

**Bristlecone Foundation**  
**Respite Overview – Services and Needs in Summit County**  
**October 2, 2015**

**Background**

Summit County has a 30 years history of fragmented respite care. In 2013, to begin to address this concern, the Summit County Respite Coalition (SCRC) was formed via a partnership of families and Early Intervention Colorado. SCRC joined the statewide Colorado Respite Coalition and attended several statewide meetings during 2013-2014. A community roundtable, attended by County Commissioners and Town of Dillon Mayor and Manger was held in July 2014 to advocate for respite. The purpose of SCRC is to address the lack of and need for accessible, affordable, and sustainable respite care in Summit County. SCRC consists of several community agencies and individuals who utilize and provide respite services (a committee list is included in the Attachments).

In the spring of 2015, Bristlecone Foundation secured funding from The Summit Foundation to implement a strategic planning process focused on respite care. The Bristlecone Foundation retained Virginia Bradley and Susan Bridges Robertson to facilitate this process, with a focus on creating capacity for sustainable, affordable respite care in Summit County. The target population for this planning project is anyone in need of respite services, regardless of age or disability status.

**Process**

Beginning in May 2015, Ms. Bradley and Ms. Robertson conducted extensive research on respite services. Methodologies included:

- Facilitation of a caregiver focus group, with representation including parents of children with disabilities, parents of adults with disabilities, the spouse of an Alzheimer’s patient, adult children managing care for aging parents, and a caregiver for a elderly companion
- An internet-based provider survey targeting 12 service providers in Summit County
- Interviews with 25+ regional and state-wide providers of respite and related services. (A full list of interviews is included in the Attachments).

**What is respite?**

“Respite” is a temporary, substitute support or living arrangement to provide a brief period of rest for caregivers. It is provided via a variety of models and can take place in multiple settings, including homes, hospitals, hotels, recreation centers and other facilities.

Research demonstrates that respite care reduces stress levels, reduces caregiver burnout, bolsters family stability, preserves marriages and family units, improves caregiver health, helps families to stay involved in their communities and develop

additional support systems, and delays or prevents out-of-home placements<sup>i</sup>. This may translate to an ability to remain in the workforce and an increased ability for families to remain in Summit County rather than relocate to communities with more extensive service options.

Today's high number of family members providing care for family members illustrates the need for respite services. In Colorado alone, an estimated 584,000 family caregivers provided 543 million hours of caregiving in 2013 at an estimated economic value of \$7,430 million dollars<sup>ii</sup>. Many of these people experience emotional and physical stress (29%) and negative consequences to their own health (54%) as a result of their caregiving role<sup>iii</sup>. Another 69% of family caregivers nationally (for adults 18+) report making work accommodations because of caregiving, including arriving late, leaving early, taking time off, cutting back on work hours, changing jobs, or stopping work entirely.<sup>iv</sup>

### **Colorado Respite Efforts**

In 2006, the Lifespan Respite Care Act was signed into law, authorizing Lifespan Respite programs at state and local levels to support increased access to respite services. Two years later, the Colorado Respite Coalition (CRC) was formed via Easter Seals Colorado and received its first funding from the Lifespan Respite Care Act beginning in 2011. Currently, CRC provides a statewide resource list, provides Technical Assistance to communities working to enhance respite care, maintains three regional coalitions (none of which encompass Summit County), and provides mini-grants to communities for respite care. CRC technically receives funds from HB12-1226, a surcharge on people convicted of crimes against at-risk or immobile populations, but because this fund generates few revenues, the State Legislature began allocating funds to CRC in 2013 (\$250,000 in 2015).

The need for respite services continues to be a key concern in Colorado. In May 2015, HB15-1233 was signed into law, creating a task force to study respite supply and demand in Colorado. The work of this task force is underway, with a report due to the General Assembly by December 1, 2015.

### **Respite Need in Summit County**

According to the most recent Summit County Community Survey, and validated by Early Intervention and Summit School District, respite is one of the community's most acute needs. Multiple service providers report respite to be a top concern for parents in Summit County. While anecdotal information abounds about the need for respite care, the actual number of individuals and families in need of respite is difficult to quantify. The population in need of respite may include but is not limited to:

- 55 children and infants served by Early Intervention
- 351 children (Pre-Kindergarten through 12<sup>th</sup> grade) with Individual Education Plans (IEPs) in place. Note that these numbers reflect varying

needs and not all of these children are necessarily in need of respite care. Of these:

- 195 have significant learning disabilities
- 19 are emotionally disabled
- 28 have physical or orthopedic disabilities
- 25 have developmental delays
- Less than 16 are diagnosed with each of the following: autism, Traumatic Brain Injury, Hearing Disability, Visual Disability, Significant intellectual disability, and multiple disabilities
- Approximately 45 individuals on Medicaid waivers and/or on waitlists for waivers the County (per Summit County Social Services)
- Approximately 120 clients annually involved in hospice care via Bristlecone Health Services
- More than 40 individuals on the caregiver support list via the Summit County Community and Senior Center
- An increasing number of elderly individuals in Summit County.

The need for respite service is only expected to increase in Summit County. The County's 65+ population is the fastest growing in the state, with a 180% increase from 2000-2010 and an expected 250% increase between 2010 and 2039. Additionally, Early Intervention and school district staff report increased acuity of special needs among children enrolled in Early Intervention and School District programs.

Respite services currently available in Summit County include:

- Respite for Bristlecone hospice patients (4-8 monthly)
- Private pay CNA services via Bristlecone for Activities of Daily Living (ADL)
- In-home support via Early Intervention (10 annually), funded by The Summit Foundation (\$2,500) and historically by CRC
- Limited voucher funding (approximately \$3,000 annually) via Northwest Colorado Council of Governments via the Older Americans Act
- A summer Easter Seals Camp for children with special needs (8-12 annually)
- Adult day services via Timberline (although not identified by Timberline as respite services).

While these limited services exist, providers and caregivers report tremendous need for respite care. Participants in a caregiver focus group reported that private-pay options are too expensive for most families, and that a lack of providers prevents use of benefits via Medicaid vouchers. Many caregivers report using siblings or other family members to provide care as well as a lack of utilization of respite services. While friend and neighbor networks are used, they are reported to be unsustainable due to the level and difficulty of need of the individual in care.

For those in need of respite services, current payment options are as follows:

- Private pay (via such services as Visiting Angels, Nannies, Inc., and To The Rescue). This service typically costs \$25-\$30 per hour.
- Private pay through independent care givers found through churches, camps, care.com, word of mouth and/or other sources
- Long-term care insurance for elderly clients, if long-term care was purchased
- Medicaid waivers, for those who qualify and are awarded vouchers

The reimbursement system for Medicaid vouchers is complex. Three different systems -- Community Centered Boards (serving Summit via the Developmental Disabilities Resource Council or DDRC based in Jefferson County), the Office of Long Term Care (serving Summit via Northwest Options for Long-Term Care in Glenwood Springs), and the Aging and Disability Resource Center (serving Summit via Northwest Colorado Council Of Governments in Summit County) – all play a role in the administering voucher-supported services. As illustrated in the attached map, the DDRC region only intercepts the other two in Summit County, providing greater complexity in coordinating service delivery systems.

Currently in Summit County, there are no overnight facilities for respite care, and only very limited options for daytime care. There are no agencies in the County that can serve as conduits for billing via Medicaid vouchers. While respite coordination is a challenge throughout the State, Summit County lags behind fellow rural resort communities that have available respite services (Horizons, for example, in Grand, Jackson, Rio Blanco, Moffat and Routt Counties, provides some respite services as part of its role as a Community Resource Center).

Challenges identified in the planning process include the following:

- The lack of a Program Approved Service Agency (PASA) to employ respite providers for Medicaid payment
- A lack of available information and coordination of respite, reimbursement, and other disability services among caregivers and providers
- Limited grant or other funding for respite services
- Relatively low client numbers and varying health care needs, creating difficulty in retaining respite providers due to lack of critical mass
- The inability for private agencies to maintain adequate staff and funding to support Summit County respite needs.

### **Identified Purpose**

SCRC has identified as its purpose assurance that accessible, quality respite care exists in Summit County for all those in need from cradle to grave. To achieve this purpose, it has identified an urgent need to:

- Create / identify a formal host and structure to further organize the respite model in Summit County
- Create awareness, knowledge, educational opportunities and support for respite needs and efforts in Summit County

- Develop services and programs to assist with short term respite needs in Summit County
- Implement a long term, sustainable respite model in Summit County

The immediate intention of the SCRC is to secure initial planning funds to enable this work to commence.

### **Summary**

Although limited respite options exist in Summit County, respite repeatedly surfaces as a pressing need for families and caregivers in Summit County. Many caregivers report having no option for respite care to provide a temporary break from their responsibilities.

While Summit County is often seen as a leading county in human services coordination, it appears to be behind the curve in coordination of disability and long term care services, with a great deal of confusion and frustration reported in accessing services. As the County population grows – and with it numbers of children and adults with special or long term care needs -- so too does the need to address this need in a comprehensive and systematic manner. Given current energy statewide and nationally to address respite needs and strongly identified local concerns, now is the time to create a mechanism for this acutely felt need.

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<sup>i</sup> Colorado Respite Coalition Webcast, June 23, 2015

<sup>ii</sup> Colorado Respite Coalition Webcast, June 23, 2015

<sup>iii</sup> Family Caregiving: The Facts, Centers for Disease Control,  
<http://www.cdc.gov/aging/caregiving/facts.htm>

<sup>iv</sup> AARP, 2008: Houser, A., et al., AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, 2008,  
[http://www.aarp.org/relationships/caregiving/info-11-2008/i13\\_caregiving.html](http://www.aarp.org/relationships/caregiving/info-11-2008/i13_caregiving.html)