

Tales and Travel: Developing Community Partnerships to Expand Library Services

Approval of Final Report by emails:

From: Layton, Beth [<mailto:balayton@uic.edu>]

Sent: Wednesday, April 27, 2016 12:06 PM

To: Jacqueline Leskovec <leskovec@uic.edu>; Miriam Lytle <mlytle@gailborden.info>

Subject: Re: Fwd: OCR NN/LM Project Final Report

Miriam,

I have approved your report.

I am impressed with the program and the evaluation. I'm glad you are all communicating about the impact of the program with many others. It is truly groundbreaking.

I thank you and all involved for your commitment to helping people suffering from dementia and their caregivers. It has been an honor to work with your group.

Sincerely, Beth

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On 4/18/2016 2:22 PM, Jacqueline Leskovec wrote:

Dear Miriam,

Thank you for your excellent project and detailed report. It clearly has had an impact on many participants. The scenario you described of the non-verbal resident who showed her understanding of the travels in a non-verbal way is a most wonderful example; thank you for sharing.

...Thank you for your work in support of the NN/LM mission.

Jacqueline
Jacqueline Leskovec, MLIS, MA, RN
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Tales and Travel: Developing Community Partnerships to Expand Library Services

National Network of Libraries of Medicine: Greater Midwest Region

Project Target Award Final Report

submitted online by Miriam Lytle 4/14/16

Project Overview

The NN/LM will make these summaries available to the public via the NN/LM web site. The project overview should provide a concise summary of your project that can be shared publicly. Your summary should provide a brief description that presents the most important information about your project to those who do not have access to your full report.

Guiding questions:

1. What were your primary goals for this project?
2. What was the target population and why did you choose it?
3. What organizations and partners were also involved in implementing the program?
4. What were the project's major accomplishments? How did it make a difference?
5. If you have an article that is or will be published about this project, please include URLs or reference information.

Underserved populations continue to exist within public libraries' service areas. The Gail Borden Public Library, Elgin, IL adopted the Tales and Travel program with the purpose of expanding community outreach services to target a stigmatized minority population, older adults with early to middle stages of dementia. The program was offered in memory care units at assisted living facilities within the Gail Borden Public Library District's 60 square mile area.

Tales and Travels is a one-hour "excursion" designed to engage individuals with dementia both socially and cognitively. In addition, a carry-on suitcase, called "travel kits," were created and made available for check-out at the Main Library and Rakow Branch for at-home caregivers and their loved ones with dementia.

While individuals with dementia lose elements of cognition, some elements remain and when engaged, their quality of life improves. In an effort to promote the Tales and Travel program nationwide, the Library sought to gain evidence of the program's effectiveness in several areas. The project was a collaborative endeavor as the Library project team partnered with an expert on dementia, Dr. Susan Wesner, Judson University, Elgin, IL, eight assisted living memory care unit directors, activity directors with their staff and volunteers (Highland Oaks, Manor Care, Oak Crest, Rosewood, Sherman West Court, South Elgin Rehabilitation, Tower Hill, White Oaks on Spring Street), as well as library program volunteers.

Previous professional library publications recognized the Tales and Travel program the importance of addressing this underserved and often misunderstood population.

[“Five Million and Counting,”](#) by Phil Morehart. Published in American Libraries, March 14, 2014. Retrieved from <http://americanlibrariesmagazine.org/blogs/the-scoop/five-million-and-counting/> 11 April 2016.

[“Stimulating Minds: Libraries develop programs to serve patrons with Alzheimer’s disease and other dementias,”](#) by Terra Dankowski. Published in American Libraries, February 9, 2015. Retrieved from <http://americanlibrariesmagazine.org/2015/02/09/stimulating-minds/> 11 April 2016.

[“Serving People with Alzheimer’s and Dementia: Excellent 21st Century libraries must reach underserved and isolated populations,”](#) by Mary Beth Riedner, Karen Maki, and Miriam Anderson Lytle. Published in Strategic Library, July 2014. Retrieved from <http://cld.bz/L41Qhuo#8/z> 11 April 2016.

However, this study specifically charged the Gail Borden Public Library District staff and its partners to find qualitative evidence that Tales and Travel was an effective library program for serving this often forgotten population, and for revealing stigmas sometimes projected on people who suffer with dementia. Accomplishments also included getting the word out at professional library and aging conferences, and the creation of a website. These presentations and the virtual presence provides library staff, caregivers, and memory care providers an awareness of what can be done, and the ability to download and use the Tales and Travel “excursion guides,” logos and resources and for free. See <http://talesandtravelmemories.com/>

Approaches and Interventions Used

Describe the specific steps or activities used in the following areas: identifying and scheduling sessions; promotion/marketing; training; personnel/staffing; equipment/telecommunications; web site development.

Guiding questions:

1. List your goals and objectives for this project.
2. What were the steps and activities you used to accomplish your goals and objectives?
3. How did each team member contribute to the project?
4. Please list URLs to project resource material that is publicly available (e.g., abstracts, posters, promotional material, slide presentations.) URLs for all web-based training materials should also be submitted to the MLA Educational Clearinghouse (<http://cech.mlanet.org/>)

The project explored whether the Tales and Travel program:

1. Engages and improves the cognitive and social interactions of individuals with dementia.
2. Positively impacts the relationship between caregivers and individuals with dementia by providing stimulating activities and reducing the number of stressful interactions.

3. Expands the Library's outreach to an underserved population.
4. Decreases stigma and stereotypes of adults with dementia by demonstrating elements of cognition that remains throughout the course of the disease.

The areas of exploration formed the framework for the four study objectives which included the following: Objective 1: Older adults with dementia will demonstrate increased cognitive and social interaction during the Tales and Travel program. Objective 2: After engaging in the Tales and Travel program (both in facility and at home), relationships between individuals with dementia and their caregivers show improvement as a result of skills developed through the program, ultimately resulting in less stressful interactions. Objective 3: During the next year, the library will expand its outreach to the community by 2% through the Tales and Travel Program. Objective 4: Stereotypes of adults with dementia and stigma related to their cognitive abilities will be reduced by demonstrating cognition that remains during the course of the disease throughout the administration of this program.

Key individuals in the study included 1) individuals with dementia living within the local assisted living facilities and in the community 2) Formal caregivers 3) Program Volunteers. Program participants completed Informed Consent forms to indicate agreement with involvement in the study.

Evidence was gathered through qualitative measures, primarily questionnaires and pre/post-tests. Data has been collected from August 2015-April 2016. Programs from ten facilities yielded the following surveys:

- 78 Volunteer surveys
- 15 Formal caregiver observations
- 1 Check Out kit caregiver observation
- 9 Pre-tests
- 5 Post-tests

The project team and responsibilities involved Susan Wesner, D.M.H., Judson University, Elgin, IL who designed study, survey questions, and provided the approved Informed Consent Form. Dr. Wesner also made first hand observations at some programs in action. With data, she tabulated the results, wrote the findings in quarterly and final reports. Dr. Wesner also created the poster for the Aging in America Conference where she presented in Washington DC. Gail Borden Public Library staff, Miriam Lytle was project director; Angela Bouque, Tracey Degnan, Ana Devine (until October 2015) Benjamin Bahl (beginning November 2015) and Library volunteers (all former librarians) Karen Maki, Mary Beth Riedner, and Kathy Simonetta comprised the Steering Committee.

Life Enrichment Liaison Tracey Degnan communicated directly with assisted living facilities in every aspect, trained volunteers, and coordinated details from order supplies to scheduling.

Tracey put together the traveling kits and worked with her supervisor Ben and technical services staff for check out policies and procedures, labeling and cataloging. As Library on the Go Manager, Ben worked on obtaining competitive bids for a web developer, migrated web content, ordering of equipment, budget management and trouble shooting. In addition, Sara Johnson Business Manager proved a key team member, as proof of payment and bookkeeping was critical for the budget. Volunteer Kathy Simonetta developed a copyright free folktales and stories that are important pieces of the Excursion Guides, now available on the website. Karen Maki and Kathy are also program volunteers. Mary Beth Riedner presented A poster entitled “Reaching Out to Persons with Dementia Through Library Resources” at the Annual Meeting of the Midwest Chapter of the Medical Library Association in Louisville, KY on Oct. 4, 2015. On Nov. 8, 2015, Mary Beth Riedner participated in a panel entitled “How can information science contribute to Alzheimer’s disease research?” at the 2015 Annual Meeting of the Association for Information Science and Technology held in St. Louis, MO. A poster session entitled “Libraries: An Overlooked Community Resource for People with Dementia” was presented by Karen Maki, Mary Beth Riedner, Susan Wesner on Tuesday, March 22, 2016 at the American Society on Aging’s 2016 Aging in America Conference in Washington, DC.

Ben Bahl, Tracey Degnan and Miriam Lytle presented to the Bookmobile and Library Outreach Networking Group at the Elmhurst Public Library, Elmhurst IL 60126, and Tracey presented at other local libraries to show how Tales and Travel works and could work for them.

Problems or Barriers Encountered

The NN/LM will make this section available to the public via the NN/LM web site. List any major problems or barriers you encountered when pursuing your objectives, including (but not limited to) the areas of promotion/marketing; scheduling; training; equipment/telecommunications; personnel/staffing; unanticipated budgetary issues; web site and resource development; exhibiting; translations; and partnerships.

In March 2015 with submission of the grant proposal, the following ten assisted living facilities within the Gail Borden Public Library District boundaries agreed to partner on this study by signing an agreement of understanding: Heritage Health, 355 Raymond St., Elgin, 60120; Heritage Woods of South Elgin, 700 McLean Blvd, South Elgin, 60177; Highland Oaks, 2750 W. Highland Ave., Elgin, 60124; ManorCare Health Services, 180 S. State St., Elgin, 60123; Oak Crest at 204 S. State St., Elgin, 60123; River View 50 N. Jane Dr., Elgin, 60123; Rosewood Care Center, 2355 Royal Blvd, Elgin, 60123; South Elgin Rehab & Health Center, 746 W. Spring St., South Elgin, 60177; Tower Hill Healthcare Center, 759 Kane St., South Elgin, 60177; The Vines at Countryside, 971 Bode Rd., Elgin 60120.

However, when it came time to gather Informed Consent Forms, four facilities bowed out of the study. Tracey Degnan attributed this to turn over in facility directors and other key memory care staff, and overworked facility staff who explained they were not able to handle additional tasks. The following facilities, therefore, did not participate in the study: Heritage Health, River

View, The Vines, and Heritage Woods of South Elgin. Yet the opening of a memory care facility in summer 2015 named The White Oaks – Spring Street, South Elgin, 60177 joined the study, making the total seven participating facilities.

Another challenge was natural attrition of participants due to advancement of the disease or departure from this earth. At the same time, new residents at facilities became participants. Turnover of facility staff and program volunteers, including our own team member Ana Devine who was promoted to Director of Branch Services. Benjamin Bahl joined us as Library on the Go Manager in Fall 2015.

Unanticipated budgetary changes included both our successes and our underestimation. The Library's collection was weeded, making DVDs and books that were useful to the program available, and the Library's book sale "Gail's Sales" donated many items in our Excursion subject areas. These donations to the project reduced our estimated supply costs. The cost of web development, promotional materials, and the Aging in America conference were higher than anticipated. Project team member and volunteer Mary Beth Riedner, the academic librarian who created Tales and Travel is an irreplaceable advocate for services to people with dementia. Every proposal Mary Beth Riedner submitted to present at professional organizations was accepted. The double-edge sword: she really got the word out about Tales and Travel and NNLM study; travel costs increased dramatically, paired with an error of the location of the Aging in American conference (Washington DC rather than Chicago).

Evaluation

How was the project evaluated? What results were achieved based on the objectives of the project?

Guiding questions:

1. What methods did you use to assess whether or not you met your goals and objectives?
2. Were your original project goals and objectives met?
3. What goals and objectives were not accomplished and why?

The purpose of this study was to gather evidence of the Tales and Travel program's effectiveness in engaging individuals with dementia. The results indicate social and cognitive engagement occur during the program. The level of engagement varied from normal and increased, depending on the level of relationship between the respondent and the individuals with dementia. Formal caregivers noted a more significant increase in social and cognitive engagement.

Objective 1: Older adults with dementia will demonstrate increased cognitive and social interaction during the Tales and Travel program.

Objective 1 Conclusions: The measure of success for this objective was that older adult participants would demonstrate increased cognitive and social interactions during this program. While library volunteers indicated that most cognitive and social interactions were normal from program to program, formal caregivers noted that both cognitive and social interactions were increased. The significance of this finding is that program volunteers observe engagement during a shortened timeframe whereas formal caregivers have a deeper understanding of the older adults. The responses provide some evidence that cognitive and social interactions are increased during this program. (See three-page Results attachment.)

Objective 2: After engaging in the Tales and Travel program (both in facility and at home), relationships between individuals with dementia and their caregivers show improvement as a result of skills developed through the program, ultimately resulting in less stressful interactions. To measure this objective, individuals checking out the kits from the Library were to complete a questionnaire with questions similar to those noted above. Four kits were checked out and one survey returned.

Objective 2 Conclusions: Since the response is too low to draw conclusions, the data is not recorded in this report. However, the measure of success in the proposal was met by formal caregivers who indicated more satisfying relationships with individuals with dementia, and increase in skills.

Objective 3: During the next year, the library will expand its outreach to the community by 2% through the Tales and Travel Program.

Objective 3 Conclusions: Through this program, the library expanded its reach by 31% to residents in the community. From June 22, 2015 through April 14, 2016, the Library reached 147 more (non-unique) attendees compared to the ten months prior to the project launch. In total, the Library reached 621 program (non-unique) attendees.

Objective 4: Stereotypes of adults with dementia and stigma related to their cognitive abilities will be reduced by demonstrating cognition that remains during the course of the disease throughout the administration of this program. A Pre-Test was administered to program volunteers prior to program participation and a Post-Test was administered after the program. Results were compared to determine whether stigma and stereotypes existed before and after the program

Objective 4 Conclusions: Participants noted a change in their perceptions of individuals with dementia. Views of cognitive and social abilities increased as a result of participating in the program (see attached Study Results, page 3-4).

Continuation Plans

What parts of this project will continue and how?

Guiding questions:

1. What activities will be continued and which partners will participate in the continuation?
2. If there are plans to expand or replicate this project, explain how this will be done. Who will provide the funding and staffing to continue project activities?

Mary Beth Riedner was invited to present a program entitled “Restoring Connections: Meeting the Needs of People with Dementia” at the 2016 Annual Conference of the Texas Library Association on April 21, 2016 in Houston, TX. The session will provide details about the benefits of the Tales and Travel program and how it works in order to encourage Texas libraries to replicate the program in their own communities.

LibraryWorks, Inc. Jenny Newman, Vice President / Publisher confirmed a one-hour webinar on Tuesday, May 17 at 1 pm CST on libraries serving persons with dementia, including the results of this study. Tracey Degnan, Mary Beth Riedner and Susan Wesner submitted a proposal to the Illinois Library Association October 2016 in Chicago.

Tales and Travel programs will continue to flourish with yet another facility slated to open in the Library District this year. The travel kits are just beginning their sojourn into family homes, a new and growing service for which statistics can be gathered over ample time.

The Gail Borden Public Library District Foundation’s Karen Maki Fund for Memory Care Program was established last year when Karen Maki retired as deputy director after more than three decades of service. Karen had cared for her mother with dementia, and knows the importance of a sustaining vital programs.

Lessons Learned

The NN/LM will make this section available to the public via the NN/LM web site. If answers to these questions are contained elsewhere in your report, repeat them here.

Guiding questions:

1. What unexpected results (positive or negative) did you have with the program?
2. What recommendations would you have for someone who wanted to apply your program in their region?
 - What significant lessons were learned which would be of interest or use to others conducting outreach projects?

- Which strategies were the most effective in implementing the project?
- Which of your strategies would you not use again and why?
- If you offer this program in the future, what will you do differently?

Conclusions:

The purpose of this study was to gather evidence of the Tales and Travel program's effectiveness in engaging individuals with dementia. The results indicate social and cognitive engagement occur during the program. The level of engagement varied from normal and increased, depending on the level of relationship between the respondent and the individuals with dementia. Formal caregivers noted a more significant increase in social and cognitive engagement.

Further, even though there is a small base of volunteer responses, those who participated indicate a positive change in the perception of individuals with dementia. The change in perception will benefit communities because volunteers who may not have been exposed to individuals with dementia can engage with them in a meaningful activity and draw similar conclusions, ultimately reducing stigma in the community and increasing outreach to this vulnerable population.

Older adult participants demonstrated increased cognitive and social interactions during the Tales and Travel program. While library volunteers indicated that most cognitive and social interactions were normal from program to program, formal caregivers noted that both cognitive and social interactions were increased. The significance of this finding is that program volunteers observe engagement during a shortened timeframe whereas formal caregivers have a deeper understanding of the older adults. The responses provide some evidence that cognitive and social interactions are increased during this program.

The Gail Borden Library far exceeded its expectations through this program. The goal was to see a 2% increase but the Library expanded its reach by 31% to residents in the community.

In addition to serving the Elgin area, nationwide interest was promoted through presentations and poster sessions focused on the benefits of using library materials with persons living with dementia. The Tales and Travel program was highlighted along with preliminary positive results from the ongoing National Library of Medicine study. At the Aging in America Conference, the poster was well received by attendees from a wide variety of organizations, including academic institutions, faith groups, and health care organizations from California to Kansas to Pennsylvania and even Canada. Handouts were distributed to nearly fifty interested parties and 24 provided their email addresses in order to receive additional

information. The poster was one of 100 posters selected to be displayed during the two-hour session.

Lessons learned include understanding that there will be surprises. In this project, surprises included onboarding a newly opened facility, budget changes as a result of accepted proposals and increased costs, several partners signed on to the study rescinding, and the generosity of the Foundation's Gail's Sales donating books and DVDs.

Impact

The NN/LM will make this section available to the public via the NN/LM web site. Why do you think this project was important?

Guiding questions:

1. What was the impact of your project? For example, did the project:
 - Help a low-resource organization serve a high risk population?
 - Contribute toward the ability of your organization's or your partner organization's ability to meet its mission, values and priorities?
 - Benefit any of the partner organizations, e.g. raising visibility; increasing utilization)?
2. Please tell a "success story" that gives an example of your project's impact.
3. How do you plan to share your project and lessons learned with colleagues, such as through a conference presentation or publication?

Tales and Travel is a meaningful programming that makes a difference in the lives of individuals suffering from dementia. It is up to each public library to discover how to best serve this often forgotten population. The Tales and Travel has been proven to be effective and engaging, reducing stigma. The Gail Borden Public Library District invites others to take a tour of the Tales and Travel program. It is easily replicated by going to the website <http://talesandtravelmemories.com/> and downloading free excursion guides, logos and resources.

One observation during a Tales and Travel program was relayed by Dr. Wesner. One attendee who was non-verbal appeared unable to enjoy the read aloud story. However, she listened excitedly to the folktale. She repeated over and over "I"..."I"..."I"... but that was the extent of her verbal discourse. Becoming increasingly agitated, the woman walked quickly down the hall to her room, returning with an armful of stuffed animals, including a large white bear and other critters that directly related to the story that had been read aloud. The woman was unable to engage verbally but certainly proved comprehension to a stunned and delighted circle of friends.

It is not uncommon to hear these comments when the big globe is spun and the destination pointed out for their “trip” that day:

“I can’t afford it!”

“I don’t feel like traveling today!”

and once when Ireland was the excursion, “I’d rather go back to Italy!”

Other

Contact your RML or Center for additional reporting requirements for this field. If available, include URLs for press releases, advertisements, and newsletter articles.

Attachment 1

Activity Reporting Form (AR) summary data: Subcontractor activities

Emailed to Jacqueline: Susan’s grid in separate doc

Attachment 2

Exhibit summary data: Subcontractor exhibits and health fairs

Emailed to Jacqueline: MLA Poster and AiA poster

Note: Miriam was unable to upload these documents on the NNLM site, which Jacqueline confirmed and accepted documents by email.