

GUIDE TO SUCCESS:

Navigating Montana's Developmental Disabilities Program

*A GUIDE TO UNDERSTANDING THE
DEVELOPMENTAL DISABILITY SERVICES SYSTEM*



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A Publication of

Montana's Parent Center

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DISABILITY SERVICES SYSTEM**

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First Printing (September 2010), Second Printing (January 2011), Third Printing (November 2011), Fourth Printing (March 2015) Fifth Printing (January 2016)

*Contents written and published by***PLUK**

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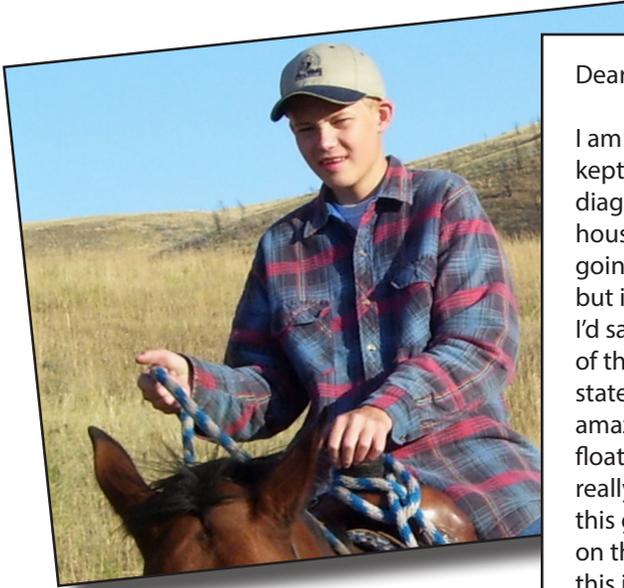
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*To download the electronic version of this guide, and view other resources, please visit:
<http://www.pluk.org/ddpguide>*

Letters from Jeff Sturm (former DDP Director) and Dianne Booth (parent):



Dear parents/readers,

I am one of the parents who worked on writing this guide. We kept thinking of what we went through when our kids were first diagnosed and then how these people started showing up at our houses. No one really explained what was happening or what was going to happen. They were nice people, and they did good things, but it was confusing. Asking for help and receiving it was also hard. I'd say we parents that worked on this really had no understanding of the DDP system until we got together with the folks at the state office to talk about putting this guide together. That was an amazing day. We were able to ask these questions that had been floating around in the back of our minds all these years. A picture really came together in my head that day, and that is what I wanted this guide to do for other parents, especially those just beginning on this road. I am proud of what we have done and know that this is going to help you. This guide isn't about all the laws and regulations, but it does give enough information so you can track down information about any question you might have. We'll never be able to know all the details, but I know who to call, and with this guide, so will you.

And this is just a start. We want to get parents and everyone's feedback on this. We want to have more information on a web site and post updates and an electronic version that anyone can print. The other thing that I learned is that we need to be involved and connect with other families. The people that make the decisions need to hear from us so they can be smarter. They can make us smarter too, and show us how the system can be changed. When we work together, we can make those changes that will help our kids. That's one of my jobs now along with the rest. I'm putting my e-mail address here. Just let me know if you want to help.

Dianne, mother to Logan (pictured)
primrose@mtintouch.net

Dear self-advocates and families,

Over the past several years, the Developmental Disabilities Program has gone through many changes. The changes happened for many reasons and, at times, seem pretty confusing. This guide is an attempt to help you understand the Developmental Disabilities Program service system so you can better access services for yourself or your family member. The guide contains information that should make things less confusing or where to go for questions.

The Developmental Disability systems in Montana and across the country are changing constantly due to the different needs of individuals in services, their families, funding, as well as changes in national and state policy. As a result, this guide will be updated as those changes occur.

Our goal is to make sure that families and individuals receiving services not only understand what services and options are available but also act as our partners in designing the system for the future. Please share your thoughts, ideas and concerns with us so we can provide a service system that truly meets your needs.

Thank you,

Jeff Sturm
former Developmental Disabilities Program Director, Helena



TABLE OF CONTENTS

1.	What are Developmental Disability Services?	1
2.	What is a Developmental Disability?	1
3.	What is the Developmental Disability Program (DDP)?.....	2
4.	Where is DDP Located?.....	3
5.	What is Eligibility?	4
6.	How is Eligibility Determined?	4
7.	What is the Wait List, Eligibility and Services?	5
8.	What are Community Providers?.....	5
9.	What is the Montana Developmental Center?	6
10.	What are Support Plans?.....	6
11.	What are Waiver Services, Non-Waiver Services & Case Management?	8
12.	What is Transition?	10
13.	How do I Settle Disagreements?	12
14.	Other Considerations for Families	13
15.	Other Resources	14
16.	Glossary and Acronyms	17

Introduction

In Montana's Developmental Disabilities Program, services are available at no cost for eligible individuals of any age. There are many kinds of services available. Currently, there are two ways to access these services: through community-based providers, and through self-direction. We will explain these options later. You need to know enough about these options to choose which ones are best for you. You will also want to know who provides the services, how they do business, who works for them, how their values fit with yours, and how you can best use their services. Don't be afraid to ask lots of questions!

1. What are Developmental Disability Services?



All parents grow with their children, and parents of individuals with developmental disabilities are no different. For much of what a child needs, family is the BEST resource. Still, there may come a time when additional support from people outside the family would make all the difference in the world. That extra support comes through the

Developmental Disabilities Program and is referred to as “services.”

You will need to understand how the Developmental Disabilities Program (DDP) eligibility process works, as well as how to get services. But don't worry, eventually you'll become familiar with the terms and language, and learn how to build successful relationships with community-based service providers.

We know that Montana's DDP operates in a maze of regulations which are difficult to understand. It's no wonder -- the **Developmental Disabilities Program (DDP)** currently has a budget of \$114 million and serves over 4,000 individuals.

This Success Guide was written for and by parents and self-advocates to help you understand what DDP's services are and how these services can work for you. That's why we've organized our guide in a way that will help you begin your journey.

It is important to understand that all of the programs described in this guide were created to help people with developmental disabilities. Even though navigating this system can be difficult sometimes, remember that you're not alone. Many families may have the same questions that you do, and communicating with other parents and professionals within DDP and the community will help create a strong support system.

2. What is a Developmental Disability?

The word “disability” has different meanings for different people. For some, the word suggests a specific medical condition, while others think of how well a person can perform the everyday tasks of living.

Developmental Disability – A documented delay in cognitive or behavioral function compared to others in the person's age group. See Section 2 for formal definition.

Developmental Disabilities Program (DDP) – The Developmental Disabilities Program is a program within the larger DPHHS agency. DDP administers, provides funding, processes payments, and monitors all the different services that are offered through DDP (see Section 11). DDP is separate from services or assistance someone might receive through school, Mental Health, Public Assistance, State Medicaid, etc.

Below is the official definition, from Montana State law, of developmental disability that is used by Montana's DDP to decide if someone is eligible for services:

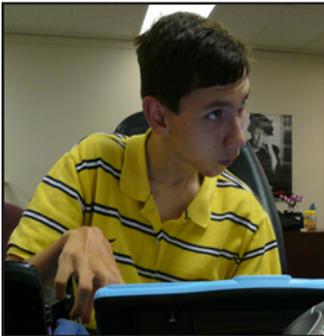
“Developmental disabilities” means a disability attributable to intellectual disability, cerebral palsy, epilepsy, autism or other neurological disabling condition closely related to intellectual disability and requiring treatment similar to that required by intellectually disabled individuals if the disability originated before the person attained age 18, has continued or can be expected to continue indefinitely, and results in the person having a substantial disability.

Children or adults with developmental disabilities are often able to do many things that others can do -- they just need some extra help. Most of this help is provided by families, but sometimes there are situations where more assistance and training is needed than the family can provide. One option for this additional support may be DDP.

Department of Public Health and Human Services (DPHHS)

The Montana State agency that oversees all public health and human service programs.

3. What is the Developmental Disabilities Program (DDP)?



The Department of Public Health and Human Services (DPHHS) is a large, state-run agency that is in charge of many programs, including Medicaid, Public Health and Safety, Public Assistance, Children's Mental Health, and the Developmental Disabilities Program (DDP), and more.

DDP provides oversight and funding for the service system that supports individuals with developmental disabilities and their families. They currently have an annual budget of \$114 million, serve over 4,000 individuals and work with over 60 service providers across Montana.

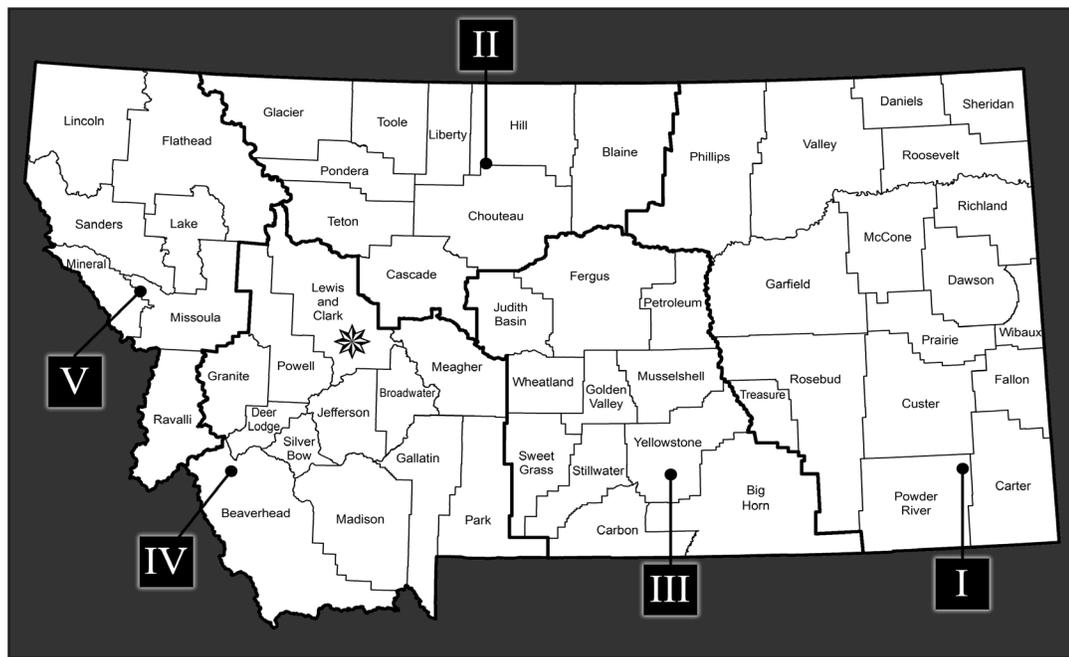
DDP Mission: Create a system that coordinates resources, supports and services for people to have meaningful lives in their communities.

DDP Values:

- People choose their providers, services, and supports. Plans of care are developed by the person and the people who support them
- People have opportunities for personal growth.
- People are treated with respect and dignity.
- People live and recreate in safe and healthy environments.
- People have opportunities to work in safe, integrated community employment of their choosing.

4. Where is DDP Located?

The Developmental Disabilities Program has one central office in Helena with five regional offices throughout Montana. You may contact your regional office for unbiased information about services and providers at any time.



<p>Central DDP Office: 111 Sanders, Room 305 PO Box 4210 Helena, MT 59604 (406) 444-2995 (406) 444-0230 FAX</p> 	<p>Region III DDP Office: 2121 Rosebud Drive Suite H Billings, MT 59102 (406) 259-8122 (406) 652-1895 FAX</p> 
<p>Region I DDP Office: 226 6th Street South PO Box 472 Glasgow, MT 59230 (406) 228-8264 (406) 228-8263 FAX</p> 	<p>Region IV DDP Office: 111 Sanders, Room 104 PO Box 202955 Helena, MT 59604 (406) 444-1714 (406) 444-0826 FAX</p> 
<p>Region II DDP Office: 201 First Street South Suite #3 Great Falls, MT 59405 (406) 454-6085 (406) 454-6082 FAX</p> 	<p>Region V DDP Office: 2675 Palmer, Suite B Missoula, MT 59808 (406) 329-5415 (406) 329-5490 FAX</p> 

5. What is Eligibility?

Before services can be received, a person must first be found “**eligible for services.**” Being determined eligible for DDP services means that a person of any age with an intellectual or cognitive disability (occurring before age 18) has been found to have a significant level of difficulty doing things that are important to everyday life. Specific programs under the umbrella of DDP may have particular eligibility requirements unique to that program.

It is important to note that there are different services offered for different age groups (e.g: infant, child, youth or adult). You can get more information about what services are available from your local regional office.

It is also important to understand that the eligibility criteria used for DDP services are separate from the services you or your family member may receive through your school district, insurance, Medicaid, Social Security, or other sources. For example, you do not have to be eligible for DDP services in order to receive school services (or vice versa).

6. How is Eligibility Determined?

If you think you or a family member may be eligible for services and supports, contact the DDP office in your region. Your doctor, school, or someone else involved with your child may also suggest you contact DDP.



The regional DDP office will either help you apply for services directly or refer you to a provider agency that can help you fill out an application.

The eligibility process helps to determine the assistance you or your family member needs. This may involve having several different people in your home to make evaluations and ask questions. You may also need to submit doctors' reports/evaluations, hospital records, school district evaluations, or other documentation to determine if the disability meets the requirements set by the state for eligibility.

After submitting the application and documentation, you will receive notification of eligibility for disability services through DDP.

If you are not considered eligible, you may submit additional documentation for a redetermination or appeal the decision. The letter regarding eligibility will explain how the appeals process works.

Eligible for services means that a person of any age with an intellectual or cognitive disability (diagnosed before age 18) has been found to have a level of difficulty doing things that are important to everyday life, and may receive DDP services.

Personal Insurance (Autism)

The Montana Autism Reform Law requires many private insurers to begin covering the costs of diagnostic assessments for autism and of treatments for individuals with autism through:

1. \$50,000 per year for a child 8 years or younger.
2. \$20,000 per year for a child 9 years through 18

The specific terms and provisions of this law are described in more detail at: <http://www.pluk.org/autismvotes>

Healthy Montana Kids is a free or low-cost health coverage plan. The plan provides health coverage to eligible Montana children and teenagers up to age 19. More information can be found at: <http://hmk.mt.gov/>

7. What is the Wait List, Eligibility and Services?

If you are determined eligible for services, through the DD program, you will need to request to be placed on a waiting list (Except for eligible children under 36 months, who should immediately receive Part C services. See Section 11). This happens because there are more people needing services than there are funds available. Developmental Disabilities (DD) services are available based on funding provided by the Governor's budget or the state legislature (state general fund) and



federal funding (Medicaid). It can take anywhere from a few months to a couple years or more to get selected for the service(s) you need, so don't wait to request to be on the waiting list(s)! You should receive something in writing that confirms placement on the waiting list(s). If you don't receive anything or want to check your status on the waiting list, you can call your DD regional office at any time (see Section 4).

Once you are selected for services you will be notified and given a list of provider agencies in your community, as well as a list of the services each one is qualified to provide.

Before selecting an agency, it's a good idea to visit, meet with staff, and talk to other families to see which is the best match for you. Once you have selected a service provider (or providers), they will help you develop your support plan (a list of services you need). Keep in mind that you do not have to select all of your services through one provider. For example, you may use day services from one provider, and respite from another. The choice is yours.

In addition, there is a new service option available called self-directed services. This means the individual or family directs the service and manages the cost plan with help from a fiscal agent. More and more services are being offered with the self-direction option. Contact your case manager or regional office for more information, or go to:

<http://dphhs.mt.gov/dsd/developmentaldisabilities/DDPselfdir>

As always, you may contact your regional office for unbiased information about services and providers at any time.

8. What are Community Providers?

In order to coordinate services to individuals and families, the Developmental Disabilities Program contracts with providers across the state of Montana to deliver services. In larger communities, there may be several agencies to select your services from, while many smaller communities might only have one or two providers to choose from. Before you decide on a service provider, you may want to talk with other individuals and families who already use their service(s). For a directory of providers, please visit:

<http://mtcdd.org/directory-of-services/>

For more details of provider agencies in your area, and the services they are qualified to provide, call your regional office.

9. What is the Montana Developmental Center?

The Montana Developmental Center (MDC) in Boulder, Montana serves individuals, 18 and older, who are determined to be a danger to self or others and in need of more intense treatment. Placement is made through a court process when services in the community cannot safely meet the individual's needs.

Their mission is: *To improve, preserve, strengthen, and protect the health, well-being and self-reliance of all individuals served, in an environment that respects and develops those individuals charged with providing services.*

10. What are Support Plans?

As we touched on before, when you, a guardian, or family member has chosen your service delivery option (self directed or traditional) and providers are chosen (if applicable), a comprehensive plan of care will be written. A team with members of your (or a guardian's) choice will work to develop the plan based on input from the team members. Components of all plans of care require formal and informal assessments of needs. This means you will not get services that are for convenience purposes. All plans of care should have measurable, meaningful activities, and give an idea of what the intended outcome/result is. There are certain components of a plan of care that are required, and case managers are responsible for writing plans of care that are appropriate per federal and program regulations. They have been given general guidance that except for certain circumstances, they should not approve a plan of care they disagree with. If you ever have questions or concerns with a plan of care, contact your Regional Office (see map in Section 4). Needs assessments and a comprehensive review of the plan of care must be done at least every 12 months for everyone receiving waiver services.



Services vary depending on the age of the individual with the disability. For individuals under age 16 receiving DDP services, support is provided through a plan called an **Individualized Family Support Plan (IFSP)** which assesses the needs of both the child and his/her family. The appropriate services identified in an IFSP will support and build upon the individual strengths of the family. For example, children's services may include respite (a break for unpaid caregivers), assistance with household responsibilities, caregiver training and support (education and training for the family) that is focused on the needs of the child/family. These plans (for kids younger than 16) are entered in a web-based program by the person/agency providing case management to the child and family. It can be accessed at any time by the case manager if a parent wants to review it with them. If you ever have questions or concerns with a plan of care, contact your Regional Office (see map in Section 4).

Individual Family Service Plan (IFSP) is a plan of care for a person through age 15 who is receiving services administered through DDP. It is separate from any support plans developed through the school system; however, both plans may have similarities. The plan of care lists the assessed needs and what services will be provided to both the child and his/her family to meet those needs.

Personal Support Plan (PSP) is a plan of care for a person age 16 or older who is eligible to receive services administered through one of the DDP waiver programs. The plan of care lists the assessed needs and what services will be provided to the person to meet those needs.

Individual Cost Plan (ICP) is a component of a person's plan of care if they are receiving services from one of the DDP Waiver programs. Specific providers, services to carry out the plan, and dollars are managed.

(Continued from "10. What are Support Plans?")

For ages 16 or older, the plan will be tailored to the individual needs of the person being served through a PSP (Personal Support Plan). Services are community-based and are generally provided in the area where the individual lives. Services may include activities to develop or maintain skills for daily living both at home and in the community, assistive items to enhance independence, guidance with referrals for employment supports or supports to maintain a job, as well as assistance with transportation to work, shop, or attend community activities, help with budgeting or paying bills, or respite for caregivers. In short, services provided are designed to promote independence through skill building, person-centered approaches, as well as a focus on the health and safety of the individual being served. Most people age 16 and older who are waiting for waiver services through DDP still have a brief plan of care.



The **Personal Support Plan (PSP)** document reflects a person's vision of their desired life. It includes descriptions of the person's situation, skills, capacities, and needed supports, as well as the outcomes necessary to achieve their desired life. The PSP describes the actions, supports and services required, and those responsible for the desired outcomes. The PSP is developed by the person with the involvement of others identified by the person, such as family, friends, and service providers, and is facilitated by the person's case manager. The planning team uses the PSP to guide needed supports and services among these groups, and others in the community.

For more information on PSP's, tools, and guidelines go to:

<http://dphhs.mt.gov/dsd/developmentaldisabilities/DDPforms-tool> and scroll down to Personal Support Plans.

Finally, for those receiving waiver services (both children and adults), a budget or **Individual Cost Plan (ICP)** is created with the assistance of a case manager to detail the specific services, levels of services, and providers that will carry out activities in the comprehensive plan of care. Those details translate to the person's individual budget and are considered to be a component of the waiver plan of care. The person's ICP is a web-based program which can be accessed by the Case Manager at any time, and should be made available to view by the individual and/or their guardians as requested, during planning processes, or to monitor service delivery. This system allows a case manager to review what is spent in the individual's budget and can be a useful tool for everyone who is a part of the person's planning team. You have a right to see all of your services directly from this web-based system. If your case manager indicates they do not have access, notify the case management agency and inform them that you wish for your case manager to have access. Also let your DD Regional Office know you have made this request. When or if necessary, you can request that your Regional Office follow up.

In addition, a person's waiver funds are portable, which means they can be moved to other providers and/or services in order to meet the assessed needs of the individual at any time. These changes start with an update to the plan of care. Then the ICP is changed (if applicable) to reflect any updates in the plan of care.

11. What are Waiver Services, Non-Waiver Services & Case Management?

DDP services are funded through two different sources: state legislature (general fund) and federal (Medicaid).

Waiver programs are created through Medicaid to keep individuals with disabilities in their home communities and out of institutions, hospitals, and nursing facilities. None of these waivers is an entitlement program, so the child or adult needing waiver services may be placed on a waiting list.

Montana's DDP Program funds services through three Medicaid waivers:

- **Children's Autism Waiver (CAW** (or 0667) is for children 15 months through age 7 diagnosed with Autism Spectrum Disorder who have difficulties with adaptive behavior (e.g.: social difficulties, communication delays and/or behavior impairments).
- **Comprehensive Waiver** (sometimes referred to as "The Big Waiver" or 0208) is for individuals of any age. It provides more comprehensive supports in the community to increase and maintain independence through training, residential, recreational and vocational supports.



Children's Autism Waiver (CAW) – Medicaid program administered by DDP for children 15 months through age 7 who are diagnosed with Autism Spectrum Disorder and have difficulties with adaptive behavior. Services are intense, specific, and closely monitored. This program is time-limited, and it's likely the eligible child will be on a waiting list to be selected to receive services.

Comprehensive Waiver – Medicaid program administered by DDP for any age. May be referred to as the 'Big Waiver' or 0208 Waiver. Provides skills (habilitation) training, residential, recreational, and vocational supports. It's likely an eligible person will be placed on a waiting list before getting selected to receive services.



For more information on all of the waivers through DDP, go to: <http://dphhs.mt.gov/dsd/developmentaldisabilities/DDPmedicaidwaivers>

Word of caution: A lot of this information is complicated and may be difficult to navigate. The most important parts of the waivers are the services offered through each one. For an abbreviated description of each service, under each waiver section, click on the links that indicate 'waiver definitions' or 'waiver service definitions'.

In addition to the two Medicaid waiver programs, there are two non-waiver programs which are funded and administered through DDP.

- **Part C Early Intervention Program** (Infant and Toddler Program - birth to 36 months) is a non-waiver, non-Medicaid, entitlement program which means everyone who is eligible for this program will receive services, regardless of financial or other restrictions. There is no wait list. Services may include: parent education and coaching, coordination of care, assessment and evaluation, and other services based on the needs of the child and family. For more information on Part C (early intervention) services, go to: <http://dphhs.mt.gov/dsd/developmentaldisabilities/PartC-EarlyInt/aboutpartc>
- **Family Education and Support (FES)** (FES - birth through age 21) is a non-waiver, non-Medicaid program, and services are limited. It is not an entitlement program and eligible children may be placed on a waiting list. Services may include: family education and coaching, coordination of care, assistance with transition and other services based upon the needs of the child and family.



Part C Early Intervention Program

(Infant and Toddler Program) is a Federal program (different from Waiver) administered by DDP for children birth to 36 months. This program is entitled. Eligible children and their families can get assistance with educating parents on the disability as well as coaching on how to give the best support to the child, help with coordination of their child's care, and others based on specific needs of the child and family.

Family Education and Support (FES)

– Non-medicaid program administered by DDP for eligible individuals from birth through age 21. Children may be placed on a waiting list to be selected for services. Assistance may include a menu of services and supports, coordination of care, assistance with transitions, and others based on specific needs of the individual and their family.

Case management is a key Medicaid service provided for eligible individuals of any age. There are two types: waiver case management for those age 0-22 who are receiving waiver services, and Targeted Case Management for any eligible person 16 and older.

If you or the individual are already receiving services, you can choose which type of case management you want any time between the ages of 16-21. At age 22, Targeted Case Management is the only choice. Because Targeted Case Management is an entitled service (no need for Medicaid), ALL eligible individuals age 16 or older can receive it, even individuals waiting to be selected for services (on the waiting list).

A case manager is responsible for the following assistance:

- Comprehensive assessment and periodic reassessment of an individual to determine the need for any medical, educational, social or other services
- Development and periodic revision of a specific plan of care. (people age 16 and older that are waiting for waiver services may have an abbreviated plan of care)
- Referral to resources and related activities to support the plan
- Monitoring and follow up activities to ensure the plan of care is implemented and adequately addressing the individual's needs



You can request a different case manager at any time by speaking to the case management agency, and then the DDP regional office if necessary. (see Section 4)

Your support plan will address all of the services available through these programs. Some services may be available as self-directed. Please contact your regional office for details.

12. What is Transition?

Transition means change. When it comes to DDP services, there are many changes and transitions you need to be aware of and prepare for in advance. Thankfully, there are several different people who can help you: teachers, counselors, family and friends. You'll need to work together closely with your case manager to plan for these changes, especially before the ages when service eligibility ends.

Early Intervention to Special Education and other DDP services - 36 Months

It is required for families receiving Part C services that, three to six months before a child's 3rd birthday, the IFSP Team must meet to plan your child's transition from Part C (Early Intervention Program) to Part B (Special Education - School). This is also the time to ask about the possibility of transitioning to, or getting referred for, other services (DDP and others).

Children's Autism Waiver (CAW)

If your child is receiving services through the CAW waiver, you and your case manager should work closely as your child approaches his or her 3rd year in the CAW waiver or approaches age 7 (depends on what age the child started in the waiver) to write a transition plan to other DDP services.

Transition is an expected change in the future for which planning may be necessary. There are several types of transitions that can occur including, but not limited to: transition into school, transition out of school, transition between services administered through DDP due to age limits and/or eligibility requirements, transition from family-focused services to individual, adult services for teenagers.

(Continued from "12. What is Transition?")

Children's Services to Adult Services - Age 16

ALL children with an IEP (Individualized Education Plan) who are reaching the age of 16 should start planning for transition from school to the adult world (whether receiving any services or not). School is an entitlement service, and many of the supports provided through school will no longer be available after graduation. A transition plan is a required part of each student's school IEP starting at age 16. It addresses issues like employment, education, housing, finances, and skills for independent living. Other agencies from adult systems may participate in the planning process (such as Vocational Rehabilitation). The Office of Public Instruction (OPI) and the Rural Institute on Disabilities can provide excellent resources on transition processes and planning. It is important to start this process early and to never forget that with the right planning and supports, employment is achievable and should be an expectation -- not an exception.

- **Already in DDP services:**
 - ▶ Transition from high school to adult living. A Case Manager is required to be part of this process. Make sure your case manager has adequate notice about meetings or calls that are scheduled. The case manager will continue to provide supports after the child graduates from high school, so it's important for them to be involved in transition planning to best guide and prepare the family and young adult for adulthood.
- **Not in DDP services:**
 - ▶ May be eligible for **Targeted Case Management (TCM)** through DDP to help during the transition from high school to adult living. Contact your regional office for more information.
 - ▶ As a part of the transition plan written in the **Individualized Education Plan (IEP)** through the school district, a psychological evaluation should be included if possible. This will assist the eligibility process for adult DDP services if DD eligibility has not already been established.
 - ▶ Adult services are not entitled programs and you may be placed on a waiting list. Please call your regional office well in advance.

Vocational Rehabilitation (VR) is a Department of Labor program that helps people who have disabilities get and keep a job. VR helps people who have physical, mental or emotional disabilities.

Office of Public Instruction (OPI) provides vision, advocacy, support and leadership for schools and communities to ensure that all students meet today's challenges and tomorrow's opportunities.

The University of Montana Rural Institute is a Center for Excellence in Disability Education, Research, and Service, is part of a network of programs funded by the Federal Administration on Developmental Disabilities (ADD) committed to increasing and supporting the independence, productivity, and inclusion of persons with disabilities into the community.

Website:
<http://ruralinstitute.umt.edu/>



Remember that planning ahead is key. Don't wait until your child turns 18 to start this process, especially if you are not already on the wait list or already receiving services through DDP!

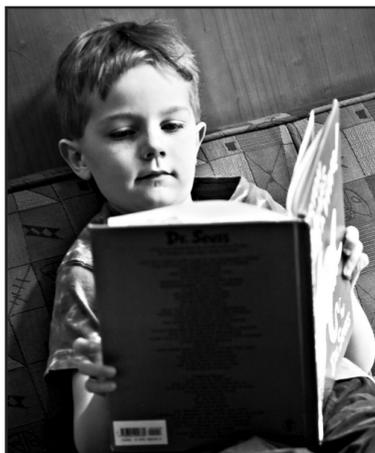
For transition tools, check out:

<http://ruralinstitute.umt.edu/transition>

13. How do I Settle Disagreements?

If you have a disagreement about anything to do with the services you are receiving or your child/family member is receiving, first try to:

- Resolve the disagreement or issue informally with the individual or service provider
- Utilize the service provider's internal procedures
- Contact your Regional Office



Ask questions and gather as much information as possible. You have the right to good services. The best way to get good services is to educate yourself and speak up. You cannot be forced out of services because you have a disagreement with DDP or a provider.

Don't be afraid to request information or responses in writing, especially if there is a disagreement. A person receiving services or legal guardian may also be entitled to request a fair hearing and should be appropriately notified of those rights.



Targeted Case Management (TCM) – May also be referred to as just Case Management (CM). TCM is offered to an eligible person age 16 or older. Targeted Case Management is entitled, which means a person meeting eligibility requirements will receive TCM services, even if they are not getting any other services administered through the Developmental Disabilities Program. For all who are eligible, the Case Manager will assess an individual to determine needs for medical, educational, social, or other services. For those who are selected to receive other DDP services, the TCM develops and/or revises the plan of care; can refer to other resources and activities to support the plan; monitors to ensure the plan of care is implemented and is adequately meeting the assessed needs of the individual.

Individual Education Plan (IEP) – A Support Plan developed through the school system to address educational needs and supports. The IEP is separate from a plan of care developed for someone receiving services through DDP; however, they may have similarities.

14. Other Considerations for Families

Guardianship and Alternatives

It comes as a great surprise that, under Montana law, parents have no legal responsibility or control over their child after he or she reaches 18 years old. Formal guardianship through the court system is an option, but it isn't the only one -- there are many informal and semi-formal arrangements that can be made to meet the needs of the individual.

Contact the PLUK office at 1-800-222-7585 or *e-mail* info@pluk.org for more information about these options.

Guardianship applies to parents of a child who is determined to have a developmental disability and is turning or is already age 18. Guardianship is establishing a formal or semi-formal arrangement that will allow a parent to legally make life decisions for their 'adult' child.

Family Financial Planning

Planning for the economic well-being of a child with special needs is a complex issue for parents. During transition planning, parents must address financial issues with the assistance of a lawyer, accountant or banker. It is helpful for overall planning if parents have made a will. Most financial planners advise parents to avoid leaving money or assets (e.g., home, car, business) to their children with disabilities.



Any inheritance that a child might receive would have to be spent completely before that individual would be eligible for certain government benefits (waiver programs). There are several financial options for families, such as a special needs trust, where assets may be protected for the individual so they do not affect his or her government benefits. Contact the PLUK office for additional information.

Sex Education and Marriage

We know that it can be an embarrassing subject, but a young adult who is headed for a more independent life will need the information and skills to deal with sexual maturity. Very few disabilities impair sexual function, so you can assume that your child will mature sexually and need help with understanding and managing his or her sexual functions.

Families should consider how much and what kind of sex education would be useful for the child. As a parent, you may need to deal with issues of birth control. Don't forget that young adults, whether they are disabled or not, are free to marry when they have reached the legal age of 18 and have complied with state requirements (e.g., physical examination).

15. Other Resources

Addictive & Mental Disorders Division

Phone: (406) 444-3964

The mission of the Addictive and Mental Disorders Division (AMDD) of the Montana Department of Public Health and Human Services is to implement and improve an appropriate statewide system of prevention, treatment, care, and rehabilitation for Montanans with mental disorders or addictions to drugs or alcohol.

Website - <http://www.dphhs.mt.gov/amdd/>

Adult Protective Services (APS)

Toll Free: 1-800-551-3191 (Information Line)

APS is an agency given authority by the Montana legislature to investigate reports of abuse, neglect, and exploitation of individuals over 60 years of age or developmentally disabled and over 18 years of age. In instances of imminent danger to the individual, APS may remove the individual from danger and arrange for a safe, temporary living situation.

Website - <http://dphhs.mt.gov/SLTC/APS.aspx>

Children's Mental Health Division

Phone: (406) 444-2995

State funded mental health services for children under age 18 are administered through the Children's Mental Health Bureau of the Developmental Services Division of the Montana Department of Public Health and Human Services.

Website - <http://dphhs.mt.gov/dsd/CMB>

Child Protective Services (CPS)

Hotline: 1-866-820-5437 (toll free, 24 hours)

Hotline: 1-866-341-8811 (TTY-hearing-impaired)

To protect children who have been or are at substantial risk of abuse, neglect or abandonment. We strive to assure that all children have a family who will protect them from harm. We recognize the protective capacities of families and incorporate them in assessments, decision making and actions with the goal of improving safety, permanency and well being for children.

Website - <http://www.dphhs.mt.gov/cfsd>

Children's Special Health Services (CSHS)

Phone: (406) 444-3622 (local)

Toll Free: 1-800-762-9891 (in the state of MT)

CSHS supports the development and implementation of comprehensive, culturally competent, coordinated systems of care for children and youth who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Website - <http://www.cshs.mt.gov>

• **Email - cshs@mt.gov**

Developmental Disabilities Program (DDP)

Phone: (406) 444-2995

DDP supports choices and opportunities for people with developmental disabilities in their communities.

Website - <http://dphhs.mt.gov/dsd/developmentaldisabilities>

Disability Rights Montana (DRM)

Phone: (406) 449-2344

Toll Free: 1-800-245-4743

DRM protects and advocates for the human, legal, and civil rights of Montanans with disabilities while advancing dignity, quality, and self determination.

Website - <http://www.disabilityrightsmt.org>

• **Email - advocate@disabilityrightsmt.org**

Early Edge Montana

Every Montana child should have the opportunity to reach their full potential. The best and most cost-effective way of doing this is by providing every Montana 4 year old with the opportunity to take part in high quality pre-kindergarten programs.

Website - <http://earlyedge.mt.gov>

Family Support Services Advisory Council (FSSAC)

The Council advises appropriate local and State agencies regarding the integration of services and supports for infants and toddlers and their families, regardless of whether the infants and toddlers are eligible for Montana's Part C services or for other services in the state.

Website - <http://dphhs.mt.gov/dsd/developmentaldisabilities/PartC-EarlyInt/PartCfssac>

Governor's Office

Phone: (406) 444-3111

The Governor will carry out the executive power vested by the Montana Constitution and see that the laws of the state are faithfully executed.

Website - <http://governor.mt.gov/>

Healthy Montana Kids

Phone: See website for contact information by category
A free or low-cost health coverage plan. The plan provides health coverage to eligible Montana children and teenagers up to age 19. A child can qualify for HMK based on family size and income. Call to have an application sent to you, or visit Healthy Montana Kids.

Website - <http://hmk.mt.gov/index.shtml>

Healthy Montana Kids Plus (HMK Plus)

This used to be called children's Medicaid, before October 1, 2009. HMK Plus is health care coverage for low-income children, ages 0-19, in Montana and is also run by DPHHS. All medically necessary services are provided to children covered by HMK Plus.

Website - <http://dphhs.mt.gov/MontanaHealthcarePrograms/Welcome/MemberServices>

Human and Community Services Division - DPHHS

Other Resources... Continued

Support the strengths of families and communities by promoting employment and providing the assistance necessary to help families and individuals meet basic needs and work their way out of poverty.

Website - <http://dphhs.mt.gov/hcsd>

Independent Living Services

To make independent living a reality for Montanans with disabilities by promoting and practicing a philosophy of consumer control, development of peer relationships and peer role models, self-determination, self-help, equal access, and advocacy in order to maximize independence, integration and full inclusion of persons with disabilities into mainstream Montana.

Website - <http://dphhs.mt.gov/detd/independentliving>

Montana Council on Developmental Disabilities (MCDD)

Phone: (406) 443-4332

Toll Free: 1-866-443-4332

The Montana Council on Developmental Disabilities is a citizen based advocacy group. Its members, appointed by the Governor, work to provide increased independence, integration and productivity for persons with developmental disabilities.

Website - <http://www.mtcdd.org>

• **Email - deborah@mtcdd.org | dee@mtcdd.org**

MCDD Service Directory

The purpose of this directory is to provide a telephone and address list of the organizations and agencies that provide services and/or support to people in Montana with developmental disabilities.

Website - <http://mtcdd.org/directory-of-services/>

Montana Child Care Resource & Referral Network, Inc.

Provide statewide leadership to shape collaborations and strengthen regional child care resource and referral agencies and other partners to build a diverse, professional, high quality early care and education system accessible to all Montana families.

Website - www.mtchildcare.org

Montana Developmental Center (MDC)

Phone: (406) 225-4411

Montana Developmental Center is a residential facility for individuals with developmental disabilities that provides 24-hour care for those with the most severe behaviors or severe self help deficits.

Website - <http://dphhs.mt.gov/dsd>

MontanaDevelopmentalCenter

Montana Food Bank Network

Works as the only statewide food bank striving to end hunger among Montana's most vulnerable populations through food acquisition and distribution, education and advocacy.

Website - <http://mfbn.org/>

Montana Get Connected

Phone: 211

Dial 211 or use the website below to connect you with important community services and volunteer opportunities.

Website - <http://www.montana211.org/>

Montana Health Insurance Answers

Phone: See website

Confused about health insurance? You've come to the right spot. How do you pick the right health insurance plan? How much should you pay? Can you get a tax credit to bring down the cost? These are not always easy questions to answer. We are Montana insurance experts and we already work for you. For free.

Website - <http://montanahealthanswers.com/families/health-insurance-buyers-guide/>

Montana Home Choice Coalition (MHCC)

Phone: (406) 449-3120

A Coalition of Montana Citizens, Advocates, Providers, Federal, State, Tribal, and Local Agencies, the Housing Finance Community, Realtors, and the Home-building Industry working together to create better community housing choices for all people with disabilities.

Website - <https://www3.aware-inc.org/awareinc/montanahomechoice/main.asp>

Montana Job Service – Disability Resources

Job Services across the state can answer questions and help job seekers with disabilities access federal, state, and community resources.

Website - <http://wsd.dli.mt.gov/service/navigator.asp>

Montana Public Transportation

Use this resource to see which areas have public transportation and to access information about public transportation in those local areas.

Website - www.mdt.mt.gov/travinfo/public_trans.shtml

Montana Rotary Club

Rotary Clubs lend helping hands to people in Montana and throughout the world. Through their hard work and generous donations, they are able to help fund many projects to benefit the community.

Website - <http://www.montanarotary.org/>

• **Email- district5390_news@msn.com**

Montana Youth Leadership Forum

MYLF (pronounced "my life") is a unique career and leadership training program for high school sophomores, juniors, and seniors with disabilities. By serving as delegates from their communities at a 5-day intensive training, youth with disabilities will cultivate leadership, citizenship, and social skills.

Website - www.montanaylf.org

Montana Youth Transitions

Phone: (406) 442-2576

Transition is the change from one event to another. Life has MANY transitions...changing from preschool to kindergarten, switching from middle school to high school, graduation from high school into adulthood...to name a few. Getting ready for adult life is exciting...and scary. BUT....there are many people to help if you know where to look.

Website – <http://montanayouthtransitions.org/>

National Transit Planning/Coordination

Empowers people with disabilities and older adults to be actively involved in designing and implementing coordinated transportation systems.

Website – www.transitplanning4all.org

NeighborWorks Montana (Montana Homeownership Network, Inc.)

Helps low and moderate income families buy or rent a home and keep their home by providing education and financial assistance throughout Montana.

Website - www.nwmt.org

Office of Public Instruction (OPI)

Phone: (406) 444-3095

The Montana Office of Public Instruction provides vision, advocacy, support and leadership for schools and communities to ensure that all students meet today's challenges and tomorrow's opportunities.

Website - <http://www.opi.mt.gov>

Parents, Let's Unite for Kids (PLUK)

Phone: (406) 255-0540

Toll Free: 1-800-222-7585

Provides information, training and support to insure that families of children with disabilities have access to high quality services.

Website - <http://www.pluk.org>

• **Email - info@pluk.org**

Rural Employment Opportunities, Inc.

Phone: 1-800-546-1140

Help Montanans find jobs, develop work skills and increase financial security. Our programs connect participants to job search, training, financial education and funding resources.

Website - www.reomontana.org

Social Security Employment and Incentives

Phone: 1-800-772-1213

TTY: 1-800-325-0778

Use these sites and tools to learn more about employment support programs and work incentives sponsored by Social Security that can help with resource planning and other supports to help you obtain or return to work.

www.socialsecurity.gov/work/awiccontacts.html

www.chooseworkttw.net/resource/jsp/searchByState.jsp

www.ssa.gov/disabilityresearch/workincentives.htm

Special Olympics Montana

Phone: (406) 216-5327

Toll Free: 1-800-242-6876 (in MT)

Provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

Website - <http://www.somt.org/>

• **Email- info@somt.org**

Supplemental Security Income (SSI)

Toll Free: 1-800-772-1213

TTY: 1-800-325-0778

The SSI Program pays benefits to disabled adults who have limited income and resources.

Website - <http://www.ssa.gov/ssi>

The University of Montana Rural Institute

Phone: (406) 243-5467

Toll Free: 1-800-732-0323

A Center for Excellence in Disability Education, Research, and Service, is part of the national network of programs funded by the Federal Administration on Developmental Disabilities (ADD) committed to increasing and supporting the independence, productivity, and inclusion of persons with disabilities into the community.

Website - <http://ruralinstitute.umt.edu/>

• **Email- rural@ruralinstitute.umt.edu**

Vocational Rehabilitation Services (VR)

Phone: (406) 444-2590

Toll Free: 1-877-296-1197

To promote work independence for Montanans with disabilities.

Website - <http://dphhs.mt.gov/detd/vocrehab>

16. Glossary and Acronyms

Case Manager (CM) – May also be referred to as Targeted Case Manager (TCM) or Waiver Children's Case Management (WCCM), or just Case Manager (CM). A CM is somebody who can assess an individual to determine needs for medical, educational, social, or other services; develops and/or revises support plan; can refer to other resources and activities to support the plan; monitors to ensure the support plan is implemented and is adequately meeting the assessed needs of the individual. Depending on the eligible person's age, this service may be entitled.

Child Find – A component of the Individuals with Disabilities Education Act (IDEA) that requires states to identify, locate, and evaluate all children with disabilities between the ages of birth to 21, who are in need of early intervention or special education services.

Children's Autism Waiver (CAW) – Medicaid program administered by DDP for children 15 months through age 7 who are diagnosed with Autism Spectrum Disorder and have difficulties with adaptive behavior. Services are intense, specific, and closely monitored. This program is time-limited, and it's likely the eligible child will be on a waiting list to be selected to receive services.

Comprehensive Waiver – Medicaid program administered by DDP for any age. May be referred to as the 'Big Waiver' or 0208 Waiver. Provides skills (habilitation) training, residential, recreational, and vocational supports. It's likely an eligible person will be placed on a waiting list before getting selected to receive services.

Department of Public Health and Human Services (DPHHS) – The Montana State agency that oversees all public health and human service programs.

Developmental Disability – A documented delay in cognitive or behavioral function compared to others in the person's age group. See Section 2 for formal definition.

Developmental Disabilities Program (DDP) – The Developmental Disabilities Program is a program within the larger DPHHS agency. DDP administers, provides funding, processes payments, and monitors all the different services that are offered through DDP (see Section 11). DDP is separate from services or assistance someone might receive through school, Mental Health, Public Assistance, State Medicaid, etc.

Early Intervention Services – Federal program (different from Waiver) administered by DDP for children birth to 36 months. May be referred to as Part C, or the Infant and Toddler Program. This program is entitled, which means there is no wait list and every child who meets eligibility criteria will receive services at no cost to families. It is a broad array of services that helps babies and toddlers with developmental delays or disabilities. It focuses on helping eligible babies and toddlers learn the basic and brand new skills that typically develop during the first three years of life such as crawling/walking, thinking/problem solving, talking/understanding, playing/feeling secure, and eating/dressing.

Entitled – Services for which there is no waiting list. People who meet eligibility requirements for 'entitled' services will receive that service right away. Examples are Part C (Early Intervention) and Targeted Case Management.

Family Education and Support (FES) – Non-medicaid program administered by DDP for eligible individuals from birth through age 21. Children may be placed on a waiting list to be selected for services. Assistance may include a menu of services and supports, coordination of care, assistance with transitions, and others based on specific needs of the individual and their family.

Family Support Specialist (FSS) – Staff who generally provide services to children and their families through the DD system. FSS staff may provide Children's Case Management, Caregiver Training Support (parent education) or BOTH to a child and family receiving waiver services. An FSS may also provide supports and coordination if a child/family is receiving Part C or FES services through DDP.

Guardianship – This applies to parents of a child who is determined to have a developmental disability and is turning or is already age 18. Guardianship is establishing a formal or semiformal arrangement that will allow a parent to legally make life decisions for their 'adult' child.

Individual Cost Plan (ICP) – A component of a person's plan of care if they are receiving services from one of the DDP Waiver programs. Specific providers, services to carry out the plan, and dollars are managed.

Individual Education Plan (IEP) – A Support Plan developed through the school system to address educational needs and supports. The IEP is separate from a plan of care developed for someone receiving services through DDP; however, they may have similarities.

Individual Family Service Plan (IFSP) – A plan of care for a person through age 15 who is receiving services administered through DDP. It is separate from any support plans developed through the school system; however, both plans may have similarities. The plan of care lists the assessed needs and what services will be provided to both the child and his/her family to meet those needs.

Part C Early Intervention Services – Federal program (different from Waiver) administered by DDP for children birth to 36 months. May be referred to as just Early Intervention, or the Infant and Toddler Program. This program is entitled, which means there is no wait list and every child who meets eligibility criteria will receive services at no cost to families. It is a broad array of services that helps babies and toddlers with developmental delays or disabilities. It focuses on helping eligible babies and toddlers learn the basic and brand new skills that typically develop during the first three years of life such as crawling/walking, thinking/problem solving, talking/understanding, playing/feeling secure, and eating/dressing.

Personal Support Plan (PSP) – A plan of care for a person age 16 or older who is eligible to receive services administered through one of the DDP waiver programs. The plan of care lists the assessed needs and what services will be provided to the person to meet those needs.

Targeted Case Management (TCM) – May also be referred to as just Case Management (CM). TCM is offered to an eligible person age 16 or older. Targeted Case Management is entitled, which means a person meeting eligibility requirements will receive TCM services, even if they are not getting any other services administered through the Developmental Disabilities Program. For all who are eligible, the Case Manager will assess an individual to determine needs for medical, educational, social, or other services. For those who are selected to receive other DDP services, the TCM develops and/or revises the plan of care; can refer to other resources and activities to support the plan; monitors to ensure the plan of care is implemented and is adequately meeting the assessed needs of the individual

Special Education Services – Children and youth (ages 3-18, or through age 21 in some districts) receive special education and related services under the federal Individuals with Disabilities Education Act (Part B). The purpose is to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

Special Needs Trust – Enables a person with a physical or mental disability, or an individual with a chronic or acquired illness, to have, held in Trust for his or her benefit, an unlimited amount of assets. In a properly-drafted Supplemental Needs Trust, those assets are not considered countable assets for purposes of qualification for certain governmental benefits.

Supplemental Security Income (SSI) – Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people who have little or no income; and provides cash to meet basic needs for food, clothing, and shelter.

Transition – An expected change in the future for which planning may be necessary. There are several types of transitions that can occur including, but not limited to: transition into school, transition out of school, transition between services administered through DDP due to age limits and/or eligibility requirements, transition from family-focused services to individual, adult services for teenagers.

Waiver Children's Case Management (WCCM) – May also be referred to as Case Management (CM). The staff that perform Children's Case Management is usually referred to as an FSS, so this service is associated with an FSS staff, and may even be called FSS.

WCCM is offered to a person receiving services through one of the Waiver programs, up to age 22 if desired. A CM is somebody who can assess an individual to determine needs for medical, educational, social, or other services; develops and/or revises support plan; can refer to other resources and activities to support the plan; monitors to ensure the support plan is implemented and is adequately meeting the assessed needs of the individual.

Guide to Success: Navigating Montana's Developmental Disabilities Program

A GUIDE TO UNDERSTANDING THE DEVELOPMENTAL DISABILITY SERVICES SYSTEM.

"Wow, this is great. Now I know why those people were coming to my house." (Parent)

"This is going to be very useful for families like mine." (Parent)

"I like everything about the guide and appreciate the updated information, the concise delivery, and the support for families and parents." (Professional)

"This guide is going to make my life easier and save some time chasing down information to provide to families. It answers a lot of the questions I've had, too. Thanks for doing this." (Service Provider)

The "Guide to Success: Navigating Montana's Developmental Disabilities Program" was developed through a unique collaboration between parents of children who benefit from services provided through Montana's Developmental Disabilities Program and the State of Montana Developmental Disabilities Program office.

The goal was to create a handbook that was written in a way that would be understandable to any parent, self-advocate, or community member and would teach the reader about the program as a whole, how it works, how it is funded, and who it serves.

We hope this information will assist in the process of finding the help and services you need.

The Developmental Disabilities Program provides oversight and funding for the service system that supports individuals with developmental disabilities and their families. They currently have an annual budget of \$114 million, serve over 4,000 individuals and work with over 60 service providers across Montana. The mission of DDP is to ensure choices and opportunities for people with developmental disabilities in their communities.

PLUK is a network of over 30,000 families of children with special needs in Montana dedicated to providing training, information, and support at no cost to individuals of any age, their family members, and the dedicated educators, professionals, and others that serve them. We become as well informed as possible in the fields of education, medicine, law, human services, rehabilitation, and technology to help empower individuals and families to make informed decisions about their lives and futures.

PLUK
516 N 32nd St.
Billings MT 59101
406-255-0540
<http://www.pluk.org>

Developmental Disabilities Program
DPHHS Building 111 Sanders, Room 104
PO Box 202955
Helena MT 59620
406-444-2995
<http://dphhs.mt.gov/dsd/developmentaldisabilities>



PLUK services are available throughout Montana and are free to individuals with special needs and their families.

