

Semi-Annual Report

Grant #: 90DS2006-01-00

Project Title: Creating a Dementia-Capable HCBS System in Iowa

Grantee Name: Iowa Department on Aging

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

Reporting Period: **03/01/2016 to 08/31/2016**

Final Reporting Period: 09/01/2017 to 08/31/2017

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

During this reporting period Iowa Department on Aging [IDA], Iowa State University [ISU], and The Alzheimer's Association of Greater Iowa [AAGI] worked as a collaborative team supporting the advancement of the evidence informed Health and Resilience Outreach [HERO] project. The primary goals of the HERO project remain the same -- to maintain or improve caregiver resilience and effectively manage the health care of the person with dementia. The advancement of the HERO project was accomplished through referrals from the networks with various health organizations, physicians, and Area Agencies on Aging [AAA].

The networks with the health organizations have occurred through trainings, conferences, and organizational partnerships. Another primary goal was to develop a working partnership with the AAAs throughout Iowa allowing for warm handoffs of referrals. As the geographical area of HERO coverage expands, the relationship between AAGI and the AAAs is growing throughout the state. The referrals and training opportunities between AAGI and the AAAs have continued to expand and strengthen as cross-supportive roles between the organizations continue to be solidified. It is through this cross-supportive work that AAGI and AAAs are streamlining access to home community based services [HCBS] in Iowa.

Thorough training and education was another important goal of the grant by creating a dementia-capable home community based service system. During this reporting period, the team and AAGI developed a webbed based training. Currently there are two web-based trainings, available 365 days a year, with pre and posttests to track improvement of

knowledge base. Trainings are also available quarterly to all of the AAA staff. The encouraged standard is that all new hires complete the web based trainings of “Know the 10 signs” and “Effective Communications”

The collaborative team of IDA, ISU, and AAGI have updated and surveyed the volunteers of the HERO program to collect data on the quality of the program from the volunteer’s perspective and to continually improve training and to ensure collection of person-centered data is being gathered in a conversational style . It is through the referral to AAAs and AAGI that the volunteers are able to assist caregivers, persons living with Alzheimer’s and related dementias, thereby streamlining access to services. The training of the Options Counselors provides a comprehensive dementia capable planning and support system for the families that live with dementia.

A year two goal to enroll 100 persons into the HERO program was accomplished. Data was collected on the caregiver strain index from the beginning of the project to develop new understandings of the caregivers needs. Originally, the theory was the length and frequency of phone contact with the caregiver or person living with dementia was what made an impact and would reduce caregiver strain. The data has revealed is that a 15-minute weekly phone call appears to be more effective than a bi-monthly 30-minute phone call for the caregiver. The data also reveals that the initial contact has a certain level of trust validity by the caregiver and possibly skews the initial caregiver strain data. We are anxious to compare and report in the future with three years of collected data.

One component of the grant is to assure areas of sustainability. It is good to report that the LifeLong Links [LLL], Iowa’s no wrong door system, and the relationship that was built in year two between the AAAs and the AAGI is continuing to solidify and expand.

The AAAs and the AAGI are beginning to look at sustaining the HERO program jointly and continue beyond the grant funding. The AAAs are looking at the volunteer training and placement with AAGI to meet the needs of Iowa families who live with dementia. A second area that has met a level of sustainability is the online trainings. The online training provides flexibility and a knowledge foundation base for the AAAs and other stakeholders. The AAAs are encouraged to make the 3-phase training part of their new hire program. The training involves a pre and posttest component that allows ISU and IDA to track the growth of dementia capabilities growing in Iowa.

2. **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(s), or activities that were made as a result of challenges faced.**

LLL experienced a delay in going active due to some technical issues that in turn delayed our second round of testing which will begin the end of October or the beginning of November 2016. Due to the delay, the team will test the LLL system in waves in year three of this grant. The multiple testing will allow the team to determine the usability of LLL for caregivers and persons affected by dementia before and after improvements have been made to the LLL system.

One of our initial challenges came from expansion of the HERO project to encompass the entire state. The Alzheimer's Associations are not state wide but rather have regions or other areas. AAGI provides services for the majority of the state of Iowa but there is another program that provides services for some of the areas that are to be included in the HERO program. In order for this to be a successful venture with all of the Alzheimer's associations in the state, a memorandum of understanding was executed with East Central

Iowa Alzheimer's Association. The memorandum has been signed, and the training has begun so that the year three goals of the HERO project going statewide can be met.

Sustainability is a challenge as there continues to be more competition for the money to provide direct services for the caregivers and care receivers of Iowa. AAGI and the team looked at the direct service dollars for the coming year and the number of persons served; a decision was made that the year three area will not receive direct service dollars. The decision was made to maintain quality and relevance of services verses total number of persons served that resulted in the scholarships previously provided to families were reduced from \$250.00 to \$150.00. The team all agree that there is a tipping point that the scholarships do not become helpful if taken to a smaller amount. In addition to adjusting the scholarship amounts and not moving those dollars to the year three area we will be able to identify the actual strengths of the HERO project. In year 3 the area of expansion will receive all HERO services with the exception of scholarships for HCBS. This will answer the important question: Is the success of the HERO project based on the emotional support or the financial support?

One of the strategies being taken to meet the direct service dollar needs began in year two but will not come to actualization until year three. The strategy is to have some of the University interns research and form a foundation that will provide an ongoing funding stream for the caregivers and care receivers of Alzheimer's and related dementias. In addition, the team is considering proposing policy changes that will provide a funding stream to support caregivers and families with respite and support.

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

A measurable outcome was to create and sustain a dementia-capable home and community based system through Iowa's LLL system. With the training, the AAA staff are becoming dementia capable.. The partnership and collaborations between the AAAs and AAGI has streamlined the referral system for caregivers and persons who live with Alzheimer's and related dementia resources, assisting them to remain in the home safely and longer. The HERO project is also showing preliminary data indicating a potential reduction in hospitalizations of the caregiver and care receiver of those living with Alzheimer's and related dementias.

The team is measuring the "dementia capabilities" of the AAA's Information and Referral specialists and the Options Counselors through training pre and posttests. Each training builds on the other and assists the information and referrals that are provided to individuals to be relevant, and dementia capable. The Option Counselors provide choices to the caregiver and the persons living with Alzheimer's and related dementias. The choices that are provided to the families by the Option Counselors are person centered and involve all stages of planning in the long-term care continuum for the present and futures stages of dementia for those who live with dementia.

LLL is being tested and updated to meet the dementia capable standards, real-time data is being collected on the usability and quality of information. The families that live with Alzheimer's and related dementias often have many health concerns or are providing care for more than just the person who is living with dementia, meaning that quick, easy, accurate information and resources are a vital source of support.

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

1. Revised satisfaction surveys were released in early August. Those surveyed included active clients and any client discharged since November 2016. (See Attachment HERO Survey)
2. Changes were made to the LLL survey and the Institutional Review Board [IRB]approved new changes (See attached)
3. Slides for the Iowa Governor's Conference on Aging (See Attached)
4. A HERO timeline was developed for the foundation to building a toolkit for publication in year 3. The toolkit is being developed to aid in the duplication of the HERO project for other states. The toolkit will include lessons learned, and best practices of the HERO program.
5. The data collected from the HERO project shows less re-hospitalizations for the first part of the survey. (Attachment)





Workshops and Conferences

1. Des Moines 2016 BrainWorks Conference
2. Davenport 2016 BrainWorks Conference
3. Medical Conference
4. Iowa Governor's Conference on Aging 2016

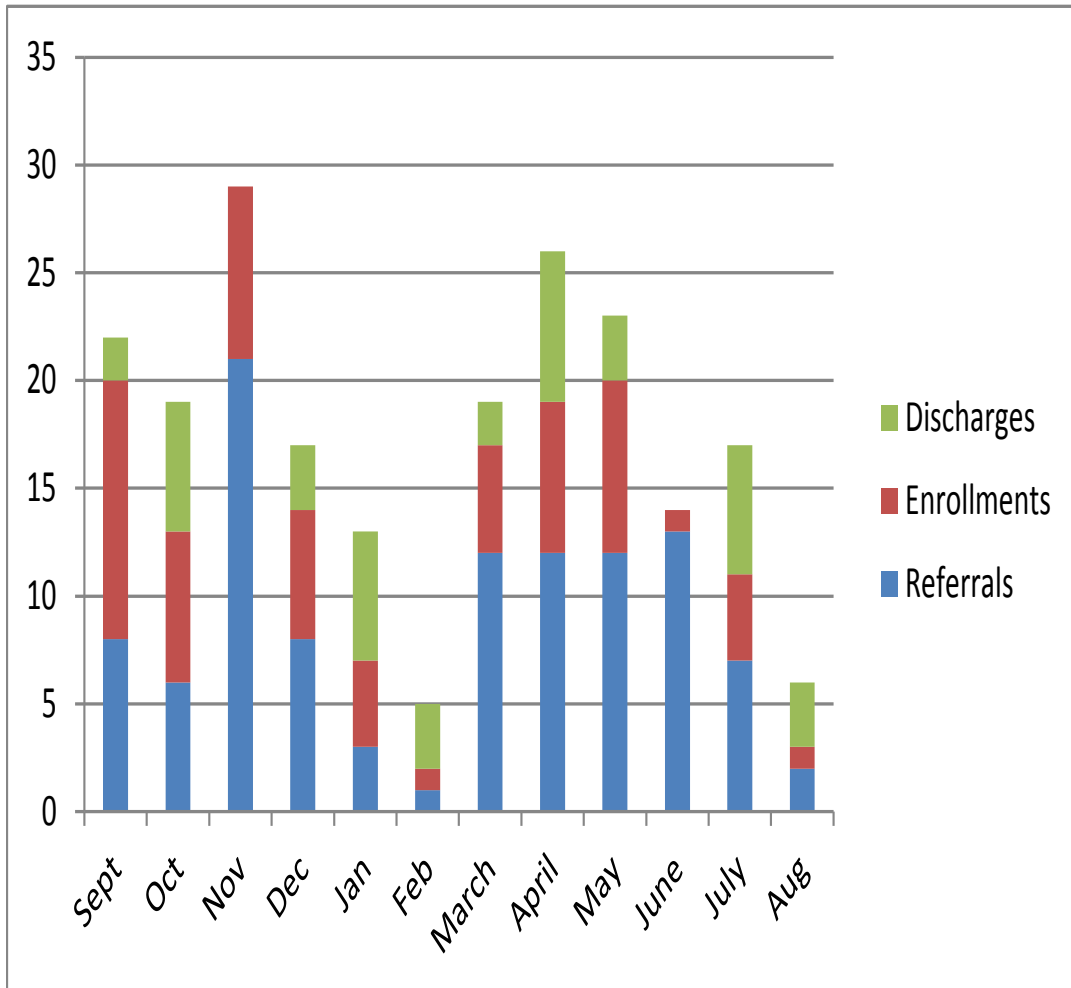
Upcoming Events:

American Society on Aging Chicago, IL 2017

Attachments

A	 HERO Project IGCOA.pdf
B	 Post_Lifelonglinks_ website_evaluation
C	 HERO Project Grant Timeline (002).docx
D	 modified caregiver survey 7-5-16.docx

The following table represents the first ten months of Year 2 of the HERO project for referrals, enrollees, and discharge data.



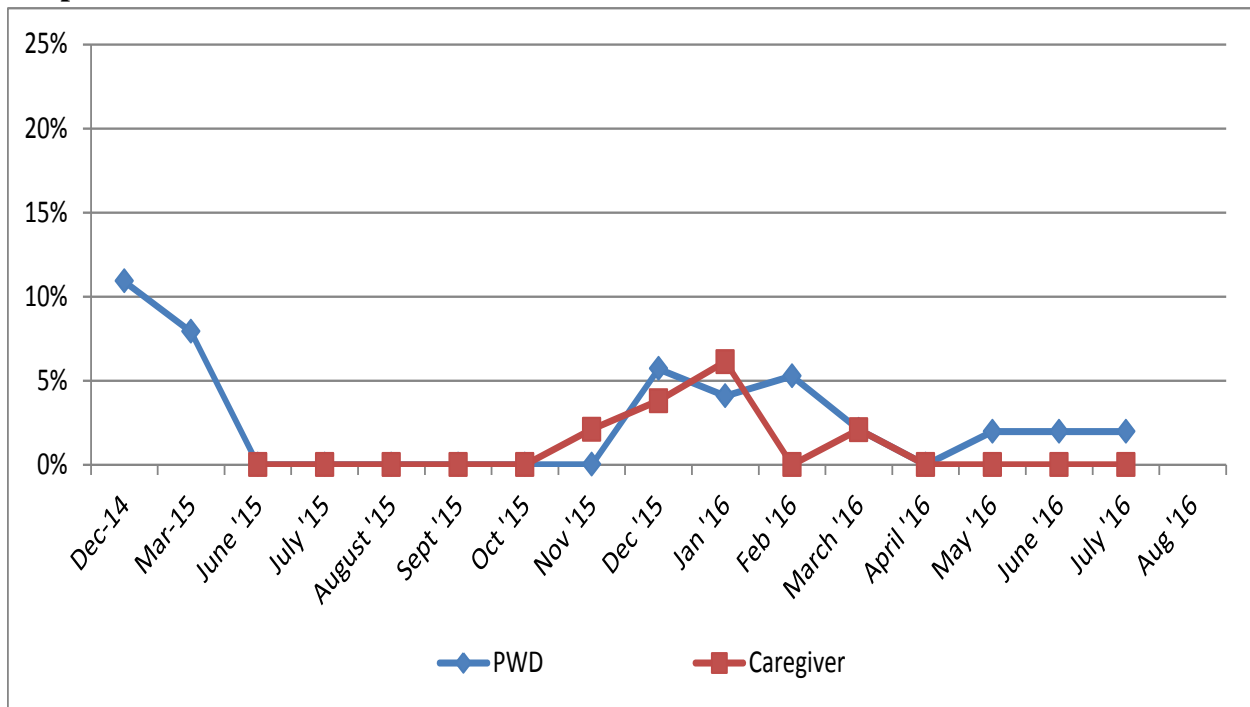
Transitions of Care Project: HERO Project

The following table represents Care Transitions Project metrics, outlining the last month, contract Year 1, and Contract Year 2 YTD. Please note this table only contains HCBS direct service dollars.

Metrics	Aug 16	Year1	Year 2 YTD
Referrals	2	74	103
New Enrollments	1	39	64
Current Participants			53
Discharges	3	13	41
PWD Hospitalizations	1	1	10
Caregiver Hospitalizations	1	0	5
Direct Service Dollar Recipients		13	34
Direct Service Dollars Spent	\$ 2,758.21	\$ 2,547.00	\$ 53,626.35
Direct Service Hours	104.71	178.10	2,377.42
Direct Service Waiting List	4		
Caregivers awaiting a volunteer	8		
# new Volunteers	2	12	26
HERO Volunteer Hours	52	143	518
Other Volunteer Hours	125	148	1140

The graph below shows hospitalization data as a percentage of active enrollees. National hospitalization data has been reported at 17.9%. Persons with dementia have been reported to have almost twice the hospitalization rate than those without dementia. The data shown below suggest that the work of the HERO Project is making a difference in hospitalization rates.

Hospitalization Patterns for Contract Year 2



HERO Project Caregiver Survey

Thank you for taking this brief survey.
Your responses will help us continue to provide high quality programs and services for people with Alzheimer’s disease and their families.

Please select the best answer for each question below:

	Strongly <u>Disagree</u>	Disagree	Neither Agree or Disagree	Agree	Strongly <u>Agree</u>
1. I am satisfied with the HERO program.					
2. I had enough time to discuss concerns with my HERO volunteer.					
3. The HERO program provided me with strategies to better care for my loved one.					
4. I know more about resources that I can access.					
5. I know how family, friends and others in the community can assist with care and support.					
6. Participating in HERO has helped to keep my loved one at home longer.					
7. I feel less stressed.					
8. I feel more hopeful.					
9. I feel less alone.					

	Not at all likely	Maybe	Extremely Likely
10. How likely are you to recommend the Hero project to others?	0	1 2 3 4 5 6 7 8	9 10
		<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	

11. If you didn't rate the above question (#9) as a 8, 9 or 10, why not?

12. What are the most beneficial aspects of HERO for you?

13. Can you identify any beneficial aspects of the HERO Project for your loved one?

Other Comments:

Caregiver Survey Results:

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree	% Strongly Disagree - neutral	% Agree- Strongly Agree
I am satisfied with the HERO program.		1	3	5	17	15%	85%
I had enough time to discuss concerns with my HERO volunteer.			3	9	14	12%	88%
The HERO program provided me with strategies to better care for my loved one.			3	10	13	12%	100%
I know more about resources that I can access.	1		4	9	12	19%	81%
I know how family, friends and others in the community can assist with care and support.			6	10	10	23%	77%
Participation in HERO has helped to keep my loved one at home longer.	2		8	6	10	38%	62%
I feel less stressed.	2		2	13	9	15%	85%
I feel more hopeful.		2	4	12	8	38%	77%
I feel less alone.	1		5	8	9	26%	74%

	Not at all likely					Maybe		Extremely Likely			
	0	1	2	3	4	5	6	7	8	9	10
How likely are you to recommend the HERO project		1.....2.....		2.....		...1.....3.....17

What are the most beneficial aspects of HERO for you?

- Knowing that the info may help someone else in the future.
- The prospect of respite care.
- Access to resources.
- The “Guide to Caring for People with Alzheimer’s and related dementias” notebook and “Coach Broyles’ Playbook for Alzheimer’s Caregivers” gave me numerous ideas.
- Can direct questions of actual problems or concerns.
- Since I am caring for my wife’s mother- I appreciate someone outside of family to talk to.
- Have appreciated the financial help. My HERO volunteer has been such a wonderful source of help and strength to me as a caregiver. For such a young woman she has an amazing grasp of the struggles and such empathy.
- Someone who seems to really care and tries to help- listens without judgement.
- Care assistance, financial assistance, references, stress relief.
- Financial support to provide part time for caregiver.
- Gave me some time to myself. Also, saved me money.
- Speaking with a good listener- getting his/her input. Assistance with financial help allows me to get more in home help- which is greatly needed and appreciated.
- Making it possible to have time for myself- and will start more and more. My husband absolutely loves being at Family Circle of Friends.
- Knowing I have someone to talk to, my volunteer is excellent!!
- Having a caring contact person to talk with, financial help with respite care.
- It helped with the house work.
- Receiving support from a professional, receiving strategies for dealing with behaviors, medication, specialist, choosing long term care facility.

- The literature was extremely helpful. Although my volunteer and I agree on time to check up. I know that I can call at any time if a problem arises.
- Weekly calls and references for various resources. Dollars for caregiver help.
- I have always known when I got a HERO call that it was an opportunity to vent, which is something I just periodically need to do. And I find that just helpful to my overall well-being.
- It was helpful to be able to talk with my volunteer. She is knowledgeable, kind, and non-judgmental.
- Having someone to ask questions of and support resources.
- Looking forward to the call from my volunteer and talking with someone who has been there. The financial help to get away several hours per week.
- Having the volunteer to talk to, she always provides excellent advice. She is great.

Can you identify any beneficial aspects of the HERO Project for your loved one?

- It was more for the caregiver helping them cope with the patient.
- It made me more patient.
- I am a better caregiver.
- I get the ideas of activities to try- to benefit my loved one.
- I think everything that encourages and benefits me gets passed on in increased patience and understanding as I give home care. I think the survey questions have helped my awareness. One of the wonderful things she did was to link me to another caregiver who has become a trusted and valuable friend. Neither of us could be away from husbands to go to a support groups so we talk each week by phone. Such a gift!!
- A place to vent- keeping me sane.
- Better care.
- Continued quality care when I was gone.
- Volunteer gave me ideas on how to handle certain problems. Always good advice.
- My being able to leave to do something for myself more often- allows me to return as caregiver- refreshed and less burdened.
- My husband says the volunteers really care about him and others; they are friends, so he looks forward to going, not having to persuade him to go.
- I'm less stressed, so that benefits him.
- Extra respite care for socialization.
- Some care givers had an interest in her and would have her singing songs.
- Last felt, after discussing the situation with the volunteer. I was able to cope with the inability to travel by taking my husband on a day trip which we both enjoyed.
- She is too far gone to know- but a better me is a benefit to her.
- Well if I'm better able to cope, it sure is better for him in the all- around. And at some point, when he can no longer stay alone, I will be able to be supported by the HERO project and those resources.
- Yes, I have been more patient because of the help and support I received.
- Because I was able to leave the house I returned refreshed and more patient.
- Having a free companion visit with my twin brother is invaluable.

Other comments:

- It would be helpful to have a volunteer that can relate to having a family member with dementia so they can relate emotionally. Also, have volunteers educated in all dementias not just ALZ.
- Still looking for respite care.
- Thanks!
- Suggest face to face meetings, where possible.
- I always look forward to the calls.
- Another great thing was my introduction to Teepa Snow, the caregiver trainer. Her online lessons and CD's are extraordinarily valuable in increasing my understanding of my husband's needs. I am super grateful!!
- Would like to see some kind of letter or literature to family members to realize how needed their encouragement can be to the caregiver.
- My husband is now in assisted living and doing very well there.
- Everyone genuinely wants to be there as a volunteer, bless all of them.
- This is a wonderful program!
- It's a shame that the program had to be cut back in funds \$125. It is a good program for the caregiver.
- I truly appreciate this program and all you do!
- The HERO program is amazing, a life-saver-Thank you!
- Love the program & Thanks!