Report to:
Developmental Educational Assistance Program

Montana Lifespan Respite Environmental Scan

October 31, 2012

Bloom

Contact: Kirsten Smith
ksmith@bloomconsult.org
(406) 570-0058

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1. Executive Summary

Family caregivers provide assistance to their loved ones who need additional support caring for themselves. According to the AARP, Montana had 134,000 family caregivers in 2009, providing caregiving services valued at $1.39 million.[1]

Families consistently identify respite care as one of the most important services allowing them to care for loved ones at home, avoiding or delaying expensive out-of-home placement. Respite care, including crisis care, " provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs, or who may be at risk of abuse or neglect."[2] Respite care has been shown to benefit both caregivers and their family members being cared for by lowering stress and increasing physical health.

Yet, many caregivers cannot or do not access respite services. National data shows that only 12% of caregivers receive respite services,[3] meaning that approximately 118,000 of Montana's caregivers are not receiving a break from their full time caregiver responsibilities.

Montana family caregivers do not utilize respite services because they:[4]

- Do not meet income, resource, and categorical eligibility criteria associated with the majority of respite services in the state, or are on a waiting list.
- Cannot find a quality provider, or providers are not available when they need the help.
- Do not trust anyone enough to help with their loved ones.
- Live too remotely to be able to access respite provider services.

The Department of Public Health and Human Services (DPHHS or Department) received a grant from the Administration on Aging to develop infrastructure to support a lifespan respite model in Montana. This environmental scan is intended to support this work by outlining the respite funding and services currently available in Montana, and identify where needs are going unmet. The Department is working with the Montana Lifespan Respite Coalition and the Aging and Disability Resource Centers (ADRCs), and has contracted with the Developmental Educational Assistance Program (DEAP) to execute a large portion of the lifespan respite grant. DEAP subcontracted with Bloom Consulting to conduct this environmental scan. This analysis is intended help focus the work being done under the grant.

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[1] AARP, "Across the States: Profiles of Long Term Services and Supports," 9th Edition, 2012.

[2] ARCH Lifespan Respite National Respite Coalition Task Force, working definition of respite, online, http://archrespite.org/national-respite-coalition/lifespan-respite-task-force.

[3] National Alliance for Caregiving in collaboration with AARP, "Caregiving in the US 2009," November 2009.

[4] DEAP, 2012 Family Caregiver Survey.

This analysis validated that a significant amount of unmet demand for respite services exists across Montana caregivers. The primary gaps identified in respite services are:

1. **Inadequate organizational infrastructure to support respite.** Respite services are provided through disparate programs based on categorical and financial eligibility. This patchwork approach means limited focus on respite, which translates to a system that does not acceptably meet consumer demand.
2. **Insufficient funding to support respite needs**. Siloed and limited programs funding respite services are not adequate to meet caregiver needs. Many individuals are required to pay privately for respite services, which often is a financial hardship.
3. **Insufficient provider capacity to meet respite needs.** Montana does not have enough trained respite providers to satisfy demand. It is very challenging to meet specialized health needs with a small provider pool, particularly in rural areas. Caregivers often struggle to find respite services on weekends, evenings, and holidays.
4. **Insufficient information about respite services.** Many people do not know what respite services are, despite perhaps needing them to increase their ability to thrive as caregivers. For those aware of respite, it is often challenging to identify local provider resources because there is no central, current, publicly available repository of information regarding these services.

Montana has the opportunity to create an infrastructure under its 2011 Lifespan Respite Care Act grant to begin to strategically address these issues. This report recommends several approaches for the state in concert with the Lifespan Respite Coalition, ADRCs, and DEAP to consider in implementing Montana's lifespan respite program.

1. **Continue to include caregivers, consumers, providers, and community organizations** in the lifespan respite project.
2. **Create state level lifespan respite support structure** to guide the work of the lifespan respite coalition and statewide efforts to increase respite availability and utilization.
3. **Increase provider capacity** in terms of the number of providers, provider availability, and provider training. The state should explore expanding self-direction opportunities to increase the pool of respite providers.
4. **Provide respite to caregivers not eligible under existing programs** possibly through a voucher or stipend program.
5. **Seek out additional respite funding sources** to maximize financial support.
6. **Promote volunteer-based initiatives** at the local level to increase provider capacity and meet the needs of individuals not eligible for respite services through existing programs.
7. **Educate the public about respite services** through public relations efforts and via other providers and organizations serving similar consumers.

8. **Promote a sliding fee scale or cost sharing** of respite services more broadly to allow existing dollars to stretch further.
9. **Create a publicly available respite database** so individuals and organizations can identify respite local providers.

The remainder of this report provides more detail on Montana's current respite services, national best practices, gaps in Montana's approach, and recommendations for improvement.

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2. Methodology

This environmental scan was developed using information gathered through national best practice research, key informant interviews, caregiver surveys, caregiver focus groups, and a provider survey.

Best practices research was conducted in an effort to provide DEAP and DPHHS with information about how other states are implementing lifespan respite programs as well as trends and promising practices at the national level. To these ends, we interviewed lifespan recovery experts from the Administration on Aging and three states, New York State, Alabama, and Oklahoma. A literature review was conducted, relying particularly on information from the ARCH National Respite Network and Resource Center. Best practices information is used to help identify gaps in Montana's lifespan respite system.

The author conducted key informant interviews with stakeholders in DPHHS and other state programs funding respite care, in addition to regional and local organizations providing respite services throughout the State. These conversations focused on defining respite, funding sources, service utilization, gaps in respite services, and lifespan respite model implementation. The full list of interviewees is included in Appendix 8.4. Interviewees provided data on respite funding and utilization cited in the report.

DEAP created and distributed a survey focused on caregiver respite demand, usage, unmet needs, and caregiver support services. Montana Lifespan Respite Coalition members distributed the survey to caregivers statewide. DEAP received 132 responses from caregivers providing care for a wide variety of populations and ages. An analysis of the results is included in Appendix 8.2.

DEAP also conducted four consumer focus groups throughout 2012 in Miles City, Helena, Billings, and Bozeman. A total of 19 agency staff and eight caregivers attended these focus groups. The groups defined respite, their individual or community needs for respite, respite providers and payment sources, and what would increase respite accessibility.

DEAP additionally created and distributed a provider survey in September 2012 to identify the types of functional respite services provided, the client groups served, the payment sources accepted, and the education and training received by community providers statewide. The survey also asked questions about the strength and weakness of respite services in Montana, providers' understanding of the lifespan respite model, and how consumers learn of and access services. DEAP received 25 responses from providers as of October 30, 2012. Analysis of the results is included in Appendix 8.3.

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3. Defining Respite in Montana

Montana offers respite services to caregivers of children, youth, adults, and seniors needing additional care through a wide variety of funding sources and models, including self-directed care, agency-based services, and institutional models. In general, caregivers receiving respite support need to fit within categorical and financial eligibility criteria or have the ability to privately pay for care. Caregivers requiring financial support for respite and other support services must navigate eligibility requirements for various health and human service programs, which is time intensive and confusing.

The Montana Lifespan Respite State workgroup in its April 2012 meeting defined respite as:

> Planned or emergency care provided to an individual with need for support and supervision in order to provide temporary relief to the primary caregiver of that individual.

This definition is consistent with the definitions of respite used in the Montana programs primarily funding respite services, as outlined in the table below.

Table 1: Montana Program Respite Definitions

Program	Respite Definition
• Home and Community Based Services (HCBS) 1915c Waiver for individuals who are elderly or physically disabled (Big Sky Waiver) • HCBS 1915c Waiver for individuals with Severe Disabling Mental Illness (SDMI)	Respite care is temporary, short-term care provided to consumers in need of supportive care to relieve those persons who normally provide the care. Respite care is only utilized to relieve a non-paid caregiver.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities • HCBS 1915c Children's Autism Waiver	Respite care includes any services (e.g. traditional respite hours, recreation or leisure activities for the recipient and caregiver, summer camp) designed to meet the safety and daily care needs of the recipient and the needs of the recipient's caregiver in relation to reducing stress generated by the provision of constant care to the individual receiving waiver services.
HCBS 1915i State Plan Program for Youth with Serious Emotional Disturbances (SED)	Respite Care is the provision of supportive care to a youth so as to relieve those unpaid persons normally providing day-to-day care for the youth from that

Program	Respite Definition
	provided only on a short-term basis, such as part of a day, weekends, or vacation periods.
Child and Family Services Division	Respite care provides foster parents relief from the daily care of a foster child whose mental or physical condition requires special or intensive supervision or care. Respite care is an aid in the prevention of abuse of foster children, foster parent burnout and the loss of experienced quality foster parents

Other services and supports may function as respite, despite not being labeled as such. Any service that provides a break for caregivers can be considered to provide respite. Appendix 8.1 outlines these functional respite services and their definitions. Respite services generally cost less than other services that functionally provide respite. This is because there are often fewer requirements for providers. Most waiver consumers define their plans of care based on a budget. Respite's lower rate allows consumers to include relatively more respite services. Consumers receiving services through waivers for individuals with developmental disabilities self-directing their care are able to pay even lower rates to respite providers, further stretching their budgets and creating additional provider choice by allowing consumers to pay individuals in their natural support structure.[5] Self-directing developmental disability waiver recipients must pay administrative rates in addition to wages, including for family caregivers exempt from minimum wage requirements. Acumen's current administrative rates are approximately 15 percent.

The low rates associated with respite services across funding programs may serve as a disincentive for agencies to provide respite services, when other services may provide the same value to the consumer and caregivers by functioning as respite, and result in additional revenue for agencies. See Appendix 8.1 for a list of services that function as respite. This may result in less availability of respite services for consumers, particularly those not self-directing their care.

[5] MCA 39-3-406 (p) exempts family members providing respite care from minimum wage and overtime requirements. Family member is defined as natural parents, adoptive parents, licensed foster parents, grandparents, step-parents, sibling, aunt, uncle, guardians and an individual who has a legally granted conservatorship or properly executed power of attorney responsibility for overseeing the disabled persons finances or general care.

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Where Lifespan Respite Fits within this Picture

The purpose of lifespan respite is to expand the availability and increase coordination of quality respite services for family caregivers regardless of age, race, ethnicity, or special need or situation.

The concept of lifespan respite has been active in Montana since 1999. Support and Techniques for Empowering People (STEP) in Billings and DEAP, located in Miles City were the first to implement the lifespan respite model using State and Developmental Disabilities Planning and Advisory Council (DDPAC) grant funds. Additional federal funds were awarded by the Administration on Children and Families (ACF), Administration on Intellectual and Developmental Disabilities (AIDD) to continue the pilot projects.

STEP and DEAP used different models to implement lifespan respite services. DEAP integrated all respite services under the title of lifespan respite, and matched consumers to funding sources on the back end. DEAP hires respite providers to work for the agency, which can include family members or friends of the consumer/caregiver. STEP had lifespan respite as a standalone service and did not employ providers directly. Caregivers paid respite providers directly, and STEP reimbursed the caregivers. This was done to support increased family control and choice. STEP stopped providing lifespan respite services in 2009 because of funding challenges and a leadership change.

DEAP is the only community-based provider using the lifespan respite model to serve all caregivers, providing services to 17 counties in eastern Montana. DEAP uses a variety of funding sources to support its lifespan respite program. The table below outlines functional respite services provided by DEAP from 2010 through 2012. The number of consumers receiving respite services has reduced by over 50 percent in this timeframe.

Table 2: DEAP Functional Respite Usage

	2010			2011			2012		
Service	Caregivers	$	Hours	Caregivers	$	Hours	Caregivers	$	Hours
Respite	90	$108,000	15,637	52	$86,399	11,168	41	$92,006	10,838
Habilitation Aide		$221,742	21,613		$207,515	20,216		$212,057	19,726
Homemaker		$8,098	586		$8,342	585		$8,830	618
Social, recreation, residential habilitation, education								$14,782	1,728

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4. Following the Money

The vast majority of respite in Montana is not provided through a lifespan respite model. Rather, respite is associated with discrete funding sources, which often have related categorical and financial eligibility requirements. Federal funding supports the majority of respite care in Montana. The State of Montana also funds a significant portion of respite services through the state match required for many federally funded programs, in addition to standalone state respite funding. However, the recent financial downturn has reduced state general funding allocations for respite services.[6] Additional local and nonprofit dollars also support respite services at the community level. These funding sources are often less tied to financial and categorical eligibility constraints, but may have geographical limitations.

This section of the report primarily focuses on state agencies and divisions and their funding for respite services. Local financial resources used to support caregiver respite are also outlined. The table below provides annual expenditures for each of the primary state respite funding sources in Montana. The figures represent respite consumers and expenditures in years between 2010 and 2012, depending on the data source.

Table 3: Summary of Montana Respite Funding

Funding Source	Annual Expenditures	Number of Beneficiaries
HCBS 1915c Comprehensive Waiver for Individuals with Developmental Disabilities[7]	$2,210,438	399
Title XX for IDEA Part C[8]	$29,741	Unknown
HCBS 1915c Community Supports Waiver for Individuals with Developmental Disabilities[9]	$129,141	31
HCBS 1915c Children's Autism Waiver[10]	$47,920	42
HCBS 1915c Waiver for Youth with Serious Emotional Disturbance[11] [12]	$74,224	20
Supplemental Services Program[13]	$3,078	Unknown

[6] Montana ceased operating its Developmental Disabilities Community Services Program in 2011 to save State general fund dollars, as outlined in Rule number 37.34.224. Online. Available: http://www.mtrules.org/gateway/ruleno.asp?RN=37.34.224.

[7] 2010 total beneficiaries and expenditures, including federal and state match.

[8] 2012 expenditures.

[9] 2010 total beneficiaries and expenditures, including federal and state match.

[10] 2010 total beneficiaries and expenditures, including federal and state match.

[11] Program is shifting to HCBS 1915i State Plan Program for Youth with Serious Emotional Disturbance in 2012.

[12] 2012 total beneficiaries and expenditures, including federal and state match.

[13] 2012 expenditures.

Funding Source	Annual Expenditures	Number of Beneficiaries
Children's System of Care Account[14]	$549	Unknown
CMHB Respite General Funds[15]	$424,098	Unknown
CMHB Title XX Funds[16]	$209,933	Unknown
Area Agencies on Aging[17]	$377,150	311
HCBS 1915c Big Sky Waiver for Individuals who are Elderly or Physically Disabled[18]	$210,777	95
Child and Family Services Division Respite Care for Foster Children[19]	$67,172	346
HCBS 1915c for Individuals with Severe Disabling Mental Illness[20]	$4,503	1
TOTAL	**$3,788,724**	**1,245[21]**

Disability Services Division

The Disability Services Division funds respite services through its Developmental Disabilities Program as well as the Children's Mental Health Bureau, which previously resided within the Health Resources Division.

Developmental Disabilities Program

The Disability Services Division, Developmental Disabilities Program (DDP) funds a significant amount of respite services in Montana. The majority of funding spent on individuals with developmental disabilities is federal monies spent through three HCBS 1915c waiver programs. Other services may function as respite within these programs, but are generally less used, with the exception of habilitation services. The table below includes DDP waiver consumers and expenditures for respite and functional respite services in state fiscal years 2008 through 2010. Over 2000 individuals received services through the Comprehensive Waiver, compared to fewer than 300 individuals on the Community Supports Waiver and just over 50 on the Children's Autism Waiver for the

[14] 2012 expenditures.

[15] 2012 expenditures.

[16] 2012 expenditures.

[17] 2011 beneficiaries and expenditures. Includes Title III funding in addition to a variety of other state, county, and local funding sources.

[18] 2010 total beneficiaries and expenditures.

[19] 2010 total beneficiaries and expenditures.

[20] 2010 total beneficiaries and expenditures.

[21] This total underestimates the number of beneficiaries because we were not able to obtain the number of beneficiaries for approximately $650,000 of respite expenditures.

years shown. The Children's Autism Waiver began operating in 2010; meaning earlier data is not available.

Table 4: DD Waiver Functional Respite Usage

1915c Comprehensive Waiver for Individuals with Developmental Disabilities						
	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Respite	363 (18%)	$1,337,312 (2%)	38 (20%)	$1,981,334 (3%)	39 (20%)	$2,210,438 (3%)
Personal Care	3 (0%)	$11,520 (0%)	(0%)	$28,240 (0%)	(0%)	$27,022 (0%)
Homemaker	48 (2%)	$43,079 (0%)	5 (2%)	$58,569 (0%)	4 (2%)	$77,992 (0%)
Adult Companion	9 (0%)	$282,360 (0%)	2 (1%)	$651,310 (1%)	4 (2%)	$947,168 (1%)
Residential Habilitation	1,670 (82%)	$48,847,575 (64%)	1,579 (77%)	$49,564,612 (64%)	1,592 (79%)	$50,297,242 (63%)
Day Habilitation	1,480 (73%)	$19,259,736 (25%)	1,422 (70%)	$18,441,367 (24%)	142 (70%)	$19,329,363 (24%)
1915c Community Supports Waiver for Individuals with Developmental Disabilities						
	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Respite	40 (18%)	$145,597 (9%)	43 (16%)	$179,406 (12%)	3 (12%)	$129,141 (9%)
Personal Care	1 (0%)	$779 (0%)	0 (0%)	0 (0%)	(0%)	0 (0%)
Homemaker	6 (2%)	$5,362 (0%)	9 (3%)	$11,990 (1%)	(3%)	$12,152 (1%)
Adult Companion	25 (9%)	$87,047 (6%)	19 (7%)	$43,592 (3%)	4 (18%)	$151,569 (10%)
Residential Habilitation	87 (32%)	$293,651 (19%)	80 (31%)	$292,431 (19%)	9 (34%)	$323,818 (21%)
Day Habilitation	35 (13%)	$125,731 (8%)	32 (12%)	$126,174 (8%)	5 (21%)	$233,444 (15%)
1915c Children's Autism Waiver						
	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Respite					4 (74%)	$47,920 (3%)
Children's Autism Training					5 (93%)	$790,540 (50%)

A relatively stable percentage of Comprehensive Waiver consumers use respite services, the value of which has been growing commensurate with the number of consumers. Other services that may function as respite when the consumer lives with a caregiver are used to a lesser degree than respite, although adult companion services usage climbed steadily from 2008 through 2010.

Waiver consumers with developmental disabilities were able to self-direct their care beginning in 2010. This allows family caregiver employers to pay less than minimum

wage for respite care to family members of the consumer. Presumably, this change would increase the units of respite care used by consumers self-directing care.

HCBS Medicaid waiver programs are funded with a blend of federal and state dollars. In federal fiscal year 2012, the federal government paid approximately 66 percent of the cost of HCBS services, with the state matching the remaining 34 percent.

In addition to the Medicaid waiver programs, DDP also funds respite services through Social Services Block Grant, Title XX funds. Title XX funding provides services similar to Medicaid HCBS waivers. These funds may be used to provide respite for families receiving services under Individuals with Disabilities Education Act (IDEA) Part C State Grants. Many agencies do not use these funds for respite services because of the way they allocate their funds. Montana previously used general funds to provide community services to individuals with developmental disabilities. General funds were the source of respite funding for families receiving IDEA Part C funding, but ceased being so on July 1, 2011. DDP refinanced the general fund community services program to Title XX funds to leverage additional federal dollars and preserve state general funds. Until recently, no new families could receive Title XX dollars because of funding limitations. This changed in September 2012 to allow additional families on the Title XX waiting list to receive services. The table below outlines general funds and Title XX funds used for respite in SFYs 2010 through 2012.

Table 5: Respite Title XX and General Funds Used for Individuals with Developmental Disabilities

SFY	Title XX Funds	General Funds	Total
2010	$29,706	$28,541	$58,246
2011	$25,993	$24,973	$50,966
2012	$29,741	$0	$29,741

Children's Mental Health Bureau

The Children's Mental Health Bureau (CMHB) provides respite services to caregivers of youth with serious emotional disturbance (SED) through a variety of federal and state funding sources. The primary source is the HCBS 1915c psychiatric residential treatment facilities (PRTF) demonstration waiver/grant. The waiver began operating in 2007, and expired on September 30, 2012. CMHB has submitted a 1915i HCBS State Plan request to make these HCBS services available statewide. CMS has not formally approved Montana's State Plan program. Proposed Administrative Rules of Montana have been filed to support these changes. The following table shows HCBS 1915c PRTF demonstration waiver/grant respite expenditures for SFYs 2010 through 2012. During that timeframe, the number of unique consumers receiving services under the waiver grew from 22 in 2010 to 74 in 2012.

Table 6: HCBS 1915c PRTF Demonstration Waiver Respite Utilization

SFY	Consumers	% Total	Expenditures	% Total
2010	7	32%	$20,015	10%
2011	12	22%	$30,240	7%
2012	20	27%	$74,224	9%

In addition to the waiver, CMHB also provides respite services through the Supplemental Services Program (SSP) to youth eligible for Medicaid, the Children's Health Insurance Program (CHIP), or the Children's Mental Health Service Plan with family incomes up to 185 percent of the federal poverty limit (FPL) who cannot otherwise access respite services. Montana funds the SSP program through Temporary Assistance for Needy Families (TANF) Maintenance of Effort (MOE) dollars from the general fund. TANF MOE is providing approximately $350,000 annually in 2012 and 2013 to support SSP. Only a small percentage of these funds are used for respite. SSP expended $0 in SFY 2010, $4,117 in 2011, and $3,078 on respite.

CMHB also provides respite services to caregivers through the Children's System of Care Account, which is funded by state general funds. This funding is designated for Medicaid eligible youth receiving services from multiple Medicaid agencies. This account allows funding to be coordinated across state programs, and may be used to reimburse providers for services allowing high-risk youth to be treated in home and community based settings. CMHB spent $900 in SFY 2010, $0 in 2011, and $549 in 2012 on respite within the System of Care Account.

CMHB additionally has general fund dollars for youth receiving Medicaid and in therapeutic family care, which may be used to support respite services. This funding was overspent in previous years, and will be reduced in SFY 2013. The following table outlines CMHB general fund respite expenditures for SFYs 2010 through 2012.

	SFY 2010	SFY 2011	SFY 2012	Total
CMHB General Funds	$438,447	$547,634	$424,098	$1,410,179

In addition, CMHB also expended $209,933 in Federal Title XX funds on respite in SFY 2012. CMHB did not use these funds in previous fiscal years to support respite services.

Senior Long Term Care Division

The Senior Long Term Care (SLTC) Division provides respite services through its Aging Services Bureau and its Community Services Bureau.

Aging Services Bureau

SLTC's Aging Services Bureau receives funding from the Administration on Aging Title III-E funds of the Older Americans Act, National Family Caregiver Support Program, which can be used to support respite services. SLTC provides services through ten regional AAAs statewide and their contracted local networks of service providers. AAAs allocate funding based on the individual needs of their local community. The table below shows the amount of funding used for respite services from 2010 through 2012, and the respite budget for 2013. A large percentage of this funding is Title III-E funding, but additional state and local funding supplements this source including state general funds, county funds, county and local mill levies, local foundations, and donations.

Table 7: AAA Respite Funding

	Actual						Budgeted
	2010		2011		2012		2013
	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures	
Total Respite	318	$352,573	311	$377,150	197	$606,278	$587,144
Title III-E Respite		$146,451 (42%)		$196,434 (52%)		Not Available	Not Available

Respite funding increased significantly in 2012, however the number of clients is smaller than previous years because the data represents only a portion of the calendar year. Some areas are putting greater funds toward respite care because of the increasing demand for these services. Many areas have waiting lists for services. The data, however, is inconsistent between AAAs because agencies use different working definitions of respite. Only one of the ten AAAs uses cost sharing for respite services, implementing a sliding scale fee dependent on a family's income.

AAAs also fund functional respite services through Retired and Senior Volunteer Programs (RSVP), Senior Companion Programs, and Foster Grandparent Programs. AAAs receive grants through the Corporation for National and Community Service established by the National and Community Service Act. Montana has 14 RSVP programs, three Senior Companion Programs, and four Foster Grandparent Programs statewide.

Montana also has six Aging and Disability Resource Centers (ADRCs) throughout the state, and recently received a grant to implement two additional ADRCs. AAAs become ADRCs by expanding their role to encompass a broader disability population of all ages, and to include additional responsibilities beyond those required of AAAs. Montana's ADRCs do not have additional funding sources supporting respite services, but may support the respite provider database being created within the lifespan respite grant.

SLTC is also the lead agency in DPPHS implementing a Money Follows the Person (MFP) demonstration project and Community First Choice (CFC) State Plan services. Montana submitted its grant application to CMS in August 2012 requesting funding to implement an MFP demonstration to support an increased number of individuals transitioning from

institutions to HCBS services. The state projects that 235 Medicaid eligible individuals will transition under this program, many of whom may use respite services. The state is conducting analysis to determine the impact of implementing CFC, which provides services similar to Personal Assistance Services. The state legislature will have to approve CFC before DPHHS submits a State Plan. If CFC is implemented, respite services may be further available to caregivers across population groups.

SLTC's Aging Services Bureau is also administering the lifespan respite grant, under which this analysis is being performed.

Community Services Bureau

SLTC Community Services Bureau funds respite services through the HCBS 1915c Montana Big Sky Waiver for individuals who are elderly or have physical disabilities, Medicaid State Plan Personal Assistance Services, and Medicaid hospice services.

Approximately 2,000 individuals receive services through the Big Sky Waiver, but many do not live with a caregiver, and thus do not need or qualify for respite services. The table below outlines respite service utilization along with other services identified by DPHHS leadership as potentially functioning as respite when the consumer is living with a caregiver. But because many Big Sky Waiver consumers do not live with caregivers, these figures cannot be seen as representing a true comparison of respite to functional respite services. Data is included for state fiscal years 2008 through 2010. Some of the services included in Appendix 8.1 as functional respite services are not included in this table because they were not included as services in the CMS 372 report for the years cited.

Table 8: Big Sky Waiver Functional Respite Usage

	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Respite	90 (4%)	$189,705 (1%)	9 (4%)	$196,472 (1%)	9 (4%)	$210,777 (1%)
Adult Day Health	31 (1%)	$120,918 (0%)	2 (1%)	$104,944 (0%)	2 (1%)	$87,299 (0%)
Day Habilitation	2 (0%)	$13,505 (0%)	(0%)	$13,338 (0%)	(0%)	$12,996 (0%)
Homemaker	648 (29%)	$1,947,913 (7%)	70 (31%)	$2,030,012 (6%)	71 (30%)	$2,202,326 (6%)
Homemaker Chore	61 (3%)	$42,348 (0%)	8 (4%)	$69,476 (0%)	5 (2%)	$27,937 (0%)
Non-Med Transp.	723 (33%)	$151,653 (1%)	80 (36%)	$252,001 (8%)		
Personal Assistance	832 (38%)	$4,547,876 (16%)	92 (41%)	$5,441,001 (17.3%)	106 (45%)	$6,088,466 (18%)
Residential Habilitation	46 (2%)	$1,571,452 (5%)	55 (2%)	$1,698,874 (5%)	5 (2%)	$1,976,308 (6%)
Specialized	5 (0%)	$42,608 (0%)	4 (0%)	$58,786 (0%)	(0%)	$0 (0%)

	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Child Care						
Attendant Care	9 (0%)	$172,283 (1%)	(0%)	$1,152 (0%)	5 (0%)	$3,848 (0%)
Meals	314 (14%)	$183,643 (1%)	37 (17%)	$282,220 (1%)	43 (18%)	$366,089 (1%)

The State Plan Personal Assistance Services (PAS) can be used by any Medicaid eligible consumers, including those who are elderly, have physical disabilities, have developmental disabilities, or have SDMI. Consumers can receive both PAS services and 1915c waiver services for any population type. PAS can be self-directed or agency-based. These services may be more used than respite care under the Big Sky Waiver because they are broader than respite. The populations receiving PAS are also more likely to have caregivers. The higher reimbursement for PAS compared to respite care may also be an incentive to agencies to provide care under PAS than through a waiver. The table below outlines total PAS expenditures and consumers for state fiscal years 2008 through 2012, although data for 2012 is not complete.

Table 9: PAS Expenditures and Consumers

	2008	2009	2010	2011	2012[22]
Expenditures	$28,777,613	$36,937,216	$45,315,539	$43,651,264	$42,452,638
Consumers	3,093	3,144	3,323	3,542	3,561

SLTC's Community Services Bureau also operates the state's Medicaid hospice program, which includes respite services. Medicare also offers respite to caregivers of consumers receiving hospice services. Medicare covers 95 percent of the cost of respite services provided in a facility for up to five sequential days. Medicare does not pay the cost of transportation to the facility or for room and board. However local hospice providers have often negotiated flat rates (generally $160/day) with skilled nursing facilities, which bundle the cost of room and board with respite services, so families only need to pay the 5 percent differential. Hospice agencies may also cover the cost of transportation for facility based hospice respite.

Child and Family Services Division

Child and Family Services Division (CFSD) provides respite services to youth in foster care. Services follow the child, rather than being associated with the caregiver, and are limited to 111 hours or $444 per child per year. In state fiscal year 2012, 346 foster children, 19 percent of the total foster population, received respite care for a total of

[22] Data for SFY 2012 is incomplete.

$67,172. Children from birth to ten years of age were the primary recipients of respite services. Many foster parents may obtain respite services through their informal networks or through trade with other foster families. CFSD funds respite services for foster children through general fund dollars, partially funded by TANF MOE funds as well as Child Abuse Prevention and Treatment Act (CAPTA) Basic State Grant funds. Foster families rely on Child Protective Services (CPS) workers to provide information about available services, including respite, in their community.

Youth in foster care assessed as having SED receive services through the Therapeutic Family Care program, which is administered jointly with CMHB. CMHB funding sources are often used to provide services to these youth and foster families.

Montana also receives limited funding through the CAPTA Community Based Child Abuse Prevention Grant. Montana's funding from this source was approximately $200,000 in 2008. In 2011, CFSD funded 15 programs serving 7,000 individuals statewide with these grant dollars. A portion of these funds can be used for respite services, often through parent education classes, child abuse prevention programs, or family resource centers. CFSD did not have combined budgets from these programs available for this report.

Addictive and Mental Disorders Division

The Addictive and Mental Disorders Division (AMDD) provides chemical dependency and mental health services. AMDD has an HCBS 1915c waiver for individuals with severe disabling mental illness (SDMI) in five geographic areas. Montana is one of only a small number of states (less than five) in the country with such a waiver. The waiver was approved in 2006 for 125 slots, and has since been expanded to 168. AMDD is hoping to receive legislative approval to further expand the waiver to 298 by the end of 2015.

Consumers receive a wide variety of services through the SDMI waiver and often also through the PAS State Plan program that function as respite. The following table lists the functional respite services provided through the HCBS 1915c SDMI waiver, their usage, and budget information for state fiscal years 2008 through 2010. Services that may function as respite only do so when a caregiver lives with the consumer, meaning only a subset of the utilization across services that may function as respite listed below actually represents caregiver respite. Respite is not a widely used service in this program. Consumers are much more apt to use specialized attendant care and homemaker services.

Table 10: HCBS 1915c Waiver for Individuals with SDMI Functional Respite Usage

	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Respite	0 (0%)	$0 (0%)	(6%)	$11,309 (0%)	(1%)	$4,503 (0%)

	2008		2009		2010	
Service	Consumers	Expenditures	Consumers	Expenditures	Consumers	Expenditures
Adult Day Health	3 (3%)	$15,590 (1%)	(4%)	$18,613 (1%)	(5%)	$12,447 (1%)
Day Habilitation	0 (0%)	$0 (0%)	(0%)	$0 (0%)	(1%)	$1,815 (0%)
Homemaker	17 (16%)	$45,080 (3%)	5 (38%)	$144,506 (6%)	5 (42%)	$112,796 (7%)
Homemaker Chore	3 (3%)	$2,175 (0%)	1 (11%)	$6,678 (0%)	(4%)	$873 (0%)
Non-Med Transp.			8 (63%)	$25,902(1%)	7 (59%)	$20,914 (1%)
Residential Habilitation	1 (1%)	$474 (0%)	(3%)	$101,868 (4%)	(3%)	$46,607 (3%)
Attendant Care	45 (43%)	$419,718 (30%)	10 (76%)	$1438,922 (18%)	8 (64%)	$291,544 (19%)
Meals	8 (7%)	$5,956 (0%)	4 (29%)	$60,877 (2%)	3 (24%)	$37,354 (2%)

Veterans Affairs

The US Department of Veterans Affairs (VA) funds in-home and facility-based respite services for Montanans. Currently, Montana's VA primarily provides respite services to older veterans' caregivers or younger veterans caring for older family members. Families can receive up to six hours of respite a day, for up to 30 calendar days annually. All families have to pay a co-pay based on income. Some families also pay privately to supplement the VA respite benefits. Of the 350 veterans using home health services, approximately 50 percent, or 170 caregivers, use respite.

Montana's VA is just beginning to implement a Veteran Directed Care Program in Missoula and Ravalli counties. It is not clear what impact this will have on respite usage, but the VA believes that it may bring additional respite providers into the system because caregivers and recipients are not always satisfied with existing provider options.

Another program through which veterans' caregivers can receive respite is the new Caregiver Support Program, established by the Veterans Omnibus Health Services Act of 2010. Nurses assess caregivers of veterans returning from the recent wars in Iraq and Afghanistan, and the VA provides a stipend based on need. Caregivers are required to take a course and be assessed quarterly for the stipend, which can be spent on caregiver services including respite. Since its establishment in July 2011, the program has grown to serve 58 caregivers in Montana. The VA received 25 referrals in the fourth quarter of 2012, which is double the amount received in the first quarter.

The VA focuses a lot of energy on educating their clients about the full range of services available to them, including respite. Social workers, doctors, and nurses in the VA's 13 statewide clinics have all received training on the benefits of respite, and work closely

with family caregivers to ensure they are aware of the positive impact respite could have for them and their care recipients.

Tribal Entities

Indian Health Services and Tribal health departments throughout Montana also provide respite services to tribal members through a variety of funding sources. Some tribal entities provide respite services to tribal members using Title III-E funds from AAAs, which are sometimes matched by tribal funds. In addition, some tribal entities use Title VI-C Older Americans Act funding for American Indian caregiver grants. Tribes apply for Title VI-C caregiver grants every three years.

Local Respite Resources

Communities throughout the state have found creative ways to help meet local demand for respite services.

- **Foundations** – Some communities are fortunate to have local foundations or corporations financially supporting respite services. The Gilhousen Family Foundation in Bozeman and the Hampton Collins Memorial Foundation in Great Falls support respite service provision in their regions.
- **Donations** – The Bozeman Senior Center is able to provide limited in-home respite services for $3 an hour because of a generous donation earmarked for respite.
- **Respite houses** – The Comprehensive Development Center in Missoula developed respite houses in Kalispell and Missoula, which accept a variety of funding sources in exchange for their services. The Kalispell house is closing because of funding challenges. Another community uses the Margaret Stuart Youth Home as a respite placement for youth in need of overnight care. Youth receive supervision, structure and support while they work with their families to return home. Another provider can use a dedicated bed in a group home as a temporary crisis/respite bed when needed.
- **Fundraising** – DEAP holds an annual fundraiser with local community leaders serving dinner to attendees. Funds raised through this event supplement respite funding for consumers' caregivers who do not receive Medicaid waiver or other benefits.
- **Volunteers** – Some communities use Court Appointed Special Advocates (CASAs) to provide volunteer respite care to foster families.

5. National Best Practices

States began seeking ways to offer respite services to unserved and underserved families by implementing State Lifespan Respite programs. Oregon was the first state to support a lifespan respite program, beginning in 1997. Oregon's and other State Lifespan Respite programs' successes paved the way for the passage of the federal Lifespan Respite Care Act (LRCA) of 2006. The LRCA authorized states to receive competitive awards to:

1. Expand and enhance respite care services to family caregivers.
2. Improve statewide dissemination and coordination of respite care.
3. Provide, supplement, or improve access and quality of respite care services to family caregivers.

The Administration on Aging (AoA) has been implementing the LRCA program through state grants since 2009. Currently, there are 30 LRCA grantees funded by the AoA.

Table 11: Lifespan Respite Care Act State Grantees

2009 Grantees		
Alabama	Illinois	Rhode Island
Arizona	Nevada	South Carolina
Connecticut	New Hampshire	Tennessee
District of Columbia	North Carolina	Texas
2010 Grantees		
Delaware	Minnesota	Pennsylvania
Kansas	Nebraska	Utah
Louisiana	New York	Washington
Massachusetts	Oklahoma	Wisconsin
2011 Grantees		
Colorado	Montana	Ohio
Hawaii	New Jersey	Virginia

States are using several effective approaches to connect family caregivers of children and adults of all ages with special needs to respite services. This section focuses on self-direction of respite services through voucher programs and effective means for developing localized approaches to meet respite needs. These approaches may shed some insight for Montana on how to approach its funding and provider capacity limitations. Best practices highlighted in this section are primarily derived from the states with which we spoke directly for this report – specifically Alabama and Oklahoma. These best practices do not represent the full range of lifespan respite program best practices. They are highlighted because of their relationship to the gaps identified through this analysis.

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Respite Vouchers Supporting Self-Direction

Vouchers are one approach states are employing to provide respite services to individuals not eligible for existing respite funding and expand provider choice. By their nature, vouchers limit a state's liability because caregivers are responsible for all aspects of provider hiring and management. Vouchers are the means many states use to implement self-direction for caregivers over respite services. Organizations administering voucher programs charge an administrative fee generally between ten and 15 percent.

Oklahoma provides Title III-E vouchers in addition to Lifespan Respite Grant vouchers, for those not eligible under Title III-E. The Aging Services Division reviews caregiver respite voucher applications forwarded from the Oklahoma Areawide Services Information System (OASIS), and assigns applicants to one of the two voucher programs. The lifespan respite voucher program ensures individuals with families earning less than $60,000 annually can receive vouchers regardless of age or categorical need.

Alabama also uses respite vouchers, which are managed through the Alabama Respite program run by the United Cerebral Palsy organization. Their statewide respite vouchers are funded through two sources requiring caregivers' care recipients to fall into categorical eligibility groups – children with disabilities and individuals of all ages with intellectual disabilities. The Department of Child Abuse and Neglect Prevention funds the first, and the Department of Mental Health funds the latter. Both Departments require proof of age and disability to receive vouchers. Some counties also have additional monies, including private donations, corporate grants, and community foundations, allowing them to serve a broader population through their voucher programs.

Developing Local Respite Solutions

Because services are provided at the local level, states and respite programs have been looking to localities to come up with creative approaches to providing respite services. Alabama does this through their Sharing the Care Program, which brings together local organizations to collaboratively develop respite resources and address funding needs unique to that community. Sharing the Care is active in ten Alabama communities. One community is using local nursing school students as volunteers to provide respite care. Another community serves hundreds of children using community volunteers managed through a local church program. Volunteer mobilization generates additional provider capacity with limited budgetary impact, but does create liability concerns for the Alabama Respite program.

Oklahoma uses a portion of its LRCA funds to provide seed funds to organizations developing innovative respite programs. Oklahoma selected nine projects through two

separate requests for proposal processes. Each project is funded up to $5,000. Examples of projects include a faith-based group setting up a care center for what they call a “Special Angels Ministry” to assist parents to care for children with special needs, family night out events, or a day camp for children with disabilities.

Oklahoma is also trying to implement a Mobile Respite Project through a competitive procurement process. This project will provide respite care in non-traditional locations using a bus and a mobile respite team.

6. Gaps in Montana's Respite System

While respite services are available in Montana through a wide variety of funding sources at the federal, state, and local level, there is a consistent feeling from state program agencies, advocates, caregivers, and providers that it's not enough. Families who have figured out how to navigate the maze of bureaucratic eligibility requirements and are connected to HCBS waiver or State Plan program funded services represent only a small percentage of the overall need. The families who are caring for their loved ones who are on waiting lists for waiver services, who have too much income or resources, who are too young or too old, who do not meet medical criteria, or fail to qualify for services for some other reason are left without support unless they have the means to pay for it on their own.

According to advocacy groups, local service delivery agencies, caregivers, providers, and state agencies, unmet respite needs exist across the consumer population and age spectrum. For example, caregivers of Medicare clients who do not qualify for Medicaid and do not need hospice services have limited options for respite besides private pay and local charitable agencies. This includes a large population of individuals with Alzheimer's, dementia, or other illnesses that require intensive caregiving to remain safely and successfully in the community and out of institutions. Caregivers for children and youth with special medical needs or developmental disabilities, not receiving Medicaid services, often struggle to afford respite services. Families of these children spend significant money on medical care for these children, and often have to travel far to receive it. Their need for respite is great, but their financial ability to private pay may be very limited.

Four primary gaps exist in Montana's respite care system, which inhibit caregivers from accessing adequate respite care:

1. Organization
2. Funding
3. Provider Availability and Training
4. Knowledge

The following table discusses each of these gaps in more detail.

Table 12: Gaps in Montana's Respite Care System

Organization	Montana does not have a statewide lifespan respite program or infrastructure. This means no one agency or network of regional organizations is focused on seeking out funding for the service, working with communities to define local strengths and creative approaches to meeting respite needs, or looking to other communities in Montana and elsewhere to learn from their successes and failures. Montana's disparate approach to providing respite is related to the other gaps in the

	respite system.
Funding	The caregiver survey identified funding as the primary gap inhibiting access to respite services. Very few people statewide are able to access respite via federal or state funded programs. In home respite care with a skilled aid generally costs $17 to $25 an hour. Respite in a skilled nursing facility is approximately $10 to $12 hourly, plus the cost of room and board. This is out of reach for many families needing services. The siloed nature of program funding make it challenging to support a lifespan respite model. There is limited funding available to support services outside of categorical and financial eligibility requirements. Programs, often with waiting lists, struggling to provide adequate services to their consumers may be unable or wary to contribute financially to a cross-agency, lifespan respite program.
Provider Availability or Training	Caregivers struggle to access appropriate, trained providers. This is particularly challenging in rural and frontier areas where there are fewer providers and larger distances separating individuals. The caregiver survey demonstrated the unmet need for respite care during evenings, weekends, and holidays. Family caregivers also face difficulties in finding respite providers with whom they feel comfortable leaving their family members. The discomfort may result from limited training in the care recipient's specific needs or lack of familiarity with the care recipient and family. Caregivers and consumers self-directing their services have had more success in securing providers because they are able to bring new providers from their natural support network into their system of care, increasing overall provider capacity. Less than ten percent of individuals with developmental disabilities receiving HCBS waiver services self-direct services at this point. Agencies will hire family members as respite providers for those not self-directing care. However, this approach can present challenges for agencies in terms of liability and for families in terms of managing their loved one as providers. Montana has limited volunteer-based respite initiatives through civic and religious organizations. Communities using these approaches are able to increase their supply of respite providers, but this tactic is not widespread.
Knowledge	Many caregivers and consumers do not know what respite is or what respite services are available in their communities. Caregivers needing a break may have limited health literacy and not know the terminology to ask for help. Respite services are not advertised through public service announcements. Caregivers who are familiar with the term may be reticent to ask for help.

	Even when a caregiver or consumer connects with a local service provider, there is a likelihood that this organization will struggle to identify the full range of available respite services. There is no centralized resource listing respite options across consumer groups in Montana communities.

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7. Next Steps

DPHHS and DEAP are collaboratively working to implement a lifespan respite program in Montana. The gaps identified in this report will help focus this work on areas of particular need. Lifespan respite efforts can focus on the following areas to positively impact the availability of quality respite services for caregivers statewide.

1. **Continue to include caregivers, consumers, providers, and community organizations in the lifespan respite project** – DEAP and DPHHS have been working with these groups to identify respite services and gaps for this environmental scan and in the Statewide Coalition. This collaboration should continue to ensure the solutions developed represent the needs throughout the state.

2. **Create state level lifespan respite support structure** – there was widespread agreement from interviewees that the only way to ensure lifespan respite receives adequate attention to thrive as a model in Montana is to have someone at the state level focusing on this work with support from senior leadership. Increased structure may support improved collaboration across funding streams. State level leadership could support, sustain, and grow coalition membership involvement. A state leader in conjunction with the Lifespan Respite Coalition and the ADRCs could jointly define the program infrastructure, define roles and responsibilities, create and implement a strategic plan, and help the model thrive.

3. **Increase provider capacity** – Montana needs to invest in respite providers through accessible, affordable, and widespread training. Additionally, the state should consider increasing the use of self-directed services or agency-based use of family members to attract new providers through caregivers' and consumers' natural support networks. As a frontier state, Montana is suffering from a caregiver gap that will continue to grow. The provider pool must grow to create adequate capacity. HCBS and State Plan programs should revisit self-direct requirements and ensure consumers and families can easily self-direct care if they so desire.

4. **Provide respite to additional caregivers** – the state should consider using a voucher or stipend program to reach caregivers not receiving Medicaid benefits. A voucher or stipend approach would further increase caregiver choice and decrease administrative costs. These methods could help address the shortage of respite providers available in the evenings, weekends, holidays, and for longer timeframes.

5. **Seek out additional respite funding sources** – there are additional funding sources available to support respite service provision, particularly federal grant opportunities. Having an individual focused on respite services, in collaboration with the Lifespan Respite Coalition and ADRCs, could help ensure the state pursues these opportunities. Currently they may be lost with competing priorities in more broadly

focused bureaus and divisions. The lifespan respite program can use materials created by ARCH that outline all of the possible respite funding sources as guides in this effort.

6. **Promote volunteer-based initiatives at the local level** – A lifespan respite program could promote creative approaches to respite service provision in communities statewide through seed grants, education, and training. The state could tie respite volunteerism with programs already managing volunteers such as RSVP to take advantage of the existing infrastructure.

7. **Educate the public about respite services** – caregivers need to know what respite is and how to access it before they reach a crisis point. Marketing and outreach materials must be written in a culturally competent way to ensure individuals not familiar with long term services and supports can understand the messaging. Education and outreach can be accomplished partially through increased coordination with and education of providers and organizations with which caregivers interact. This could include discharge planners at hospitals, doctors nurses, county health departments, long term care facilities, Offices of Public Assistance, Montana State health clinics, Best Beginnings, the Commissioner of Securities and Insurance's Medical Homes Project, and other public health initiatives. If there is a widespread understanding of the benefits associated with respite, these providers and organizations can help educate the public. The lifespan respite coalition could create and implement a communication plan to guide this effort.

8. **Promote sliding fee scale or cost sharing respite services** – a lifespan respite program could promote additional respite services availability through a sliding fee scale or cost sharing. These approaches can generate income for programs by charging individuals with higher incomes more, allowing the funding available to support a larger number of individuals needing respite. AAAs are permitted to implement cost-sharing in Montana. This approach can also be used more broadly.

9. **Create publicly available respite database** – the lifespan respite grant specifically outlines this as a goal. Environmental scan participants universally identified the need to map resources for each community and have this information in a centralized, online location for caregivers and local provider agencies. The results of the DEAP provider survey will help define this information in conjunction with the lifespan respite coalition. The ADRCs may be able to maintain the database in collaboration with the resource and referral database project currently underway.

8. Appendices

The following sections contain additional information supplementing the lifespan respite environmental scan.

8.1 Functional Respite Services

This table below outlines services associated with HCBS 1915c waivers and 1915i State Plan programs in Montana that function as respite services. These functional respite services have to be considered in context, meaning if an individual lives independently without a caregiver, the services are not respite. This variable makes it challenging to measure when these services function as respite.

Table 13: HCBS 1915c Waiver and 1915i State Plan Program Functional Respite Services

Program	Functional Respite Service Definition
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Adult Companion** services consist of non-medical care, supervision and socialization, provided to a functionally impaired individual. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks, which are incidental to the care and supervision of the individual.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Adult Day Health** provides a broad range of health, nutritional, recreational, and social services in settings outside the person's place of residence in an outpatient setting, and includes transportation to the adult day health provider.
HCBS 1915c Children's Autism Waiver	**Children's Autism Training** is a direct training service designed to assist the child in acquiring, retaining and generalizing the self-help, socialization, cognitive, communication, organizational skills and the positive behaviors necessary to function successfully in home and community settings. The staff person will provide hands on training using evidence based Applied Behavior Analysis practices and methods. Training goals will be outcome based and progress toward goals will be evidenced by training data. Children's Autism Training seeks to develop skills in the following areas, including, but not limited to:

Program	Functional Respite Service Definition
	1) Social skills, and related skills to enhance participation across all environments (school, home and community settings) and relationships, including but not limited to imitation, initiation of social interactions with adults and peers, reciprocal exchanges, parallel and interactive play with peers and siblings; 2) A functional communication system which may include expressive verbal language, receptive language and nonverbal communication skills and augmentative communication; 3) Increased engagement and flexibility in the exhibition of developmentally appropriate behaviors, including, but not limited to, play behavior, attending behavior, responding to environmental cues (including cues from the training staff and others) and cooperation with instructions; 4) Replacement of inappropriate behaviors with more conventional and functional behaviors; 5) Working with caregivers and others in the environment to promote the child's competence and positive behavior; 6) Fine and gross motor skills used for age appropriate functional activities, as needed; 7) Cognitive skills relating to play activity and academic skills; 8) Adaptive behavior and self-care skills to enable the child to be more independent, and/or; 9) Independent exhibition of organizational skills including, but not limited to, initiating and completing a task independently, asking for help, giving instructions to peers and following instructions from peers, following routines, self-monitoring and sequencing behavior. The training effort will occur where the child lives, attends childcare and/or socializes with peers.
HCBS 1915c Big Sky Waiver, Bonanza Option	**Community Supports** services include assisting the consumer with: • Basic living skills such as eating, drinking, toileting, personal hygiene, dressing, transferring and other activities of daily living • Improving and maintaining mobility and physical functioning

Program	Functional Respite Service Definition
	• Maintaining health and personal safety • Carrying out household chores and preparation with meals and snacks • Accessing and using transportation (with providers possessing a valid Montana driver's license) • Participating in community experiences and activities • Relieving unpaid caregivers at those times when such relief is in the best interest of the consumer or caregiver • Receiving day care for medically fragile children who, because of their disability, cannot be served in traditional child care settings
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Day Habilitation** services focus on enabling individuals to attain their maximum functional level. Day Habilitation includes assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills, which takes place in a non-residential setting, separate from the home or facility in which the consumer resides. Services are normally provided four or more hours per day on a regularly scheduled basis, for one or more days per week.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Day Habilitation** services are designed to assist individuals in acquiring, retaining, and improving self-help, socialization, and adaptive skills necessary to reside successful in home and community based settings. These services are provided in day programs/settings.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Health and Wellness** offers consumers opportunities to engage in recreational, health promoting and wellness activities within their community. The service includes: • Classes on weight loss, smoking cessation, and healthy lifestyles such as "Living Well with a Disability" offered by Centers for Independent Living • Health club memberships • Art therapy • Costs associated with adaptive recreation activities such as skiing, horseback riding, and swimming

Program	Functional Respite Service Definition
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Homemaker** services consist of general household activities provided to consumers unable to manage their own home or when the individual normally responsible for homemaking is absent. Homemaker services do not include personal care services available under State Plan Medicaid.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Homemaker** services consist of general household activities provided by a homemaker when the person regularly responsible for these activities is unable to manage the home and care for himself/herself or others in the home, or is engaged in providing habilitation and support services to the individual with disabilities. Services include meal preparation, cleaning, simple household repairs, laundry, shopping for food and supplies, and routine household care.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Homemaker Chore** services are provided to consumers unable to manage their own home or when the consumer normally responsible for homemaking is absent. Homemaker Chore activities includes cleaning a home requiring extensive cleanup beyond the scope of general household cleaning available under the Homemaker service; such as heavy cleaning (e.g., washing windows or walls); yard care; walkway maintenance; minor home repairs; wood chopping and stacking.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Meals (Nutrition)** service provides hot or other appropriate meals once or twice a day, up to seven days a week.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Non-medical Transportation** are transportation means travel furnished by common carrier or private vehicle for non-medical reasons as defined in the individual service plan. Transportation Services must meet the following criteria: Be provided only after volunteer, state plan or other publicly funded transportation programs have been exhausted or determined to be inappropriate; and be provided by the most cost effective mode.

Program	Functional Respite Service Definition
• Medicaid State Plan • HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Personal Assistance** services may include supervision for health and safety reasons, socialization, escort and transportation for non-medical reasons, or an extension of State Plan personal assistance services. Since the provision of personal assistance by legally responsible individuals is not available under the State Plan, individuals may use this service for assistance with activities of daily living (ADLs) by legally responsible individuals.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Personal Care** services include: 1) Assistance with personal hygiene, dressing, eating and ambulatory needs of the individual. 2) Performance of household tasks incidental to the person's health care needs or otherwise necessary to contribute to maintaining the individual at home. 3) Supervision for health and safety reasons.
• HCBS 1915c Comprehensive Waiver for individuals with developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Personal Supports** are only available to participants who self-direct some or all of their services with employer authority. The personal supports worker is hired by and the employee of the participant or the participant's representative. The personal supports worker assists the participant in carrying out daily living tasks and other activities essential for living in the community, including assistance with homemaking, personal care, general supervision, and community integration.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Residential Habilitation** is provided in an Adult Foster Home (AFH), Group Home, Assisted Living Facility (ALF) or Residential Hospice. Residential habilitation is a bundled service that may include personal assistance supports or habilitation to meet the specific needs of each resident; homemaker services; medication oversight; social activities; personal care; recreational activities, transportation; medical escort; and 24-hour on-site awake staff to meet the needs of the residents and provide supervision for safety and security.
• HCBS 1915c Comprehensive Waiver for individuals with	**Residential Habilitation** services are designed to assist individuals in acquiring, retaining, and improving self-help, socialization, and adaptive skills necessary to reside

Program	Functional Respite Service Definition
developmental disabilities • HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	successfully in home and community based settings. Habilitation is provided to an individual wherever she/he may live.
HCBS 1915c Big Sky Waiver	**Senior Companion** services are directed at providing companionship and assistance. The service includes respite, socialization, supervision, and homemaking.
HCBS 1915c Community Supports Waiver for individuals with developmental disabilities	**Social, Leisure, and Recreational Supports** are designed to address needs related to personal growth and development, community integration, formation of friendships, relationships and social skills and to enhance the quality of life of the individual. These supports often serve to provide primary care givers limited relief from the responsibilities of care giving and supervision.
HCBS 1915c Big Sky Waiver	**Specialized Child Care for Medically Fragile Children** provides day care for medically fragile children who, because of their disability, cannot be served in traditional childcare settings.
• HCBS 1915c Big Sky Waiver • HCBS 1915c Waiver for individuals with SDMI	**Specially Trained Attendant Care** provides a higher reimbursement rate than personal assistance – have specialized training and can work with person on mental health (use peer support specialist with 40 hours of training).

In addition to the services listed above, Medicaid State Plan Personal Assistance Services (PAS) may also function as respite. Services available through Montana's PAS program include assistance with activities of daily living such as bathing, dressing, grooming, toileting, eating, medication assistance, ambulation, and exercising.

Meals on wheels, provided through the ten regional AAAs, also may function as respite services for family caregivers.

8.2 Caregiver Survey

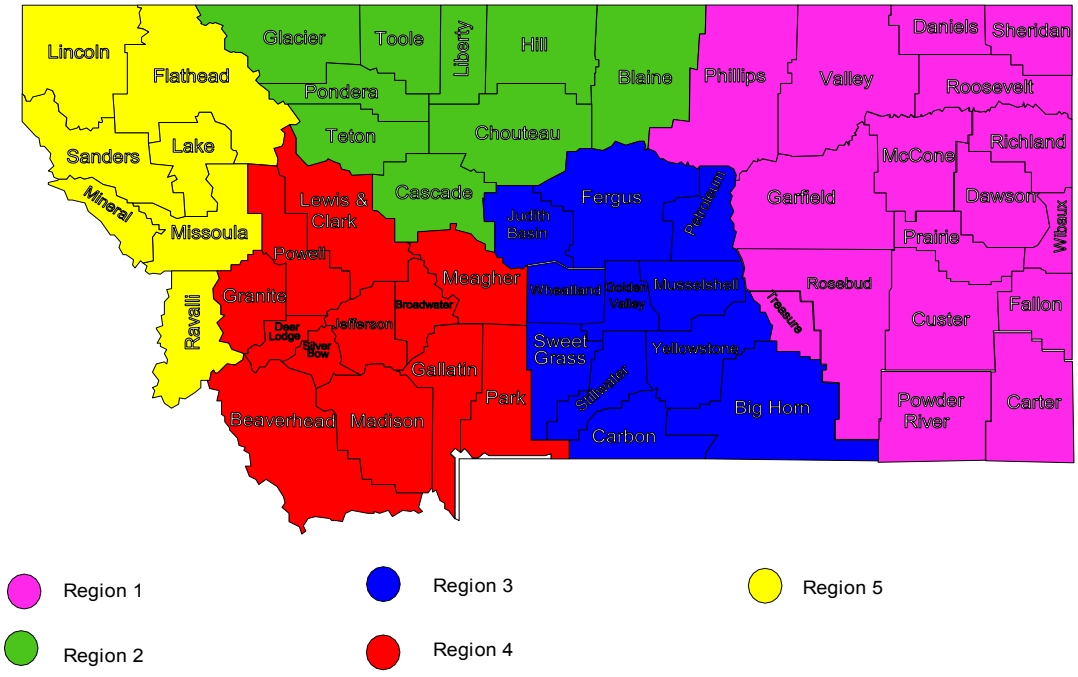
DEAP surveyed respite caregivers in spring 2012. This appendix includes an analysis of the survey results.

Caregivers responded statewide, yet the majority of respondents were from Region 5, which is western Montana.

Table 14: Caregiver Survey Responses by Region

Region 1	26
Region 2	8
Region 3	18
Region 4	21
Region 5	44

Figure 1: Lifespan Respite Regions



Respondents were most often caregivers for individuals with developmental disabilities, making up over 20 percent of respondents. Many care recipients do not fall neatly within one consumer category. Approximately 55 percent of respondents identified their loved ones as falling within multiple categories of need.

Figure 2: Consumer Populations Represented by Caregiver Respondents

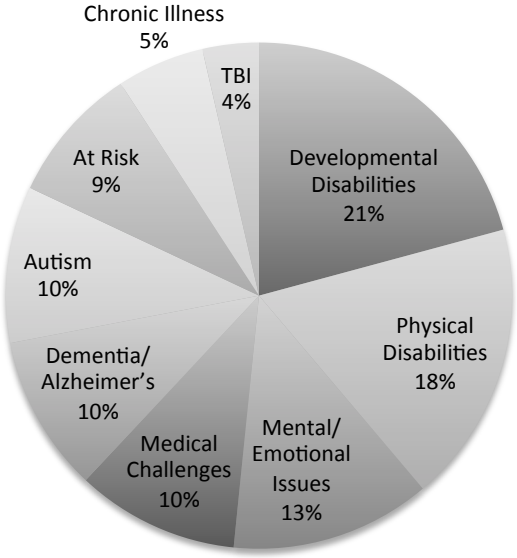
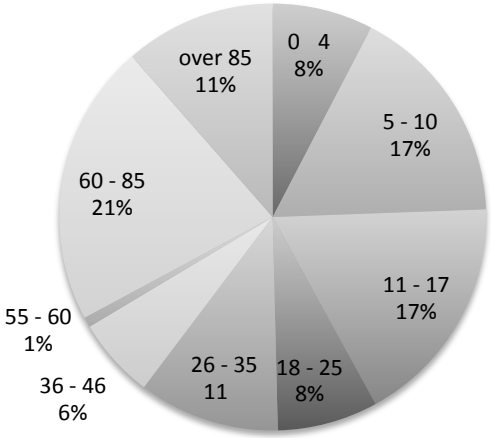
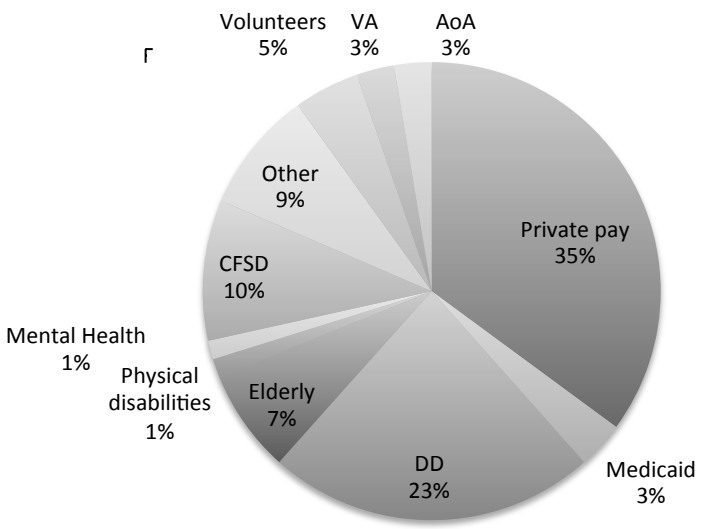


Figure 3: Consumer Ages Represented by Caregiver Respondents



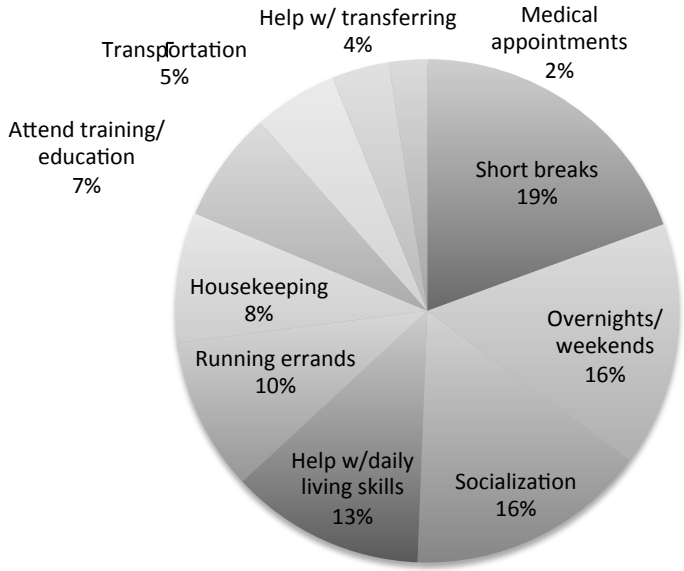
About one third of the respondents pay privately for respite care. Approximately 16 percent of respondents privately paying also had other payment sources, which they supplemented with private pay. About one third of total respondents had various sources of Medicaid paying for respite care, most notably HCBS 1915c waivers for individuals with developmental disabilities and the HCBS 1915c waiver for individuals who are elderly or have physical disabilities.

Figure 4: Respite Payment Source



Caregivers would like to use respite services for a variety of reasons. The same caregiver often cited the top three reasons.

Figure 5: How Caregivers Would Use Respite Services



Caregivers cited various barriers to receiving respite services, many citing multiple barriers.

Table 15: Barriers to Accessing Respite

Barrier to Accessing Respite	# Respondents (%)
Financial	54 (22%)
Shortage of providers	50 (20%)
Providers not available when needed	33 (14%)
Concerned about quality	33 (14%)
Don't trust anyone	25 (10%)
Traveling distance	12 (5%)
On a waiting list	10 (4%)
Too overwhelmed to seek help	10 (4%)
Respite not offered	7 (3%)
Don't know where to go	5 (2%)
Don't know what it is	4 (2%)

Financial issues, the most significant barrier, were evenly divided between ages 0 – 50 and ages 50 and up.

Provider capacity issues are represented in a number of responses, including provider shortage, providers not available when needed, traveling distance, and respite not offered. In sum, these represent approximately 100 (47 percent) responses. Provider shortage was more noted by caregivers in western Montana, with 54 percent of caregivers in the western portion of the state citing provider shortages compared to approximately 27 percent in eastern Montana.

Caregivers listed other supports used beyond formal respite services. Approximately 50 percent rely on their natural support networks of friends, family, church and civic organizations, and support groups.

Table 16: Other Caregiver Supports

Other Caregiver Supports Used	# Respondents (%)
Family	85 (25%)
Friends and neighbors	54 (16%)
Other agency or organization	37 (11%)
Home health/personal care	25 (7%)
Area Agency on Aging	24 (7%)
Church or civic group	20 (6%)
Support groups	20 (6%)
Habilitation aide	18 (5%)
Caregiver training	14 (4%)
Meals on wheels	13 (4%)

Other Caregiver Supports Used	# Respondents (%)
Mental health	13 (4%)
Caregiver education	11 (3%)
Specialized nursing	5 (2%)

8.3 Provider Survey

DEAP surveyed Montana respite providers in September 2012. As of October 30, 2012, DEAP received 25 responses. Responses were received from providers throughout the state in rural and urban areas. Large and small providers are represented in the responses.

When asked about the strengths of respite services, providers cited their training, reliability, and dedication. Some also noted flexible hours/days in which services are available, including overnight options.

Strengths of Respite Services
• Provide trained and experienced caregivers that have had background checks • We have the required training. • Staff training, background checks, availability. • We provide well-trained, truly dedicated caregivers to provide the respite that families often need. All of our caregivers have a lot of personal and professional experience but most importantly they have a love for seniors. • Available in a few areas, compassion displayed. • We are reliable. • We have very knowledgeable and caring people. • We use the Margaret Stuart Youth Home as a respite placement for youth in need of overnight care. We have solid programming set up in this home to take in youth as respite, shelter or group home placements. Youth receive supervision, structure and support while they work with their families to return home. • We offer 20 hours per month of discounted services to those that qualify. We use a sliding scale model so consumers contribute to the program. We have a bottom base hourly rate of $5.00 per hour. We also provide support group and Powerful Tools for Caregivers, Medicare/Medicaid counseling as well as Caregiver consultations. • CASA volunteers know the child or children and the children are comfortable with having a CASA volunteer to take care of them or help with their needs. • We have a dedicated bed in a group home that is a temporary crisis/respite bed that can be utilized if there is a bed. We have extra staff hired to provide the service within the home. We can provide respite to rural elders and their caregivers. We provide trained respite workers (they receive 16 hours of PCA training before they begin work). We provide training for caregivers and grandparent raising grandchildren. We provide support groups and network of community resource providers. • Trained staff, private quarters, home environment, and 24-hour care available. Varied hours available, services provided seven days/week. • The patients do not have to pay anything for my services. It is included in the passport program. I can go to their home or meet them at my office or another neutral setting. The choice is left up to the patient. It is very patient driven and

Strengths of Respite Services
oriented towards success.

When asked about weaknesses, providers discussed limited funding, challenges associated with providing care in remote areas, limited provider availability, and limited ability to respond to emergent needs without sufficient notice. Many providers discussed limitations in more than one area, particularly how limited funding/ reimbursement creates challenges in attracting enough providers to meet the demand for respite services.

Figure 6: Weaknesses in Respite Services

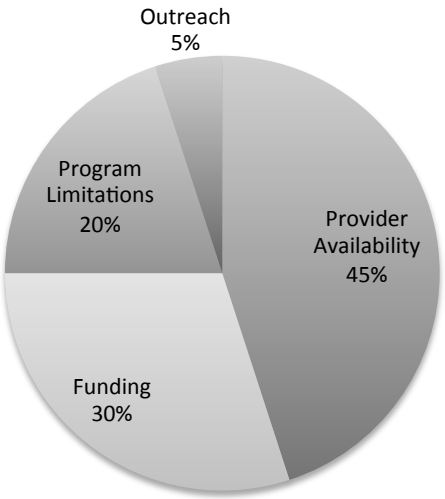


Table 17: Weaknesses in Respite Services

Provider Availability	• Not enough caregivers. • Finding workers. • Lack of on-site nursing, availability of trained staff, difficulty to staff drop-in or short notice respite. • There is a greater need for companion services than we have volunteer staff for. • Some CASA volunteers are unable to help with respite. • I would like to have more responsible, accountable quality providers. • Limited availability – staff and area. We do not provide service, only authorize and approve • We often have a waiting list for respite care. We have very limited ability to provide partial day respite care for youth. • Our respite program can be difficult to provide in our more remote areas without advanced planning.
Funding	• The pay we can offer is generally too low to attract workers. Respite

	reimbursement from other sources is less than it was in the past. • The state rate very low. • Only funded through one program in our agency. • Funding. • Funding, not provided equally to all with needs. • Lack of adequate reimbursement.
Program Limitations	• Hard to supervise and the waiver definition is weak. • I would like to be able to offer more hours especially to people providing end of life care that are struggling to provide care and work and take care of their own home and responsibilities. • Can only provide services to one person at a time. • It is not a mandatory program so the patients that are in the most need do not have to participate.
Outreach	• We are not known well enough in the community yet.

When asked about barriers, responses generally reflected the weaknesses listed above. Fifty-seven percent of respondents cited funding as a barrier, 21 percent discussed provider availability, seven percent discussed program limitations, and the remainder listed other barriers such as cultural barriers, and limited awareness of the services.

Providers universally cited eligibility related issues as the primary gap in connecting caregivers with respite services. Often these eligibility concerns relate to Medicaid, since this is the primary funding source for respite services.

Gaps in Service
• Some have mental health issues, which we don't cover. Some have physical or developmental disabilities but don't meet eligibility criteria. • They don't meet the eligibility requirements of QLC's contract with the DD program. • They are Medicaid ineligible, do not meet level of care criteria or services are not available in area of residence. • We have had people that are not 60 years old so they're not eligible for COA money. Most people do not like to private pay even though it is relatively inexpensive and they would benefit from help. • Lack of funds to pay for services, not Medicaid eligible • Too high of income or under age. • Not full Medicaid. • Yes, in the form of custody hearings. • Diagnosis must include developmental disabilities. • Not deemed eligible or on the waiting list for the state. • Often this is a funding issue. Occasionally, we find that for one reason or another program criteria cannot be met by the consumer in need of services. • With the funding we receive from AoA Title VI Part C, we can provide services to

Gaps in Service
enrolled member only. Tribal enrolled caregiver or tribal enrolled elder. Also with limited funding we can only provide services to about 12 people a year. We have many others needing respite but don't have the funding. • Too high functioning. • Some are out of service area, some are in need but don't meet eligibility requirements. • I have been asked to give services for people who have no PD funding. • Mental health families, older DD kids. • Require too much care (e.g. require 2 staff to transfer or require nursing). Rate does not pay to have 1:1 or 2:1 staffing for respite. • Particularly patients that come into the community health center but do not have Medicaid. • We accept private pay/long-term care insurance payment but not Medicaid. If they cannot private pay, we cannot serve them.

When asked about their knowledge of the lifespan respite, the majority, 58 percent, of providers knew little or nothing of the model. Twenty-six percent of providers knew something of the model. The remaining 16 percent were familiar with the model. Seventy-one percent are interested in implementing lifespan respite; 21 percent are not.

8.4 Interviewee List

The following stakeholders were interviewed in August and September 2012.

Table 18: Interviewee List

Name	Program
Kerrie Reidelbach	Senior Long Term Care Division, Aging Bureau
Robin Homan	Senior Long Term Care Division, Community Services Bureau
Kimme Evermann	Senior Long Term Care Division, Aging Bureau
Jane Wilson	Addictive and Mental Disorders Division
Joli Schroader	Disability Services Division, Developmental Disabilities Program
Erica Swanson	Disability Services Division, Developmental Disabilities Program
Jane Bernard	Disability Services Division, Children's Mental Health Bureau
Laura Taffs	Disability Services Division, Children's Mental Health Bureau
Jackie Stoeckel	Child and Family Services Division
Kevin Higgins	Child and Family Services Division
Robin Suzor	Child and Family Services Division
Denise Brunett	Public Health and Safety Division, Family/Community Health Bureau
Denise Higgins	Public Health and Safety Division, Family/Community Health Bureau
Roger Holt	Parents Let's Unite for Kids
Kathy Wise	Rocky Mountain Hospice
Sheila Thompson	Opportunity Resources Inc.
Mike Mayer	Summit Independent Living
Mike Giddings	Summit Independent Living
Jude Monson	Summit Independent Living
Sandy Bailey	Montana State University Extension Services
Laura Booth	Billings Aging and Disability Resource Center
Kelli Jacobson-Wheat	Montana Veterans Affairs
Alex Bailey	Montana Veterans Affairs
Java Bennett	Alabama Respite
Bonnie Kolar	Oklahoma Department of Human Services
Karen Iovino	New York State Office for the Aging
Joan Grauman	STEP (retired)
Carmon Marceau	Blackfeet Heart Butte Senior Center
Kerrie Bear Chief	Blackfeet New Eagle Shields Senior Center
Barb Plouffe	Confederated Salish-Kootenai Tribe Health Services