



Jessie Parker Building  
510 E 12th Street, Ste. 2  
Des Moines, IA 50319  
515.725.3333 | 800.532.3213  
[www.iowaaging.gov](http://www.iowaaging.gov)

## **Expanding and Sustaining Iowa's Lifespan Respite Program**

**Grant # 90LI0013-01-02**

Iowa Department on Aging

510 E 12<sup>th</sup> St., Ste. 2

Des Moines, IA 50319

(515) 725-3332

Project Period: 09/01/2014 – 08/31/2017

Reporting Period: 03/01/2016 – 8/31/2016

Final Reporting Period: 8/31/2017

Project Director & Report Author: Julie Bergeson, Project Planner

515-725-3332

[julie.bergeson@iowa.gov](mailto:julie.bergeson@iowa.gov)

Date of Report: October 2016

ACL Program Officer: Kevin Foley

**What did you accomplish during this reporting period and how did these accomplishments help you reach your stated project goal(s) and objective(s)? Please note any significant project partners and their role in project activities.**

During this reporting period, there have been strides made in the enhancement and expansion of the statewide coordination of respite service with education, advocacy and outreach. Along with the continued work by the initial partners, there have been a number of new members added to the coalition. The expanded reach of the coalition provided the impetus to begin defining the mission and future of the organization. With the limited respite funds available, there were a number of lives impacted. To ensure that respite funds had a positive impact, the implemented a statistically valid tool to collect data and other information to improve the program. The *Care for Caregivers* conference is in its initial stages of planning to provide education and training opportunities for caregivers and other professionals. The lack of qualified direct care workers has been identified as a focus area and several steps have been implemented by the interested parties. A significant advancement for caregiver's ability to obtain service occurred when the LifeLong Links system went live.

The Lifespan Respite Coalition is a primary partner in Iowa's Lifespan Respite project and held meetings in May and July 2016. Member enrichment and education is a critical component to Coalition meetings and outside presenters have brought both a national perspective on respite and other issues to recent meetings. This period the Coalition added members from the Alzheimer's Association [Greater Iowa Chapter] and Easter Seals. Another crucial partner in project activities is the project sub-contractor, Capture Marketing Group. Capture Marketing Group specializes in association management,

advocacy, coalition building and development of best practices for non-profit governance and Capture Marketing provides the day-to-day administration and processing of emergency respite funds, planning and conducting Coalition meetings.

During this reporting period, the Coalition engaged in strategic planning session that involved completing an empathy mapping and visioning exercise. These initial steps allowed the Coalition define their mission, vision and goals. Based on the visioning exercise, the Coalition will investigate both partnering with a current organization to manage the coalition or to start a nonprofit entity for long-term sustainability. The Contractor and grant manger will arrange one-on-one meetings with interested parties to gauge capacity. The group did not find the Sustainability Toolkit particularly helpful in strategic planning. The completed Strategic Action Plan is attached. [Attachment A]

The Iowa Department on Aging, the Lifespan Respite Coalition and project sub-contractor [Capture Marketing Group] have developed the administration of the application, approval and reimbursement procedures for Iowans to access crisis respite funds. This is an on-going, successful and essential component of grant activities and caregivers are receiving direct and necessary respite services. Highlights of this reporting period are as follows:

- 29 applications for emergency respite funds were received. Five applicants had multiple family members in need of care. Most common reasons for respite include caregiver in emotional crisis and caregiver in medical crisis. Of those applicants, 14

requested referral to LifeLong Links™ [Iowa's ADRC] for more information/referral and assistance with planning for long-term services and supports

- \$2,850 was distributed in reimbursement to 14 families [average of \$203 per family]

- “Average” caregivers range in age from 2-85 years old with the following additional demographics:

89% female | 11% male

83% Caucasian/White | 17% African American/Black

- Families served in 18 Iowa counties

- Top three conditions of individuals served include those with autism, ADHD and memory loss/dementia. Individuals in need of care range in age from 2-85 years old and 25% being multiracial or African American/Black.

The Lifespan Respite Coalition is currently implementing the use of a statistically valid and reliable empirical survey tool. At this time qualitative data is being collected via both caregiver and care recipient information on the emergency respite applications. This has resulted in useful demographic information, identifying service gaps and capturing respite needs of caregivers. The fall conference provided in-person accounts and the conference survey will provide a snapshot of unmet needs and interests of caregivers and service providers. This survey will be utilized in planning the next year's conference.

Time was spent this reporting period in initial planning for the Lifespan Respite conference, *Care for Caregivers*. Again this year, the *Care for Caregivers* conference will be a training rich environment for caregivers, professionals, advocates and families regarding respite services and issues in Iowa. Topics that will bring awareness to respite include compassion fatigue, navigating family dynamics, brain wellness and mindfulness. The conference will also feature two sessions of a nationally recognized, evidence-based caregiver training program, Powerful Tools for Caregivers. The Coalition partnered with AARP to bring two nationally recognized keynote speakers and authors on caregiving and the benefits of respite.

One of the goals of Iowa's Lifespan Respite project is to train more direct care workers throughout the State of Iowa. The team partnered with Kirkwood Community College [Cedar Rapids, IA] that offers the Prepare to Care curriculum and sponsored two young women to obtain advanced certification as a Health Support Professional [HSP]. Participants completed the following modules: Core, Health Monitoring and Maintenance and Personal Activities of Daily Living. The grant manager continues membership in the Direct Care Worker Advisory Council to stay apprised to issues and policy relating to the direct care workforce.

The new LifeLong Links™ website ([www.lifelonglinks.org](http://www.lifelonglinks.org)) “went live” during this reporting period. LifeLong Links™ is Iowa's No Wrong Door [NWD] comprehensive system to connect Iowans to resources to achieve goals for independence and full participation in their community. The redesign features a more user-friendly, visually

compelling layout that will enable both consumers and caregivers to easily connect with a variety of home and community-based services and supports that assist in maintaining long-term independence. From the home page, users will be able to immediately start a self-assessment or begin searching for local service providers through a cloud-based database that is updated in real time. A list of service categories will also be available so users can conveniently navigate to interior pages about specific topics that include calls to action, resources and additional links. Each interior page includes an icon linking to the database, so users can begin a search for providers at any point or be connected to an options counselor to provide more comprehensive assistance in planning for long-term services and supports. Screen shots of the new design and caregiver/respice pages are attached. [Attachment B] <sup>1</sup>

**What, if any challenges did you face during this reporting period and what actions did you take to address these challenges? Please note in your response changes, if any, to your project goal(s), objectives that were made as a result of challenges faced.**

The Iowa Lifespan Respite Coalition membership remains small but is dedicated group and gaining momentum. Many service providers and social service organizations are finding themselves in a volatile environment due to implementation of Iowa's move to Medicaid Managed Care in April 2016. The project director, contractor and the Coalition continue to network and seek out individuals that are dedicated to expanding respite services in Iowa. The grant manager continues to attend technical assistance webinars/conference calls from ARCH National Respite Network for technical assistance on this topic.

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<sup>1</sup> Prepare to Care is a train-the-trainer model that provides a state-approved training certification for direct care workers who complete required coursework.

The Council advises the Iowa Department of Public Health [IDPH] on the regulation and certification of direct care works, standardization requirements for supervision and functions for direct care workers.

The amount allocated for emergency respite funds this grant year was \$27,712 and this was dispersed in the first four months of the grant year. The contractor first attempted to extend the reach of funds by reducing the amount allocation from a one-time reimbursement of \$500 to \$250. After application to the program, follow-up procedures were immediately initiated.

Personal letters and phone calls were made to applicants and providers outlining the situation and encouraged follow-up with LifeLong Links™ or other age/disability appropriate service providers and/or organizations. A wait list was initiated and updated by the contractor.

Through the first two years, it has proven difficult to make the appropriate connections with community colleges that offer the Prepare to Care curriculum in a routine, on-going fashion. For year three, the project will focus on offering two evidence based caregiver training[s] across rural parts of Iowa. The Powerful Tools for Caregivers [PTC] program has met with highest-level criteria of evidence-based disease prevention and health promotion programs by the Administration for Community Living/Administration on Aging. PTC also offers a train-the-trainer curriculum to advance more trainers throughout Iowa. The project director will continue meeting with the Direct Care Worker Advisory Council for workforce issues but this change will have a direct impact on more caregivers throughout the state.

**How have the activities conducted during this project period helped you to achieve the measurable outcomes identified in your project proposal?**

Fine-tuning the processes and data collection for emergency respite funds have allowed the project to collect accurate and timely data about the funds distributed and demographics of both the caregiver and care receiver. Data clearly shows this project is reaching a statewide audience and providing needed respite to a wide range of Iowa families. This year's Lifespan Respite Conference provided valuable training opportunities for both family and professional caregivers,

advocates and direct care workers across Iowa. Survey results indicated great overall satisfaction with the conference speakers, networking opportunities and the opportunity for caregivers to meet other caregivers.

**What was produced during the reporting period and how have these products been disseminated? Products may include articles, issue briefs, fact sheets, newsletters, survey instruments, sponsored conferences and workshops, websites, audiovisuals and other information resources.**

Initial conference marketing began with two different Save the Date postcard. The postcard was created in both print and electronic format to announce the conference. Print copies were provided to all Coalition members statewide for distribution within their network, offices and clientele. The electronic conference announcement was sent to any individuals, families or providers in the respite database, Area Agencies on Aging, and Coalition members/organizations for distribution to their networks. The Iowa Department on Aging sent electronic conference notifications via newsletters through e-newsletter publications to the aging network during the month of September. [Attachment C] Registration for participants and the call for exhibitors was sent via e-mail through Coalition contacts and <http://www.cvent.com/events/2016-care-for-caregivers-conference/event-summary-f9085275b36f45a9b04aeb7b2215dafc.aspx>.

[Attachment D]

**Iowa Lifespan Respite Sustainability Plan**

**Background**

Coalition members of the Iowa Lifespan Respite went through an empathy mapping exercise to gain a deeper understanding of the constituents needs we serve. From the empathy mapping exercise we identified pains and gains and turned them into potential goals for the organization. Below are the results of those findings.

**Strategic Planning Exercise Recap**

**Empathy Mapping**

- What do caregivers Say or Do?
- What do caregivers See?
- What do caregivers Listen to?
- What do caregivers Think or Feel?

Think or Feel	Fear Fulfilled Not able to juggle work + caregiving Not knowing where to turn Grief Tired	See	Family members Issues that are ignored Disorders Professionals Navigating the system Physical Environment
Listen to	Person they care for Medial advisors Teachers Lots of Information Differing Opinions	Do	I can only give the care Yes, but-ers Everything is ok... Doing more than is needed Asking for acknowledgement Loss of independence

**Pain**

- Loss of privacy
- Financial
- Nobody can give the care like I can
- Loss of relationships
- Work life balance and being pulled in different directions
- Not knowing where to turn
- Change in family member situation
- Death and dying
- Falling apart
- Hoops having to be jumped through
- Loss of independence and identify
- Pain for the person caring for
- Loss of identity

**Gain**

- Unconditional love
- Network of peers
- Satisfaction of being there for the loved on

# Iowa Lifespan Respite Sustainability Plan

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## Strategic Planning Exercise Recap

### Empathy Mapping

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Think or Feel	<p>Fear</p> <p>Fulfilled</p> <p>Not able to juggle work + caregiving</p> <p>Not knowing where to turn</p> <p>Grief</p> <p>Tired</p>	See	<p>Family members</p> <p>Issues that are ignored</p> <p>Disorders</p> <p>Professionals</p> <p>Navigating the system</p> <p>Physical Environment</p>
Listen to	<p>Person they care for</p> <p>Medial advisors</p> <p>Teachers</p> <p>Lots of Information</p> <p>Differing Opinions</p>	Do	<p>I can only give the care</p> <p>Yes, but-ers</p> <p>Everything is ok...</p> <p>Doing more than is needed</p> <p>Asking for acknowledgement</p> <p>Loss of independence</p>

## Pain

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## Iowa Lifespan Respite Sustainability Plan

- Peace of mind
- New life perspective
- Bringing family and friends together
- Hope
- Giving to others
- Gain confidence
- Gave back to who gave to you
- Strengthen relationships
- New relationships

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### Opportunities Learned

- Emergency Respite Funding- work on increasing the amount through private/public/appropriations funding.
- Be the resource in Iowa for help and education for respite services for family and professional caregivers.
- Outreach with employers in understanding respite and respite policies in the workplace.
- Be an educational resource and advocate for individuals and family caregivers for the managed care organizations.

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### Goal Setting Discussion

- **Sustainability:** Do we look at becoming our own non-profit 501(c) 3 organization?
  - Coalition- Yes
  - Lobbying is important so do we look at becoming a 501(c)4 organization?
  - Allows us to focus on fundraising somewhat similar to REST or selling trainings.
- Do we legislatively go after appropriation for emergency respite funding?
  - Coalition- Yes, however very difficult and must be a long-range goal.
- **Education:** Blended approach
  - Online Training
  - REST/Powerful Tools
  - Pool resources around state
  - Create survey after 6 months with MCO's to see:
    - Training available
    - Perception of respite available
  - Be the advocate for direct care caregivers – organizations are not paid enough to be sustainable
  - No one wants to talk about the issue.
  - Create or be a part of The Family Caregiver Network for Iowa.
  - Conference being a vehicle for education to family and professional caregivers
- **Funding:** Continue sustainable efforts with the coalition and provide emergency respite funding.
  - Grants (Regional)
  - MCO's can we create a value add for them and help our members
  - Membership to coalition
  - Sponsorship to coalition or conference
  - Conference being a fundraiser
- **Advocacy and Marketing:** How do we advocate for those who feel like they have lost their identity or voice?
  - Create a website and collaboration community to belong to

## Iowa Lifespan Respite Sustainability Plan

- Educate stakeholders and legislators
- Direct care providers- better pay rates
- Marketing to Lifelong Links resources
- Marketing to coalition resources available

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### Goal Setting for Organization

**SMART Goals**

**S-Specific**

**M-Measurable**

**A-Attainable**

**R-Realistic**

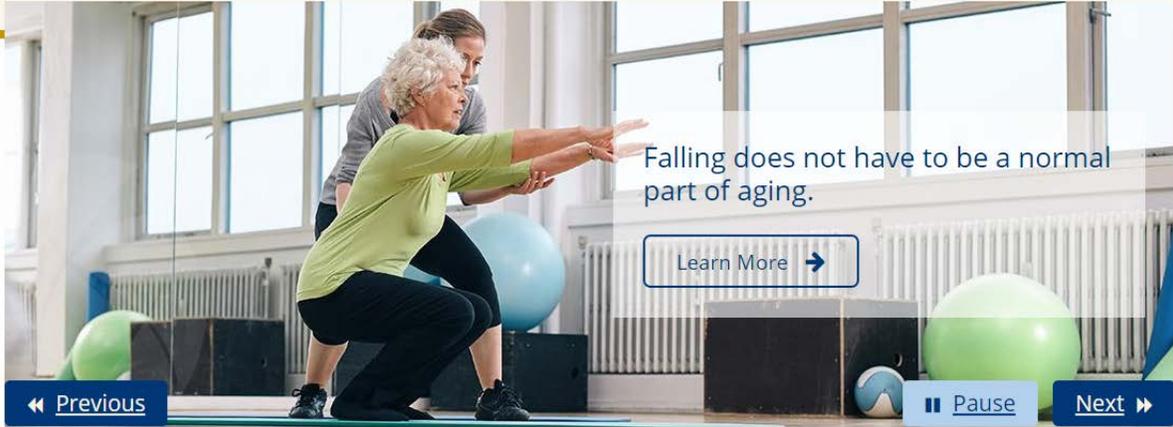
**T-Timely**

<b>Objective :</b>	<b>SMART Goal:</b>	<b>Timeline or Deadline:</b>
<i>Sustainability Education Funding Awareness/Marketing</i>		
1. Sustainability	Create bylaws and corporate governance documents.	November 2016
2. Sustainability	Create a non-profit entity with Iowa Secretary of State's office and apply for IRS exemption status.	December 2016
3. Awareness/Marketing	Create a website that includes education, meetup, database to easily find respite and coordinates with Lifelong Links.	February 2016
4. Funding/Sustainability	Work with other established entities to seek partnerships in carrying out the mission of the organization	December 2016
5.		
6.		

## Iowa Lifespan Respite Sustainability Plan

	<p>Iowa Lifespan Respite Coalition Sustainability Plan 2016-2017</p>
<p><b>Our Mission</b></p>	<p>Expanding, enhancing and improving access to respite services across Iowa.</p>
<p><b>Who We Serve</b></p>	<p>The Lifespan Respite Coalition is open to all providers, advocates and consumers of respite care. We are committed to ensuring representation across the lifespan.</p>
<p><b>Our Programs and Services</b></p>	<p>Iowa Lifespan Respite accomplishes its mission in the following ways:</p> <ul style="list-style-type: none"> <li>• Provide emergency respite funding for individuals in need.</li> <li>• Survey recipients of emergency respite funding to adjudicate needs and gaps in state.</li> <li>• Direct support to respite caregivers and providers to find appropriate resources.</li> </ul>
<p><b>Our SMART Goals</b></p>	<ol style="list-style-type: none"> <li>1. Create bylaws and board governance documents by November 2016.</li> <li>2. Create a non-profit entity with Iowa Secretary of State's office and apply for IRS tax exempt status by December 2016.</li> <li>3. Create a website for awareness, education and resource by February 2016.</li> <li>4. Look at opportunities to partner with other organizations for continued sustainability by December 2016.</li> </ol>

# LifeLong Links™ Home Page, Attachment B



### Find a Service Provider in Your Area

[Service Providers Directory](#)

### Search LifeLong Links by Keyword

[Search](#)

## ➔ Frequently Viewed Services

<a href="#">Adaptive Equipment &amp; Technology</a>	<a href="#">Caregiver Assistance</a>	<a href="#">Education</a>
<a href="#">Elder Abuse Prevention</a>	<a href="#">Employment</a>	<a href="#">Falls Prevention</a>
<a href="#">Financial Resources</a>	<a href="#">Food &amp; Nutrition</a>	<a href="#">Health &amp; Medical Services</a>
<a href="#">Home &amp; Community-Based Servi...</a>	<a href="#">Housing</a>	<a href="#">Legal Services &amp; Advocacy</a>
<a href="#">Medicare / Medicaid / Insurance</a>	<a href="#">Mental Health Services</a>	<a href="#">Planning for the Future</a>
<a href="#">Recreation &amp; Sports</a>	<a href="#">Transportation</a>	<a href="#">Veterans</a>

## Respite Services

Respite services give you a much-needed break for your daily challenges as a caregiver while ensuring your loved one's needs are met.

### Resources

#### The ABCs of Respite: A Consumer's Guide for Family Caregivers

This guide from the National Respite Network and Resource Center covers the basics — types of respite, choosing a respite provider and how to play for respite services.

#### [The ABCs of Respite: A Consumer's Guide for Family Caregivers](#)

#### Iowa Lifespan Respite Coalition Emergency Care Application

Emergency respite care is a service that provides access to care for an individual of any age, at any time of the day or night, when a caregiver is facing a crisis.

#### [Iowa Lifespan Respite Coalition Emergency Care Application](#)

#### Family Caregiving – Why Respite?

The lack of a conscious plan of self-care can result in caregiver burnout. The ALS Society offers advice on developing and implementing a plan that will be beneficial both the caregiver and the person receiving care.

#### [Family Caregiving – Why Respite?](#)

#### Finding and Choosing Respite Services

Respite care can take many forms, but boils down to two basic ideas: sharing the responsibility for caregiving and getting support for yourself. According to HelpGuide.org, finding the right balance requires persistence, patience and preparation.

#### [Finding and Choosing Respite Services](#)

### You might also be interested in:

[Adult Day Care](#)

[Caregiver Options Counseling](#)

[End-of-Life / Bereavement Services](#)

[Grandparents Raising Grandchildren](#)

[Power of Attorney / Guardianship / Substitute Decision-Making](#)

[Respite Services](#)

[Support Groups](#)

[Resources](#)

[Care Transitioning](#)

[Chronic Disease Self-Management](#)

[Home Health Care](#)

[Hospice Services](#)

## Links

### Respite Connection

Respite Connection is here to listen to families, understand their needs and connect them with the people and resources needed to follow their dreams!

 [Respite Connection](#)

### National Respite Network and Resource Center

The search tool provided on this site will help you find respite services near you, as well as resources about payment and insurance information.

 [National Respite Network and Resource Center](#)

### Area Agencies on Aging

Iowa's six Area Agencies on Aging have family caregiver specialists to help assess your needs and inform you about services, supports and other options available to you.

 [Area Agencies on Aging](#)

### AARP

AARP's website includes a section that covers many aspects of legal and financial issues facing caregivers.

 [AARP](#)

### National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations focused on improving the lives of family caregivers.

 [National Alliance for Caregiving](#)

[Medicaid / Medicare / Insurance](#)

[Mental Health Services](#)

[Non-Emergency Medical Transportation](#)

[Outpatient Medical Services](#)

[Pharmacy Delivery](#)

[Prescription Assistance](#)

[Support Groups](#)

[Veterans Medical Services](#)

[Health Resources](#)

## Conference Save-The-Date Postcard, Attachment C

# CARE

FOR  
CAREGIVERS

2016 CONFERENCE

HOSTED BY



At no cost, the Iowa Lifespan Respite Coalition wants to provide caregivers across Iowa with tools and resources to help develop a caregiving network and learn more about the benefits of recharging through respite.



THURSDAY | NOVEMBER 3, 2016

8:30 am - 3:30 pm



STONEY CREEK HOTEL & CONFERENCE CENTER

5291 Stoney Creek Court  
Johnston, Iowa 50131



FREE TO ATTEND

FEATURED  
SPEAKERS

NOVEMBER 3, 2016 | SAVE THE DATE!



DR. JAMES COYLE

### COMPASSION FATIGUE

Authentic and sustainable self-care begins with you: enhance your awareness with education, clarify your personal boundaries, be kind to yourself, talk and listen to other caregivers, eat healthy, develop consistent sleep patterns, and take a "rest area" exit off the interstate of care.



JOY ROUSE & CHERYL CLARK

### POWERFUL TOOLS FOR CAREGIVERS

Caregiving is rewarding but it can be stressful physically, emotionally, and financially. Powerful Tools for Caregivers provides tools to help them become more comfortable with their role as a caregiver whether they are new to caregiving or have been in the role for some time.



DR. ROBERT BENDER

### BRAIN WELLNESS

As a geriatrics doctor, Dr. Bender will describe new insights into the brain's potential and ways to keep the brain healthy. He received his medical degree from Saint Louis University School of Medicine and has been in practice for more than 20 years.

# CARE

## FOR CAREGIVERS

2016 CONFERENCE

HOSTED BY



SPONSORED BY  **AARP** Real Possibilities in Iowa



At no cost, the Iowa Lifespan Respite Coalition wants to provide caregivers across Iowa with tools and resources to help develop a caregiving network and learn more about the benefits of recharging through respite.



**THURSDAY | NOVEMBER 3, 2016**

8:30 am - 3:30 pm



**STONEY CREEK HOTEL & CONFERENCE CENTER**

5291 Stoney Creek Court  
Johnston, Iowa 50131



**FREE TO ATTEND**

To register visit  
[www.bit.ly/careforcaregivers2016](http://www.bit.ly/careforcaregivers2016).

## FEATURED SPEAKERS

Hear personal stories and learn about resources available to you from local professionals and nationally recognized speakers!



**DR. JAMES COYLE**

**COMPASSION FATIGUE**  
*Chaplain, mental health specialist and professor*



**BARRY J. JACOBS, PSY.D.  
JULIA L. MAYER, PSY.D.**



**MEDITATIONS FOR CAREGIVERS**  
*Clinical psychologists, co-authors, husband and wife*



**ROBERT BENDER, M.D.**

**BRAIN WELLNESS**  
*Geriatrics doctor and speaker*

**TO REGISTER** visit [www.bit.ly/careforcaregivers2016](http://www.bit.ly/careforcaregivers2016).



## 2016 CARE FOR CAREGIVERS CONFERENCE

At no cost, the Iowa Lifespan Respite Coalition wants to provide caregivers across Iowa with tools and resources to help develop a caregiving network and learn more about the benefits of recharging through respite. By taking care of yourself, you're able to provide emotionally healthier care to those around you. This conference will provide encouraging reminders as to why you give your time to serve someone you love!

**Limited respite funds are available.** If you are interested in these funds to provide yourself a greater chance of attendance, please contact Jeanne Fitzgerald at [jeanne@capturemarketinggroup.com](mailto:jeanne@capturemarketinggroup.com) or at (515) 725-3312.

**Attention Social Workers:** Five contact hours of continuing education are available when you attend the conference. A signup sheet for these credits will be available at the registration desk the day of the event.

### SPONSORS

A big thank you to this year's conference sponsors! We appreciate every sponsor's contribution and participation.

#### GOLD



#### SILVER

### DETAILS

**WHEN**  
Thursday, November 3, 2016  
8:30 AM - 3:30 PM  
Central Time



**WHERE**  
Stoney Creek Hotel & Conference Center  
5291 Stoney Creek Court  
Johnston, Iowa 50131



**PLANNER**  
[Iowa Lifespan Respite Coalition](#)

[Register](#)