

# Living a Self Determined Life

A guide for navigating support services for  
individuals with disabilities in Pulaski County

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# Introduction

## **This guide is for you if...**

- you are an individual with a developmental disability, and you are eligible for Pulaski County Special Services.
- 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

This handbook explains how the Pulaski County Special Services (PCSS) system works. It will walk you through the process of being actively involved in creating quality support services. PCSS uses Person-Centered Planning. Person-Centered Planning gives individuals with disabilities (with help as needed) control to direct the support they receive as much as possible. This handbook talks about how to have choices in your life— where you work, where you live and who helps you out.

These are hard budget times. It seems that there are fewer and less resources available to help individuals with disabilities and waiting lists continue to grow. It is more important now more than ever for individuals with disabilities and their *daily representatives* to have a loud voice regarding what they really need, and to have opportunities to speak out. Person-centered Planning helps to give you a voice.

If you have any questions about the process, you can ask your Support Coordinator or the Executive Director. Their contact information is written at the back of this book.

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## **GUIDING PRINCIPLES of SELF-DETERMINATION**

Ideas we believe in and make decisions by

### **Principle 1**

Individuals with their family and friends must have the control, power, resources, and authority to decide their own destiny. This includes planning their own future.

#### **YOU ARE IN CHARGE OF YOUR LIFE**

### **Principle 2**

Decision-making includes having the control, power, resources, and authority to make choices and accept responsibility for those choices.

#### **YOU ARE RESPONSIBLE FOR YOUR DECISIONS**

### **Principle 3**

Each individual will have the opportunity and support to enter gainful employment and to accumulate wealth. As individuals accumulate wealth, it is expected that they will contribute to the cost of their services and supports.

#### **YOU CAN GET A JOB TO HELP PAY FOR THE THINGS YOU NEED AND WANT**

### **Principle 4**

Each individual will have the advantage of the available funding sources, and community or natural support that are consistent with the vision, goals and principles of the project.

#### **YOU CAN GET HELP FROM OTHER PLACES BESIDES PCSS**

### **Principle 5**

Each individual will receive services and support which are built on the individual's strength and are valued or needed. This will contribute to the individual's perception of quality. Individuals may eliminate support that they do not value or need.

#### **WE WILL NOT WASTE YOUR TIME, BUT ONLY WORK ON THINGS THAT ARE IMPORTANT**

### **Principle 6**

Each individual will have an option to live where and with whom he or she chooses. The choice shall not require the participation of other individuals with disabilities.

#### **YOU CAN LIVE WITH WHOM YOU WANT AND WHERE YOU WANT IF YOU HAVE THE MONEY**

### **Principle 7**

Individuals and their families will have opportunities to participate in advocacy groups and public forums to make important changes at the local, state, federal level.

#### **YOU CAN CHANGE THINGS FOR YOURSELF AND FOR PEOPLE WITH DISABILITIES IN THE FUTURE**

### **Principle 8**

Individuals are offered choices in participating in community activities and functions they want to be involved in.

#### **YOU CAN DESIGN WHAT YOU WANT YOUR LIFE TO LOOK LIKE**

### **Principle 9**

Through the planning process each individual and family will work towards building natural supports and advocates.

#### **YOU ARE AN IMPORTANT PART OF YOUR COMMUNITY**

### **Principle 10**

Individuals and families are asked to give feedback on our services and supports. Your ideas, criticisms and compliments help us to continually rethink and redesign our systems to make them better. You are a part of our team.

#### **WE WORK FOR YOU**

### **Choice Has Limits**

Public funds will not be used to support choices that are illegal or harmful to the individual 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 will not be used that way in Pulaski County. It is not acceptable to offer a “choice” of either too many restrictions or no support at all. We believe individuals must be healthy and safe. Self-determination means becoming more creative in helping individuals find ways to learn decision-making and manage their 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 dreams, respect their dreams, and help their dreams come true.

\* \* \*

## **Chapter 1: Living Your Life**

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 can help you get the supports that will help lead you to your vision of the Good Life.

# S

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 meet your goals in life.

When people 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 state 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 individuals gain control of their money and their futures.

## Chapter 2: Getting Started

**H**ow do individuals with developmental disabilities receive assistance?

1. Individuals with disabilities, parents, teachers, or other interested parties call **the Rolla Regional Office at 573-368-2200**. The intake coordinator will ask for permission to gather written information about the individual with a developmental disability.
2. The Intake Coordinator will talk with the individual with a disability and family and/or the individual's daily representative.
3. The Intake Coordinator uses written information and a personal interview to determine *eligibility* for services.
4. If the person qualifies for services a Support Coordinator is assigned from PCSS.
5. A person-centered plan is written. The Support Coordinator knows many of the resources in the community. They are able to provide individuals with information and ideas about other places to look for help.

### Waiting Lists

There are waiting lists for help from PCSS and the Regional Office. You may be on one of the waiting lists. Why do they exist? Simply, there are more individuals who need services than there is money to help buy what they need.

You may wonder why some individuals receive assistance and others stay on the waiting list. PCSS staff assist in putting together a packet for Utilization Review Committee and they make very difficult decisions, based upon guiding principles from the Department of Mental Health Developmental Disabilities Division. If you have a question about the waiting list, you can always call your Support Coordinator.

Waiting lists are another reason that everyone must use money carefully. If we can save just a little, we can help someone else move off of a waiting list and assist with their needs.

## Chapter 3: Support Coordination

The first step to directing your own services is working with your Support Coordinator through the planning process. Your Support Coordinator will work with you to find the help you need. The Support Coordinator works for you.

Sometimes it helps to have a friend or relative join you at the planning sessions. Sometimes it is easier to make important decisions when you have help from people you know.



### **Before asking people to your planning session, try to figure out:**

- Do the people you want to invite have your best interests in mind?
- What type of people do you trust to help you?
- Do you want the members on your planning team to be family or friends or a combination of both?
- How do you want the Support Coordinator to work with your family, friends, representative and service providers?
- Is there information you want to keep private?
- Are there things you want to do by yourself?

### **Some questions you might want to ask your Support Coordinator:**

- Do you have experience supporting individuals with lives similar to mine?
- If individuals want a change in their life, how have you helped individuals make those changes?
- If individuals want things to stay exactly the same, is that okay?
- How many individuals do you work with?
- How often can I expect to see you? What if I need some extra help for a short time?
- Do you have a good relationship with support agencies?
- How have you been an advocate for the individuals you work with now?
- How do you handle situations when people on the team have different opinions or might not be getting along?
- How would you help me understand my budget?
- How would you help me plan for my future and help me achieve my goals?

- How can I find out what the individuals you support think about you?
- How often would you want me to tell you how you are doing?
- How do you learn about the things Support Coordinators are supposed to know?

***Support Coordinator:*** A person who provides information, helps people develop personal support plans, works to get needed supports and provides ongoing monitoring and coordination of those supports.

**A Support Coordinator needs the skills to . . .**

- Develop a person-centered plan.
- Coordinate paid and unpaid supports in a manner that fits the person-centered plan and stays within an individual’s budget.
- Help prioritize needs and wishes so an individual receives the support most important to them.
- Investigate community resources.
- Assist in connecting individuals to their communities.
- Represent individuals when dealing with service providers.
- Create options for additional support when needed.
- Develop informal as well as formal supports.
- Be a good listener.
- Be a team player who can work with individuals, families, and support providers.
- Represent different viewpoints while maintaining an individual’s priorities and following their wishes.
- Resolve conflicts respectfully.

**Once you have a Support Coordinator . . .**

1. The Support Coordinator will get to know you and your family.
2. The Support Coordinator will help you develop a person-centered plan that balances the support you need and what you want. This person-centered plan helps identify your goals and hopes for the future.
3. The Support Coordinator will meet with you and your team regularly to make sure the person-centered plan is working or to help you make the changes you want.
4. The Support Coordinator can help if the people on your team agree about the best way to help you.

5. You can change your person-centered plan as often as you want, but your Support Coordinator must help you update it at least once a year.
6. If you are unhappy with your Support Coordinator you can call the Executive Director of PCSS.

## Chapter 4: **Person-Centered Planning**

Everyone has a person-centered plan. We use a person-centered planning process to develop your individual service plan. *Person-centered planning* helps you figure out what is important for you and to you in order to improve the quality of your life. The Support Coordinator will help develop a person-centered plan with you (and your guardian if you have one). You are encouraged to invite others that you like and trust to help you. This might include your family, friends, co-workers, paid professionals, or *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 Coordinator will help you to develop, start and change your person-centered plan as needed. They will write your person-centered plan and help you to share it with the people on your team. The person-centered plan will state what support you want, who will provide the support, when it will be provided and how much it will cost. The person-centered plan should also include things that you want that do not cost money. Some free things that are important to individuals are time spent with family, favorite foods, favorite activities, church membership, club memberships, favorite neighborhood hang-outs, the way individuals like their home decorated or how their personal care is completed. All person-centered plans need to address health and safety.

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

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

The person-centered plan is reviewed regularly with you and your circle of support or support team. This helps make sure your person-centered plan describes the supports you need correctly. At times you and members of your support team may disagree about support needs or personal goals. This often happens when an individual wants to try something new that other people think sounds too risky. Your Support Coordinator will help you express your opinions, while listening respectfully to the people who are important to you. The Support 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 individuals try new things but looks out for health and safety concerns.

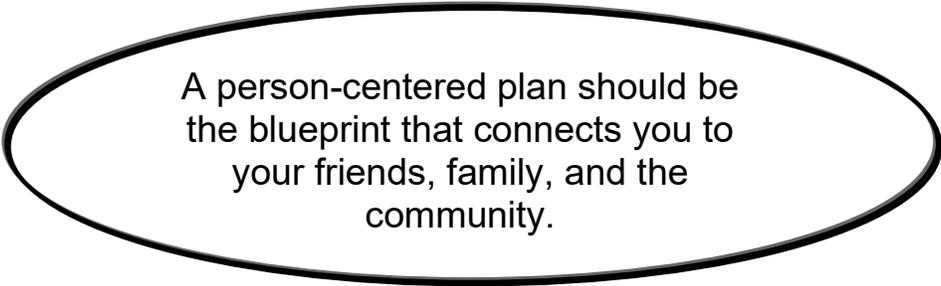
## **Deciding on Supports:**

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

Everyone's person-centered plan is different. One individual may get support entirely from agencies that specialize in helping individuals with developmental disabilities. Another may have a combination of an agency and more informal support. A third individual may decide not to utilize agency support, but instead use their natural support system. The only limitation to choosing support is to stay within your individual budget (and not do anything illegal).

## **Things to think about when developing a person-centered plan:**

- What do you want your life to look like in the next 12 months? 2 years? 5 years?
- What do you need to stay healthy and safe?
- What support is most important to you?
- What supports cost money and how can family, friends or community members help?
- If you can't afford everything you want, what are the top things you want?
- If there are personal funds available, how can these help you get what you want?
- Can you get more of the support you want if you share? For example, some individuals have housemates, share home staff, go out with friends, etc. to save money.



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

## **Some ideas for learning about types of support that others use:**

- Ask your Support Coordinator about the different types of support that individuals use.
- Talk with individuals who receive 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 5: Designing Supports**

After a Support Coordinator is assigned and the initial person-centered plan is written, it is time to figure out who will provide the supports described in the person-centered plan. The Support Coordinator will help you with this. The Person-Centered Plan is only the initial planning phase. Designing Supports within your Individual Life Plan is the second phase. Both of these phases can occur during a planning session.

### **First Steps**

The person-centered planning process probably came up with many ideas about how the supports should be carried out.

- Talk with your Support Coordinator about who can help you reach the goals of your person-centered plan.
- Prepare to compromise. There can be problems in getting the right services.
- There may not be as much funding available as you would like.
- Someone else may get services before you get them. That happens when someone is having a crisis and needs services in an emergency. Although it is frustrating to have to wait or share resources, your Support Coordinator will continue to work with you on your goals.

### **Considering Your Options**

Start by working on what you need. This may be different from what you want. Often there are things you want that you can't afford. Or perhaps you can't figure out how to do it. Then it's time to think creatively!

#### ***Some ideas:***

- Pool resources with someone else. Maybe you can afford some of what you want; someone else might be in the same situation.
- Share resources. You might like to find a friend to do something with you. Perhaps you can share a support person to make that happen.
- Have a housemate. Perhaps you thought you wanted to live alone. However, it is almost always too costly to afford a place to live and support staff to help you by yourself. A housemate shares costs and can-do things with you.
- Check on other funding resources. Social Security has programs that may help you. So does the Vocational Rehabilitation, a state program. HUD Housing aids with affordable housing. Tri-County Center for Independent Living may be able to assist, too.
- Families and friends can help.

## About Provider Agencies

Provider agencies are companies that specialize in providing support services to individuals with disabilities. Your Support Coordinator can assist in looking for provider agencies that might best meet your needs.

Agencies can send you information regarding their services, policies, philosophies, fees, and their experience with specific issues. You may find that some agencies have experience or philosophies that meet your needs better than others.

Agencies have experience being service providers. If you need help in your home or at work, there is probably an agency that understands how to do that. However, sometimes individuals feel that an agency's policies or procedures may interfere with their choices or preferences. Then you may want to find or create more flexible connections and supports.

## Interviewing Provider Agencies

Chat with the provider for a few minutes. Tell them about yourself, including your interests, your job, your friends, and family. Let them tell you why they like helping individuals and how they help individuals to be part of the community. Learn what their values are.

### Questions regarding support staff:

- How are employees screened?
- How is staff matched to individuals?
- What training is available to employees?
- How are staff supervised?
- How are employees evaluated; will you have input in the evaluation process?
- How is backup handled when a staff person is absent?

### Specific questions for Vocational Agencies (job-related):

- How do individuals get jobs?
- How long does it take to find a job?
- Who helps the individuals learn the job?
- What will you do all day if you lose your job?
- What if you want more things to do during the day?

### Specific questions for Residential Agencies (home-related):

- How is health and safety ensured in the home?
- Who does the home upkeep, the cooking, and the cleaning?
- Who will help you plan your evening and weekend activities?

### Other questions to consider asking:

- Discuss costs. If services are "packaged," make sure all the items in the package are needed. If not all the services in the package are needed, figure out if there is a way to pay for only those services you want.

- All agencies will have administrative costs. Administrative costs include items such as supervisory time, health insurance for staff, clerical and accounting costs, office space, equipment and so forth.
- Identify what funds can be moved to other choices and what funds cannot.
- Be clear about your expectations. For agency personnel to give you a realistic idea of how they can help you, they need to know what you expect.
- Get into details. For example, if you need support going to the doctor, who will take you? How are supports provided when your staff person wants to take a vacation? Can you choose your own staff?
- Talk to other individuals who have received services from the agency.

## **Thinking About Supports Creatively**

Assistance with a variety of life’s activities can be purchased outside of a provider agency. You can create more flexibility in your person-centered plan and find support for activities in places other than provider agencies. You can also combine services from a provider agency and services from elsewhere.

Here are some examples:

### **What if you need to wake up at a certain time to get to work?**

*You can have your residential staff wake you up...  
...or you can ask a neighbor to stop by and make sure you are up on time.*

### **Or, what if you want to go swimming at the Y?**

*Your residential staff can take you to the Y,  
... or you could take a swimming class with a friend.*

### **When your house needs cleaning**

*Your residential staff can clean the house,  
...or someone can teach you to clean the house,  
...or you might hire a cleaning service*

### **If you need a job**

*Your vocational agency can help you  
...or you could pay a private job developer to find a job.  
...or a friend or family member might have some ideas.*

## **Chapter 6: Paying for Services**

Where does the money come from to purchase supports for individuals with developmental disabilities?

PCSS receives money for services from a variety of sources— the State of Missouri, the federal government, and local government. There are many rules and regulations connected to these different funding sources.

**Once your individual budget is approved by PCSS and the Regional Office, your providers are notified by the county board they may begin services. They are paid for by the Regional Office. Services can be waived or non-waived. There are specific criteria to waive an individual's Medicaid.**

**What is a Waiver?**

The Missouri Department of Mental Health's Division of Developmental Disabilities (DD) administers several 1915(c) Home and Community Based Medicaid Waiver programs for individuals with mental retardation or other developmental disabilities. Some of the waivers are the:

- Comprehensive Waiver;
- Missouri Children with Developmental Disabilities Waiver (MOCDD or Sarah Jian Lopez Waiver);
- Community Support Waiver;
- Partnership for Hope.

Authority for 1915(c) waivers is the result of a special arrangement between the state and federal government that allows the state to use Medicaid funding for specialized services provided only to a target group of people and not to all people with Medicaid eligibility. Each waiver service a targeted group of individuals who have developmental disabilities. The state determines the number of people it will serve, what services it will cover, and how much it will spend on services in each waiver. Medicaid funding in Missouri consists of matching approximately 40 percent state tax dollars with 60 percent federal dollars.

**Who qualifies for a Division of DD Waiver?**

**Comprehensive, Community Support, Partnership for Hope and Autism Waivers:**

- Eligible for Medicaid as determined by the Missouri Department of Social Services' Family Support Division under an eligibility category that provides for Federal Financial Participation (FFP).
- For the Comprehensive Waiver, service needs cannot be met in the Community Support Waiver.
- For the Community Support, and Partnership for Hope waiver service needs cannot exceed an annual amount and the participant must not require residential services.
- There is a process to receive a waiver slot. Just because you receive Service Coordination does not mean you will qualify to receive a waiver slot or that you get one even if you meet the qualifications.

**All Waivers:**

Determined by the Division of DD regional office initially and annually thereafter to require an ICF/MR level of care if waiver services are not provided. The ICF/MR level of care requires that an individual have mental retardation or a related condition as defined in federal rule (42 CFR 435.1010), plus a need for the level of care provided in an ICF/ MR. In addition, it requires a determination that if a person does not receive services under a waiver, the person is likely to seek admission to an ICF/MR.

For more specific eligibility criteria, contact your Support Coordinator.

**Are there participation limitations?**

The number of individuals who may be served in each year of a waiver is pre-approved by the Centers for Medicare and Medicaid Services (CMS) based on the state's request. Once the waiver serves the approved number of eligible individuals, no additional individuals may be enrolled. The number of participants requested by the state is limited by the Division of DD's state appropriation designated for the state portion of the match. If a person is determined eligible to participate in a waiver, but the maximum number of individuals is being served

within the appropriation, the Division of DD Regional Office will offer to add the person's name to its list of persons waiting for regional office services. People are selected for services from this list according to most critical need.

**How are services accessed through a waiver?**

Requests to access waiver services may be made through the support coordinator. A determination of ineligibility for a waiver will not necessarily disqualify individuals from other regional office services for which they qualify and for which funding is available.

**What are the responsibilities and duties of those requesting waiver participation?**

- To report fully all circumstances affecting the application;
- To report any changes in circumstances which affect Medicaid eligibility;
- To cooperate in efforts to establish eligibility; and
- To cooperate with the support coordinator to ensure all state and/or federal participation requirements are met, i.e., maintaining a current, approved person-centered plan.

**\* Individuals denied participation in a waiver program have appeal rights with both the Departments of Mental Health and Social Services. Individuals are encouraged to begin with the Department of Mental Health's appeal process. Once the appeal process is started with the Department of Social Services, all appeal rights with the Department of Mental Health shall terminate since a decision rendered by the single State Medicaid agency would supersede a decision made by the Department of Mental Health. However, an appeal can be made to the Department of Social Services before, during, or after the Department of Mental Health process. The Support Coordinator will assist persons who decide an appeal is necessary. An appeals brochure is sent in the intake packet from the Regional Office. If you would like an additional brochure please contact your Support Coordinator.**

**All budgets including State and Federal Monies have to go through Utilization Review Committee**

**What Is It?** Utilization Review is a process that all Regional Offices follow to review each person's plan and budget to ensure that these documents reflect the individual's specific service/support needs, the amount of service/support needed, and the desired outcome for the individual using the service. This process also ensures a fair and consistent system used by all Regional Offices to prioritize the level of need for services/supports.

**How does it work?** Each Regional Office has a Utilization Review Committee which may consist of Representatives from Quality Assurance, Service Coordination, Business Office, Administration, and Resource Specialist. This Utilization Review (UR) Committee meets a minimum of once per week to specifically review the following: 1) an individual's plan/budget if this is his/her first plan with costs paid through the DMH billing system; 2) plan/budget changes that increase the amount of funding needed, such as adding a new service or changing to a provider that charges a higher rate; 3) plans/budgets at the discretion of the Committee, such as when services and funds are underutilized. After the Committee has reviewed the documentation, they make a recommendation to the Center Director to either approve or to not approve the plan/budget. If the Committee is unable to make a recommendation, the plan/budget is returned to the Support Coordinator for follow up of any action needed such as more information or clarification. The individual, guardian, and/or family are notified of the action needed and of the Committee's final recommendation as well as the Center Director's final decision.

**How are plans and budgets reviewed?** An individual's personal plan/budget is forwarded to the UR Committee after the personal plan meeting. The UR Committee uses a checklist to

ensure that the necessary documentation in the personal plan and budget is available to support the service need. The checklist is divided into four categories: Planning, Financial, Missouri Values, and Residential. The Committee also uses a Prioritization of Need form to assist in scoring requests for new or additional services. This tool has six categories: Emergency, Health and Safety, Family Support, Daily Living Supports, Inclusion and/or Recreational Supports, and Long-Term Planning. The UR score for a needed service is used to determine priority on waiting lists.

**What is my involvement in this process?** The individual, his/her family member, and guardian are a vital part of the planning team in developing his/her personal plan. It is essential that the planning team clearly documents the needs, dreams, goals, and expected outcomes for all services and funding requested. This information will be used by the UR Committee to assist them in making a final recommendation regarding approval of the personal plan and budget. The individual is highly encouraged to review his/her plan with the Support Coordinator before signing to determine that it accurately reflects what he/she wants to express.

**What if I don't agree with the UR Committee's recommendation and the Center Director's final decision?** The individual has the right to appeal the Center Director's final decision. Your case manager can provide copies of the UR documents if you are interested. Your case manager provides information regarding your appeal rights annually but can provide updated information at your request.

**You, your Support Coordinator, and other team members develop an Individual Budget (IB) after the completion of your person-centered plan. The individual budget lists the costs of supports. The person-centered plan describes how the supports will be provided. You will be requested to sign a plan authorization page. You may also private pay provider agencies or services. Your Support Coordinator can assist you in meeting and linking to these entities.**

## **Chapter 7: Creating Quality**

Quality Assurance means that there are standards that must be met so that individuals can live safe and productive lives. The Quality Assurance process monitors services to help make sure that individual's lives are going well.

### **Quality Assurance asks these questions**

- Are your needs being met?
- Are your supports being delivered timely with care and respect?
- Do you have choices and opportunity in your life?

### **How does having choice of services improve quality?**

1. You, and those who know you best, will define what quality services mean in your life. You should tell others if you do not like the services that you are receiving.
2. Your person-centered plan describes what results you want from your services. If those outcomes are reached, you and those around you will know you have good supports.

3. You may continue those supports that meet your needs. You may be able to look at different options and choose new supports if you're dissatisfied.

## **Your Team Creates Quality**

Your *Team* makes sure that things are going well in your life.

Members of the team include:

- *Support Coordination.* The Support Coordinator is the primary Quality Assurance monitor. It is important for you, the guardian, and your family to have an open relationship with your Support Coordinator. All of you should feel free to speak out and ask questions.
- *Family, Guardian, Daily 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.
- *Staff.* An Individual may have paid support staff that helps them at work and/or home. Staff help individuals be more independent and have a fulfilling life. They are key team members because they are with the individual every day. Staff are trained to provide services based on each individual's needs and goals. Most are employed by agencies that work hard to provide good services.

*Working Together:* A good support team respects each team member's opinions. The team knows that sometimes things are very difficult, but 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 that their job is to work together to reach the goals in the person-centered plan.

## **Other Quality Assurance Support**

Some services are available outside of the person-centered plan. They are available if you need some specialized help.

- PCSS staff are available to address complaints from individuals, families, and guardians. A Support Coordinator is assigned to each individual as a resource to you. There is a clearly stated county grievance process.
- PCSS staff meet regularly with agencies to address agency and individual issues. Provider agencies are required to report any incidents that could jeopardize an individual's health and safety. Background checks are required on all staff. PCSS staff conduct regular evaluations of services provided by provider agencies.
- The Executive Director of the PCSS has an open-door policy to meet with individuals, families and/or guardians to discuss any issues regarding the quality of their services.

## **Chapter 8: Some Commonly Asked Questions**

What happens to the money if you don't use it up?

If you didn't need the total amount allocated for a year, your rate will be reviewed by your Support Coordinator and the Utilization Review Committee at the Regional Office to see

if it should remain the same or be reduced. Money not needed for one individual's support can be used for other individuals with developmental disabilities on waiting lists.

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

If you need more support, the Support Coordinator will complete a packet to ask for an addendum to increase the individual budget. This can occur any time of the year and is also reviewed each year when the person-centered planning is reviewed. The increase may be put on a waiting list if there are no available funds.

Are there things or services that can't be purchased with an individualized budget?

Obviously, purchases must be legal and cannot be unduly restrictive. Home and Community-Based Waivers have rules and regulations that must be followed. An acceptable person-centered plan is one you develop with a Support Coordinator and others who know you best, meets your health and safety needs, and is within your individual budget.

What if you disagree with a support provider?

The first step is to talk with the provider and try to work things out. Try to hear each other's viewpoint. If a problem continues, contact your Support Coordinator. The Support Coordinator will assist you in presenting your point of view and try to help solve the problem. Most problems can be resolved by talking openly about them. Some problems can be solved by talking it over with someone separate from the situation, such as your Support Coordinator

If the problems are serious enough, you may no longer want to receive support from the provider. The service agreement describes the conditions under which you and the provider can stop working together. The Support Coordinator can help you arrange for new supports. It is often not easy to find a new provider of supports. That is why it is best to think carefully when hiring a support provider and to try to maintain open communication with the provider.

Why do I need a housemate to help share costs?

If you need help 24 hours a day, you will probably not be able to afford to live alone. Typically, individuals have housemates to share costs.

How do I find a housemate?

A housemate can share costs and may also become a friend. A housemate may be someone you know from school, church, a self-advocacy group or other activities. The Support Coordinator can be helpful in finding a housemate. Support providers may know someone they think you may like as a housemate. It is important to let others know that you are looking for a housemate, and to have an idea of what your ideal housemate 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 the opportunities to speak in front of others. We all learn from experience.
- Here are some ways people can help you have those opportunities:
  - 1) Before meetings, review the agenda with them and let them know things you want to say.
  - 2) After meetings, review what was decided and let the team know if there are things you did not understand. Most individuals 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. Changes come with time.
- Take opportunities to make choices in your life. The more choices you make, the better you will get at it.

**How others can become good daily representatives for individuals with disabilities.**

- Listen to the individual with the disability. Think about how the individual communicates and ask questions in a way that is useful for that individual. For example, if an individual doesn't speak, use pictures or drawings to explain concepts. Continue to explore ways to pull the individual into the decision-making process.
- Don't speak for the individual, even if you think you know the answer. Try to control your own opinion.
- You may disagree with the decision of the individual receiving services. However, it is their decision. Recognize that we all learned about decision-making by making some decisions that were smarter than others.
- Listen to others who know the individual in different settings.
- Don't let someone's credentials or position get in the way of your knowledge of the individual.
- Encourage individuals to explore opportunities, develop their own individual gifts, and let others have the chance to know them.
- Avoid the word "CAN'T." Instead, substitute "How can we..." or "What if ..."

**Chapter 9: Your Rights**

It is important for every person to know his or her rights. These are your rights if you receive services from a county board, Regional Office, or a habilitation center. No one can take them away from you.

**Individual Rights**

1. A person receiving Division services shall be entitled to the following rights without limitation:
  - To be treated with respect and dignity as a human being;
  - To have the same legal rights and responsibilities as any other person unless otherwise limited by law;
  - To have the right to due process review when any limitation to rights is proposed or is alleged to have taken place;
  - To receive services regardless of gender, race, creed, marital status, national origin, disability or age;
  - To be free from physical, verbal, mental and sexual abuse and neglect;
  - To receive appropriate humane and high-quality services and supports as determined by the person's support team, which may include, but not be limited to, the person, parents, guardian or authorized representative;
  - To receive these services and supports in the most integrated setting appropriate for the person's particular needs;
  - To have access to Division rules, policies and procedures pertaining to services and supports;

- To have access to personal records;
  - To have personal records maintained confidentially; and
  - To have services, supports and personal records explained so that they are easily understood.
2. A person receiving services and/or the person's parents, guardian or authorized representative shall be informed of the person's rights in language that is easily understood.
    - At the time of enrollment and whenever changes are made to the description of individual rights, the Division shall provide to the person and/or the person's parents, guardian, or legal representative a written description of the person's rights and how to exercise them.
    - A representative of the Division shall read and explain the description of rights to people who require assistance because they are unable to read or unable to understand the written description.
  3. If a person receiving services has complaints of abuse, neglect or violation or limitation of rights, the person, the person's parents, guardian, or authorized representative may contact the county board, regional office or habilitation center representative, or they may contact the Department's client's rights monitor at 800-364-9687 or TT 573-526-1201 or assistance.
  4. The Division shall have policies and procedures that enhance and protect the human, civil and statutory rights of all persons receiving services.
  5. The Division and each service provider shall have policies and procedures for providing positive supports to person's receiving services. Those policies and procedures shall be consistent with the enhancement and protection of human rights.
  6. The Division shall report abuse and neglect as mandated by law. Any violation of rights shall constitute, at a minimum, inadequate care and treatment.

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*The following is an explanation of your rights in people first language.*

**Due Process**

- When you apply for services, the regional offices must give you, your parents, your guardian, or any other person you choose a written copy of your rights. If any changes in your services are made, you will receive a new copy of your rights.
- County boards, regional offices, and provider agencies that have staff who work with you have rules to provide you with good help. They have rules to make sure you learn and understand your rights, and that no one takes your rights away before you have a chance to speak to yourself or have someone you choose to speak for you. This is called due process.
- Someone from the county board, regional office or habilitation center will read and explain your rights to you in a way you understand them.
- You have the same legal rights and responsibilities as any other person unless the court says you do not. For example, if you have a guardian, you do not have the same legal rights as people without a guardian.
- You have the right to be treated with respect and dignity as a human being.
- You have the right to get help. You cannot be denied help because of your race, your religion, your disability, or your age. It does not matter if you are a man or woman, married or single.

- Before your rights or services can be limited or taken away, you have the right to be heard or to have someone you choose to speak for you. This is called due process.

**Services and Supports**

- You have the right to get your services and supports in the most integrated setting and in a way that best meets your needs. To determine those services, these people may be involved: you, your parents, your guardian, or any other person of your choice.
- You have the right to know what the county board; regional office rules are for the services and supports you receive.
- You have the right to have your services, supports and personal records explained to you, so you understand them.
- You have the right to receive and read your personal records.
- You have the right to receive and sign a copy of your personal plan.
- You have the right to have your records kept private.

**Abuse and Neglect**

- You have the right not to be abused or neglected. Abuse can be physical, verbal, mental, sexual, or financial. Neglect is not getting the things you need to be healthy and safe.
- If you think you are being abused, neglected, or your rights taken away, you, your parents, your guardian, or any other person you choose can contact your Support Coordinator with the county board, regional office, or habilitation center for help. You can also call the client’s rights monitor in Jefferson City at 1-800-364-9687 or TT: 573-526-1201 for help.
- People who work for the county board, regional office or habilitation center must report any abuse or neglect that they see or that people report to them.

**Chapter 10: Grievance and Complaint Process**

It is the policy of Pulaski County Special Services (PCSS) to ensure a process for filing consumer complaints and grievances from consumers served and/or their legal representatives in order to provide guidance for receiving, considering, and resolving consumer complaints and grievances filed with the agency. All complaints and grievances shall be heard promptly, investigated appropriately, and where possible, resolved informally. No consumer served by PCSS shall be retaliated against or be denied services for filing a complaint or grievance. A review of formal complaints, grievances and appeals can give the organization valuable information to facilitate change that results in better customer service and results for the consumers served.

**PROCEDURES:**

I. The consumer or their legal representative may file a complaint with regard to the Service Coordination services provided by PCSS, if the consumer/guardian believes their rights have been violated, abuse or neglect has taken place, and/or to voice general concerns with regard to the Service Coordination services being provided by PCSS. A complaint form may be requested from the Executive Director.

II. The PCSS Executive Director will initially review all written complaints/grievances and determine a resolution/disposition of a complaint. Complaints shall be categorized by the Executive Director within one of three categories:

- **Information-** An informational report of dissatisfaction which may include but not limited to: violation of a DMH standard or PCSS policy, contract provision, rule or statute, or a practice or service is below customary business or medical practice.
- **Grievance-**Consumer reporting a violation of client rights per 630.110.1.
- **Suspicion/Allegation of Abuse & Neglect-**class I neglect, misuse of funds/property, physical abuse, sexual abuse, or verbal abuse has occurred as defined in 9 CSR 10-5.200.

### III. Abuse/Neglect or Rights Violations

If in initially reviewing the written complaint the Executive Director finds evidence of abuse or neglect, or evidence of a violation of client's rights on the part of Service Coordination staff or other PCSS employee in reviewing a grievance, this shall be reported immediately per the relevant state statutes/Division Directives, and steps shall be taken to ensure client safety, if necessary. Complaints with regard to human rights violations by PCSS staff may be made within this process or can be made with the Dept. of Mental Health Client Rights Monitor at:

Client Rights Monitor  
 Department of Mental Health  
 P.O. Box 687  
 Jefferson City, Mo 65102  
 1-800-364-9687

### IV. Dissatisfaction with Services

In the case of "informational" grievances including dissatisfaction with Service Coordination services, the following steps shall be taken:

1. If informal efforts do not produce a satisfactory solution, a complaint with regard to the Service Coordination services provided by PCSS may be filed in writing by completion of a PCSS Complaint/Grievance Form. In all cases, review actions taken, and documentation made will remain confidential.
2. Complainants shall be informed in writing within three (3) business days that the formal complaint has been received and is being reviewed. In addition to completing the form, complainants have the right to present any additional information they feel to be pertinent to the complaint in a meeting with the PCSS Executive Director. Before considering filing a complaint, it is encouraged that the complainant tries to resolve the matter informally by discussing it first with the Support Coordinator.
3. Within seven (7) working days after the complaint is filed, the Executive Director will submit his findings to the PCSS Board Chairperson. A letter confirming/not confirming the allegations will be sent to the consumer and/or their legal representative and PCSS staff alleged to have been involved. If the letter confirms the allegation(s), further actions will be outlined in the letter.
4. If the complainant disagrees with the Director's disposition of the complaint, they can appeal to the PCSS Board Chairperson, who will have 30 days in which to decide with regard to the complaint. In this decision, the PCSS Board Chair may accept, reject, or modify the Executive Director's initial recommendation, or s/he may return the case to the Executive Director for further proceedings.
5. The Board Chair shall specify the matters to be addressed in the further proceedings and shall specify the period within which those proceedings shall be conducted, not to exceed seven (30) working days.

6. If the complainants disagree with the decision of the PCSS Board Chairperson, they can appeal to the full PCSS Board of Directors, whose decision on all complaints shall be final. The PCSS Board of Directors shall review such appeals at the next regularly-scheduled board meeting, in closed session if deemed appropriate.
7. The complainant shall be encouraged to file a grievance with the Dept. of Mental Health/Rolla Regional Office if s/he is not satisfied with the outcome/disposition of the complaint decision rendered by the PCSS Board of Directors.
8. Obstruction of a complaint investigation shall be reported to the PCSS Executive Director (or Board Chair, or Board of Directors, as appropriate) who shall take action to eliminate the obstruction. Staff members are subject to disciplinary action for engaging in any obstruction of a complaint.

V. The decision-maker at each step for good cause may extend time limits designated in this policy.

VI. PCSS shall annually review all formal complaints that have been filed with the agency in an effort to identify trends and areas of needed improvements and develop a Plan of Action to mitigate such complaints.

## **EMERGENCY On-Call**

If you need to reach our staff after hours on weekends or holidays in an emergency, you can call Rolla Regional at 573-368-2200, they have a 24 hour on call system that will relay a message to the Executive Director. You might wonder what would be appropriate to call about. Here are some of the events we would want to be called about:

- All individual's deaths
- Any abuse/neglect allegation
- An individual's injuries that require hospitalization
- An individual's elopement

**Please ensure that the appropriate agencies are called first to address the immediate health and safety need such as the police, ambulance, fire department, etc.**

## **Glossary**

**advocate**— a person whose only role with the individual with the disability is to assist in presenting the individual's point of view and assisting the individual in having informed choices.

**circle of support**— a group of people who care about an individual with a disability and want to assist with support on a long-term basis.

**daily representative**— a designated person who is responsible on a continuing basis for providing the individual with representation, advocacy, advice, and assistance related to the day-to-day coordination of services in accordance with the person-centered plan.

**eligibility**— meets conditions of eligibility through the Department of Mental Health Developmental Disabilities Division.

**grievance policy**— a policy that outlines a formal process that an Individual or guardian can take when they are dissatisfied with their services. See Individual/Guardian Grievance and Complaint Process

**Medicaid Waiver (Community, Comprehensive, Autism, Lopez, etc.)** — the federal funding source for support services in county

**individualized budget**— the amount of money needed to implement the person-centered plan; will be within the individual budget.

**person-centered plan**— a personalized blueprint for developing supports for the individual.

**provider agency**— a company that provides support services to individuals with disabilities.

**quality assurance**— 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.

**Support Coordinator**—PCSS staff available as a resource to individuals receiving services. Provides information, helps individuals develop personal plans and budgets, and gets needed supports within an individual's budget.

**support team**— the paid and unpaid people who assist the individual receiving services.

**supports**— the help that enables an individual with a developmental disability to live and work successfully in the community.

## CONTACT INFORMATION

Your Support Coordinator: \_\_\_\_\_

Phone number: \_\_\_\_\_

Email: \_\_\_\_\_

Executive Director: Tonya Brown

Phone number: 573-855-7240 Fax: 573-774-0500

Email: [mail@pcbh.net](mailto:mail@pcbh.net) Web address: [www.pcbh.net](http://www.pcbh.net)

Facebook: @PulaskiCountySpecialServices

Address: 105 Ichord Avenue, Waynesville, MO 65583

Our office is located in the Cross-Creek Plaza. We do not hold regular office hours. For this reason, you may want to call first to ensure someone will be available.



I \_\_\_\_\_ have received the consumer handbook which reviews the guiding principles, person centered planning, services, my rights, the grievance and complaint process, emergency on call information, and my Support Coordinator's contact information. My Support Coordinator has reviewed this document with me.

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Individual	Date
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Parent or Guardian	Date
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Support Coordinator	Date
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