Caregiver Survey Results Summary

Objective 2; Task 5 of the Work plan:

Survey caregivers to gather information on target populations served, their demand for respite and unmet respite needs; and other caregiver support services (such as caregiver support groups or caregiver education and training programs)

The answers to survey questions were multiple choice so responses are not unduplicated.

Responses Received:

1. Populations

   Developmental Disabilities 52  
   Physical Disabilities 45  
   Mental/Emotional Issues 32  
   Medical Challenges 26  
   Dementia/Alzheimer’s 25  
   Autism 25  
   At Risk 22  
   Chronic Illness 14  
   TBI 9

   Individuals may be listed in more than one population or be dually diagnosed.

2. Would use Respite for:

   Short Breaks 79  
   Overnights/Weekends 64  
   Socialization 63  
   Help w/daily living skills 51  
   Running Errands 40  
   Housekeeping 34  
   To attend training/education 29  
   For transportation 22  
   Help w/transferring 15  
   Medical appointments 10

   Many caregivers would like to use respite in a variety of ways, the top three together often needed by the same caregiver.

Barriers to Receiving Respite

1. Financial 54  
2. Shortage of Providers 50  
   Providers not available when needed 33  
   Concerned about quality 33  
   Don’t trust anyone 25
Traveling distance 12
On a waiting list 10
Too overwhelmed to seek help 10
Respite not offered 7
Don’t know where to go 5
Don’t know what it is 4

Caregivers may have faced more than one barrier in accessing respite.

1 Financial issues were evenly divided between ages 0 – 50 and ages 50 and up. When divided between the Eastern and Western sides of the state it was quite different with 42 caregivers from the Western side of the state feeling like finances were an issue compared to only 15 caregivers from the Eastern side of the state.

2 Approximately 27% of the caregivers in the Eastern side of Montana list shortage of providers as a barrier compared to 54% of the caregivers in the Western side of Montana.

3 Other Caregiver Supports Used

Family 85
Friends & Neighbors 54
Other Agency or Organization 37
Home Health/Personal Care 25
Agency on Aging 24
Church or Civic Group 20
Support Groups 20
Habilitation Aide 18
Caregiver Training 14
Meals on Wheels 13
Mental Health 13
Caregiver Education 11
Specialized Nursing 5

3 Over 50% of the caregivers choosing “Other Agency or Organization” listed the agency that provides them respite, but not everyone listed their respite providing agency in the “Other” category reducing the number of other agencies used.

4 Funding Source for Respite

Self-pay 41
Developmental Disabilities 34
Other 22 (includes Medicaid(5) and VA(2))
Child & Family Services 15
Elderly Funding 15
Family/Private Pay 13
Volunteers 7
Physical Disabilities 3
Addictive/Mental Health 2
Twenty-two of the forty-one caregivers responding with “Self pay” are over 60 years of age. The remaining nineteen are distributed among the other age groups under 60.

**Additional Information: Number of surveys received per Region:**

<table>
<thead>
<tr>
<th>Region</th>
<th>Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 5</td>
<td>44</td>
</tr>
<tr>
<td>Region 1</td>
<td>26</td>
</tr>
<tr>
<td>Region 4</td>
<td>21</td>
</tr>
<tr>
<td>Region 3</td>
<td>18</td>
</tr>
<tr>
<td>Region 2</td>
<td>8</td>
</tr>
</tbody>
</table>

The survey did not ask for city so in many cases the postmark or phone prefix was used to determine Region. The number of surveys from each region however is unduplicated.

In summarizing, these are the survey responses that stand out:

- Funding and shortage of providers seem to be the most widespread issues for Montana caregivers
- Needs that are not being adequately addressed are overnight, weekend and extended stays
- Adults between the ages of 25 and 60 seem to have less available resources than any other age group
- Caregivers overall are concerned about the quality, reliability and integrity of respite providers in general