

What is the Value of a Respite Care Task Force for Your State?

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What is the Value of a Respite Care Task Force for Your State?

- Brings stakeholders, policy makers, providers, government entities to the table
 - Established common concerns, values
 - It is not all about funding
- Learned that most of us wanted the same thing



It's Not Always About Money

Focus, focus, focus

Primary and Common Issues:

OUTREACH AND EDUCATION

- Found that many decision makers did not understand how respite impacts health challenges and the families coping with health challenges due to chronic conditions, aging, disabilities, accidents, long term illnesses etc.

COST BENEFIT STUDY

- Important to establish the economic value of respite
- Quantify health and other associated savings or increased costs tied to lack of or reduction in respite services--- determine fiscal impact of respite

TRAINED PROVIDERS

- Without trained providers it does not matter how much funding you have, no providers, no respite

Where to Start

- We are there - we are all part of collaborations
- Collaborations build information, resources, common cause, consensus and a network of committed individuals, organizations
- Get a strong government partner (State Unit on Aging, State Medicaid, Department of Developmental Disabilities, Department of Health, University Partner etc.)
- Start talking and sharing concerns with legislators, policy makers, (ask them how to bring respite issues forward)
- Build your state Coalitions



Example of What We Did in Colorado

Advocacy History

Laying the groundwork

2011- 2014	Colorado Lifespan Respite Care Program – Federal Grant
2011	HB12-1226 - Crimes against at-risk population
2013	State Allocation (Training and Respite funds - \$150,000)
2014- 2017	Federal Grant Lifespan Respite
2014	State Allocation (Training and Respite Funds - \$250,000)
2015	State Allocation (Training and Respite funds - \$350,000)
2015	HB15-1233 – Creation of statewide Respite Care Task Force
2015	Awarded Colorado Collaboration Award
2016	State Allocation (Training and Respite funds \$350,000)
2016	HB16-1398 - Bill to fund respite task force recommendations (2 year, possible renewal)
2017	State Allocation (Training and Respite Funds \$350,000)

Funds are available for:

Serving three purposes

1. Building a foundation

2. Seeding the project

3. Funds to sustain project after grants

Maintain primary focus with all funding and messaging

→Outreach

→Education and Training

→Respite Services

Family Vouchers

Grants to service providers

Key Value

Build Long-term and Sustainable Solutions

- The Task Force became a way to establish credibility
- Study of findings was published and shared with legislature
- Reasonable budget created to cost out recommendations
- Required report to legislature
- Included list of collaborators who endorsed process
- Process lead by key government entity (Colorado- State Unit on Aging)
- Found champions within the State Unit on Aging



The Big C's

Credibility

Conflict reduction

Cooperation

Completion

Cost

Creativity

Courage

Champion

Create Change

Commitment

Coalition

Communication



Why Are We Putting More Funds into Services?

The Question Caregivers Are Asking

- Assumption that money is the answer is not a long-term solution (money comes and goes)
- Convince families and other stakeholders it is about building long-term solutions
- Respite and Caregiver health is an important issue for families, businesses, communities, and government agencies



Respite and caregiver support needs to be embedded into laws, regulations, and our countries commitment to families

Colorado Respite Care Task Force

- House Bill 15-1233 created the Respite Care Task Force within Colorado Department of Human Services
- Purpose: to study the dynamics of supply and demand with regard to respite care services in Colorado
- Timeframe: July 2015 to January 2016
- Challenges = tight timeline and broad scope of work (lifespan respite)
- Opportunities = funding for facilitator and study and clear charge from legislation

House Bill 15-1233 Legislative Declaration

- The current extent of demand for respite care in Colorado is unknown, although it is apparent that there is a lack of adequate respite care facilities and respite training programs in Colorado
- Caregivers work twenty-four hours per day, seven days per week to ensure their loved ones have the support and tools they need to live their best lives
- It is critical that caregivers in our communities have access to respite care so that they have time to rejuvenate and spend time with their families and friends
- It is important that caregivers are able to trust and depend on the individuals providing respite care to their loved ones
- Reliable access to affordable respite care will be beneficial to caregivers and to their families and loved ones

Respite Care Task Force Requirements

The Task Force was required to study, through data collection, the supply of, and demand for, respite care services in Colorado which could include:

- a) Access to respite care services
- b) The types of services that are most in demand and the services that are currently available
- c) The availability and level of culturally competent care and patient-centered care
- d) The number of respite caregivers in the State and their locations
- e) Solutions to increase the number of respite caregivers
- f) The funding of respite care services, including access to that funding
- g) Other respite care issues are determined appropriate by the task force

Who was on the Task Force?

- Members from State Departments
- Member of an organization that provides mental health services
- Person who provides services, education, and outreach for persons with chronic conditions,
- Person who represents a licensed home health care agency
- Person who represents a nonprofit entity that provides services to persons with disabilities
- Person who represents a licensed hospice organization
- Person from an organization that represents person with developmental disabilities
- Owner or operator of a respite care facility
- Member of an organization that provides services, education, outreach to seniors
- Member of an organization that advances research to end Alzheimer's disease
- Person who represents person with brain injuries
- Person from Rural Area who utilizes respite care

What we did...

Date	Task Completed
July 2015	Task Force members appointed, facilitators hired, first meeting held, webpage designed
August 2015	Task Force members interviewed, resources collected, Documented quote posted for study
September 2015	Task Force identified their ideal vision, HMA contracted to conduct the study
October/ November 2015	HMA collected data, conducted analysis, reported out to Task Force
November/ December 2015	Task Force and facilitators identified findings and recommendations, drafted report overview
January 2015	Findings, recommendations, and report finalized

Health Management Associates Respite Care Study

TOPICS COVERED:

- Supply and Demand/ Unmet Needs
- Funding
- Return on Investment
- Training
- Availability of Person-Centered and Culturally Competent Respite Services
- Awareness of Respite/PR



HMA Research Methods

- Previous Research
- Respite Care Provider Indexes
- Utilization Data
- Interviews with Providers
- Interviews with Individuals and/or Families
- Population Projections



HMA Key Findings and Recommendations

- Supply and Demand
- Marketing and Awareness
- Return on Investment
- Cultural Competence and Training



Supply and Demand

- Data are limited; must use multiple sources of data to estimate supply and demand
- The Family Caregiver Alliance estimates that 843,000 Colorado caregivers provided 551 million hours of care in 2012
- State and local caregiver surveys show that one of the most frequently requested support services is respite care
- Some major barriers to respite care services in Colorado: affordability, geographic accessibility, an inadequate supply of culturally competent respite care providers, a shortage of providers who can care for high needs individuals
- Conclusion: Strong indications of needs and gaps in respite services in Colorado - unmet needs may be greater in rural areas

Marketing and Awareness

Example of Effective Marketing Campaign From Minnesota:

YOU CALL IT

"taking grandma to the doctor."

WE CALL IT

"caregiving."

GET SUPPORT SO YOU CAN BE THE BEST CAREGIVER YOU CAN BE:

Senior LinkAge Line 1-800-333-2433

Return on Investment: Economic Value and Costs of Caregiving

- Qualitative, anecdotal, and limited research data suggest that respite services have a positive return on investment
- Data are extremely limited and minimal - recommend a rigorous quantitative study
- We learned that we needed to know more return on investment to make the case for respite services in Colorado



Training and Cultural Competence

- State government and state respite coalitions can serve as a coordinators of training for providers in the state
- There is diversity in caregivers that needs to be addressed in respite
- Some core standards for cultural competence exist
- Cultural competence includes “disability competence”
- Additional training for respite care providers and incorporation of best practices around cultural competence may be helpful in Colorado

Respite Care Task Force

Findings and Recommendations

The Task Force provided a final report to the House Public Health Care and Human Services Committee and to the Senate Health and Human Services Committee by 1/31/16

- A study on, *Return on Investment of Respite Care* was deemed critical due to the lack of available national data
- Several other “infrastructure” related items were identified to ensure the state has the capacity to provide quality, effective respite services
- Other ideas raised during the process formed into recommendations

For More Information

Respite Care Task Force Webpage:

<https://sites.google.com/a/state.co.us/cdhs-cai-aas/respice-care-task-force-overview>

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"Never doubt that a small group of thoughtful, committed people can change the world. Indeed it's the only thing that ever has."

-Margaret Mead