



**REPSITE ACROSS THE LIFESPAN SUSTAINABILITY PLAN  
2016-2017**

**Executive Summary**

According to research studies, 4 of 10 United States adults are caring for a child or adult with significant health issues. In the state of Nebraska, through a study done by AARP, it is estimated that there are over 195,000 family caregivers. Many of them have indicated the need for respite care. Respite Across the Lifespan, along with five other regional programs in the state of Nebraska, work diligently to address the need for respite care to Nebraska's family caregiver. Respite Across the Lifespan, through outreach and education activities, strives to reach family caregivers to inform them of the importance of taking a break to rest and refresh from their caregiving duties. In addition, Respite Across the Lifespan seeks out new avenues to recruit a diverse group of independent respite providers as well as new agencies that offer respite as one of their services.

Respite Across the Lifespan's regional coverage is both Douglas and Sarpy counties in Nebraska. The largest numbers of the Nebraska population are located in the Eastern part of the state even though geographic coverage is small compared to the regional areas across the state. There are vast differences in the income levels of residents in these counties, ranging from individuals on Medicaid and other types of public assistance to millionaires.

Two primary needs are to encourage and assist more families in our lower income areas to utilize respite care and seek financial assistance in order to finance this service. We have a higher concentration of independent providers in Northeast Omaha, for example, and not as much usage from this area. In addition, we get calls from the far western portion, including the rural portion of Douglas County and it has been more of a challenge to find individuals interested in becoming respite providers in this area. More efforts are going to be made to address these issues.

There are three universities and a few colleges located in the two county area that could be potential sources of recruitment of providers. Over the next two years' efforts will be made to reach these possible sources of providers through education and marketing strategies. Efforts have already begun to reach paraprofessionals working in the school districts in the community to recruit providers in areas where providers are limited.

Through ongoing collaborative efforts with Munroe-Meyer Institute and behavioral health programs, Respite Across the Lifespan hopes to be able to recruit and adequately train providers interested in assisting individuals that experience behavioral health issues. This is a particular shortage in our counties and the need continues to grow.

The mission of Respite Across the Lifespan is to promote and provide support to caregivers and their families across the lifespan through education, training, respite care and partnerships. Respite Across the Lifespan also has a Respite Advisory Committee that meets quarterly to discuss issues related to respite in our geographic area. This committee is made up of professionals, parents, and respite care providers.

Respite Across the Lifespan is staffed by two professionals, both having achieved higher education at the Master's level, one in Clinical Counseling and Human Services and the other in Sociology, Public Administration and Gerontology. Both staff members are trainers in Respite Education Support Tools (REST), which they offer periodically throughout the year to train current and new independent respite care providers. One staff member is also a trainer in Powerful Tools for Caregivers, a six-week program designed to help train caregivers on how to better take care of themselves.

The Respite Coordinator maintains relationships with other organizations that offer respite care and encourages them to become part of the state of Nebraska's data base of qualified providers. The Coordinator works diligently to locate new providers that offer their services on a limited basis instead of requiring long term commitments from family caregivers. Staff at Respite Across the Lifespan attend a meeting of a large networking system bringing professionals interested in issues related to aging issues monthly. The Coordinator also attends another networking group that meets monthly and distributes information at these meetings.

The Respite Coordinator stays in contact with area agencies and support groups that address the needs of individuals and families that experience intellectual and developmental disabilities, mental health conditions and other types of chronic health issues. Presentations and marketing materials about respite and our training offerings are distributed through many of these groups.

The staff have been able to assist most individuals in their requests for information and respite services. As mentioned earlier in this summary, more efforts are needed to address areas where our agency has limited service capabilities, especially for those families with teens with behavioral health needs. Mental health services are significantly lacking in our geographic area.

Over the next two years Respite Across the Lifespan would like to increase the number of adequately trained respite care providers to meet the growing needs of our family caregivers. Outreach will continue to recruit providers from more diverse cultural backgrounds and with the ability to speak different languages. In finding and training more providers Respite Across the Lifespan hopes to be able to increase the number of families utilizing respite care services.

Another strong emphasis over the next two years will be to reach the business community to educate Human Resource departments, wellness groups, and employees about respite and the need for family caregivers to seek rest and refresh to enable them to better care for their loved ones.

In order to achieve the goals established by MMI/Lifespan Collaborative, additional funds will need to be raised. Fundraising activities will need to be planned and implemented to meet the day-to-day operations of the agency. Grants will continue to be sought to address the growing needs of the community and enable the Eastern Nebraska Respite Across the Lifespan Program to hire additional staff to meet these needs. Integration of the project into the MMI University Center of Excellence in Developmental Disabilities (UCEDD) program and the DHHS employee engagement program and statewide respite assessment at UNMC will allow for further planning on pertinent issues and determine the best course of action to attempt to meet the growing needs in our community.

### **History, Progress and Future Plans**

In 2016, the Eastern NE Respite project moved from Partnerships in Caregiving, Inc. (PIC) to MMI's UCEDD project. The MMI UCEDD is funded by the Administration on Intellectual and Developmental Disabilities with a funding history of over 30 years. PIC was originally formed as Partnerships in Aging in 1996 by the Eastern Nebraska Office on Aging as a 501 (c)(3) corporation to identify needs and seek funding to support, expand and develop programs for the elderly.

Since 2012 Partnerships in Caregiving has received funding from the Department of Health and Human Services to be the agency responsible for the Respite Resource Center for the Eastern Service Area of the Nebraska Lifespan Respite Network. This catchment area covers the Nebraska counties of Douglas and Sarpy. The current Respite Program at MMI focuses on assisting family caregivers of individuals across the lifespan with disabilities and chronic health concerns. The Respite Resource Center locates respite providers, helps families access funding for respite services, and refers families to other types of support services they may need such as where to turn for medical equipment, support groups that are specific to their loved one's disability or chronic health concern. Family support is a key driver in an individual's ability to remain in one's home and in the community. The staff of the Respite Resource Center offer training in Respite Education Support Tools (REST) a program for training respite care providers and interested family members. These services are offered to family caregivers free of charge.

### **State Initiatives**

In 1999, the Nebraska Legislature established the Nebraska Lifespan Resource Program (LB 148). Based on this legislation, the Department of Health and Human Services established six

Lifespan Respite Service Areas to coordinate respite resources across Nebraska. The Lifespan Respite Network was established to:

1. Create a single point of contact within each Service Area to provide information and referral regarding respite resources;
2. Increase the public's awareness of respite and provide community outreach by involving interested stakeholders and building on existing resources;
3. Increase access to respite resources by recruiting appropriate providers and promoting the expansion of respite services;
4. Ensure training is available for both consumers and providers by coordinating existing training resources and recruiting additional resources to meet the training needs across the Lifespan; and
5. Implement ongoing evaluation of providers, caregivers and the respite system to determine unmet needs.

Standards for delivery of services are outlined in Neb. Rev. Stat. §68-1520 and adherence to the standards is a requirement of each Lifespan Respite Service Area agency that has been awarded sub grants to implement and manage the Lifespan Respite Program.

### **Needs in our community**

Education of the general public on what respite care is, why it is important to family caregivers and how to access and fund these services. The toll on the caregiver's health appears to increase over time. Those caring for a close relative such as a spouse or parent, are at a much greater risk of declining health as a result of caregiving. In a 2015 survey done by AARP of family caregivers, 88% would find information about caregiver resources helpful and 85% would find information about respite care helpful. There appears to be a lack of trained providers in behavioral health at all ages in Nebraska. Mental health programs and services have declined significantly leaving families with minimal support to care for their loved ones in need of these types of programs. There are only a couple of behavioral support programs offered for children and next to nothing available for teens and young adults.

Many family caregivers do not consider themselves as caregivers and do not seek out help in caring for their loved one. Over six of 10 caregivers perceive themselves to be the primary unpaid caregiver. Alzheimer's or dementia caregivers are more likely to have other unpaid help (61% vs. 51% of those caring for someone without these issues). Often the family caregiver is unaware of the toll that providing care to persons with disabilities or chronic health concerns has on themselves.

There is a lack of adequate funding sources to assist families in securing the types of respite and other support services they need to remain healthy. Caregiving comes at a substantial cost to the caregivers themselves, to their families and to society. AARP Public Policy Institute stated that if family caregivers were no longer available, the economic cost to the U. S. health care and long term services and supports systems would increase astronomically.

There is also a lack of employer understanding of the costs of lost productivity of those individuals that are providing care to loved ones. Often this loss of productivity is related to stress experienced by the caregiver. Four of 10 caregivers consider their caregiving situation to be highly stressful (38% rating stress 4 or 5 on a 5-point scale as reported in a 2015 study done by AARP and the National Center for Caregiving. Caring for a loved one is an activity that cuts across most demographic groups, but is especially prevalent among adults ages 30 to 64, a group traditionally still in the workforce. Family caregiving concerns will have an increasing impact on both employees and workplaces because of the aging of the population and the labor force. Older workers, those most likely to have eldercare responsibilities, are an increasing proportion of the workforce.

Nebraska has a shortage of behavioral health professionals. This has made it significantly more difficult for individuals with behavioral health needs to get help when and where they need it. 88 of Nebraska's 93 counties are recognized as mental health professional shortage areas by the U.S. Health Resources and Services Administration. In 2009 the Nebraska Legislature passed LB 603 and created Behavioral Health Education Center of Nebraska (BHECN) whose mission is to improve the numbers, accessibility and competence of the Nebraska Behavioral Health Workforce through the collaboration of academic institutions, providers, governmental agencies and the community. BHECN collaborates with partners, listens to stakeholders, identifies resources and barriers and includes consumers and their families in their work. PIC is working to collaborate with BHECN to identify and train individuals interested in providing respite care services to families of persons that experience behavioral health issues.

The National Alliance for Caregiving and AARP released the results of the 2015 Caregiver Survey. This survey revealed that an estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the past 12 months. They also determined that 85% of family caregivers are not receiving respite. Caring for an older relative or friend is now the "new normal" of family caregiving in the United States.

### ***Programs that address the needs of children***

The Early Development Network (EDN) serves children from birth until August 31 of the year in which they are three. EDN is Part III of IDEA (Individuals with Disabilities Education Act). EDN is the single point of entry to services coordination for eligible infants and toddlers as identified by each planning region team via the systems contract. EDN is a Medicaid-funded program which pays for services coordination and respite care for infants and toddlers in the Early Intervention Program who have needs which qualify them for Nursing Facility level of care. There are 28 Early Childhood Planning Region Teams in the state of Nebraska.

### ***Programs that address the needs of children and adults with chronic illness/disabling conditions***

*Aged and Disabled Waiver* (Home and Community-Based Waiver Services for Aged Persons or Adults or Children with Disabilities) ( Home and community-based waiver services offer eligible

persons a choice between entering a Nursing Facility (NF) or receiving supportive services in their homes. Medicaid funding through the Nebraska Medical Assistance Program (NMAP) is used to fund either service option.

*The Munroe-Meyer Institute (MMI)* is a federally designated University Center for Excellence for Developmental Disabilities Education, Research and Service. MMI specializes in providing services and support for persons with intellectual, developmental and/or genetic disorders.

Health and Human Service Services Coordinators for the *AD Waiver* serve children from August 31 of the year in which they are three through age 17.

Individuals with behavioral health concerns are living in their community and unfortunately there has become a shortage of behavioral health professionals to work with these individuals. In 2009 the Nebraska Legislature passed LB 603 and created *BHECN* to recruit, retain and increase competency of the state's behavioral health workforce.

There are two child care centers in the Greater Omaha area that serve children with disabling conditions and behavioral issues. *Children's Respite Care Center* works with children with special needs from birth to age 21 by providing comprehensive educational, nursing and therapeutic care through behavioral health, day and overnight weekend programs. *Behaven Kids* offers a specialized day program for children ages 18 months to 8 years. They focus on helping children to get their behaviors back on track so they can be healthy, happy and ready for school.

*The League of Human Dignity* is a source of information and resources for people with disabilities. They have a wide array of equipment available to assist persons with disabilities and do both home and vehicle modifications.

*The Office of Public Guardian* is designed to serve as the guardian or conservator for an individual when no other alternative is available. In addition to providing the means of last resort as guardians or conservators for those situations where no family member or suitable individual is available, the Office of Public Guardian provides education, training, and support for volunteer and family guardians and conservators, and recruits individuals to serve as guardians and conservators for Nebraska's vulnerable individuals. They are also planning to have volunteers to help gather and provide information on Potentially Incapacitated Persons to local county courts during Guardianship Petition hearings.

Respite Across the Lifespan will continue to assist family caregivers in identifying funding sources such as those through the Enrichment Foundation funds. These funds can be used to purchase of respite care, adaptive equipment and software, and other restricted services to families of children and adults with intellectual and other developmental disabilities and those with chronic health conditions.

### ***Programs that address the needs of elderly***

Area Agencies on Aging (AAA's) serve persons age 65 and older. AAA's provide services coordination and resource development for the Aged and Disabled Waiver and is a Medicaid related program. The Eastern Nebraska Office on Aging (ENOA) is the AAA covering the counties of Douglas, Sarpy, Cass, Dodge and Washington counties in Nebraska.

AARP is a nonprofit, nonpartisan membership organization for people age 50 and over. It is dedicated to enhancing quality of life for all as we age. They are influential in leading positive social change and delivering value to members and others through information, advocacy and service. In 2015 AARP commissioned a telephone survey of 1,200 registered voters nationwide, age 40 and older, to learn about their experiences with family caregiving. This survey supplies a wide array of information about caregiving and issues related to it.

HELP Adult Services offers in-home support services through volunteers and has a wide-array of medical equipment available for rent or sale at reasonable prices.

Volunteers Assisting Seniors provides a number of services to seniors, family members, caregivers, and employers who want to better understand senior benefits and programs. They are a resource for Medicare information and workshops, Health Insurance Marketplace information, homestead exemptions, and guardianship and conservatorship.

### **Local networks**

The MMI UCEDD project has collaborated with the Nebraska Lifespan Respite Network in providing REST trainings and will continue to be part of the Nebraska Resource and Referral System (NRRS) of providers. MMI currently shares information about the Nebraska Lifespan Respite Network so that becoming partners has strengthened respite services for eastern Nebraska, to inform parents of children and adults with developmental and other disabilities about respite.

The Respite Resource Advisory Committee is made up of representatives from Children's Respite Care Center, the Salvation Army, PTI-Nebraska, Vocational Rehabilitation and other agencies that represent the populations we work to reach with the Respite Resource Center. These relationships will be worked on to increase involvement on projects from the advisory committee.

Efforts have begun to establish stronger relationships with school districts in our area by identifying special education teachers, counselors, advisors, and PTO groups at all grade levels. This fall there will be an increase in our outreach to area school districts by making face-to-face contact with Principals, Counselors and others.

We have been working to improve relations with disability-specific organizations to get the word out about respite to their constituents that are family caregivers (Ollie Webb Center, Inc.,

Autism Center of Nebraska, Autism Society, Parkinson's support groups, Alzheimer's Association, etc.).

## **Future Plans for Growth and Development**

### ***Desired Outcomes***

- Increase outreach into the community to spread the word about respite and its impact on family caregivers.
- Increase outreach to the business community about respite and how they can better assist their employees that are family caregivers in receiving the types of support that could help them both personally and in the workplace.
- Increase outreach to the medical community to tell them about respite and how to access it for their clients.
- Maintain and develop stronger relationships with local network partners.
- Identify and share information on more training opportunities for providers, especially in the area of behavioral health.
- Continue efforts to identify and network with support groups that are disability-specific and enter them into the state-wide database for easier access for families.
- Increase the number of adequately trained providers in our local network (with special emphasis on finding training to meet the needs of individuals with more significant behavioral issues) and those on the NRRS system.

### ***Steps toward the goals***

- We designed a short, one-page flyer that defines what respite is that we have posted on our website and use to send information out to the community. The MMI Eastern NE Respite project plans to educate individuals on what respite is and the benefits of utilizing respite can be for them by doing presentations to disability specific groups, churches, businesses, counselors, special education teachers, and others that work with families,
- In addition, we have been spreading the word about respite through our newsletter and through area media sources.
- The MMI website has been redesigned to recognize respite services (<http://www.unmc.edu/mmi/about/ucedd/respite.html>)
- Efforts will be made to collaborate with Wellcom to work with employers that have wellness programs
- By staying in contact with our local networks Respite Across the Lifespan hopes to stay on top of training opportunities in behavioral health and other topics of interest to our independent respite care providers. These training opportunities will continue to be posted on our website and distributed through our newsletter.
- Several times per year we advertise or have stories about respite care in O'Hana Kids, an electronic newsletter that covers the state. Our focus is on the Greater Omaha area.



This newsletter is for families who have children with intellectual and other developmental disabilities.

- Efforts will be made to give presentations at more disability-specific support groups to inform families about respite care. We have limited this in the past because we have not had as many independent providers wishing to work with children and younger adults.
- Efforts will be made to reach out to more places to recruit independent providers interested in working with children and young adults that experience disabilities. This effort is being addressed, in part, with our collaboration with MMI.
- Two REST trainings are planned for the 2016-2017 year. Outreach will be made for current providers to attend this training, as well as new people that are interested in becoming providers.
- Create materials that are culturally appropriate, address all disabilities/chronic illnesses and family circumstances.
- Educate family caregivers on the NRRS statewide respite network so they can identify qualified respite care providers when our office is closed.
- Increase the number of family caregivers who have access to respite care as a result of presentations made to the business community.
- Continue to utilize MMI's website and increase our presence on Facebook and other forms of social media.

#### **Other Programs that offer respite**

- HELP Adult Services provides in-home family care support through volunteers in the eastern Nebraska and southwest Iowa region. Their services are limited.
- Respite Across the Lifespan identifies agencies that provide in-home care services that will go out for a minimal amount of time and on a short-term basis. These agencies become part of our database and are offered to those family caregivers that contact us and have need for this type of care. In addition, Respite Across the Lifespan works with assisted living and nursing homes that offer short-term (respite) stays and maintains these businesses on our database.
- There is only one child care center that specializes in working with children with behavioral disorders that offers respite care. Children's Respite Care Center allows children with special needs from birth to age 21 reach their potential by providing comprehensive educational, nursing and therapeutic care through behavioral health, day and overnight weekend programs.
- Some of the community-based service providers have offered limited respite care to individuals who participate in their programs. ENCOR (previously called the Eastern Nebraska Community Office on Retardation) is the major agency that has provided this in past years.

## **Achieving our Local Level Goals**

### **The Federal Context**

The Lifespan Respite Care Act was passed in 2006 (Public Law 109-442, 42 U.S.C 201). Its goals are to expand and enhance respite care services to family caregivers; improve the statewide dissemination and coordination of respite care; and to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain. The Act also creates a National Lifespan Respite Resource Center that is designed to maintain a national database on lifespan respite care; provide training and technical assistance to State, community and nonprofit respite care programs; and provide information, referral, and educational programs to the public on lifespan respite care. Funds are used for the development and enhancement of lifespan respite care at the State and local levels. Funding to support the Nebraska Lifespan Respite Network, of which Partnerships for Caregiving, Inc. receives grant funding, comes as a result of this Act through the Department of Health and Human Services.

On a national level the National Association of States United for Aging and Disabilities (NASUAD), Human Services Research Institute and the National Association of state Directors of Developmental Disabilities Services have a collaborative effort underway in 2015 to support states in assessing and improving the performance of their programs and delivery systems of services for older adults, individuals with physical disabilities and caregivers by collecting and providing states with reliable data on how publicly-funded services affect the quality of life and outcomes of service recipients.

The National Center on Caregiving was established in 2001 as a program of Family Caregiver Alliance. The National Center on Caregiving (NCC) works to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. United in research, public policy and services, the NCC serves as a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders and family caregivers throughout the country.

The National Respite Network (ARCH) and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

### **The State and Community Context**

#### **Economic Trends**

Funding to support the Lifespan Respite Network have been cut over the past couple of years thus providing regional offices decreasing funding to operate in their regions.

No increases have been given to families receiving the Lifespan Respite Subsidy, making the amount of money they have available to purchase respite care services more limited.

Costs of providing respite and other forms of in-home care continue to rise due in part to the rise in the minimum wage.

Increases in the overall cost of living will impact family caregivers needing to remain in the workplace.

With the average household income of in Nebraska is \$50,296, caregivers report not only emotional strain, but financial strain. Caregivers that live more than an hour away from their care recipient also report higher levels of financial strain because they need to rely on paid help (41 percent have indicated they have had to use paid help). About one in five caregivers report experiencing financial strain as a result of providing care.

There is an increase in the number of baby boomers currently providing care to their loved ones. Baby boomers will also need to receive increasing amounts of care as they age as well. The increase in the number of persons receiving care will have an impact of the number of care providers that will be needed in the future.

A rise in the retirement age will have more, older individuals in the workplace that may become family caregivers while they are still employed.

We have seen an increase in the number of part time jobs instead of full time employment because businesses are not willing to provide health care coverage to their employees. This may have an impact on individuals needing to work multiple jobs, increasing their stress in balancing caregiving and employment.

### **Social and Demographic Influences**

Baby boomers are now reaching the time when they are more likely to be family caregivers for their parents and other family members. In addition, baby boomers are also moving into the time when they will also be potentially in need of care. There will be increasing few people available to provide care to the aging population.

Over 12 Million Americans require assistance with daily tasks—such as eating, dressing, bathing, and transportation—as a result of physical limitations or cognitive impairments. This number is expected to more than double by 2050. In 2009 family caregivers provided over 40 billion hours of unpaid care, valued at an estimated \$450 billion. Some 85% of family caregivers are not receiving respite.

People are living longer and may have more disabling conditions, which will have an impact on spouses and children who will be in caregiving situations.

There will be a significant impact on family caregivers because of increasing numbers of individuals identified with early onset of such chronic health conditions as Alzheimer's and

Parkinson's and with more children being diagnosed with Autism. There will be more need for respite services to assist these family caregivers in getting a break from the demands of caring for individuals with disabilities and other chronic health conditions. Approximately 59% of the caregivers in the AARP poll reported they have a difficult time taking a break from caregiving.

Family caregivers will be put in a position of having to care for individuals for a longer period of time, which will increase their level of physical and emotional stress. Of those providing care for 5 years or more, 20% report their health is fair or poor." This will have an impact on family caregivers that are working. Some 58% of these caregivers report it is difficult to balance job and family. Chronic or long-term conditions among care recipients, such as Alzheimer's, mental health issues, or long-term physical conditions, seem to be particularly likely to cause emotional stress for caregivers. Among working caregivers, half say their employer offers flexible work hours (53%) or paid sick days (52%). Nearly a third say their employer offers paid family leave (32%), but less than a quarter offer employee assistance or information referral programs (23%).

Adult children are now living farther away from their parents who may require caregiving. This may cause the adult child and their family to need to quit their job and move closer to their parent(s).

Approximately 87% of older Americans desire to age-in-place instead of moving into assisted living or other types of care facilities. This may mean that the family caregiver moves in with the parent or the parent moves into the caregiver's home. More in-home options for care will be needed in any case. Family caregivers will need assistance in the coordination of services needed.

An Increased number of children and adults with a wide array of disabilities are able to live and flourish in their communities with their families. Families will require greater access to support services.

According to the 2015 poll done by AARP, more than two thirds of voters say they will be more favorable to members of Congress who want to improve resources for family caregivers. Also this poll found that 68% of family caregivers are using their own money to provide care for their loved ones.

Today, nearly a quarter of American's caregivers are millennials between the ages of 18 and 34 and are equally likely to be male or female. On the other end of the spectrum, caregivers ages 75 and older are typically the sole support for their loved one, providing care without paid help or help from relatives and friends.

Dr. Susan Reinhard, senior vice president and director of AARP Public Policy Institute states in a 2015 article of the new study they did on the challenges for family caregivers, that "we're facing a caregiving cliff". She goes on to state that "By mid-century, there will be only three family caregivers available for each person requiring care. That means, to avoid putting them

at higher risk as they age, we need to provide support for existing caregivers who are underserved by the current long-term services and support system.”

In a 2015 study, it was reported that 56% of employed caregivers work full time and another 16% work between 30 and 39 hours. Caregivers who work do so for 34.7 hours per week on an average. Caregivers have been caring for 4 years on average, spending 24.4 hours per week helping with activities like bathing, dressing, housework and managing finances. One in four work fewer than 30 hours a week. Younger caregivers are more likely to work full time (57% of those age 18 to 49 and 60% of those age 50 to 64).

### **Fiscal Context**

Funding to support family caregivers has remained the same or has been cut in recent years. The United States military is no longer covering the limited amount of respite they had previously funded for veterans. This will add increasing financial stress to military families.

Most companies do not fund respite care services to their employees. Insurance companies often do not have respite care coverage in their policies.

Many companies offer little sick leave or FMLA which could impact family caregiver’s income in times of high need in care.

### **Internal Capacity**

#### ***Governance and Leadership***

The respite program of MMI’s Eastern NE Lifespan Respite project receives its funding from the Department of Health and Human Services and is part of the Nebraska Lifespan Respite Network. All program activities must be in compliance with the standards for delivery of services as outlined in Neb. Rev. Stat. §68-1520 and adherence to the standards is a requirement of each Lifespan Respite Service Area agency that has been awarded sub grants to implement and manage the Lifespan Respite Program. Data on program operations is handled on the state’s eLifespan data base and is monitored closely by the Nebraska Lifespan Respite Network Program Coordinator.

MMI is a unit of the University of NE Medical Center, nonprofit organization and is bound by laws of reporting to the Federal government all funds that are processed through the agency. MMI is governed by the University of Nebraska Medical Chancellor who reports to the President of the Nebraska University system and then ultimately to the NE Board of Regents.

The MMI UCEDD project is a federally funded grant program within the Munroe-Meyer Institute that is an academic unit of the University of NE Medical Center located in Omaha, NE. The director of the MMI UCEDD is Wayne Stuberger, PhD who is also the Associate Director and who reports administratively to the Director of MMI. The MMI UCEDD is a member of the Association of University Centers on Disability, a network of 65 federally funded programs

across the US whose mission is to provide services, capacity building, advocacy and system's change for individuals with special needs ([www.aucd.org](http://www.aucd.org))

The MMI UCEDD has a Community Advisory Committee that meets four times per year to discuss issues related to the UCEDD projects that includes respite and the needs of our community in this arena. The committee is made up of individuals with special needs, individuals representing agencies that work with children and adults with developmental and other disabilities, vocational rehabilitation, and advocacy groups.

### ***Management and Administration***

One member of the staff of Respite Across the Lifespan has a Master of Science degree in Clinical Counseling and a Master of Science degree in Human Services from Bellevue University. She received a provisional license as a Mental Health Practitioner and also passed the National Counseling exam in 2012. She has years of experience in a wide variety of human services.

The other member of the staff of Respite Across the Lifespan has a Master of Science degree in Sociology and a Master's Certification in Gerontology both from the University of Nebraska at Omaha. In addition, she has created and managed a nonprofit organization that secured employment opportunities for adults with intellectual and other developmental disabilities and has been the coordinator of several human service programs.

### ***Recruitment, Training, and Retention of Professional Staff and Volunteers***

As a project within the MMI UCEDD, the Respite Across the Lifespan project follows all University of NE Medical Center policies or procedures for the recruitment of professional staff. The UCEDD Director and the Lifespan staff are responsible for the recruitment, training and retention of any additional professional staff and volunteers. The Respite Across the Lifespan coordinator and staff are responsible for recruiting independent and agency-based respite care providers. The Coordinator is also responsible for scheduling REST training and identifying other training opportunities that would increase the skill level of our independent providers.

### ***Strategic Partners***

- The Nebraska Lifespan Respite Network main office and the other five regional directors.
- Nebraska Caregiver Coalition in Lincoln who works diligently on advocacy and other issues related to the needs of caregivers in the state of Nebraska.
- Nebraska Developmental Disabilities Council for guidance and outreach across the state for education on the needs of respite care providers and how they can access respite care services in their communities.
- Douglas County Commissioners could address the needs of respite care providers.

- Human Resource Association of the Midlands professionals for opening the doors to visiting with them, their businesses, their wellness committees and their employees that may be family care providers.
- Omaha Community Foundation who manage a large number of private philanthropic foundations and who are the gatekeepers of these, along with funding opportunities they offer through the foundation.
- Organizations such as AARP, the Alzheimer’s Association and others who are making major statements about caregivers and their needs.

### **Information and Outreach Systems**

The Department of Health and Human Services – Statewide Respite Network – provides grant opportunities to the six regions in the state of Nebraska to provide statewide respite programs. The state office manages these grants and the funding programs. In addition, the state office has a statewide respite database where family caregivers can access the names of independent respite care providers on a 24-hour basis. The six regional programs work in collaboration with the state office to spread the work of respite care services and other support services to family caregivers.

National Respite Network (ARCH) and Resource Center assists and promotes the development of quality respite and crisis care programs in the United States; helps families locate respite and crisis care services in their communities; and serves as a strong voice for respite in all forums.

The Area Offices on Aging inform their clients and their families about respite care availability and tell them about potential funding sources to assist with the costs of respite care.

This year the Aging and Disability Resource Demonstration Program Act (ADRC) was passed by the Nebraska Legislature. The ADRCs will provide information to consumers and caregivers about available services and supports that will enable independent living and help them find the most appropriate care.

The Alzheimer’s Association of Omaha provides support groups to those caring for individuals with Alzheimer’s. They share information with caregivers on the importance of utilizing respite care services and they provide a minimum amount of funding yearly to help pay for these services.

Parkinson support groups, especially the one operating in Bellevue, Nebraska, encourages their family caregivers to learn more about respite care and helps to spread the word about these services throughout their support network.

## **Action Plan: The Road Map for Achieving our Goals**

### **Narrative of Logic Model**

Over 12 million Americans require assistance with daily tasks—such as eating, dressing, bathing, and transportation—as a result of physical limitations or cognitive impairments. It has been reported that 85% of family caregivers are not receiving respite that could benefit from these services.

The overriding outcome is that all family caregivers in Douglas and Sarpy counties in Nebraska are aware of respite care, understand why it is important to them and how they can access respite care services. In order to address this goal, Respite Across the Lifespan plans to do the following to reach out to the community of family caregivers to deliver the message of respite care.

- Creation and dissemination of well-developed materials that define respite and explain the need for respite in ways that are culturally appropriate and address all disabilities/chronic illnesses that consider all family circumstances.
- Increased data collection for the state-wide “Respite Evaluation Plan”.
- Provide access to the NRRS state wide respite network system to all families we work with and have done outreach to.
- Collaborate with staff at MMI to inform Respite providers of the NRRS System, the Respite Network and establish a pathway for them to become respite providers.
- Increase by 10% the number of family caregivers who have access to respite care resources as a result of employer engagement activities.
- Distributed these materials to faith-based organizations, community organizations, medical professionals, employers, and organizations that represent disabling conditions or chronic illnesses across the lifespan. These efforts will be mapped out and outreach will be made to at least two new groups each month over the next two years.
- Make presentations will be made to any groups (such as Alzheimer’s and Parkinson’s support groups), disability organizations that work closely with parents of children and young adults with intellectual and other developmental disabilities or businesses that are interested in learning more about respite and how they can help their constituents access these services. Six presentations will be planned in 2015-2016. Other presentations will be worked in over the following two years.
- Present to employees about respite at those businesses that will allow us to come in and make these presentations. We are planning to offer four “lunch and learn” presentations at businesses to inform employees about respite during 2016. Additional presentations will be made as requested.
- Increase the number of articles and interviews with local media sources, sharing stories of how families have been helped by taking advantage of utilizing respite care. In addition, more emphasis will be made to share information on issues related to respite



care along with helpful tips for caregiving. Three articles or interviews will be planned in 2015-2016.

- Help to maintain the NRRS statewide respite network system of all providers in our network so that families have access to provider names and contact information 24 hours per day, seven days per week.
- Increase our presence on MMI website, Facebook and other social media to reach more family caregivers seeking support services by 10%.
- Due to the high costs of paying for respite care, will inform families of grants and other funding sources, such as Lifespan Respite Subsidy, and how they apply for these funding sources.
- Offer two information networking events during 2016-2017 to provide family caregivers an opportunity to meet some of the independent providers that are part of our local registry.
- Offer employee informational training opportunities with businesses.
- Collaborate with area partners, such as the Munroe-Meyer Institute and the local AARP office to provide family caregivers information on respite care.

In order to cover the needs of family caregivers as a result of more structured outreach to the community the need will be to increase the number of adequately trained respite care providers. Emphasis will also need to be done on increasing the number of agencies and businesses that provide services to consider offering respite care.

- Collaborate with other Munroe-Meyer Institute (MMI) UCEDD programs to establish a pathway for their students from various departments (such as Pre-Med, Speech Pathology OT, PT, and nursing) that go through the REST trainings provided at MMI for them to become respite care providers and get registered on the state's NRRS system.
- To meet the need of the lack of adequately trained respite providers, Respite Across the Lifespan plans to hold 2 Respite Education and Support Tools (REST) training classes over the course of the next year. Individuals to take the training will come from our current provider list, from recruitment efforts made in the community, and from those individuals contacting our office to become providers.
- Respite Across the Lifespan will notify respite providers of additional training opportunities that become available in the area that will increase their skill level, especially in the area of behavioral health and caring for those with more significant behavioral challenges. This will be done at new provider orientation and via email and postings on the MMI website.
- Respite Across the Lifespan will continue efforts to identify in-home and facility-based agencies and businesses that offer short term respite services and get them to become part of our registry of providers.
- This year we plan to identify additional target groups that may be sources of respite care providers. We plan to increase our provider network by 20% from FY 2016

baseline. In order to meet this objective, we plan to make five presentations to schools and faith-based groups and participate in at least two community events such as health fairs to recruit new providers.

- We plan to increase efforts to retain our current respite providers by more direct contact with them, through networking opportunities, by featuring new providers on our website and increasing the number of family caregivers seeking respite care assistance.

The following activities are projected as part of the fiscal management plan for the program in the coming year:

- Two new grant proposals will be written during 2017.
- The agency will identify one potential fundraising activity that can be done by June 30, 2017.

## **Financing Plan**

### **Fiscal needs**

We also need funds to offer REST trainings once the NE Lifespan Respite funding is over with this as an objective. The costs to run one REST class, staff time, purchasing 10 books, offering food and covering mileage for trainers would be \$850.

### ***Current and Projected Resources***

#### ***Federal Funding***

The MMI UCEDD program received direct federal funding through the Administration on Intellectual Development Disabilities, but the Lifespan Respite project does not receive any federal funding.

#### ***State-Level Funding***

We receive expenditure reimbursement for three grant that we receive through the Department of Health and Human Services through the state office. A present funding level of \$66,667 is anticipated to be available for annually for the next two years.

#### ***Local-level Funding***

We are working with five other agencies that work with our target populations to offer a caregiver retreat in the fall of 2016. The group has met several times thus far to strategize what would be involved with this conference. We have made arrangements and are working with the Department of Gerontology at the University of Nebraska at Omaha to be able to secure the University Alumni House free of charge to hold this retreat. A grant of \$10,000 was awarded for this event and is being administered by one of the partner agencies.

### ***In-kind contributions***

Presently the office space, equipment and utilities are paid in-kind through the MMI UCEDD project. This agreement offers space and equipment for two staff and access to copy and fax machines, technical staff, IT staff, a public relations writer and a graphic designer.

### ***Anticipated budgetary gap***

It is difficult to break the budget down by strategy, program and activity when they all seem to be contingent on the other. In order to perform the proposed activities, staff need to be available to bring them to fruition. We presently have two staff members available to work on all programs and activities, including any activities required to handle basic day-to-day operations of the nonprofit and the respite program. As indicated in the program budgets, the vast majority of funding received goes to personnel and benefits. As wages rise available funds to add any additional activities become increasing difficult.

It is not anticipated that we will experience a budgetary gap in 2016-2017. If all funding options remain at their current level gaps arise in year 2017-2018.

### ***Summary of funding needed over two years***

The MMI Eastern NE Respite project will need to raise additional funds over the next two years. At this point it is hard to determine exactly how much money will need to be raised or how we will address these budget deficits. We will be working closely with Wayne Stuberg and the MMI finance office to address these needs.

### ***Strategies for securing needed funds***

The Lifespan Respite project will need to determine what type of fundraising activities they can handle given the limited number of staff and the level of support available from the MMI UCEDD project.

### **Plans for Building Local Organizational Capacity and Community Support**

***Adaptability to changing conditions:*** The MMI Eastern NE Respite project will work closely with the MMI UCEDD project and our Respite Advisory committee to solicit more of their involvement in assisting in the identification on ways we can better serve the needs of our caregivers, providers, and the community at large on issues related to respite care.

***Broad-base of community support:*** Seek out and identify more avenues of community support by getting the advisory committee more involved. Establish sub-committees to identify and solicit more wide range of community support options. Efforts are being made at the present time to encourage a broader base of support when speaking to local businesses to get their “buy in” on the idea of educating their employees about respite care.

### ***Key champions***

The Munroe-Meyer Institute is a great key champion with their work on this project and their ability to help all of the regional programs in Nebraska.

Viv Ewing and the members of our local Alzheimer's Association are also seeking to spread the word about respite and the need for respite for family caregivers. Partnerships are possible with them over the next few years.

AARP has provided a significant amount of research that is available for our use when reaching out to the Omaha area community about caregivers. We are already working with Mike Kelly from AARP, as well as his involvement at the state level with Sharon Johnson.

We are hoping to get at least one major business in the greater Omaha area to speak out on behalf of their employees that are caregivers and help us in our efforts to reach more businesses to present directly to their employees about respite care.

Michaela Williams, owner of Care Consultants for the Aging, is well-known and respected in this community and might be someone who could do PSA's on the importance of respite care. She also serves on our Respite Advisory Committee and is a great resource.

We are working with Respite Advisory Committee member and spokesperson, Amberly Wagner-Connelly, Assistant Professor, Clarkson College to assist us in spreading the word of needs of family caregivers across the lifespan.

### ***Strong internal systems:***

We believe the move to Munroe-Meyer Institute/UNMC will provide a stronger level of internal system support. More collaborative opportunities and interested UCEDD project staff members are available.

### **Summary**

The top priority will involve efforts to reach out and educate the community on who family caregivers are, what respite is, and why respite is important to families. These priorities will be addressed through the MMI website and other forms of social media. We also plan to continue work on having articles and ads in local social service newsletters such as New Horizons, The Omaha Star, O'Hana Kids and Early Learning Connection Omaha Region newsletter.

We plan to work collaboratively with representatives from Wellcom to identify employers with wellness programs to share information about respite. We will continue to attend Wellcom events that bring businesses interested in supporting the wellness of their employees.

We will continue to deliver brochures on the program to doctor's offices to educate medical personnel and to have materials available that they can provide their patients and their

families. Our desire will be to drive individuals to seek out information on the MMI/UNMC website.

Behavioral health has been an area of concern for this area as Respite Across the Lifespan continues to receive requests from families that experience difficulties in finding caregivers for their loved ones with behavioral health issues. The Respite Coordinator has been in contact, and will remain in contact with, agencies and organizations that offer training in behavioral health. Whenever possible, Respite Across the Lifespan staff express their concerns about this gap in services in our community. Any training opportunities that we hear about will be posted on the MMI website related to the respite project.

During 2015-2016 Respite Across the Lifespan offered two Respite Education and Support Tools (REST) training programs. We hope to offer two REST trainings each year in future years. We are working closely with the MMI, UNMC and Nebraska Medicine staff to encourage their staff attending their REST trainings to become independent respite care providers and become part of the Nebraska Resource and Referral System (NRRS).

Respite Across the Lifespan staff attends early childhood planning region team meetings for several school districts in order to reach teachers and paraprofessionals working with special needs children and their families. In addition, efforts are constantly underway to reach out to a wide variety of disability-specific groups across the lifespan. Respite Across the Lifespan staff attends the monthly meeting of area agencies that are interested in issues related to the aging population. Information on respite and family caregivers is distributed periodically to this group via email and at the monthly meetings. Presentations are made to these groups as opportunities arise. Over the course of this year, efforts will be made to get articles placed in several disability-specific newsletters.

Respite Across the Lifespan staff work on maintaining and developing relationships with our local network partners. This is an on-going effort and will continue to be addressed on a monthly basis.