



# Respite Task Force Report





# Respite Task Force Report

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## Acknowledgements

The Respite Task Force is a workgroup made up of family caregivers, state and community nonprofit agencies, and coordinators from the Nebraska Lifespan Respite Network. This group was formed in October 2017 in response to a grant awarded to the University of Nebraska Medical Center's Munroe-Meyer Institute (MMI) by the Nebraska Planning Council on Developmental Disabilities. Also providing feedback were members of the Nebraska System of Care group, faculty and staff at the MMI University Center for Excellence in Developmental Disabilities (UCEDD), and the University of Nebraska-Lincoln Center on Children, Families and the Law. Reference also is made to the "Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families 2015-2017 Evaluation Final Report". This respite evaluation was conducted by Jolene Johnson, Ed.D. of MMI, made possible with federal funding awarded by the Nebraska Department of Health and Human Services Lifespan Respite Program.

### **Partners on the Respite Task Force**

Nebraska Department of Health and Human Services (DHHS) Representatives:

- Division of Children and Family Services
- Division of Developmental Disabilities
- Division of Medicaid and Long Term Care
- Six local Lifespan Respite Networks

Nebraska Caregiver Coalition

Aging Partners, Lincoln

Nebraska Total Care

Parents and other family caregivers

Nebraska Family Collaborative (now Promise Ship)

Brain Injury Alliance of Nebraska

Special Education Para-Educator, Big Springs, Nebraska

UNMC Munroe-Meyer Institute, University Center for Excellence in Developmental Disabilities

We wish to acknowledge the many family caregivers across the state who responded to a needs survey looking at gaps and barriers to accessing respite care services in Nebraska.

This report provides an overview of respite programs in the state and addresses the identified gaps and barriers to the utilization of respite care services in Nebraska. Members of the Respite Task Force (hereafter referred to as RTF) generated recommendations to address these issues.





## Preface

The following narrative was written by Mandy Sullivan and Mary Ann Carson, a mother and daughter who served on the Respite Task Force. These two family caregivers paint a picture of the support afforded to family caregivers in our state and the negative outcomes that occur when support is not provided.

### **Carry Another Person's Burden for a Few Steps, and You Can See for Miles**

Carrying another person's burden is the very definition of respite. Yet, how do you go about it? How do you sustain it? These are the questions posed by those who control the fate of this quintessential program. The answer is, you invest in your people, your Nebraskans. If you are from Nebraska, chances are you have heard individuals from other states say, "Nebraskans are just so down to earth. Why is that?" Because we Nebraskans work with the earth. We work with Mother Nature, and we have learned that when we work against her, we lose every time. The same holds true for our Nebraska family caregivers. If the policies and laws work against our caregivers, we will all lose every time.

We want to grow our state. We want the young to return to Nebraska and carry the legacy of their parents. The problem is, the family farm has been sold. Grandpa and Grandma outlived their money. Mom and Dad had to sell their retirement investment, the family farm, to pay for the

\$7,000-per-month nursing home bill. There was not enough help or assistance to keep them home. Now the kids and grandkids have nothing to return to.

The same holds true for our Nebraska families with a child who has a disability. Quite often, one parent will need to step away from their career path to care for their child's special needs, usually crippling an already strained household budget. For families in the agricultural sector, this equates to equipment, livestock or land sales.

Nebraskans are proud people. They want to care for their own. Neither snow nor rain nor heat nor gloom of night deters these caregivers of the land and livestock from completion of their duties. Neither lack of funding nor unfavorable governmental policies nor self-need deter these caregivers from the completion of their duties for their loved ones.

The truth is, without “respite” the family caregiver works him or herself into the ground. They ignore their own health needs. They ignore their own financial limits. They ignore their own social and emotional needs. They find themselves abandoning their routine religious practices because Grandpa gets too disruptive during the service. Their marriages are strained because all their energy is devoted to their special needs child, leaving them emotionless for their spouse. Weekly invitations for coffee stop coming because they canceled one too many times. The most devastating outcome is, they forget to put on their own life vest, canceling a mammogram because their husband fell again this morning.

We’re not asking for millions of dollars. We’re not asking for tracts of real estate with brick and mortar facilities to fund and maintain. We’re asking you to invest in your people. The people you so faithfully serve – the Nebraska caregivers. The very people who believed enough in you to get the job done right. Please believe in them so they can continue to do their job right.

“Carry another person’s burden for a few steps, and you can see for miles. Lighten another person’s load and together you can complete the journey.”





## Executive Summary

According to Jill Kagan, Director of the Access to Respite Care and Help (ARCH) National Respite Network and Resource Center,<sup>1</sup> Nebraska historically has been held as a national model for respite programming (2017). Success of the Nebraska Lifespan Subsidy Program<sup>2</sup> became the model for Congress to pass the National Lifespan Respite Care Program of 2006, which has been reauthorized annually.

Research shows that family caregivers continually face increased levels of depression, stress, risk for heart disease, and other health conditions.<sup>3</sup> Research also demonstrates that providing family caregivers access to respite decreases caregiver and care recipient stress (Jolene Johnson, 2017), lowers sibling strain,<sup>4</sup> improves marital quality,<sup>5</sup> and decreases long-term care expenditures by

keeping individuals in their homes rather than in long-term care facilities.<sup>6</sup> As our population ages, the need to identify strategies to better support family caregivers will be paramount as the caregiver support ratio declines from 1:7 in 2010 to 1:3 by 2050.<sup>7</sup> This means that for every person in need of long-term care services and supports (LTSS) in 2050, there only will be three family caregivers who will be available to provide this support.

The Eastern Region of the Nebraska Lifespan Respite Network, housed at MMI, was awarded a grant from the Nebraska Planning Council on Developmental Disabilities in October 2017 to tackle the pressing issues around respite in Nebraska. The Respite Task Force (RTF) was gathered in November 2017, comprised of an array of stakeholders from across the state, to actively

Respite: Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

*Lifespan Respite Care Act definition (PL 109-442)*

<sup>1</sup> <https://archrespite.org>

<sup>2</sup> [http://dhhs.ne.gov/Pages/hcs\\_services\\_respite.aspx](http://dhhs.ne.gov/Pages/hcs_services_respite.aspx)

<sup>3</sup> <https://www.caregiver.org/caregiver-health>

<sup>4</sup> <https://www.canchild.ca/en/resources/206-respite-services-a-critical-review-of-the-literature>

<sup>5</sup> <https://link.springer.com/article/10.1007/s10803-013-1812-0>

<sup>6</sup> Impact of Respite Care Services for Families With Children Experiencing Emotional and Behavioral Problems. *Children's Services: Social Policy, Research, and Practice*, 3(1), 39-61).

<sup>7</sup> <https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>

## CAREGIVER SUPPORT RATIO



collaborate in addressing the needs of family caregivers in Nebraska. The RTF met monthly, offering face-to-face meetings as well as reaching online stakeholders from across the state through online technology.

It was the aim of the RTF to develop a framework to strengthen, support, and expand the Nebraska Lifespan Respite Network and to advance the capacity to deliver respite care services to family caregivers in our state.

Based on survey results and RTF discussions, this report identifies gaps and barriers in accessing respite services as well as recommendations on how to address

these pressing issues. Members of the RTF worked to address recommendations/strategies at the systems level, programmatic level and consumer level to strengthen and improve the utilization of respite services in all programs. Special consideration was given to the Nebraska Lifespan Respite Subsidy Program within the DHHS Division of Children and Family Services, as it provides wider program eligibility and flexibility due to not being governed by Medicaid rules.

### State and National Respite Programs

**The Nebraska Lifespan Respite Network** began with a group of individuals coming together at a statewide conference in August 1997. In the spring of 1998, a request for proposals was issued by Nebraska DHHS to convene a statewide initiative to promote respite, develop permanent funding, promote the development of training of providers and families, and establish a centralized information and referral source for services. In 1999, LB148 was introduced by state Senator Dennis Byars. The bill was passed, establishing the Nebraska Lifespan Respite Services Program in state statute (Neb. Rev. Stat. §68-1520 through 1528). It consists of the following:

1. The Lifespan Respite Network was designated to coordinate community respite services; and
2. The Lifespan Respite Subsidy Program was designated to provide funding for caregivers to purchase respite services.

The Nebraska Lifespan Respite Subsidy Program is centralized and administered through Nebraska DHHS and supported with state funding from the Nebraska Cash Settlement Tobacco Fund. The Lifespan Respite Network became operational in 2000. The state was divided into six areas, contracts were awarded, and coordinators were hired for each area. A map and local contact information is included in the appendix of this report.

In 1999, Lifespan Respite Subsidy Program funding was made available with the rate set at \$125 per month to offset the costs of securing respite services for families (Title 464 NAC 1-4). The legislature annually allocates \$404,464 for administrative support and \$810,000 for services to support the Nebraska Lifespan Respite Subsidy Program. The monthly subsidy amount has not been increased since the program start in 1999.

There are additional sources of respite funding available for family caregivers. However, the amounts of funding for respite services is often limited in scope and requires stringent eligibility criteria with no two programs having the same requirements. Some of these government-funded sources include the following:

- The Aged & Disabled Medicaid Waiver (Aged, Adults and Children)
- The Development Disabilities Waiver
- Adult and Child Protective Services, Foster Care, Subsidized Adoptions
- Title III Older Americans Act
- U.S. Air Force Exceptional Family Member Program and Veterans Caregiver Support.

The need to enhance the supports provided to family caregivers is gaining national attention. A bipartisan bill called the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act<sup>8</sup> was passed by Congress and signed into law by President Donald Trump in 2018. The Act creates an advisory council charged with making recommendations to support family caregivers.<sup>9</sup>

The RTF determined that a short statewide respite needs survey to build upon the results of the previous respite evaluation authored by UNMC/MMI in 2015-2017<sup>10</sup> would be beneficial. A survey was developed and disseminated across the state through the six local networks, on Facebook, and distributed to constituents of RTF members, through agency newsletters, and more. Approximately 250 survey responses were received with many people sharing stories about their respite experiences and needs. Additional insights were shared by RTF members drawing from their own personal experiences with respite and issues shared by their friends and colleagues. Similar needs were identified between the RTF survey and the 2015-2017 evaluation conducted by UNMC/MMI.

The need to support family caregivers will become a more pressing issue as our aging population requires more long-term services and supports. Many states are starting to provide more services to better support the needs of family caregivers to reduce or delay the need for 24/7 services in efforts to reduce Medicaid expenditures.

8 <https://www.aarp.org/politics-society/advocacy/info-2017/senate-passes-family-caregivers-act-fd.html>

9 <https://www.aarp.org/politics-society/advocacy/info-2018/senate-family-caregivers-act.html>

10 [https://arch.wildapricot.org/resources/Documents/2016\\_Natl\\_Respite\\_Conf/PPTs/C-4%20J.%20Johnson%20Nebraska%20Eval.pdf](https://arch.wildapricot.org/resources/Documents/2016_Natl_Respite_Conf/PPTs/C-4%20J.%20Johnson%20Nebraska%20Eval.pdf)



### **Nebraska Lifespan Respite Services Program Mission**

(Neb. Rev. Stat. 68-1520 through 1528)

*A service designed to give family caregivers a break from the demands of providing ongoing care for an individual with special needs.*

A term unfamiliar to many, respite is help for the helpers. The Nebraska Lifespan Respite Network provides information and referral, provider and caregiver training, and resource development for respite services. The availability and usage of respite enables family caregivers time for themselves to refresh and rejuvenate, thus improving their physical and emotional health.



## Introduction

The majority of long-term services and supports are provided by unpaid caregivers – family or friends.<sup>11</sup> According to the American Association of Retired Persons (AARP), it was estimated that in 2015 there were more than 200,000 family caregivers in Nebraska (this number may not be inclusive of those families caring for children and adults with intellectual and developmental disabilities). Families are the backbone of Nebraska’s long-term care system. They provide care to their loved ones who experience Alzheimer’s disease and other types of dementia, those with intellectual and developmental disabilities (IDD), those with significant health diagnoses, and serious emotional and behavioral conditions. They provide care across the lifespan, from young children to aging family members.

Most individuals who experience IDD, as well as older Nebraskans, reside in their family homes. In order to retain and sustain family caregivers, they need a break. A critical issue identified by the Nebraska Planning Council on Developmental Disabilities is ensuring that family caregivers can access respite care services, especially for those with loved ones having high medical needs and behavioral health issues. One of the Council’s goals is to increase community inclusion for individuals with intellectual and other developmental disabilities of diverse identities. One way to achieve this objective is to expand and enhance respite care

**The economic impact of uncompensated care provided by family caregivers in 2013 surpassed total Medicaid spending (\$449 billion) and nearly equaled the annual sales (\$469 billion) of the four largest U.S. tech companies combined (Apple, Hewlett-Packard, IBM and Microsoft).\***

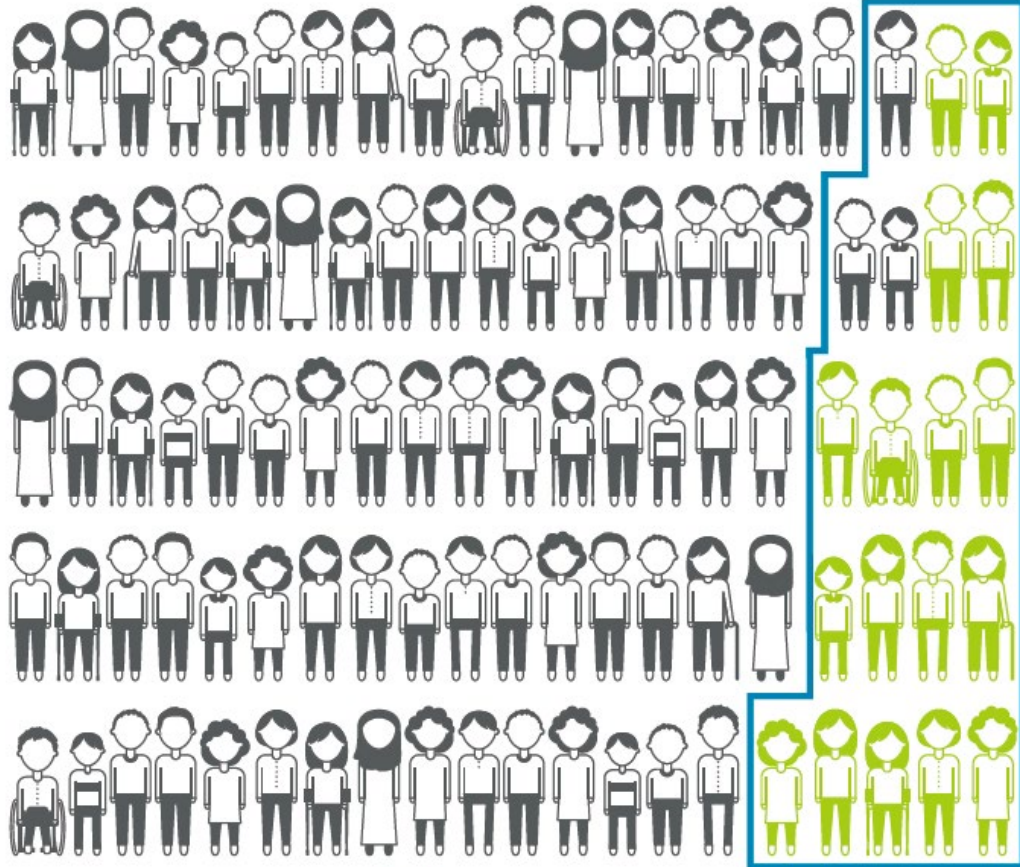
services throughout the state. This is supported by the 2015-2017 Respite Evaluation that demonstrated that individuals providing caregiving can suffer from various serious health conditions if they do not have access to at least brief periods of respite to enable them to refresh and rejuvenate. Family caregivers without access to respite are more inclined to consider alternate placements for their loved ones. This limits the individual’s access to their community and family members.

<sup>11</sup> <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>

\* <https://www.aarp.org/caregiving/financial-legal/info-2017/family-caregiving-costly-jj.html>

## People with IDD in the United States and the Proportion Who Receive Services

**7.37 million** people in the United States had Intellectual or Developmental Disabilities (IDD) in 2016



**20%** 1.49 million people with IDD were known to or served by state IDD agencies

**17%** 1.23 million people with IDD received long-term supports or services through state IDD agencies

Sources: Prevalence rates for children with ID, ASD, or DD from the 2016 National Health Interview Survey (NHIS; Zablotsky et al, 2017), prevalence rates for adults with ID, DD, or both from the 1994/1995 NHIS (Larson et al, 2001), estimated U.S. service recipients with IDD from the FY 2016 RISP report (see citation below).



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Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

# Concerns Identified Through the Respite Report

*The process to access respite funding and usage is perceived as “too confusing and bureaucratic.”*

*Quote from surveyed family member*

## 1. THE PROCESS TO ACCESS RESPITE FUNDING IS CONFUSING.

Each program that provides respite has specific rules and requirements pertaining to respite eligibility, usage, and determination of access to respite funding.

- The Nebraska Lifespan Respite Subsidy Program is supported with state general funds and has requirements for eligibility and established requirements for providers.
- State Medicaid Waiver Programs (Aged & Disabled Waiver and Developmental Disability Waivers) have their own eligibility respite requirements and different requirements for providers.
- The Nebraska Lifespan Respite Program statute requires that the Lifespan Network (consisting of the 6 regional coordinators across the state) coordinate all community respite programs; however, in practice, the Lifespan Respite Subsidy is the primary program supported by the Nebraska Respite Network.

Efforts are needed to simplify the Nebraska Lifespan Respite Subsidy eligibility process for families and align the requirements of respite providers across all programs.

## 2. NEBRASKA LIFESPAN RESPITE SUBSIDY APPLICATION AND ELIGIBILITY PROCESS.

The process to determine eligibility for the Nebraska Lifespan Respite Subsidy has stringent financial guidelines as referenced in Title 464 NAC 1-4.<sup>12</sup> Efforts to simplify the Lifespan Respite Subsidy application process have been attempted, but families still indicate that the application process is long and cumbersome. Many families have shared that the application process is not worth the time that it takes to provide all of the necessary documents and to complete the paperwork. Others indicate that the allocation of \$125 per month does not cover the expenses necessary to provide respite care. Our survey showed, and the Nebraska Respite Network Services coordinators corroborate, that many

families who are determined “over income” for eligibility are still struggling financially. This is particularly true for farmers and ranchers who are “land rich but money poor.” Often, when families are asked to submit bank statements in order to determine eligibility for the subsidy, many already feel they will be denied and do not continue the process because their financial situation is very different on paper than in actuality.

Recently, the Nebraska Lifespan Respite Subsidy Program has implemented two initiatives that are working to help meet family needs: the ability for families eligible for the subsidy to bank their monthly allocation to use for special respite activities, and the creation of an enhancement to funding for families who have exceptional needs or circumstance. While families may be eligible for an additional \$1,000 for *Exceptional Need/Circumstances*, they cannot receive this funding until they have been approved for the initial Lifespan Respite Subsidy funding, a process which can take an average of a month or more.

Unfortunately, this keeps those who are in crisis from accessing respite. Many family caregivers are in fight-or-flight mode and often hit a point where a crisis condition is immediate but, because of the way Nebraska’s programs are set up, they cannot access any respite supports without already being eligible for a program.

Another concern that families who are subsidy-eligible have is the potential to lose their program eligibility if they are not consistently using the program monthly. Families who don’t bill for 60 or more days are contacted by a Respite Coordinator and offered assistance with locating providers, instructed on billing, given suggestions on how to use authorized respite funds, etc. Families are advised that if they don’t bill, it indicates a lack of respite need, and they risk having the respite case closed. Program staff regularly offer to bank unused months to prevent families from losing respite funds. Unfortunately, **this policy does not allow the family flexibility to self-direct respite services and denies families the ability to use respite supports when they need it.** For example, a family fighting the flu bug reported that they did not want any respite providers to come to their home for fear of transmitting the virus. The following month, the respite provider fell ill. Without the Respite Coordinator stepping in and suggesting that the family bank these two

<sup>12</sup> <http://dhhs.ne.gov/Documents/Title-464-Complete.pdf>

months, based on the current program, the family would likely have lost their eligibility for this program.

### 3. PAYMENT PROCESSES AND BARRIERS LEAD TO SLOW PAYMENTS.

Several respite providers have indicated that Nebraska DHHS does not pay in a timely manner, creating additional barriers for providers. However, much of the issue seems to be that providers are submitting billing documents with errors, including not keeping addresses updated, having incorrect dates, or changing banking information while a payment is processing. When an error occurs, it's likely that DHHS will request that the family/provider submits a new billing document.

Payment processes vary by program but do share the issue of claims processing going through several steps and departments before a payment can be generated. Nebraska Medicaid is currently exploring electronic options to meet the 21st Century Cures Act.<sup>13</sup> Having the Respite Subsidy Program consider this may reduce payment processing times in the future.

***Funding provided to family caregivers for respite services is perceived as “woefully inadequate.”***

*Quote from surveyed family member*

### 4. INCREASE THE NEBRASKA RESPITE LIFESPAN

While the Lifespan Respite Subsidy provides eligible families with up to \$125 per month for respite services, families can supplement the provider payment and are able to dictate or negotiate the rate with the respite provider. However, this funding amount falls very short for families who provide care for individuals with high medical or behavioral health needs. Inadequate subsidy funding for costly specialized in-home or in-facility respite care impacts families and respite providers.

**The Nebraska Respite Subsidy was established in 1999 and established the allocation of \$125/month to family caregivers. This rate has not been increased since the program started – almost 20 years ago.**

*Quote from an RTF Stakeholder*

When families must pay \$25 - \$40 per hour in order to obtain the services of a skilled provider, this allows only three to five hours per month of respite, making it difficult for family caregivers to obtain a sufficient amount of time to truly take a break from the ongoing responsibilities of providing care. Due to the limited amount of funding provided by the subsidy, many families find it difficult to recruit providers needed to meet the higher care needs of their loved one or retain providers with whom they have developed relationships.

### 5. THERE ARE GAPS IN SUPPORTING INDIVIDUALS WITH HIGH MEDICAL NEEDS OR WHO EXPERIENCE HIGH BEHAVIORAL HEALTH NEEDS IN BOTH HOME AND AGENCY SETTINGS.

Families who are supporting an individual who meets a nursing home-level-of care, may be eligible for one of the state's Medicaid Waiver Programs. Sometimes these programs may provide more funding for respite. However, even with this increased funding, many families indicate they cannot find properly trained providers.

***“Respite money is not enough to pay for a caregiver with the skills necessary to meet my daughter’s needs: suctioning, tracheotomy care, low body temps, oxygen needs, feeding pumps, g-tube feeds and medications, lifting, transferring, positioning and so much more. My husband and I have not been***

***“My child was highly volatile, and we were unable to find someone qualified to provide respite for him for the money allotted by the respite program. Our child would have needed much more time to develop a relationship with the care provider and feel safe with them... When you have the fulltime care required of a child with serious mental illness, locating a cheap but qualified provider in the community is really burdensome and acts as a serious deterrent to families using the Nebraska system.”***

*Quote from surveyed family member*

<sup>13</sup> The 21st Century Cures Act, signed December 13, 2016 by President Barack Obama, promotes and funds the acceleration of research into preventing and curing serious illnesses; accelerates drug and medical device development; attempts to address the opioid abuse crisis; and tries to improve mental health service delivery. The Act includes a number of provisions that push for greater interoperability, adoption of Electronic Health Records Systems (EHRs), and support for human services programs.

***out, alone, for over 5 years. Not having respite not only affects the caregiver, it affects marriages and families.”***

*Quote from surveyed respondent*

This sentiment was reflected across the state as family caregivers who need respite services the most are frequently those who cannot find or afford the costs associated with paying for higher skilled workers, such as behavior specialists or nursing staff. One family wrote that the husband had to quit his job in order to stay home and care for their son because they were unable to find adequate care. Another mentioned they had to make the decision to move their child into an institutional facility because the stress of caring for their child with no back-up support was too great for their family.

There is also a need to identify ways to better support Independent providers. Independent providers face their own challenges as they assume the risk of providing services. Under Nebraska’s current system, in case of injury by the care recipient or in the event an accident would occur, the family and care provider would have to negotiate the cost and decide who will be liable. This risk is frequently cited as one reason respite providers will not provide care for those who have higher care needs. These individual providers are considered self-employed and most likely lack benefits such as workers’ compensation, pay for their own health care insurance, and frequently cannot afford to not have funds to address these additional costs. They are also responsible for paying for all their income taxes which also cuts deeply into the limited hourly pay they receive.

***In order to keep families together and defer institutional placements, the state likely needs to invest in additional training for respite provider and other direct care staff.***

## 6. MORE SPECIALIZED TRAINING FOR RESPITE PROVIDERS IS NEEDED

The lack of training for individual respite care providers and, conversely, the corresponding pay increase typically identified with providers who have received continuing education are frequently cited as barriers to accessing qualified respite providers.

***“It takes a certain level of knowledge and experience to care for a special needs child with autism.”***

*Family member quote*

While the Nebraska Lifespan Respite Network requires a general online orientation for network-screened respite providers, this orientation only covers basic information about providing respite care. It does not address the specialized skills necessary to work with individuals who have intellectual and developmental disabilities, significant behavioral health or high medical needs, including Alzheimer’s disease, stroke, or traumatic brain injuries. Additionally, this training is not required across other respite programs nor is there any consistent training requirement across all state respite programs. ***There is a need to offer uniform training that leads to higher wages or a career-path which improves the quality of care and helps to sustain the current workforce.***

The Nebraska Behavioral Health System of Care<sup>14</sup> partners discussed that even when they have individuals skilled in caring for persons with more significant behavioral needs, they are often unable to get them to become respite providers. Without a systematic approach to train and retain both independent and agency-based providers, the state’s 3% unemployment rate means that many people who could be respite providers realize that they can make more by working at fast food restaurants or local businesses and be eligible for pay raises, college reimbursement, and benefits packages.

## 7. CAPACITY BUILDING NEEDS

Finding child care was another concern expressed by survey respondents. Family caregivers state that the barriers to identifying childcare providers willing/able to take their child with special needs deters their ability to remain employed and support their families. For example, two daycare programs in Omaha originally established to care for those with medical and/or behavioral needs have stopped serving children who have more extensive behavioral needs. One of the two is focusing only on children with more significant medical needs.

**Respite coordinators frequently field calls by frantic parents/guardians looking for childcare for children with high needs. While childcare is not considered respite, obtaining more specialized childcare is a barrier for family caregivers and one that the state Respite Coordinators are frequently asked to meet.**

*LTC Stakeholder*

<sup>14</sup> [http://dhhs.ne.gov/behavioral\\_health/SOC/Pages/Home.aspx](http://dhhs.ne.gov/behavioral_health/SOC/Pages/Home.aspx)



“Honestly, there needs to be facilities across the state for individuals with severe behavioral needs so well-trained staff can provide the short-term breaks that families need. We have nothing like this in western Nebraska.”

*LTC sStakeholder*

Barriers also exist for young adults with disabilities who, because of their age, are considered too old to be in day care settings but still need support. For example, young adults on the autism spectrum typically need additional supports during the summer months and over school breaks.

Some families of children or adults with significant behaviors express interest in having places outside of the home where their loved one can receive care on a short-term basis. Many families who have children/adults with co-occurring conditions (e.g., mental health and developmental disabilities) have also expressed the need for having more of a break than just a few hours of respite. They are needing a day or even a weekend to be able to take care of their whole family without constantly devoting their undivided attention to the individual with the

co-occurring condition. This is a critical issue across the state of Nebraska as there are very limited numbers of agencies or individuals who are trained and willing to provide care for those individuals with high medical or behavioral health needs.

**There is a need in Nebraska for places providing emergency or crisis respite care for those situations where the family is in a crisis** or the individual happens to be in a behavioral condition that makes it unsafe for themselves or their family. Frequently, respite coordinators receive incoming calls from stressed family caregivers looking for emergency facilities where they can take their loved one. Currently, there are not sufficient programs that support families in crisis. If they exist, there are additional barriers for those with both developmental disabilities and mental health issues. **These calls exceed the current services available within Nebraska’s Respite programs.** In these situations, the Respite Coordinator offers support and assists with referrals to the Nebraska Family Helpline, mental health providers or law enforcement, if necessary.

## Recommendations to Improve Access to Respite and Support Family Caregivers

Many of the following recommendations are specifically targeted to the Nebraska Lifespan Respite Network and Subsidy programs. However, there are several recommendations that apply to all programs that provide respite services to support family caregivers. The RTF believes that having the state programs work together to better support family caregivers will lead to better outcomes for both the care recipient and care provider. This will likely also reduce Medicaid expenditures by supporting the families and keeping them in their caregiving role and the individuals who need long-term care outside of costly institutional care.

### Programmatic Suggestions

- 1. Increase the Lifespan Respite Network Subsidy rate.** The Nebraska Lifespan Respite Subsidy program should be increased from the \$125 monthly subsidy that was established when the program was created. The increase should account for the cost of living increases that have occurred in the past twenty years and should also establish a required cost of living increase for future years so the program will remain competitive and viable. Additionally, the respite subsidy should provide a higher amount of funding to those families who are providing care for individuals who have higher care needs. Assessments administered by the Nebraska Division of Developmental Disabilities could be referenced as one way to determine the level of care an individual needs and corresponding funding allocated to meet the individual’s needs.
- 2. Pilot the use of Medicaid Support Waivers.** In an effort to keep individuals in less costly home- and community-based settings, and to decrease the waiting

lists for home – and community-based services, states are starting to implement Medicaid Support Waivers. These waivers provide a limited budget to families and budget predictability for states. Families are allocated a set budget which can be self-directed and utilized to pay for respite, transportation, and specialized childcare as examples. States such as Tennessee, Pennsylvania, and Massachusetts are implementing these waivers with an annual budget range starting at \$12,000.<sup>15 16 17</sup> This would also remove the issue of not utilizing services in a uniform basis from month to month or have the program interrupted without intervention by the case worker.

It is recommended that the Division of Children & Family Services and Nebraska Lifespan Respite Network, together with the Division of Medicaid and Long Term Care, plan to submit for a Medicaid Support Waiver. Initially, the Nebraska Lifespan Respite Subsidy state funds (Tobacco Cash Settlement Funds) could be used to pilot a limited number of family support waiver slots to demonstrate impact. This would allow data to be collected in order to build the business case to expand the program through a Medicaid match.

#### **Family Support Waivers could:**

- Provide a higher annual budget to enable families to pay providers a higher rate, thus better compensating providers who have obtained specialized training to support individuals with high medical and behavioral health needs.
- Help retain effective providers who have developed relationships with the family and care recipient.
- Help remediate many concerns articulated by Nebraska stakeholders by allowing families to direct their budget to provide for the services they need.
- Expand state funding with Medicaid match to both enhance and maximize the support available for family caregivers.

The Nebraska Lifespan Respite Network could coordinate this new program. This program shift aligns with the original legislative intent of the Nebraska Lifespan Respite Network and Subsidy Program, and also aligns with the network's current sustainability plan. Medicaid match could be utilized for respite service costs and could be used to support the administrative costs associated with the respite coordinator salaries,

which creates both enhanced funding and program sustainability.

- 3. Provide a higher reimbursement for providers who must drive long distances to provide care.** In many locations, respite providers must drive significant distances in order to offer in-home respite care services. This is true in rural, urban, and western geographic areas. Driving to a person's home encompasses both the provider's time and money. The cost of gas and upkeep on their vehicles are expenses that currently are not reimbursed. While the Nebraska Lifespan Respite Subsidy Program will allow families to pay a higher rate to offset these expenses, this cuts into the families' funding to access respite. The lack of reimbursement can deter individual providers from wanting to travel long distances to provide in-home respite care. DHHS should consider allocating a higher reimbursement for families living in rural communities or for providers who must drive over a set number of miles (20 miles or more).
- 4. Identify strategies to eliminate the risk to families and providers.** Families consistently indicate that they cannot find providers who are willing to provide support for those with high medical and behavioral health needs. A root cause for this is the self-directed consultant model that Nebraska uses for the Nebraska Lifespan Respite Program. Under this model, the risk of providing care for an individual with high needs is shared by both the family and the provider. Unfortunately, in a time when even the best of intentions can result in a lawsuit, many independent providers feel they cannot afford to take on the risk of providing care for someone with high needs. Most independent providers do not have the funds to purchase liability or workers' compensation insurance, or even have adequate health insurance to pay for an unintended injury to themselves or their care recipient. However, there are options that would likely remove these barriers.

**A. Set up agreements with agencies in each local network to provide respite.** DHHS could contract with developmental disability agencies, childcare providers or assisted living facilities, paying them a daily rate for families deemed eligible for the Lifespan Respite Subsidy Program. A suggestion would be to allocate two days per month of respite care in an agency setting. Agencies have liability insurance and

<sup>15</sup> Tennessee Community First Choice: <https://www.tn.gov/content/dam/tn/tenncare/documents/introductionToEcfChoices.pdf>

<sup>16</sup> Maryland Family Supports Waiver Frequently Asked Questions: <https://dda.health.maryland.gov/Documents/Family%20Supports%20Waiver%20FAQs%207-10-17%20Final.pdf>

<sup>17</sup> Pennsylvania Person/Family Directed Support Waiver: <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/personfamilydirectedsupportwaiver/index.htm>

typically offer medical and workers' compensation insurance to their staff, so the majority of the risk is shouldered by the providing agency. This would give families who are providing care for an individual with higher needs the opportunity to have a break while their loved one is supported in a setting that could accommodate their needs.

- B. Adopt a fiscal intermediary agency model.** As part of the state's long-term care redesign, a priority recommendation is to utilize a fiscal intermediary agency to manage independent providers.<sup>18</sup> The report by the National Association of States United for Aging and Disabilities (NASUAD) explains that this will help individuals hire and train their own providers but not have the responsibility for

payroll or tax withholding, nor purchase workers' compensation and liability insurance. The use of a fiscal intermediary minimizes the risks that Nebraska's current model places on both the respite provider and the family. DHHS could subcontract this role out to a community-based organization or issue a competitive Request for Proposals for an organization to assume the role to manage all independent respite providers across all Nebraska programs. The Respite Network coordinators could serve as the brokerage service, detailed in the NASUAD report, which would be needed to provide the supports for individuals and families to locate and train respite providers for those who choose to participate.<sup>19</sup>

## Administrative Suggestions

- 1. Investigate a change in policy when considering a family's assets in determining financial eligibility for the Lifespan Respite Subsidy.** Farmers, ranchers, and others may appear to have significant assets on paper but actually have very limited "liquid" assets available to pay for the cost of respite care. While the RTF believes that the income guidelines for eligibility are pretty lenient, it was felt that adjustments should be considered for those whose assets are attached to land and equipment and retirement accounts that are not readily converted into cash.

*Note: Program currently disregards irrevocable burial funds, educational savings accounts while child is school-age, retirement savings for working-age adult, and IDEA savings.*

- 2. Improve the current billing system requirements for providers to receive payment for providing respite services.** Families and their respite providers must submit DHHS billing documents monthly. Both families and providers have expressed concern and frustration in having to complete monthly billing documents in their entirety when the Department already has most of the information on file. While DHHS has a multi-step review and approval billing process, there is a need to improve efficiencies and streamline this process. Payment delays occur when staff find billing documents which have not been completed, resulting in the provider not getting paid for the respite services they provided the previous month. Improvements need to be made to both

billing requirements and reimbursement processes. The Nebraska Lifespan Respite Network has lost respite providers due to the slow payment process.

- 3. Streamline the application process for those individuals seeking to become respite providers.** Currently, the Nebraska Lifespan Respite Network is working to develop an online application process for those applying to become independent respite providers through the respite website ([www.nrrs.ne.gov](http://www.nrrs.ne.gov)). This will expedite the screening process for those interested in becoming a respite provider for the Nebraska Lifespan Respite Network. However, because there are different requirements for respite providers across programs, families are not able to draw from one single pool of respite providers. Instead, anyone who is an independent provider must go through a separate process for each program to be reimbursed. This process is confusing for many providers and limits the provider pool. To help streamline and simplify this process, encouraging the same requirements across all programs may be beneficial. Another option might include having the Respite Network-screened providers go through the same process required by Medicaid-funded programs.
- 4. Address the lack of understanding of how respite is defined and where to go to access services.** While many individuals who responded to our survey appeared to know about respite, we also learned that some families are not aware of what respite actually means. The RTF

<sup>18</sup> <http://dhhs.ne.gov/medicaid/Documents/Nebraska-Long-Term-Care-Redesign-Plan.pdf>

<sup>19</sup> <http://dhhs.ne.gov/medicaid/Documents/Long%20Term%20Care%20Redesign%20Plan%20-%20Draft%20by%20Mercer%20Health%20Benefits,%20Inc%20v2.pdf> (see pages 28-29)

reviewed the existing Network brochure and determined more clarification was needed. A new respite brochure was drafted, reviewed by the RTF, and finalized by DHHS graphic designers and approved. A copy of the newly designed brochure is included in this report in the Appendix. Additional outreach will be needed to help family caregivers understand the importance of respite and how they can access this valuable program.

## Summary

There are many actionable activities that can be immediately adopted by the Nebraska Lifespan Respite Network and other DHHS programs to better support family caregivers. As programs have shifted from institutional placements to support home- and community-based systems, the increased caregiving demands placed on family caregivers have not been adequately addressed. The adverse impacts of providing continual care by families who are also working is becoming a significant public health issue. As our population ages and the corresponding demands of family caregivers increase, it is imperative for states to identify ways to enhance the supports provided to family caregivers now. Research consistently demonstrates that access to respite care is one way to improve both care recipient and caregiver health. When the burden of family caregivers is lightened, these caregivers are more able to continue in their caregiving role.

## Respite Funding Sources

For more information on respite funding go to:

[nrrs.ne.gov/respite/funding](http://nrrs.ne.gov/respite/funding)

- Aged & Disabled Medicaid Waiver (Aged, Adults & Children)
- Adult Protective Services
- Alternative Response
- Child Protective Services/ Foster Care
- Developmental Disabilities Medicaid Waivers
- Disabled Children's Program
- Nebraska Lifespan Respite Subsidy Program
- Private Pay
- Subsidized Adoption
- Title III Older American's Act
- U.S. Air Force Exceptional Family Member Program
- Veterans Caregiver Support

For assistance with respite funding or finding a respite provider, contact your local Respite Coordinator.



## Did You Know ...

There are over 219,000 identified family caregivers in Nebraska.

### Providers Wanted

Are you interested in becoming an independent respite provider?

- Do you enjoy setting your own hours?
- Do you enjoy working with families?
- Do you want to make a family caregiver's life a little easier?

Contact your local Respite Coordinator at the number listed on the inside of this brochure or go to [nrrs.ne.gov/respite](http://nrrs.ne.gov/respite) to apply.

**Call Statewide**

**1-866-RESPITE**

**1-866-737-7483**

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CFS-PAM-26 5/2018

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**NETWORK**

**Taking care of yourself—is one of the best ways to help your loved one!**

**We Care for Those Who Care for Others**

**1-866-RESPITE**

**1-866-737-7483**

<http://nrrs.ne.gov/respite>

## What is Respite

Help for the helpers. Respite is a break for unpaid family caregivers caring for a loved one with special needs.

Respite allows the family caregiver time away to care for their personal needs.

Research shows that when family caregivers take time for themselves, they improve their physical and emotional health.

### You can use respite to:

- Go to the grocery store
- Visit the doctor
- Have lunch with a friend
- Take a nap
- Or anything else you need or want to reduce stress

## Am I a Family Caregiver?

A family caregiver is a person who provides ongoing care for an individual unable to care for themselves due to age, physical or mental disability, or illness. If your loved one cannot be left alone due to a special need, we can help.



## What is the Nebraska Lifespan Respite Network

Caring is rewarding, but also demanding and stressful. We offer information, education & support.

We are the place to contact to discuss your respite needs.



## Who Provides Respite

There is some flexibility in finding providers. Your local Respite Coordinator can assist you with finding a provider in your area. You may be able to use family members, friends or neighbors as paid providers. Depending upon funding source,

other possibilities include: organizations, camps, a trusted agency, a local volunteer-led organization or group, volunteer-led school-based program, equine program, faith-based or other approved activities. While your loved one is attending an activity, you are getting a break—and that's what respite is all about!

You can locate screened respite providers at: [nrs.ne.gov/respite](https://nrs.ne.gov/respite)

Click on: "Find a Provider"

## Contact Your Local Coordinator to Learn More:

- Western Area**  
 308-432-8190  
[respite@wchr.net](mailto:respite@wchr.net)
- Southwest Area**  
 308-345-4990  
[respite@swhealth.ne.gov](mailto:respite@swhealth.ne.gov)
- Central Area**  
 308-745-0780 ext. 139  
[respite@centralnebraskacap.com](mailto:respite@centralnebraskacap.com)
- Northern Area**  
 308-745-0780 ext. 145  
[respite@centralnebraskacap.com](mailto:respite@centralnebraskacap.com)
- Southeast**  
 402-300-8448  
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- Eastern**  
 402-559-5732  
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