

# **Southeast Respite Network**

Sustainability Plan

---

2015 - 2018

Acknowledgements

---

***SUSTAINABILITY PLANNING GUIDE TEAM***

***The Southeast Nebraska Respite Network recognizes the following individuals for their dedication and commitment to developing the Sustainability Planning Guide.***

**Mary E. Shada, MS, HS,**  
Southeast Respite Coordinator  
Nebraska Respite Network  
YWCA, Lincoln NE

**Jennifer Auman**  
Program Manager  
Lifespan Health Services  
NE-Maternal Infant Early Childhood Home Visiting  
Nebraska Department of Health and Human Services

**Valerie Franssen, MA**  
Associate Public Guardian  
Office of Public Guardian  
Nebraska Supreme Court

**Linda Kallhoff**  
Associate Public Guardian  
Office of Public Guardian  
Nebraska Supreme Court

---

---

**CONTRIBUTORS**

The sustainability plan was developed in collaboration with the Southeast Nebraska Respite Network Advisory Board, along with the YWCA of Lincoln, Nebraska Executive Director and Associates who contributed subject-matter expertise and editorial guidance.

**Advisory Board Members**

Jennifer Auman

Program Manager

Lifespan Health Services

NE-Maternal Infant Early Childhood Home Visiting

Nebraska Department of Health and Human Services

Lincoln, NE

Sandra Berman

Marketing Coordinator

Community Home Care

Lincoln, NE

Suzy Campbell

Caregiver Chick

Caregiver Education Coalition

Author

Lincoln, NE

Kathy Erickson, RN, BSN

Choices Unit Supervisor

Blue River Area on Aging

Beatrice, NE

Valerie Franssen, MA

Associate Public Guardian

Office of Public Guardian

Nebraska Supreme Court

Lincoln, NE

Adam Feser  
Executive Director  
The Arc of Lincoln  
Lincoln, NE

Linda Kallhoff  
Associate Public Guardian  
Office of Public Guardian  
Nebraska Supreme Court  
Lincoln, NE

Mel Luetchens  
Pastor  
Waverly, NE

Dr. Allen Meyer, PhD  
Behavioral Medicine Clinic  
Fairbury, NE

Shelly Noerlinger  
Family and Youth Investment  
Region V Systems  
Lincoln, NE

Teresa Thompson  
Caregiver  
Brain Injury Association  
Lincoln, NE

---

**YWCA**

**Andrea Curtis**

Executive Director

**Lynette Glazebrook**

Receptionist

**Carrie Hansen**

Executive Assistant

**Quinn Hullett**

Social Media Intern

Nebraska Wesleyan University

**Taylor Lord**

Executive Assistant

**Melissa Swanson**

Assistant Respite Coordinator

*I would like to give special consideration to my assistant Melissa Swanson, who worked diligently with me on this project, her exceptional writing skills and great eye for detail allowed us to complete this project on time. Thank you so much!*

Table of Contents

**INTRODUCTION**.....9

PURPOSE OF THIS PLAN.....10

**DEFINITIONS**.....10

Nebraska Respite Network.....10

Nebraska Respite Coordinator.....10

Caregiver.....11

Provider.....11

Respite Subsidy Program Across the Lifespan.....11

Aged and Disabled Waiver.....11

Early Development Network.....12

Early Intervention Medicaid home and Community-based waiver.....12

Area Agencies on Aging.....12

Independent Living Centers.....12

HHSS Service Coordinators for the AD Waivers.....13

EDN Service Coordinator’s for the AD Waiver.....13

Developmental Disabilities System.....13

**BACKGROUND**.....13

What does respite do?.....14

Who needs respite?.....15

Why is respite care important?.....15

Respite for caregivers with special needs children.....15

Respite for families with adolescents.....16

Respite for families with chronic illness/disabling conditions.....17

Respite for families with elderly members.....18

**FEASIBLE QUESTIONS**.....18

Who needs respite?.....18

What are the problems regarding caregivers?.....18

What types of providers are needed for respite?.....19

What are the problems regarding providers?.....19

What kind of training do providers need?.....19

What are some of the identified barriers?.....19

**VISION STATEMENT**.....19

**MISSION STATEMENT**.....19

**FUTURE PLANS FOR GROWTH AND DEVELOPMENT**.....20

Goal 1.....20

Goal 2.....20

Goal 3.....20

Goal 4.....20

**ACHIEVING OUR GOALS: STRATEGIC CONSIDERATIONS**.....21

**THE FEDERAL CONTEXT** .....21

**THE STATE AND COMMUNITY CONTEXT: THREATS AND OPPORTUNITIES**.....21

Economic trends.....21

Social and demographic trends.....22

Political and planning developments.....24

Fiscal context.....25

**INTERNAL CAPACITY** .....25

Governance and leadership.....25

Management and Administration.....25

Recruitment, training, and retention of Professional staff and volunteers.....26

Strategic Partners-State level and local level policy makers, opinion leader and gate keepers.....26

Information and outreach systems.....26

**LOGIC MODEL: ROAD MAP FOR ACTION**.....27

Ultimate outcomes and indicators.....27

**FINANCING PLAN**.....31

Fiscal needs.....31

Current and projected revenues and resources.....32

Expected funding gap.....32

Strategy, program and activity.....32

Budgetary line item.....35

**SWOT ANALYSIS**.....40  
Strengths, weaknesses, opportunities, and threats.....40

**PLAN FOR BUILDING ORGANIZATIONAL CAPACITY AND  
COMMUNITY SUPPORT**.....43

**IMPLEMENTATION OF THE PLAN**.....47  
Goal 1.....47  
Goal 2.....48  
Goal 3.....50  
Goal 4.....51

**REFERENCES**.....53

## Introduction

In 1999, LB 692 was passed and the Nebraska Lifespan Respite Network was established to support respite initiatives in the state of Nebraska.

Over the past 16 years the Department of Health and Human Services (DHHS) has created expanded access to information and referral regarding respite resources, including access to qualified providers and funding support available to caregivers of individuals with special needs. DHHS receives Tobacco Cash Settlement funds allocated to Nebraska Respite Network, an Administration on Aging Grant and the Nebraska Department of Education Grant to support varied respite activities. Key activities include outreach and marketing, respite service information and referral, recruitment of respite providers, training opportunities for both caregivers and providers, and direct respite care.

Based on this legislation, DHHS established six Lifespan Respite service areas to coordinate respite resources across Nebraska. The Lifespan Respite Network has committed 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 resources.

4. Ensure that training is available for both consumers and providers by coordinating existing training resources and recruiting additional resources to meet the needs across the lifespan; and
5. Implement ongoing evaluation of providers, caregivers and the respite system to determine unmet needs.

The Nebraska Lifespan Respite Network is a statewide system and as such, these standards are intended to establish continuity across the six local networks that make up that system. These agencies are referred to as “local networks.”

### **THE PURPOSE OF THE PLAN**

Though the goals of the Southeast Nebraska Respite Network (SNRN) will align with those of the state and other networks, this plan is centered on the sustainability of the Southeast Network region. This plan is meant to strengthen the heart of the network as a whole, by concentrating on the sustainability of this separate entity, which will enable the Nebraska Respite Network to function stronger throughout the state.

### **DEFINITIONS**

**Nebraska Respite Network:** A statewide network responsible for the coordination of a statewide system that coordinates respite resources through six offices located in different geographic areas of the state.

**Nebraska Respite Network Coordinator:** One of six coordinators across Nebraska responsible for the coordination of respite resources within a multiple-county area.

**Caregiver:** Friend, family member, or legal guardian residing with and providing ongoing care for an individual unable to care for him or herself. (For respite, Caregivers must be "available on a 24-hour per day basis to assume responsibility for the care and supervision of the client. This may include a caregiver who is employed outside the home if s/he retains 'on-call' responsibility while away from the client."

**Provider:** The individual or agency that provides temporary relief (care, assistance or supervision) for the usual caregiver.

**Respite Subsidy Program Across the Lifespan:** Funding for caregivers to purchase respite services. The program is centralized and administered through the HHSS Central Office.

**Aged and Disabled Waiver:** (AD) (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 average cost of waiver services funded by Medicaid must not exceed the average cost to Medicaid for NF services.

To be eligible for support through this "Aged and Disabled Waiver," a potential client must meet the following general criteria:

1. Have care needs equal to those of Medicaid-funded residents in Nursing Facilities;
2. Be eligible for Medicaid; and

3. Work with the services coordinator to develop an outcome-based, cost effective service plan.

**Early Development Network (EDN):** serves children from Birth until August 31 of the year in which they are three. EDN is Part III of Individuals with Disabilities Education Act (IDEA). 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 was formerly the Early Intervention Program.

**Early Intervention Medicaid Home and Community-Based Waiver:** A Medicaid-funded program which pays for services coordination and respite care for infants and toddlers in the Early Development Network who have needs which qualify them for Nursing Facility level of care.

**Area Agencies on Aging (AAA's):** Serve persons age 65 and older. For purposes of this document the area of the agency that provides services coordination and resource development for the Aged and Disable Waiver is the Medicaid related Program.

**Independent Living Centers (ILC's):** Serves ages 18 to 64. For purposes of this document the area of the agency that provides services coordination and resource development for the Aged and Disable Waiver is the Medicaid related Program. Currently the League of Human Dignity and the Center for Independent Living have contracts with the AD Waiver Program.

**HHSS Services Coordinators for the AD Waiver:** Serves children from August 31 of the year in which they are three through age 17.

**EDN Services Coordinator's for the AD Waiver:** Serves children from Birth until August 31 of the year in which they are three.

**Developmental Disabilities System (DD):** Serves all ages For Purposes of this Document the HHSS Service Coordinators and supervisors are your contacts.

## **BACKGROUND**

Respite provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. Respite does much to strengthen the family system while protecting the health and wellbeing of both caregiver and care recipient. Respite is a key component of family support, long-term care services, and benefits businesses by improving worker retention, productivity, stress levels and health among employees who are caregivers. The Lifespan Respite Care Act defines respite care as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.”

Respite means a break from something difficult or unpleasant. It is short-term, temporary relief from ongoing caregiving responsibilities for those who are caring for a family member(s) with special needs. It is intermittent, flexible for the family, and beneficial to all family members. It can be provided in-home or in the community by paid providers, volunteers, family members or friends.

While the spectrum of individuals classified as “family caregivers” is growing in number and diversity, one fact remains: caregivers often do not recognize the fact that what they are doing is caregiving. Caregivers often do not know how, nor do they want, to ask for help. However, if they do ask for assistance, they often encounter fragmented, narrowly targeted programs or are unable to afford the options available to them. Many others simply lack sufficient information about where to find assistance.

With limited resources and great need, SNRN must be strategic in their approach for how available funds will be used. Proposed activities must meet the unique respite care needs of the communities in which we operate as identified in current fiscal year reporting. SNRN must employ an accessible, community-based and coordinated approach for ensuring statewide access to respite services for family caregivers of children or adults of all ages with special needs. Further, it is essential to build upon existing respite infrastructure to identify previously un-served/under-served populations and address barriers to respite service delivery.

### **WHAT DOES RESPITE DO?**

Respite care provides short-term relief to a family caregiver who needs time off from caring for an ill or elderly loved one. Whether respite care is utilized for a vacation, to run errands or see a movie, or just for a much-needed break, caregivers use this time off to recharge, regenerate, and avoid becoming burned out. Respite care can be just for a few hours, or for a few days, depending on the type of respite care that is desired. It can be in the form of in home care where a private home-care agency is hired to care for the loved one while the family caregiver is running errands, or on

vacation. Respite can also be a temporary stay at an assisted living facility. Another option is an adult daycare center.

### **WHO NEEDS RESPITE?**

Unpaid caregivers who need a temporary break from providing ongoing care to persons of any age with special needs. Examples of special needs are developmental disabilities, chronic illness, physical disabilities, emotional, mental, or physical conditions that require supervision, special health care needs, cognitive impairments such as those from dementia or Alzheimer's disease, and persons at risk of abuse and neglect.

### **WHY IS RESPITE CARE IMPORTANT?**

According to the Administration of Aging (2007) taking care of an elderly family member can be physically and emotionally draining on a caregiver. If you ask a family caregiver, you will hear how hard it can be to care for a loved one full time. This same study found that:

- 54% of caregivers said their own health has gotten worse due to caregiving.
- 29% of caregivers stated that they have difficulty balancing work and family responsibilities.
- 35% of caregivers have difficulty finding time for themselves.
- 29% experience emotional and physical stress from their role.

### **RESPITE FOR CAREGIVERS WITH SPECIAL NEEDS CHILDREN**

Taking care of a child with special needs can present relentless stress and challenges. Ultimately, caregivers are bound to get enveloped in those everyday stressors that come with day-to-day living. Marriage and family

relationships are impacted. There is a lack of time and energy for personal, marital, and family activities, and social seclusion affect many families.

“Caring for a child with special needs is a full-time job. It is easy to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care needs. That is why respite, as the word implies, is truly an interval of rest. Respite can be your answer to renewed energies and give a new perspective to thinking and to planning ahead.”

*(National Information Center for Children and Youth with Disabilities briefing paper, Devitt, June 2009).*

## **RESPITE FOR FAMILIES WITH ADOLESCENTS**

There are unique challenges associated with caregiving for adolescents with special needs. Caring for adolescents with special needs may grow more difficult as the child's body becomes larger and heavier and their personalities become more complex (especially once they reach puberty). The daily physiological and psychological toll on caregivers of adolescents and adults with autism is documented; “Revealing patterns of chronic stress, fatigue, work interruptions and a significantly greater investment of time in caregiving than caregivers of children without disabilities.” (Diament, 2009). Family members and friends care for many adults with special needs. While tending to the needs of an adult with special needs can be time-consuming, energy draining, and expensive (medicines, medical equipment, etc.), these caregivers are most often unpaid for all that they do. Caregivers with

adolescent children with special needs are found to have a hormone associated with stress consistent with people experiencing chronic stress such as soldiers in combat, writes psychologist Michelle Diamant (2009) in the Journal of Autism and Developmental Disorders. Respite would not only be a welcome reprieve, but a vital and necessary one for a caregiver caring for an adolescent with special needs.

### **RESPITE FOR FAMILIES WITH CHRONIC ILLNESS/DISABLING CONDITIONS**

- Nearly 1 in 2 Americans (133 million) has a chronic condition.
- By 2020, about 157 million Americans will be afflicted by chronic illnesses, according to the U.S. Department of Health and Human Services.
- That number is projected to increase by more than one percent per year by 2030, resulting in an estimated chronically ill population of 171 million.
- Sixty percent are between the ages of 18 and 64.
- 90% of seniors have at least one chronic disease and 77% have two or more chronic diseases.
- In the United States 4 in 5 health care dollars (78%) are spent on behalf of people with chronic conditions (Anderson, 2004).

Without the multitude of unpaid family caregivers, many people would live in institutions. How can we as a society provide education and support for these caregivers? We'd like to propose some intervention tools to assist medical personnel in assessing the needs of family caregivers. By promoting respite and providing high quality trainings for providers and caregivers alike will enhance the overall quality of life for these family caregivers.

**RESPITE FOR FAMILIES WITH ELDERLY MEMBERS**

Family caregivers play a key role in delaying and possibly preventing institutionalization of chronically ill elderly patients. It is estimated about 80% of help in the home (physical, emotional, social, economic) is provided by family caregivers. When the patient is mildly or moderately impaired, a spouse or adult children often provide care, but when the patient is severely disabled, a spouse is more likely to be the caregiver (Kaplan & Berkman, 2013). The sandwich generation, those who are caring for an aging parent, and those who still have children in the home, is a growing population. With these statistics, it is evident that something will have to be in place that will offer these caregivers a reprieve that will help to maintain their overall physical and mental health. By providing caregivers respite, it will ultimately save millions of dollars on the national level in medical costs.

**FEASIBLE QUESTIONS****Who needs respite?**

Caregivers; a family member, friend, relative, neighbor; anyone caring for a loved one 24 hours a day/seven days a week.

**What are the Problems regarding caregivers?**

Many caregivers do not realize that they are caregivers.

Many caregivers do not feel like they deserve a break.

Caregivers find it hard to leave their loved one because of guilt.

Caregivers do not want to leave their loved one because of the lack of trust with the provider.

Caregiver's are not aware of respite resources.

**What types of providers are needed for respite?**

There is a need for all types of providers from basic skills to highly skilled nurses to give care.

There is a need for providers from different ethnic backgrounds.  
 Providers who are bi-lingual and who are both skilled and non-skilled.  
 Rural areas are in high need of providers from all skill levels.

### **What are the problems regarding providers?**

It is hard to find and retain providers at any skill level.

People are not aware that they can make money-providing services for caregivers.

It is hard to find providers from diverse cultures because of the language, law, and custom differences.

Providers need to have an accessible profile that will provide a picture for the caregiver describing the kind of person the provider is, what skills they possess and what background they have in those skills.

### **What kind of training do providers need?**

Providers need high quality trainings.

Providers need to have annual trainings in various areas of interests such as, autism, ADHD, behaviors, Alzheimer's, dementia etc.

Trainings need to be easily accessible throughout the state.

Trainings need to be convenient, such as online, but also need to be given in person for those who don't have use of computers.

### **What are some other identified barriers?**

People are unable to locate services.

People are unable to afford respite.

People do not qualify for respite services.

## **VISION**

**All caregivers regardless of location have knowledge about respite resources and are able to access respite services and use them in a timely and effective manner.**

## **MISSION**

**Our mission is to create a better future for caregivers and their families through support, advocacy, education, and training. Everyday the Nebraska Respite Network makes differences in the lives of caregivers by:**

- **Providing support through connections to groups and professionals, and directing caregivers to resources that can improve their overall quality of life.**

- **Advocating for the caregiver’s need to remain socially engaged with family and friends, their mental, physical, and emotional well being to necessitate a full life.**
- **Educating and training providers so they can give care to the recipients with confidence that will allow the caregiver a greater piece of mind.**

### **FUTURE PLANS FOR GROWTH AND DEVELOPMENT**

This sustainability plan highlights the Southeast Nebraska Respite Network’s three-year approach to increasing the availability of respite services throughout the 17 counties of the Southeast region of Nebraska. The Southeast Respite Network is funded by the state of Nebraska through Tobacco Settlement Funds, the Area on Aging grant, and the Department of Education grant.

**Goal 1:** By June 2018, southeast NE has knowledge of the easy access respite database and respite resources across all 17 counties, including rural areas.

**Goal 2:** By June 2018, the 17 counties of Southeast NE incorporate high-quality training, education, outreach materials for respite consumers and providers within businesses, medical units, and educational institutions.

**Goal 3:** By June 2018, develop public awareness campaigns for families, professionals, legislators, and physicians on the importance of respite and how to access respite and respite resources for their consumers and associates.

**Goal 4:** By June 2018, businesses throughout the Southeast region implement respite in their overall health plans and promote clear messaging about respite and respite resources.

### **ACHIEVING OUR GOALS: Strategic Considerations**

#### **The Federal Context**

Public Law 109–442 109th Congress An Act To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes. Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, SECTION 1. SHORT TITLE. This Act may be cited as the “Lifespan Respite Care Act of 2006”. SEC. 2. LIFESPAN RESPITE CARE. The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following: “TITLE XXIX—LIFESPAN RESPITE CARE (*LEGISLATIVE HISTORY—H.R. 3248: HOUSE REPORTS: No. 109–716 (Comm. on Energy and Commerce). CONGRESSIONAL RECORD, Vol. 152 (2006): Dec. 6, considered and passed House. Dec. 8 considered and passed Senate*).

## **The State and Community Context: Threats and Opportunities**

### **1) Economic Trends**

In the past few years, the United States has experienced an economic recession and disruptions in the mortgage and financial markets that have had widespread impact on the financial wellbeing of millions of Americans. Evercare by United Healthcare and the National Alliance for Caregiving felt that it was important to take a look at this current economic downturn and its impact on the nation’s estimated 44 million family caregivers. This particular group in our society represents a \$375 billion annual economic value to the United States. Family caregivers are the backbone of our health care system by providing long-term care in the home to those with chronic illness or disabilities.

A past study by the National Alliance on Caregiving and Evercare was the first study to really look at the out-of-pocket costs for caregivers. Their findings were published in 2007 in an article titled *Family Caregivers-What They Spend, What They Sacrifice*. This article stated they found that caregivers who cared for a person over the age of 50 were spending more than 10% of their annual income – an average of \$5,532 per year. The same study also found that 34 percent of caregivers had used some of their savings to cover caregiving costs.

With the present-day economic situation having a great impact on Americans, it is vital to look at some exact associations of how this economic recession was affecting family caregivers and their loved

ones. This study acknowledged family caregivers are vulnerable in these uncertain economic times to maintain their financial stability as well as continue to provide quality care to their loved one.

This study also found that the economic downturn has effected family caregivers in some substantial ways including their present-day work situation, their use of savings or additional debt to cover caregiving expenses, their living situation with regards to their care recipient and the impact to the caregiver's health in terms of stress.

The financial burden of caregiving when it relates to the workplace, coupled with economic realities are causing caregivers either to be more unwilling to take time away from work for caregiving or to take on additional work to cover caregiving costs. In terms of caregiving costs, the economic downturn has caused caregivers to spend more on caregiving expenses. Of these, more than half of these caregivers are struggling with just basic needs and are putting their own financial futures at risk.

## **2) Social and Demographic Trends**

### **1) The aging population in America.**

The rising number of aging adults surges demand on the public health system and on social and medical services. Chronic diseases, which affect older adults excessively, contribute to disability; lessen quality of life, and increased health- and long-term-care costs. Increased life expectancy exposes, in part, the success of public health interventions, but public health programs must react to the challenges created by this achievement, including the growing burden of chronic illnesses, injuries, and disabilities and increasing concerns about future caregiving and healthcare costs.

In the last one hundred years the amount of older Americans have tripled. This phenomenon can be explained by not only the increasing life expectancy, but also by the decline in the birth rate.

In the year 2000 there were an estimated 35 million Americans over the age of 65 representing 12.4% of the American population (AoA, 2001 U.S. Census Bureau, October, 2001). By 2020 persons 65 or older are expected to encompass 20% of the population (Judy & D'Amico, 1997). By 2030, older Americans are expected to outnumber children under the age of 18 ((Bronfenbrenner, McClelland, Wethington, Moen, & Ceci, 1996).

There are more than 13 million Americans with long-term care needs in the U.S., more than half of who are over the age of 65 (ASPE, DHHS, 1995). Over the next 25 years, as the Baby Boom generation ages, some have estimated that the number of persons requiring long-term care may double.

#### 2) The aging of the American workforce.

The combination of a declining birth rate and aging workforce suggests that support for the growing older population will be limited. This is supported by the decrease in family members available to help, and because public health care dollars generated through income taxes will be diminished due to the smaller workforce (Wagner, 2000).

#### 3) More women in the workforce.

December 2014, there were over 73 million workingwomen in the U.S. While women were just under half of the general workforce (47 percent), they represented a majority of those in professional and technical occupations (51 percent). The proportion of women to men in the workforce changed dramatically from only a generation ago. In 1972, women represented just 38 percent of the workforce. After years of steady growth, the number leveled off in the mid-1990s and has remained close to the current percentage for the last two decades (Wang, Parker, & Taylor, 2007).

#### 4) Changes in family size and composition.

The traditional family, whose father went to work, and a wife who stayed at home to raise children, has been replaced by the dual-earner or the single-parent household. Couples often cohabitate without formally marrying, and in most couples, both partners work. Marriages occur later and rarely last and births are later and fewer in number. Most children have mothers who work. The number of single-parent families has skyrocketed. Many families today are “blended” families, with stepchildren and stepparents. And many families have multiple responsibilities for children and elders who are either living with the families or apart. The number of three-

generation households is growing, and the number of grandparents raising grandchildren is increasing (U.S. Census Bureau, 2001).

#### 5) Rising health care costs.

This key trend has resulted in the implementation of cost containment measures and reinforcement of care, that is, increased dependence of family and friends to provide informal care to substitute for formal health care services. In the past older working caregivers remained in the hospital for most of their recovery period from an illness or accident are now sent home after considerably fewer days and with less “formal” support.

Family members and other informal supports are left to manage the overall care of an elder and to perform sometimes very complicated health care tasks. This often comes at great personal expense and frequently with little or no training or resources from health care professionals (Wagner, 2000).

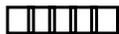
Taken together, these aging, workforce, family, and health care-related trends mean that there are growing numbers of people who must juggle the demands of their work with those of their families. The cost of replacing the work of these informal caregivers with paid home care has been estimated to range from \$45-75 billion (AoA, May 2011) to \$196 billion dollars per year (Arno, Levine, Memmott, 2009).

### 3) Political and Planning Developments

1) Most long-term care for the elderly is provided at home by family caregivers.

Changes in demographics, workforce patterns, and health care economics have increased the need for—and complexity of—caregiving.

Family caregivers are often marginalized by health care professionals and denied access to information that they may need to do a good job.



Bioethics has traditionally focused on patients, but has recently explored the unmet needs of family caregivers.

5 help an understanding of the ethical c  
 policymakers improve the quality of caregiving and the well being of  
 caregivers (Livine & Murray, 2004).

#### **4) Fiscal Context**

One-fifth of all Americans currently live in rural areas of the United States. In Nebraska, more than 40 percent (NE Rural Report DHHS, 2010), of the population lives in non-metropolitan areas of the state. Rural residents are subject to many of the same health problems that urban-dwellers are, but they also face some additional challenges related to living in rural areas.

Nebraska faces a number of challenges in meeting the needs of older individuals living in rural and frontier areas, including providing support for caregivers, in-home programs and adequate transportation. The service network for older individuals in Nebraska will be more pressed to provide support, including education, training, and respite support for caregivers.

Funding to support family caregivers is limited. Most companies do not offer any type of funding for respite care to their employees. The government no longer offers respite coverage to military families increasing additional stress to an already overstressed environment.

### **Internal Capacity**

#### **1) Governance and Leadership**

- A) Grant Specialist and Administration monitors the grant objectives and financial matters.

#### **2) Management and Administration**

- A) DHHS Statewide Respite Coordinator
- B) Executive Director of the YWCA
- C) Southeast Respite Coordinator
- D) Assistant Respite Coordinator
- E) Additional YWCA Associates and Interns

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

- A) The YWCA is a nonprofit organization, recruitment and training is offered on a needs basis through staff and outside contacts.
- B) Respite operates on grant funding.

### **4) Strategic Partners-State level and local level policy makers, opinion leaders and gate keepers**

- A) DHHS Statewide Coordinator
- B) State Coordinators
- C) ARCH
- D) Caregiver Alliance
- E) Caregiver Coalition
- F) Alzheimer's Association
- G) University Medical Center
- H) Monroe Institute
- I) Hastings Respite Center
- J) AARP
- K) Administration on Aging
- L) Nebraska Department of Education

### **5) Information and Outreach Systems**

- A) [nrrs.ne.gov/respitesearch](http://nrrs.ne.gov/respitesearch)
- B) eLifespan
- C) Coordinator's Support site
- D) Connect
- E) Trainings
- F) Health and Educational Fairs
- G) Mass Mailings
- H) Lunch and Learns
- I) Presentations at support groups and senior centers
- J) Presentations with the Caregiver Education Group
- K) Planning Regional Team Meetings and Interagency Meetings

**Logic Model: Road Map for Action**

WHAT TO SUSTAIN	HOW WILL WE MEASURE PROGRESS
<p><b>ULTIMATE OUTCOMES</b></p> <ul style="list-style-type: none"> <li>• Caregivers throughout the Southeast 17 counties know about Respite and how to obtain respite resources.</li> <li>• Provider increase throughout the 17 counties of the Southeastern region; with special emphasis in rural areas.</li> <li>• Caregivers from diverse backgrounds understand and have knowledge of respite and resources within the SE 17 counties.</li> <li>• Provider increase within diverse backgrounds in all 17 counties.</li> <li>• Key informants from diverse backgrounds are REST trained to better reach diverse populations.</li> </ul>	<p><b>INDICATORS</b></p> <ul style="list-style-type: none"> <li>• Improved understanding on respite and respite resources.</li> <li>• Promoting respite throughout the 17 counties of the SE region: more people are accessing nrrs site.</li> <li>• Public is aware that they can provide respite as a paid or volunteer worker for caregivers.</li> <li>• Diverse populations become aware of respite and respite resources and how to obtain them.</li> <li>• Diverse populations are aware that they can provide respite care as a paid or volunteer worker.</li> <li>• Diverse populations are able to train providers within their cultural community.</li> </ul>

<ul style="list-style-type: none"> <li>• Respite and respite resources are implemented within business’s health plans throughout SE 17 counties.</li>   <li>• Yearly Social Media Calendar pertaining to all 17 counties for both caregivers and providers.</li>   <li>• Online trainings available for providers and caregivers throughout the SE 17 county region.</li> </ul>		<ul style="list-style-type: none"> <li>• Businesses have information about respite and how to obtain respite resources as part of their overall wellness plans.</li>   <li>• Professionals are educated and provided resources about the benefits of respite and how to access it to help employees with appropriate relief services.</li>   <li>• Develop marketing campaign and message targeting.</li>   <li>• Electronic newsletter in place.</li>   <li>• Workable media plan for training events and respite news marketed for both providers and caregivers that includes diverse populations throughout the seventeen counties of the SE region.</li>   <li>• Public awareness campaign developed and used to promote resources.</li>   <li>• Online sight for trainings is active on the nrrs site for providers and caregivers.</li> </ul>
---	--	--

<ul style="list-style-type: none"> <li>• Provider REST trainings and education training offered quarterly throughout the year and accessible in SE 17 counties.</li> <li>• 2 trainings per fiscal year to develop Coordinator’s professional skills.</li> </ul>		<ul style="list-style-type: none"> <li>• Trainings are offered throughout the year for providers and accessible for all 17 counties and diverse populations.</li> <li>• Coordinator is developing skills that will enhance performance.</li> </ul>
<p style="text-align: center;"><b>INTERIM OUTCOMES/CONDITIONS AND CAUSES THAT MUST CHANGE</b></p> <ul style="list-style-type: none"> <li>• People are not aware that an income can be generated for providing respite to caregivers.</li> <li>• The lack of knowledge about respite in the 17 counties of the SE region.</li> <li>• Social media is lacking in promoting respite.</li> </ul>		<p style="text-align: center;"><b>INDICATORS OF INTERIM OUTCOMES</b></p> <ul style="list-style-type: none"> <li>• An increase of caregivers by 15% from the FY 2015 126 currently active baseline.</li> <li>• Increase by 15% appropriately trained Network approved respite providers from FY 2015 baseline of 43 providers.</li> <li>• Increase of information on respite and respite resources for businesses and faith-based organizations, hospitals, medical and mental health clinics, educational institutions, support groups, and the public.</li> <li>• Media campaign in place for a full FY by the end of the FY 2015.</li> </ul>

<ul style="list-style-type: none"> <li>• Diverse populations need a voice within their own culture to answer respite questions.</li>   <li>• Diverse populations needed to provide trainings within their own cultures.</li>   <li>• More provider and caregiver trainings available throughout the year.</li> </ul>		<ul style="list-style-type: none"> <li>• Contacts list of key informants from diverse populations who are knowledgeable on respite and respite resources.</li>   <li>• Key informants to provide respite information on all resources including on becoming providers and getting paid to increase providers within targeted populations by 15% of FY 2015's baseline of 2.</li>   <li>• Trained key informants in targeted populations to answer questions on respite and respite resources.</li>   <li>• Trained key informants in REST training to provide trainings within their own community.</li>   <li>• REST trainings are offered quarterly throughout the year.</li>   <li>• Diverse population REST trainings are offered quarterly by targeted population's key informant.</li> </ul>
--	--	--

<ul style="list-style-type: none"> <li>• Businesses are not aware of the benefits of having respite information on hand as part of their overall wellness plans.</li> <li>• Trainings need to be more accessible.</li> <li>• Coordinator skills in various areas need to remain sharpened.</li> <li>• Diverse populations are difficult to reach to explain about the benefits and resources of respite and how to attain those resources.</li> <li>• Diverse populations are not aware that people from their community can provide respite within their own culture and receive an income.</li> </ul>		<ul style="list-style-type: none"> <li>• Increase the FY 2015 of 2 by 15%.</li> <li>• Online trainings are implemented on the nrrs.ne.gov site by the end of the FY 2015.</li> <li>• Coordinator will attend two strong trainings in the area of their choosing to remain skilled in job performance.</li> </ul>
---	--	--

**Financing Plan**

**1) Fiscal Needs**

- A) We operate on limited funds; additional funding is needed to keep talented workers and to work outside the box, to do more media messaging, and additional trainings.

## 2) Current and Projected Revenues and Resources

- A) Nebraska State Respite Grant
- B) Administration on Aging Grant
- C) Department of Education Grant
- D) Keno Grant

## 3) Expected Funding Gap

- A) By Strategy, program, and activity

Program Element	Estimated Cost
<b>Start-up Costs</b>	
Planning	
Community assessment	
Initial staff recruitment and training	<b>None</b>
Equipment and supplies	
Facilities renovation/expansion	
<b>Ongoing Operating Costs</b>	
Staff	<b>61,527</b>
Supplies	<b>500</b>
Training and technical assistance	<b>1,800</b>
Transportation	<b>1,700</b>
Facilities (rent, utilities, and maintenance)	<b>In-Kind</b>
Administration and overhead (insurance, planning, evaluation, reporting)	<b>12,600</b>
Other	
<b>Infrastructure</b>	
Planning and coordination	
Training and technical assistance	

Evaluation	
Management, administration, and overhead	
Other	
<b>Total Costs</b>	<b>\$78,127</b>

<b>Program Element</b>	<b>Estimated Cost</b>
<b>Start-up Costs</b>	
Planning	
Community assessment	
Initial staff recruitment and training	<b>None</b>
Equipment and supplies	
Facilities renovation/expansion	
<b>Ongoing Operating Costs</b>	
Staff	<b>63,810</b>
Supplies	<b>500</b>
Training and technical assistance	<b>950</b>
Transportation	<b>1,700</b>
Facilities (rent, utilities, and maintenance)	<b>In-Kind</b>
Administration and overhead (insurance, planning, evaluation, reporting)	<b>15,752</b>
Other	
<b>Infrastructure</b>	
Planning and coordination	
Training and technical assistance	
Evaluation	
Management, administration, and overhead	

Other	
<b>Total Costs</b>	<b>82,712</b>

<b>Program Element</b>	<b>Estimated Cost</b>
<b>Start-up Costs</b>	
Planning	
Community assessment	
Initial staff recruitment and training	<b>None</b>
Equipment and supplies	
Facilities renovation/expansion	
<b>Ongoing Operating Costs</b>	
Staff	<b>65,694</b>
Supplies	<b>600</b>
Training and technical assistance	<b>1,000</b>
Transportation	<b>1,800</b>
Facilities (rent, utilities, and maintenance)	<b>In-Kind</b>
Administration and overhead (insurance, planning, evaluation, reporting)	<b>15,736</b>
Other	
<b>Infrastructure</b>	
Planning and coordination	
Training and technical assistance	
Evaluation	
Management, administration, and overhead	
Other	
<b>Total Costs</b>	<b>84,830</b>

**Budgetary Line Item**

Respite Budget Narrative July 2015-June 2016			2016-17	2017-18	2018-19
<b>Income</b>					
<b>1. Grants</b>					
Southeast Respite Network	66,667.00	66,667.00			
AoA (Confirmed) until 9/30/15	4,100.00	4,100.00			
NDE (Confirmed) until 9/30/15	5,900.00	5,900.00			
Keno (confirmed) January 2015 to Dec 2015	3,675.00	3,675.00			
<b>Total</b>	<b>80,342.00</b>	<b>80,342.00</b>			
<b>2. In Kind Donations</b>					
Food donations for Rest Trainings and/or Advisory Board*	1,400.00	1,400.00			
<b>Total income with in kind donations</b>	<b>81,742.00</b>				
<b>Expenses</b>					
<b>1. Salaries</b>					
Respite Coordinator Salary 1 FTE \$32,320	32,640.00	32,640.00	33,619.20	34,627.78	35,666.61
Assistant Respite Coordinator 20 hours x \$10/hour x 52 weeks	10,400.00	10,400.00	10,712.00	11,033.36	11,364.36
Respite Intern 20 hours x \$9.00/hour x 34 weeks	6,120.00	6,120.00	6,303.60	6,492.71	6,687.49
Director of Programs and Administration \$35,500 x .10					
Respite + .01 TAB	3,905.00	3,905.00	4,022.15	4,142.81	4,267.10
TAB Staff 5 staff x 4 hours x \$10/hour x 12 weeks	2,400.00	2,400.00	2,472.00	2,546.16	2,622.54
TAB Coordinator 2 hours x \$10/hour x 12 weeks	240.00	240.00	247.20	254.62	262.25
<b>Total salary/wage expenses</b>	<b>55,705.00</b>	<b>55,705.00</b>	<b>57,376.15</b>	<b>59,097.43</b>	<b>60,870.36</b>
<b>2. Payroll taxes</b>					

\$51,025 x .0765= **(rounded) is the total payroll taxes**

**Total 3,903.00 3,903.41**

**3. Benefits**

Health Insurance Coordinator \$3,600	3,600.00	3,600.00	3,870.00	4,160.25	4,472.27
Health Insurance Director \$2400 x .11	264.00	264.00	283.80	305.09	327.97
Retirement \$35,500 x .11 x .05	195.25	195.25	209.89	225.64	242.56
<b>Total Benefits</b>	<b>4,059.25</b>	<b>4,059.25</b>	<b>4,363.69</b>	<b>4,690.97</b>	<b>5,042.79</b>

**4. Utilities**

Gas (heat) 2700/year x .0846		228.42	0.00	0.00	0.00
Electricity (2700/year x .0846)		228.42			
Rugs, Toilet Paper, Paper Towels (720/year x .0846)		60.91			
Pest Control (420/year x .0846)		35.53	0.00	0.00	0.00
Water (230/year x .0846)		19.46	0.00	0.00	0.00
<b>6,770 x 8.46% Total Utilities</b>	<b>573.00</b>	<b>572.74</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>

**5. Occupancy**

Rent 36000 x .0846	3,045.00	3,045.60	3,045.00	3,045.00	3,045.00
<b>Total Occupancy</b>	<b>3,045.00</b>	<b>3,045.60</b>	<b>3,045.00</b>	<b>3,045.00</b>	<b>3,045.00</b>

**6. Postage**

Workplace Wellness Program Mailings 75 x \$2.50	187.50	187.50	208.13	231.02	256.43
Provider Packets 5 x 12 x 2.50	150.00	150.00	166.50	184.82	205.14
General Correspondence 45/month x .49	264.60	264.60	293.71	326.01	361.88
Early childhood program mailings 150 x \$2.50	375.00	375.00			
<b>Total postage</b>	<b>977.10</b>	<b>977.10</b>	<b>668.33</b>	<b>741.85</b>	<b>823.45</b>

**7. Office Supplies**

Paper	180.00	180.00	198.00	217.80	239.58
#10 Business Envelopes 1000	60.00	60.00	66.00	72.60	79.86

Folders 150	14.00	14.00	15.40	16.94	18.63
Presenter Post It Notes	80.00	80.00	88.00	96.80	106.48
Notebooks	25.00	25.00	27.50	30.25	33.28
Large Envelopes 500	60.00	60.00	66.00	72.60	79.86
Misc	100.00	100.00	110.00	121.00	133.10
Large padded envelopes 100	100.00	100.00	110.00	121.00	133.10
<b>Total Office Supplies</b>	<b>619.00</b>	<b>619.00</b>	<b>680.90</b>	<b>748.99</b>	<b>823.89</b>
<b>8. Food</b>					
In Kind Advisory Board Meetings (6) x 15 x \$10.00	900.00	900.00			
Food for 5 Rest Trainings x 15 participants x \$10.00	750.00	750.00			
<b>Total</b>	<b>1,650.00</b>	<b>1,650.00</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>
<b>9. Mileage</b>					
142 miles x 35 trips x .575	2,857.75	2,857.75	3,000.64	3,150.67	3,308.20
<b>Total</b>	<b>2,857.75</b>	<b>2,857.75</b>	<b>3,000.64</b>	<b>3,150.67</b>	<b>3,308.20</b>
<b>10. Telecommunications</b>					
Vonage VoIP 32.01 per month x 2 phones	768.24	768.24	768.24	768.24	768.24
TWC \$140 per mo. X 25%	420.00	420.00	420.00	420.00	420.00
Cell Phone Stipend \$50.00 x 12 months	600.00	600.00	600.00	600.00	600.00
Windstream 1-800 Respite Line \$20.00 x 12 months	240.00	240.00	252.00	264.60	277.83
<b>Total</b>	<b>2,028.24</b>	<b>2,028.24</b>	<b>2,040.24</b>	<b>2,052.84</b>	<b>2,066.07</b>
<b>11. Technology</b>					
Firespring Website is \$80 per mo. x 25%	240.00	240.00	240.00	240.00	240.00
DropBox \$105 x 3 users renews in May, 2016	315.00	315.00	315.00	315.00	315.00
<b>Total</b>	<b>555.00</b>	<b>555.00</b>	<b>555.00</b>	<b>555.00</b>	<b>555.00</b>
<b>12. Printing and Publishing</b>					
Copier maintenance fees:	300.00	300.00	300.00	300.00	300.00

450 Black and white copies/month x .03	162.00	162.00	162.00	162.00	162.00
Brochures	500.00	500.00	500.00	500.00	500.00
<b>Total</b>	<b>962.00</b>	<b>962.00</b>	<b>962.00</b>	<b>962.00</b>	<b>962.00</b>

**13. Equipment**

Furniture and Copier Lease: 233.63 per month x 33%	925.17	925.17	925.17	925.17	925.17
Computer: 52.75 per month x 3 months x 2 computers	316.50	316.50	316.50	316.50	
<b>Total</b>	<b>1,241.67</b>	<b>1,241.67</b>	<b>1,241.67</b>	<b>1,241.67</b>	<b>925.17</b>

**14. Insurance**

Property and Casualty: (\$7,022.28 X 16.67%)	1,170.61	1,170.61			
Worker's compensation: (2580X 30.32%)	782.26	782.26			
<b>Total</b>	<b>1,952.87</b>	<b>1,952.87</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>

**15. Professional Fees**

Audit FY14/15 Dana Cole .25 x 7050	1,762.50	1,762.50			
Accounting \$250 per month x .25	750.00	750.00			
Audit FY15/16 Dana Cole .2 x 8050	1,610.00	1,610.00			
<b>Total</b>	<b>4,122.50</b>	<b>4,122.50</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>

**16. Specific Assistance to Individuals**

\$300 x 3 caregivers (emergency respite)	<b>900.00</b>	<b>900.00</b>	900.00	900.00	900.00
--	---------------	---------------	--------	--------	--------

**17. Consulting Fees**

Stipend for 5 Culturally Responsive Trainers to take REST Train the Trainer 16 hour training x 15/hour=	1,200.00	1,200.00	720.00		
Stipend for Culturally Responsive Trainers to help recruit and provide 2 REST Trainings x 16 hours training and preparation x 15/hour=	480.00	480.00	504.00		
Evaluation for TAB, including 2 focus groups	700.00	700.00	700.00		
<b>Total</b>	<b>2,380.00</b>	<b>2,380.00</b>	<b>1,924.00</b>	<b>0.00</b>	<b>0.00</b>

**18. Advertising/Marketing**

Pens/SWAG			1,500.00	1,500.00	1,500.00
Advertising	1,325.00	1,325.00	1,656.25	2,070.31	2,587.89
<b>Total</b>	<b>1,325.00</b>	<b>1,325.00</b>	<b>3,156.25</b>	<b>3,570.31</b>	<b>4,087.89</b>

**19. Conference Registration**

Health Fairs	250.00	250.00	250.00	250.00	250.00
Trainings	200.00	200.00	1,000.00	1,040.00	1,081.60
<b>Total</b>	<b>450.00</b>	<b>450.00</b>	<b>1,250.00</b>	<b>1,290.00</b>	<b>1,331.60</b>

<b>Total Expenses \$</b>	<b>89,306.38</b>	<b>89,307.14</b>	<b>81,163.87</b>	<b>82,046.73</b>	<b>84,741.42</b>
--------------------------	------------------	------------------	------------------	------------------	------------------

SWOT ANALYSIS

STRENGTHS	WEAKNESSES
<p><b>What advantages does your organization have?</b></p> <p>A list of approved providers</p> <p>A one stop place to get information on respite and respite resources</p> <p>We are able to offer information and connections to questions and organizations that people might need</p> <p>We offer trainings</p> <p>We are a statewide program</p> <p>We are able to help families get a break</p> <p>We think outside the box</p> <p>We are not afraid to take risks</p> <p>Train our people</p> <p>Networking</p> <p>Advisory board</p> <p><b>What do you do better than anyone else?</b></p> <p>We get people in touch with a provider 24 hours a day 7 days a week through our database</p> <p>NRN offers an easier possibility to get respite funding</p>	<p><b>What could you improve?</b></p> <p>Our contact with caregivers</p> <p>Contact with providers</p> <p>A provider profile</p> <p>Better surveys; more specific</p> <p>Advertising</p> <p>Getting the nrrs.ne.gov site out in all materials</p> <p>Getting caregivers to use their respite funding and realize that they need and deserve the break</p> <p>Coordinator turnover throughout the state</p> <p>Coordinator and state not communicating on the same wave length</p> <p>Understanding how the support sight is suppose to work for the coordinators</p> <p><b>What should you avoid?</b></p> <p>Keeping things that work for your area to yourself because it could be beneficial to other coordinators</p> <p>Not asking questions to the director and other coordinators</p>

<p><b>What unique or lowest-cost resources do we have?</b></p> <p>NRN database    Flyers</p> <p>College Newspapers</p> <p>Trainings    Email</p>	<p>Waiting to long to advertise before a scheduled event</p> <p>Not setting deadlines or goals</p>
<p><b>OPPORTUNITIES</b></p>	<p><b>THREATS</b></p>
<p>A caregiver and provider meet and greet</p> <p>An updated provider profile application that expresses experiences and willingness to work with caregivers</p> <p>Online training that engages providers and caregivers alike</p> <p>A Facebook page with online newsletter</p> <p>Health pages/tips for caregivers and providers</p> <p>Finding a spokesperson</p> <p>Focus groups</p> <p>Community outreach</p> <p>Meet your politicians</p> <p>Fundraising</p> <p>Partnerships throughout the community</p>	<p><b>What obstacles do you face?</b></p> <p>Coordinator turnover</p> <p>Politician changeovers</p> <p>Policies change</p> <p>Limited funding</p> <p>Demographic changes</p> <p>Limited resources</p> <p><b>What are your competitors doing?</b></p> <p>Getting help from local politicians</p> <p>Advertising everywhere</p> <p>Having fundraisers like walks and auctions</p> <p>Having gala events</p>

<p><b>What interesting trends are you aware of?</b></p> <p>Social Media    Pinterest    Flyers    Emails                  Facebook        Public Access Television</p> <p>Twitter            Online Education</p> <p>Radio    Posters</p>	<p><b>Are quality standards or specifications for your job, products or services changing?</b></p> <p>Going toward a REST trained provider</p> <p>Limited mileage funds for promoting in rural areas</p>
---	--

**TIP**

Strengths and weaknesses are often internal to your organization, while opportunities and threats generally relate to external factors.

A useful approach when looking at opportunities is to look at your strengths and ask yourself whether these open up any opportunities.

**Plan For Building Organizational Capacity and Community Support**

Vision	Conditions	Indicators	Strategies	Activities	Performance Measures
<p>People in all 17 counties know what respite is and how to get resources</p> <p>Greater number of identified, trained, bilingual providers</p> <p>Free online REST training</p> <p>Multicultural approach for training purposes</p> <p>More people accessing the nrrs site and data dash board</p> <p>Respite resources and database are shared in businesses wellness plans</p>	<p>Lack of knowledge</p> <p>Lack of knowledge in the community that they can provide respite and get paid</p> <p>Programs need to be easily accessible</p> <p>Multicultural trainers who can implement training “normalization” within cultures</p>	<p>What proportion of family caregivers have information of resources</p> <p>What barriers do we overcome to get knowledge to them</p> <p>The number of steps to receive services is decreased</p> <p>Key leaders and respite coordinator report that partnerships are resulting in increased users of respite database and dashboard</p>	<p>Meet with key informants within cultures</p> <p>Trainings provided online in several languages</p> <p>Meet with members of Human Resources to get respite included in wellness plans</p> <p>Providers are trained within their cultural needs</p>	<p>Public outreach Flyers and Posters in multiple languages to reach specific populations</p> <p>Media campaign that is culturally sensitive</p> <p>Hold advertised meetings throughout the region explaining what respite is, how to get resources, and on becoming a provider</p> <p>Continue to do lunch and learns for area businesses</p>	<p>Survey via phone and email</p> <p>Database records show increase in online users</p> <p>Keep track of visited worksites and contact information in excel spreadsheet</p> <p>Track the number of lunch and learns provided</p>

ASSUMPTIONS	EXTERNAL FACTORS
<ol style="list-style-type: none"><li>1. Caregivers want to participate</li><li>2. Providers will want to participate</li><li>3. Honest responses in evaluations</li><li>4. Businesses will be willing and interested in participating</li></ol>	<ol style="list-style-type: none"><li>1. Health</li><li>2. Transportation</li><li>3. Economy</li><li>4. Language</li><li>5. Cultural differences</li></ol>

Vision	Conditions	Indicators	Strategies	Activities	Performance Measures
<p>Two to four trainings per year with all coordinators and administration</p> <p>One to two trainings per year to develop skill of coordinator</p> <p>Establish a support group for caregivers</p> <p>Host meet and greet for caregivers and providers two times each year</p>	<p>The cost and travel expenses</p> <p>Cost</p> <p>Time and cost</p> <p>Caregivers ability to get away</p>	<p>The meetings will allow all coordinators to have open discussions on training and concerns</p> <p>The training will allow the coordinator to develop in areas needed to better their work performance</p> <p>This will give caregivers and providers a chance to meet each other and build relationships</p>	<p>Administration can break meetings into regions in groups of two or three</p> <p>Provide Skype if traveling is not possible</p>	<p>Can learn the best ways to share resources and ask how to operate the database, dashboard, and about other technical problems</p>	<p>Coordinators and administration will track what they brought back from meetings</p> <p>Coordinator will track the trainings and document its purpose and if it has been put into practice</p> <p>Track signup sheets</p>

ASSUMPTIONS	EXTERNAL FACTORS
<ol style="list-style-type: none"><li>1. That there will be money available</li><li>2. That they will be able to use the training</li><li>3. That providers will want to participate</li><li>4. That caregivers will want to participate</li></ol>	<ol style="list-style-type: none"><li>1. If the training will make a difference</li><li>2. If the right training will come along</li><li>3. The meeting place</li><li>4. Transportation and care costs</li></ol>

## IMPLEMENTATION OF THE PLAN

**Goal 1:** By June 2018, southeast NE has knowledge of the easy access respite database and respite resources across all 17 counties, including rural areas.

### 2015-2016 Strategies and activities

- a) Continue to promote respite and respite resources throughout the 17 counties by attending health and educational fairs, meetings, senior centers, and other community outreaching events.
- b) Send out mass mailings through emails and the U.S. postal mailings.
- c) Develop surveys asking the caregiver's what their unmet needs and concern's are.
- d) Develop surveys asking what the provider's needs and concerns are.
- e) Develop a provider outreach campaign; message friendly to reach all ethnic groups.

### 2016-2017 Strategies and activities

- a) Continue to promote respite resources throughout the 17 counties by attending health and educational fairs, senior centers, meetings and community outreaching events.
- b) Continue to send mass mailings.
- c) Report survey information for caregivers and write a summary online with goals and objectives to meet those needs.
- d) Report provider survey information and write a summary with goals and objectives on conference call with DHHS and state coordinators.
- e) Continue to send surveys out to caregivers and providers requesting information on their needs and concerns.
- f) Continue to recruit providers.

### 2017-2018 Strategies and activities

- a) Continue to promote respite resources throughout the 17 counties by attending health and educational fairs, senior centers, meetings and community outreaching events.
- b) Continue to send mass mailings.

- c) Report survey information for caregivers and write a summary online with goals and objectives to meet those needs.
- d) Report provider survey information and write a summary with goals and objectives on conference call with DHHS and state coordinators.
- e) Continue to send surveys out to caregivers and providers requesting information on what their needs and concerns are twice each year.
- f) Continue to report findings on caregiver and provider surveys.
- g) Follow up with goals and action plans on meeting the needs of provider's and caregiver's.
  - a. Educate key informants throughout the 17 counties on respite and respite resources and trainings (examples: Librarians, school counselors, principals, teachers, etc.).
- h) Develop an action plan to get key informants involved in trainings.
- i) Continue to recruit providers.

**Goal 2:** By 2018, the 17 counties of Southeast NE incorporate high quality training, education, and outreach materials for respite consumers and providers within businesses, medical units, and educational institutions.

#### 2015-2016 Strategies and activities

- a) Develop an awareness campaign that demonstrates the value of the unpaid family caregiver with research and stat information on local, state, and national levels.
- b) Identify what the educational needs are for caregivers and providers.
- c) Identify the barriers that cause immigrants from receiving and giving respite.
- d) Identify key informants in culturally diverse populations willing to be trained and who are willing to train others in their populations.
- e) Research businesses, medical centers, private practices and educational institutes and provide them with educational material promoting the importance of respite and respite resources.
- f) Identify gaps in educational materials for private sectors and create necessary materials to be distributed containing needed information for caregiver populations.
- g) Create a workbook containing materials geared to helping caregivers balance their caregiving and workplace responsibilities.

- h) Request the state hold another “REST” train the trainer session to train at least four key informants from culturally diverse populations.

#### 2016-2017 Strategies and activities

- a) Continue to demonstrate the importance of caregivers with research and statistical information on local, state and national level.
- b) Analyze the educational findings that are lacking for caregivers and providers and develop an action plan with goals and objectives to achieve these shortcomings.
- c) Continue to research businesses, medical centers, private practices and educational institutes and provide them with educational material promoting the importance of respite and respite resources.
- d) Identify at least 2 colleges willing to connect coursework to respite for college credit.
- e) Identify at least 2 high schools willing to connect course work to respite for high school credit.
- f) Document how the coursework is linked to respite and the benefit to students.
- g) Keep connected with key informants on diversity training issues.
- h) Work with CCFL to get workbook for caregivers online through the [nrrs.ne.gov](http://nrrs.ne.gov) website.

#### 2017-2018 Strategies and activities

- a) Continue to demonstrate the importance of caregivers with research and statistical information on local, state and national level.
- b) Execute the action plan with goals and objectives on education for caregivers and providers.
- c) Continue to research businesses, medical centers, private practices and educational institutes and provide them with educational material promoting the importance of respite and respite resources.
- d) Implement respite coursework for college and high school students' for academic credit.
- e) Continue to keep connected to key informants on diversity training.
- f) Continue to improve workbook for caregivers and working with CCFL on updating the workbook online.

**Goal 3:** By June 2018, develop public awareness campaigns for families, professionals, legislators, and physicians on the importance of respite and how to access respite and respite resources for their families and associates.

#### 2015-2016 Strategies and activities

- a) Create multicultural public outreach campaign.
- b) Develop culturally sensitive materials for outreach purposes.
- c) Work with Nebraska Lifespan Respite Center on Children, Families and the Law (CCFL) to develop a link on the referral site where caregivers can communicate to respite coordinators and to legislatures their unmet needs so their voices are heard and plans can be made to rectify those needs.
- d) Online newsletter located on the referral site with tips for caregivers on health, work, and everyday living.
- e) Mass mailings on the importance of respite to families, professionals, legislators, and physicians.
- f) Locate a state legislative champion.

#### 2016-2017 Strategies and activities

- a) Strengthen the outreach campaign by identifying populations who are not being heard and develop an action plan and goals to strengthen awareness with those populations.
- b) Continue to work with CCFL on making the referral site a user-friendly page where caregivers and providers can communicate their unmet needs.
- c) Continue mass mailings.
- d) Continue to improve written materials on respite and making sure they are culturally sensitive.
- e) Have public and legislative awareness meetings to engage the public with respite concerns.

#### 2017-2018 Strategies and activities

- a) Continue to identify areas in the outreach campaign where people are not being heard and work to strengthen those overlooked areas.
- b) Continue with mass mailings.

- c) Work with CCFL on the referral for caregivers to give real life stories about the benefits of respite to further increase awareness of caregiver issues.

**Goal 4:** By June 2018, Businesses throughout the Southeast region implement respite in their overall health plans and promote clear messaging about respite and respite resources.

#### 2015-2016 Strategies and activities

- a) Develop a list of businesses and human resource personnel who are willing to listen about the importance of respite for caregivers in the workplace.
- b) Provide information on the importance of respite for caregivers in the work place.
- c) Provide stats to businesses regarding caregivers in the workplace and on caregiver issues.
- d) Provide businesses with the nrrs referral site information and state the importance of associates who are caregivers in utilizing this site.
- e) Find a legislative champion to help promote the nrrs referral site to businesses for those associates who are also caregivers.

#### 2016-2017 Strategies and activities

- a) Continue to develop lists of businesses with human resource contacts that are willing to listen about the importance of respite for caregivers in the work place.
- b) Continue to provide information on the importance of respite for caregivers in the work place.
- c) Continue to provide stats to businesses regarding caregivers in the workplace and on caregiver issues.
- d) Continue to provide businesses with the nrrs referral site information and state the importance of associates who are caregivers in utilizing this site.
- e) Continue to work with a legislative champion on promoting the importance of respite for caregivers in the workplace and to have information at the work place as part of their overall wellness work plans.

2017-2018 Strategies and activities

- a) Continue to develop lists of businesses with human resource contacts that are willing to listen about the importance of respite for caregivers in the work place.
- b) Continue to provide information on the importance of respite for caregivers in the work place.
- c) Continue to provide stats to businesses regarding caregivers in the workplace and on caregiver issues.
- d) Continue to provide businesses with the nrrs referral site information and state the importance of associates who are caregivers in utilizing this site.
- e) Continue to work with a legislative champion on promoting the importance of respite for caregivers in the workplace and to have information at the work place as part of their overall wellness work plans.

## REFERENCES

- AoA (Administration on Aging) (May, 2001). Family caregiving fact sheet.  
[<http://www.aoa.dhhs.gov/may2001/factsheets/family-caregiving.html>].
- Administration on Aging. *A profile of older Americans: 2005. (2007)*  
Washington, DC, Department of Health and Human Services.
- Anderson, G. (2004) "The growing burden of chronic disease in America"  
*Public Health Reports*; May/June (19).
- Arno, P.S., Levine, C. & Memmott, M. (2009). *The economic value of informal caregivers*. Health Affairs Quarterly. Vol. 18, 2, 182-188.
- ASPE, DHHS (1995). Population estimates of disability and long-term care.  
Washington, DC: Bronfenbrenner, U., McClelland, D., Wethington, E.,  
Moen, P., & Ceci, S. J. (1996). *The state of Americans*. New York: The Free  
Press.
- Devitt, J., (2009) "Coping with Disabilities", *University of Communications*;  
*University of Wisconsin Press*, Madison, WI., 13(4)
- Diamant, M., (2009) "Autism Mothers have Stress Similar to Combat Soldiers"  
Disability Scoop, November 10.
- Carol Levine and Thomas H. Murray, eds., *The Cultures of Caregiving: Conflict  
and Common Ground among Families, Health Professionals, and Policy  
Makers*, Johns Hopkins University Press, 2004.

Judy, R. W., & D'Amico, C. (1997). *Workforce 2020*. Indianapolis: Hudson Institute.

Kaplin, D., & Berkman, B. (2013). "Family Caregiving for the Elderly" *Geriatrics/Social Issues of the Elderly, 23(11) National Information Center for Children and Youth with Disabilities briefing paper, June, (1996)*

Respite Network Services Standards, Department of Health and Human Services, State of Nebraska. Retrieved July 17, 2015 Rules and Regulations available on the HHSS website. <http://www.hhs.state.ne.us/reg/regs.htm>

U.S. Census Bureau (September, 2001). Age: 2000 - Census 2000 Brief. [[www.census.gov/prod/2001pubs/c2kbr01-12.pdf](http://www.census.gov/prod/2001pubs/c2kbr01-12.pdf)].

Wagner, D. L., Hunt, G.G., & Reinhard, S. (2000, March). *Identifying and addressing barriers to workplace eldercare programs*. Paper presented at the "Work and Family: Expanding the Horizons" Conference, San Francisco, CA.

Wendy Wang, Kim Parker, and Paul Taylor. "Breadwinner moms: Mothers are the sole or primary provider in Four-in-Ten Households with Children; Public Conflicted about the Growing Trend." *Pew Research, Social and Demographic*. Washington, D.C. May 29, 2013.