

RESPIRE PROGRAM ACROSS THE LIFESPAN OUTCOMES

December 2014

INTRODUCTION:

The Nebraska Department of Health and Human Services (DHHS) is responsible for administering the Nebraska Lifespan Respite Services Program in accordance with Nebraska Revised Statutes §§68-1520 through §§68-1528.

The Lifespan Respite Care Act established the Nebraska Lifespan Respite Services Program, which consist of the following:

1. The Lifespan Respite Network designated to coordinate community respite services; and
2. The Lifespan Respite Subsidy Program designated to provide funding for caregivers to purchase respite services. The program is centralized and administered through the Department of Health and Human Service.

The Lifespan Respite Subsidy Program supports Respite Services, which provide short-term relief for primary caregivers from the demands of ongoing care for an individual with special needs. The Lifespan Respite Subsidy Program offers qualified families a maximum of \$125.00 per month to obtain respite services. The program is family focused and encourages each family to choose their own providers, decide how much to pay the providers per hour or per day, the location for respite service delivery, and determine their own schedule based on the family's needs. This program is limited to those families who do not receive respite services from other governmental programs. The need for time-sensitive crisis respite support was incorporated into the Lifespan Respite Subsidy program in FY 2014. This was possible following pilot efforts to define criteria for the most cost-effective, yet beneficial means to support families. Lifespan Respite Subsidy eligible persons were able to request crisis respite support up to \$1,000.00 per eligibility year above the authorized \$125.00 per month planned respite.

The Lifespan Respite Network is a statewide system divided into six service areas. DHHS provides a Lifespan Respite Network contract to one agency in each of the areas, which is responsible for providing the required network activities. The following agencies currently hold a contract in their respective service areas:

1. Central Area - Central Nebraska Community Services, Inc.
2. Eastern Area – Partnerships in Aging
3. Northern Area - Central Nebraska Community Services, Inc.
4. Southeast Area - YWCA - Lincoln
5. Southwest Area – Southwest Nebraska Public Health Department
6. Western Area – Panhandle Partnership for Health and Human Services

The Lifespan Respite Network in each area is responsible for providing the following activities:

1. Recruiting respite providers
2. Offering training for providers, caregivers, and consumers
3. Providing information and referrals regarding respite resources and services

4. Marketing availability and need for respite
5. Matching families with appropriate respite providers and payment resources

NEBRASKA LIFESPAN RESPITE NETWORK

The Network's goal was to ensure families had increased knowledge and access to quality and inclusive lifespan respite resources to meet their specific respite needs. DHHS contractors were provided technical assistance to not only sustain, but further develop, the Lifespan Respite infrastructure and resources developed in recent years. Activities involved a cross-agency focus with enhanced data collection resources to demonstrate need and cost while identifying and promoting resolution of local and state-level respite policy concerns.

Currently the Lifespan Respite Network has 995 approved agency and individual providers statewide accessible to caregivers through a 1-866-RESPITE phone line that enables access to local Respite Network representatives. When caregivers called 1-866-RESPITE to seek assistance, Respite Coordinators empowered and helped with the following:

- Informed decision-making about respite need;
- Assisted with general resource questions, including questions about available funding, caregiver support groups, access to Medicaid programs, information about special trainings/events;
- Program eligibility and referral, if appropriate;
- Guidance on selecting competent providers to meet their individual needs; and
- When needed, identifying translators and interpreters to help non-English speaking families.

Lifespan Respite Network approved providers are required annually to pass criminal background checks, Adult Protective Services/Child Protective Services checks, sex offender registry checks, and personal reference checks. Providers represent both agencies and individuals. Efforts are made to recruit providers, through strategic outreach and collaboration, who are willing to work with targeted needs such as children with difficult behaviors and bilingual providers by contacts through the Nebraska Association for Translators and Interpreters (NATI). Respite Coordinators continue to be challenged in rural areas with a shortage of respite providers dissatisfied due to the lack of work and distance. Collaboration with DHHS Resource Developers and contracted agency staff responsible for provider recruitment was utilized to identify individuals and agencies interested in serving multiple populations and minimizing duplication in provider approval requirements.

Respite provider training was offered in the area of managing mental/behavioral health issues. REST (Respite Education & Support Tools), a nationally-recognized training to assist providers and caregivers with the skills and tools needed to provide quality, compassionate respite care, was offered in multiple locations by certified trainers throughout the state of Nebraska. All the Respite Coordinators have completed the national training and have conducted one or more training events in their local regions. The Eastern region also offers Powerful Tools for Caregivers, a six week series provided to community groups and organizations. This created referrals for respite providers as well as an increased awareness of respite.

CAREGIVER TRAININGS

Southwest – 1
Western - 0
Northern – 16
Central – 24
Eastern – 19
Southeast – 1

PROVIDER TRAININGS

Southwest – 2
Western - 1
Northern – 3
Central – 6
Eastern – 12
Southeast – 5

At every outreach opportunity family caregivers were reminded of the importance of recognizing themselves as caregivers, taking respite and how to access Nebraska Respite Network representatives. Families were provided information and assistance on respite programs and eligibility criteria, depending upon personal need and circumstance. In addition, overcoming issues of provider “trust” and problems of long distance caregiving were addressed. Caregivers were informed of local support groups. Caregivers were free to choose their respite providers. Caregivers routinely received a caregiver packet, in addition to an offer of free REST training (discussed in previous paragraph), with educational information on priority topics that included, but were not limited to:

- How to hire, train and provide ongoing supervision of care providers;
- Billing instructions, available financial assistance, reporting changes of condition or need, and fraud;
- Philosophy of client choice, client direction and family centered services;
- How to identify and report abuse and/or neglect;
- The Nebraska Nurse Practice Act, particularly for providing an understanding of the health maintenance activities a provider is allowed to conduct;
- Handling emergencies, stress relief, positioning and transferring, behavior management, speech pathology, respite goals, limits, confidentiality, and more.

DHHS Program staff, in collaboration with UNL’s Center on Children, Families and the Law - Answers4Families and Network Respite Coordinators, continue to enhance the secure online data management and workspace system launched in September, 2012. This system is a core source of collecting data of caregiver and provider contacts facilitated by Respite Coordinators. In addition, the system serves as a training/peer mentoring resource. This system is referred to as eLifespan Respite used by Network Respite Coordinators, DHHS Program staff and authorized federal, state and community partners. Key features of the system:

- Allows real-time provider matching with care recipients that best meet their needs;
- Supports real-time recording of subgrantee activity and financial reporting, including caregiver and provider contacts;
- Project management functions to support a quality assurance process; and
- Access to respite utilization data by authorized federal, state and local partners.

Nebraska Resource and Referral System (NRRS) maintains a dedicated section to support 24/7 statewide access to respite resources to families, providers, and community partners. The website <https://nrrs.ne.gov/respitesearch/> is supported by Answers4Families under contract with DHHS. Key features of the system on the Answers4Families website:

- Educate visitors about the role and function of the site and respite provider search functions;
- Allows families and advocates to maintain direct contact with local Respite Coordinators;
- Public access to Network-approved provider information allows caregivers to independently match care recipient and caregiver needs as closely as possible from the convenience of their home. Provider information is exported each evening from the eLifespan Respite system to the NRRS Respite Resource section; and
- Provides nightly provider data download to the Aging and Disability Resource Center site managed by the Nebraska State Unit on Aging.

Beginning in FY 2014 efforts were initiated to add data of cross-agency, program-specific care, recipient eligibility, service utilization, numbers and qualifications of providers used by families or provider training, and evolving quality assurance activities. DHHS understands there is a great deal of variability across service areas with respect to program structures, respite availability, service gaps, unmet needs, and the role of key stakeholders. Therefore, by improving cross-agency understanding of the program structure, respite availability, service gaps, unmet needs, caregiver population, and the role of stakeholders statewide, the collection and integrity of data is essential to demonstrate service benefit. This project will continue to be formalized in FY 2015.

Monthly Respite Network Coordinator conference calls are held to provide technical assistance and training opportunities to support successful workplan implementation. Meetings, including formal and informal presentations, are routinely attended/provided to cover all 93 counties to offer external partners opportunities to improve awareness of respite resources and available information for families. Examples of staff development training include Norfolk Early Childhood Conference, Grand Island Stress and Its Management, Lincoln Trauma across the Lifespan, Norfolk Sibshop Facilitators Training, Fremont Child Abuse 101, Holdrege RAD Workshop, Caring for the Caregiving Partner, Nebraska Brain Injury Conference, Engaging Employers in Respite, northeast AAA Caregivers Conference, Holy Cow, What Now Transition Conference, and O'Neill Health Conference.

Description of outreach and marketing activities:

- 18,528 calls, emails or NRRS/Respite Search requests for information or assistance; and
- All contacts by telephone, personal contacts, USPS mailings, social and print media, presentations, email communications with providers and caregivers totaled 496,543 contacts.

To date, DHHS and Lifespan Respite Services contractors have made progress towards building upon existing infrastructures of multi-faceted caregiver services. Strategies included providing training for caregivers and respite providers, enhancing the provision of information about available respite and other supportive services, and assisting caregivers in accessing services available to them. Additional Network accomplishments:

- Conducted needs assessments/environmental scans to determine the respite funding streams available, programs in existence, data collection, populations served and the gaps in each area;

- Broadened stakeholder collaborations to ensure representation of all age, disability groups as well as the broadest possible cross section of the provider network;
- Communicated with community partners and family caregivers to inform project activities;
- Strengthened collaborations between local respite programs and DHHS to increase access to respite resources;
- Designed and implemented awareness campaigns to promote knowledge and understanding of caregiver needs, respite services, and the importance of utilizing respite;
- Expanded state and local respite websites and Network-approved provider databases to centralize respite services for caregivers and providers in order to improve capacity for agencies to make referrals to appropriate respite resources. Nebraska Resource and Referral System (NRRS) provides 24/7 access to respite resources at www.nrrs.gov/respitesearch;
- Utilized Crisis Respite funds to assist caregivers in paying for crisis respite services and train emergency first responders. As stated earlier, in 2014 crisis respite was incorporated into the Lifespan Respite Subsidy Program;
- Improved collaboration among state agencies offering respite resources. For example, sharing responsibilities for provider background checks and referring qualified providers to multiple programs to improve their independent income potential and retention; and
- Meaningful involvement of family members, family caregivers, and care recipients to match identified care recipient needs and analyze outcomes.

LIFESPAN RESPITE SUBSIDY:

The Lifespan Respite Subsidy program is currently serving 514 individuals with special needs. Between July 1, 2013 and June 30, 2014, the Lifespan Respite Subsidy Program served 758 individuals and received 400 new referrals. Clients eligible for other programs providing respite services are referred to those appropriate programs. Total expenditures of appropriated subsidy funds for FY 2014 was \$589,081.20 (*\$547,081.21 for direct services + \$42,000 for UNL Board of Regents/CCFL contractual aid*).

The 758 individuals had one or more of the following special needs:

Special Need	Number Served
Behavior Disorders (ages 0-18)	183
Alzheimer/Dementia	125
Autism	112
Developmental Delay	112
Other Health Impairments	96
Multiple Impairments	96
Neurological Disabilities/Disorders	77
Mental Illness/Depression/Anxiety	74
Heart Conditions	52
Intellectual/Developmental Disabilities	49

Respiratory System Disorders	45
Diabetes	44
Orthopedic/Spinal Impairments/Injuries/Disorders	39
Visual Impairments	39
Brain Injury/CVA	38
Speech-Language Impairments	36
Seizure Disorder	29
Cancer	22
Arthritis	20
Cerebral Palsy	14
Hearing Impairments	11
Kidney/Renal Failure	11
Brain Injury/TBI	2

By age group

Ages 0-18	391
Ages 19-59	102
Ages 60+	265

