

**HJR 39 WHITE PAPER:
COMMUNITY SERVICES
FOR DUALY DIAGNOSED INDIVIDUALS**

DRAFT

A REPORT TO THE CHILDREN, FAMILIES, HEALTH, AND HUMAN SERVICES
INTERIM COMMITTEE

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INTRODUCTION

More than 4,200 Montanans with developmental disabilities receive state-funded services through programs offered in communities around Montana. Some of the programs provide them with assistance as they go about their daily activities, whether they're doing the laundry, shopping, or going to work. Other programs provide housing, through group living settings or more independent arrangements. Still others offer employment or training.

Most of these services are considered long-term in nature. Once individuals qualify for state-funded services, it's expected that they will remain eligible for decades to come because their developmental disability is expected to continue.

Contrast that to the system of state-funded mental health services, which provides more than 28,000 Montanans with services such as therapy, medication, and case management. This system sets a goal of recovery for the people receiving the services and expects that most of them will eventually live independently in their communities. They're expected to need the services for periods in their lives, but not their entire lives.

Some Montanans live with one foot in each of these worlds and, as a result, are considered to have a dual diagnosis. They and the people who provide services to them must navigate two different systems that inherently have conflicting approaches and goals. Neither system is necessarily well equipped to work with the issues or behaviors usually handled by the other.

Recognition of the unique challenges of providing services to the dually diagnosed has increased over the years. However, the service systems themselves generally haven't kept pace with that growing awareness.

State governments and national organizations are starting to take steps to respond to the needs of the dually diagnosed. The Montana Legislature joined this group in 2009, when it approved a study of the services needed at the community level to serve the dually diagnosed. This report summarizes the results of that study.

The Evolution of Community Programs

In the early to mid-1970s, an effort began nationwide to move people out of state institutions and into less restrictive community settings. Much of the change was spurred by federal legislation that required states to develop plans to eliminate inappropriate placement of people with developmental disabilities in institutions¹ and to provide educational and other services for handicapped children in the least restrictive environment possible.² The congressional action built on a movement by many people who wanted their disabled family members to live and be supported in the community, rather than an institutional setting.

The deinstitutionalization movement in Montana resulted in a striking reduction in the number of people being cared for at what was then the Boulder River School and Hospital for the developmentally disabled. The population at the Boulder facility — now known as the Montana Developmental Center, or MDC — dropped from 865 residents in 1970³ to 401 residents in 1975, 241 residents in 1980, and 173 residents in 1990.⁴ The census has been below 100 since 1997 and at about 65 residents the last few years.

However, the state has never been able to fund all of the community services needed by Montanans with developmental disabilities. In September 2009, the state Developmental Disabilities Program was funding services for 4,247 Montanans — 2,515 adults and 1,732 children. But 783 people were on a waiting list for community services as of March 2010; 389 of those individuals were not receiving any services, while the remainder had some services.

And at any given time, a dozen or so of the approximately 65 residents at MDC are waiting for a spot to open up in a community program because they are no longer under an order committing them to the institution. Still others are under a commitment order but cleared to move to community services if a spot were available. A majority of MDC

¹ Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103), 1975.

² Education for All Handicapped Children Act (P.L. 94-142), 1975.

³ "Statewide Universal Health Care Access Plans: Report to the Legislature," *Montana Health Care Authority* [online], available from http://www.archive.org/stream/statewideunivers03mont/statewideunivers03mont_djvu.txt, Sept. 16, 1994, accessed March 19, 2010.

⁴ "Montana Developmental Center FY End Census, 1975-2010," prepared by MDC Medical Records Administrator Laura Carney, April 1, 2010.

residents are dually diagnosed, having both a developmental disability and a mental illness. This often makes it more difficult to find a suitable community placement because not all communities have the mental health services that they need or developmental disabilities (DD) providers who are willing to accept them as clients.

House Joint Resolution 39: A Search for Solutions

The 2009 Legislature authorized a study of the availability of community services for dually diagnosed individuals through passage of House Joint Resolution No. 39.⁵ In the post-session poll of legislators, HJR 39 was ranked 13th out of the 17 study resolutions approved by lawmakers. The Legislative Council assigned the study to the Children, Families, Health, and Human Services Interim Committee, to be conducted as a staff-researched study and presented to the Committee as a white paper.

Staff proposed a study plan that covered a limited number of the topics included in the study resolution. The Committee adopted the study plan at its June 2009 meeting.

Accordingly, this white paper:

- summarizes the existing services available through the DD and mental health systems and the ways in which the services are funded;
- explains how individuals are identified as eligible for services;
- identifies, to the extent possible, the size of the dually diagnosed population;
- presents some of the key barriers to services and proposed solutions, as identified by stakeholders; and
- reviews efforts undertaken elsewhere to better serve the dually diagnosed.

HJR 39 study activities included:

- interviews with key stakeholders, including state agency personnel, DD providers, mental health providers, and advocacy groups;⁶

⁵ See Appendix A on P. 49 for a copy of the resolution.

⁶ See Appendix B on P. 51 for a list of individuals interviewed for this study.

- a survey of the agencies that provide community services of one type or another to the developmentally disabled;⁷ and
- a review of efforts at the national level and in selected states.

HJR 39 and the HB 243 Study

This white paper does not take a separate, in-depth look at services for dually diagnosed children. Instead, it anticipates that many of the issues will be explored by a separate study of the system of care for high-risk children who need services from more than one agency. The 2009 Legislature authorized that study through passage of House Bill No. 243. The Department of Public Health and Human Services is overseeing the HB 243 study, which is to result in recommendations on whether to maintain or modify the system of care.

The Department will present the results of the HB 243 study at the Committee's June 2010 meeting. Because children with developmental disabilities and mental health issues are typically served by more than one program, it's expected that the HB 243 study will discuss many topics that apply to dually diagnosed children. Thus this report does not attempt to cover ground expected to be reviewed in that study. However, many of the barriers and proposed solutions identified in this white paper apply to the service systems for both adults and children.

⁷ Nineteen individuals representing 18 providers in 14 communities responded to the survey. See Appendix C on P. 53 for more information about the survey and the responses.

MONTANA'S DUALY DIAGNOSED POPULATION

Determining just how many individuals may have a dual diagnosis is difficult, both nationally and in Montana.

NADD, an association for people with developmental disabilities and mental health needs, makes this observation: "Estimates of the frequency of dual diagnosis vary widely, however, many professional have adopted the estimate that 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder."⁸

Having a general psychiatric disorder, however, may not be enough to lead to a dual diagnosis. States set differing eligibility standards for receiving publicly funded mental health services, making it difficult to come up with any general estimates of the dually diagnosed population. The National Association of State Mental Health Program Directors has also noted that the difficulty in pinning down a number stems in part from the fact that several different agencies or programs are usually involved in providing services "and their data is not easily shared or integrated."⁹

That's the case in Montana. The Department of Public Health and Human Services (the Department) oversees both the services for people who are developmentally disabled and the services for those who are suffering from mental illness. However, the services are provided through three different programs within that agency:

- Developmentally disabled children and adults receive services administered by the Developmental Services Division, through its Developmental Disabilities Program.
- Children with mental health problems also receive services administered by the Developmental Services Division, but through the Children's Mental Health Bureau.

⁸ Robert Fletcher, "Information on Dual Diagnosis," *NADD, an association for people with developmental disabilities and mental health needs* [online], available at <http://www.thenadd.org/pages/about/ddinfo.shtml>, accessed Oct. 7, 2009.

⁹ "Serving Individuals with Co-Occurring Developmental Disabilities and Mental Illnesses: Systems Barriers and Strategies for Reform," *National Association of State Mental Health Program Directors*, October 2004, P. 6.

- Adults with mental illness receive services administered by the Addictive and Mental Disorders Division.

Each program determines eligibility for the people it serves, tracks and pays for the services under its auspices, and works with the providers in its respective purview. Matching up the information kept by each program is complicated by the fact that the programs use different computer systems and contractors for tracking eligibility and paying the people and facilities that provide services.

The Department was able to match its list of adults receiving mental health services against the list of people currently receiving developmental disability (DD) services in the community. That match in November 2009 found 360 dually diagnosed adults. In addition, 49 of the 67 adults at the Montana Developmental Center (MDC) in Boulder were dually diagnosed as of March 9, 2010.¹⁰

And the Children's Mental Health Bureau had identified 31 children as of Jan. 22, 2010, who were receiving mental health services and also had been determined to have a developmental disability.

The Department was unable, however, to match its list of adults receiving mental health services against the list of adults who have been determined to be developmentally disabled but are on a waiting list for services. Department officials indicated there could be some overlap between those two lists because the mental health system may end up as the default provider for a developmentally disabled person who is in need of services but can't obtain them through the DD system. The Department did not try to match those lists against each other because of time and cost constraints.

The dually diagnosed individuals identified by the Department also do not represent the entire universe of the population that HJR 39 proposed to study. The resolution sought a study of community services for people with developmental disabilities "who have mental illness or challenging or aggressive behaviors."

This white paper focuses on the services available for people who meet eligibility requirements for state-funded DD and mental health services, because the state does not have a system for tracking individuals who may have the behaviors described in HJR 39 unless they are receiving state-funded services. While some developmentally

¹⁰ E-mail from MDC Superintendent Kathy Zeeck, March 9, 2010.

disabled people have challenging or aggressive behaviors or may even suffer from a mental illness, they may not meet the state's criteria for receiving mental health services and thus would not be on any list that could be used for purposes of identification.

The eligibility requirements for each system are described below.

Eligibility in the DD System

Generally, individuals are determined to be developmentally disabled if they meet all of the following criteria:¹¹

- They have an I.Q. score of 70 or lower.
- They have an adaptive behavior score of 70 or lower. This score measures the ability to perform daily personal care and social activities; Montana uses an assessment tool that yields a score that approximates an I.Q. score.¹²
- Their disability originated before their 18th birthday.
- The disability is expected to continue indefinitely.

A person who is determined to be developmentally disabled may apply for those services that meet the person's needs. If the programs providing any or all of the services are full, the person is placed on a waiting list for the services.

As of September 2009, a total of 4,247 individuals were receiving community-based services through the DD Program. Of those, 2,515 were adults and 1,732 were children. The waiting list for services in March 2010 totaled 783 individuals; 661 were adults and 122 were children. Of those, 389 were not receiving any services at all, while the remainder were receiving some services, but not all the services for which they qualified.

In addition, approximately 65 adults live at MDC at any given time.

¹¹ William Cook, "Determining Eligibility for Services to Persons with Developmental Disabilities in Montana: A Staff Reference Manual (4th Edition)," *Department of Public Health and Human Services*, July 1, 2007, P. 60.

¹² *Ibid*, Pp. 16-17.

Eligibility in the Adult Mental Health System

To receive publicly funded mental health services, an individual must meet clinical and financial criteria that are set out in law and administrative rule.

Adults qualify financially if they are eligible either for Medicaid, which has income guidelines as low as 33% of the federal poverty level for a non-disabled adult who is caring for a related child, or for the Mental Health Services Plan (MHSP), which provides services to people with incomes at or below 150% of poverty.

They also must have a severe disabling mental illness (SDMI), which is defined in administrative rule.¹³ To be considered SDMI, a person:

- must have been involuntarily hospitalized for at least 30 consecutive days at the Montana State Hospital in Warm Springs; or
- must have a moderate to severe mood, psychotic, or personality disorder and also have an ongoing functional impairment as a result of the mental illness.

A person has an ongoing functional impairment if they meet two of the following criteria:

- is on medication to control the symptoms of mental illness;
- is unable to work in a full-time competitive situation because of the mental illness;
- is determined by the Social Security Administration to be disabled because of mental illness;
- is able to maintain a living arrangement only with ongoing supervision or is homeless or at risk of homelessness because of the mental illness; or
- has had or will predictably have repeated episodes in which the mental illness worsens and makes the person dangerous to the person or others.

The Department funded community services for 18,523 adults in fiscal year 2009.

¹³ 37.86.3501(7), Administrative Rules of Montana.

Eligibility in the Children's Mental Health System

Children qualify for state-funded services if they have been diagnosed with a serious emotional disturbance (SED) and have a family income at or below 250% of the poverty level and thus are eligible for the Healthy Montana Kids program. Under administrative rule, a child aged 6 through 17 meets the SED criteria if the child has a moderate to severe presentation of any one of 20 mood, psychotic, or personality disorders and — as a result of the diagnosis — has consistently and persistently demonstrated a significant degree of behavioral abnormality in any two of the following areas:¹⁴

- failure to establish or maintain relationships with adult caregivers or authority figures;
- failure to demonstrate or maintain appropriate peer relationships;
- failure to demonstrate appropriate range and expression of emotion or mood;
- disruptive behavior that leads to isolation in or from school, home, therapeutic, or recreational settings;
- behavior harmful to the child's growth, safety, or welfare or the welfare or safety of others; or
- behavior that results in substantial documented disruption to the family.

A child under the age of 6 meets the SED criteria if the child exhibits one of six behavioral abnormalities that cannot be attributed to intellectual, sensory, or health factors and that results in a substantial impairment in functioning for at least six months and is likely to continue for at least six months.

The Children's Mental Health Bureau funded community and residential mental health services for 9,490 children in fiscal year 2009. About 190 additional children were receiving extended mental health benefits paid for with Children's Health Insurance Program (CHIP) funds.

¹⁴ 37.87.303, Administrative Rules of Montana.

The Effort to Identify Dually Diagnosed Children

In the past year, the Children's Mental Health Bureau has begun a concerted effort to identify the number of children who have both a mental illness and a developmental disability. One staff member is trained to determine DD eligibility and will conduct an assessment of a child if a parent or guardian has given permission. Until that process began in spring 2009, the Bureau had no system in place for identifying dually diagnosed children and often was unaware that a child might need services from both systems until the child turned 18 or was about to turn 18 and was about to lose eligibility for children's mental health benefits.¹⁵

Children in the mental health system who also have a developmental disability may be able to move into DD services after they turn 18, if the disability has been identified. Because a waiting list for DD services exists, it's important to identify a developmental disability before children have aged out of the children's system and have no services available to them as an adult. The Bureau is now reviewing cases in which children receiving mental health services may have a dual diagnosis to make sure DD eligibility has been established, if appropriate. The Bureau is focusing particularly on those children who will turn 18 before July 1, 2011, in order to have information to report to the 2011 Legislature.

As of Jan. 22, 2010, the Bureau was reviewing DD eligibility for a group of 77 children who had been identified as possibly having a dual diagnosis. At the time, it had determined that 31 of the children did, in fact, have a developmental disability in addition to their mental health diagnosis. Sixteen of those children were 16 or older. Nine of the children were in the custody of the Child and Family Services Division, and one of them was receiving services out of state.

This study did not attempt to more broadly match the list of children receiving mental health services against the list of children receiving DD services, for several reasons. The majority of the children receiving DD services are in early intervention programs for children under the age of 3. The payment system for these services does not always break out individual identifying information. In addition, many of the children have not yet been determined to be developmentally disabled but are instead receiving services because they appear to be at risk for delays or disabilities and thus qualify for services under federal law. A child may receive DD services until age 8, but must be determined to meet the definition of a developmental disability by age 8 to remain in services.

¹⁵ Interview with Children's Mental Health Bureau Chief Bonnie Adee, Jan. 4, 2010.

Finally, mental health problems in children are not usually identified until children are older, so the likelihood of finding additional dually diagnosed children beyond those identified on an individual basis appeared slim. Legislative staff did not request further matching efforts because of the time and costs to the Department.

In the Corrections System

Some stakeholders expressed concern that dually diagnosed individuals may come into contact with the justice system because of their behaviors and may end up inappropriately placed in a correctional facility.

The Department of Corrections does not specifically screen for developmental disabilities, but does do a test of cognitive functions when a person first enters the Montana State Prison. The Corrections Department reviewed its screening of inmates admitted in 2009 and found that seven of the 596 inmates it had tested had an IQ score of approximately 70 or less. Intake screening of these seven inmates did not indicate the presence of a dual diagnosis of mental illness and developmental disability.¹⁶

Summary of the Numbers

Based on figures the Department could provide, the 360 dually diagnosed adults in community DD services represent about 14% of the adults receiving DD services and 2% of the adults receiving mental health services. The 49 dually diagnosed residents at MDC make up 73% of the institution's population. Added together, the 409 dually diagnosed adults at MDC and in community services would represent about 15% of adults receiving DD services and slightly more than 2% of the adults receiving mental health services.

The 31 children who have a confirmed dual diagnosis represent about 2% of the 1,732 children determined to have a developmental disability and less than half of 1% of the children receiving state-funded mental health services.

For those individuals, a lack of community services could be significant. Some may be living in more restrictive settings than necessary. Others may not be receiving the full range of services they need and, as a result, may end up in a crisis situation that requires a more intensive level of services.

¹⁶ E-mail from DPHHS/DOC Behavioral Health Facilitator Deb Matteucci, March 22, 2010.

THE PUBLICLY FUNDED DD AND MENTAL HEALTH SYSTEMS

Both the DD system and the mental health system provide a wide array of services to those who are eligible for assistance. However, not all services are available in all areas. Much of eastern Montana, for example, lacks mental health providers. Likewise, not all areas of the state have a full array of community services for people with developmental disabilities.

The gaps in services in both systems create special challenges in providing services for dually diagnosed individuals. Sometimes, a DD provider has an opening but the necessary mental health services aren't available in the community or within a reasonable distance. At other times, the services an individual needs are all available in the same community — but not in the community in which the individual is seeking placement.

THE DD SYSTEM

Title 53, chapter 20, of the Montana Code Annotated establishes the state's policy of providing services to developmentally disabled individuals in a community setting when possible, limiting the use of institutional services to those instances "only when less restrictive alternatives are unavailable or inadequate and only when a person is so severely disabled as to require institutionalized care."¹⁷

The Range of DD Services

Approximately 60 different organizations operate community services for the developmentally disabled around the state. These services are broadly categorized as follows:

- community living and residential services, which range from intensive group homes for people with few self-help skills to supported living arrangements in which people might live on their own in an apartment but receive assistance from the provider in such skills as managing their money or planning their meals. These services are provided to both adults and children.

¹⁷53-20-101, Montana Code Annotated.

- work and other day services, which range from intensive habilitation services for people not yet ready for work-oriented programs to supported employment opportunities in the community. These services are available to adults.
- home-based services to families, which include coordination of services for children with intensive needs, respite care, and general assistance and education for people who have a disabled family member.
- other support services, which range from case management to transportation and adaptive equipment.

The table below shows the different types of services provided and the number of counties in which developmentally disabled individuals were receiving those services as of September 2009.

Service	Number Served	Counties
Children's Autism Waiver	50	18
Community Supports	291	32
Group Living	803	30
Group Work/Day Programs	1,551	33
Individualized Living	1,015	50
Individualized Supports	415	45
Individualized Work/Day Programs	183	18
Personal Services	430	46
Therapies	163	16
Transportation	2,073	46
Waiver Children's Case Management	299	42

Source: Department of Public Health and Human Services

The 2009 Legislature appropriated \$101 million in fiscal year 2010 and \$108.3 million in FY 2011 for community services.¹⁸ The amount of funds spent per person varies, based on the level of services each person needs.

The Montana Developmental Center (MDC) is the state institution serving severely developmentally disabled adults who cannot be served effectively in the community. Approximately 65 individuals live there at any given time. MDC provides the most restrictive setting for people receiving state services. Individuals are placed there based on a court order committing them either because they are seriously developmentally disabled and pose a danger to themselves or others or because they have committed a crime but are more appropriately served at MDC than in prison. Many of the MDC residents have a dual diagnosis.

The 2009 Legislature appropriated approximately \$17.7 million in each year of the biennium to operate MDC.¹⁹ The institution is funded with general fund and state special revenue funds. The average cost of providing services at MDC for a year is about \$267,000 per person.

The DD Provider Network

The DD system is divided into five regions,²⁰ with a variety of providers offering services of one type or another in 53 of Montana's 56 counties. As of September 2009, no provider was offering services in Golden Valley, Mineral, or Prairie counties.

Some providers offer services in more than one region of the state. The regions and the number of providers in each are listed below.

- Region 1, with seven providers, is made up of the 17 easternmost counties in the state.
- Region 2, with 12 providers, stretches from the southern border of the state to Fergus and Petroleum counties on the north and Judith Basin, Wheatland, and Sweet Grass counties on the east.

¹⁸ E-mail from Matt Bugni, finance manager for the Developmental Services Division, March 26, 2010.

¹⁹ Ibid.

²⁰ See Appendix D on P. 57 for a map showing the DD service regions.

- Region 3, with 15 providers, encompasses northcentral Montana with Cascade County on its southernmost border, Blaine County on the east, and Glacier County on the west.
- Region 4, with 15 providers, covers southwestern Montana, bounded by Granite County on the west, Lewis and Clark County on the north, and Meagher and Park counties on the east.
- Region 5, with 25 providers, is made up of the seven westernmost counties.

Only one DD provider is also a licensed mental health center — A.W.A.R.E. Inc., which is headquartered in Anaconda but has offices in 26 communities and provides services in most counties in the state. However, it does not have mental health providers in every community in which it has an office.

The DD Waiting List

Montana has never fully funded the community programs needed to serve all eligible individuals. Thus the state has a waiting list of 661 adults and 122 children who have been identified as developmentally disabled and are in need of services.²¹

People are placed from the list into services according to the type of service available and the highest need for that service. For example, if a group home slot opens up in a region where several people have indicated they would like to live, the person whose living situation is most precarious at the time of the opening is likely to be placed in that slot — even if that person has been on the list a much shorter time than other individuals who are also waiting for a spot in a group home.

Individuals living at MDC may be ready for a community placement but may not rise to the top of the waiting list when a slot opens up, because their need for a placement may not be as high as someone who doesn't have a stable living situation. In addition, they may not be accepted into community services because they may not be compatible with other residents in a group home. Twenty-five of MDC's 67 residents were waiting for a community placement as of March 9, 2010. The commitment orders for 14 of the residents had expired. Another 11 residents were under commitment orders but had

²¹ E-mail from Karen Cech, administrative support person for the Developmental Disabilities Program, April 1, 2010.

been determined to be ready for a community placement.²² The people whose commitment orders had expired had been waiting for a community placement for anywhere from 76 to 433 days, with the waiting time averaging out to 232 days.²³

How DD Services Are Established

Montana allows organizations that want to provide community services to apply to the Developmental Disabilities Program to become a qualified provider. Among other things, the applicant must provide detailed information about the services the nonprofit will provide and how it will provide them; the duties, qualifications, and pay levels for all employees; and the organization's budget and sources of financing.

Existing providers also may add services to their programs through a similar process.

Providers usually go into business because they believe they will have enough clients to make the effort successful. When the Legislature has appropriated funds to expand the number of slots available in the DD program, the Department in the past has divided the funds among the five regions on a per-capita basis and given providers the opportunity to determine where services are most needed.

How DD Service Costs are Determined

When a person is identified as having a developmental disability, the Department uses a system called the Montana Resource Allocation Protocol (MONA) to start the process of determining the services the person needs. Based on the MONA, the Department develops an individual plan that is used to determine the financial resources necessary for purchasing the services for that person. This process results in an Individual Cost Plan (ICP) for each person.

The person uses funds from the ICP to purchase the services that have been identified as needed. For example, the ICP may pay for the costs of housing, through a group home or other arrangement, and for a day program in which the person receives habilitation services or subsidized employment in the community.

²² E-mail from MDC Superintendent Kathy Zeeck, March 9, 2010.

²³ Ibid.

Depending on an individual's needs, a cost plan can range from a few thousand dollars to — in rare instances — \$200,000 or more. The average cost is \$36,000 a year for adults and \$15,000 a year for children.²⁴ The ICP for a dually diagnosed individual covers only the costs of DD services. Mental health services are funded through the state's mental health programs.

The Use of Medicaid Waivers in the DD Program

Most individuals in the state-funded DD system qualify for Medicaid funding for the services they receive. Medicaid most often pays for medical expenses on a per-visit or per-procedure basis. However, the Medicaid program allows states to apply for a waiver from federal regulations in order to provide certain types of services with more flexibility. To do so, a state must certify that the costs of the waiver-funded services will not exceed the costs of providing services in the usual manner to the same group of people.

Montana began moving to a system of using waivers for its DD services in 1981. The waivers are authorized under a provision of the Medicaid laws that allows a state to pay for services provided in the home or community for people who would otherwise require institutional care. Over time, Montana has created three different waiver programs:

- The Comprehensive Waiver covers the costs of a broad range of services for most of the people in the DD system. Services range from group homes or other living arrangements to habilitation services, support services, and day programs. About 2,000 people of all ages receive services through this waiver.²⁵
- The Community Supports Waiver provides up to \$7,800 per year for services for people whose needs can be met in the community for that amount of money or less. About 270 adults receive support through this waiver; many live with family members who provide largely unpaid care, while others have most of the skills they need to live alone but require some small level of support or supervision.²⁶

²⁴ Interview with Developmental Disabilities Program Director Jeff Sturm, Dec. 18, 2009.

²⁵ "DDP 0208 DD Comprehensive Services Waiver Overview," *Department of Public Health and Human Services* [online], available from <http://www.dphhs.mt.gov/dsd/ddp/qualprovprocess/0208compserviceswaiveroverview.shtml>, accessed Feb. 8, 2010.

²⁶ "DDP 0371 Community Supports Waiver Overview," *Department of Public Health and Human Services* [online], available from <http://www.dphhs.mt.gov/dsd/ddp/qualprovprocess/commsupportswaiveroverview.shtml>, accessed Feb. 8, 2010.

- The Children's Autism Waiver is the newest Medicaid waiver program, created in January 2009. The waiver will pay an estimated \$45,000 per child per year for intensive early intervention services for up to 55 children who have an autism spectrum disorder. The child must be between 15 months and 4 years of age at the time of application and can receive services for up to three years.²⁷

Because of the way in which the waivers are structured, they may fund only those services identified in the waiver application and approved by the Centers for Medicare and Medicaid. Montana's DD waivers do not provide coverage of mental health services. Instead, those services are paid for through the Addictive and Mental Disorders Division, Children's Mental Health Bureau, or Healthy Montana Kids program.

Other Resources

The Developmental Disabilities Assistance and Bill of Rights Act created a network in each state that is made up of a state council on developmental disabilities, a protection and advocacy entity, and a university center for excellence. In Montana, the organizations are known, respectively, as the Montana Council on Developmental Disabilities, Disability Rights Montana, and the Rural Institute at the University of Montana. The state-level entities receive federal funds that are allocated through a formula. They work with state and local governments and the private sector on areas identified in the federal law to ensure the integration of people with developmental disabilities into the community.

The Montana Council on Developmental Disabilities is a private, nonprofit corporation that operates on a federal allotment of about \$460,000 a year. The Council is made up of up to 29 members appointed by the governor. The members create five-year plans of action based on public input and have sole authority in deciding how to spend the Council's funds. The allotment covers Council operating expenses, including a staff of two. It also may be spent on activities related to providing comprehensive DD services, helping the state with planning activities, and contracting with public or private agencies to establish model programs, undertake demonstration projects, or train people who provide services.²⁸ The Council uses its funds in areas of emphasis identified in federal

²⁷ "DDP Children's Autism Waiver (CAW) Overview," *Department of Public Health and Human Services* [online], available from <http://www.dphhs.mt.gov/dsd/ddp/qualprovprocess/caw.shtml>, accessed Feb. 8, 2010.

²⁸ "About the MCDD," *Montana Council on Developmental Disabilities* [online], available from http://www.mtcdd.org/index.php?option=com_content&task=view&id=14&Itemid=28; accessed Oct. 7, 2009.

law, which include transportation, housing, recreation, early intervention, employment, education, quality assurance, community supports, and inclusion.

The Council has, in recent years, used much of its funding for a project working on ways to assist children with developmental disabilities as they transition into adult services and new living and work situations. Its next five-year plan will cover federal fiscal years 2012 through 2016. The plan will be based on the comments received at a series of 12 public forums held around the state in fall 2009. Council members will use the plan to identify the areas in which they want to invest Council funds.²⁹

THE MENTAL HEALTH SYSTEM

Community-based mental health services for adults are provided by licensed mental health centers and private practitioners to adults who are eligible for Medicaid or the Mental Health Services Plan (MHSP) and to children who are eligible for the Healthy Montana Kids Program, which encompasses both Medicaid and Children's Health Insurance Program (CHIP) funds and services.

Individuals qualify for mental health services by meeting both financial and clinical guidelines, with only the most severely mentally ill Montanans receiving state-funded services.

The Array of Mental Health Services

State-funded mental health services include individual and group therapy, psychotropic drugs and medication management, crisis intervention services, case management, assertive community treatment, day treatment, and some residential services.

The state also has placed some limitations on the amount of some mental health services that individuals may receive without authorization from the Department. For example, basic outpatient services are limited to 24 visits under both Medicaid and the MHSP. Individuals receiving services under the MHSP also are limited to \$425 in psychotropic drugs each month, while payment for case management services is limited to \$120 a month. Inpatient hospital treatment for Medicaid patients must be pre-authorized, while the MHSP does not cover hospitalization at all.

²⁹ Interview with Deborah Swingley, executive director of the Montana Council on Developmental Disabilities, April 7, 2007.

In addition, children in the Healthy Montana Kids program may receive varying mental health benefits depending on whether their coverage is funded through Medicaid or CHIP. Healthy Montana Kids is a combination of those two publicly funded insurance programs. Children at or below 133% of poverty receive their coverage through the Medicaid program, which covers more mental health services than does CHIP. Children between 134% of poverty and 250% of poverty receive coverage through the CHIP-funded portion of Healthy Montana Kids.

The Mental Health Provider Network

Montanans may receive publicly funded mental health services from a wide range of providers. They include psychiatrists, psychologists, licensed clinical professional counselors, licensed clinical social workers, advanced practice registered nurses, and primary care physicians who may be in private practice or work for a health care provider. Individuals are also served by licensed mental health centers, community health centers, personal care agencies, and hospitals.

The ease with which people can access services, however, depends on a number of factors, including:

- where they live. For example, in 2008, just 17 child psychiatrists practiced in Montana, and none were practicing in eastern or northcentral Montana.³⁰ There were 83 psychiatrists serving adults, but none in the eastern region of the state.³¹
- whether the private practitioners in their area have an opening. As some providers have retired or left the state, caseloads for remaining practitioners have increased, and some providers no longer accept new patients.
- whether a practitioner is willing to accept the rates paid by Medicaid and the MHSP. These rates typically fall well below the amount paid for patients who have private insurance or pay on their own.

³⁰ "Report to the State of Montana: Legislative Mental Health Study," *DMA Health Strategies*, Nov. 18, 2008, P. 14.

³¹ *Ibid*, P. 46.

The most seriously mentally ill adults may receive inpatient treatment at the Montana State Hospital in Warm Springs, which is licensed for 189 patients. Most of the patients at MSH are placed there involuntarily, through court-ordered commitments.

Children with the most severe mental health problems may be placed in therapeutic residential settings outside of their homes and communities. These settings range from foster homes to group homes or inpatient facilities; inpatient and residential facilities are located both in and out of state. Montana doesn't have a children's equivalent to the Montana State Hospital.

How Mental Health Services Are Paid For

While the DD system relies on Medicaid waiver programs to cover a package of services, the state's mental health system pays community providers primarily on a fee-for-service basis. That means that providers bill for the service that a patient receives, often in increments that reflect the amount of time spent with the patient.

The 2009 Legislature appropriated about \$50.9 million for community mental health services for adults in fiscal year 2010 and \$56.8 million in 2011.³² It appropriated \$62.2 million for children's mental health services in 2010 and \$67.2 million in 2011.³³

³² E-mail from Addictive and Mental Disorders Division Administrator Lou Thompson, March 22, 2010.

³³ E-mail from Deann Willcut, budget analyst for the Developmental Services Division, March 26, 2010.

BARRIERS TO SERVICES AND IDEAS FOR IMPROVEMENT

Montana's separate systems for providing and paying for services to people with developmental disabilities and mental illness are not unique. And across the country, that separation of systems is often seen as one of the biggest barriers to providing the services that dually diagnosed individuals need.

In 2004, the National Association of State Mental Health Program Directors noted: "In most states, people with these co-occurring disorders face barriers to services related to a lack of coordination and collaboration across service systems, as well as gaps in research, clinical expertise, and access to appropriate programs."³⁴

Some of the barriers stem from the simple fact that the mental health and DD systems focus on different needs and often operate independently of each other. This fact has led NADD to observe: "Each system may expect the other to serve the person with a dual diagnosis."³⁵

Interviews with stakeholders and a survey of community-based DD providers indicate that the problems noted on a national level exist in Montana. Some of those problems are exacerbated by Montana's rural nature and the lack of mental health providers in many parts of the state.

Key barriers identified in interviews and the survey are discussed in this section, grouped by whether they involve the mental health system, the DD system, or both. This section also contains some of the solutions suggested by stakeholders.

³⁴ "Serving Individuals With Co-Occurring Developmental Disabilities and Mental Illnesses: Systems Barriers and Strategies for Reform," *National Association of State Mental Health Program Directors*, October 2004, P. 2.

³⁵ Robert Fletcher, "Information on Dual Diagnosis," *NADD, an association for people with developmental disabilities and mental health needs* [online], available at <http://www.thenadd.org/pages/about/ddinfo.shtml>, accessed Oct. 7, 2009.

BARRIERS IN THE MENTAL HEALTH SYSTEM

With Montana's mental health providers largely concentrated in the state's larger cities, it's no surprise that the lack of mental health services was most frequently identified as a barrier to providing services to dually diagnosed individuals. Problems were noted even in those communities where mental health services are available, because some providers simply aren't accepting new patients. A perception also existed that many providers aren't interested in serving people with developmental disabilities. Several reasons were suggested for the lack of interest, ranging from payment issues to providers' discomfort in treating a person who has a disability with which they have little familiarity.

The following points summarize the barriers and possible solutions raised in relation to obtaining mental health services.

Barrier #1: Montana has a shortage of mental health providers. The shortage of providers makes it difficult for many dually diagnosed clients to obtain services, particularly if they live in a rural area. While many DD providers indicated that their clients could receive mental health services in the community, others indicated that clients must travel from 30 to 280 miles one way to receive services. Nearly all of the survey respondents listed increased access to psychiatrists or psychologists as necessary for improving services, as did most of the stakeholders who were interviewed.

- **Possible Solution: Use of telemedicine for mental health services.** Some stakeholders suggested that telemedicine could offer a way to offset the lack of community mental health providers. While a need would still exist for additional mental health providers, a telemedicine network was seen as potentially making it easier for some dually diagnosed individuals to live in communities that don't have a mental health provider in town or nearby.
- **Possible Solution: Provide financial incentives for mental health practitioners — especially psychiatrists — to practice in Montana.** The State of Montana supports loan repayment programs for physicians who practice in underserved areas, and some people indicated that similar incentives are needed to encourage mental health providers to locate in low-population areas of the state.

- **Possible Solution: Require dually diagnosed individuals to accept placement in communities where mental health providers are located.** The DD system strives to place people in the least restrictive setting available and in the community of their choice. Individuals identify the areas in which they would like to live, and the Department tries to match them to community services in one of their preferred locations. Some stakeholders said that the state may need to require dually diagnosed individuals to live in areas where they can best obtain the range of both DD and mental health services that they need.

Barrier #2: Some mental health providers will not accept DD clients. Stakeholders identified a number of potential reasons behind this barrier, but the primary factors focused on reimbursement issues, on a possible lack of cooperation from DD providers, and on a mental health provider's preparation for working with DD clients.

Stakeholders noted that diagnosing and treating mental illness in dually diagnosed patients is usually more difficult than doing so for non-DD patients because the individuals may be less able to communicate their emotions, the reasons behind their behavior, or the factors triggering the behavior. Often, members of a person's treatment team, including the DD direct-care staff, must be interviewed in order to diagnose the patient and must be involved in the treatment plan and followup. The mental health provider also may need to participate in meetings with the DD team. Many of these activities are not reimbursable under the current fee-for-service system used for billing for mental health services and thus result in unpaid time for the mental health provider.

In addition, DD clients usually are Medicaid patients, and Medicaid reimbursement rates are lower than actual charges and are usually significantly lower than reimbursement rates paid by other insurers. For instance, a licensed therapist (non-psychiatrist) who charges \$100 to \$110 for a 50-minute therapy session is reimbursed about \$57 for seeing a Medicaid patient.³⁶

- **Possible Solution: Adjust Medicaid reimbursement rates.** Stakeholders suggested that the state could increase its Medicaid reimbursement rates to reflect the higher cost of providing services to the dually diagnosed. The

³⁶ "Medicaid Mental Health Individuals 18 Years of Age and Older Fee Schedule," *Department of Public Health and Human Services*, July 1, 2009, P. 1.

adjustment would be a recognition of the amount of additional time required for diagnosing and treating dually diagnosed patients.

Barrier #3: Mental health providers lack the training to work with developmentally disabled individuals. Providers of all types believe that mental health professionals generally are not trained to work with DD clients. Training is rarely provided during their formal education or through subsequent continuing education opportunities. The lack of exposure to information and to clinical experiences involving developmental disabilities not only makes providers unprepared to work with DD clients, but also perpetuates stereotypes or misperceptions they may have about people with developmental disabilities.

- **Possible Solution: Encourage curriculum changes in higher education programs for mental health providers.** A number of stakeholders emphasized the need for colleges and universities to expand their mental health curricula to include information and training on working with people with developmental disabilities.
- **Possible Solution: Provide continuing education opportunities.** In 2009, the Department conducted a training session for mental health professionals to provide them with information on dually diagnosed individuals and how to assess and treat mental illness in this population. Department officials hope to conduct further trainings in the future, in hopes of expanding the pool of mental health providers who are willing to work with the dually diagnosed. Other stakeholders said additional continuing education opportunities need to be made available and easily accessible to mental health providers across the state. They indicated that a number of organizations or associations may be able to provide those types of opportunities and suggested that the state encourage that they do so.

BARRIERS IN THE DD SYSTEM

DD providers are used to working with people with cognitive delays, but are less familiar with behaviors caused by mental illness. In a dually diagnosed person, a mental health problem may aggravate behaviors caused by the developmental disability, posing a variety of difficulties for DD providers.

The following points summarize the barriers and possible solutions raised in relation to providing DD services.

Barrier #4: Providers may experience additional or hidden costs. Stakeholders noted that dually diagnosed individuals may have more impulsive or aggressive behaviors, requiring DD providers to have a higher staffing ratio to make sure the clients and staff members are safe. In addition, if a client's condition destabilizes, the chances of damage to the provider's facility may increase. The full costs of transporting clients to mental health appointments can be substantial, particularly if additional staff members are needed to ensure the client's or staff's safety. These factors may not be adequately reflected in the amount of money the state is paying the DD provider, making some providers reluctant to accept dually diagnosed clients. Some concern exists that the state's MONA process doesn't identify and compensate for some of the potential costs providers could incur because of a client's mental illness.

- **Possible Solution: Involve DD providers in the process used to match clients with openings in community services.** The process the Department currently uses for matching clients with available openings for DD community services does not include DD providers in the discussion. Some stakeholders indicated that they could offer the Department additional information about the potential costs of placing clients in areas that lack services or about potential community programs that have the necessary services but are not being considered by the placement teams because members of the team aren't familiar with the community.
- **Possible Solution: Revise transportation rates.** Stakeholders suggested that the additional costs of higher staffing ratios and other transportation-related costs need to be reflected in the rates the state sets for reimbursing transportation costs.

Barrier #5: Providers have difficulty averting and responding to crisis situations.

When a dually diagnosed client experiences a mental health crisis, providers often are unable to handle the situation or don't know how to react. They may end up seeking to have the person committed to MDC or placed in a higher level of treatment and care. They also may not want to accept the person back into their services after the condition has been treated and the crisis situation has passed.

- **Possible Solution: Establish crisis beds within a community.** Some stakeholders suggested that one or two secure beds should be created at community facilities around the state, such as hospitals, existing group homes, or mental health centers. When necessary, a dually diagnosed individual could be

placed in a facility with a designated crisis bed until his or her condition stabilizes. Because the need for the beds would vary, the state might need to pay a fee to a facility so the beds would be available when needed. Stakeholders said this option would allow people to receive the additional mental health services they need while still retaining their spots in community programs, removing the threat they may pose to staff or other residents in their regular living situations, and keeping them in a community or setting that is more familiar to them.

- **Possible Solution: Establish a "mobile" crisis response capability.** The Developmental Disabilities Program has established a new position of crisis and transition specialist. This staff member is based in Boulder but travels around the state when DD providers notify state officials that they are having problems with a client and are considering having the person committed to MDC because they can no longer serve the person. The staff member meets with the provider and client in an effort to see how services can be maintained in the community. The Department has suggested hiring more of these specialists to work in specific regions of the state.

In addition, some DD providers elsewhere — particularly in states with larger populations — have a mental health professional on staff who can provide both routine and crisis services, traveling as needed to meet with clients. Some stakeholders suggested that Montana develop a similar model.

- **Possible Solution: Train DD staff to recognize behavioral health triggers.** Some stakeholders suggested that DD direct-care workers need to be made more aware of the signs that an individual's mental health condition is worsening, so they can provide appropriate interventions before the situation has deteriorated. In addition, they suggested that if staff were more aware of the factors that triggered a person's behavioral changes, they may be able to reduce the stress factors in the person's living environment and thus avoid some problems.
- **Possible Solution: Create a resource directory of mental health services.** Some stakeholders suggested that DD providers could benefit from knowing what mental health services are available in their community and region. They said mental health programs may be able to offer some immediate advice in crisis situations or could be contacted in advance of any problems, simply to provide information about services and options available in the area.

Barrier #6: Many direct-care workers for DD providers are unaware of their role in the mental health treatment process. The people who provide supports and services to DD clients day in and day out are in a good position to observe a client's behavior and catch the signs of changes that may be related to something other than the developmental disability. They also are in a position to monitor a client's daily activities and report to a mental health provider about any factors likely to trigger a mental health event. However, some stakeholders said that the direct-care workers don't seem to recognize the need for their involvement. As a result, they sometimes fail to make sure their clients attend mental health appointments, to notify mental health providers of significant meetings involving the DD team, to monitor medication usage properly, or to recognize behaviors related to a client's mental illness.

- **Possible Solution: Provide direct-care workers with training on mental health issues.** Some stakeholders suggested that improved training would lead to better services for the dually diagnosed by drawing DD staffers more directly into the treatment process and helping them recognize the importance of the role they play.

BARRIERS THAT CROSS JURISDICTIONAL LINES

Many of the barriers discussed by stakeholders cut across both the mental health and the DD systems and often involved one of three factors:

- an actual or perceived reluctance of providers in both systems to accept dually diagnosed clients;
- a lack of contact between the two systems; and
- territorial issues stemming from a fear by both types of providers and both systems that they may lose control over services or funding sources.

Taken together, those factors contributed to two frequently mentioned barriers that cross jurisdictional lines.

Barrier #7: Workers in the mental health system and the DD system know little about the other system. Conversations with stakeholders indicated that providers are knowledgeable about the requirements of the system in which they work but have little familiarity with the other system, whether it's the DD or the mental health system. Many

providers have little time to concentrate on doing more than supplying the services they're licensed to provide to the population they generally serve. Many have little contact with the other system because they have few dually diagnosed clients. The lack of knowledge creates barriers simply because providers are unaware of the needs of the other system.

- **Possible Solution: Create a liaison position between the two systems for each DD region.** Having a designated Department employee that providers in both the DD system and the mental health system could contact with questions about their dually diagnosed clients would help providers in both systems navigate the intricate eligibility, service, and funding requirements of each system. At least one stakeholder suggested that such a liaison person in each DD region would be a sought-after resource by providers of all types.
- **Possible Solution: Require cross-education of providers.** Stakeholders generally agreed that they could do a better job of providing services to the dually diagnosed if they knew more about the other system. However, they suggested that it's unlikely that providers will have the time or opportunity to learn about the services offered and the issues faced by each system unless the state requires them to do so and provides a forum for cross-educational activities.
- **Possible Solution: Create a special endorsement and a payment system recognizing the endorsement.** Some stakeholders suggested providing a special endorsement for a mental health provider who has received some training in developmental disabilities, or vice versa. The endorsement would create more capacity within the system because more providers would be able to work with dually diagnosed individuals. It also would indicate to clients and their families that providers had knowledge of and training in both mental health and DD issues. Stakeholders also suggested that a higher reimbursement rate be created for a person with a license in one field and an endorsement in another.

- **Possible Solution: Require cooperation among the state programs offering mental health and DD services.** Some programs within the Department have established informal structures for working on issues involving dually diagnosed or high-needs individuals. However, not all the programs serving these individuals are always involved in the discussion. And some stakeholders said that without a directive from the Department director, the Governor, or the Legislature, state agencies are unlikely to devote the time and attention needed to ensure greater cooperation in providing comprehensive services to the dually diagnosed. Stakeholders also suggested that the Department should require cross-training of all Department staff, from the administrative level on down.

Barrier #8: Funding requirements allow little flexibility in providing services.

Stakeholders often suggested that the state should mix, or "braid," funds from different programs to better serve people with a dual diagnosis. However, much of the current funding inflexibility stems from federal rules for using Medicaid funds. Stakeholders also believed that state programs were fearful that their base budgets would be affected if they used any of their funding for services usually provided by another agency.

- **Possible Solution: Establish a way to pool funds.** Stakeholders urged the state to find a way to pool funds from various sources to provide more flexibility in providing the types of comprehensive services that dually diagnosed individuals often need. A model of sorts exists in the system of care account, created in 52-2-309, MCA, as a way to allow various departments and programs to share funds and serve high-risk children needing services from more than one state program. However, such an account would accomplish its purpose only if agencies directed funds into it or the Legislature appropriated funds for it.

Two Sides to Every Story — and Solution

Although the ideas proposed in this section may improve services to the dually diagnosed, stakeholders also identified problems inherent in adopting some of them.

For instance, almost everyone agrees that providers of all types could benefit from additional training. However, some DD providers noted that many of the DD direct-care jobs pay relatively low wages and are subject to fairly high turnover. Thus their investment in training workers may not pay off in the long run, because many workers may leave or may not want the training. DD providers suggested that it may be better to focus on training for mental health providers in how to work with the DD population.

Likewise, the idea of providing mental health services via telemedicine may seem like an appealing solution for DD providers in rural areas. But mental health providers caution that telemedicine may have limited uses, particularly when it comes to diagnosing a person's mental illness. Because a developmentally disabled person may have trouble communicating, a diagnosis of the mental illness may not be possible without discussing the person's behavior with several people and observing the person in his or her daily environment. In addition, alternative therapies to traditional talk therapy are often necessary, potentially making it more difficult to use technology as a treatment tool.

Some stakeholders questioned whether community options for dually diagnosed individuals should be limited to areas of the state that have all the DD, mental health, and medical services they need. The flip side, however, means limiting the ability of those individuals to specify where they would like to live. Concentrating the dually diagnosed population in certain areas also could overburden providers in those areas, result in fewer mental health providers locating in other areas of the state, and reduce the number of clients that DD providers in other areas of the state could serve.

A number of stakeholder suggested that incentives should be used to draw mental health providers to sparsely served areas of the state. However, existing incentives for psychiatrists have had limited success. All or portions of 53 of Montana's 56 counties are designated as mental health professional shortage areas of one type or another.³⁷ This federal designation is used as a criterion for many programs, including the National Health Service Corps (NHSC) program that provides scholarships to students and loan repayments of \$50,000 over two years to providers who commit to practicing in a shortage area. As of January 2010, 49 mental health providers who had received NHSC assistance were practicing in 25 Montana communities of all sizes; only one, however, was a psychiatrist.³⁸ The Legislature also has created the Montana Rural Physician Incentive Program, which provides loan reimbursements of up to \$100,000 for physicians who practice for five years in an underserved community. The program has provided incentives to primary care physicians, but not to psychiatrists.

³⁷ "Montana Mental Health Health Professional Shortage Areas (HPSAs) November 2009," *DPHHS Primary Care Office* [online], available at <http://www.dphhs.mt.gov/PHSD/Primary-Care/documents/2009MHHPA1109.pdf>, accessed March 23, 2010.

³⁸ Statistical information provided by DPHHS Family and Community Health Bureau Chief Jo Ann Dotson, March 26, 2010.

While the idea of involving DD providers in the process of matching clients to community services appeals to some providers, others see it as potentially creating confusion for DD clients and their families as they try to sort through the options. They also fear it could lead to a "bidding war" designed to encourage a client to choose one provider over another.

And finally, many of the proposals would require more state spending — increasing Medicaid reimbursement rates, providing more incentives to mental health providers to locate in the state, establishing crisis beds, or creating liaison staff positions or more crisis support specialists. Stakeholders acknowledge that putting these types of initiatives into place could be difficult at a time when Montana is faced with the prospect of reducing state spending because of budget shortfalls.

However, they also point out that the proposals could save money in the long run if they allow more dually diagnosed adults and children to be served in their communities, rather than more restrictive and often more costly settings. For example, the per-person cost of providing services at MDC is about \$267,000 a year — well above the \$36,000 average cost of providing services in the community. While most people acknowledge the cost of serving a dually diagnosed person in the community is more than \$36,000, it would certainly be less than the cost of serving that same person at MDC.

RECENT EFFORTS IN MONTANA

In recent years, the Department has taken steps to better identify and serve individuals with a dual diagnosis. This section summarizes some of the Department's efforts.

Crisis and Transition Specialist

In May 2009, the Developmental Disabilities Program created the position of crisis and transition specialist. This person primarily works with community DD providers to stabilize dually diagnosed individuals who are in or approaching a crisis situation and may be facing the prospect of commitment to MDC.

When a provider notifies the Department of a potentially problematic situation, the specialist works with the provider to try to keep the person in community services. The specialist reviews the client's medical and behavioral information, travels to the community to observe the client and his or her interactions with others, and determines the interventions needed to stabilize the situation. Those interventions may range from updating the client's mental health diagnosis and treatment or medication plan to training the DD staff in how to deal with the client's behavioral problems and triggers.

The staff member had worked with 30 individuals in the community through late March 2010; of those, only four were placed in the more restrictive setting of MDC.³⁹ She also has had numerous phone consultations with providers around the state.

Provider Training Sessions

In 2009, the Developmental Disabilities Program conducted two training sessions at MDC to educate providers of other services about working with DD clients.

In September 2009, the program held a training session on treatment for people with sex-offending behaviors. Some MDC clients have been committed to the facility because they have committed sexual offenses — a fact that makes finding a community placement for them more difficult. The training session included a discussion of the MDC treatment program for sex offenders and of the differences between developmentally disabled individuals who have committed sexual offenses and other sex offenders.

³⁹ E-mail from Crisis and Transition Specialist Connie Orr, Developmental Disabilities Program, March 26, 2010.

In November 2009, the Department held a training session for mental health providers on identifying and treating mental health disorders in people with intellectual disabilities. The session provided an overview of the issues involved in dual diagnosis, the clinical presentations of mental health problems in the dually diagnosed population, and the treatment needs of dually diagnosed individuals.

In past years, the Department also has provided training sessions for direct-care workers that cover a number of topics, including mental health issues.

Formal and Informal Collaborations

Recognizing the need to plan better for services to the dually diagnosed, staff members of the various divisions within the Department have been meeting on both a formal and informal basis to see how they can identify some of the needs and, when necessary, pool funds to serve certain individuals.

Representatives of state programs that work with high-risk children meet regularly to discuss ways to build and improve on services that provide these children with the array of services they need, with a goal of developing in-state services that meet their needs. Title 52, chapter 2, part 3, MCA, establishes the Children's System of Care Planning Committee and outlines the group's responsibilities. The committee examines issues related to all high-risk children needing services from more than one agency, not just dually diagnosed children.

However, the Children's Mental Health Bureau and the Developmental Disabilities Program have been working together to identify children with extraordinary needs who are in danger of losing services or not having their needs met. In those instances, staff members work to identify which services are most appropriate and how they can be funded. The programs also have been working on transition issues for children who will be leaving the children's mental health system because they are turning 18. If those children have developmental disabilities but have not been determined to be developmentally disabled by the time they turn 18, they may not have a spot available to them in the adult DD system when they age out of children's mental health services. The Department has identified a number of children who are receiving mental health services and may be dually diagnosed and is working to ensure that DD eligibility determinations are made, if appropriate, before they turn 18.

In addition, staff members from the Adult Mental Health Bureau and the Developmental Disabilities Program meet periodically to discuss cases involving adults who are being served by both programs. The staff members usually focus on the needs of specific individuals and how the programs can work together to provide the package of services a person may need. They look at such things as how to provide day treatment services through the mental health system and housing through the DD Program.

Interim DPHHS Studies

The 2009 Legislature approved two bills related to services provided to high-risk children who may be served by more than one state program:

- HB 243 required the Department to conduct a study of the state's progress in developing a statewide system of care for children with multi-agency needs. The Department is to publish a report that summarizes current activities to date, analyzes the effectiveness of the current system and the barriers to developing it further, and recommends how the system should be structured and funded. The Department has hired a consultant to conduct the study, and the report is to be presented to the Children, Families, Health, and Human Services Interim Committee in June 2010.
- Senate Bill No. 399 required the Department to collect a variety of information about children with multi-agency needs to determine whether children placed in out-of-state treatment programs could be served in Montana. The bill also requires the Department to attempt to reduce out-of-state placements. The Department must provide the Children and Families Committee with a twice-yearly report on the information it has collected.

EFFORTS ELSEWHERE

National organizations and state governments have been reviewing the ways in which services are provided to the dually diagnosed and how to close the gap between the services that are needed and the services that exist. NADD tracks efforts around the country and assists in those efforts. From his vantage point as founder and executive director of this national organization, Robert Fletcher offers this assessment: "I can't say there's any state doing it well. However, I can say there are states that are trying."⁴⁰

A National Push for Certification

NADD itself is developing a certification program in dual diagnosis that it sees as a way to "raise the bar in information, education, and ultimately, competency."⁴¹ Individuals or facilities would be able to apply for the certification, which would indicate that they have met the association's standards for education and experience. In the case of facilities, it also would indicate that their buildings meet the certification standards. People applying for certification would need to obtain the required education and experience on their own. NADD expects to complete the standards this year and start the program next year.

Certification will be provided to:

- direct staff, which includes the people who work with clients in either group homes, institutions, vocational workshops, or other similar day-to-day settings;
- clinicians, which includes mental health professionals; and
- facilities, such as MDC or a group home.

At the state level, Dr. Fletcher singled out Ohio as the state with the best system in place and New Jersey as a state that's trying to improve. In addition, a number of other states have examined their systems for serving the dually diagnosed, to see where they can make improvements. In addition, Connecticut has started a project designed to move people out of restrictive institutional settings toward community placement.

⁴⁰ Interview with NADD Executive Director Robert Fletcher, Feb. 24, 2010.

⁴¹ Ibid, Feb. 24, 2010.

Ohio's Coordinating Center of Excellence

Ohio established a Coordinating Center of Excellence in Dual Diagnosis in 2004 to create a more coordinated and comprehensive system for serving dually diagnosed individuals. The Center supports local and statewide efforts that are designed to improve the ability of the state and Ohio communities to provide needed services. The Center focuses its efforts on four areas:⁴²

- community development, which increases capacity for services by providing "mini-grants" of \$2,000 to counties that develop dual diagnosis intervention teams. Most of the counties used the grants for local training efforts.
- education, which has ranged from regional programs presented by partner organizations to training programs provided at college psychiatric programs. A curriculum has been developed that can be presented in a number of settings.
- consultation and assessment, which has included services provided by Ohio universities and the establishment of a regional system of clinics where local dual diagnosis teams can bring individuals for assessment.
- research into a number of areas, including the attitudes of individuals who work with the dually diagnosed, medication prescribing practices, and models of care that vary based on case severity and the ability of the system to respond.

The Center is operated by departments at three Ohio universities and a provider organization. It's funded by the Ohio Department of Mental Health, Ohio Department of Developmental Disabilities, and Ohio Developmental Disabilities Council.

New Jersey's Dual Diagnosis Task Force

In New Jersey, the Commissioner of the state Department of Human Services established a Dual Diagnosis Task Force in January 2008 to create a plan for developing services and supports. The Task Force recommended that the state:

- develop collaborative, county-based planning efforts;

⁴²"CCOE Summary," *Coordinating Center of Excellence in Dual Diagnosis* [online], available at http://www.ohiomidd.com/Ohio_Coordinating_Center_of_Excellence_%28CCOE%29/CCOE_Summary.html, accessed March 2, 2010.

- train direct-care and professional staff to work with the dually diagnosed;
- develop a continuum of crisis-response services that could either prevent the need for crisis intervention or provide access to crisis services when needed;
- increase education and support for family members and other caregivers, so they are better prepared to manage behaviors; and
- develop outpatient centers that could provide comprehensive assessment and evaluation, as well as medical care, dental care, and mental health treatment.⁴³

A board made up of state agency representatives is now overseeing and supporting the process of putting the recommendations into place.

Cross-Training and "Step Down" in Connecticut

State agencies in Connecticut began working in 1999 on collaborative planning efforts that included training sessions for all staff members, so they could be more aware of the eligibility requirements, referral process, and delivery systems of both the mental health and DD systems. The agencies felt they were making progress in many areas, but were having trouble discharging dually diagnosed people from the state psychiatric facility because the state had not provided additional funds to increase residential supports.

Most of the individuals ready for discharge had previously lived with their families and could have returned if some supports were in place for them. Instead, they were hospitalized longer than necessary.⁴⁴ Connecticut decided to go to a "step-down program," known as the Woodbridge Project, in an effort to move people from the psychiatric hospital to an intermediate level of services. The project provides a 30- to 60-day residential program in which individuals receive continued assessment, cross-system crisis services, and community transition planning.

⁴³ "Commissioner's Task Force on Dual Diagnosis," *New Jersey Department of Human Services, Division of Developmental Disabilities* [online], available from <http://www.state.nj.us/humanservices/ddd/programs/ddtf>, accessed March 17, 2010.

⁴⁴ Joan B. Beasley and Kathryn duPree, "A Systematic Evaluation and Implementation Strategy to Promote Effective Community Service Systems for Individuals with Coexisting Developmental Disabilities and Mental Illness: National Service Trends and the 'Connecticut Blueprint,'" *Mental Health Aspects of Developmental Disabilities* [online], Pp. 12-13, available from <http://www.nasddd.org/pdf/Beasley-duPree.pdf>, accessed March 24, 2010.

FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

The HJR 39 review of services to the dually diagnosed found that approximately 410 adults and 30 children are known to have a dual diagnosis in Montana. The numbers may seem small and represent only a fraction of the total number of Montanans receiving DD and mental health services. However, the consequences of inadequate community services for those individuals could be significant and could result in a more restrictive placement than necessary. The potential for inappropriate placement is particularly evident at the Montana Developmental Center, where 73% of the residents are dually diagnosed and more than one-third were waiting for a community placement in March 2010 because they did not need the intensive services and restrictive setting provided by the Boulder facility.

Stakeholders identified several barriers to providing adequate and appropriate community services, with many hinging on the unfamiliarity of providers in one service system with the needs of the other system. The simple shortage of mental health providers in Montana also was cited as a key barrier. Stakeholders proposed a number of ideas for alleviating some of those barriers and moving to a better system of delivering services in the least restrictive setting possible.

Those ideas ranged from offering incentives to draw mental health providers to Montana and the more rural areas of the state to increased reimbursement rates for serving the dually diagnosed, better training of both mental health and DD providers, a designated Department liaison between the two systems in each DD region, and increased reimbursement rates for a number of services.

At a time when Montana is experiencing a downturn in state revenues, stakeholders acknowledged the difficulty of putting some of the ideas into action. But should the Committee or future legislatures contemplate taking action on any of these ideas, it may be helpful to note that the proposals most often mentioned by stakeholders were:

- training, particularly for mental health providers;
- services to help stabilize individuals who approaching a crisis situation, so they are able to remain in the community and avoid commitment to MDC;

- increased reimbursements for mental health or DD providers who serve dually diagnosed individuals; and
- improved or mandated cooperation among the state programs that provide mental health and DD services.

Is There a Silver Bullet?

As with so many of the topics with which policy makers grapple, no single quick and easy solution appears to exist for improving services to the dually diagnosed population — except, perhaps, for money. With unlimited funds, the state likely could attract mental health professionals, add temporary crisis beds and crisis teams to the DD system, improve reimbursement rates, and make sure all individuals who work with the dually diagnosed are familiar with the two systems that serve them.

The reality, however, is that the state faces possible revenue shortfalls and budget constraints into the next few fiscal years.

Given that scenario, few significant expansions of any types of state services are likely to occur. But many stakeholders discussed the importance of training and awareness for both mental health and DD providers. The Department could take steps on its own to require more cross-training of its own staff members. Stakeholders also felt the Department should take the lead in providing or arranging for training for providers, as well. This option may provide a relatively low-cost solution that could be financed through the pooling of existing state resources, including those federal funds allocated to the Montana Council on Developmental Disabilities.

Robert Fletcher, founder and executive director of NADD, stressed that training could have a big impact on services to the dually diagnosed.⁴⁵ He said that even when a state may be unable to mix mental health and DD funds to provide services, state agencies usually have the ability to share their training funds. Cross-training state agency staff members in dual diagnosis would lay a good foundation for improving services, he said, while training for mental health and direct-care workers would break down attitudinal issues and resistance among providers.

"It needs to start with training," he said. "Training at all levels."

⁴⁵ Interview with NADD Executive Director Robert Fletcher, Feb. 24, 2010.

Options for Committee Consideration

After reviewing the draft HJR 39 report and receiving public comment, the committee may want to consider making recommendations to the 2011 Legislature, to the Department, or to others involved in providing services to individuals who are dually diagnosed.

Some options for Committee consideration include:

- asking the Governor and the Department Director to develop a plan for cross-training Department staff in issues related to dual diagnosis and to report back to the Legislature and the interim committee on efforts the Department has undertaken;
- asking the Department to take the lead in identifying and, if necessary, arranging educational opportunities for providers in the mental health and the DD system that would prepare both types of providers to better serve dually diagnosed individuals;
- creating a special revenue account that would allow various agencies and programs to pool funds to meet the needs of dually diagnosed individuals in certain instances and that would establish a mechanism for the agencies and programs to contribute funds to the account;
- allocating additional committee time to hear more about proposed solutions that may require new funding or changes to existing uses of funding, including proposals for crisis response, use of telemedicine for some mental health services, revised Medicaid reimbursement rates for certain services, or regional liaisons who can help both DD and mental health providers navigate the other system;
- providing a copy of the final HJR 39 white paper to the three state-level entities funded under the Developmental Disabilities Assistance and Bill of Rights Act — the Montana Council on Developmental Disabilities, Disability Rights Montana, and the Rural Institute of the University of Montana — for their consideration as they work on issues involving people with developmental disabilities; or
- other ideas as proposed by Committee members.

APPENDICES

APPENDIX A: HOUSE JOINT RESOLUTION 39

HOUSE JOINT RESOLUTION NO. 39

INTRODUCED BY P. NOONAN, FRENCH, MCCLAFFERTY, SESSO, JOPEK, A.
NOONAN

A JOINT RESOLUTION OF THE SENATE AND THE HOUSE OF REPRESENTATIVES OF THE STATE OF MONTANA REQUESTING THAT AN INTERIM COMMITTEE STUDY THE DEVELOPMENT OF ADDITIONAL COMMUNITY SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES AND CO-OCCURRING MENTAL ILLNESS OR CERTAIN BEHAVIORS.

WHEREAS, the Montana Legislature has passed statutes with the purpose, as stated in section 53-20-101, MCA, of providing developmentally disabled individuals with services that whenever possible will help them live in their communities in the least restrictive environment possible; and

WHEREAS, individuals with developmental disabilities who have mental illnesses also need to be served with care and compassion in the least restrictive environment that serves the individuals and the community; and

WHEREAS, studies in previous legislative interims have addressed issues regarding services for mentally ill Montanans, but have not addressed the specific issue of serving persons with developmental disabilities who also have mental illness; and

WHEREAS, developmentally disabled people who also are mentally ill may exhibit challenging or aggressive behaviors that put them at risk of involvement in the criminal justice system, where they are unlikely to receive the treatment and habilitation services they need and where they are at risk of victimization by other suspected and convicted offenders; and

WHEREAS, the Montana Legislature has an interest in reviewing community services for people with developmental disabilities who have mental illness or challenging or aggressive behaviors and in providing a forum for stakeholders to discuss options that may provide both urban and rural communities with flexibility in providing services, based on their varying levels of resources.

NOW, THEREFORE, BE IT RESOLVED BY THE SENATE AND THE HOUSE OF REPRESENTATIVES OF THE STATE OF MONTANA:

That the Legislative Council be requested to designate an appropriate interim committee, pursuant to section 5-5-217, MCA, or direct sufficient staff resources to study and monitor the development of community services for developmentally disabled children and adults with mental illness across the state and to respond to any underlying issues that have limited the development of community services.

BE IT FURTHER RESOLVED, that the committee include in its study of community services the following topics:

- (1) the ways in which community services should be planned for, prioritized, developed, and provided at the community level;
- (2) the types of community services that should be provided and the populations they could appropriately serve;
- (3) ways to encourage cooperation between and within communities in the planning, development, and provision of community services;
- (4) funding and cost considerations in the provision of community services;
- (5) the ways in which individuals may be identified and served in the community at the youngest possible age; and
- (6) any other topics identified by the committee.

BE IT FURTHER RESOLVED, that the study engage the public and relevant stakeholders, including the Department of Public Health and Human Services and Department of Corrections, to identify any barriers to providing services and to develop findings and recommendations for the next legislative session.

BE IT FURTHER RESOLVED, that if the study is assigned to staff, any findings or conclusions be presented to and reviewed by an appropriate committee designated by the Legislative Council.

BE IT FURTHER RESOLVED, that all aspects of the study, including presentation and review requirements, be concluded prior to September 15, 2010.

BE IT FURTHER RESOLVED, that the final results of the study, including any findings, conclusions, comments, or recommendations of the appropriate committee, be reported to the 62nd Legislature.

APPENDIX B: HJR 39 STAKEHOLDER INTERVIEWS

Legislative Services Division staff interviewed the following stakeholders as part of the HJR 39 study:

State Agency Personnel

- Bonnie Adee, Chief, Children's Mental Health Bureau
- Dr. Bob Caldwell, psychiatrist on contract with Montana Developmental Center
- Karen Cech, Administrative Support, Developmental Disabilities Program
- Mary Dalton, Manager, Medicaid and Health Services Branch
- Leslie Howe, Services Coordinator, Developmental Disabilities Program
- Novelene Martin, Regional Program Officer, Children's Mental Health Bureau
- Deb Matteucci, Behavioral Health Facilitator, DPHHS/Department of Corrections
- Montana Developmental Center Staff Members
- Glenda Oldenburg, Chief, Mental Health Services Bureau
- Connie Orr, Crisis and Transition Specialist, Developmental Disabilities Program
- Bob Runkel, Administrator, Developmental Services Division
- Deb Sanchez, Program Manager, Mental Health Services Bureau
- Jeff Sturm, Manager, Developmental Disabilities Program
- Lou Thompson, Administrator, Addictive and Mental Disorders Division
- Kathy Zeeck, Superintendent, Montana Developmental Center

Other Stakeholders

- Charlie Briggs, Easter Seals Goodwill Northern Rocky Mountain
- Jan Cahill, Montana Association of Community Disability Services
- Rhonda Champagne, Executive Director, Center for Mental Health, Helena
- Jody Daly, Southwest Deputy Director, Western Montana Mental Health Center, Butte
- Jeff Folsom, A.W.A.R.E. Inc.
- Roger Holt, Parents, Let's Unite for Kids (PLUK)
- Gordon Jackson, Associate Director, Eastern Montana Community Mental Health Center, Glendive
- Craig Jensen, Creative Options
- Jani McCall, Yellowstone Boys and Girls Ranch
- Nancy McVean, Licensed Clinical Professional Counselor, Helena
- Greg Olsen, Helena Industries
- Anita Roessmann, Disability Rights Montana
- Deborah Swingley, Montana Council on Developmental Disabilities
- Diana Tavary, Parents, Let's Unite for Kids (PLUK)

Many thanks to the Department of Public Health and Human Services and Department of Corrections staff members who provided information about existing programs and eligibility requirements, identified dually diagnosed individuals, and reviewed material for this report.

Thanks also to the staff members of the Montana Developmental Center who shared their experiences and ideas during a Feb. 22, 2010, meeting.

The Legislative Services Division appreciates the assistance that all stakeholders provided in completing this study.

APPENDIX C: PROVIDER SURVEY

As part of the HJR 39 study, Legislative Services Division staff surveyed 51 organizations that provide community services to the developmentally disabled. The survey was designed to determine whether providers accepted dually diagnosed clients and to hear from providers about the barriers they see in this area and the solutions they might have.

Providers were notified in advance about the study and the upcoming survey. The survey was e-mailed to all providers on Jan. 28, 2010, with a deadline of Feb. 16, 2010, for returning responses. Staff also attended the Montana Association of Community Disability Services meeting in Lewistown on Feb. 10, 2010, to discuss the study and encourage participation in the survey.

Staff received 19 responses from individuals representing 18 providers in 14 communities. Four of the providers indicated they did not provide services to dually diagnosed individuals; 14 providers do serve those clients.

The survey questions and a summary of the responses follow.

PROVIDER SURVEY

Services to Clients with Co-Occurring Mental Health Problems

1. Do you provide services to adults who have a co-occurring SDMI diagnosis or children with an SED diagnosis?

14 Yes (please proceed to question 8)

Respondents represented 14 providers in 10 communities.

4 No (please answer questions 2-7)

Respondents represented four providers in four communities.

ANSWER QUESTIONS 2 THROUGH 7 ONLY IF YOU MARKED "NO" TO QUESTION 1.

2. Please indicate which of the reasons listed below factor into your decision to not accept clients with a co-occurring SDMI or SED diagnosis. Please mark as many of the reasons as apply:

Client's mental health problems create behavior problems that can't be addressed in the community setting

No mental health services available in the community

No mental health services available within a reasonable distance

Mental health services available, but not the services needed to allow community placement of the individual (please indicate, in the space provided below, the services you feel are lacking)

1 Lack of funding to cover the necessary services

4 Other (please specify)

Two providers listed concerns related to the safety of their other clients; one listed access problems; and the fourth serves only two clients.

3. If appropriate services existed in the community or region, would you accept clients who had a co-occurring SDMI or SED diagnosis?

1 Yes

3 No

4. If yes, what types of services would be most useful, based on your experience?

Crisis beds

Client access to a psychiatrist or psychologist

Mental health case management services

School-based services

Training for staff in dealing with mental health issues

1 Other (please specify)

Day activity services

5. If no, why not?

Two providers cited fear of jeopardizing client safety; the other provider serves only two clients.

6. What barriers exist to providing appropriate community services for this dually diagnosed population?

Respondents mentioned difficulty in obtaining services from both systems and safety, transportation, staffing, and funding concerns.

7. Please provide your ideas for how those barriers could be addressed.

Respondents suggested making low-cost transportation available to disabled people and making sure that adequate funds were available for wages for extra staff members to help with dually diagnosed clients.

ANSWER QUESTIONS 8 THROUGH 19 ONLY IF YOU MARKED "YES" TO QUESTION 1.

8. What difficulties do you encounter in serving dually diagnosed clients and how do you handle those difficulties?

Responses focused primarily on the lack of access to mental health services, lack of training for both DD and mental health providers, lack of mental health providers with experience in working with developmentally disabled individuals, and the fact that inconsistent behavior caused by a client's mental health problems may be problematic for DD direct-care workers and require more staff time.

9. How frequently have you had to ask that a client with mental health problems be admitted to a more restrictive setting?

2 Never
10 Occasionally
0 Frequently
2 No response

10. What types of services do you provide?

Providers responding to the survey represented the full array of community services.

11. Do your clients receive mental health services through other providers?

12 Yes
1 No
1 No Response

12. If yes, what types of services?

Respondents indicated their clients receive a wide variety of mental health services.

13. Is the provider a licensed mental health center?

8 Yes
3 No
1 Not Sure
1 No Response

14. If not, what type of provider is serving the client?

Responses included primary care providers, Indian Health Service, private providers, and a local clinic.

15. How far must the client travel to obtain the mental health services?

Four providers indicated services were available primarily in the community. Six providers indicated that clients had to travel anywhere from 50 to 280 miles one way to obtain services.

16. Are additional services needed in your community or region to allow for more stable and/or more successful placement of dually diagnosed individuals?

13 Yes

0 No

1 No Response

17. If yes, what types of services would be most useful, based on your experience?

8 Crisis beds

12 Client access to a psychiatrist or psychologist

3 Mental health case management

2 School-based services

11 Training for staff in dealing with mental health issues

2 Other (please specify)

Responses in the "Other" category included follow-along services, therapeutic foster care, and training for psychologists and psychiatrists in working with DD clients and dual diagnosis needs.

18. What barriers exist to providing appropriate community services for this population?

Responses included lack of mental health providers; lack of funding for appropriate staffing levels; a need for dedicated crisis beds and/or on-call crisis responders; lack of training; lack of funding for transportation to services; and lack of time for the two systems to learn about each other.

19. Please provide your ideas for how those barriers could be addressed.

Responses included telemedicine or Web-based provision of mental health services and medication review, increased reimbursement rates, incentives to bring psychiatrists to the state, more flexible funding alternatives, funding for crisis services, continuing education for DD staff, and education for mental health providers.

ALL RESPONDENTS SHOULD PROVIDE THE FOLLOWING INFORMATION:

Please indicate the region in which you provide services:

4 Region 1

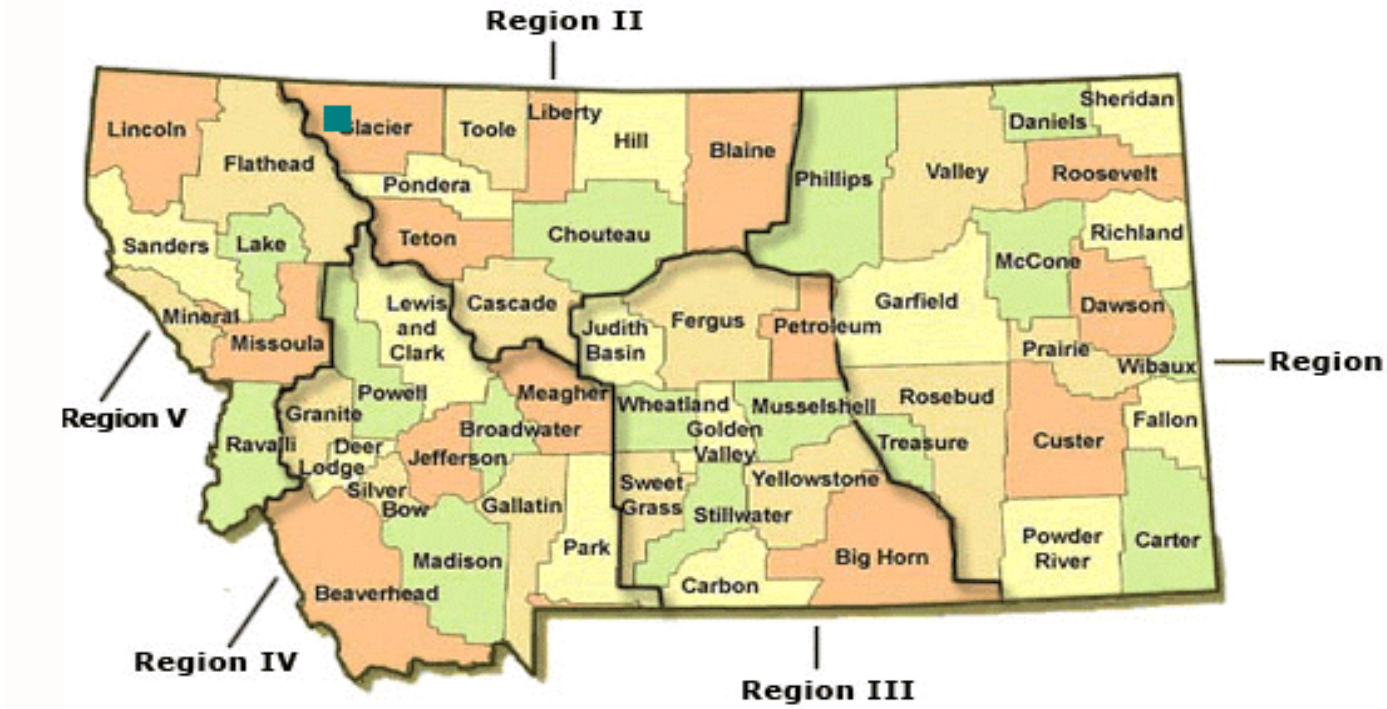
3 Region 2

3 Region 3

5 Region 4

3 Region 5

APPENDIX D: DD SERVICE REGIONS



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