

Nebraska Lifespan Respite Network Evaluation Executive Summary

From 2015-2017, the Nebraska Lifespan Respite Network was the subject of a comprehensive evaluation process. The evaluation examined need, access, family caregiver outcomes, systems outcomes and cost-effectiveness. Stakeholders involved in the process were the Nebraska Department of Health and Human Services (DHHS), the Lifespan Nebraska Respite Network, regional respite coordinators, community agencies, respite care providers and family caregivers. The majority of the evaluation focused on who was being served by the Lifespan Respite Network and the outcomes associated with those family caregivers.

There are approximately 1800 family caregivers registered in the statewide database serving over 1400 care recipients. However, there are only 239 respite care providers that are registered with the statewide network resulting in a shortage of respite care providers. It is very likely that there are far more family caregivers than those in the database as some do not know about respite or are unwilling to access the service for a variety of reasons.

Based on three years of data and input from nearly 200 family caregivers, the results are clear on the impact of the services provided through the statewide network. For family caregivers, the opportunity to have respite care services positively impacts multiple areas of daily life including stress levels, relationships, mental health and other health symptoms. Respite care services are providing a valuable resource and are reducing negative life stressors and events.



When receiving respite care services.....

- Stress Levels Decreased
- Anxiety and Depression Decreased
- Sleep Problems Decreased
- Headaches Decreased
- Relationship Strain Decreased

Family caregivers reported high levels of satisfaction with respite care when they receive it with **89% were satisfied with the level of care provided to their care recipient.** However, the statewide respite network has challenges to address including respite provider shortages particularly rural areas of the state. Only **53% of family caregivers report being satisfied with the ease of finding a respite care provider.**

Family Caregivers are impacted financially in terms of their employment, annual income and expenditures necessary to keep a loved one at home and not in an out of home placement. Families reported being in a better financial situation when receiving respite and yet, 36% of family caregivers reported not having enough money at the end of the month to make ends meet. Part of that could be the impact that family caregiving has on employment as **16% of respondents missed 10 or more days of work** within the past year due to caregiving responsibilities.

In 2017, **31% were considering an out of home placement prior to receiving respite compared to 23% currently considering an out of home placement even with respite.** Respite services may be providing necessary support to families enabling them to keep their family member at home.

Areas that have been addressed and are under continuous improvement within the Nebraska Lifespan Respite Network include 1) Working to develop an increase in qualified respite providers; 2) Creating and implementing a high quality training program designed to build capacity of respite care providers; 3) Tracking and partnering with volunteers, agencies and faith-based organizations that are providing respite care; 4) Increasing the data input and data utilization from the data dashboard and 5) Increased dissemination of information and marketing materials to families and agencies to raise the numbers of families who access respite care.

It is recommended that these initiatives and improvements continue in the system. One area of need is to address the mental health needs of family caregivers in addition to the mental/behavioral health needs of the care recipients. Ongoing evaluation efforts may continue to identify gaps and improve other services provided to families.

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