

Got Choice?

Self-Directed Supports & Self- Determination

Services for Individuals with Developmental Disabilities



This document is in draft form and will remain so pending stakeholder review. All comments and suggestions are welcome and encouraged. Please forward questions, comments and suggestions to Kyla Eversman, Director of Special Community Services, at kyla.eversman@dmh.mo.gov.

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Acknowledgements

Many thanks to everyone who contributed to this publication,

For additional copies

See it online at the Division of Developmental Disabilities' website
www.dmh.mo.gov/mrdd/selfdirect.htm
Use it online or print your own copy.

Forward

This handbook is for you if...

- you are an individual with a developmental disability and you are eligible for services through MO Department of Mental Health's Division of Developmental Disabilities
- you are a friend or family member of an individual with a developmental disability
- you work in the field of disabilities
- you care what happens to individuals with developmental disabilities
- you are interested in self directed supports

This handbook explains how Missouri Self-Directed Supports work. It will walk you through the process of being actively involved in creating quality support services. Person-Centered Planning and Individual Budgets give individuals with developmental disabilities (with help, as needed) control to direct the supports they receive as much as possible. This handbook outlines the steps to creating choices in your life such as where you work, where you live and who helps you out.

These are hard budget times. It seems there are less and less resources available to help individuals with developmental disabilities and waiting lists continue to grow. Now, more than ever, it's important for you and those who support you to have a loud voice regarding what you really need, and to have opportunities to speak out. **Person-Centered Planning** and individual budgets help give you that voice.

If you have any questions about the process you can call your service coordinator or call your Developmental Disability Regional Office and speak with the **Self-Directed Supports Coordinator (SDSC)**.

Albany Regional Office 800-560-8774
Central MO Regional Office 888-671-1041
Hannibal Regional Office 800-811-1128
Kansas City Regional Office 800-454-2331
Kirksville Regional Office 800-621-6082
Joplin Regional Office 888-549-6634

Poplar Bluff Regional Office 800-497-4214
Rolla Regional Office 800-828-7604
Sikeston Regional Office 800-497-4647
Springfield Regional Office 888-549-6635
St. Louis Regional Office 800-374-6458
St. Louis Tri-County Office 800-358-7665

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Glossary at the back of this guidebook.

Introduction to Self-Directed Supports

Self-Directed Supports (SDS) is an option for service delivery for persons with developmental disabilities and families who wish to exercise more choice, control and authority over your supports. SDS is founded on the principles of **Self-Determination**. Under this option you have employment and budget authority.

- Employment authority allows you to recruit, hire, train, manage, supervise and fire staff.
- Budget Authority allows you flexibility over managing your yearly budget allocation. For example, you may request that more services be authorized in one month and less in another or request to change from one approved waiver service to another as long as you stay within the authorized budget.

Self-direction includes six core components: person-centered planning, individual control of budgets, independent support brokerage, financial management services, a backup plan & quality enhancement & improvement.

Self-direction is firmly based in the principal of self-determination.

Self-determination refers to individuals with developmental disabilities exercising control over their own lives, working toward achieving individualized life goals, and obtaining the skills and supports necessary to realize their visions for the future to build opportunities and relationships.

The following services may be self-directed:

- **Personal Assistant**
- **In-Home Respite**
- **Community Specialist/Community Professional**
- **Support Broker**

The service coordinator will assist you and/or your **designated representative** in understanding the choice of self-directed supports and transitioning from provider driven to self-directed services. You can also hire a **support broker** to help you in self-directing your supports.

When you choose to self-direct your services you or your designated representative is the **employer**.

The Division of DD contracts with a single **Vendor Fiscal/Employer Agent (F/EA) Fiscal Management Service (FMS)** to assist the employer with payroll-related functions. These functions include conducting a background screening of your employee candidates, collecting and processing required human resource related forms and information (such as the IRS Form W-4, the US CIS Form I-9 and information necessary to register employees in the state's new hire reporting system), collecting and processing employees' time sheets, processing employees' payroll and the associated federal and state income tax withholding and employment taxes and other related payroll activities (such as issuing annual IRS Forms W-2 and refunding over-collected Medicare and Social Security taxes, as needed).

GUIDING PRINCIPLES of SELF-DETERMINATION

A broad concept that means individuals have overall control of their lives and are part of their community. It is based on five basic principles:

Principle 1

Freedom: You have the freedom to plan and create a meaningful life for yourself.

Principle 2

Authority: You have authority over the money used to support you. With your individual budget you can purchase the supports you need to live the life you have chosen. You will pay for just what you need and receive. You get a life, not a program.

Principle 3

Support: You get the support you need to live the life you want. You have a **circle of supports** around you which is made up of family, friends, both paid and unpaid supports, and other **natural supports**.

Principle 4

Responsibility: You have the responsibility for using your individual budget wisely, helping with your own support and for giving back to your community. You cannot have freedom without taking on more responsibility. You can assume responsibility for giving back to your community, for seeking employment whenever possible, and for developing your unique gifts and talents.

Principle 5

Confirmation: You can be an important part of your community based on what you give back to the community. You can have a leadership role in the design of government and the services used to support all people with developmental disabilities.

Choice Has Limits

Public funds will not be used to support choices which are illegal or harmful to you or others. The choices must be available to all. Public funds will be used as the payor of last resort.

Self-Determination is Not An Excuse

Self-determination is not an excuse for leaving someone in an unsafe situation on the grounds that he or she “chose” it. Self-determination is sometimes used as an excuse for letting individuals do things that are unsafe because “it is their choice.” It is not acceptable to offer a choice with either too many restrictions or no support at all. Self-determination means becoming more creative in helping you find ways to learn decision-making and manage your actions.

Whatever It Takes

An answer of “No, we can’t” is replaced by “How can we make this happen?”

There is a commitment to help individuals determine their future, respect their wishes, and plan to help them reach their goals.

* * *

Shifting Pattern

From		To
Professionals planning for you		You and your ‘Circle of Supports’ planning for your supports
Counting on a paid professional who is only temporarily part of your life		Reliance on the lifelong commitment of people you have chosen to be in your life, your family, friends and other natural supports
A view that only professionals can be responsible		Respect for the fact that you, your family and your friends have a vested interest in acting responsible on your behalf
Service Coordination as a means to let people into existing services		Use of Independent Support Broker as a way for you, your family and your friends to organize services in response to your needs and dreams.
The belief that quality is created by relying on regulations, oversight and monitoring		The belief that true quality is created by enhancing your circle of supports and connecting you to your community

Chapter 1: *Living Your Life:* *Person-Centered Planning*

What is the Good Life? Most individuals say it's about the basics--a pleasant home, a decent job, health, safety, having caring people around you, and feeling good about yourself. Person-Centered Planning and self-direction can help you get the supports that will help lead you to your vision of the Good Life.

Self-determination and Person-Centered Planning means:

- Making your own choices
- Taking responsibility for your decisions
- Speaking up when you are not happy about something
- Having control over your own life
- Being willing to try new things
- Figuring out what you do and don't like
- Asking for help when you need it
- Knowing the whole story

Having control and making your own decisions is powerful. Everyone needs help in different parts of his or her life. You can choose the people who will help you attain your goals in life.

When you are an employer and your employees are working for you as part of your team, you know everyone has the same goals. Those goals are based on the things that are important to you.

Many of the things you want in your life will cost money. You may need to buy some of the help you need. Other goals you have will cost little or no money. You may have some money from the county, state or federal government to purchase support in your home, community or at work. Determining how money is spent is especially important when there isn't enough money to go around for everyone who needs it. Using money carefully helps you gain control of your life and your future.

Everyone has an Individual Service Plan. We use a person-centered planning process to develop your individual service plan. Person-centered planning helps you figure out what is important to you and for you in order to improve the quality of your life and plan for your future.

You have the choice to facilitate your own planning meetings, have a friend, family member, or guardian facilitate for you, or you may choose an **independent plan facilitator** (Community Specialist/Community Professional or Support Broker). Many individuals and families have found it helpful to hire someone who works specifically for them during the dreaming and goal setting aspect of the planning process. Others have found it helpful to hire someone to help with the alternative funding portion, natural support building or other elements of the planning process.

You are encouraged to invite others whom you like and trust to help you. This might include your family, friends, co-workers, paid professionals or others to create your circle of support. Together you will also discuss ideas for implementing the person-centered plan and changing it when necessary. This is the time to dream; the time to develop a vision of what you want in your life.

Your support broker or service coordinator will help you develop, start and change your Individual Service Plan (ISP) as needed. They will write your plan and share it with the people on your team.

The plan will state what support you need, who will provide the support, when it will be provided and how much it will cost. The plan should also describe things you want in your life which do not cost money. Some of these free things might include time spent with family, favorite foods, favorite activities, church membership, club memberships, favorite neighborhood hang-outs, the way you like your home decorated or how your personal care is completed. All ISPs need to address health and safety issues as necessary.

Some people assume that individuals with severe developmental disabilities may not be able to be involved in the decision making process. You must be offered the opportunity to be as involved in decision-making as possible. A service coordinator's job is to guarantee this occurs. Having a strong circle of support or support team can help ensure that your needs, preferences and priorities are met.

Person-Centered Planning helps you figure out what is important to you and for you in order to improve the quality of your life and create your future.

The ISP is reviewed regularly with you and describes the supports you need accurately. At times you and members of your support team may disagree about support needs or personal goals. This often happens when you want to try something new that other people think sounds too risky. A good service coordinator will help you express your opinions, while listening respectfully to the people who are important to you. The service coordinator can help you resolve these conflicts to make sure that your support needs are met and the people important to you continue to work as a team. A strong support team helps you try new things and works with you to balance health and safety concerns as well.

Deciding on Supports:

Your ISP will document your support needs and priorities. It will describe the things that maintain, enhance or improve your life. During the planning process, you and your support team will decide how to provide these supports in a manner that meets your needs.

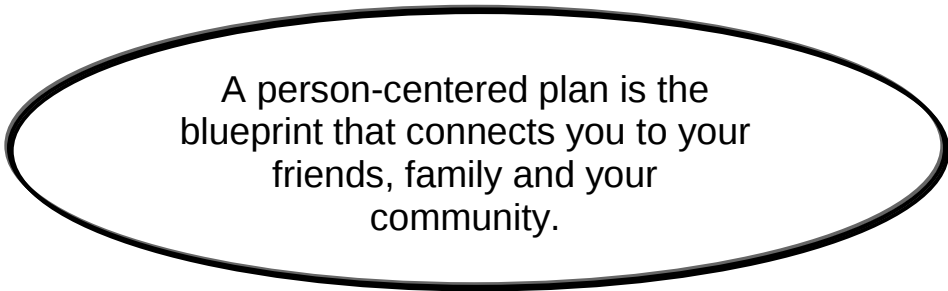
Everyone's plan is different. One individual may choose to purchase support entirely from agencies that specialize in helping individuals with developmental disabilities. Another may choose a combination of an agency and self-directing some supports such as hiring a coworker to help you with your needs at work. A third individual may decide not to utilize any agency support, but instead self direct all supports, hiring and supervising his or her own staff. The only limitations in choosing your supports are to stay within your individual budget and ensuring your Individualized Service Plan addresses all your health and safety needs.

Things to think about when developing an ISP:

What do you want your life to look like in the next 12 months? 2 years? 5 years?

- Who is important to you?
- What is important to you?
- What do you need to stay healthy and safe?
- What support is most vital/important to you?

- What supports cost money and how can family, friends or community members help?
- In what areas do you need help/support?
- If you can't afford everything you want, what are your top priorities?
- If there are personal funds available, how can these help you get what you want/need?
- Can you get more of the support you want if you share staff? For example, some individuals have roommates, share home staff, go out with friends, share a job coach, etc. to save money.
- What is your back-up plan if your employee, who is providing essential supports, is unavailable?



A person-centered plan is the blueprint that connects you to your friends, family and your community.

Some ideas for learning about types of support which others use:

- Ask your Service Coordinator, Regional Office SDSC, Advocacy Specialist or local advocacy group about the different types of supports individuals can use.
- Talk with individuals who self-direct their support services and their families.
- Conduct informational interviews with service providers.
- Consider generic forms of services typically provided by service agencies. For example, you may be able to pay your bills through internet banking.
- Think about community connections. Taking a neighborhood walk, finding a favorite hang-out place, volunteering at the community center or attending a local place of worship all create feelings of belonging to the community.

Chapter 2: *Creating an Individualized Budget*

After your initial person-centered plan is written, it is time to figure out how to meet your needs and make your dreams and goals or outcomes happen. Your service coordinator and the Regional Office SDSC will help you do this.

They will work with you and/or your designated representative to figure out how to pay for the things you want and need. They will talk to you about using the different funding sources available, including your own resources as well as formal and informal supports.

You may want or need help in directing your supports and services as well as figuring out different ways to pay for things. You can hire a support broker to help you do this. The support broker can teach you to advocate for yourself. You may want to hire a support broker who is good at finding different ways to pay for the things you want. For example, if your goal is to buy a house, you may want to hire a support broker who has the experience to connect you to special programs which can help when purchasing a home. These special programs may be for people with low income and limited resources, or they may be resources for the general public. Once a goal is reached you may want to hire a new support broker who has expertise or experience in helping you reach a different goal.

Individualized Budget Checklist

You or your designated representative, along with your support broker (if you choose to have one) and your service coordinator will work together to develop an individual budget. You will work together to figure out different ways to use funding resources. Some find the process of developing a budget confusing and overwhelming, while others enjoy trying to piece the puzzle together.

The following guidelines are helpful when developing budget scenarios:

- Decide what support you must have in order to be healthy and safe and to reach your goals and which supports may not be as important right now.
- Look at all the resources you have right now - natural supports, formal and informal supports, and your personal income.
- Talk about the help you may need to increase the amount of natural supports in your life and increase your income.
- Talk about different funding sources and programs available. Discuss the purpose of each funding agency and how they can be used. All of these sources will have rules you have to follow or strings attached. Use the funding with the most strings attached first. The money you earn is the most flexible because it does not have string attached.
- Discuss other ways to reach your goals such as scholarships, grants, loans, sponsorships, bartering, cooperatives, etc.
- Make sure all your needs and goals are covered.

Chapter 3: *Designing Self-Directed Supports*

You now have your initial ISP and your budget. So it's now time to design your self-directed supports.

When you self-direct supports someone must be the employer. You can be the employer, your guardian can be the employer, or you may choose someone to be your designated representative to be the employer on your behalf.

Your service coordinator, SDSC or other team members will help you with this. They will also discuss the role of the FMS organization in assisting you with:

- Managing your budget; processing;
- Completing, processing and maintaining employer enrollment and employee human resource related forms;
- Processing prospective employees' background checks;
- Verifying your employees' citizenship or legal alien status;
- Verifying that your employees have received required training;
- Processing and paying payroll and filing associated federal and state income tax withholding and employment taxes;
- Facilitating the receipt of a workers' compensation insurance policy and processing premium payments for you and your employees; and
- Providing you with a Monthly Spending Report to help you keep track of your budget.

Who is eligible to work for you through SDS?

Anyone over the age of 18 with a high school diploma or GED (4 year degree required for Community Professional/Community Specialist) who you choose to hire, with the following exceptions:

- Your spouse
- Your parent if you are a minor
- Your legal guardian or anyone with any legal authority over you
- Your designated representative
- Under the Lopez Waiver, an employee cannot be a member of your immediate family (natural, half-or step-relationships with parent, child, sibling or spouse)
- Anyone with a felony which is disqualifying.

Self-Directed Services

You can self-direct the following services:

- Personal Assistant
- In-Home Respite
- Community Professional/Community Specialist
- Support Broker

Each of these services has a different function and may have different training requirements for employees.

Personal Assistant

A personal assistant can help you with these daily activities, which may include:

- Bathing
- Toileting
- Transfer and ambulation
- Skin care
- Grooming
- Dressing
- Extension of therapies and exercise
- Care of adaptive equipment
- Meal preparation
- Feeding
- Incidental household cleaning and laundry
- Shopping
- Banking
- Budgeting
- Using public transportation
- Social interaction
- Recreation and leisure activities

Your personal assistant may be at your side while you do these activities, may teach you how to be more independent in these areas or may help you do the things you cannot do for yourself. Your personal assistant can help you to be part of your community. Personal assistance may also include someone being at your side to make sure you are safe and get what you need.

Under special conditions you may need enhanced medical/behavioral personal assistance services. These services have training requirements which cannot be waived. Because of these conditions you may need a Community Specialist/Community Professional to provide training and oversight for your personal assistance services.

In-Home Respite

If you live with a family member, friend or other person who is not paid to support you, you may receive In-Home Respite Services. You would use this service so you can get support if the person you live with is absent or needs relief for a short period of time.

Support Broker

A Support Broker is someone who is selected by you or your designated representative and works under your direction to help you get the things you need. You define what you want the support broker to do for you.

The type of support typically requested includes, but is not limited to:

- Helping you find employees to provide your personal assistance; helping with interviews, hiring, training, etc.
- Helping you use community resources
- Help with making a work schedule for your employees based upon the person-centered plan
- Assisting and implementing a back-up/emergency plan
- Seeking other supports or resources outlined by your person-centered plan (adaptive equipment, home modifications, etc.)
- General assistance with your person-centered planning process

Community Professional/Community Specialist

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A community professional/community specialist is a qualified professional from your community. This means that this person has a degree and special training and knowledge in providing support in their particular area of expertise. A community professional/community specialist can help with your person-centered planning process or other community supports. For example, you may choose to hire a community professional/community specialist to develop specialized supports to assist you with medical/behavioral oversight, to help train your employees and to assist you in achieving your goals when professional expertise is necessary.

Being An Employer with a Vendor Fiscal/Employer Agent Fiscal Management Service Organization

In self-directed supports you have the freedom, authority and responsibility of being the employer of the people you hire directly. You will receive supports from an FMS organization, your service coordinator, the Regional Office SDSC and other online resources to perform the tasks associated with being an employer. You also may hire a support broker to assist with managing your supports and the workers who provide them.

As the employer you have additional benefits and responsibilities which you would not have in the traditional agency-based system, like an **Individualized Supported Living (ISL)** arrangement or **group home**.

As the employer, you have the opportunity (benefit) of recruiting and hiring your own employees. You also have the freedom and authority of setting the hourly wage for your employee(s), within the guidelines established in your budget.

In addition, you also have the responsibilities that come with being an employer. As an employer you are required to:

- Recruit your employees.
- Interview your employees and review their references.
- Receive notice from the FMS organization that your employee candidate has passed the criminal background check before hiring him or her and allowing them to do any work for you.
- Hire your employees.
- Train your employees.
- Establish a mutually agreeable work schedule for your employees.
- Establish a list of tasks to be performed by your employees based on your ISP and a description of your preference on how they are to be performed.
- Manage your employees.
- Review your employees' performance and provide feedback either to acknowledge good performance and/or point out areas that may need improvement.
- Fire your employees when necessary.
- Work with the FMS organization to complete and submit for processing all required employer and employee related paperwork.
- Review, approve, sign and submit your employees' time sheets to the FMS organization. If you feel a time sheet does not correctly reflect the authorized hours worked, you must report any differences to the FMS organization and work with your employees to correct any errors.
- Ensure that your employees complete all required documents such as log notes and time sheets.
- Complete a monthly summary document that describes the progress you have made towards achieving your ISP goals and objectives and provides an overall picture of how things are going for you.
- Make sure your employees have received and keep up with all required training. The **Training Checklist** form will help you track this.
- Maintain a personnel file for each of your employees which contains their training records, contractual agreements and a copy of their high school diploma or GED certificate.
- Create and maintain an emergency back-up plan in the event that an employee does not show up for work for any reason.
- Inform the FMS organization immediately when you have terminated an employee. Make sure the employee has been fired in accordance with state department of labor fair firing

practices and that you inform the FMS organization of the reason for firing so it can be documented in the employee's file.

Vendor Fiscal/Employer Agent (F/EA) Financial Management Service (FMS)

Everyone who self-directs their supports uses the single Vendor Fiscal/Employer Agent (F/EA) Financial Management Service (FMS) organization. The Vendor F/EA FMS organization performs as the *agent* to the employer assisting you and/or your designated representative in managing some of the financial responsibilities of being an employer. For example, they assist you with:

- Managing your budget;
- Processing and completing employer enrollment and employee human resource related forms;
- Processing prospective employees' background checks;
- Verifying your prospective employees' citizenship and legal alien status;
- Verifying that your employees have received required training;
- Processing and distributing your employees' payroll and filing and paying associated federal and state income tax withholding and employment taxes; and
- Facilitating the receipt of a workers' compensation insurance policy and payment of premiums for you and your employees.

Additionally, the FMS organization will provide you with monthly spending reports to help you keep track of your budget.

The FMS organization will verify that your employment-related paperwork is completed correctly. They will notify you if there are any errors which prevent your or your employees' paperwork from being processed. It is important that you submit corrected forms to the FMS organization in a timely manner to prevent any service delays.

The FMS organization also will notify you once your prospective employees are clear for hire based on the results of a background check. **You must not allow any person/applicant/prospective employee to begin working for you until the FMS organization notifies you that your prospective employee has passed their background screening.**

Voluntary Termination and Involuntary Termination of Self-Directed Supports

Voluntary Termination

If you decide you do not want to continue self-directing your supports, you can stop at any time. Your service coordinator can help you begin that process and assist you in transitioning to agency-based services.

Involuntary Termination of Self-Directed Services

In the event the planning team determines your health and safety is at risk, there are concerns regarding your willingness to ensure proper records are accurately kept, or that you are unwilling to supervise employees to receive services according to the plan, the choice of self-directing your supports may be terminated. Before terminating self-directed options, the service coordinator and other appropriate staff will first counsel you to assist you in understanding the issues, let you know what corrective action is needed, and offer you assistance in making changes. If the SDS option is terminated, the same level of services will be offered to you through a traditional agency-based model.

Chapter 4: *Creating Quality*

Quality Enhancement (QE), means there are standards which must be met so you can live a safe and productive life. The QE process monitors services to help make sure that your life is going well.

Quality Enhancement asks these questions:

- Are your needs being met?
- Are your supports being delivered on time with care and respect?
- Do you have choice and opportunity in your life?

How does having choice of services improve quality?

1. You, along with those who know you best, will define what quality services mean in your life. You should tell others if you do not like the supports you are receiving.
2. Your ISP describes what results you want from your services. If those outcomes are reached, you and your support team will know you have good supports and things are working as they should.

Your Team Helps Create Quality

Your support team makes sure things are going well in your life.

Members of your team will include:

- **Service Coordinator:** The SC is the primary Quality Enhancement monitor. It is important for you, your guardian, and/or your family to have an open relationship with your SC. Each of you should feel free to speak up and ask questions.
- **Family, guardian, designated representative, and friends:** People who care about you help keep an eye on how things are going. They are encouraged to be active members of your support team. They know you in a special way, and often have a unique perspective.
- **Your employees:** Most individuals have paid support staff who help them at work and/or at home. These employees can help you be more independent and lead a fulfilling life. They are key team members because they are with you a lot. These employees are trained to provide services based on your needs and goals.

Working Together: A good support team respects each team member's opinions. The team members know that sometimes things are very difficult, but know they are stronger and smarter when working together. Each team member needs to value the role of the other members. Each person brings useful ideas to the group. Everyone knows their job is to work together to reach the goals in your ISP.

How families and employees can become good advocates and team members for you:

- They listen to you. They think about how you communicate and ask questions in a way that is useful. For example, if you don't speak, they use pictures or drawings to explain concepts. They continue to explore ways to involve you in the decision-making process.
- They don't speak for you, even if they think they know the answer. They try to control their own opinions.

- They may disagree with a decision you've made, however, they realize it is your decision. They recognize that we all learned about decision-making by making some decisions that were smarter than others.
- They listen to others who know you in different settings.
- They don't let someone else's credentials or position get in the way of their knowledge of you. They work as a team and remember **you** are the most valuable part of it.
- They encourage you to explore opportunities, develop your own individual gifts, and let others have the chance to know you.
- They avoid the word "CAN'T." Instead, substitute "How can we..." or "What if ..."

Other Quality Enhancement Support

Some services are available outside of the ISP. They are available if you need some specialized help.

- Grievance process
 - Services monitoring
 - Event Management Tracking
 - Employee background checks
 - Ensuring the availability of back-up services
 - Quality Enhancement services through your Regional Office and the Department of Mental Health
- Grievance process: Your service coordinator has a supervisor and or a director who is available to address complaints from you, your family or your guardian. A service coordinator is assigned to you as a resource. Whether you receive service coordination from the regional office, a SB 40, or a non-profit entity, each is required to have a clearly stated grievance process.
- Services monitoring: Your service coordinator will meet you face to face no less then every 3 months to monitor your services and address any issues. They will also work with you to ensure that you have the support you need to fulfill your employer responsibilities.
- Event Management Tracking: DMH tracks events to ensure your health and safety. The department looks at these events to improve programs and services. You and your unpaid family members are not required to report these incidents but any employee paid to provide Medicaid Waiver services **is** required to report any events that could jeopardize your health or safety. If any of the following occur, your employee should first ensure your health and safety and then should contact your employer, if it is someone other than you, and your service coordinator or the office on-call staff as soon as possible:
1. Abuse (physical, sexual or verbal)
 2. Misuse of Funds or Property
 3. Neglect
 4. The death, by any cause, of an individual.
 5. Any incident involving an individual that requires the involvement of law enforcement.
 6. Attempted suicide by the individual.
 7. An incident in which an individual can not be located (elopement) for a period of time longer than specified in the individual's plan of if other circumstances indicate that the individual is in immediate jeopardy.
 8. Medical emergency, which means the sudden onset of a medical condition or injury which

- requires emergency medical intervention or unplanned hospital admission.
9. Medication errors, which means the individual did not receive their medicine or received it in any manner which varies from the physician's order (i.e. wrong dose, form, route, time, etc.)

Upon receiving information regarding an incident listed above, your service coordinator will ensure your immediate health and safety needs are met. He or she will then write a report detailing the event. In some cases your team will meet to talk about what occurred prior to the event and what can be done to prevent a reoccurrence in the future.

- Background Checks: These are required for all of your potential employees prior to beginning their employment. These are processed by the FMS organization and the employer is informed if the screening is clear. If your potential employee has any 'hits' or flags on their report your SDSC and other team members will work with you to determine if this potential employee can be cleared to work with you. **Remember, you must not allow any person/applicant/prospective employee to begin working for you until the FMS organization notifies you that your prospective employee has passed their background screening.**
- Back-up plan: As with all Medicaid services you are required to have an emergency back-up plan to handle situations when your employee, who is providing essential supports, is unavailable. The ISP needs to include the method to deal with these situations. You need to identify back-up friends, family or other natural supports, trained and qualified employees, or agency providers whom you can call for assistance. The ISP must also address the means for summoning assistance should the need arise. All members of your support team need to be educated about your back-up plan. All emergency numbers must be accessible to your employees.
- QE services through your Regional Office and the DMH: The Quality Assurance advisory group provides input and recommendations to the Division of Developmental Disabilities on development and enhancements to the comprehensive quality management system of the DDD service continuum. The group was created in response to requests by families and individuals with disabilities to have a more active voice in the quality assurance system, decision making, and to improve communication regarding policy issues.

Chapter 5: *How Can I Access Self-Directed Supports?*

- If you are interested in participating in SDS you should first talk to your service coordinator.
- Your service coordinator will contact the Regional Office SDSC.
- Please note that SDS can be chosen *along with* services provided by contracted providers in order to meet all of your needs.
- You may utilize the SDS option if you receive funding through Medicaid Waiver (Comprehensive, Community Support, Lopez or Autism) or POS, pending the Regional Office Utilization Review Committee approval.
- The total service cost authorized must include the hourly rate of pay for the service PLUS approximately 15%, which covers your employee taxes and workers' compensation insurance. You and your support team, including your service coordinator, will determine the service hours you need and will determine each employee's hourly rate of pay so that service funding is not exhausted and the budget is balanced.
- The Regional Office SDSC is available to assist with this start-up process and can provide any training or guidance necessary.
- You or your designated representative will complete all necessary paperwork through the FMS organization's website which will be provided for you. Once you have worked with your service coordinator to get enrolled, you will be issued a user name and password to access your employer and employee information online.
- Your service coordinator acts as a bridge builder between you and the FMS organization, with the assistance of the SDSC as needed. You or your designated representative should eventually be communicating DIRECTLY with the FMS organization most of the time regarding employee issues.

Chapter 6: *Some Commonly Asked Questions*

What happens to the money in your individual budget if you don't use it all?

If you don't need the total amount allocated for a year, your rate will be reviewed by your service coordinator to see if it should remain the same or be reduced for the next year. Money not needed for one individual's supports can be used for other people with developmental disabilities who are on waiting lists.

What if you need more money for support than the individual budget allows?

If you need more support, your service coordinator (SC) will write an addendum requesting an increase to your individual budget. The SC will forward this information to the Regional Office Utilization Review Committee; this committee allows the SC to explain to the committee why the increase is needed. This can occur at any time during the year and is also reviewed, at a minimum, each year when the ISP is reviewed. The SC, Utilization Review Committee and RO director or designee must approve all increases. **Please note that requesting additional funds does not mean they are available.**

Why do I need a roommate to help share costs?

If you need help 24 hours a day, you may not be able to afford to live alone. Typically, many people have roommates to share costs.

How do I find a roommate?

A roommate can share costs and may also become a friend. A roommate may be someone you know from school, church, a self-advocacy group or recreational activities. Your service coordinator will be helpful in finding a roommate if you want or need one. Also, your friends, family or employees may know someone they think you might like as a roommate. It is important to let others know you are looking for a roommate and to have an idea of what your ideal roommate would be like.

How can you become a good advocate for yourself?

- It takes confidence to speak up and express your opinions. The way to develop self-confidence is to have opportunities to speak to and in front of others. We all learn from experience.
- Here are some ways people can assist you in creating those opportunities:
 - 1) Before meetings, review the agenda with them and let them know what you want to say.
 - 2) After meetings, review what was decided and let the team know if there are things you did not understand. Many people have questions about what happened at meetings.
- Let things move at their own pace. Don't be impatient with yourself as you learn to become a better self-advocate. Change comes with time and experience.
- Take opportunities to make choices in your life. The more choices you make, the better you will get at it. Remember, practice makes perfect!

Can my family members work for me?

Your family member(s) may provide all services under self-direction with the exception of support broker. When you hire a family member, your ISP must reflect:

- You are not opposed to your family member providing the service,
- The services to be provided are solely to support you and not a typical task for the family unit (i.e. family laundry),
- Your support team agrees that your family member will best meet your needs,
- Your family member cannot be paid for over 40 hours per week; any support provided above this amount would be considered a natural or unpaid support that a typical family member would provide.

Glossary

advocacy specialist: The advocacy specialist is a Regional Office employee who helps create a strong advocacy voice in the system of developmental disabilities by participate in regional and statewide committees and workgroups. He or she provides training and mentoring to peers by developing a list of speakers in your area; partners with others to deliver training; and can help with the development, growth, coordination and support of self-advocacy groups.

advocate: A person whose only role is to assist you in presenting your point of view and helping you make informed choices.

circle of supports: This is a group of people who care about and advocate for you and want to assist with your support on a long-term basis. This may also be called a 'support team.'

common law employer: See Employer

Community Event Report (CER): A CER is completed if an event happens or is suspected to have happened which is harmful to your health and safety. These events include abuse or neglect and other types of events that create unpleasant effects or create unpleasant effects for you. You and your unpaid family members are not mandated to report these events but any employee/provider paid to provide Medicaid Waiver services **is** required to report any events that could jeopardize your health or safety. If an event happens or is suspected to have happened your employee is required to ensure your immediate safety and to contact your service coordinator or designated on-call staff as soon as possible.

The department tracks these events to help improve the quality of life for individuals with disabilities. **See Event Manager Tracking (EMT).**

community professional/community specialist: A community professional/community specialist is a qualified professional from your community; which means this person has a degree and special

training and knowledge in providing support in their particular area of expertise. A community professional/community specialist can help with your person-centered planning process or other community supports. For example, you may choose to hire a community professional/community specialist to develop specialized supports to assist you with medical/behavioral oversight, to help train your employees and to assist you in achieving your goals when professional expertise is necessary.

designated representative: When you self-direct your supports someone needs to be the employer. The employer must be able to direct and manage the worker's day to day activities, making sure the services and goals are provided as written in your plan and perform other the duties of an employer. You or your guardian can be the employer or you may choose someone else to be the employer. The following can be designated as your representative, as available and willing:

- spouse (unless a formal legal action for divorce is pending);
- your adult child;
- your parent, brother, sister or another relative;
- a friend

If you want a representative but are unable to identify one of the above, you along with your service coordinator and other members of your planning team, can select a representative. This representative needs to be an adult with knowledge of your preferences, values, needs, etc. You and your planning team are responsible to ensure that the selected representative is able to assist you with all the employer-related responsibilities and follows the policies associated with representing you in directing services and supports. The planning team and Fiscal Management Service organization (FMS) will recognize your representative as a decision-maker and provide the representative with all of the information, training, and support they would typically provide to you when you are self-directing. The representative must sign an agreement which lists his or her responsibilities and states that he or she will act in your best interest. This person may not be paid to provide services to you. You may, at any time, revoke the agreement with your designated representative.

Employer: When you self-direct your supports someone needs to be the employer. This person becomes the common law employer or the employer of record. The employer must be able to direct and manage the worker's day to day activities, making sure the services and goals are provided as written in your plan and provide other duties of an employer. The FMS files taxes and manages payroll functions for the employer. The employer must approve all hours worked prior to submitting time cards to the FMS.

Employer of Record: See Employer

Enhanced medical/behavioral personal assistance: If you have special medical or behavioral support needs you may need a personal assistant who has a higher level of training. Because of advanced training requirements, these employees may be paid at a higher rate. This advanced training is related to your medical needs as outlined in your ISP and as prescribed by your physician or advanced practice nurse or the training will be related to your behavioral needs as outlined in your ISP and your Behavior Support Plan (BSP).

In both cases you may need the support of a community professional/community specialist to assist in the development of your ISP and training and monitoring of your personal assistant(s).

Event Manager Tracking (EMT): EMT is the reporting system mandated by Missouri law that sets a procedure to review and report allegations of abuse, neglect and potentially serious events that occur in the DD system.

Fiscal Management Services (FMS) –The FMS is under contract with The Division of Developmental Disabilities to act on the behalf of each self-directed supports employer to handle employer-related functions, pay your workers and help keep track of your funds. These services are provided as an administrative service and not as a waiver service and do not come out of your individual budget.

The Centers for Medicare and Medicaid Services (CMS) defines Financial Management Services as: *A service/function that assists the family or participant to: (a) manage and direct the distribution of funds contained in the participant-directed budget; (b) facilitate the employment of staff by the family or participant by performing as the participant's agent such employer responsibilities as processing payroll, withholding and filing federal, state, and local taxes, and making tax payments to appropriate tax authorities; and (c) performing fiscal accounting and making expenditure reports to the participant and/or family and state authorities.*

group home: There are many contracted providers in the state of Missouri which provide services in Licensed, Certified or Accredited group settings. Group Homes serve between 4-16 individuals in each setting. These structured homes provide safe, healthy environments where people can learn skills for independence.

Home and Community-Based Waiver (HCBW): The waiver is used as the primary source of funding for people who live in the community. The division uses general revenue funds to match federal Medicaid dollars to pay for services under the waiver. The waiver includes people who live in group homes, supported living, and with their families. The Center for Medicare and Medicaid Services (CMS) is the federal agency that regulates the use of these funds. For more information about HCBW go to <http://dmh.mo.gov/mrdd/new/manual/wvrfactsheet9-09.pdf>

independent plan facilitator: Someone you hire to help you create your ISP.

individual: A person who is or has been receiving services from the DMH's Division of DD.

individualized budget: The amount of money available for services needed to implement your ISP. When you self-direct your services, you are in control of this money and can move it between services with the approval of the Regional Office's Utilization Review Committee.

Individual Service Plan (ISP): A personalized blueprint for developing supports for you.

Individualized Supported Living (ISL): ISL services are provided to individuals who want to live in the community, either alone or with up to 2 roommates in an apartment or home of their own. People receiving ISL services choose a contracted residential provider, who will supervise the employees that provide direct support. Services are based on the needs of the individual(s), and can range from one hour a week to 24/7 services.

in-home respite: A service which can be self-directed. This service provides relief for your primary care-giver.

natural supports: A person or other resource which is available in the community and can be used to help you in the process of being integrated, accepted, and satisfied in the community by helping you with your goals and interests.

personal assistant: A service which can be self-directed. This person may help you with your daily activities.

person-centered planning: Person-centered planning is a process-oriented approach to empowering people with disabilities. It focuses on individuals and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society.

Quality Enhancement (QE): A set of activities intended to monitor standards regarding support services.

self-advocate: An individual needing support services who makes choices and decisions regarding his/her chosen lifestyle, independent of interference or undue influence from others.

Self-Determination: A broad concept that means individuals have overall control of their lives and are part of their community. Self-Determination is based on five basic principles:

- 1) **freedom** to lead a meaningful life in the community
- 2) **authority** over a dollars needed for support
- 3) **support** to organize resources in ways that are life-enhancing and meaningful
- 4) **responsibility** for the wise use of public funds
- 5) **confirmation** of the importance of leadership that self-advocates must hold in a newly formed system

Self-Directed Supports Coordinator (SDSC): An employee of the Regional Office who has the job of coordinating self-directed supports for your region. He or she is available to answer questions your team may have about self-directed supports.

support broker: A service that can be self-directed. This person is selected by you or your designated representative and acts as your agent to secure the supports and services in order to address the needs identified in your ISP.

support team: The paid and unpaid people who assist you in obtaining and securing needed services. See ‘circle of supports.’

supports: The services and help that enable you to live and work successfully in your community.

training checklist: A worksheet you use to track your employees’ training. Your service coordinator will check this when they visit you.

Utilization Review Committee (URC): A formal committee established at each Regional Office to review proposed ISP’s and individualized budgets and make recommendations before services are approved and authorized.

Vendor Fiscal/Employer Agent (VF/EA): A type of FMS which we use in Missouri which operates under IRS rules and acts as an “employer agent” for you—performing all that is required of an employer for wages paid on the employer’s behalf.