



**MMI Respite 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. A majority of the family caregivers have indicated the need for respite care. The NE Respite Across the Lifespan program works diligently to address the need for respite care to Nebraska's family caregivers.

In April, 2016 the Eastern region of the statewide respite network, moved from the Eastern Nebraska Office on Aging to its new home at the Munroe-Meyer Institute, University of Nebraska Medical Center. The Munroe-Meyer Institute (MMI) is a federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service (UCEDD). MMI specializes in providing services and support for persons with intellectual, developmental and/or genetic disorders. The MMI/Respite Across the Lifespan (MMI Respite), 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, MMI Respite 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.

This decision was made due to continued collaborative work between the two organizations. We now are able to work more closely with the UNMC Employer Engagement program within the University of Nebraska Medical Center and with Sarah Swanson and Wayne Stuberg, with the UCEDD program. In addition, the MMI Respite program has access to professionals in information technology and public relations to assist in getting the word of respite out to family caregivers. The goal of the MMI Respite project is to promote and provide support to caregivers and their families across the lifespan through education, training, and respite care.

MMI Respite 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.

MMI Respite 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. The Advisory Committee will continue to be used to gain community input to the MMI Respite program.

As the Eastern Region of the Nebraska Statewide Respite Network (serving Douglas and Sarpy counties) MMI Respite provides services to the largest number of citizens in Nebraska. 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.

More efforts are planned to address the issue of limited utilization of independent providers residing in the North side of Omaha. We also have a higher concentration of independent providers in Northeast Omaha. We believe the limited utilization is due to limited financial resources of persons residing in North Omaha. 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.

Over the next two years MMI Respite 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 MMI Respite hopes to be able to increase the number of families utilizing respite care services.

We will continue efforts to recruit and screen providers from various cultures and nationalities, to better serve family caregivers within the various cultural groups residing in Douglas and Sarpy counties. Several materials have already been translated into Spanish. Additional materials will be translated on an as needed basis.

Another emphasis area over the next two years will be to reach the business community to partner with Human Resource departments, wellness groups, and employees to learn more about and access respite services. This will help family caregivers to seek rest and refresh to enable them to better care for their loved ones, prevent institutionalization, out of home placement and costlier care.

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 MMI behavioral health programs, MMI Respite plans to be able to recruit and provide training opportunities to those persons interested in

assisting individuals that experience behavioral health issues. This is a particular shortage in our counties and the need continues to grow.

The MMI 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 screened providers. All screened providers are then entered into eLifespan, a secure site hosted by the Nebraska Respite Network. The MMI Respite Coordinator will work diligently to locate new providers that offer their services on a short term basis instead of requiring long term commitments from family caregivers. Staff at MMI Respite will continue to attend monthly meetings of a large networking system bringing professionals interested in issues related to aging issues. The Coordinator also attends another networking group monthly and distributes information at these meetings.

The MMI Respite Coordinator will stay 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 will be distributed through many of these groups.

Historically, 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 program has limited service capabilities, especially for those families with teens with behavioral health needs. Mental health services are significantly lacking in Nebraska which makes the needed support difficult to acquire for individuals with special needs requiring respite.

In order to achieve the goals established by MMI Respite, 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 MMI Respite 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 MMI Respite Program focuses on assisting family caregivers of individuals across the lifespan with disabilities and chronic health concerns. The MMI/Respite program 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 MMI Respite 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 is an ongoing activity of our program. 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 and behavioral health programs and services in Douglas and Sarpy counties have declined significantly leaving families with minimal support to care for their loved ones in need of these types of programs.

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. Eighty-eight (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. MMI Respite 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.

Many family caregivers do not consider themselves as caregivers and do not seek out help in caring for their loved one. According to a 2015 AARP Survey 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 years, 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.

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 Nebraska Department of Education’s Early Development Network (EDN) serves children from birth until August 31 of the year in which they are three years of age. EDN is Part III of the federal 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***

*The Division of Developmental Disabilities in the NE Department of Health and Human Services oversees a number of waiver programs in the state.*

*The 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 Age and Disabled (AD) Waiver serves children from August 31 of the year in which they are three through age 17*

*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.*

There are two child care centers in the Omaha 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 years 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 ages 18-64 years. 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.

*Right Turn – Nebraska* is available to help and support families who have adopted a child or entered into a guardianship. This includes international, domestic, foster care and step-parent adoption. As a statewide service - located in 8 offices covering the entire state - we can help make a difference in the lives of parents and their children. Right Turn helps families identify places to receive respite care.

*Easter Seals Nebraska* provides exceptional services to help ensure all people with disabilities have an equal opportunity to live, learn, work and play. The Alternative Financing Program is an outreach program that provides low interest rate loans to individuals with disabilities to purchase assistive technology devices such as wheelchair ramps, modified vehicles, braille equipment, hearing aids and many more items.

*PTI Nebraska* is a statewide resource for families of children with disabilities and special health care needs. They provide training, information and support to Nebraska parents and others who have an interest in children from birth through twenty-six and who receive or who might need special education or related services. This enables parents to have the capacity to improve educational outcomes for all children.

*Camp Kesem* is a national organization that provides a free week of overnight camp to children whose parents have or had cancer. The organization is college run by over 3,000 college students across the U.S. in over 80 different chapters. In 2015 they served over 5,000 children, and this summer will be serving over 6500 children. The chapter in Nebraska is run by University of Lincoln, and served 80 children from across the Nebraska.

There are also some of the community-based service providers who have offered limited respite care to individuals who participate in their programs. An example is ENCOR (previously called the Eastern Nebraska Community Office on Retardation) is the major agency that has provided this in past years.

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

The NE Area Agencies on Aging (AAA's) serve person's age 65 years 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. ENOA sponsors neighborhood senior centers and provides lunches. They also have a Meals on Wheels program.

AARP is a nonprofit, nonpartisan membership organization for people age 50 years 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-NE 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 historically 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 with the formation of MMI Respite program. 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.).

MMI Respite staff attend monthly networking meetings with organizations that address the needs of seniors in our community. The networking groups are called Partnerships in Aging Network (PIA Network) and the Metro Eldercare Network (MEN's). By attending these networking meetings staff learns more about the types of programs offered by these organizations and shares this with family caregivers calling our office for assistance.

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

### ***Desired Outcomes***

- Increase outreach into the community to increase community knowledge 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 promote utilization of respite services and how to access it for their clients.
- Maintain and develop stronger relationships with local network partners.
- Identify and share information on training opportunities for providers, especially in the areas of mental and 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 (by 10% annually) 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.ne.gov respite search system.

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

- Dissemination of a short, one-page flyer that defines what respite is that we distribute whenever possible.
- MMI Respite 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,
- The MMI website has been redesigned to recognize respite services (<http://www.unmc.edu/mmi/about/ucedd/respite.html>) and we are working with public relations to determine what types of additional media outreach we can do.

- Staff are collaborating with representatives from Wellcom, a network of employers that partner to deliver wellness programming, impacting employee well-being and wellness, to share information about respite care with employers that have wellness programs
- By staying in contact with our local networks for respite services we plan to stay on top of training opportunities in mental and 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 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 FY2017 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.
- Utilize MMI’s website and increase our presence on Facebook and other forms of social media.
- MMI Respite plans to identify 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, MMI Respite will work with senior centers, assisted living and nursing homes that offer short-term (respite) stays and maintains these businesses on our database.

## **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 MMI Respite receives contract funding, comes as a result of this Act through the Nebraska Department of Health and Human Services.

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 since 2015 to support states in service delivery. Support includes resources for 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, 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 allocated to the Lifespan Respite Network regions has been reduced over the past years reducing regional office support to operate. For example, funding in FY 2013 was decreased by approximately \$10,000 resulting in reduced staffing of our regional program. Each year additional objectives are added to the regional program responsibilities, however, the funding allocations have remained the same. Additional funding will need to be secured in future years in order to fund staff and other program objectives or services will no longer be able to be increased.

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.

According to the 2010 US Census the average household income in Nebraska at \$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% 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.

News reports state there have been 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.

The 2010 US Census reported that 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 2015 survey reported they have a difficult time taking a break from caregiving.

The AARP 2015 survey went on to report that 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 Nebraska survey 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 by AARP, 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***

MMI’s 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. Adherence to approved standards is a requirement of each Lifespan Respite Service Area agency that has been awarded respite contracts to implement and manage the Lifespan Respite Program. Data on program operations is handled on the state’s secure eLifespan respite 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, also Associate Director of MMI and 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 Board 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. The MMI Respite program will be reported to the CAB for input that can be used as both community feedback and information for planning.

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

One member of the staff of MMI Respite 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 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, MMI Respite follows all University of NE Medical Center policies or procedures for the recruitment of professional staff. The UCEDD Director and the MMI Respite staff are responsible for the recruitment, training and retention of any additional professional staff and volunteers. The MMI Respite 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 DHHS, Division of Children and Family Services Nebraska Lifespan Respite Network central office and the other five regional coordinators.
- 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.

- Representatives with Wellcom have agreed to work with us to share respite information to employers with wellness programs and/or interested human resources departments.
- Organizations such as AARP, the Alzheimer’s Association and others who are making major statements about caregivers and their needs.
- Planning Region team meetings, representing early childhood education, throughout Douglas and Sarpy counties.

### **Information and Outreach Systems**

The Department of Health and Human Services – Statewide Respite Network – contracts with agencies in the six regions in the state of Nebraska to provide statewide respite programs. The state office manages these contracts as required by state statutes. 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, going live 7/2016. 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 and resources including respite resources.

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 indication of the data and desired outcome for the MMI Respite program is that all family caregivers in Douglas and Sarpy counties in Nebraska would be 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, MMI Respite plans to do the following outreach to community of family caregivers:

- 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.
- Increase data collection for the statewide “Respite Evaluation Plan”.
- Provide access to the [NRRS.ne.gov/respite](http://NRRS.ne.gov/respite) search statewide 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.
- Distribute 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.
- Presentations will be planned for FY2017 and FY2018 to 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.
- Connect with employers to schedule presentations about family caregiving needs and respite services. The goal will be to offer “lunch and learn” presentations at businesses during FY 2017 and FY 2018.
- Work with MMI/UNMC public relations department to determine the possibilities of having 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.
- 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.
- 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 the Enrichment Foundation grants, and how they apply for these funding sources.

- Offer two information networking events during FY 2017 to provide family caregivers an opportunity to meet some of the independent providers that are part of our local registry.
- Collaborate with area partners, such as AARP NE, Midlands Eldercare Network (MEN'S), Partnerships in Aging (PIA) Network, schools and churches to provide family caregivers information on respite care.

A structured outreach plan to the community will be developed in order to cover the needs of family caregivers. One area to be addressed will be the need for providers to be trained to work with individuals with mental and behavioral health concerns.

- Collaborate with other Munroe-Meyer Institute (MMI) UCEDD programs and MMI departments 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.
- Hold 2 Respite Education and Support Tools (REST) training classes over the course FY 2017. These training opportunities will be schedule in September/October 2016 and in April 2017. 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.
- 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. Information on trainings will be posted on the MMI website, NRRs.ne.gov and on the calendar of trainings offered through REST.
- 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.
- FY 2017 we plan to identify additional target groups that may be sources of respite care providers. We plan to increase our provider network by 10% 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.
- Increase efforts to retain our current respite providers by more direct contact with them, though networking opportunities, by featuring new providers on our website and increasing the number of family caregivers seeking respite care assistance.

## **Financing Plan**

### **Fiscal needs**

Ongoing funding support for REST trainings once the NE Lifespan Respite funding is no longer available is an objective, if the decision is made to continue to utilize this training within the NE Respite Network. 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 receives federal funding through the Administration on Intellectual Development Disabilities and will work with the MMI Respite project to also utilize part of this funding either directly or as match. The MMI UCEDD is also a member of the NE Developmental Disability Network with the NE Council on Developmental Disabilities (DD Council). The DD Council offers annual opportunities for program funding that relates to respite so this can be explored for ongoing support to the MMI Respite project.

#### ***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. As a project within the MMI UCEDD, MMI Respite now has availability to grant funding through the Meyer Foundation for Disability and also The Munroe-Meyer Guild to support projects related to respite services.

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

Presently the MMI UCEDD project offers in-kind support for the 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, a graphic designer, collaboration with the UCEDD Community Advisory Board and technical assistance by UCEDD staff.

#### ***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 Respite 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 Dr. Wayne Stuber, the UCEDD Director and the MMI finance office to address these needs.

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

MMI Respite 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. This will be done collaboratively with UCEDD staff to secure additional funds.

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

***Adaptability to changing conditions:*** MMI Respite 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 family 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-NE 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, family advocate, from AARP, as well as his involvement at the state level with Sharon Johnson, DHHS Respite Program Coordinator.

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 with MMI 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, MMI publication, publications statewide through the MMI UCEDD project 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.

Mental and behavioral health has been an area of concern for this area as MMI Respite continues to receive requests from families that experience difficulties in finding caregivers for their loved ones with mental and behavioral health issues. MMI will be a contacted entity NE Medicaid Heritage Health and as such a direct service provider on a statewide basis to individuals receiving support through NE Medicaid. This direct service delivery network will allow access to hundreds of providers involved with families receiving services. The Respite Coordinator has been in contact, and will remain in contact with, agencies and organizations that offer training in behavioral health.

During FY2017 MMI Respite will offer two Respite Education and Support Tools (REST) training programs. 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).

MMI Respite 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. MMI Respite 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.

MMI Respite 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.