Lifespan Respite Grantee Lead Agency: Iowa Department of Aging (IDA)

Funding Period: 2014-2017

Primary Goal: Fully integrate a high-quality and sustainable Lifespan Respite program into Iowa’s long-term supports and services system so that all Iowans who are eligible for respite services receive them.

Key Performance Measures

Project staff utilized both qualitative and quantitative methods, including statistically validated tools, throughout the project to evaluate progress. The grantee collected data to document increased caregiver knowledge of respite services available in the caregiver’s community and ways to easily access those services; increased respite provider knowledge and skills to address the diverse needs of care recipients regardless of their age, disease, or chronic condition; and increased access for caregivers facing emergency situations including support to resolve crises and an individualized plan for ongoing respite services and other supports. Expected products include a strategic plan and outreach materials designed for the private sector.

Notable Achievements

To make and keep their Coalition strong, Iowa used an outside source, Capture Marketing Group, which specializes in association management, advocacy, coalition building and development of best practices for non-profit governance. Significant effort is put into education and marketing opportunities to raise awareness of the Lifespan Respite Coalition, including a Facebook page to raise awareness of respite and caregiving issues, generate interest for annual fall conferences and provide a social media platform for caregivers to ask questions.

Key Objectives, Activities and Outcomes

Objective 1: Enhance and expand the statewide coordination of respite services by implementing a strategic plan for achieving sustainable, system changes.

- The Coalition engaged in strategic planning sessions that involved completing empathy mapping and an exercise in envisioning exercise that helped the Coalition to define their mission, vision and goals. Based on this planning work, the Coalition decided to investigate both partnering with a current organization to manage the coalition or to start a nonprofit entity for long-term sustainability. The Coalition also completed a Strategic Action Plan to guide their development.

- Throughout the grant period, member enrichment and education was an essential component in Coalition meetings. For example, during one Coalition meeting, outside presenters brought information on Iowa’s network of Mobility Management and perspective on issues facing working caregivers to recent meetings.

- To address sustainability, Coalition leadership led a meeting with agency directors and policy makers to determine the Coalition’s future in Lifespan Respite planning and services.

State Respite Coalition/Organization Role

- The Lifespan Respite Coalition consists of twenty provider agencies, three state agencies, and two Lifelong Links™ ADRCs. With facilitation by The Arc of Iowa, the coalition focused on local activities and met monthly to complete the National Respite Network’s Lifespan Respite Sustainability Toolkit. The coalition also worked with the Lifespan Respite Coalition Coordinator to organize and synthesize information provided by consumer survey respondents, evaluate impact of training activities, and review crisis respite funding activities in order to develop recommendations for the policy council.
Objective 2: Improve respite services by utilizing consumer surveys to identify service gaps and barriers.

- Regional focus groups were used over the years, and after review the Coalition decided the focus groups did not yield information sufficient to justify the time and effort necessary to conduct them. The Coalition decided to focus instead on statewide conferences in order to provide a forum for a dialogue among stakeholders about current gaps in respite services.

Objective 3: Improve the quality and consistency of respite services through a training program for providers and caregivers.

- Annual Care for Caregivers conferences provided education and training opportunities for caregivers, advocates, direct care workers and other professionals.
- To meet the goal of training more direct care workers throughout Iowa, a nationally recognized, evidence-based training program—Powerful Tools for Caregivers—was used to train informal caregivers. The Coalition partnered with Easterseals to offer two sessions of this 6-week training in rural Iowa communities.
- The grant manager stays apprised of issues and policy relating to the direct care workforce with a membership in the Direct Care Worker Advisory Council.

Objective 4: Improve access to and knowledge of respite services by refining ADRC information/referral system and by outreach to the private sector.

- Iowa’s No Wrong Door [NWD] system, LifeLong Links™, is a comprehensive system that connects Iowans to resources that assist them in attaining independence and full participation in their community. The redesigned LifeLong Links™ website, which went live in 2016, features a user-friendly design for consumers and caregivers to connect with home and community-based services, gain more information on specific topics, and connect with an options counselor for comprehensive assistance in planning for long-term services and supports.

Objective 5: Reduce caregiver strain by providing crisis respite funds and follow-up services to address long-term needs.

- The Iowa Department on Aging, the Lifespan Respite Coalition and project subcontractor, Capture Marketing Group, developed procedures for administration of applications, approval and reimbursement for Iowans to access crisis respite funds.
- Approximately 30 families in emergency or crises situations received respite funds during each reporting period.

Aging and Disability Resource Center (ADRC) Role

- In addition to expanding services and implementing the No Wrong Door model, ADRCs worked closely with the mental health system during a significant administrative redesign in moving from a county-based system to a regional one. Grant objectives and attendant activities were incorporated into these initiatives so that caregivers could in future easily access the respite services they need in their communities.

State and Community Partners

- Iowa Lifespan Respite Coalition
- Iowa Medicaid Enterprises (IME)
- Veteran’s Administration
- The Arc of Iowa
- ADRCs
- Iowa Developmental Disabilities Council
- Iowa Department of Health
- AARP
- Alzheimer’s Association – Greater Iowa Chapter
- Access for Special Kids (ASK) Resource Center
- One Iowa
- Iowa’s community colleges
- State agencies
- Consumer representatives