Who are we?

- The Applied Self-Direction team works with self-direction programs to maximize the level of choice and control that participants can exercise over their services and supports.
- We provide training to state program administrators, service coordinators, support brokers, Fiscal Intermediaries (FI) agencies, and stakeholders across the country.
Agenda

- What is self-direction
- Overview of the guidebook
- Successful self-direction respite programs
- Time for Q&A
What is Self-Direction?
A quick introduction
What is self-direction?

- Self-direction is a model of delivering services in which the person receiving those services has a **high level of choice and control**
- A person who self-directs decides *when*, *how*, and *from whom* their services are delivered
- Self-direction is based on the principle that **people with disabilities know their own needs best** and should lead the planning and managing of their services
- In self-direction programs people with disabilities are empowered to **hire and fire their own staff** and manage a **flexible budget**
What is Self-Direction?

Choice and Control

Participant controls

- What
- When
- Who
- How
Benefits of Self-Direction

- Self-direction allows people to hire who they want to be providers, expanding the pool of available workers.
- The model can be cost effective, because the participant takes on the responsibility of being the employer which can lead to lower administrative costs.
- Self-direction has a positive impact on satisfaction and involvement in the community.
- Family caregivers are more likely to choose self-direction because they “retain control, choice, and flexibility.”
Benefits of Self-Direction

- Family caregivers also report greater well-being and higher satisfaction rates than do family caregivers receiving agency-based or ‘traditional’ services”
- If caregivers are more likely to utilize self-directed services, it may have a greater impact on relieving caregiver burnout
- The benefits of self-direction for people who live in rural settings and/or living with high care needs have been found to be especially pronounced
The Truth about Self-Direction

For everyone with the right supports

Increases choice and control

Reduces unmet needs

No more fraud than traditional services
Overview of the Self-Directed Respite Voucher Guide
Section 1: Introduction

- Introduction
  - How to Use the Guidebook
  - Definition of Terms
  - Overview of Self-Direction
  - Overview of Respite
  - Additional Resources on Self-Direction Overview
  - Stakeholder Involvement in the Program
  - Stakeholder Involvement Case Study Examples
  - Additional Resources on Stakeholder Involvement
Section 2: Program Structure

- Program Structure
  - Administrative Roles
  - Marketing & Outreach
  - Factors That Influence the Participation in a Self-Direction Respite Program
  - Determining Eligibility
  - Tracking Enrollment
  - Offering Information and Assistance
  - Employment and Financial Considerations
  - Financial Management Services
  - Spending Limits
  - Time Limits
  - Rate Setting
Section 3: Quality and Risk Management

- Quality & Risk Management
  - Elements of a Good Quality Management System
  - A Few Quality Tips
  - A Note on Electronic Visit Verification
  - Data Collection
The Importance of Stakeholder Engagement

- “Nothing about us without us”
  - People using services must be able to give input on how it works
- The voices of stakeholders should be heard and listened to from design, implementation, evaluation and continuous quality improvement
- There are several ways to get stakeholder feedback:
  - Formal advisory groups
  - Focus groups, surveys and telephone response lines
  - Peer support and mentoring
  - Involving additional agencies
    - Respite coalitions
    - ADRC
    - State Agencies
Factors that Influence Participation in Self-Directed Respite Programs

- #1 Factor that influences if people choose self-direction is how it is presented
  - Presented as a lot of work with a lot of responsibilities, it will not be chosen
  - Emphasizing the choice and control that comes along with self-direction will make it more appealing

- If they have friends and family members they can hire
  - Resources such as worker registries and information on how to be an employer can be given to help with this concern

- People staying in self-direction is completely dependent on their experience in the program
Offering Information & Assistance (I&A)

- The goal of information and assistance is to offer flexible and personalized support regarding information about self-direction and assistance and training with self-directed tasks.

- As choice and control are key in self-direction, I&A Providers should empower participants and families to make decisions, with assistance as needed.

- Specific types of assistance can include:
  - Developing a backup plan if a worker fails to show or other emergencies happen.
  - Identifying and obtaining services, supports, and resources.
  - Recruiting, hiring, and managing workers.
  - Navigating employer responsibilities.
Financial Management Services (FMS)

- Many participant-directed programs include one (or more) Financial Management Services (FMS) provider(s)

- The primary duties of an FMS provider are to:
  - Support participant employers with Federal and State tax and labor law compliance
  - Complete financial transactions on behalf of participants in accordance with spending plans, authorizations and/or program rules
    - Including payments for workers, agency support, and goods and services
  - Deposit taxes and file all tax and labor reports
  - Support participants becoming employers and hiring employees
  - Provide protections and safeguards for participants, their representatives and program administrative agencies
  - Generate reports for individuals and program administrative agencies

- With most models of FMS, the participant/employer is still the managing employer and retains the choice and control
Employment and Financial Considerations

- FMS help support employment and financial considerations for self-directed programs. Additional guidance can be found in the guidebook, including:
  - Guidance how to classify a worker: employee or independent contractor
  - Tax exemptions, such as the Live In Exemptions that exempt employees from overtime pay
  - How the relationship between the worker and employer effects taxes, as seen in the chart below

<table>
<thead>
<tr>
<th>Parent/Representative Employer is:</th>
<th>And Employee is their:</th>
<th>Then, Employer &amp; Employee are exempt from:</th>
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<tbody>
<tr>
<td>Child (adult or minor)</td>
<td>Parent</td>
<td>FICA, FUTA, SUTA</td>
</tr>
<tr>
<td>Parent</td>
<td>Child under 21</td>
<td>FICA, FUTA</td>
</tr>
<tr>
<td>Spouse</td>
<td>Spouse</td>
<td>FICA, FUTA, SUTA</td>
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</tbody>
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Quality in Self-Directed Respite Programs

- Successful quality and risk management strategies in self-directed programs:
  - View caregivers and disabled people as the experts in their own lives and needs
  - Respect the need for accountability in publicly funded programs
  - Place a strong emphasis on quality improvement

- Quality assurance requires programs to:
  - Design quality management strategies as part of program operations
  - Provide support for participants to obtain high-quality services
  - Use data to continually improve the program
Risk Management in Self-Directed Respite Programs

- Research affirms that rates of fraud in self-directed programs are very low (Applied Self-Direction, 2021)
- Many programs require both the employer and respite provider to sign the payment voucher to reduce the risk of fraud
- OKDHS has only 1 point of entry for services, so that duplication of services is minimized
  - Also has an electronic referral record
- The FMS has safeguards in place to reduce risk
- Programs have paper trails to reduce risk
- LRW efficiently and effectively vets all new providers to ensure the best caregivers for their populations
Successful Self-Direction
Respite
Program Examples
Alabama Lifespan Respite Resource Network (Alabama Respite)

- Program details
  - Caregiver is approved for respite and receives a voucher, which states the amount approved and the dates it is valid
  - The family recruits, interviews and chooses a respite provider and arranges everything
  - Once respite has been provided, the caregiver submits a reimbursement form
  - The allotment can be used all at one time, or many periods of respite provision
  - Staff process the 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
  - The caregiver is responsible for payment to the respite provider
Alabama Lifespan Respite Resource Network (Alabama Respite)

- Other details:
  - Eligibility and criteria is dependent on funding stream
  - Proof of age and disability or direct referral from the funding source are required
  - There is a waitlist, but every effort is made to move through it quickly
  - Amounts depend on the number of participants and available funding
  - Vouchers expire in 3 months, and can’t be rolled over
  - Caregiver is allowed to set the payment rate with some restriction within state guidelines
    - Some providers are paid a set amount for a period of time (for example, $200 to provide care for a weekend)
  - Alabama Respite charges an administrative fee of 10-12.5% and handles everything in house, instead of using an FMS
Alabama Lifespan Respite Resource Network (Alabama Respite)

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

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

Program details

- Caregiver is approved for respite and have full discretion on how to use their respite funding, whether all at once or throughout the 4-month period
- Caregivers recruit, hire and arrange for respite worker
- Caregivers determine the rate for respite providers
- Can be provided in the caregiver’s home, someone else’s home, a center-based program or care center, such as an adult day services center or nursing facility
- Once respite is provided, both the provider and caregiver fill out a voucher and the caregiver sends it to Sooner SUCCESS
- A check is sent to the provider
- After four months, given the availability of funds, the caregiver is eligible for an additional voucher
Oklahoma Lifespan Respite Program

Other details:

- To be eligible the care recipient must be 59 or younger and need assistance with activities of daily living in order to stay at home.
- The care recipient must not qualify for respite services or payment through any other program.
- The caregiver must also meet certain requirements, including be age 18 or older and serve as a full-time, unpaid caregiver or be a grandparent or other relative age 54 or younger raising a child, and not receive respite services from any other programs.
- Up to $400 worth of respite vouchers can be issued to each person to be used within a 4-month period.
- General yearly limit is $1,200, but funders can make exceptions.
- Sooner SUCCESS utilizes WovenLife as a FMS.
- There is no waiting list.
Oklahoma Lifespan Respite Program

- **Successes:**
  - Self-directing caregiver is given autonomy and control
  - OKDHS and Sooner SUCCESS partnership is highly effective
  - OKDHS has been successful in obtaining numerous grants
  - Respite subcommittee has incredible connections and collaborations

- **Challenges:**
  - Expanding the availability of respite, especially for families without immediate family in the area
  - High incarceration rates, results in families unexpectedly taking on significant caregiving responsibilities with no built-in respite
  - No opportunities to showcase program outcomes and successes to state officials
Lifespan Respite Washington (LRW)

- Program details
  - Caregivers apply via an online application for mini grants in the form of vouchers for respite services
  - Caregivers choose a respite provider from a database of registered provider agencies
  - The caregiver support team offers one on one support by phone, email, or text to assist family caregivers
  - If caregivers request a program or agency not included in the registry, LRW PAVE staff contact the preferred agency and provide customer service to become a registered respite provider
  - Vouchers are held in the caregiver’s name
  - Vouchers are paid out directly to the caregiver’s selected provider
  - The respite provider bills LRW directly
Lifespan Respite Washington (LRW)

- Other details
  - Eligible applicants must reside in Washington State and provide 40 or more hours per week of care or support to someone (of any age) with a special need or condition and the 40 or more hours must include supervision of the person receiving care.
  - Care recipients can be any age and must have a special need or condition and must require 40 or more hours per week or care, including supervision.
  - Caregivers receive $1000 vouchers (per family) which they are typically required to use within 90 days.
  - Vouchers may be used with more than one provider either sequentially or simultaneously.
  - In Washington, LRW can pay registered providers, but cannot pay friends and/or family members of a voucher recipient.
  - Caregivers do have a choice in their respite provider agency, the staff, and manage the range of service options they receive.
Lifespan Respite Washington (LRW)

Successes:
- Database enables LRW to process caregiver and provider applications quickly
- Database is user-friendly, and accessible
- Provides person-to-person family caregiver support throughout process
- LRW Coalition model is also self-directed with meetings where members share many resources for families and for providers

Challenges:
- Other self-directed programs offer more flexibility, including hiring friends and family
- Obtaining funding has been a major challenge
- Meeting the needs of rural communities has been difficult
- Condition, culture, and/or trust factors needs are difficult to navigate
Lessons Learned

- Flexibility is key
- Caregivers should be afforded as much choice and control as possible, as they are best able to meet their own unique needs
- Caregivers benefit greatly from one-to-one, personalized attention and contacts
- Recycling unused money significantly extends the amount of funding and caregivers who can use it
- Spending time limits greatly increase the likelihood of using the money and the amount of unused money available
- The value of respite to people currently receiving services and the dire need for more funding
- Subcontractors will make or break the program
Questions?

www.appliedselfdirection.com