

RESPITE PROGRAM ACROSS THE LIFESPAN OUTCOMES

December 2011

INTRODUCTION:

The Nebraska Department of Health and Human Services (DHHS) is responsible for administering the Nebraska Lifespan Respite Services Program in accordance with Neb.Rev.Stat. §§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, and set 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 program.

The Lifespan Respite Network is a statewide system divided into six service areas. The Lifespan Respite Network provides outreach, marketing, recruitment of respite providers, information and referral services and training opportunities for caregivers and providers. DHHS provides a Lifespan Respite Network grant to one agency in each of the areas, which is responsible for providing the required network activities. The following agencies currently hold Lifespan Respite Network grants:

1. Central Area - Central Nebraska Community Services
2. Eastern Area – Partnership in Aging
3. Northern Area - Central Nebraska Community Services
4. Southeast Area - YWCA -Lincoln
5. Southwest Area – Southwest 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

LIFESPAN RESPITE SUBSIDY:

The Lifespan Respite Subsidy program is currently serving 541 individuals with special needs. Between July 1, 2010 and June 30, 2011, the Lifespan Respite Subsidy Program served 793 individuals and received 330 new referrals. Clients eligible for other programs providing respite services are referred to those appropriate programs.

The 793 individuals had one or more of the following special needs:

Special Need	Number Served
Developmental Disabilities	209
Alzheimer/Dementia	151
Behavior Disorders	139
Autism	94
Brain Injury	77
Heart Condition	48
Speech-Language Impairments	43
Orthopedic Impairments	40
Visual Impairments	38
Cerebral Palsy	37
Diabetes	37
Neurological Disabilities	33
Respiratory System Disorder	33
Cancer	28
Parkinson	26
Seizure Disorder	23
Arthritis	19
Kidney/Renal Failure	13
Hearing Impairments	12
Spinal Disorder/Injury	12
Other	29

NEBRASKA LIFESPAN RESPITE NETWORK

The Lifespan Respite Network currently has 649 individual and agency providers recruited to provide respite services for caregivers statewide. The Respite Network Coordinators regularly meet with Medicaid Service Coordinators from the Department of Health and Human Service, Developmental Disabilities, Area Agencies on Aging, Independent Living Centers, the Early Development Network and Medically Handicapped Children’s Program to identify gaps and barriers and to recruit providers as needed.

Activities Supported

1) Training and Tools

- a) The Lifespan Respite Network, Respite Coalition, and other partnering agencies provided a caregiver retreat in April 2011, at Mahoney State Park. This caregiver retreat was a great success as feedback from the participants was very positive. Plans are underway to continue the retreat partnerships with added partners to provide two retreats in 2012. The retreats will target both the Western and Eastern areas of the state to ensure access for participants across Nebraska.
- b) Educational handbooks were provided to families/caregivers and providers after initial contact was made with the Respite Network Coordinators. The educational handbooks provided information on the following topics:
 - Philosophy of client choice, client direction and family centered services.
 - How to hire, train and provide ongoing supervision of care providers.
 - How to identify and report abuse and/or neglect.
 - The Nebraska Nurse Practice Act, particularly an understanding of the health maintenance activities a provider is allowed to conduct.
 - Administrative issues surrounding respite care billing, available financial assistance, reporting changes of condition or need, and fraud.
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2) Marketing

Through marketing efforts, the Respite Network Coordinators have reached an estimated 265,000 individuals this past year. This was accomplished by:

- a) Public Service announcements on radio, television and newspaper
- b) Visits to community facilities such as child care, adult day care and assisted living facilities to continually recruit providers to ensure availability of respite for temporary or emergency respite situations
- c) Presentations and informational booths were provided statewide to promote respite needs, recruit providers and educate families about respite services. The Lifespan Respite Network Coordinators have participated in Husker Harvest Days, County Fairs, Health Fairs, Community Events, and Conferences such as:
 - Fetal Alcohol Spectrum Training Disorders Workshop
 - Autism Syndrome Disorder Conference
 - Working with Youth and Young Children with Autism and Behavioral Problems
 - Social Emotional Development
 - Western NE Early Childhood Trainings
 - Traumatic Brain Injury Conference
 - Nebraska Youth First Conference
 - Caregiver Retreat at Mahoney State Park
 - Planning Region Team Summer Retreat in Kearney
 - Families Care Retreat
 - Hastings Day of Caring
 - State Lifespan Health Conference
 - Nursing Assistance Classes
 - Parenting Classes

- Grandparents and Extended Family Workshop

3) Communication/Outreach

- a) In state fiscal year 2011, the Respite Network received 5,376 calls from caregivers, individuals and agencies requesting assistance with finding providers and securing funding or expressing an interest in becoming a respite provider.
- b) The local Respite Network newsletters and other respite information were sent to over 6,000 caregivers, providers and interested programs. This information is provided on a continual basis.

Special Projects: The Nebraska Lifespan Respite Network Coordinators in partnership with each of their Advisory Committees have granted \$150,000 (\$25,000 goes to each of the six respite areas) to provide funding to expand or develop programs dedicated to the provision of respite services in each of their areas. These projects continue to enhance respite delivery services in each coverage area.

CENTRAL SERVICE AREA

The Central Service Area granted 7 organizations funds to expand or develop programs dedicated to the provision of respite services in their area. The following agencies were awarded the funds:

1. ARC of Buffalo County- Kearney, received \$8,000. ARC of Buffalo County worked year round with individuals from the 6th grade to age 25. Programs included summer activities every Friday from 10 a.m. to 4 p.m., which offered age appropriate classes and training. Also funded was a play group for girls held at the Children’s Museum.
2. Custer Care Center-Broken Bow, received \$3,800. Custer Care Center expanded their respite services to working with children ages 12-18 years old. A group of high school students was formed to work with the children who are on the Aged & Disabled Waiver Program in the Broken Bow area. A program of activities was offered on either Saturdays or weekday evenings each month.
3. Families CARE-Kearney, received \$3,600. Families CARE held four events during the year. The Respite events included a Parent’s Day Out, a picnic, a pumpkin patch outing, and a movie night.
4. Hastings Respite Care-Hastings, received \$3,000. Hastings Respite Care was funded to support the “Let’s Take a Break Caregiver Night Out” Support Group. Activities included special night out events offered every other month. Also regular outreach through radio and news releases were used to promote these events.
5. Webster Co. Senior Citizens Committee, Inc. received \$3,300. Webster County Senior Citizens Committee, Inc. transports people with special needs to the Senior Center for respite which included activities, lunch, sharing current events and family events to allow their caregivers a break.
6. The Autism Society of Nebraska-Grand Island Support Group received \$2,500. Respite care was offered to families of children with disabilities every third Saturday morning of the month at the Third City Christian Church in Grand Island. They also expanded the

program by offering in home care for families whose children could not participate in the community event.

7. The remaining \$800 was used for Emergency Respite Services. These funds are utilized when other sources of funding cannot be secured.

EASTERN SERVICE AREA

The Eastern Service Area granted 11 organizations funds to expand or develop programs dedicated to the provision of respite services in their area. The following programs received funding:

1. Take Flight Farms received \$2,000 to provide respite activities for youth with special needs and their siblings through their equine therapy program.
2. ALS in the Heartland received \$2,000 to provide approximately 100 hours of respite to families caring for loved ones diagnosed with ALS.
3. Yachad received \$1,000 to match funding for respite programs that provide individual and group respite for individuals with Developmental Disabilities.
4. Franciscan Adult Day Service received \$4,128 to provide respite for individuals with early on-set Dementia/Alzheimer's while caregiver received training related to this diagnosis.
5. Pilgrim Baptist Church received \$1,000 to provide respite to families that have a difficulty leaving their homes due to the care needs of their loved one.
6. Easter Seals received \$600 to provide scholarships for families needing assistance to pay for day or weekend respite stays.
7. Autism Action Partnership received \$1,072 to provide training to the Children's Respite Care Center staff that provides respite to children with Autism.
8. House of Hope received \$600 to provide the first day of a three day respite stay for free.
9. Aging Partners received \$6,100. Aging Partners used the funding to support the retreat for caregivers and their families at Mahoney State Park in April 2011.
10. Wagner Connolly, RN received \$500 to work with Clarkson College students to provide respite days for parents. Funds were used to purchase snacks and supplies students volunteered their time to the project.
11. The Respite Resource Center used \$6,000 to pay for providers and caregivers to attend Nursing Assistant training programs. Twenty four scholarships were provided. Twenty-two of the twenty four scholarship recipients signed up to provide respite services for Medicaid programs upon completion of the training.

NORTHERN SERVICE AREA

The Northern Service Area granted the following 3 organizations funds to expand or develop programs dedicated to the provision of respite services in their area. The following programs received funding:

1. Redeemer Lutheran Church, received \$3,434. Redeemer Lutheran Church began a support group offering caregivers of spouses and adult children of the elderly. The support group offered training in coping skills and information about resources available to them.

2. Building Blocks for Community Enrichment received \$11,566. Building Blocks for Community Enrichment provides foster care services and respite services to families and youth. Building Blocks expanded their respite services and provided four additional activities throughout the year: a spring pizza party, a summer swimming party, an autumn-fest with games and treats, and a winter party with swimming and pizza.
3. SMILE Inc. received \$10,000. S.M.I.L.E., Inc. expanded the equine and canine therapy for people of all ages with disabilities to include more individuals through scholarships and by having more qualified respite instructors.

SOUTHEAST SERVICE AREA

The Southeast Service Area granted 4 organizations funds to expand or develop programs dedicated to the provision of respite services in their area. The following programs received funding:

1. YWCA of Lincoln, Take a Break Program received \$5,000. The Take a Break Program provided families in need of a break, respite on the first three Fridays of every month.
2. Aging Partners received \$9,000. Aging Partners provided respite services for 25 families in 8 counties in Southeast Nebraska and supported the caregiver retreat at Mahoney State Park in April 2011.
3. The Nebraska State Stroke Association received \$5,000. The Nebraska State Stroke Association used the funds to help with a stroke camp for individuals that have had a stroke and their family members.
4. Lincoln Parks and Recreation received \$6,000. The Lincoln Parks and Recreation Program provided scholarships to families for their camps and adult day program.

SOUTHWEST SERVICE AREA

The Southwest Service Area granted 5 organizations funds to expand or develop programs dedicated to the provision of respite services in their area. The following programs received funding:

1. Family Resource Center – McCook received \$6,145 to provide a Family Day Out for families with children who have special needs and their siblings.
2. Ladybug Crossing Daycare - North Platte, received \$3,350 to update daycare equipment for children with special needs to increase safety and accessibility.
3. Community Outreach Services – North Platte & Ogallala, received \$8,843 to provide respite for parents of youth age 9-12 with verified disabilities.
4. Kingdom Kids Christian Daycare– McCook received \$5,170 to make the facility accessible and to purchase educational items for children with special needs.
5. Ogallala/North Platte Autism Support Group received \$1,492 to provide respite for support group meetings for parents/caregivers of children with Autism Spectrum Disorder in Ogallala and North Platte. The funds supported Parents Day Out activities.

WESTERN SERVICE AREA

The Western Respite Service Area utilized the special funds to increase the availability of respite services and caregiver support programs.

1. Respite Days Program received \$17,000. Respite Days offered families 8 hours of respite six times each year. Providers needed a background check on file to be paid. A family maximum of \$100 was allowed each time with this program. Generally Respite Days are scheduled around holidays.
2. FUN Days Program received \$5,000. FUN Days brings children with disabilities and their siblings together for a day of fun. FUN Days were offered in Chadron, Sidney and Scottsbluff. One respite day this past year was funded by the United Way.
3. The remaining \$3,000 was used for Emergency Respite Services. These funds are utilized when other sources of funding cannot be secured.