRN has a ‘Respite Guide for Families’ that was developed by the Oklahoma State Department of Health, Office of Child Abuse Prevention that is distributed to families who receive respite vouchers. In terms of respite provider training, after speaking with families across Oklahoma, ORRN found that they desired disability specific training for their respite care providers, rather than general respite care training. Therefore, ORRN collaborated with partners in the community and received permission to allow caregivers and respite providers to access any training from the following

funding partners: Developmental Disabilities Service Division, Aging Services Division, Division of Child Welfare (Adoptions, Title IV-E), Family Support Services Division (Title V & TANF), Oklahoma State Department of Health and the Department of Mental Health and Substance Abuse Services. If the primary provider needs training for a respite provider, they call OASIS to connect them to the needed training, which has an updated training calendar from all participating agencies.

Financial Considerations

There are numerous tax thresholds that programs must take into account when setting acceptable payment amounts. If respite is being provided by a personal respite provider (rather than an agency or adult day care provider), then that provider will be classified by the Internal Revenue Service (IRS) as 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, 2007). If an employer ever pays an employee more than \$1,000 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. Consult with your state’s Department of Labor to determine local thresholds.

Furthermore, if a domestic employee earns \$1,700 or more in a calendar year, then both the employee and employer are liable for Federal Insurance Contributions Act (FICA) tax.

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 \$1,700 a year or \$1,000 in a quarter, they are not responsible for FICA or FUTA.

Another consideration is that, in some states, domestic employers are required to furnish a workers’ compensation policy. Many states do have exemptions for employers of domestic workers, so programs should review state requirements prior to starting a participant-directed program.

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. 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 family caregiver is responsible for payment to the respite provider, and reimbursement for respite services to the caregiver may take 30-60 days.

Oklahoma’s Respite Resource Network - ORRN utilizes the Oklahoma Department of Human Services (DHS) as a fiscal intermediary. DHS maintains a discrete account for each state agency that it contracts with, and upon receipt of authorization from an agency it issues and mails a voucher to the family or caregiver. In

order to increase the ease for both ORRN and families, accounts were developed through the DHS foundation. By going through a foundation, they are able to operate under foundation policies and procedures, significantly decreasing the number of steps and rules that must be followed by state agencies in dispersing money. This means that respite care providers are paid much quicker after a voucher is submitted; in fact, respite care providers are paid within 7-10 days of DHS receiving the completed voucher. DHS' assumption of these responsibilities eliminates the need for administrative fees, as the associated costs are paid for in-kind.

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

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. For more information about FMS, please watch [this FMS 101 video](#). Additional financial resources are listed at the end of this section.

How Can the Allocation Be Used?

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 both 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 – In Alabama Respite, caregivers can receive up to \$600 of vouchers each year to procure respite services. This figure is dependent on program demand, the availability of funds (in fiscal year 2011 the budget was over \$334,882), and specific funder requirements. As a result of increasing demand, the frequency with which funds are offered varies from quarterly for some funders to annually for others.

Oklahoma's Respite Resource Network - ORRN provides participating caregivers with \$200-\$400 of vouchers quarterly as long as funds are available. As in Alabama, the specific figure depends on the authorizing agency; all but one Area Agency on Aging (AAA) in Oklahoma participates in ORRN and each has a different allowable amount. The determining factors are mainly demographic, such as the number of children that the caregiver has. The general yearly limit is \$1,200, but funders are able to make exceptions to this rule. To date, there have been two instances that justified exceeding this cap. Such scenarios are examined and funding amount determined on a case-by-case basis by program staff.

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 in three months, without the ability to roll over funds to future vouchers, in both Alabama Respite and ORRN.

Rate Setting

The Companionship Exemption in the Fair Labor Standards Act (FLSA) allows household workers who are serving as companions of their employers to be paid less than minimum wage and to not be paid overtime for hours worked in excess of 40 per week. The Department of Labor defines a domestic/household employee as someone who provides services of a household nature in or about a private home (permanent or temporary) of the person by whom he or she is employed. This is important because in states that recognize the Companionship Exemption, caregivers have much more flexibility in the rates that they can set.

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

Rate Setting Case Study Examples:

In both Alabama Respite and ORRN, the caregiver is allowed to set the rate, maximizing their choice and control and adhering to the principles of participant direction. In Oklahoma, the caregiver receives a book of six blank vouchers and can use up to their total allotment in any way they choose. The desired rate is written on the voucher, which is then signed by all parties and then submitted to ORRN who pays the provider. The average payment in the program is around \$6/hour. Alabama Respite has a \$10/hour limit, but no minimum hourly rate.

Additional Resources on Program Structure:

Early Considerations for Program Administrators

Developing and Implementing Participant Direction Programs and Policies: A Handbook

Changing Practices and Roles: Case Managers as Consumer-Directed Counselors

Person Centered Planning for Consumer-Directed Care

Fair Labor Standards Act Tip Sheet

IRS Notice 2003-70

Handbook Chapter 7: Fiscal/Employer Agent Services

QUALITY & RISK MANAGEMENT

Whether a participant-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 participant-directed programs because agencies will not be supervising home care or respite workers or protecting participants from fraud, abuse, and neglect.

The Cash & Counseling Demonstration and Evaluation showed that participants and their families care deeply about quality and that the participant-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, Carlson, Dale, Foster, Phillips, & Schore, 2007). Successful quality management strategies in participant-directed programs view caregivers and people with special needs 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 participant-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. These include:

- Is the individual satisfied with services and supports?
- Are individual rights, desires and preferences acknowledged as key?
- Is well-being 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?

A quality system is one that sets expectations, builds a process to meet those expectations, measures and determines if the processes are in place and are they effective, and works to continuously improve the system. All these components are integral to designing and operating a quality program.

A second essential part of quality is to observe how the program is doing. Is it meeting its intended purpose? Is it operating as required by its funding source? This step includes collecting data, analyzing results, assessing performance, and identifying areas needing improvement. This phase produces information that can be used to inform and guide management and policy development.

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 reoccurrences of problems.

A Few Quality Tips

Establish operational policies, procedures, and practices – Policies, procedures, and practices specific to participant direction should be clearly specified to set realistic expectations and provide clear direction. These should be consistently applied throughout the program. Participant 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, participant 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 participant direction programs.

Monitor the Program – Monitoring can take many different forms. Programs can and do use their existing monitoring staff—as long as training is conducted on participant direction—to oversee the performance of providers unique to participant 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 are 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 over-spending.

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.

Quality & 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. Java Bennett, the Director of Respite Services, reported that there have only been a few issues with the vouchers in the eighteen years

that they have been implementing the programs. One in particular that she remembers involved a caregiver reporting that they did not receive money that was mailed and the check cashed, although another person with the same name and family member in a different part of the state had received the voucher reimbursement. It was determined within the agency that this was a case of fraud and the family would no longer qualify for respite services (Bennett, Lamberth, & Formby, 2011).

Alabama Respite has done satisfaction surveys over the years with CTF grants focusing mainly on addressing if respite is effective as a prevention technique for child abuse and neglect. For example, CTF requires that an evaluation survey is 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 that they could receive more money in vouchers.

In 2011, they will administer a survey that is specific to respite services with the DMH funding. This will help them share information with their funders regarding the benefits of respite, but also provide Alabama Respite staff with information on satisfaction with services and any unmet needs. However, Alabama Respite staff are in constant contact with the families receiving respite vouchers, so they are hoping that the surveys will mainly serve to reinforce what they hear in regular conversations with families and caregivers.

Data Collection

As mentioned, 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. Additionally, they collect and track demographic data from the demographic form that caregivers are asked to complete with the enrollment form. Families are asked to update this demographic form annually. General contact information, income, age, ethnicity, and educational level are collected regarding the caregiver, along with diagnosis information about the care recipient. Most of this information is collected because of reporting requirements from funders. Finally, all caregivers using vouchers are given an opportunity annually, using an open questionnaire format, to share their “story” about how they used respite and in what ways it was helpful.

Oklahoma’s Respite Resource Network - ORRN uses a few different methods to manage risk and ensure a quality program. First, by having one point of entry – OASIS – they can minimize duplication across agencies. Additionally, the voucher system 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 caregiver are required to sign the voucher. Finally, ORRN performs random audits of respite families every other year. This “look-back audit” involves home visits to a random 3% of the families being served with respite vouchers. Above all, Percival notes, “because you have taken away a lot of the barriers, most people will do exactly what they say they are doing because they are able to directly purchase a service that they need” (personal communication, 2011). There have only been six cases of confirmed fraud in the 11 years that ORRN has issued vouchers. These families receive a red flag in the system for at least two years, which bans them from using the program.

ORRN has conducted program evaluations throughout the years. These have mostly consisted of surveys sent to families and caregivers that utilize ORRN services. In their most recent evaluation, conducted in 2009, they found that over 80% strongly agreed that respite relieved stress in their family, almost 80% strongly agreed that the financial assistance of the respite vouchers helped them to take care of social and/or personal

needs, and 94% were either very satisfied or extremely satisfied with the ORRN respite voucher program (Salehezadeh & Nguyen, 2009). In addition, the survey assists ORRN in evaluating and communicating the cost-effectiveness of the respite voucher program; they have been able to show that, on average, respite costs about \$6 per hour.

Data Collection

As mentioned above, ORRN does periodically collect some information from a selection of its participants. The survey asks about the type of person providing respite care, demographics of the caregiver and care receiver (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 ORRN as a program. Additionally, ORRN collects and tracks some information that is provided on the Respite Voucher Program application, including annual income, age, gender, relationship between caregiver and care receiver, number of household members, marital status, race/ethnicity, and type of disability/need.

Additional Resources on Quality & Risk Management:

[Safe at Home? Developing Effective Criminal Background Checks and Other Screening](#)

[Policies for Home Care Workers](#)

[Fraud & Abuse Webinette](#)

[Managing Changes: Introducing Consumer Direction to Aging Network Management](#)

Additional General Resources for Participant Direction:

[Participant Direction Handbook](#)

[National Resource Center for Participant-Directed Services Website](#)

[Home and Community-Based Services Clearinghouse Website](#)

[National Resource Center for Participant-Directed Services' Videos](#)

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Appendix I: Case Studies and Additional State Examples

Oklahoma Respite Resource Network (ORRN)

The Oklahoma Respite Resource Network (ORRN) is an informal coalition of private and public agencies who have voluntarily come together to increase the availability of respite for families and caregivers. ORRN was formed in 1998, after a group of five practitioners in the field found that respite was one of the most needed, yet unavailable services in the community. This group of five grew to a Respite Task Force of 35 partners, including the Department of Human Services, Developmental Disabilities Services Division (DDSD), Division of Children and Family Services (DCFS), Oklahoma Health Care Authority (OHCA), Oklahoma State Department of Health, Department of Mental Health and Substance Abuse, and the Oklahoma Area-Wide Services Information System (Oklahoma Respite Resource Network, 2010). The Respite Task Force worked to build the infrastructure needed to meet the respite care needs of families in Oklahoma. The Task Force soon became ORRN, with a strong focus on participant-directed services in the form of a respite voucher program. They issued their first voucher in 2000.

ORRN is housed within the Oklahoma Area-Wide Services Information System (OASIS). OASIS provides free statewide information, referrals, and one-on-one assistance in locating services for adults and children with disabilities. OASIS is the entry point for applications and information regarding respite services. OASIS receives the completed application and forwards it on to ORRN to approve. Once approved, vouchers are sent to families, which they then use to hire a respite care provider of their choice. Another partner is the Department of Human Services (DHS), which acts as the fiscal intermediary. DHS issues and mails the vouchers to the family or caregiver, receives the completed vouchers and sends the payment directly to respite care providers.

The system that is set up by ORRN is extremely family-friendly. It gives families one place to find information and obtain an application for respite services, regardless of the funding source. Staff at OASIS and DHS are knowledgeable about the various eligibility criteria set up by each individual funding source, and are able to easily and directly inform families and caregivers as to whether they are eligible and if funding is available. DHS is able to maintain discrete accounts by program, county, area, and statewide designation; therefore, they established accounts earmarked for specific programs and geographical areas. Additionally, in order to increase the ease for both ORRN and families, accounts were developed through the DHS foundation. By going through a foundation, they are able to operate under foundation policies and procedures, significantly decreasing the number of steps and rules that must be followed by state agencies in dispersing money. This means that respite care providers are paid much more quickly after a voucher is submitted, usually within 7-10 days of DHS receiving the completed voucher.

Participant Involvement

Rose Ann Percival is the current Chair of ORRN, and has been with the program since its inception. As she stated, “we never considered anything but a program that families and caregivers directed” (personal communication, 2011). 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 and firing their own respite care providers, respite care is now more accessible and widely used.

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) the provider cannot live in the same house as the person receiving care. This can include informal providers, such as family, friends and co-workers, as well as formal providers, such as child care centers, adult day care 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. If the family or caregiver needs assistance in finding a provider, OASIS will provide referrals. Caregivers can use the voucher for respite either in the home or in an adult day care center, childcare center, or recreational program setting.

Not only are participants involved in the actual selection and direction of their respite care providers; they are also members of ORRN. As members, many families and caregivers participate in planning and strategy sessions to sustain, improve and build ORRN's voucher program.

How the Oklahoma Respite Voucher Works

Once a caregiver is approved for respite, they receive six vouchers that are assumed to be worth the amount of money for which they have been approved. A guidebook that explains how to use the vouchers is sent to each family. Each voucher has a space to write the balance at the top. For example, if they have \$400 and spent \$100 on the first voucher, then they would put the balance of \$300 at the top of the next voucher. Once the respite is provided, both the provider and caregiver fill out the voucher, which includes the amount claimed, the agreed hourly amount, and the provider's address and social security number. The caregiver and provider each sign the voucher and the caregiver sends it to DHS. Given that these are already encumbered funds, a check is immediately sent to the provider. If the caregiver uses all six vouchers, they can request more blank vouchers. The average amount of vouchers that caregivers use is four. Families are given the option to spend their entire voucher at once, or stretch it out over a three-month period. After three months, given the availability of funds, the caregiver is eligible for additional vouchers, and the process repeats.

Marketing and Outreach

ORRN relies on OASIS, which is widely used as an information and referral line for people with disabilities, and the internet to link families to the program. Outreach includes: OASIS statewide conference presentations, disability-specific conferences across the state, articles and newsletters and an ORRN brochure.

To enroll in the program, families and caregivers simply have to call OASIS to determine if they qualify, and subsequently receive an application. The two-page application asks basic demographic questions related to the caregiver and person with a special need, why the caregiver is requesting respite and special needs of the care receiver. Additionally, applicants are required to provide proof of Medicaid or Social Security Income. If they do not receive either of these sources of income, then they must submit the first page of their tax return to show their adjusted gross income. As described above, after the application is received by OASIS, it is forwarded on to DHS staff, who approve and issue vouchers. OASIS maintains a database of all applications.

ORRN is unique in that it has no administrative costs, and all funds go directly towards respite vouchers for families. Oklahoma Developmental Disability Services Division (DDSD) and Aging Services Division within the Oklahoma DHS, each fund a portion of a full-time and part-time position at OASIS to deal solely with respite. All other administrative costs are in-kind from DHS. Additional volunteers in both public and private agencies throughout the state serve as members of ORRN.

Eligibility and Budgeting

Eligibility for respite vouchers is dependent on the funding stream, which includes federal, state and private dollars. ORRN receives funding from the following: DDSD, Aging Services Division, Maternal Child Health (Title V), Older Americans Act, Adoptions (Title IV-E), Child with Special Health Care Needs (Title V), SSI-Disabled Children's Programs, Temporary Cash Assistance for Needy Families (TANF) and Mental Health Systems of Care. Additionally, in partnership with several Oklahoma agencies, they received a three-year federal Lifespan Respite Care grant in FY2010. The program budget has grown from \$65,000 in 2000, to \$1.8 million in 2009 (Salehezadeh & Nguyen, 2009).

While most categories have no financial eligibility and are dependent only on eligibility related to the funding source, a few require that families earn less than \$60,000 per year to qualify (i.e. DDSD, Maternal Child Health, and TANF). Subsequently, the following categories of people qualify for respite vouchers in Oklahoma:

- families who are being served through the Oklahoma State Department of Health's Children First and Healthy Families programs;
- adoptive parents of a child who was formerly in the custody of the Department of Human Services (DHS) and who needs health and behavioral supports;
- parents of a child participating in the DHS SSI-Disabled Children's Program;
- caregivers providing care for a person with a developmental disability who is not receiving DHS Developmental Disabilities Services Division waiver services or the Family Support Assistance payment;
- caregivers with a family member age 60 or older who is not receiving Advantage waiver services;
- grandparents raising a grandchild;
- families with children being served through a mental health center that is contracted with the Department of Mental Health Substance Abuse Services; and
- two-parent families with children under the age of 18 who have any disability – physical, mental or chronic illness.

Oklahoma is now also able to serve those that do not meet any of the above criteria with Lifespan Respite Care grant dollars. In addition, they have an "emergency clause", whereby ORRN will step in and help the family with additional money in extreme situations. As Rose Ann Percival stated, "Sometimes you just get a family that is collapsing and getting ready to explode, and you just need a little bit of money to keep that family together" (personal communication, 2011). The amount of money that a family may receive in vouchers is sometimes also dependent on the situation or need of the family, such as the number of kids in the family or if the caregiver is taking care of a spouse in advanced stages of Alzheimer's disease. ORRN often negotiates with funders, combines multiple funding sources, or finds flexible dollars to assist these

families. They have found that it is often the “sandwich generations” that need additional funding (i.e. those family members taking care of a child with a disability as well as an aging parent).

Vouchers are between \$200-\$400 for three months as long as funds are available. 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. To date, there have been two instances that justified exceeding this cap. At the end of the three months, the caregiver only needs to call OASIS and request another set of vouchers for the following three months. Every two years, the family or caregiver is required to complete a new application. Given that funding of the vouchers is not an entitlement, but rather based on available dollars, voucher renewal every three months cannot be automatic. Towards the end of the fiscal year, ORRN may run out of funding; consequently, they must tell families to wait for the beginning of the next fiscal year to receive more vouchers.

ORRN utilizes the Oklahoma DHS as a fiscal intermediary. DHS maintains a discrete account for each agency that it contracts with, and upon receipt of authorization from an agency, it issues and mails a voucher to the family or caregiver. DHS’ assumption of these responsibilities eliminates the need for administrative fees, as the associated costs are paid for in-kind.

Although ORRN does not keep a waitlist because of limited time and resources, they often review denied applications to better understand those that are not getting served or are underserved. Before receiving the Lifespan Respite Care grant, ORRN was turning away about 200-250 people each year simply because they did not qualify under one of the funding categories. Over the years, they have found that the groups not being served include those with a chronic illness, a neurological disease, and those between the ages of 18-55 years old without a developmental disability. The Lifespan Respite Care grant is used to help “plug these holes.”

Supporting Provision of Respite Services

ORRN has a ‘Respite Guide for Families’ that was developed by the Oklahoma State Department of Health, Office of Child Abuse Prevention that is distributed to families who receive respite vouchers. In terms of respite provider training, after speaking with families across Oklahoma, ORRN found that families desired disability specific training for their respite providers, rather than general respite training. Therefore, ORRN collaborated with partners in the community and received permission to allow caregivers and respite providers to access training from the following funding partners: Developmental Disabilities Service Division, Aging Services Division, Division of Child Welfare (Adoptions, Title IV-E), Family Support Services Division (Title V & TANF), Oklahoma State Department of Health and the Department of Mental Health and Substance Abuse Services. If the family caregiver needs training for a respite provider, they call OASIS to connect them to the needed training. OASIS keeps an updated training calendar from all participating agencies.

Quality and Risk Management

ORRN uses a few different methods to manage risk and ensure a quality program. First, by having one point of entry – OASIS – they can minimize duplication across agencies. Additionally, the voucher system 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. Finally, ORRN conducts random audits of respite families every other year. This “look-back audit” involves home visits to a random 3% of the families being served with respite vouchers. Above all, Rose Ann notes, “because you have taken away a lot of the barriers, most people will do exactly what they say they are doing because they are able to directly purchase a service that they need” (personal communication, 2011). There have only been six cases of confirmed fraud in the 11 years that ORRN has issued vouchers. These families receive a red flag in the system for at least two years, which bans them from using the program.

ORRN has conducted a couple of different program evaluations. These have mostly consisted of surveys sent to families and caregivers that utilize ORRN services. In their most recent evaluation, conducted in 2009, they found that: over 80% strongly agreed that respite relieved stress in their family; almost 80% strongly agreed that the financial assistance of the respite vouchers helped them to take care of social and/or personal needs; and 94% were either very satisfied or extremely satisfied with the ORRN respite voucher program (Salehezadeh & Nguyen, 2009). In addition, the survey assisted ORRN in evaluating and communicating the cost-effectiveness of the respite voucher program; they have been able to show that, on average, respite costs about \$6 per hour.

Data Collection

As mentioned above, ORRN does periodically collect some information from a selection of its participants. The survey asks about the type of person providing respite, demographics of the caregiver and person with a special need (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 ORRN as a program. Additionally, ORRN collects and tracks some information that is provided on the Respite Voucher Program application, including annual income, age, gender, relationship between caregiver and person with a special need, number of household members, marital status, race/ethnicity, and type of disability/need.

Building Support for the Program

Although the founders of ORRN knew that respite was a much needed, yet unavailable service in Oklahoma, 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. Although Rose Ann Percival admits that you can never completely ensure that the vouchers will be spent in the way in which they are intended, for the most part, families need the service and will therefore use the vouchers appropriately (Percival, 2011).

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, ORRN members persisted with the type of participant-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

Over the past twelve years, ORRN 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 participant-directed voucher system can learn from ORRN's experiences.

Successes:

- Getting the cooperation of several agencies, including the major public agencies in Oklahoma. Not only did these agencies collaborate with ORRN, they took on major roles in the organization, all as in-kind contributions. For example, DHS offered to be the fiscal agent, OASIS houses the program, and DDS and Aging Services provide funding for a full-time staff member.
- ORRN is simple and runs incredibly smoothly. With the cooperation of 35 members, including public and private agencies, as well as caregivers and people with special needs, they have been able to offer a program that is easy to run and simply provides a needed service. As Percival notes, "we try to keep it really simple so that we don't get so involved in other things that we lose sight of actually finding the money to serve families" (personal communication, 2011).
- Every dollar that is provided to ORRN goes to a family in the form of respite vouchers. With all administrative costs in-kind from different organizations, money not only is able to go directly to families, recruiting donations is much easier and more fruitful.

Challenges:

- Expanding the availability of respite, especially for families without immediate family in the area. There are many caregivers interested in participant-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 for ORRN to work with these families to locate appropriate respite providers.
- Funding. Money will always be a challenge, especially in more difficult economic times. ORRN still does not have enough funding to meet the needs of all families, and often is forced to turn people away when funding is depleted.

Lessons Learned:

- Putting a time limit on the use of vouchers. As explained above, respite vouchers expire at the end of three months. ORRN 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 three-month time limit allows ORRN to recover the unused money and provide it to other families needing respite.
- Setting income eligibility criteria high enough to provide services to those that do not qualify for other programs, but also serving the people that really need it the most. By analyzing their community, ORRN found that those families taking care of a child or adult with a disability, or an aging family member with a household income from \$32,000 - \$60,000, do not qualify for government programs but still live in poverty. While remaining cognizant of the fact that they have limited dollars and need to serve those most in need, they feel that \$60,000 is an appropriate limit for income eligibility, where it is applicable.

- Staying in contact with participants. ORRN remains in contact with many of their participants. Participants are not only involved in meetings to help with development of the program, but ORRN also actively solicits family and caregiver opinions regarding program satisfaction and changes.

The Oklahoma Respite Resource Network is one of the longest running participant-directed respite programs in the country, and was used as a model when the Lifespan Respite Care Act was first developed. They have many plans for the future of the program, including: 1) using money from the Lifespan Respite Care grant to provide seed grants to organizations developing innovative respite programs, such as a family night out event or a day camp for children with disabilities; and 2) transitioning to an Electronic Benefits Transfer (EBT) system for the respite vouchers, in which families and caregivers will have the money for vouchers deposited directly into an account that they could use to pay a provider. As is evident, ORRN is a well-established participant-directed program. They are continually evaluating their program with input from participants in order to make changes and evolve over time. ORRN provides an invaluable service in Oklahoma by increasing the availability and accessibility of respite services for many families and caregivers.

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Alabama Lifespan Respite Resource Network

The Alabama Lifespan Respite Resource Network (Alabama Respite) is a statewide resource and referral program with a mission “to increase the availability of and accessibility to high-quality respite care services across the lifespan” (Alabama Lifespan Respite Resource Network, 2010). The primary goal of Alabama Respite is to maintain a database of known respite programs and facilitate expansion of respite resources; they also create new options for respite services, advocate for increased funding, support a statewide respite coalition, provide public awareness regarding respite care and manage voucher respite programs.

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 non-profits. 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. Currently, they are piloting a voucher respite program with Southern Alabama Regional Council on Aging (SARCOA), one of Alabama’s thirteen Area Agencies on Aging (AAAs). Finally, Alabama Respite has a small Community Foundation grant that provides gap funding for respite vouchers in one county in Alabama.

All voucher programs are run with similar policies and procedures. Families requesting respite call the Alabama Respite office, or go on the Alabama Respite website in order to complete an enrollment form. After Alabama Respite staff approves the respite request, the family is mailed 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.

Staff at Alabama Respite have worked hard to develop the program over time, making changes with input from participants. Currently, they have identified and approved about 800 families from DMH and 150 families who could use CTF funding for respite services. Of those, about 500 families request and receive respite vouchers annually. 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 participant-directed respite programs. They have also created many forms to use in a voucher respite program that can easily be adapted; most of these forms can be found on their website:

www.alabamarespite.org.

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 Respite Coalition, the local Sharing the Care initiatives, and a statewide faith-based coalition where respite programs are developed.² Essentially, participants are involved in planning and development of respite programs throughout the state. Alabama Respite offers stipends for caregivers to attend respite planning and organizational meetings.

Caregivers are able to direct their respite services with the use of vouchers. Caregivers are able to select, hire, set the pay rate (up to \$10.00 per hour), and train the respite provider of their choice, whether that is a formal or informal provider, or a skilled or unskilled respite. 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 are mailed a brochure about Alabama Respite, a pamphlet 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, but ranges from \$100 - \$600 per year, and may be issued quarterly, bi-annually, 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 in the community to service coordinators, caregivers and other stakeholders; 2) media outreach via the television,

² Sharing the Care is a new volunteer initiative that was piloted in 2005, and has grown to other counties since 2009, with help from a Federal Lifespan Respite Care grant and a grant from ACDD. Each county or region participating brings together local stakeholders to increase access to respite, raise public awareness regarding the need for respite and find ways to increase respite resources by identifying faith based organizations or other funding streams that might be specific to that community, such as community foundations or corporations.

radio, billboards, community news magazines, agency newsletters and the internet; 3) membership in the Alabama Respite Coalition, Sharing the Care, and the faith-based 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, a demographic data sheet, and attaching proof of the care recipient's diagnosis, 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, ethnicity, educational level, household income, county of residence and information regarding the care recipient's diagnosis. 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 four, including: 1) the Director of Respite Services, who works out of the UCP in Huntsville; 2) the Alabama Respite Program Manager, housed in Anniston; 3) an Administrative Assistant who coordinates the voucher program; and 4) and the coordinator of the Sharing the Care initiative, working from Montgomery. 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 Lifespan Respite Care grant, United Cerebral Palsy of Huntsville and Tennessee Valley, Federal stimulus funds, Department of Mental Health, Council for Development Disabilities and various grant programs (Alabama Lifespan Respite Resource Network, 2010). Funding specifically for the voucher program comes from DMH, CTF, AAA of South Alabama, and a small community foundation grant in one county. The budget for the voucher program in FY2011 was \$334,882.

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. SARCOA has income guidelines and age requirements, and also serves grandparents of grandchildren with special needs. The community foundation grant is able to fund respite for caregivers who have no access to other funds for respite and live in a specific county.

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 about 20 adults and 10 children on their waitlist; however, this does not account for a list that Alabama Respite maintains of families that do not qualify for any known statewide or local programs. Most of the funding for the Alabama Respite Voucher programs is for children with disabilities or children and adults with intellectual disabilities. They are piloting a program for older adults with SARCOA, and are able to refer families to other available respite voucher programs in the state, such as the Head Injury Foundation and Medicaid programs. Nonetheless, they find that there are many gaps in services, especially for those with chronic illnesses and those age 19 – 55 years old.

In Alabama Respite, caregivers can receive up to \$600 of vouchers each year to procure respite services. This figure is dependent on program demand, the availability of funds (in fiscal year 2011 the budget was over

\$334,882), and specific funder requirements (Alabama Lifespan Respite Resource Network, 2010). As a result of increasing demand, the frequency with which funds are offered varies from quarterly for some funders to annually for others. Vouchers expire in three months, without the ability to roll over remaining funds to future vouchers.

The caregiver is allowed to set the payment rate with some restrictions. The program has a \$10/hour limit, but no minimum hourly rate. It is not uncommon for a provider to be paid a set amount for an extended period of time (for example, \$100 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

Alabama Respite supports caregivers by providing multiple caregiver training sessions through the Alabama Cooperative Extension Services program and statewide and local caregiver support groups, which teach caregivers about: 1) the need to take respite; 2) where respite is available in the state; and 3) how to access it. Once caregivers are connected with respite vouchers, Alabama Respite provides several documents that support the family in the provision of respite services. Specifically, a brochure is provided, entitled “Give Me a Break,” which provides brief information on finding and keeping respite providers, writing an agreement and keeping records. Additionally, Alabama Respite has 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.

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. Java Bennett, the Director of Respite Services, reported that there have only been a few issues with the vouchers in the eighteen years that they have been implementing the programs. She remembers one in particular that involved a caregiver reporting that they did not receive money that was mailed and the check cashed, although another person with the same name and family member in a different part of the state had received the voucher reimbursement. It was determined within the agency that this was a case of fraud and the family would no longer qualify for respite services (Bennett, Lamberth, & Formby, 2011).

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 is 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.

In 2011, they will administer a survey that is specific to respite services with the DMH funding. This will help Alabama Respite share information with their funders regarding the benefits of respite, but also provide staff with information on satisfaction with services and any unmet need. However, Alabama Respite staff are in constant contact with the families receiving respite vouchers, so they are hoping that the surveys will mainly serve to reinforce what they hear in regular conversations with families and caregivers.

Data Collection

As mentioned, 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. Additionally, they collect and track demographic data from the enrollment form. Families are asked to update this demographic information annually. General contact information, income, age, ethnicity and educational level are collected from the caregiver, along with diagnosis information about the care recipient. Most of this information is collected because of reporting requirements from funders. Finally, all caregivers using vouchers are given an opportunity annually, using an open questionnaire format, to share their “story” about how they used respite and in what ways it was helpful.

Building Support for the Program

Most of the Alabama Respite voucher programs developed because an agency approached Alabama Respite after hearing of the success of the original CTF respite voucher program started in 1994. The remaining five UCP affiliates, DMH and SARCOA have all asked Alabama Respite to replicate and manage a similar respite voucher program. Therefore, most support for the program has grown through previous successes and word of mouth.

On the other hand, Alabama Respite has found that some state agencies that have respite funding for primary providers are reluctant to consider using their respite funding for something other than home healthcare agencies. Although they educate the agencies to the cost-savings of using a voucher program, many are still resistant to the idea (i.e. instead of spending \$25-\$35 per hour to use a home health agency, they could be spending as little as \$10.00 per hour). Alabama Respite continues to conduct outreach and training in the community regarding the benefits of participant-directed respite programs.

Successes, Challenges, and Lessons Learned

The Alabama Lifespan Respite Resource Network has had many successes, challenges and lessons learned over year 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:

- Being flexible as a program, and also offering flexibility to the participants. Alabama Respite has taken the time to talk with their participants, listen to any concerns, and make appropriate changes when needed. Additionally, the voucher program itself has enabled caregivers to have a vast amount

of flexibility, including the ability to choose their own providers, train them, handle payment themselves and receive respite at times that work for their family.

- Support for caregivers receiving respite vouchers. Alabama Respite has several documents, described in detail above, that assist caregivers with all aspects of hiring and managing their own respite providers. In addition, they provide trainings in the community, and remain in constant contact with the families. This support is invaluable to many caregivers who have never hired or trained someone to look after their loved one.

Challenges:

- Funding to be able to provide enough money for consistent respite. Alabama Respite continually struggles with being able to serve everybody, but also ensuring that they are receiving enough money. As Bennett notes, “at some point you have a finite amount of money and it gets down to everybody gets \$80 a year and that’s not even close to best practice” (personal communication, 2011). Options they have considered include implementing a first come, first serve system, or providing more money to new families.
- Training respite providers and having them listed in a central place. Often, caregivers ask Alabama Respite for assistance in finding a respite provider, but at this point, funding does not allow for Alabama Respite to train, certify and complete background checks for respite providers. Some other state agencies have providers, but the caregiver may not qualify to get their services. Increased communication among state agencies could help with instituting one central place for a caregiver to go to find out if they qualify for respite. If they do qualify, but do not have someone whom they trust to provide the respite, then connecting the caregiver with a trained respite provider is essential.

Lessons Learned:

- Time limits on the use of vouchers. In the very beginning, Alabama Respite learned that if they allowed families to roll over money, it often never got used and was difficult to retrieve. Some caregivers wanted to save their money just in case they needed it later. Because they risked losing funding if it was not all used at the end of the year, they began requiring the expenditure of vouchers within a shorter time period. If they are not used, then the caregiver loses that money and Alabama Respite is able to put it back in the pot for others to benefit. Primary providers are not penalized if they fail to use a voucher in the designated time and they are able to request another voucher for the subsequent time period.
- It is essential to have a staff coordinator or manager of the program. Alabama Respite staff feel that a voucher respite program needs staff support in order to ensure that it runs smoothly. At first, the program funded by DMH was run by volunteers; the result was families not getting their reimbursements in a timely manner, inconsistent program reporting and unreliable financial tracking. Alabama Respite realized early on that “the voucher program must have a person responsible for all the pieces coming together and making the program work” (Bennett, Lamberth, & Formby, 2011).
- There are many options for primary providers to take a much needed break. There are many different types of respite or ways respite may be delivered. For example, a paid family member, or a volunteer from a faith-based organization could provide respite. Alabama Respite staff feel that they need to stay informed of all the options, as well as think of creative alternatives to offer respite; then it is their job to educate communities and caregivers about all that they may have available to them.

Above all, “it takes an extreme amount of passion by the people working on it” (Bennett, Lamberth, & Formby, 2011).

Alabama Respite has worked for the last 18 years to ensure that respite resources are available and easily accessible for Alabama caregivers. The staff stand behind their mission and look toward the future with some exciting new programs and resources. As part of the Sharing the Care initiative in Birmingham, they are training students from a local university to be respite providers, and then utilizing their services when a caregiver needs assistance with locating a respite provider. They are hoping to duplicate this in other communities in the future. Additionally, they are developing a single system to track receipt of respite in the state. Currently, the lack of communication across agencies and respite programs creates a situation where services may be duplicated. With limited resources, having a single tracking system will increase the availability of respite vouchers by inhibiting some families from receiving multiple resources while others have none. Through the provision of respite vouchers, but also because of their advocacy and education across the state, Alabama Respite continues to secure funding and increase the availability of respite services to caregivers throughout Alabama.

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State Examples

There are many programs implementing participant-directed respite services in addition to the two 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 participant direction.

State	Brief Description	For Additional Information
California	<p>For more than two decades, California’s Caregiver Resource Centers (CRCs) have supplied information, education, respite and support to hundreds of thousands of California families and friends. Some of the counties in California offer participant-directed respite services using Title III-E Older American’s Act funding. These programs allow caregivers to use vouchers to hire someone privately, use an agency or registry to find a provider, go to a day program, have a short term facility visit or attend a respite camp. The majority of caregivers enrolled in participant-directed respite choose to hire someone they know to provide services.</p> <p>Although funding has been affected by the current financial climate, the CRC system recognizes that respite services need to be consistent and ongoing to be effective. Vouchers may be used throughout a fiscal year but do not carry over from year to year.</p>	<p>Call the National Center on Caregiving for technical assistance: 415.434.3388</p>
Maryland	<p>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. 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.</p> <p>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.</p>	<p>http://dhr.maryland.gov/oas/respite.php</p>
Nebraska	<p>The 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).</p>	<p>http://www.hhs.state.ne.us/hcs/programs/Lifespan-Respite.htm</p>

	<p>Participants are allowed to hire whomever they want to provide respite.</p> <p>Once respite has been provided the participant and provider sign and submit a billing document. The participant/parent may choose 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.</p>	
New Hampshire	<p>The Bureau of Developmental Services is a bureau within the Department of Health and Human Services which contracts with ten private, nonprofit agencies to provide developmental services to individuals and families statewide. Each agency has an allocation of funds (primarily Medicaid although, for individuals who do not have Medicaid, agencies typically reserve a very modest amount of state funds) that are used to fund respite services for individuals who live at home with their family.</p> <p>Individual allocations to families are determined based on need and the overall approach to respite allocation and funding is overseen by the area agency's Family Support Council which is comprised of family members. The average regional respite allocation is approximately \$1,500 per individual, per year. This comes out to approx 10-12 hrs of respite per month as the reimbursement rate is capped at \$10.15 per hour.</p> <p>Families generally identify, train and secure their own respite providers. They pay the provider and then submit documentation of service provision to the area agency and reimbursement is made to the family. Most families use their allocation on a monthly basis although the program allows flexibility for families if they wish to "save" their respite allocation for a week long break or other arrangement.</p>	<p>http://www.dhhs.state.nh.us/dcbcs/bds/index.htm</p>
New Mexico	<p>Mi Via is designed to assist participants in directing their own home and community-based services and supports. Eligible participants will have the option to control, direct and purchase services, supports and goods related to their disability or condition and Medicaid funds, using the essential elements of person-centered planning, individual budgeting, participant protections, and quality assurance and improvement. This option is available to individuals who are eligible to receive long-term services through one of the four Medicaid waiver programs. Respite services are included as part of the Mi Via program. This program uses a financial management services agency to assist with payment and taxes.</p>	<p>http://www.mivianm.org</p>

Tennessee	<p>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.</p> <p>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.</p>	<p>http://www.tnrespite.org/</p>
Texas	<p>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.</p>	<p>http://info.sos.state.tx.us/pls/pub/readtac\$ext.ViewTAC?tac_view=4&ti=40&pt=1&ch=41</p> <p>Consumer Guidebook</p>
Virginia	<p>Virginia provides options for consumer-directed respite in their Mental Retardation/Intellectual Disability Waiver (MR/ID), HIV/AIDS waiver, the Individual & Family Developmental Disabilities Support Waiver (IFDDS), Children's Mental Health Waiver, and the Elderly or Disabled with Consumer Direction (EDCD) Waiver.</p> <p>In Virginia, consumer-directed (CD) respite services provide assistance and supports to individuals that give the unpaid caregiver time to do things that they need to do for themselves or other members of the family. A respite worker assists the individual at home and in the community with things the family/caregiver normally helps with, giving the family/caregiver the needed time away. However, if skilled services are needed, skilled respite services must be provided. For the EDCD, HIV/AIDS, IFDDS, MR/ID Waivers, the attendant cannot be the parent if the employer is a minor or the individual's spouse.</p> <p>CD respite services are only allowed during times when the usual, unpaid caregiver needs a break. The most respite services an individual can have in one calendar year is 720 hours. This means that whether the individual receives traditional agency-directed or CD respite services, the total hours of both traditional and CD services cannot exceed 720 hours in any calendar year (i.e., January 1 through December 31 of each year).</p>	<p>http://dmasva.dmas.virginia.gov/Content_pgs/ltc-home.aspx or the waiver manual found here: http://www.dmas.virginia.gov/downloads/pdfs/prm-CDS_Comm_Waiv_Manual.pdf</p>

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

Building Support and Adoption of the Program

As with any program, a new participant-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 participant direction is a valuable and desirable addition to the long-term service 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 participant 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 participant 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 participant 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 participant 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 participant direction. Take ample amounts of informational materials for audience members.
- Tell stories and show photos or videos of participants who have benefited from participant 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 long-term service 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) 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 are important documents to develop, particularly to promote the participant 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. Videos are an effective supplement or alternative to written materials because they make information about the program “come alive.” Videos can be made available through program websites and/or distributed with written materials.

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 authority found at §1915(c). State programs may develop specific respite services under this authority using two different service delivery models; traditional agency respite services and participant-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 participant-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 New Mexico's Mi Via Waiver Program) but typically, with participant direction we see like services bundled into one service category. For example, North Dakota's §1915 (c) waiver for persons with disability (including elders) offers participant-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 fact sheet on federal funding listed at the end of this section.

Additional Resources on Funding:

[Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite](#)