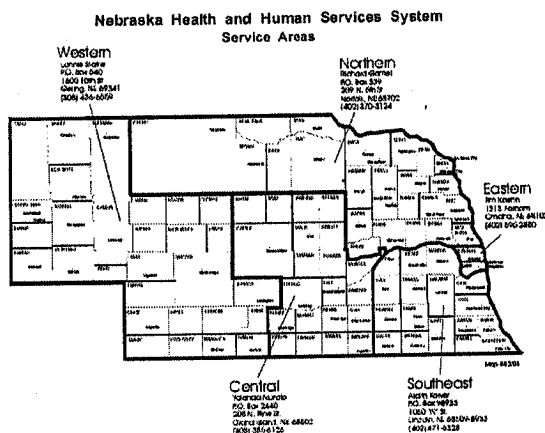


# Intent of the Nebraska Lifespan Respite Network

To establish a statewide system for the coordination of respite resources through six Service Area offices across Nebraska

Nebraska Department of Health  
& Human Services

*Service Area Boundaries*



## **THE BEGINNING.....**

- A small group of health care workers began researching Oregon's legislation
- A coalition was formed early on to get consensus and buy-in from key organizations, ex: Area Agency on Aging, Alzheimer's Association,
- Consensus was largely done up front.

- The group selected a senator to be lead sponsor and educated him on the need for a lifespan respite network.
- The legislation was drafted to first establish the six area networks and fund just the start up costs.

## **Funding to Support the Infrastructure**

- \$228,000  
State General Funds
- \$228,000  
To% Medicaid Administrative Match
- \$100,000  
Child Care Block Grant
- \$50,000  
Part C Early Intervention
- \$606,000  
Total Budget

## **THE MIDDLE.....**

- So, in 1999, the Nebraska Lifespan Respite Network was introduced
- The coalition organized testifiers
- The coalition also identified key people to communicate with the legislator's offices. They used a number of different methods for communicating with senators: cookies; magnets; pins.
- The Respite Network Coalition organized the testifiers and the testimony for the senator. They also organized written material for handouts throughout the legislative process. This ensured the information stayed consistent

## Public Hearing Testimony

- The people who testified were not professional lobbyists.
- Elderly gentleman told about taking care of his wife who had Alzheimer's. He spoke of the love and the care, of the isolation and the loneliness. Respite gave him the breaks he needed to continue her care until her death.
- A young couple testified whose baby, Austin, had been oxygen deprived during delivery resulting in severe medical issues. This couple cared for Austin every day but soon the toll was felt. Respite allowed the couple to have breaks where they could be a couple first and focus on their marriage. They were expecting their second child when the funding in LB 692 was being requested. They told of the love for their son but had it not been for respite, their marriage would not have survived. Austin eventually died at the age of three.

## LB 148

- Enacted the Nebraska Respite Network administered by Health and Human Services. This agency serves as the central point of coordination for the six service areas.
- The network helps establish a statewide system for the coordination of respite resources that serve the lifespan.

## **The First Year.....**

- May, 1999
  - > Legislation passed(148) requiring six community respite programs
- July, 1999 – April 2000
  - > RFP process
  - > Six statewide meetings
  - > Bidder's conference
  - > Proposal(s) service process
  - > Contracts negotiated
- May, 2000
  - > Six contracts in place

## **Marketing/Public Awareness**

- General Public
  - > What is Respite?
- Providers
  - > Targeted recruiting efforts
  - > How they can make a difference in families lives
  - > Need for respite to enable families to stay intact longer
- Caregivers
  - > Respite is available and how to access
  - > Importance of respite in keeping their families together longer

## **Outreach Activities**

- Form and Advisory Committee representative of their geographical area and all populations across the lifespan
- Work with Medicaid staff to help identify respite needs of families across the lifespan
- **BUILD ON EXISTING RESOURCES**

## **Recruiting Providers**

- Informational meetings across their Service Area
- Targeted recruiting efforts through the media
  - > Television commercials
  - > Print promotion
- Emphasis on recruiting providers that will serve the Medicaid population

## **Major Accomplishments**

- Statewide database linked
  - > Customized provider database
  - > Customized contacts/caller screens
  - > Data Collection ability/ongoing needs assessment
  - > Import/export capability (ability to share information statewide)
  - > Future access via the Internet

## **Major Accomplishments**

- Ease of access for the consumer
  - > 866-RESPITE toll-free numbers
  - > Single point of contact in each Service Area
  - > Coordination with Medicaid staff to access respite services

## Major Accomplishments

- Less duplication of efforts
- Caregiver evolution tool
- Nebraska recognizes respite as a needed service
- NCSL “Promising Practice”

## Building the Infrastructure

- Develop a foundation that supports a statewide system by:
  - > Identifying existing resources
  - > Building a provider database

## Identifying Existing Resources

- Develop a provider mailing list
  - > Agencies
  - > Services Coordinators
  - > Resource Developers
- Develop a Provider survey
- Send survey to provider mailing list
  - > Introduction
  - > Explain purpose and role
  - > Ask for Return of survey
  - > Obtain signature as an agreement to be on the statewide database as a referral

## After LB 148 Became Law

- In 2000, the Munroe-Meyer Institute conducted a survey caregivers receiving respite.
- Caregivers were selected from a diverse group of state programs ranging from Early Intervention, The Foster and Developmental Disabilities Program, and the Medically Handicapped Children's program to the Aged and Disabled waiver, the Nebraska Alzheimer's Association and the Area Agencies on Aging.

## Survey Results

- Almost twice as many caregivers of family members over 21 as compared to caregivers of family members under 21 indicated the likelihood of out-of-home placement without respite support.
- 63% of the families with family members over 21 reported they were more likely to place their family member in out-of-home placements if respite services were unavailable.

- Prevention or postponement of out-of-home placement ~~ultimately reduces overall care giving costs for the family, for Medicaid and for third party payers.~~
- Respite helps reduce stress and feelings of isolation for the caregiver.
- One half to two-thirds – 58% of the families with children under 21 and 65 % of the caregivers with family members over 21 – reported decreased isolation once respite was available.
- Respite helped to improve relationships with spouses and other family members

## **THE END..... For now.....**

- In 2001, LB 692
- \$1,060,000. per year allocated
  - > \$810,000 Respite Subsidy Program
  - > \$150,000 Service Areas for development of new programs
  - > \$100,000 centrally to administer Respite Subsidy Program
    - \* 2 new staff
      - Program Specialist
      - Social Services Worker

## **Success - Yes**

- The Respite Subsidy across the lifespan is available to families who do not qualify for any other respite services. Families choose their own providers, and set their own schedules.
- Nearly 1400 new respite providers have been recruited since the program began.
- Network coordinators meet regularly with Medicaid Service Coordinators from HHS and with representatives from Developmental Disabilities, Area Agencies on Aging, Independent Living Centers and the Early Development Network to identify gaps and barriers and to recruit providers as needed.

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### **Networks Can Identify Specific Gaps in Services**

- In southwestern service area a special respite was established for families caring for someone with behavior disorders, emotional disturbances or mental illness.
- Eastern area Respite Network collaborated with Area Office on Aging.
  - > 15 family caregivers received financial assistance for respite last year.
  - > If nursing homes had been used for just the respite time they received, it would have costs \$23,410.
  - > The respite program costs were less than half that amount.