

LIFESPAN RESPITE CARE PROJECT

The importance of *respite care* for family caregivers, who are caring for an individual with a special need, has been of national concern over the last decade. Research has demonstrated that respite care can make a significant positive difference in the lives of families caring for the elderly, children with disabilities and adults battling chronic conditions.

For the past three years, the U.S. Administration on Aging has been awarding lifespan respite care grants to States to develop and enhance coordinated, accessible, community-based respite care programs for caregivers across the lifespan.

The State of Colorado has qualified for the Lifespan Respite Care grant, a three-year project, which aims to improve delivery and quality of respite care offered in Colorado. The primary goal of this project is to establish a statewide, coordinated system to meet the respite care needs of Colorado's family caregivers of individuals with special needs regardless of age, income, race, ethnicity, situation or disability. Project objectives include: connecting families to existing respite services, implementing public awareness activities, coordinating resources among existing programs and increasing the availability of trained respite workers and volunteers.

In 2007, it was estimated that in the State of Colorado, there are approximately 540,000 caregivers with the economic value of caregiving being valued at \$6,500 (millions). In a survey conducted by the Colorado Respite Coalition (Fall 2008) of approximately 265 Colorado families who have children with special needs, 84% indicated that they were not able to get the respite services they needed.

Certain barriers have been well documented that discourage family caregivers from using respite. They include funding, cost, restrictive eligibility criteria, waiting lists, accessibility, limited or no respite options, inadequate supply of trained providers or appropriate programs, lack of information, or feelings related to lack of trust of outside providers, guilt, or non-identification as a family caregiver.

An effort to address these challenges has been started by multiple partner organizations interested in assuring that respite care services reaches one and all. In a first step, we are conducting a survey of local organizations/agencies. The information you provide will help us create a 'map' of the current networks of agencies and community service organizations that are points of entry for potential beneficiaries across the State and provide an invaluable resource to those who may need respite services. The survey will help us understand who you are, the level and type of assistance you provide in giving respite services and the interest you have in building capacity in this area.

We will be calling you in the next few days to learn about your program. Please view the attached survey.

Thank you for your help.

Sincerely,

Ayesha Sharma
Project Manager, Lifespan Respite Care Project

Lifespan Respite Care Survey

Introduction: Thank you for taking the time to speak with us today. As a reminder, our goal with the survey process is to better understand who in the state of Colorado is providing respite care services, the level of assistance being provided and the interest of the agencies in building capacity in this area.

Questions:

Screening Questions:

1. What is the focus of your organization and what are your major program areas or projects?
2. How does your organization provide respite services to individuals (center based vs in home)?

IF ANSWER IS YES WE PROVIDE RESPITE SERVICES GO TO FORMAL QUESTIONS IF ANSWER IS NO, ASK:

3. Would you like to provide respite services to the people you serve?
4. What are the barriers as an organization that prevents you from providing these services?
5. As this project develops, would you like for us to contact you again to update you on the efforts to improve access to respite services in Colorado?

Additional Information:

- Are you aware of the Colorado Respite Coalition?
- Can we get your permission to include you in our respite Directory on our web page until you have the opportunity to add yourself to the directory?"

We encourage you to go to the www.coloradospitecoalition.org site and register as a respite provider to increase your community recognition as a respite provider, and to help us provide families with a complete list of respite providers from one source.

Formal Questions:

6. What is the specific target population (age, only foster kids or adopted, diagnosis specific, location restrictions, seasonal – perhaps summers only) for your agency?
7. What is the method used to determine if someone is eligible for your services?
8. What is the average length of time, respite services are provided by your organization per visit?
9. How many families on average do you serve weekly, monthly, annually (not including repeat customers)?
10. Is there a waiting list of families who want respite services from your agency?
11. Do you have dedicated staff planning and carrying out respite programs?
12. What levels of training/experience/certification do you require of the staff providing respite?
13. Do you provide training for your staff or do you outsource the training?
14. Do the respite workers speak any other languages in addition to English?
15. Is there a medical professional on site for medication management and emergencies?
16. Do you offer financial assistance to families looking for respite?
17. How do your clients pay for their respite (Medicaid, Medicaid Waiver Medicare, private pay, private insurance, Community Center Board/CCB/ foster/adoption care funding/ voucher from another organization)?
18. Do you refer to or sub contact to other organizations/agencies (public and private) who provide respite services? If yes, who?
19. How do you generate awareness around your respite programs?
20. Would you be interested in being listed on a statewide data base/information system?
21. Can you list any barriers that prevent you from providing additional services?
22. Would you be interested in building your capacity in this area of work?

23. Who is the primary contact person at your agency?

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