

SELF-DIRECTED SERVICES: A HANDBOOK

Developed for the Alabama Intellectual Disabilities and Living
at Home Waiver

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Contents

Introduction.....	4
Philosophy	5
What Is Self-Direction and What Is Its Purpose?.....	5
Self-Direction Is For Everyone	5
Centering the Person.....	6
What Makes a Plan Person-Centered?	8
Key Self-Direction Terminology.....	9
Understanding Roles and Responsibilities in Self-Direction	11
Who Can Be a Representative/Employer of Record?	12
History of Self-Direction	15
Benefits of Self-Direction: Employer Authority and Budget Authority.....	16
Savings Accounts and Wage Negotiation	17
Understanding Individual-Directed Goods and Services	18
Objectives of Individual-Directed Goods and Services.....	18
Goods and Services: What’s Not Allowed?	19
Navigating the Gray Area.....	20
Getting Started in Self-Direction	22
First Meeting.....	22
Second Meeting.....	22
First Meeting with Self-Directed Liaison/Enrollment Specialist.....	23
Enrollment Meeting.....	24
After Enrollment Meeting.....	24
Follow-up Meeting(s).....	25
Hiring Workers: Strategies for Participants and Employers of Record	26
Things to Keep in Mind When Hiring.....	27
The Interview Process.....	28
Avoiding Discrimination During the Hiring Process.....	29
After the Interview	29
Offering the Job	30

Training	30
What to Do If A Problem Arises: Suggestions for Employers	31
Verbal Notification.....	31
“I Statements”	31
Example	32
Termination.....	33
Immediate Dismissal.....	33
Termination After Multiple Offenses	33
Labor Law Requirements for Employers in Self-Direction	35
Minimum Wage	35
Overtime	35
Live-In Exemption from Overtime	36
Travel Time	36
Risk Prevention and Mitigation.....	37
Understanding Risk.....	37
Dignity of Risk	37
Potential Areas of Risk.....	38
Potential Risks in Self-Direction.....	38
Risk Assessment and Mitigation.....	39
Support Coordinator and Self-Directed Liaison Responsibilities Regarding Risk.....	40
Risk Assessment Plan Meeting	40
Example.....	41
What’s Next When the Plan Is Not Being Followed.....	43
Appeals Process.....	44
Appendix A: What Services are Covered by EPSDT?.....	45
Appendix B: Waiver Services That Can Be Self-Directed	46
Personal Care.....	46
Personal Care with Transportation.....	49
Adult Companion.....	50
Environmental Accessibility Adaptations	52

Individual-Directed Goods and Services.....	53
Personal Emergency Response System	55
Skilled Nursing	57
Specialized Medical Supplies	59
Respite Services.....	59
Assistive Technology.....	61
Appendix C: Glossary of Legal Forms in Self-Direction	62
Employer Forms.....	62
Employee Forms	63
Appendix D: Self-Directed Services Operational Procedures.....	64
Referral to Self-Directed Services.....	64
Purchase of Goods, EAA, SMS, SME and PERS.....	65

Introduction

This handbook is designed to provide information to participants, representatives, family members, support coordinators, and Self-Directed Liaisons about self-directed services available through the Alabama Intellectual Disabilities and Living at Home Waiver for Persons with Intellectual Disabilities (ID/LAH Waiver).¹

The term “self-direction” refers to a service delivery option in which the individual who receives waiver services decides how, when, and from whom those services will be delivered. Self-direction is designed to make service delivery as flexible as possible for individuals and their families, and to make sure individuals who self-direct can exercise maximum choice and control over their services and supports.

Self-direction comes with many benefits, and it also comes with responsibilities. This handbook is designed to be a detailed resource about the self-directed services offered through Alabama’s Intellectual Disabilities and Living at Home Waiver.

This handbook can help people who are new to the Intellectual Disabilities and Living at Home Waiver or to self-directed services learn more about how the self-directed model works—and how to make self-direction work best for them!

¹ The word “waiver” is a special term that means that the State of Alabama has chosen to offer eligible individuals the option to receive Medicaid-funded Long-Term Services and Supports in the community instead of in an institutional setting. “Waiver programs” are programs that give individuals who need Long-Term Services and Supports access to those services in their community. Waiver programs provide cost-effective, person-centered alternatives to institutional settings.

Philosophy

What Is Self-Direction and What Is Its Purpose?

Self-direction is a model of service delivery in which an individual has maximum choice and control over how, when, where, and from whom their services and supports are provided. Self-direction is predicated on the principle that individuals with disabilities know best what their needs are and how they should be met. Because of this, individuals are the experts on how their services and supports should be provided.

Self-direction is **not** simply the individual choosing their own workers and is otherwise similar to traditional services from an agency. Self-direction is different from traditional agency services because the self-directing participant (or an individual appointed by the participant) decides who provides the services, when and how services are provided, how much service workers get paid, and how budget dollars are spent in alignment with HCBS waiver. Again, these critical decisions are made by the participant—not an agency, a support coordinator, or “the system.”

Having this level of choice and control as a participant also comes with responsibilities. Participants and those who support them are responsible for selecting and training the workers who will provide services, developing those workers’ schedules, providing feedback to workers on their job performance, and following program rules for self-direction. Luckily, even though the participant (and representative) have many responsibilities in self-direction, there is help available for those who want it. The Intellectual Disabilities and Living at Home Waiver offers several different kinds of formal supports to help make sure participants have the support and information they need to self-direct in a way that meets their needs and goals. These supports will be explored in depth in this handbook.

Self-Direction Is for Everyone

Everyone can self-direct, as long as they have the right supports in place. This does not mean that self-direction is necessarily the right fit for every person, but it is a good model for individuals and their families who would like more choice and control over their services.

It is true that self-direction requires taking on responsibilities, but that does not mean that an individual who self-directs has to “do it all” or “figure it all out” on their own. There is support available every step of the way, and this handbook will explain in detail how these supports are structured. Different people and their families may prefer or need different levels of support when they participate in self-direction. The most important things in self-direction are that the person who is receiving services remains an active participant in the service delivery process, and that that participant’s needs, and preferences remain central at all times.

As an example of a support available to participants in self-direction, many individuals with intellectual and developmental disabilities choose to designate a representative to handle

employer duties on their behalf. A key employer duty is the need for the employer to review and approve workers' timesheets before they are submitted for payment. Another employer duty is to develop a worker's schedule. Delegating such responsibilities to an employer of record (EOR) or authorized representative makes self-direction accessible to individuals who were unwilling or unable to manage them on their own. (The representative can be a parent or legally responsible individual but is not required to be.)

Deciding whether self-direction is a good fit for an individual should always be decided collaboratively on a case-by-case basis. This decision requires careful consideration by the individual and their circle of support, as well as by the support coordinator. This handbook can help families who are new to self-direction learn what to expect.

Centering the Person

Self-direction utilizes person-centered planning (PCP), which is an individualized process that takes place between the individual, their circles of support, and their support coordinator. Person-centered planning is based on the philosophy that the individual is the expert authority on their life, including their needs, goals, and preferences. Incorporating the individual's personally selected goals and preferences into the person-centered plan is just as important as protecting the individual's physical health and safety.

True person-centered planning requires meaningful engagement with participants and their circle of support. For support coordinators, this means asking participants open-ended questions, such as:

- *Tell me something about yourself. (For example, what is something you really like about yourself or are proud of?)*
- *What are your goals?*
- *What is important to you? (For example, who are the important people in your life? How do you spend your time?)*
- *What are your needs?*
- *How would you like to meet your needs?*
- *How can we help you get what you need in order for you to live a fulfilling life?*

Using person-first language is important, because person-first language is a way to emphasize the individual, not their disability or diagnosis. For example, the statement "He is living with autism" uses more person-first language than the statement "He is autistic." However, individuals always have the final say over the language they prefer and how they would like to be referred to by others.

When someone decides they would like to self-direct, that individual's needs, preferences, expectations, and goals should be documented *in detail* in their person-centered plan. This plan helps support coordinators and other staff make sure that the individual's services are helping them meet their needs and goals. For example, a statement like "Anna enjoys attending her sister's soccer games and would like to participate in a soccer league for people with disabilities" is more detailed and can more effectively guide Anna's service plan development than a more general statement like "Anna would like to make friends in the community."

What Makes a Plan Person-Centered?²

- ❑ The plan's focus is on the individual
 - The individual is an active member of the creating and designing the plan
 - The individual, and not the family or primary caregiver, is the top priority of the plan
 - The individual makes the final decision on the structure and people involved in the plan
 - **Choice and determination** for the individual are of primary importance
- ❑ Community participation is integrated in the plan
 - While living safely at home is an obvious priority, making sure the individual has access to their community is paramount
 - Plans should minimize barriers to the community, and maximize respect and equality
- ❑ Information accessibility
 - Information is provided regarding both formal and informal supports, and highlights what support they already have in place in their home and community
 - Information is conveyed in a way that can be understood and is respectful
- ❑ Support workers have the appropriate skills and training
 - Workers are respectful
 - Workers have the necessary knowledge to be an effective employee
 - Workers are trained in health and safety protocol
 - Workers are culturally competent
- ❑ Positive and Accurate Expectations
 - Workers and the individual believe they can grow and learn
 - Both are willing to engage in the process of growing and learning

² Adapted from *A National Environmental Scan of Indicators*, published by the National Center for Advancing Person-Centered Practices and Systems:

https://ncapps.acl.gov/docs/NCAPPS_Indicators%20Scan%20_191202_Accessible.pdf

Key Self-Direction Terminology

Every self-direction program has special language with which people who use the program should be familiar. This list of key terms can help readers familiarize themselves with language that will be used later in this handbook.

- **Financial Management Services Agency (FMSA):** The FMSA handles administrative responsibilities on behalf of the employer and keeps employers in compliance with all federal and state requirements. The FMSA issues paychecks to a participant's workers, pays all required taxes, and helps participants manage their budgets.

Currently, participants who self-direct their waiver services can select Allied Community Resources or Public Partnerships as their FMSA. A participant cannot have more than one FMSA at a time. If a participant would like to change FMSAs, they may do so on January 1st or July 1st of a calendar year. If they are planning to change FMSAs they must notify their current FMSA at least 30 days prior to their intended date of transfer. For example, if a participant plans to switch on July 1st, they must notify their current FMSA no later than June 1st.

- **Employer of Record (EOR):** This term designates the individual who serves as the legal employer of workers. The EOR can be a representative the participant has appointed to serve as employer on their behalf, or the participant themselves. The EOR is responsible for hiring, training, managing, scheduling, and in some cases, firing workers, as well as making sure that spending on services and supports does not exceed the authorized budget amount. The EOR is also responsible for reviewing and approving each worker's timesheets before they are sent to the FMSA for payment.

If the participant has appointed a representative, the representative who serves as the EOR is not required to be a parent or legally responsible individual for the participant.

- **Electronic Visit Verification (EVV):** This term refers to an electronic timekeeping system that records key information about a visit by a worker to a participant's home. EVV helps make sure that services are being provided as expected and that workers do not get paid for service hours they did not actually work. EVV technology can be used through landline phones, smartphones, tablets, computers, and other means. EVV will be required for some services starting January 1, 2021.
- **Authorized Representative:** If the individual needs or prefers support with hiring and managing workers, managing a budget, or other employer responsibilities, they can appoint an **unpaid** individual to assist them and serve as the EOR. The representative will not make decisions for the participant, but with them and in their best interest. Any person who has been appointed as a representative by a participant **cannot** also provide paid services to that participant.

- **Self-Directed Liaison (SDL):** The SDL is an expert on self-direction who is responsible for helping participants understand and navigate self-direction. The SDL works closely with the participant and the support coordinator to collaboratively develop a spending plan that describes how the participant's budgeted dollars will be spent. The SDL is a key support for participants and EORs new to self-direction, because the SDL is trained to answer common questions, provide information, and coach participants and employers on how to make the most out of self-direction.

Understanding Roles and Responsibilities in Self-Direction

At its core, self-direction is designed with a simple but profound goal: that people with disabilities can exercise meaningful control and authority over their lives and their services. As straightforward as this is, the Intellectual Disabilities and Living at Home Waiver has many supports at work behind the scenes to make sure self-direction is an accessible and sustainable option for families. Learning about these supports may seem complicated at first, but keep in mind that these supports are there to assist participants and families whenever help is needed.

If you are new to self-direction and have had any of the following thoughts, you're not alone.

- *I am a little confused about who is supposed to do what in self-direction.*
- *I've never been an employer before and feel nervous about hiring and managing staff for the first time.*
- *I'm not sure what is "allowed" and "not allowed" in self-direction.*
- *Am I going to have to figure all this out for myself?*

Feeling nervous or unsure when trying something new is a normal reaction. Luckily, there is *always* assistance available through the waiver to help participants and families scale the learning curve and become adept at using self-directed services. Information about these supports, and about how different roles in the program fit together, is provided below.

Participant: The participant is the individual who receives services, either via traditional models or through self-direction. In self-direction, participant responsibilities include:

- Deciding and communicating their needs, long-term goals, and personal preferences, and thinking about what types of services and supports might help best support these needs, goals, and preferences.
- Providing feedback to their circle of support and to workers about the services they receive and the quality of those services.
- Appointing a representative to serve as Employer of Record on their behalf, or in some cases, personally serving as the Employer of Record. An Employer of Record has the authority to hire, train, direct, and fire the workers who provide paid services to the participant. (Workers may include friends, neighbors, and some relatives.) An Employer of Record also decides a worker's hourly pay within wage ranges set by the State of Alabama. It is the role of the Employer of Record to identify the employee they will hire.
- Notifying the support coordinator and/or Self-Directed Liaison in any instance in which self-direction is not working well for them.

Authorized Representative: A representative can manage some or all employer responsibilities on behalf of the participant to help them successfully self-direct their services and supports. Use of representatives can make self-direction accessible to individuals who are unable or unwilling to manage employer responsibilities. If the participant has identified a representative to act on

their behalf and/or assist the participant with directing their service, that person will be responsible for the following tasks:

- Attending trainings and meetings with the participant.
- Serving as the Employer of Record on behalf of the participant and manage employer tasks, such as formally approving workers' timesheets or Electronic Visit Verification time records.
- Receiving copies of notices and correspondence sent to the participant by the Financial Management Services Agency and/or State of Alabama.
- Standing in the place of the participant. Any responsibility of the participant is a responsibility of the representative. Any action taken by the representative or failure to act will be accepted as the action or lack of action of the participant.
- Review and be knowledgeable of the Home and Community Based Settings ID or LAH waiver and ensure compliance with the regulations.
- Ensure continuous reference and use of the employer agreement
- Provide opportunities for the support coordinator to monitor safety and services provided in the participant's home
- The EOR must maintain all documents related to the services (including budgetary savings spending) provided by the waiver. Since the funds for the waiver are provided by Medicaid, then utilization of funds is subject to be audited by Medicaid.

If a representative is needed or requested by the participant but has not yet been identified, support coordinators will train the participant on how to choose a representative.

Who Can Be a Representative/Employer of Record?

- A representative may be a parent or legally responsible individual, but that is not a requirement.
- A representative may be a family member with whom the participant lives.
- A representative must be able to assure the Alabama Division of Developmental Disabilities (DDD) that he or she has no conflict of interest and will support the participant's best interests.
- For participants who live in their own private residence and need to designate a representative, some special requirements will apply.
 - This may include background checks if necessary.
- Any person serving as a representative must be at least eighteen years or older.
- The representative may not be funded by the participant's monthly budget funds and must have no conflict of interest.

What Should a Participant Look for in a Representative?

- They care about the participant.
- They understand the needs, goals, and wishes of the participant.
- They are willing and able to be the employer of the participant's workers.

Rules for Representatives:

- They cannot be paid to be a representative.
- They cannot be hired as a worker.
- They must be willing and able to fulfill all the responsibilities, including providing sufficiently close supervision to:
 - Assure the participant's health and welfare
 - Sign the worker's timesheets with assurance each timesheet is accurate and truthful
- Criminal background checks may be run in situations if questions or concerns arise

Support Coordinator: Support coordinators are responsible for coordinating services and continued oversight to ensure that the participant is living safely. Support coordinators work to understand the participant's needs, preferences, and long-term goals and help make sure the person-centered plan is responsive to the participant's needs and wants. Support coordinators should be knowledgeable about the waiver definition for self-directed services and be able to share this information with the individual/family. Support coordinators will work closely with the participant, representative, Self-Directed Liaison, and Financial Management Services Agency to guarantee the services and supports received by the participant are meeting the participant's needs.

Some of a support coordinator's duties include:

- Informing the individual/family about the option to self-direct and explaining self-directed services and provide them with the Self-Directed Services Handbook.
- Discuss the financial management service agency (FMSA) provider options and complete the Freedom of Choice Document indicating the participants chosen FMSA
- Meet with the individual/family to develop a relationship and learn about the persons interests and goals.
- Write the person-centered plan, which includes identified supports and services that was developed in collaboration with the participant and their circle of support.
- Review FMSA-generated utilization reports (spending reports) to ensure the person has ample supports.
- Discuss with the individual/EOR the appropriate process to accessing the budgetary savings account and ensure that the requests align with the HCBS waiver definitions
- Ensuring the participant understands and knows how to report abuse, neglect, and exploitation.
- In the event that an incident occurs, the Support Coordinator reports incidents following the Incident Prevention Management System (IPMS) guidelines

- Routine monitoring to ensure the participant is safe and satisfied with their services.

Self-Directed Liaison (SDL): The SDL is responsible for providing detailed explanations of self-direction to interested individuals/families, and providing expert assistance and feedback, particularly early in the process. SDLs will create a self-directed budget using the person-centered plan and authorized plan of care. The SDL can provide guidance to the participant and representative on hiring, training, firing, managing, and scheduling workers. The SDL will work closely with both the participant, the participant’s circle of support, and the support coordinator to ensure all parties are “on the same page” in terms of their understanding and expectations regarding self-direction. The SDL can also offer suggestions for remedying instances in which the participant is unsatisfied with their self-directed services. The SDL will be involved most heavily in the beginning of the service plan. The SDL’s involvement with a participant will lessen after the first 90 days of the participant’s enrollment in self-direction, as the participant and representative become more familiar with managing their services.

Financial Management Service Agency (FMSA): The FMSA handles administrative and compliance duties on behalf of Employers of Record to minimize the amount of paperwork Employers of Record must handle. The most well-known FMSA responsibility is that the FMSA issues paychecks to workers, making sure workers get paid on time and that all taxes are handled correctly. Other FMSA responsibilities include:

- Helping the participant or representative become a legally recognized employer by providing them with an employer packet that includes Federal and State employment and tax forms, Workers’ Compensation enrollment, and more
- Developing an enrollment packet for individuals that will provide services
- Performing background checks on prospective employees
- Reviewing timesheets and processing payroll
- Establishing and maintaining a savings account on behalf of each participant who elects to make Individual-Directed Goods and Services purchases using funds saved through wage negotiation
- Filing taxes with the Alabama Department of Revenue and Internal Revenue Service

History of Self-Direction

Self-direction was not designed all at once. The self-directed model developed gradually over time as part of a broader movement led by people with disabilities who wanted greater choice and control over their lives. This movement continues today, and advocacy is based on a simple principle known as self-determination: *all human beings have the right to make meaningful decisions about issues that affect their lives.*

Self-determination advocates reject the “medical model of disability”, which is a way of thinking based on the idea that there is something “wrong” with an individual who has a disability that needs to be “cured” or “fixed”. This mentality often leads to the mistaken belief that people with disabilities are not able to make decisions for themselves.

Instead, advocates continue to fight for changes that recognize that there is nothing wrong or abnormal about having a disability, and that having a disability does not define or limit a person. People with disabilities are entitled to all the same rights and opportunities for decision making that people who do not have disabilities have. This includes the right to live in the community instead of in an institutional setting.

The first formally self-directed programs in the United States began in the 1970s and 1980s, with more self-directed programs created over time. Self-direction grew rapidly in the early 2000s after a landmark United States Supreme Court case issued in 1999. This decision is known as *Olmstead v. L.C.* In this case, the Supreme Court ruled that individuals with disabilities had the right to live in the “least restrictive setting.” After this court ruling, many individuals with intellectual and developmental disabilities who had lived in institutions were able to transition to living in their communities instead. The *Olmstead* decision helped make sure all states implemented community-based alternatives to institutional settings. Self-direction is one example of such a community-based alternative.

Self-direction builds upon the principle of self-determination and the *Olmstead* decision by ensuring that individuals with disabilities who live in their communities can receive services in a flexible way with a high level of individual control.

Benefits of Self-Direction: Employer Authority and Budget Authority

Self-direction provides unique benefits to participants and their families. Unlike any other model of delivery, participants who self-direct have what are known as **employer authority** and **budget authority**.

Employer authority means that a participant or representative can directly hire workers of their choice and will train, manage, and schedule those workers. With employer authority, the participant and/or representative is quite literally “the boss”, as they legally become the employer of their workers. In fact, the FMSA registers the participant or representative as an employer with the State of Alabama and the federal government. This is required because anytime a person pays someone to provide services and controls how those services are performed, federal and state law recognize that person as an employer.

Being an employer comes with major responsibilities and major benefits. As employers, participants and representatives can define their own job descriptions and notions about what quality means for them. Then, they can train workers to provide services exactly in the way that they prefer.

In general, participants can hire anyone they like so as long as the person can meet minimum requirements set by the State of Alabama. The FMSA will help the participant with employer responsibilities by making sure workers get paid correctly and on time, and by helping participants with administrative paperwork.

If a participant or representative experiences challenges with being an employer and needs help, the Self-Directed Liaison and support coordinator are there to help get things back on track.

Budget authority means that a participant has choice and control over how their budget will be spent. This includes the ability to set workers’ rates of pay and purchase goods and services. With budget authority, the participant has the ability to pay higher-quality workers higher wages and to decide the mix of services and supports that works best for them.

For participants new to self-direction, the Self-Directed Liaison will calculate the budget allocation amount. (This amount is based on the participant’s level of need.) The Support Coordinator and Support Team will also help participants and their representative to develop a service plan that details how the dollars will be spent. Then the Liaison will use this information to create the budget for the individual. Participants and their representatives have the responsibility to make sure their expenditures do not exceed the amount of their budget. The FMSA will monitor the participant’s spending and will provide regular reports to help participants and representatives monitor their budget utilization. If something in the service plan is not working well for the participant and family, the support coordinator can collaborate with participants to make any needed changes to the person-centered plan.

Savings Accounts and Wage Negotiation

As part of budget authority, participants can choose to establish savings accounts with their budget dollars and use their savings to purchase Individual-Directed Goods and Services. Participants must save up for goods and services they wish to purchase. Savings can be accumulated through a process known as **wage negotiation**. Wage negotiation means that participants can negotiate with their workers to pay a lower hourly rate than the maximum allowable waiver rate for that service. If a lower hourly rate is agreed upon by the participant and worker, the difference between the worker's pay rate and the maximum allowable rate will be stored by the FMSA in the participant's savings account and maintained until it is used for an approved individual-directed good or service purchase. The Self-Directed Liaison can provide information to help the participant and the participant's circle of support decide whether Individual-Directed Goods and Services and wage negotiation are a good fit for the participant's needs.

Participants are permitted to save up to \$10,000 in their savings account at any given time. This savings is accrued in the current fiscal year and one fiscal year prior. If the participant disenrolls from self-direction, any remaining funds in their savings account will be refunded to the State of Alabama.

Understanding Individual-Directed Goods and Services

The State of Alabama's Intellectual Disabilities and Living at Home Waiver permits participants to purchase individual-directed goods and services using their savings accounts. Individual-directed goods and services can be one of the most helpful benefits of participating in self-direction. It is important to remember that there are some federal requirements that must be followed when deciding how the money should be spent. Following these requirements is an important responsibility for participants and Employers of Record in self-direction, and for support coordinators and Self-Directed Liaisons who support them.

This information can help participants and their circles of support think through what purchases may be right for them based on the Home and Community Based Waiver. It can also help support coordinators become familiar with federal rules on how waiver dollars are permitted to be spent on individual-directed goods and services. The federal rules only allow for a reimbursement process when purchasing goods and services. Once the purchase of item is approved, the participant/family must first purchase the item and then submit receipts to the Support Coordinator for reimbursement. If the participant/family are unable to purchase the items, then he/she should talk with the company or vendor and ask them if they are willing to submit a W-9 form to be reimbursed for the goods. If the company or vendor agrees, then the EOR needs to submit the W-9 form to the Support Coordinator for reimbursement for goods.

Objectives of Individual-Directed Goods and Services

Individual-directed goods and services are designed to help participants become healthier, safer, more independent, and/or more integrated in their community. The goods and services are subject to limits which will be reviewed annually. The Centers for Medicare and Medicaid Services (CMS) requires that these purchases should be made for one or more of the following general reasons:

- The good or service increases the participant's safety, health, and/or independence at home or in their community;
- The good or service enhances the participant's access to their community and the purchase would benefit the participant's community integration; or
- The good or service enables the participant to manage or treat their disability.

Common examples of items participants choose to purchase include:

- Electronic devices, such as smartphones or tablets, that help them communicate with others and access applications designed for individuals with disabilities
- Transportation-related purchases, such as public transportation passes (e.g., a bus pass), or ride sharing services, like Uber and Lyft

- Home or vehicle accessibility modifications, such as a wheelchair ramp or add a lift, seatbelts in floor to lock wheelchair in place
- Gym memberships, to provide opportunities for physical exercise and therapeutic recreation

Goods and Services: What's Not Allowed?

While the individual, Employer of Record, and/or family should have broad authority over deciding what goods and services best meet the individual's needs, there are reasonable limits to purchases that can be made. CMS does not allow waiver dollars to be spent on certain goods and services purchases. These include, but are not limited to the items below:

- Purchases for solely recreational purposes
 - **Note:** CMS allows purchases for "therapeutic recreation" that in some way improves the participant's health, but recreation without a therapeutic component is not allowable. For example, a gym membership would likely be considered "therapeutic recreation." On the other hand, a TV is unlikely to offer "therapeutic" benefits.
 - **Note:** Waiver dollars can be spent on helping an individual participate in a recreational event that they would not be able to access without assistance. For example, a personal care worker could be paid to attend a movie in a theater with a participant so that the participant can access this activity. But the participant's budget could not be used to purchase movie tickets.
- General home and vehicle repair
 - **Note:** Repair of an item that specifically relates to the individual's disability, such as a wheelchair ramp, is allowable under federal rules.
 - Improvements or adaptations to the home that are of general utility and are not of direct medical or remedial benefit to the participant are not allowable with waiver dollars (i.e. purchasing a new roof or new deck).
 - Adaptations or improvements to the vehicle that are of general utility, and are not of direct medical or remedial benefit to the individual can not be purchased with waiver dollars (i.e. new tires, battery, brakes, radiator)
 - Purchase or lease of a vehicle is not allowable with waiver dollars.
 - Regularly scheduled upkeep and maintenance of a vehicle except upkeep and maintenance of the modification is not allowable with waiver dollars.
- Room and board
- Purchases that are for the primary benefit of the family rather than the individual
- Paying cash directly to the individual
- Purchases on services that are available to the individual through other funding sources, such as the Medicaid state plan, until those services have been used up
- Acquiring goods and services that a household that does not include a person with a disability would be expected to pay for as household expenses

- For example, furniture that is not directly relevant to the participant's disability is not permitted.

The State of Alabama cannot waive or modify these federal requirements. All states have the right to add additional restrictions around what purchases can be made through individual-directed goods and services. For the Intellectual Disabilities and Living at Home Waiver, the State of Alabama has also specified that cigarettes and alcohol are not allowed to be purchased with waiver dollars.

Navigating the Gray Area

Sometimes families may request a goods and services purchase that falls in a gray area—that is, it might not be clear right away whether the purchase is allowable or not. Below are some rules of thumb about goods and services purchasing in self-directed services that can help support coordinators and Self-Directed Liaisons determine whether the request is allowable and appropriate under federal rules.

- Self-direction is predicated on the principle that participants and their circles of support know best what services and supports participants need to live independent, fulfilled lives. The support coordinator or Self-Directed Liaison should not make these decisions on behalf of an individual and their family.
- Medicaid is a public program funded by taxpayers, and states are tasked with making sure taxpayer dollars are spent responsibly.
- Participants and their circles of support should be the primary decision makers about what goods and services are right for them, but the support coordinator and Self-Directed Liaison should make sure these decisions are allowable under federal rules and that they are reasonable.
- Just because a good or service purchase was appropriate for one participant does not mean it is necessarily appropriate for another participant who likely does not share the exact same needs, preferences, and goals. Support coordinators sometimes hear the argument from families that “A family we know bought this item, so it is unfair if we aren’t allowed to buy it too.” But in the context of individual-directed goods and services, true fairness means that every participant and family is held to the same standard: that the purchase will enhance the participant’s health, safety, independence, and/or community integration. As long as the participant and family can demonstrate that the purchase will enhance one or more of those things and the purchase is not on the list of prohibited purchases.
- “I have enough money in my savings account” is not a sufficient reason to explain why a purchase should be made. Goods and services purchases that are made with waiver dollars must enhance the participant’s health, safety, independence, and/or community integration. This is why “I have enough money in my savings account, and this purchase will help me

access my community and/or achieve my personal goals” is a great reason for purchasing something.

- When deciding whether a good or service is allowable under self-direction, consider the following:
 1. Does the good or service help the participant become safer, more independent, or more integrated in their community?
 2. Is the good or service an allowable purchase under federal rules? (See above.)
 3. Am I confident this purchase is primarily for the benefit of the participant and not others?

If the answer to either of the first two questions is **No**, then the purchase is not permitted to be made with waiver dollars. If the answer to first two questions is **Yes**, but the answer to the third question is not clear, then extra consideration and discussion is required to demonstrate why and how that purchase will specifically benefit the participant. These reasons should be documented by the support coordinator or Self-Directed Liaison. The Alabama Division of Developmental Disabilities reserves the right to request additional evaluations or assessments to determine whether a requested purchase is appropriate.

Getting Started in Self-Direction

Self-direction is usually first offered to individuals during a meeting with their support coordinator. Often, either the individual will have heard of self-direction through a friend and is curious about it, or the support coordinator will recognize that the individual has needs that could possibly be better met by self-direction. For example, an individual who lives in a very rural area may not have an agency nearby from which to receive services, and self-direction may better fit that individual's needs.

This section will walk through the process for getting started with self-direction in the Intellectual Disabilities and Living at Home Waiver.

First Meeting with Support Coordinator

- The support coordinator will work with the individual to understand who the person is and his/her life. The Support Coordinator will use the Person-Centered Planning (PCP) process with the individual, their family and team.
 - This process includes reviewing the conversation guide, identifying the person's interests and desires.
 - This process includes questions about what they know about self-direction, what kind of support they would need, and how much responsibility they would prefer to take on versus having someone else take on their behalf.
 - The Support coordinator will introduce the self-direction option to individuals and family members and share a copy of the SDS Handbook with the family. The Support Coordinator should encourage the participant/family members to review the SDS Handbook to determine if this is the service delivery option they want to use.

Second Meeting with Support Coordinator

- The Support Coordinator meets with the individual/ family member to continue to obtain information about the participant and his/her goals, desires and potential supports needed.
- Support Coordinator will provide answers to additional questions about traditional versus Self-Directed service delivery options.

Referral Process completed by Support Coordinator

- If the individual is interested in self-direction, the support coordinator will submit a request for action (RFA) to the regional office (RO), which includes the referral form, plan of care and PCP (if completed), indicating the individual's interest in self-directed services. The regional office staff pertinent to this process is the Community Service Director (CSD), Waiver Coordinator (WC) and Self-Directed Liaison (SDL). The Self-Directed Liaison is an expert who can answer detailed questions about beginning to self-direct and can help participants and their circles of support "learn the ropes" about self-directed services.

- An approval for enrollment into self-directed services does not constitute a start date for employees in self-directed services. The FMSA will notify the EOR of the hire date for employees. Services performed prior to the hire date will not be reimbursed from waiver funds.

Support Coordinator led Person-Centered Planning Meeting

- The Support Coordinator will consult with the individual and their family to determine the time and place of the Person-Centered Planning meeting and who will be in attendance at the PCP meeting.
- The goals of the individual are identified and a detailed plan of how to achieve the goals is created.
- Informal supports such as family members, friends, or neighbors will also be identified in this meeting, emphasizing the social network of the participant so they have maximum support.
- The support coordinator will explain what supports are available to the participant and determine if capacity needs to be built to address other needed supports.
- The participant, Support Coordinator, family, representative and circle of support will collaboratively create an person-centered plan with the person's goals/desires identified, including the breakdown of what services and supports they will need to be successful, as well as a discussion of deciding how much to pay workers. If there are additional questions regarding self-directed services, the Support Coordinator should consult with the Self-Directed ... to obtain clarity.

First Meeting with Self-Directed Liaison/Enrollment Specialist

The Self-Directed Liaison will introduce the participant/family member or referral source to self-directed services. Because there is so much information to be covered before beginning self-direction, individuals who decide they want to self-direct will attend multiple meetings to learn about getting started.

- The Self-Directed Liaison/Enrollment Specialist will walk the individual through the self-directed process, including:
 - The philosophical foundations of self-direction
 - The benefits of the self-directed process
 - Program rules and requirements, including employer responsibilities
- The Self-Directed Liaison/Enrollment Specialist and individual/family member will discuss their capabilities and determine if the individual want a representative to assist them.

- A representative can assist the participant with some or all tasks, depending on the level of assistance the participant needs.
- Typically, during this meeting, the individual/family member will decide whether or not they would like to self-direct.
- The Self-Directed Liaison/Enrollment Specialist will explain the enrollment process.
- The Self-Directed Liaison/Enrollment Specialist will describe the responsibilities of an employer. This includes recruitment, hiring, training, and firing employees when appropriate, as well as managing the budget and approving worker's timesheets (including the electronic visit verification system).

Enrollment Meeting

Self-Directed Liaison or Enrollment Specialist discusses the enrollment packet with the individual/family member. After review of enrollment paperwork,

- Contact information for the fiscal management service agency
- Review payroll process and maximum rate of pay for employees
- Review EOR tax documents and employee application
- Completion and submission of timesheets process
- Review the mileage reimbursement process
- Review the privacy notice
- Remind individual/family member that documents must be notarized prior to submission

After Enrollment Meeting

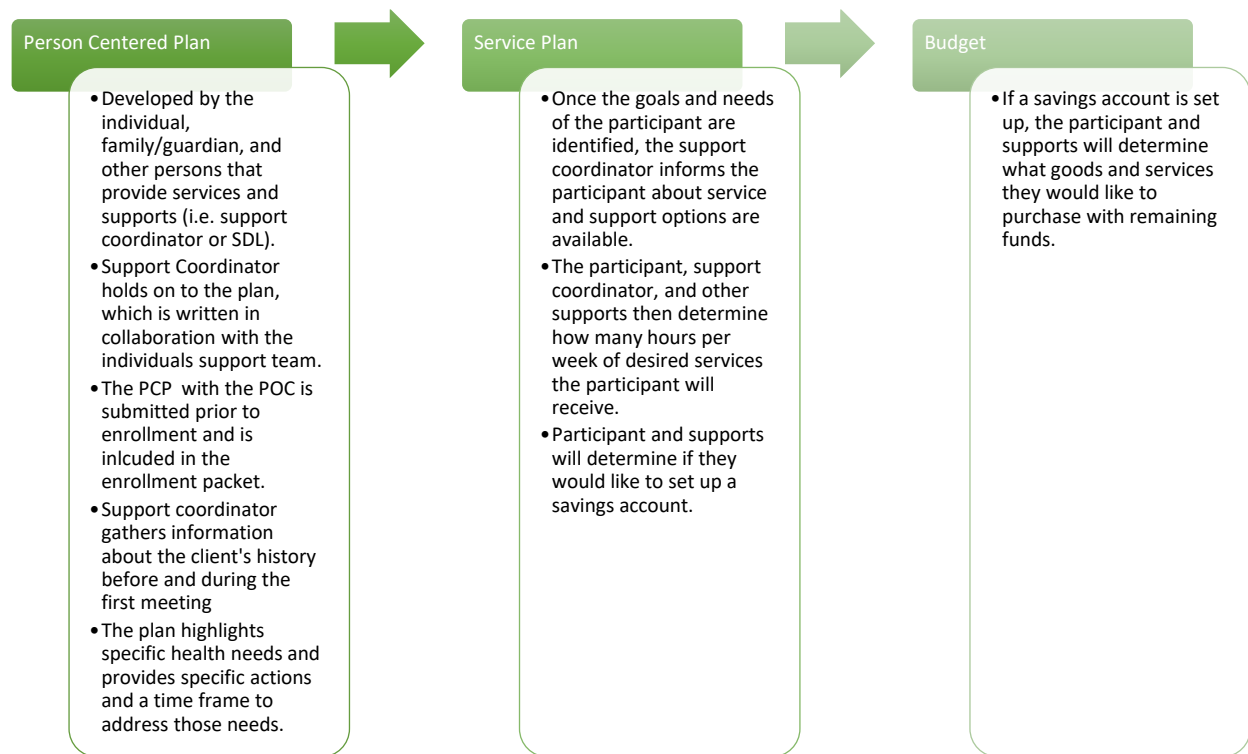
EOR must return all remaining documents to the Self-Directed Liaison /Enrollment Specialist

- Self-Directed Liaison/Enrollment Specialist will submit documents to FMSA
- FMSA will process enrollment/employee application background check
- Self-Directed Liaison will complete the budget based on authorizations after all documents are submitted properly
- FMSA issues a hire date of when the employee will be able to begin to work

Follow-up Meeting(s)

As the participant begins self-directing, the following will be addressed to ensure the participant is safe and successful as they begin hiring and managing employees.

- The Self-Directed Liaison will discuss potential risks, including fraud, neglect, and abuse, and trains the participant and representative on how to report suspected incidences of fraud, neglect, and abuse.
- The participant, Self-Directed Liaison, and representative will develop a back-up plan for instances if/when the primary designated care provider is not available.
- Going forward, any changes to the plan must be approved by the support coordinator.
- After the enrollment meeting, the individual/family has ninety (90) days to complete all enrollment paperwork (sign, submit) and to provide all necessary documents to hire staff.
- The Self-Directed Liaison will review the individual's current person-centered plan and plan of care to develop an appropriate self-directed budget. If needed, then the SDL will contact the participant to set up a follow-up meeting.

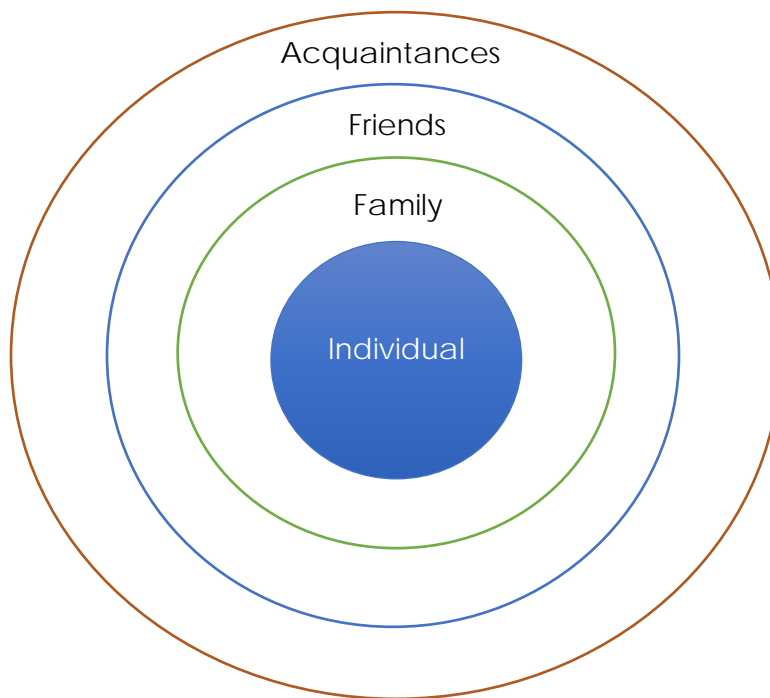


Hiring Workers: Strategies for Participants and Employers of Record

During the enrollment process, Employers of Record are encouraged to begin identifying potential employees. The EOR should not allow an employee to begin working until they receive the official hire date from the FMSA. If the EOR allows an employee to begin working prior to the official hire date, then the EOR is responsible for payment of staff from their personal funds. The Self-Directed Liaison supports the participant and Employer of Record through the process of finding and training employees.

The Self-Directed Liaison will assist the participant in identifying informal supports they may already be using, such as friends, neighbors, or members of their faith community. These individuals may be willing to provide more services in exchange for payment.

When considering potential caregivers, it can be helpful to start with individuals the participant knows best and interacts with the most, such as family members (with the exception of parent, spouse or child of individual), and then move outward to friends, then community acquaintances, and so on:



If hiring an informal support or existing acquaintance is not an option, other potential resources are Facebook, the newspaper, or a community board.

Things to Keep in Mind When Hiring

When creating a job posting, it is important to think about and describe the qualities the participant is looking for in an employee. Here are some questions to consider:

- *Do you enjoy working with people?*
- *Are you easily irritated and frustrated by others?*
- *Is it important to me that the person I hire has prior experience working with people with intellectual and developmental disabilities?*
- *What specific skills would I like or need someone to have? (For example, if meal preparation will be one of the worker's main tasks, it would be helpful if they are already comfortable with cooking and using a kitchen.)*

One of the major strengths of self-direction is that participants and Employers of Record are truly in charge of the people who work for them. This also means that it is ultimately the Employer of Record's responsibility to clearly communicate their needs and the needs of the participant to potential workers.

When making a job posting, it is essential that the participant and Employer of Record are explicit about what they are looking for and what they expect from applicants. The goal is not to have the most responses or applicants, but to have the *right* applicants who have a good understanding of what the job responsibilities will be. Making sure the job description is clear will help those who are not qualified or not interested confirm that the job is not appropriate for them.

A strong job posting includes the following details:

- A detailed job description:
 - Identifies service needs (for example, bathing, toileting, meal prep, etc.), hours, and general location(s) where the work will be performed
 - **Note:** It is important for applicants to know where the job will take place but avoid listing the participant's address in the job description. Instead, it is safer to give general location information like "We live in Tuscaloosa, about a 10-minute drive from Bryant-Denny Stadium."
 - Identifies physical requirements for the job (for example, the worker must be able to lift 100 pounds, or must be able to transfer the participant from wheelchair to bed and vice versa)
 - Clearly states the time commitment and hours expected of the applicant

- Is the schedule flexible? Is it possible or not to modify the participant’s schedule in order to hire a worker who works another job during some of the participant’s desired hours, but could work other hours?
- States whether the employee must have a car
- States what the worker can expect to make per hour
- States what applicants should expect from the hiring process, including:
 - The desired start date for the job
 - The need to provide references
 - That the applicant will need to undergo a background check before being cleared to provide services

Background checks are required for direct service provider employees who operate within the State of Alabama and who either provide direct services to the participant and/or who have access to client records. The state background checks are conducted by the FMSA and will also include a reference check with previous employers, sex offender registry, and the Nurse/Aid Registry. Verification of investigations will be conducted during audit reviews of the service providers by the State of Alabama.

REMEMBER: When hiring, the participant/EOR should hire both primary and backup workers to make sure there is no lapse in service if the primary employee is sick or unavailable.

The Interview Process

Interviews may be completed in a variety of ways, including in-person, over the phone, or using technology such as Skype or Zoom. While the Employer of Record is legally responsible for hiring workers, it is helpful for the participants who are not serving as Employers of Record to attend the interview process as well.

Safety is a top priority when hiring. It may be helpful to hold the interview in a public place such as a library, coffee shop, or community center. Employers of Record and participants may want to bring additional family members or friends to provide support during the hiring process. This will add additional safety and provide another opinion that may help the participant and Employer of Record make the right choice.

During the interview, the participant and Employers of Record should make sure to bring the following:

- A job description including hours, time commitment, and level of physical activity required for the position (for example, the worker must be able to lift the participant’s bodyweight)
- A list of duties required for the position

- Information about the participant’s disability
- Information about any special equipment the participant uses
- A list of interview questions to ask. Some example questions include:
 - *Have you worked with individuals with disabilities before?*
 - *Are you comfortable helping me get out of bed and get ready in the morning?*
 - *What drew you to apply for this job?*
 - *Do you have any questions or concerns about this job?*

Avoiding Discrimination During the Hiring Process

In the United States, it is illegal to choose not to hire someone because of certain characteristics, such as what religious background that person has. To avoid discrimination in the interview process, employers should not ask questions that are related to age (other than confirming that the applicant is over 18 years of age), race, color, religion, national origin, sexual orientation, sex, marital status or number of children, whether the applicant is pregnant or may become pregnant in the future, or disability.

Examples of questions not to ask during hiring because they could be considered discriminatory include:

- *What country is your family from?*
- *Are you a Christian?*
- *Are you a U.S. citizen?*
 - **Note:** Asking “Are you legally authorized to work in the United States?” is permitted, since workers must prove with government documentation that they are authorized to work in the United States before they are hired. (The FMSA will help participants and representatives with verifying the employee’s employment eligibility.)
- *Are you trying to start a family?*
- *What year were you born?*
 - **Note:** Asking “Are you 18 years old or older?” is permitted and is not a sign of discrimination, since the State of Alabama requires waiver service providers to be at least 18 years old.

After the Interview

If the applicant will be offered a position: Thank them for their time and ask for their references to follow up. At a minimum the potential employee must provide one work or school reference and a personal reference. References can give additional insight into the history and work ethic of a potential employee. It is the responsibility of the EOR to complete reference checks.

If more applicants stand out than there are positions available, still contact all their references. It is possible that when someone is offered the position, they will no longer be interested or may have already been hired at another job. Having back-up options will help ensure the participant begins receiving care as soon as possible.

If the applicant will not be offered a position: Thank the applicant for their time and let them know they will be contacted in the future. If the applicant is pressuring the participant to make a decision on the spot, the participant should state that they need to be fair to others they are interviewing. No one is ever under obligation to hire someone, especially if they make the participant uncomfortable. Deciding who to hire is a big choice, and the participant should make sure they are being thoughtful about who they choose to hire.

Offering The Job

Before hiring new employees, the Self-Directed Liaison will communicate with the participant regarding what Employee Paperwork new employees will need to fill out upon being hired and will make sure the participant has access to it. This paperwork will include authorization to conduct a criminal background check as well as Form I-9, which is a federal form that verifies that a person is eligible to work in the United States.

When they have identified the individual(s) they would like to hire, the Employer of Record should call the applicant and ask if they are still interested in the job. If the answer is yes, the Employer of Record can let them know what date they would like them to start and set a date and time for them to complete their new hire paperwork. Once the participant and Employer of Record identify who they would like to hire, then the Self-Directed Liaison contact the FMSA to submit the application.

If the applicant is no longer interested in the position, the Employer of Record will return to the pool of applicants and identify another applicant they would like to hire. If no applicants accept an offer, the participant, Employer of Record, will strategize about posting the advertisement again. Again, the Employer of Record should not hire someone they or the participant are not comfortable with, even in cases where the first round of interviews was not successful in locating a high-quality applicant.

If the participant needs services immediately, an Employer of Record might consider hiring a temporary employee to fill the spot until they find someone who can provide services long-term. In these cases, it is the Employer of Record's responsibility to make it clear that the job is temporary, and to be transparent about their expected timeline.

Training

Building good communication with new workers early on, especially regarding boundaries and expectations, will set the Employer of Record up for success throughout their working relationship. Maintaining verbal and/or written communication with workers is critical, and

workers should be notified in advance by the Employer of Record if there are any changes in scheduling, job responsibilities, etc. By respecting workers' time and treating them with dignity, the Employer of Record models an environment of fairness that helps build trust.

The Employer of Record should talk to a worker immediately if there are problems or if there is something, they want the worker to do differently. When this happens, clearly explain what behavior should be changed or how a task should be done correctly. If the Employer of Record does not communicate their concerns, the worker will have no way of knowing that there is something they need to improve.

What to Do If A Problem Arises: Suggestions for Employers

Verbal Notification

If a worker has done something incorrectly or that upsets the participant, it is important the Employer of Record and/or participant communicates with them as soon as is convenient for both them and the worker. While these conversations are uncomfortable, the worker is more likely to respond well if they are treated respectfully.

It is important not to "nitpick" everything a worker does. While the participant should be receiving high-quality services, being overly critical or having unreasonably high standards may make it difficult to retain workers for the long term. Workers make mistakes, just like everyone else does.

If the Employer of Record is able to speak to a worker immediately when something has not been done correctly, the Employer of Record should make sure they have the worker's full attention before they begin talking to them. If the employee is completing a task, the Employer of Record can ask them to pause or wait for them to finish before speaking.

"I Statements"

In order to diminish the possibility of the employee becoming defensive, the Employer of Record should begin sentences with "I prefer" or "I feel," instead of "you are". Sentences that begin with "you" can be interpreted by the worker as hostile or as though they are being blamed. This may cause the worker to feel the need to defend themselves instead of listening for how they can improve.

Employers of Record should keep their voice calm but firm when talking. Getting upset will most likely upset the worker as well. After the Employer of Record has finished talking, they should allow the worker to ask questions if they have any. Again, the Employer of Record should answer these questions in a calm but firm tone. After the process is complete, the Employer of Record should not mention the incident again unless the problem continues to arise. If the problem does not occur again, that is a strong indicator that the worker was listening and willing to make changes.

Example

The Employer of Record needs to provide feedback to their employee about cellphone use during the job. There are different ways the feedback can be provided:

Option One: *“I prefer for you to not be on your cell phone when I am talking to you. It makes it difficult for me to confirm that you heard me, and having your full attention is important to me. Does that make sense?”*

Option Two: *“You were on your cellphone when I was talking to you earlier. Don’t do that.”*

Option Two may cause the employee to feel defensive, and they may try to explain why they were on their cell phone. On the other hand, Option One explains why this is an important issue and that, as the worker’s employer, this is how you would like the job done. Option One does not blame the employee for the past, but instead sets a precedent for the future.

The Employer of Record should document the conversation in an employee file, including what was talked about, the date of the conversation, and the date the incident occurred. This will help the Employer of Record keep track of worker performance. If the Employer of Record needs help or advice about talking to an employee, they should ask their support coordinator or Self-Directed Liaison for assistance. Remember—those supports are there to help employers navigate this process. If it makes the Employer of Record and participant more comfortable, they can ask their SDL to help them practice these conversations, so they know what to expect.

The Self-Directed Liaison also can give recommendations and advice on how to supervise workers and give effective feedback.

Termination

Immediate Dismissal

Workers who show dangerous or threatening behavior should be terminated immediately. This includes but is not limited to:

- Physical abuse or neglect
- Stealing (for example, money, medications, or other property)
- Verbal abuse, including spoken threats
- Dangerous driving
- Working under the influence of drugs or alcohol
- Pressuring others to commit illegal actions, such as approving timesheet hours that the worker did not actually work

A participant should never continue to employ anyone who makes them feel unsafe. Abusive, neglectful, and/or exploitative behavior should be reported immediately to the support coordinator. The Support Coordinator will generate a General Event Record (GER) in the Incident Prevention Management System (IPMS). Additionally, participants or representatives can contact the State of Alabama Adult Protective Services Hotline at 1-800-458-7214.

**Report Abuse, Neglect and Exploitation
to the Alabama Adult Abuse Hotline:**

1-800-458-7214

If the participant or Employer of Record is concerned that there may be abuse or neglect, they should contact the support coordinator and explain the situation. One of the key responsibilities of the support coordinator is to protect the participant's health and safety, so it is important the participant and Employer of Record be open with them in communication and during home visits.

Termination After Multiple Offenses

Deciding to terminate a worker is at the discretion of the participant and Employer of Record. If a worker continues to make mistakes after training, reminders, and/or warnings, it may be that terminating that worker is needed because the worker is not able to provide services of a sufficient quality.

Some examples of worker mistakes that might result in termination after multiple warnings include:

- Being frequently late or not giving warning when the worker will be significantly late for a shift
- Poor communication skills, or displaying a poor attitude while performing duties
- Continued inability to follow directions

In these cases, Employers of Record should rely on their documentation from previous offenses, and explain, citing dates and times of previous offenses, the reasons why the worker is being let go.

Labor Law Requirements for Employers in Self-Direction

When a participant chooses to self-direct, the participant or the representative they appoint as the Employer of Record is legally recognized as an employer of the participant's workers. This means that there are federal and state labor laws that must be followed.

It is the Employer of Record responsibility to keep track of the legal requirement that applies to employees and ensure that participants/EORs are in compliance with all federal and state laws, including those on labor law. Additional information is available at (ADD AL DOL website and the ADMH website).

Minimum Wage

Employers of Record must pay their employees at least \$7.25 per hour. This is a federal law that applies even to paid family members who might be willing to work for less money.

Overtime

If an employee works more than 40 hours per week for their employer *and* does not live in the home with the participant, the Employer of Record must pay time and a half for every hour over 40 worked by that employee. Employers of Record should make sure to account for overtime requirements when scheduling employees. Otherwise, there may not be sufficient budget funds available.

Example

Emily is paid \$8 per hour to provide self-directed personal care services. Normally, she only works 10 hours per week. However, this week, her Employer of Record has asked her to work additional hours because some of the participant's family members are out of town and cannot provide their usual unpaid support. This week, Emily worked 42 hours total. What is Emily's gross pay this week?

Answer: Emily's gross pay must incorporate overtime. For every hour Emily worked over 40, she receives "time-and-a-half" of her base rate of \$8 per hour. In other words, her overtime rate is \$12 per hour. Emily's gross pay can be calculated as follows:

- 40 straight time hours x \$8 = \$320
- 2 overtime hours x \$12 = \$24
- ***Total gross wages for the week: \$344***

The FMSA is responsible for compliance responsibilities, including handling overtime calculations and making sure workers' paychecks are correct. For EORs, they should remember to avoid scheduling overtime unless there is an extenuating circumstance, such as an emergency. The use of overtime should be prior approved. The EOR should contact the support coordinator who submits the request for overtime to the Regional Office for approval.

Live-In Exemption from Overtime

Employees who live with the participant are eligible for the “live-in exemption” from federal overtime requirements. If the employee lives in the same residence as the participant, or the employee spends at least 5 days per week living in the participant’s home, the employee is not required to receive overtime payments for hours worked over 40. (The employer can still choose to pay overtime to a live-in worker but is not required to do so.)

If the employee does not live in the same residence as the participant, the live-in exemption cannot be used. In these cases, overtime must be paid for all hours worked over 40 in a workweek.

Travel Time

Mileage will be reimbursed at 52 cents per mile. As an example, if a worker drove 10 miles round trip to and from a community event, they would receive \$5.75 in mileage reimbursement from the FMSA for that trip.

Transportation provided by a worker must assist the participant in accessing the community per the activities documented in the person-centered plan. (Miles traveled by the worker when commuting from their house to the participant’s home will not be reimbursed.)

To receive mileage reimbursement, employees must maintain and submit a mileage log documenting their travel. Employers of Record and support coordinators should account for mileage expenses when calculating an employee’s costs.

Risk Prevention and Mitigation

Understanding Risk

Risk can be understood as the possibility of exposure to danger. While receiving self-directed services, as with most aspects of life, there are potential risks that should be discussed with support coordinators and Self-Directed Liaisons. Understanding the potential risks increases the probability of being prepared.

No two people have the exact same risk profile. Risk is dependent on the individual, their environment, their capacities, and their broader community. Each participant's risk plan should take into account the potential risks applicable to that participant and their unique environment. However, the risk plan should also acknowledge the **dignity of risk**, a concept that is explored below, as well as the participant's capacity to learn and grow over time.

Federal Medicaid rules require the state of Alabama to document the safeguards that are in place to protect participants from potential risk. All steps should be documented in the person-centered plan.

Dignity of Risk

Dignity of risk refers to the right to make mistakes and the right to live in a way where overly cautious caregivers do not prevent individuals with disabilities from living full and meaningful lives. Dignity of risk is a critical component of self-determination. It requires having the freedom to try new things that may not work out, or that may not go perfectly the first time. Everyone makes mistakes, and individuals with disabilities have the right to experiment and learn from their mistakes—just like anyone else.

Participants who self-direct have the opportunity to experiment with what will be the most effective for them personally, which leads to greater creativity in service plan design and more needs being met. Participants who self-direct know best what their needs are and how those needs should be met. This is not the same as saying that a service plan will meet the person's needs perfectly right away.

Support coordinators and Self-Directed Liaisons are responsible for balancing the dignity of risk with ensuring individuals' health and safety. This is one of their most challenging responsibilities, especially because in many cases, higher-risk choices can have greater long-term benefits for the participant if they are successful. Support coordinators and Self-Directed Liaisons should honor participants' and families' desire for growth and experimentation while making sure health and safety is maintained. In general, this means that support coordinators and Self-Directed Liaisons should avoid rejecting families' ideas as "too risky" unless there is an immediate and serious risk that cannot be mitigated. Risk can often be mitigated by thinking through back-up measures in case the original idea does not work out as intended. A real-life example of a family's initiative to

help their son grow more confident and independent while balancing risk is included at the end of this section.

Potential Areas of Risk

Risk may present itself in many forms. The list below includes common risks for people with disabilities. Participants and their circles of support should contact the support coordinator if they feel any of the following are present in the participant's life, or if they notice something else that potentially threatens the participant's health and safety. **If a risk presents an immediate emergency, dial 911.**

- Risk can manifest in environmental issues, such as:
 - Limited informal support (i.e., friends, neighbors, community members)
 - Primary informal caregivers becoming older and less able to sustain providing the level of care that the participant needs
 - Limited access to hired caregivers
 - Social isolation (i.e., living in a rural setting, limited access to reliable transportation, or having few opportunities to interact meaningfully with the participant's community)
 - Unsafe housing
- Risk can manifest in behavioral and medical issues, such as:
 - Inappropriate, violent, or otherwise dangerous behavior toward caregivers
 - Self-injurious behavior
 - Refusal to eat or take medications, or inappropriate consumption of food and/or medications
 - Substance abuse
 - Rapid weight gain or loss
 - Physical changes related to aging

Potential Risks in Self-Direction

When a participant self-directs, other risks may appear that are related to using self-direction as a service delivery model. Often, these added risks are related to the additional responsibilities related to a participant managing their own services and supports, usually doing so collaboratively with a circle of support and a representative. Support coordinators should be

aware of the potential risks and explore the situation with the participant and their circle of support if any of the following risk factors appear to be present.

- Risk around not understanding the self-direction program rules and responsibilities resulting in misuse of funds or not following program rules. For example:
 - Using the budget to purchase items that are not allowed.
 - Inability to stay within the allotted budget to pay for workers and other purchases.
 - Submitting worker timesheets for periods when the participant was hospitalized or living temporarily in an institutional setting. (Federal Medicaid rules do not allow someone to receive institutional services and Home and Community-Based Services at the same time.)
- Risk of exploitation, for example:
 - Pressure to hire a family member when the participant and/or Employer of Record does not really want to hire that person, or to keep a family member as paid staff when the family member is not providing high-quality care.
 - Pressure to pay someone for doing work they did not do.
 - Pressure to purchase a good or service for someone other than the participant.
 - Pressure to sell a good that has been purchased for the participant with waiver dollars.

Risk Assessment and Mitigation

The State of Alabama incorporates risk profiles that are customized, person-centered and effectively identify and document all potential and actual risks an individual might encounter when transitioning to and living in the community.

Risk profiles should:

- Involve the participant in the construction process.
- Honor the participant's values, preferences, and opinions.
- Include and understand dignity of risk where appropriate.
- Encourage and assist participants to live in the community and balance health and safety needs with acknowledging the dignity of risk and the value of learning from past decisions and experiences.

Support Coordinator and Self-Directed Liaison Responsibilities Regarding Risk

Both support coordinators and Self-Directed Liaisons should be familiar with both risk plans and the participant's preferences when collaborating on the risk plan. Additionally, support coordinators and Self-Directed Liaisons should be aware that risk plans do not eliminate state and program responsibilities for ensuring safety.

Risk Assessment Plan Meeting

When creating a risk profile, the support coordinator, Self-Directed Liaison, and the participant's circle of support should ask and discuss the following questions with the participant:

- "What is important to me, the participant?"
- "What is my current health?"
- "What are my daily routines?"
- "What choices do I get to make?"
- "What works for me and does not work for me?"
- "What are our hopes and fears?"
 - **Note:** This is optional and is used specifically to discuss risks.
- "What are the barriers and opportunities?"
 - **Note:** This is optional and is used specifically to discuss risks.
- "What do the team and others need to know and do to support me?"

What happens when a goal involves risk?

When a goal is identified and there is a degree of risk, that does not necessarily mean not including the goal. The risk profile should identify:

- How much risk is involved?
- Who will do what to minimize and mitigate risk?
- How the goal will aid in experiential learning?
- What training the direct support staff needs to be prepared?
- What resources are available to help the participant meet the goal safely?

In addition to the risk profile, a Safety Assessment will be completed that addresses straightforward concerns, including:

- Fire evacuation plan
- Who the participant will call when they need help?

- Whether special modifications are needed for emergency planning

Each risk assessment plan should be individualized and tailored towards the participant's living situation and supports. This includes guaranteeing that prescribed medication has been ordered and is available in the home in the correct quantity and dose and making sure participants and emergency contacts are aware of their local emergency centers. It is essential to identify the needs of a participant that, without the authorized waiver service, would cause substantial risk to health and safety. Emergency backup plans must be considered in these instances.

Example

James is a 23-year-old individual living with autism. James lives with his mother and father and self-directs his services and supports with their help.

James has never stayed home alone before but would like to do so one day. James and his parents share a goal that James will one day come home from his day activities, unlock and relock his front door, and spend 1-2 hours safely at home on his own before his parents come home from work.

James and his parents want to mitigate risk while still working toward the goal of James being able to spend time alone independently at home. Together, they identify risks, and ideas to mitigate those risks, and take these ideas to their next meeting with James' support coordinator:

- James's parents are concerned about two scenarios in particular:
 - *What if James is unable to unlock the door one day and then was at risk of wandering?*
 - *What if James unlocks the door and enters the house, but forgets to close the door behind him?*
- James's parents want to talk with the support coordinator about back-up plans with the understanding that not everything may go just right the first time—or the second or third time. They want James to have this opportunity to learn and grow, and they know James would benefit from being more independent at home and having time to himself. They also do not want James to be unsafe. They come up with the following ideas to discuss with the support coordinator:
 - James's budget could be used to purchase and install a security camera facing the front door. James's parents could check the security camera footage while at work to make sure James unlocked the door, entered the house, and closed and re-locked the door and is now safely at home. A security camera that James's parents can monitor remotely would help to reduce risk.
 - James's next-door neighbor is willing to be "on-call" as an informal support during the afternoons James will be arriving at home on his own. The neighbor could provide

assistance in case James has difficulty entering the home or closing and re-locking the door, or if something occurs at the home with which James would need assistance. Knowing a neighbor is nearby who was able to make sure James ended up in the right place and was safe would help to reduce risk.

- James could use his budget to purchase a smartphone or tablet with which he could contact his parents (or vice versa), enabling his parents to check that he is safe at home. James' having access to this technology would help reduce risk.
- James could use his budget to purchase a wearable GPS device so his parents could confirm remotely that James made it home safely. This is another potential way to reduce risk.

What's Next When the Plan Is Not Being Followed

Noncompliance from a participant or Employer of Record means that the service plan or risk plan is not being adhered to. Sometimes this means that budget dollars are not being spent in a sustainable way, putting the participant at risk of running out of funds too early.

Examples of service budget dollars not spent in a sustainable way:

- Exceeding the allocated service units
- Exceeding allocated transportation miles
- Accessing goods or services that do not meet HCBS waiver definition

When a pattern of noncompliance develops, remediation activities may be necessary to prevent risks to the participant's health and safety and/or improper use of self-directed waiver services.

- Examples of remediation activities may include, but are not limited to:
 - Notifying participant in writing of incidents.
 - Providing additional education to participants/representatives.
 - Revising participant's service plan, risk plan, and/or informed risk agreement.
 - Transitioning participant from self-directed to traditional Home and Community-Based Services.

Appeals Process

The state provides an opportunity to request a Fair Hearing under 42 CFR Part 431, Subpart E to individuals: (a) are denied the service(s) of their choice or the provider(s) of their choice; or, (b) whose services are denied, suspended, reduced or terminated. The state provides notice of action as required in 42 CFR §431.210.

The formal process of notification and appeal is in accordance with 42 C.F.R. Section 431, Subpart E and Chapter 3 (560-X-3) of the Alabama Medicaid Administrative Code. There is an appeal process conducted by the operating agency (DDD) at the applicant's choice, with the right to further appeal to the Medicaid Agency being explained to the applicant. If an appeal is made to the Medicaid Agency, a hearing officer appointed by the Commissioner of the Medicaid Agency conducts fair hearings. Medicaid legal counsel will be responsible for taking a lead role in the fair hearing process. If the individual/guardian is still dissatisfied after the Fair Hearing, he/she may appeal to the Circuit Court. The OA will be responsible for defending any appeal of the administrative decision.

The Community Service Director or designee marks Denied if Request For Regional Action is denied. According to Federal Regulations, any adverse action requires the participant to be notified in writing with explanation of the adverse action included. The participant's appeal rights will accompany a letter and Dissatisfaction of Services form.

Appendix A: What Services are Covered by EPSDT?

Individuals under the age of 21 will receive the following services from the Early and Periodic Screening, Diagnostic and Treatment (EPSDT):

- Personal Care
- Skilled Nursing
- Positive Behavior Supports
- Crisis Intervention
- Specialized Medical Supplies
- Specialized Medical Equipment
- Physical Therapy
- Occupational Therapy
- Speech & Language Therapy

Appendix B: Waiver Services That Can Be Self-Directed

Personal Care

Service Definition

Self-Directed Personal Care Services includes assistance with any activity of daily living (ADL) or instrumental activity of daily living (IADL). Assistance for ADLs includes:

- Bathing
- Toileting
- Transfer and ambulation
- Skin care
- Grooming
- Dressing
- Extension of therapies and exercise
- Routine care of adaptive equipment primarily involving cleaning as needed
- Meal preparation
- Assistance with eating
- Incidental household cleaning
- Laundry

IADLs include:

- Shopping
- Banking
- Budgeting
- Using public transportation
- Social interaction
- Recreation
- Leisure activities

-

Assistance with IADLs includes:

- Accompaniment
- Coaching and minor problem solving necessary to achieve the objectives of increased independence
- Productivity
- Inclusion in the community

Self-Directed Personal Care may also include general supervision and protective oversight reasonable to ensure the health, safety, and inclusion of the client.

Who Can Provide the Service

Personal Care Services may be provided by a relative but **cannot** be provided by legal guardians or legally responsible individuals (e.g., the participant's parent or child.)

Service Rules

The worker may directly perform some activities and support the participant in learning how to perform others; the planning team (composed at minimum of the person and family, and a support coordinator) shall determine the composition of the service. This may include supporting the participant at an integrated worksite where the participant is paid a competitive wage. There is not a separate rate or service code for this support when it is self-directed. Self-Directed personal care attendants may transport consumers in their own (the attendant's) vehicles as an incidental component of this service. For this component to be reimbursed, the personal care attendant must be needed to support the consumer in accessing the community, and not merely to provide transportation. Additional payment will be made to the worker for mileage.

Personal care is limited to no more than 12 hours/48 units each day for individuals living in the home with relatives or caregivers. There is no restriction on the place of service so long as the person is eligible for the waiver in that setting and no duplication of payment occurs. Payment is for a 15-minute unit of service delivered to the individual, not including worker's time of travel to and from the place of work. This service is not available to participants under the age of 21 years as medical supplies are covered through EPSDT for this age group.

Additional information (if applicable):

Self-Directed Personal Care Workers must meet the following requirements:

- Have at least two references, one from work and/or school, and one personal, which have been verified by the participant or family (with or without the support of a consultant)
- Have a background check as required by law and regulation
- Be at least 18 years of age
- Be able to read and write and understand instructions, as verified by the participant or family
- If providing transportation, must have valid driver's license and insurance as required by State Law
- The worker cannot be the employer of record, spouse, parent or child of the individual receiving services.

Basic elements of training shall be provided prior to the worker delivering services and includes:

- Procedures and expectations related to the personal care worker including following the service plan
- The rights and responsibilities of the worker and the participant
- Reporting and record keeping requirements
- Procedures for arranging backup when needed
- Who to contact within the FMSA
- The support coordinator agency and regional office

In addition, and as needed, training in the following areas will be provided by the family or others and recorded:

- Information about the specific condition and needs of the person to be served, including their physical, psychological or behavioral challenges, their capabilities, and their support needs and preferences related to that support.
- If administration of ordinarily self-administered medication is required by the participant, training and ongoing supervision in medication administration.
- Training as needed in communication skills; in understanding and respecting individual choice and direction; in respecting the participant's confidentiality, cultural and ethnic diversity, personal property and familial and social relationships; in handling conflict and complaints and in responding to emergencies.
- Training in assisting with activities of daily living and instrumental activities of daily living, as needed by the individual and identified by the service plan
- Training on the types of incidents and incident reporting is required

Financial Management Services

The self-directed personal care workers will be employed by the family and individual, who will be employers of record. The family and individual will be supported by a Financial Management Service Agency (FMSA). The FMSA will pay the workers employed by the family and participant, on a bi-weekly basis. Payment will be made on the basis of receipt of one time card per worker, which will document the hours the worker has worked during the bi-weekly pay period with an indication of the service rendered for that time period (i.e. adult companion, personal care).

The FMSA will withhold the necessary tax amounts, including employer's share, and pay these amounts to the proper authorities on a quarterly basis. In addition to withholding FICA and Unemployment, the Fiscal Agent will withhold and submit income taxes for the workers. The primary requirements for the FMSA are to:

- a. Handle all payroll taxes required by law
- b. Assist with the documentation of training and other qualifications of workers as required by the waiver, including verification of citizenship.
- c. Maintain records to assure the worker was qualified, the service was provided in accordance with the plan of care
- d. Furnish background checks on prospective employees
- e. Provide the person and family with easy access to resolve problems with payroll and provide a notification route for any other issues that may arise. This means that the FMSA, if it hears that a change may be needed or that a backup plan needs to start, will notify the operating agency, the self-directed liaison and the case manager. The objective is to provide a network within which, no matter which contact the person or family makes, the information is shared, and the reaction is comprehensive.

f. Also, the FMSA will help to assure the person and his or her family are and remain satisfied with the service.

Personal Care with Transportation

Service Definition

Personal Care is one service and Personal Care Transportation is a separate service. Personal care attendants may transport consumers in their own (the attendant's) vehicles as an incidental component of this service. For this component to be reimbursed, the personal care attendant must be needed to support the consumer in accessing the community, and not merely to provide transportation. The attendant must have a valid driver's license and his/her own insurance coverage as required by State law. The provider agency shall assure the attendant has a good driving record and is in-serviced on safety procedures when transporting a consumer. This service will provide transportation into the community to shop, attend recreational and civic events, go to work and participate in People First and other community building activities. It shall not replace transportation that is already reimbursable under day or residential habilitation nor the Medicaid non-emergency medical transportation program. The planning team must also assure the most cost-effective means of transportation, which would include public transport where available. Transportation by a personal care attendant is not intended to replace generic transportation or to be used merely for convenience.

Personal Care Transportation may not be used to transport to Day Habilitation. All of the levels of facility and Day Habilitation and Community Day Habilitation include options for transportation, assuming the 10-mile rule is met. Personal Care Transportation should be used in conjunction with the Personal Care or Personal Care on Worksite service, if transportation is needed for the Personal Care Service. ***Personal Care Transportation is not for the Employer of Record to be reimbursed for transportation.*** PCT for Self-directed Personal Care would be associated with whomever provided the Self-directed Personal Care. EOR is free to transport the waiver recipient to Day Habilitation or anywhere else they want but cannot bill the waiver for those miles. All levels of Day Habilitation have a transportation component which may be used, ***by the Day Habilitation provider,*** if the 10-mile rule is met.

Who Can Provide the Service

Personal care attendants may provide the service for the individual.

Service Rules

For this component to be reimbursed, the personal care attendant must be needed to support the consumer in accessing the community, and not merely to provide transportation. The attendant must have a valid driver's license and his/her own insurance coverage as required by State law. The rate of reimbursement is \$0.52 per mile.

Adult Companion

Service Definition

Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services does not include hands-on nursing care. Providers may perform light housekeeping tasks that are incidental to the care and supervision of the individual. This service is provided in accordance with a therapeutic goal in the plan of care, and not purely diversional in nature. This service is needed to prevent institutionalization.

Services include:

- a. Supervising daily living activities, to include reminding client to bathe and take care of hygiene and personal grooming, reminding client to take medication, and overseeing planning and preparation of snacks and meals.
- b. Staying with client in the evening and at night to ensure security.
- c. Accompanying client into the community, such as shopping.
- d. Supervising/assisting with laundry and performing light housekeeping duties that are essential to the care of the client.
- e. Following written instructions such as the care plan and documenting services provided.

Service Rules

Adult Companion Services are to provide support and supervision that is focused on safety, non-medical care and socialization for clients participating in the ID waiver. Medicaid will not reimburse for activities performed which are not within the scope of services.

Requirements:

- a. Services must be on the service plan of care with documentation in the case record of need for service. The service is 15- minutes of direct companion services provided to the client.
- b. The provision of the service, and the number of units of service provided to each client, is dependent upon the individual's needs as set forth in the service plan of care.
- c. Companion service is not available to group home residents.
- d. No payment will be made for companion services furnished by a member of the participant's family (parent, child, spouse or legally obligated individual).

- e. Companion services are limited to functionally impaired adults (age 21 and over).
- f. Companion service is non-medical and does not include hands-on care.

Supervision

Supervision of the self-directed adult companion workers is the responsibility of the employer of record and/or the individual.

Financial Management Services

The self-directed adult companion workers will be employed by the family and individual, who will be employers of record. The family and individual will be supported by a Financial Management Service Agency (FMSA). The FMSA will pay the workers employed by the family and participant, on a bi-weekly basis. Payment will be made on the basis of receipt of one time card per worker, which will document the hours the worker has worked during the bi-weekly pay period with an indication of the service rendered for that time period (i.e. adult companion, personal care).

The FMSA will withhold the necessary tax amounts, including employer's share, and pay these amounts to the proper authorities on a quarterly basis. In addition to withholding FICA and Unemployment, the Fiscal Agent will withhold and submit income taxes for the workers. The primary requirements for the FMSA are to:

- a. Handle all payroll taxes required by law
- b. Assist with the documentation of training and other qualifications of workers as required by
- c. Maintain records to assure the the waiver, including verification of citizenship. worker was qualified, the service was provided in accordance with the plan of care
- d. Furnish background checks on prospective employees
- e. Provide the person and family with easy access to resolve problems with payroll and provide a notification route for any other issues that may arise. This means that the FMSA, if it hears that a change may be needed or that a backup plan needs to start, will notify the operating agency, the self-directed liaison and the case manager. The objective is to provide a network within which, no matter which contact the person or family makes, the information is shared, and the reaction is comprehensive.
- f. Also, the FMSA will help to assure the person and his or her family are and remain satisfied with the service.

Frequency of Verification:

Workers employed by consumers and families will have their qualifications verified initially by the FMSA, and no further verification is necessary unless a situation or qualification changes and the participant or family reports it to the FMSA. Exclusion lists are checked monthly.

Environmental Accessibility Adaptations

Service Definition

Environmental Accessibility Adaptations are those physical adaptations to the home, required by the participant's service plan, which are necessary to ensure the health, welfare, and safety of the participant, or which enable the participant to function with greater independence in the home and without which, the recipient would require institutionalization. Such adaptations may include:

- The installation of ramps and grab-bars
- Widening of doorways
- Modification of bathroom facilities
- Installation of specialized electric
- Plumbing systems which are necessary to accommodate the medical equipment
- Supplies which are necessary for the welfare of the recipient, but shall exclude those adaptations or improvements to the home which are of general utility and not of direct medical or remedial benefit to the waiver client, such as carpeting, roof repair, central air conditioning, etc.

Who Can Provide the Service

Environmental Accessibility Adaptations **cannot** be provided by a parent, legal guardian, relative, or legally responsible individual.

Service Rules

Adaptations that add to the total square footage of the home are excluded from this benefit. An evaluation by a Physical Therapist may be necessary to assist in the determination of structural requirements and need for the EAA service. All services shall be provided in accordance with applicable State or local building codes as well as ADA Standards.

Those physical adaptations to the home, required by the recipient's person-centered plan, which is necessary to ensure the health, welfare and safety of the individual, or which enable the individual to function with greater independence in the home and without which, the recipient would require institutionalization. Such adaptations may include the installation of ramps and grab-bars, widening of doorways modification of bathroom facilities or installation of specialized electric and plumbing systems which are necessary to accommodate the medical equipment and supplies which are necessary for the welfare of the recipient, but shall exclude those adaptations or improvements to the home are of general utility and not of direct medical or remedial benefit to the waiver client, such as carpeting, roof repair, central air conditioning, etc.

The individual's home may be a house or an apartment that is owned, rented or leased. Rental and leased property are excluded from modifications as it the landlord's responsibility for ensuring property is accessible, however, in the event that costs prohibits adaptations, some modification could be considered , such as, modular ramps or any that could be moved if the participant changes residents. Adaptations to the work environment covered by the Americans with Disabilities Act, or those that are the responsibility of other agencies, are not covered. Covered adaptations of rented or leased homes should be those extraordinary alterations that are uniquely needed by the participant and for which the property owner would not ordinarily be responsible.

Payment is for the cost of material and labor. The unit of service would be the job. Total costs of environmental accessibility adaptations shall not exceed \$5,000 per year, per participant. This service does not require a prescription from the participant's physician. All other community resources should be explored and exhausted prior to expending waiver funding.

Self-Directed Environmental Accessibility Adaptations are only available to those participants who are self-directing personal care, companion and/or LPN/RN services.

Self-Directed Contractor: Meets all applicable State (Alabama Code 230-X-1) and Local Licensure requirements.

Individual-Directed Goods and Services

Service Definition

Individual-Directed Goods and Services are services available to only those participants self-directing services who are able to save funds through negotiation of worker's employment wages. Individual goods and services include equipment or supplies not otherwise provided through this waiver or through the Medicaid State Plan that address an identified need in the service plan (including improving and maintaining the participant's opportunities for full membership in the community) and meet the following requirements:

- The item or service would decrease the need for other Medicaid services; and/or promote inclusion in the community
- And/or increase the participant's safety in the home environment
- The item or service is not illegal or otherwise prohibited by Federal and State statutes and regulations
- The participant does not have the funds to purchase the item or service or it is not available through another source.

Goods and Services are required to meet the identified needs and outcomes in the individual's person-centered plan, are the most cost effective to meeting the assessed need, assures health, safety, and welfare, and are directly beneficial to the participant in achieving at least one of the following outcomes:

- Improved cognitive, social, or behavioral functioning
- Maintain the participant's ability to remain in the community
- Enhance inclusion and family involvement
- Develop or help maintain personal, social, or physical skills
- Decrease dependency on formal supports services
- Increase independence

Excluded Goods and Services include:

- Adaptations or improvements to the home or vehicle that are of general utility, and are not of direct medical or remedial benefit to the individual cannot be purchased with waiver dollars (i.e. new roof, new deck, new tires, new battery)
- Purchase or lease of a vehicle
- Regularly scheduled upkeep and maintenance of a vehicle except upkeep and maintenance of the modification is not allowable with waiver dollars.
- Experimental or prohibited treatments
- Room and board
- Items solely for entertainment or recreation
- Cigarettes and/or alcohol

Who Can Provide the Service

Individual-Directed Goods and Services may be provided by a relative but **cannot** be provided by parents, legal guardians or legally responsible individuals. The federal rules only allow for a reimbursement process when purchasing goods and services. Once the purchase of item is approved, the participant/family must first purchase the item and then submit receipts to the Support Coordinator for reimbursement. If the participant/family are unable to purchase the items, then he/she should talk with the company or vendor and ask them if they are willing to submit a W-9 form to be reimbursed for the goods. If the company or vendor agrees, then the EOR needs to submit the W-9 form to the Support Coordinator for reimbursement for goods.

Service Rules

How to Begin Receiving Goods and Services

The process begins with the enrollment meeting between the participant (and family if applicable) and the Self-Directed Liaison. The liaison will review all the Employer of Record paperwork and discuss the budgetary and employer authority responsibility. During this meeting the person's budget will be discussed along with what is considered acceptable and not acceptable uses of this service and a spending plan is developed identifying items for purchase. A list will be provided to the participant (and family) indicating items that are strictly prohibited. It is also during this time that the participant may identify items of interest and the savings plan is developed. These items will be listed on the person's budget and submitted to the FMSA. A copy of the spending plan will be kept in the client record and maintained by the support coordinator. The FMSA will follow their process of working with the participant on procurement and

reimbursement, as well as adjust the participant's budget accordingly. The FMSA will notify the Regional Office, and the support coordinator (or Self-Directed Liaison, within the first 90 days of enrollment) of the actual amount spent on Individual Directed Goods and Services monthly.

The limit on amount is determined individually based on the balance of the participant's savings account at the time of the request which is maintained by the Financial Management Services Agency annually. The duration of this service is again based on the participant's savings account balance and the participant's participation in self-directed services. If a participant returns to traditional waiver services, the ability to access any dollars from the savings account and utilize this service will be terminated. Additionally, dollars not utilized will be refunded to the Division of Developmental Disabilities. Dollars can be accumulated past the fiscal year but cannot exceed \$10,000.00 at any given time. The support coordinator/Liaison will be responsible for monitoring the balances of the savings to ensure proper utilization. Items, goods, or services that are not for the primary benefit of the participant are prohibited.

Items, Goods, and Services unrelated to the participant's assessed long-term support needs and outcomes related to those needs are prohibited. State plan services and waiver service funds should be expended prior to utilizing the Individual Goods and Services. The support coordinator has oversight of expenditures of Individual Goods and Services and must document the need of any item or service in the case record. Individual Goods and Services can be utilized prior to expenditure of waiver funds in the event there are no providers accessible in the participant's area to provide the service. This must be documented in the case record.

Personal Emergency Response System

Service Definition

Personal emergency response system (PERS) is a service that provides a direct telephonic or other electronic communications link between someone living in the community and health professionals to secure immediate assistance in the event of a physical, emotional or environmental emergency. PERS may also include cellular telephone service used when a conventional PERS is less cost-effective or is not feasible. This service may include installation, monthly fee (if applicable), upkeep and maintenance of devices or systems as appropriate. The use of these technologies requires assurance that safeguards are in place to protect privacy, provide informed consent, and that documented needs are addressed in the least restrictive manner. The person-centered plan should identify options available to meet the need of the participant in terms of preference while also ensuring health, safety, and welfare.

To Be Discussed When Acquiring PERS:

- Personal risk factors
- Information regarding data collection
- Customized list of participants/providers to be notified of alerts

- Who will be allowed access to data (service provider/staff)?
- Choice should be afforded between providers of both equipment and monitoring

The person-centered plan should also include:

- The purpose of the PERS
- Back-up system for PERS in times of electronic outages or failure
- Training of caregiver (paid and unpaid)
- Provider/caregiver response time for different events
- Safeguards for protection of the person's privacy related to remote support and data collection

If remote support includes video (in person's bedroom), informed consent must be addressed (and documented) and privacy concerns should be addressed.

Who Can Provide the Service

Relatives, parents, legal guardians, and legally responsible individuals **cannot** provide PERS.

Service Rules

Emergency Response System installation and testing is approximated to cost \$500.00; Emergency Response Monthly Service Fee (excludes installation and testing) is approximated to cost no more than \$83.00/month; Emergency Response system purchase is approximated to cost \$1,500.00. The maximum cost for all PERS per year is \$3000.00. This service will not be authorized for person's receiving residential habilitation. PERS will not replace supervision and monitoring of activities of daily living which are provided to meet requirements of another service (i.e. personal care; day habilitation). Self-directed PERS are only available to those participants who are self-directing personal care, companion and/or LPN/RN services.

Additional Information

The PERS provider should assure that these devices, where applicable, meet Federal Communication Commission standards or Underwriters Laboratory standards or the equivalent. The installation of PERS systems should be done by qualified installers representing the health agency managing the personal emergency response system. In the event these installers are not available the agency should seek experienced technicians to complete necessary line adaptations.

PERS Minimum Requirements:

- Provide an alert button or other mechanism that can be activated by the person to indicate the needs for emergency assistance and/or utilize technology to detect a possible adverse event indicating the need for immediate response
- Immediately transmit/communicate the alert to a central clearinghouse that maintains 24/7 immediate/real time recognition of and response to the alert and includes a

"failsafe" procedure that assures that every alert for assistance is responded to in a timely manner as defined in the person's person centered plan or PERS parameters

- A call tree that reflects the person's needs and preferences
- Assurance that any agency or individual who creates, collects, records, maintains, stores, or discloses any individually identifiable participant data complies with the Health Insurance Portability and Accountability Act (HIPAA) as well as all other data privacy laws and requirements
- Address the documented risk factors and preferences of the person

Skilled Nursing

Service Definition

Services listed in the service plan which are within the scope of the State's Nurse Practice Act and are provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse licensed to practice in the State. The RN completes an in-home assessment to determine if services may be safely and effectively administered in the home. The registered nurse establishes a nursing care plan complying with the plan of treatment. The RN must make monthly supervisory visits to evaluate the appropriateness of services rendered by a licensed practical nurse (LPN).

Licensed Practical Nurse Services (LPN)

The LPN may provide continuous skilled nursing services for the recipient if a licensed physician prescribes the services and Medicaid grants prior authorization. The LPN works under the supervision of the RN. The RN evaluates the recipient and establishes the service plan care prior to assigning recipient services to the LPN. There is no restriction on the place of service.

This service may also, when provided to a participant or family which is self-directing personal care services, include training and supervision related to medical care and/or assistance with ordinarily self-administered medications to be provided by the personal care worker. This training and supervising component of nursing is only available to people who receive personal care at home, either agency-based or self-directed. It is not available to agencies providing residential and day programs, because payment for the nurse supervision is already included in the rate paid for those services.

Who Can Provide the Service

Skilled nursing **cannot** be provided by a parent, relative, legal guardian, or legally responsible individual.

Service Rules

RN/LPN Services must be prescribed by a physician and is based upon the participant's assessed need. The need for continued nursing must be ordered by the participant's physician every year at the time of the annual redetermination. When Nursing is provided to self-directing participants and families, it is intended to focus on training and supervision of the personal care

worker and is not intended as a private duty nursing service. Skilled nursing service under the waiver is not available to children under the age of 21, including self-directed RN/LPN, when provided as the result of an EPSDT screening, because that service is covered under the State Plan. A record of the RN/LPN visit will be captured by an Electronic Visit Verification Monitoring system.

Additional Information

Provider Qualifications License:

- Nurses are licensed under the Code of Alabama
- 1975 Sec.34-21 Certificate (specify): Nurses typically are employed by certified waiver providers
 - Administrative Code Chapters 580-3- 23 580-5-33
- The service(s) of the nurse must be documented by a nursing note that includes the identity and Medicaid number of the consumer, the date of service, the beginning and ending time of the service, and the nursing service(s) provided within that time

In addition, the nursing note, signed and dated, should include, as appropriate:

- The nurse's assessment
- Changes in participant's condition
- Follow-up measures
- Communications with family, caregivers or physicians
- Training or other pertinent information

Nursing licenses are renewed annually. Debarment checks are conducted initially and monthly thereafter.

The FMSA (Financial Management Services Agency) will hold the provider enrollment by permission of the Alabama Medicaid Agency. Note that a nurse, either an RN or an LPN, may work for an agency and also work for an individual or family, so long as there is no duplication of payment or conflict of interest. Either issue would involve the nurse working for an agency which also provides direct services to the participant who is self-directing his or her personal care. Because both the agency's service and the self-directed service will need to be prior authorized (all waiver services are prior authorized from the service plan). This potential conflict/duplication would be apparent to the Operating Agency, which will ensure it does not arise. The service(s) of the nurse must be documented by a daily nursing note that includes the identity and Medicaid number of the consumer, the date of service, the beginning and ending time of the service, and the nursing service(s) provided within that time. The nurse must sign and date the note daily.

Specialized Medical Supplies

Service Definition

Specialized medical supplies are those which are specified in the service plan and are necessary to maintain the participant's health, safety and welfare, prevent further deterioration of a condition, or increase a participant's ability to perform activities of daily living. Specialized medical supplies are supplies that address the participant's physical health and any ancillary supplies. All items shall meet applicable standards of manufacture and design. Providers of this service must maintain documentation of items purchased for each participant. State plan services must be utilized prior to the expenditure of waiver funds for medical supplies.

Supplies reimbursed under this service shall not include:

- Common over-the-counter personal care items
- Supplies otherwise furnished under the Medicaid State plan
- Items which are not of direct medical or remedial benefit to the recipient and does **not** include items such as:
 - Soap
 - Cotton swabs
 - Toothpaste
 - Deodorant
 - Shampoo
 - Sanitary items

Who Can Provide the Service

Specialized Medical Supplies **cannot** be provided by a parent, legal guardian, relative, or legally responsible individual.

Service Rules

Costs for medical supplies are limited to \$2400.00 per year, per participant and must be prescribed by the participant's physician. This service is not available to participants under the age of 21 years as medical supplies are covered through EPSDT for this age group.

Respite Services

Service Definition

Respite care is a service provided inside or outside a family's home to temporarily relieve the unpaid primary caregiver. Respite care providers short-term care to an adult or child for a brief period of rest or relief for the family from day to day care giving for a dependent family member.

Respite is intended for participants whose primary caregivers typically are the same persons day after day (e.g. family members and/or adult family foster care providers) and is provided during those portions of the day when the caregivers typically provide care. Relief needs of hourly or shift staff workers will be accommodated by staffing substitutions, plan adjustments or location changes and not by respite care. Respite care typically is scheduled in advance, but it can also serve as relief in a crisis relief, out of home respite can also allow time and opportunity for assessment, planning and intervention to try to re-established the person in his home, or if necessary, to locate another home from him.

Some consumers are institutionalized because their community supports become exhausted, or because they don't know how to cope with an increasingly challenging behavior, or due the loss/incapacitation of a caregiver. The scope of out of home respite will allow quick response to place the person in an alternate setting and provide intensive evaluation and planning for return, with or without additional intervention and supports. Planning will be made for alternate residential supports if return is not possible. The goal is to avoid institutionalization.

Who Can Provide the Service

The employer of record (EOR) is responsible for assuring the minimum qualifications are met prior to submission of the worker application to the financial management service agency (FMSA). The FMSA is responsible for conducting the background checks and also verifying the minimum hiring qualification are met for the individuals performing this service. A prior approval will be required to accompany the receipt in order for the EOR to receive payment. The EOR is responsible for the supervision, training and general oversight of the Respite worker. The respite worker must be approved by the FMS to provide services. Requirements for employee to provide service:

- Must have at least completed the tenth grade
- Must be able to follow the person-centered plan with minimal supervision unless there is a change in the persons condition.
- Must have no physical or mental impairment (that would prevent providing the needed oversight and care to the person).

Service Rules

Respite care dependent on the individual's needs as set forth in the plan of care and requires approval by the Division of Developmental Disabilities, subject to review by the Alabama Medicaid Agency. The limitation on in home and out of home Respite Care in combination shall be 4320 15-minute units of service (equals 1080 hours or 45 days) per participant per waiver year. Respite care out of the home is typically provided in a certified group home.

Assistive Technology

Service Definition

Assistive technology means an item, piece of equipment (including any equipment not covered by Medicaid State Plan Services), service animal or product system, whether acquired commercially, modified or customized that is used to increase, maintain, or improve functional capabilities of participants. Assistive technology services mean a service that directly assist an individual in the selection, acquisition, or use of an assistive technology device that may include:

- a. the evaluation of the assistive technology needs of a participant, including a functional evaluation of the impact of the provision of appropriate assistive technology and appropriate services to the participant in the customary environment of the participant
 - b. services consisting of purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices for participants
 - c. services consisting of selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices
 - d. coordination and use of necessary therapies, interventions, or services with assistive technology devices, such as therapies, interventions, or services associated with other services in the service plan
 - e. training or technical assistance for the participant, or, where appropriate, the family members, guardians, advocates, or authorized representatives of the participant; and
 - f. training or technical assistance for professionals or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of participants.
- Providers of this service must maintain documentation of items purchased for each individual.

Who Can Provide the Service

Providers of this service must meet the same standards required for the providers under the Alabama State Plan. Licensure is by the Alabama Board of Home Medical Equipment Services Providers

Service Rules

A prescription from the participant's physician is required for this service. Items reimbursed with waiver funds shall be in addition to any medical equipment and supplies furnished under the State plan and shall exclude those items which are not of direct medical or remedial benefit to the recipient. Payment is for the cost of the item provided.

There is a \$5,000 per year, per individual maximum cost. For children 21 years and younger, State Plan Services available through EPSDT are utilized prior to expending waiver funds.

Self-Directed Assistive Technology is only available to those participants who are self-directing personal care, companion and/or LPN/RN services.

Appendix C: Glossary of Legal Forms in Self-Direction

Beginning to self-direct comes with a significant amount of start-up paperwork—much of which is from government agencies like the Internal Revenue Service and the Alabama Department of Revenue. This is because when an individual decides to self-direct, the Employer of Record legally becomes the employer of the worker(s) who provide services to the individual. It is normal for Employers of Record to have questions about the paperwork they are signing and what it means. They may also have questions about the forms their new employees are required to complete. This guide is designed to explain the purpose of each form in plain language and why it is important.

Employer Forms

IRS Form SS-4, *Application for Employer Identification Number*

This form registers the individual (or representative) as an employer with the Internal Revenue Service (IRS), so that the FMSA can pay federal taxes on their behalf and keep them in compliance with all federal requirements for employers. The IRS will assign the individual a Federal Employer Identification Number, and the FMSA will handle all taxes related to home care services from that point onward.

The individual may ask whether they will need to file their personal taxes differently now that they have a Federal Employer Identification Number. The answer is that no changes will be required on their end and they can file their personal taxes just as they always have. The wages paid by the FMSA to employees are never counted as part of the individual's income. The FMSA is responsible for handling all taxes and issues related to paying workers.

IRS Form 2678, *Employer/Payer Appointment of Agent*

This form authorizes the FMSA to file and pay federal tax on behalf of the individual. When Form 2678 is signed, the FMSA becomes liable for all of the individual's taxes as an employer. When the IRS receives a signed Form 2678, the IRS then formally recognizes that the FMSA is handling all taxes on behalf of the employer related to their involvement in self-direction. This protects the participant in the event the FMSA makes a mistake, because the IRS will hold the FMSA (and not the participant) financially responsible. Signing Form 2678 does not give the FMSA any authority or responsibility over the individual's personal taxes. Form 2678 only gives the FMSA responsibility for the taxes owed as part of paying home care workers through self-directed services.

IRS Form 8821, *Tax Information Authorization*

This form authorizes the IRS to communicate with the FMSA about an employer's tax issues. However, signing this form will not authorize the IRS to release any information about an individual's personal taxes. Personal taxes are kept separate in the IRS system from taxes related to be an employer in self-direction.

Alabama Form 2848A, *Alabama Department of Revenue Power of Attorney and Declaration of Representative*

This form authorizes the FMS to pay state taxes to the State of Alabama that are owed related due to participation in self-direction. Signing this form will not affect the participant's personal state taxes in any way, and the Employer of Record can still file their personal state tax return in the same way they always have.

Employee Forms

IRS Form W-4, *Employee's Withholding Certificate*: This form will be completed by the employee and provided to the FMSA. This form tells the FMSA how much federal income tax to withhold from the employee's pay.

USCIS Form I-9, *Employment Eligibility Verification*: This form is used to verify that an employee the Employer of Record wishes to hire is eligible to work in the United States. When completing Form I-9, the employee will have to provide proof of their identity. Therefore, employees should be prepared to provide government-issued ID, such as a passport, driver's license, Social Security card, military ID, official birth certificate, or other official documentation.

Appendix D: Self-Directed Services Operational Procedures

Referral to Self-Directed Services

Purpose:

Provide the process to refer individuals to be considered for self-directed services option.

Definitions:

SDS (Self-Directed Services) –A service delivery option; SDL (Self-Directed Liaison) –An individual who provided SDS application packet explanation of the procedures; RFA (Request for Action) – Additions to an individual’s plan of care; ADIDIS (Alabama Developmental Intellectual Deficits Information System); FMSA (Financial Management System Agency) – Agency that provides payroll services to individuals who select SDS; EOR (Employer of Record) –Individual who will be responsible for oversight of SDS with in the home; EIN (Employer Identification Number)

Procedure/Explanation:

All requests to enroll an individual into the Self-Directed Services option must be completed and submitted by the Support Coordinator to the Regional Office via the Request for Action (RFA) process. The Support Coordinator should attach self-directed services referral form with the RFA forms when submitting to the appropriate regional office.

PROCEDURES FOR SUPPORT COORDINATOR

1. Hold a meeting with the individual and/or his/her family to explain the service delivery option of self-directed services.
2. Provide the individual and/or family member with a copy of the SDS Handbook and answer questions detailing the difference between the self-directed service option and traditional service delivery option.
3. If individual and/or family indicate an interest in the self-directed services option, then the Support Coordinator must complete the entire SDS Referral form and RFA form.
4. Submit the completed SDS Referral form (Revised 6/2/2020) and RFA form to the appropriate regional office via the RFA process. When the RFA is submitted in ADIDIS the Support Coordinator should tag the CSD, waiver coordinator and SDL.

PROCEDURES FOR SELF-DIRECTED LIAISON

1. After the RFA Committee in the Regional Office renders a decision, then the Self-Directed Liaison will contact the individual.
2. If the RFA for SDS Referral is approved, then the SDL will contact the individual/family member to provide self-directed services application packet and schedule a meeting to discuss the SDS information.
3. This SDS approval is for enrollment into the SDS delivery option. The individual cannot begin to employ individuals until he/she has received a hire date from the FMSA. Services performed prior to the hire date will not be reimbursed by waiver funds.
4. Submit information to the Financial Management System Agency for review.

PROCEDURES FOR FINANCIAL MANAGEMENT SERVICES AGENCY

1. Receive documents submitted
2. Process documents and determine if individual/family can obtain an employer identification number (EIN) and become an employer of record (EOR).
3. Process employee application and background checks for potential employees.
4. If there are problems with the application or it is incomplete, this will delay the process. The FMSA will send an email to the SDL or EOR to request additional information.
5. Once the EOR has been approved, then they receive notification of their EIN number.
6. Once the employee is approved to work, then the FFMSA will send an email with the employee hire date.

Purchase of Goods, EAA, SMS, SME and PERS Services

Purpose:

Provide the process to obtain and be reimbursed for specialized medical equipment, specialized medical supplies, environmental accessibility adaptations, personal emergency response system and other goods.

Definitions:

Specialized Medical Equipment (SME), Specialized Medical Supplies (SMS), Environmental Accessibility Adaptations (EAA), Personal Emergency Response System (PERS)

Procedure/Explanation:

Procedures for Individual or Employer of Record:

1. Prior to making a purchase the individual/employer of record (EOR) should submit the request to use waiver funds for purchases to his/her Support Coordinator
2. The EOR should review his/her budgetary savings report to determine if the funds are available for the purchase of goods
3. The request should provide explicit details about the reason for the purchase and how it will benefit the waiver recipient. Please include prescriptions and letter from physician detailing how the good or service will benefit the individual.
4. The request should include three quotes for the items being purchased with the exception of specialized medical supplies.

Procedures for Support Coordinator:

1. The Support Coordinator should review the person-centered plan and plan of care to ensure that the requested good or service is identified.
2. The Support Coordinator should review the monthly utilization report (budgetary savings report) to ascertain if the individual has the funds available for purchase.
3. The RFA should include a detailed explanation of reason for purchase, most recent copy of budgetary savings report, three quotes for the item, completed prior approval form (revised 10/19/2020) and ensure the purchase aligns with waiver stipulations and person-centered plan for the service or goods.
4. The Support Coordinator must submit the request to the regional office via the Request for Action (RFA) process in ADIDIS and tag the CSD, waiver coordinator and self-directed liaison.

Procedures for Regional Office:

- 1) Verify all information is included on the RFA. If not, return to support coordinator with a note in the **NEEDED INFORMATION** section of the form. Include the date returned to the support coordinator.
- 2) Verify the documentation supports the need for service and person-centered plan
- 3) Approved; generate letter to the participant with a copy to the Support coordinator
- 4) Denied; generate letter to the participant accompanied by appeal rights with a copy to the Support coordinator
- 5) Inform the self-directed liaison of the decision

Procedures of Support Coordinator after Regional Office Review:

1. Inform the waiver recipient/employer of record of the Regional Office decision or request for additional information
2. If additional information is required by Regional Office, then request the additional information be provided by the EOR.
3. Submit additional information to the regional office.

Procedures for waiver recipient/employer of record to purchase items after receiving approval:

The EOR has two options to obtain items

1. Pay the provider directly for items and submit receipts to their Support Coordinator for reimbursement –OR–
2. Have the supply vendor send a W-9 form to financial management service agency (FMSA) so that FMSA can pay the supply vendor directly. In this scenario, receipts/invoice should also be sent to the support coordinator to keep with the person's records. The invoice for the company must include the company's name, address and telephone number along with the individual's name, item purchased and the cost of the item.

Procedure for Support Coordinator after EOR submits receipts:

1. Email or fax the previously approved Prior Approval form and receipts to financial management service agency.
2. Retain a copy of the Prior Approval form and receipts with the person's records