



## Lifespan Respite Project Expansion Supplement Grant MINI-GRANT SUMMARY REPORT

March 2012 – May 2013

### **Introduction**

In March 2012, nine local and county agencies were awarded a total of \$135,657 (ranging from \$6,250 - \$22,500 apiece) to help family caregivers of children or adults of all ages with special needs. Funding was made available through the North Carolina Lifespan Respite Project Expansion Supplement Grant.

Respite is a service for unpaid caregivers to allow them temporary time away from the often-overwhelming experience of caring for a loved one with special needs. The NC Division of Aging and Adult Services (DAAS) manages the state's Lifespan Respite Care Project.

Since 2009, Congress has appropriated approximately \$2.5 million per year nationally for grants to eligible State agencies to implement the Lifespan Respite Care Program. North Carolina was one of 12 states awarded these funds in 2009, with additional dollars for direct respite care awarded in 2011. Nine local organizations in North Carolina were selected through a state-facilitated application and scoring process to receive these additional dollars in the form of mini-grants.

**From March 2012 through May 2013, more than 235 previously un-served family caregivers in North Carolina received 14,126 hours of respite and 86 volunteers were trained through these mini-grant projects. Equally as important is the fact that as a result of these mini-grants, at least 12 new or enhanced services have been sustained after the grant period.** Results from each mini-grantee can be viewed in attachment A, entitled "Lifespan Respite Mini-Grantee Summary Tables."

While these numbers reflect an impressive measure of success in their own right, it was the aim of the NC Lifespan Respite Project to also gather information and learn from the experiences of those who received respite during this fourteen-month timeframe. This was accomplished by grantees' administration of pre- and post-service surveys, which queried caregivers on how services impacted satisfaction and perceived caregiver burden. Eighty-eight caregivers completed the pre-service form and 90% of them also completed the post-service form. Detailed results from these surveys are contained in attachment B, entitled "Lifespan Respite Mini-Grantee Survey Results" and summary remarks are included in the "Conclusion" section of this report.

Family caregivers were also provided with a document entitled "Setting Goals to Maximize Respite Time" (see attachment C). It has been widely recognized that while family caregivers will often report that they are satisfied with the respite services they have received, there is less evidence that respite has enabled the caregiver to return to their tasks rested and less burdened. The goal of this tool is to encourage caregivers to set goals so that they will more often use their respite break for restorative activities.

The following is a summary of accomplishments; lessons learned; observations about setting goals for maximizing respite time; and, project sustainability results. Again, detailed narratives from each of the nine mini-grantees can be viewed under attachment A.

### **Summary of Accomplishments (i.e. objectives met)**

Mini-grantees completed their stated project objectives from March 2012 through May 2013. During this time period they:

- Provided 14,126 hours of respite care in a variety of forms (i.e. in-home respite; adult day services; group respite; summer camp; memory cafes, etc.) to more than 235 previously un-served family caregivers.
- Recruited and trained staff and more than 86 volunteers to provide respite and other support services.
- Facilitated participation in programs such as “Powerful Tools for Caregivers” and “Support Team Leadership Training.”
- Increased awareness and educated the community about respite care and other support services for family caregivers and those receiving care.
- Created new respite programs and added new elements, such as extended evening hours; more days of respite; and, drop-in care.
- Increased capacity/enrollment within existing programs.
- Offered programs that focused on serving the whole family and fostering integration (i.e. summer camp with both typically developing children and children with I/DD; Memory Cafes and the “Sacred Journey of Dementia” conference, focused on those with the diagnosis and family caregivers).

### **Summary of Lessons Learned**

The following represents key “lessons learned,” as reported by mini-grantees during their closeout interview:

- In more than one setting, caregivers that are no longer receiving services through mini-grant funds have found respite through informal/unpaid supports. It seems that once they experienced respite, it was seen as personally valuable and they sought help on their own.
- One grantee stated that caregivers want flexibility, which can be challenging to accommodate. Another grantee found that most caregivers do not want to leave their home or their loved one for an extended period of time, as offered in their proposed 24 hour respite service.
- Though dealing with the temporary nature of the funds was challenging, one grantee found that being able to access funding and service more quickly allowed them to see how important it is to reach families as soon as possible after they ask for help.
- By knowing that these were temporary funds, one grantee stated that staff worked really hard to plan for alternatives after funding ended and in so doing were more intentional and focused on these families. It allowed them to think about things a little differently and they developed deeper relationships with their clients.
- Another stated that the most significant lesson learned over the mini-grant year was to constantly seek alternative funding sources for participants.
- Several found the pre- and post-service surveys helpful in building relationships with caregivers – an opportunity for caregivers to take a step back and recognize for themselves the extent of the stress they have been living with; the impact of this stress on their own health; and, the importance of making changes.
- One found it to be a challenge getting clients to return the completed surveys. One reason for this difficulty may be due to stress placed upon the family.
- Staffing (direct care staff) was the biggest challenge for one grantee (overnight/evening hours with greater expectations for involvement/activities).
- When running a volunteer service, a grantee stated, “Recruitment has got to be the best it can be.” They are learning to take the time to get the right people and the right match for those they will be assisting. “It’s important to be flexible and serve where you can with what you have.”

- Two grantees (The ARC of Davidson County & The Early Memory Loss Collaborative) learned a great deal from addressing the whole family and fostering integration. Here are some of their comments:
  - “It was a wonderful opportunity for typically developing children to play alongside their peers with disabilities. The issue of “differences” did not arise, neither on the part of the children nor the families. When visiting camp, unless a child presented with a pervasive disability, one could not discern the “difference” among the children. Friendships developed that we hope will carry into the school year, as children see how they are more alike than different.”
  - “The biggest lessons learned is the shared humanity among all who attend the memory cafes, which is very gratifying since this was the objective from the beginning. Volunteers have commented over and over about how they have learned more about dementia by being with their guests, how they sometimes don’t know which person in a couple has dementia and have to hold all assumptions, listen and use new discernment to figure it out.”
  - Regarding “The Sacred Journey of Dementia” conference: “As we talked about and planned this event, there was interest but a certain level of caution from a number of people who were only used to workshops and conferences that focused on the data about dementia. In the end we had a full house – nearly 200 people (many family caregivers & people with the diagnosis) and a huge response of appreciation and a call to repeat it again next year.”

### **Observations about “Setting Goals for Maximizing Respite Time.”**

Use of this form prompted several interesting comments, which seem to indicate the importance of relationship and timing in working with family caregivers on this issue. The following comments illustrate the range of reactions and ideas generated by the tool:

- “It can be difficult to persuade caregivers to use their respite time for enjoyable activities. In some instances, caregivers feel guilty for taking time for themselves. The caregivers may have health problems and really do need to use the time away for their own doctor’s appointments, while others have loved ones who cannot be left alone at all. In those instances, the caregiver feels that they need to use most of the time away to handle personal business, grocery shopping, etc.”
- “The “Setting Goals to Maximize Respite Time” document itself was not an issue, and its intention is good. However, in our experience, even though it was discussed with the caregivers, many of them did not feel that it was important to set goals. It was said by more than one that their lives are often chaotic and it is often not possible to stick to a goal; they simply handle what comes along as it happens.”
- One project loves the idea of bringing awareness of use of time and plans to use the tool in educational programs and in in-home care encounters. They found it interesting that some were receptive and others were not (i.e., “Are you kidding me? I have plenty to do”).
- Another project found the form helpful for some participants but commented that most come in with some level of crisis – a helpful tool to introduce to some, but others think of it as “naïve.” One caregiver commented, “I don’t have time to think spiritually.” Perhaps reframe the tool to ask the person “How do I construct my life?” after the crisis period has settled.
- “Families first see the program as a benefit to the loved one. After they got “caught up” with everything, they were “shocked” to hear about taking time for themselves.” Now the project coordinator is noticing that people are beginning to use their time for fun and the form helped her talk to families.
- A few people sent in the “setting goals” document to the project director, although they weren’t asked to do so. The response to the form indicated that people found that “asking the question” was helpful.
- Caregivers need considerable encouragement and support to care for themselves.

- “The greatest challenge seems to be for the caregiver to hold on to the importance of the value of claiming time for themselves, to be off-task from caregiving. Once a little time opens up, the long list of “to-dos” seem to take over and the opportunity to do something fun/refreshing/relaxing takes a back seat.... I think this will take some intentional work over time...with support. The materials were fine – but the concept requires human support.”
- The “Setting Goals to Maximize Respite Time” tool was well received by family caregivers served by a senior companion. The majority of caregivers welcomed the goals worksheet/tool and was used as a discussion tool about caregiver self-help by a staff member who goes into each companion recipient’s home during a quarterly visit. They discussed the tool and it’s purpose and plan to keep using it in their interactions with family caregivers. They also are discussing making a follow-up tool to assess how well the goals worksheet is helping the caregiver to be used during the successive quarterly visits with the caregiver.

### **Summary of Project Sustainability (i.e. What is in place that wasn’t there before?)**

One of the challenges inherent in receiving grant funding is sustaining the objectives that have been accomplished after the funding is no longer available. It is encouraging that at least 12 new or enhanced services have been sustained. The following illustrates how these grantees are continuing the work that was initiated through their mini-grant projects:

- “Through this project we were not only able to work with other agencies to identify those needing respite in our county, but were able to create a sustainable program to continue to meet their needs and the needs of future caregivers. The project confirmed the need for respite and now we’re able to go back to the county commissioners with this data/findings and ask for respite money. “
- “In addition to quality evening and overnight respite services at an affordable price, because of grant funding, there is also a permanent salon in place. To date, family caregivers are enlisting help from other family members to pay for evening/overnight respite.”
- “The CARE Café is the only group respite program in this area. Funds from the Lifespan Respite Project have doubled the amount of respite time available to caregivers.”
- “Camps continue to grow! And there are plans for after school and camps for the entire year. This grant enabled our agency to assist more families who had previously not been aware of this program, and to hire staff to fully support children who required more support. Data generated by the Lifespan Respite Grant was helpful in successfully leveraging funds from the United Way.”
- “More community members are aware of the direct family support that FIFNC offers; and families have the opportunity to have access to our supports in the future... By working with Community Resource Connections on this project, they now refer more to FIFNC – building on collaboration – “showing up on the radar.” Respite and an aging I/DD population is an emerging issue.”
- “There are now five Memory Cafes in place (at the First Baptist Church of Asheville, Unitarian Universalist Congregation of Asheville, Calvary Episcopal Church of Fletcher, Senior Resource Center of Haywood County, Waynesville, NC and the First Baptist Church of Hendersonville, NC.) with 44 volunteers trained to host these monthly events.” Also, three churches, First Baptist Church of Asheville, Calvary Episcopal Church and the Unitarian Universalist Congregation of Asheville have scheduled meetings at the denominational level in major meetings out of state to report on their Memory Cafes with the hope of inspiring other congregations to begin this ministry/mission with those living with dementia in their own home churches.
- The first conference, “The Sacred Journey of Dementia”, that involved persons with a diagnosis of dementia in leadership at the conference, is receiving strong urging from the community to hold a 2<sup>nd</sup> annual conference.

- A new effort of engaging caregivers in their own homes in thinking through how to create restorative respite for themselves has been established.
- As mentioned previously in this report, in more than one setting, caregivers that are no longer receiving services through mini-grant funds have found respite through informal/unpaid supports. It seems that once they experienced respite, it was seen as valuable and they sought out help.
- “Powerful Tools for Caregivers” is now offered each year using the staff members that were trained.”
- “These funds have allowed ACE to hone our skills in helping families move to other funding sources including PACE, Project CARE, Home and Community Care Block Grant and CAP.”
- Even though the funding from this mini-grant concluded, the senior companion program was able to transition a majority of their new care recipients to other public funding sources, and three of them began paying privately for the companion service.

## **Conclusion**

Certainly one of the primary “takeaways” of the Lifespan Respite Mini-Grant Project is that a marked impact is possible with a relatively small amount of funding. Ultimately, this funding catalyzed nine communities across the state to create and enhance services that will have a lasting effect on peoples’ lives.

Additionally, the accomplishments and “lessons learned” from this effort have the potential to inform future policies and practices. An intriguing story has emerged from the use of the pre-and post-service surveys and the “Setting Goals to Maximize Respite Time” document. While mini-grantees reported, “mixed reviews” on caregiver-receptivity to the “Setting Goals” form, the pre- and post-service surveys suggest that a significant decrease in caregiver burden was apparent only for those caregivers that talked to their provider about respite planning (see Attachment B for the complete analysis of findings).

As stated in the analysis performed by a Ph.D-level evaluator, “Given that there was not a comparison group in the study, we cannot say that the significant decrease in caregiver burden was a direct result of the respite intervention, but we can hypothesize that the Lifespan Respite Mini-Grant program along with the “consultation” has had a positive effect on the caregiver.”

It is apparent that tools, such as the pre- and post-service surveys and “Setting Goals,” can offer guidance and deepen relationships between providers & caregivers and ultimately improve the benefit of respite services. However, the effective use of these tools seems to be a matter of timing and approach. Project experiences suggest that discussions about “restorative care” appears to be most effective on a one-to-one basis; over a longer period of time, when initial crises have passed; and, when self-care awareness and information can take hold.

## **Attachments:**

- a) Lifespan Respite Mini-Grantee Summary Tables
- b) Lifespan Respite Mini-Grant Survey Results
- c) “Setting Goals to Maximize Respite Time” worksheet



**Lifespan Respite Project Expansion Supplement Grant  
MINI-GRANTEE SUMMARY TABLES  
Attachment A**

<b>Mini-Grant # 1: Alamance ElderCare</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<p><b><u>Completed Objectives:</u></b></p> <ul style="list-style-type: none"> <li>• Educated the Alamance County community about the availability of additional respite funds.</li> <li>• Accepted requests and referrals and completed assessments.</li> <li>• AEC staff completed ‘Powerful tools for Caregivers’ facilitator training.</li> <li>• Alamance County caregiving community participated in at least one ‘Powerful Tools for Caregivers’ training each year.</li> </ul>	<b>n/a</b>	<b>13</b>	<b>402.25</b>
<p><b><u>Lessons Learned:</u></b></p> <p>“We continued to find that most caregivers do not want to leave their home or their loved one for an extended period of time, as offered in our proposed 24 hour respite.</p> <p>One thing we have learned (or rather, had confirmed) is that it can be difficult to persuade caregivers to use their respite time for enjoyable activities. In some instances, caregivers feel guilty for taking time for themselves. In some cases, the caregivers themselves have health problems and really do need to use the time away for their own doctor’s appointments, while others have loved ones who cannot be left alone at all. In those instances, the caregiver feels that they need to use most of the time away to handle personal business, grocery shopping, etc.</p> <p>The “Setting Goals to Maximize Respite Time” document itself was not an issue, and its intention is good. However, in our experience, even though it was discussed with the caregivers, many of them did not feel that it was important to set goals. It was said by more than one that their lives are often chaotic and it is often not possible to stick to a goal; they simply handle what comes along as it happens.”</p> <p>Of the 13 caregivers served, 10 are no longer receiving the public funding, but have sought out informal/unpaid supports. It appears that once they experienced respite, it was seen as valuable and they sought out help on their own.</p>			
<p><b><u>Project Sustainability:</u></b></p> <p>The most sustainable part for this grantee is the Powerful Tools for Caregivers, now offered each year using the three staff members that were trained. Also, some of the caregivers became aware of other support services /products (home modifications) when introduced to respite through this grant. Ten out of 13 found</p>			

informal supports once introduced to respite.

<b>Mini-Grant # 2: Adult Center for Enrichment</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<p><u>Completed Objectives:</u></p> <ol style="list-style-type: none"> <li>1. Provided respite care to caregivers of frail and impaired adults in Guilford County who have the greatest need.</li> <li>2. Made the community aware of Lifespan Emergency and Ongoing Respite Funds</li> <li>3. Enhanced or maintained the quality of life for frail and impaired adults and their caregivers.</li> </ol>	n/a	14	3607.5

Lessons Learned:

“Though dealing with the temporary nature of the funds was challenging, being able to access funding and service sooner than we normally would have allowed us to see how important it is to reach families as soon as possible after they ask for help. Accessing these services, even a few months sooner than they otherwise would have, has allowed us to enhance the wellbeing of families we have served by minimizing stress and providing support.

We found the conversations that occurred as a result of completing these surveys were helpful in building relationships with caregivers. It was during these conversations that we would discover additional caregiver stressors such as, more than one care recipient under their care, and other responsibilities such as school, work, and children with special needs. It was an opportunity for caregivers to take a step back and recognize for themselves the extent of the stress they had been living with, the impact of this stress on their own health, and the importance of making changes.”

Regarding “Setting Goals” document: ACE loves the idea of bringing awareness of use of time – will be used in educational programs and in in-home care encounters. Grantee found that some caregivers were receptive and others were not.

Project Sustainability:

“In addition to allowing our community to provide respite care for 14 of the families on our waiting lists who were the most in need, these funds have allowed ACE to hone our skills in helping families move to other funding sources including PACE, Project C.A.R.E., Home and Community Care Block Grant and CAP. We became more familiar with the policies and procedures associated with these services and learned strategies to assist families work through barriers to accessing needed service.”

When asked by the interviewer to clarify how the grant helped staff to “hone skills,” they answered that the temporary nature of the funds caused staff to work harder to plan for alternatives after funding ended – more intentional and focused on these families. Allowed them to think about things a little differently and resulted in a little deeper relationship with caregivers.

<b>Mini-Grant # 3: CarePartners Adult Day Services</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite</b>
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			<b>Provided</b>
<p><b><u>Completed Objectives:</u></b>  “Originally the project objective was to provide overnight respite for both enrolled participants and members of the community. After the grant was awarded to us, it was confirmed that none of the monies awarded could be used directly for the pilot overnight respite program. We decided at that time to use that portion of the grant originally earmarked for overnight respite scholarships for extended evening hour scholarships instead. This provided a new service not available before.</p>	n/a	13	517
<p><b><u>Lessons Learned:</u></b>  Finding direct care staffing for overnight/evening hours was the biggest challenge, especially due to the increased expectation that there would be more activities and involvement from staff during these late hours. The grantee was also faced with the unexpected staffing of a new Henderson County adult day center at the same time. Because of the Henderson County situation, efforts that would have gone into educating our caregivers and the community were slowed. A lot of staff time had to be diverted in order to keep the only adult day center in Henderson County from closing. Now that renovations and the initial push to get things going in Hendersonville has been completed, we will begin a campaign of advertisement and education to further the use of both extended hours and overnight respite.</p> <p>“Caregivers want flexibility – this can be challenging to accommodate. Often caregivers wanted to be able to call at 5:30pm and request extended evening hours for that particular day. Sometimes we were able to provide that service, but not always.”</p> <p>“We hope to provide extended evening and/or overnight respite to some of our younger participants soon. We have some younger men and women (25-45) whose families would benefit from the respite. We have found we need to approach their respite situation a little bit differently with perhaps a "sleep-over" feel or "dance party" feel – making it more person-centered and meeting their social needs.”</p> <p>Regarding “Setting Goals to Maximize Respite Time” document: The grantee shared that it was good for some participants but most come in with some level of crisis. Helpful tool to introduce to some – others think of the tool as “naïve.” One comment was: “They don’t have time to think spiritually.” Perhaps reframe the tool to ask the person “How do I construct a life?” The tool could be more helpful after the crisis period has passed and can begin to plant a seed toward planning.</p>			
<p><b><u>Project Sustainability:</u></b>  “The biggest impact we've seen has been the seamless transition from daytime respite to evening respite to overnight respite. This part of our project worked just as we had planned. Participants were comfortable in their surroundings and with familiar staff. Caregivers were able to drop off their loved one in the morning as usual and without questions/nervousness or guilt; and not have to worry about their loved one's care for an extended period of time. Caregivers received much needed, quality respite in both planned and emergency situations.”</p> <p>What’s in place that wasn’t before? In addition to quality evening and overnight respite services at an affordable price, because of grant funding, there is also a salon in place. To date, family caregivers are enlisting help from other family members to pay for evening/overnight respite.</p>			

<b>Mini-Grant # 4: Community Adult Respite Experience, Inc.</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<p><u>Completed Objectives:</u></p> <ol style="list-style-type: none"> <li>1. Offered enriching activities for participants on Mondays and Wednesdays</li> <li>2. Recruited and trained a sufficient number of volunteers to supervise participants</li> <li>3. Offered financial assistance for participants to attend the respite program.</li> </ol>	<b>10</b>	<b>12</b>	<b>1,826</b>
<p><u>Lessons Learned:</u></p> <p>The most significant lesson learned over the past year for this grantee is to constantly seek alternative funding sources for participants. The CARE Café is still a relatively new program and respite care is a new concept in this area. A key responsibility of the Program Director is community education about respite and securing financial assistance. Since opening in 2010, the director is regularly educating the community about group respite and its differences from adult day care/adult day health.</p> <p>Regarding “Setting Goals” document: The director reports that families first see the program as a benefit to the loved one. After they got “caught up” with everything, they were “shocked” to hear about taking time for themselves as the worksheet suggested. While the director did not have any direct feedback from caregivers on whether they used time wisely because of the worksheet, she is noticing that people are beginning to use their time for fun and the sheet helped her talk to her client families about planning for their time.</p>			
<p><u>Project Sustainability:</u></p> <p>The CARE Café is the only group respite program in this area. Funds from the Lifespan Respite Project have doubled the amount of respite time available to caregivers. Scholarship funds have made it possible for caregivers to receive respite care that otherwise would not be able to afford it.</p> <p>The Program Director is actively seeking other grants in order to provide scholarships to those in need. The Family Caregiver Support Program and the NC Respite Care Coalition are currently assisting some participants with program fees. They continue to seek additional private pay clients.</p>			

<b>Mini-Grant # 5: Montgomery County Council on Aging, Inc.</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<p><u>Completed Objectives:</u></p> <ol style="list-style-type: none"> <li>1. Provided “Support Team Leadership Training to volunteer teams</li> <li>2. Created Caregiver Respite Program</li> </ol>	<b>32</b>	<b>13</b>	<b>1008</b>

**Lessons Learned:**

A Care Team Training was held January 18, 2013 in cooperation with Randolph Hospital and Project Compassion. This Care Team Training is designed to help community leaders and volunteers help caregivers organize and recruit their own support members from their community to assist them in times of need.

Caregivers in need of respite services were identified, enrolled and provided with services. Those still enrolled in the program at the ending date were transferred to a new respite program provided by the Council on Aging through its Family Caregiver Support Program resources.

“It was difficult to engage churches in Montgomery County to participate in the Care Team Training. By joining with Randolph County we had enough interest to offer the training. Through this project we were not only able to work with other agencies to identify those needing respite in our county, but were able to create a sustainable program to continue to meet their needs and the needs of future caregivers.”

Didn't use “Setting Goals to Maximize your Respite” due to early change in respite coordination function at grantee agency.

**Project Sustainability:**

“The project has been a great service to the caregivers and their care recipients and has provided much stress reduction to all involved.” Montgomery County Council on Aging Inc. has been funded in both 2012-13 and 2013-14 for Respite services under Montgomery County Family Caregiver Support Program and has been endorsed by the County Aging Planning Committee to continue as a funded program. Montgomery County Commissioners are currently reviewing a budget that would add county funds to the Respite Program.

The project confirmed the need for respite and adds impact to the discussion with county commissioners to consider adding additional FCSP funds for respite.

<b>Mini-Grant # 6: The Arc of Davidson County, Inc.</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<b><u>Completed Objectives:</u></b> <ol style="list-style-type: none"><li>1. Additional families/children had the opportunity to participate in a recreational program</li><li>2. Stress was alleviated through the knowledge that their child(ren) is being cared for in a safe, healthy environment by trained staff.</li><li>3. Families with both typically developing children and children with I/DD had the opportunity for all children to enjoy the same summer program.</li><li>4. Families in need of drop-in care had the ability to access the respite program without many of the barriers that may exist at typical summer programs.</li></ol>	<b>n/a</b>	<b>32</b>	<b>2171</b>

**Lessons Learned:**

“There were no significant problems. It is always a challenge to coordinate programs with another agency (in this case, Davidson County Parks and Recreation). However, any challenges are overshadowed by the wonderful opportunity for typically developing children to play alongside their peers with disabilities. The issue of “differences” did not arise, neither on the part of the children nor the families. When visiting camp, unless a child presented with a pervasive disability, one could not discern the “difference” among the children. Friendships developed that we hope will carry into the school year, as children see how they are more alike than different.”

Regarding the “Setting Goals” tool: The director reported that a few people sent in their completed “setting goals” document to the project director. This was not required, but the director noted that some caregivers had indicated on their form that they found that “asking the question” was helpful.

**Project Sustainability:**

Camps continue to grow! There are plans for after school and camps for the entire year. “ This grant enabled our agency to assist more families who had previously not been aware of this program, and to hire staff to fully support children who required more support. Several families brought their child to one day of respite, and were so pleased with the experience that they returned. Families with a child with a disability later enrolled the typically developing siblings as they noted the benefits of the respite experience for their child with the disability. According to the surveys completed pre-and post, as well as other surveys of staff, children, and families, families found this to be a positive experience. “

Data generated by the Lifespan Respite Grant was helpful in leveraging funds from the United Way (outcomes-focused). ARC used pre- and post- survey results on the UW application. While not an increase over last year’s support, in a tough economy, they are grateful to sustain. They expect that all of the positive feedback from last summer’s program enhanced their ability to remain at the funding level.

<b>Mini-Grant # 7: First in Families of North Carolina</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<b><u>Completed Objectives:</u></b> <ol style="list-style-type: none"> <li>1. Produced and distributed flyer</li> <li>2. Focused on outreach to aging population and caregivers of individuals with TBI</li> <li>3. Increased service provided</li> </ol>	<b>n/a</b>	<b>16</b>	<b>895</b>

**Lessons Learned:**

“Our biggest challenge was getting clients to return the completed surveys. One reason for this difficulty may be due to stress placed upon family, signaling the need for respite services.”

Regarding “Setting Goals” tool: “We found that many people did not take the time to complete the document and surveys due to time constraints and stress levels.”

**Project Sustainability:**

More community members are aware of the direct family support that FIFNC offers; and families have the opportunity to have access to our supports in the future. FIFNC was able to serve more families because of the funding this grant provided to allow direct family support to be stretched further among more individuals/families.

Respite and an aging I/DD population is a reported emerging issue. By working with Community Resource Connections on this project, providers now refer more to FIFNC. They welcome the increased collaboration to help increase their reach and the community’s awareness of their services.

<b>Mini-Grant # 8: Early Memory Loss Collaborative – Park Ridge Health</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<b><u>Completed Objectives:</u></b> <ol style="list-style-type: none"><li>1. Created 5 Memory Cafes in the Asheville area.</li><li>2. Met with couples in their home to offer new concept of restorative respite within the home.</li><li>3. Offered a conference with a new focus on dementia to educate the community (originally part of the preparation for Memory Cafes)</li></ol>	<b>44</b>	<b>100+</b>	<b>1946</b>

**Lessons Learned:**

**1. Memory Cafés:**

“Significant findings: The Memory Cafes were established in four places and each one meets monthly, with a fifth scheduled to launch in June 2013. Each café has opened to guests every month and seem to be establishing to be sustainable. Several couples move around to attend multiple cafes. Each Memory Café has invited musicians to provide live music at several of their cafes, which has been successful. Caregivers and those with a diagnosis have expressed appreciation for the opportunity to get out of their houses and enjoy the company of other guests and volunteers at the cafes.

Challenges: Getting the training content for the cafes in good balance was a challenge and time consuming. Finding the right balance in the content about what dementia is, how to deal with the fear of it, what is required of volunteers and the right people to do the training went through several revisions. The last training worked best.

It has been a challenge for the volunteers in each of the café’s to do great outreach. They need to be more intentional going forward about outreach, both within their own congregations/ organizations as well as in the larger community.

Lessons learned/learning: The grantee looks forward to having collaborative meetings between/among the Memory Café leaders and volunteers going forward to see how they might learn from one another in how to be effective hosts, do outreach, meet the needs of their guests, and be more engaging.

The ‘marketing’ and outreach for the Memory Café’s has been and will continue to be a challenge.

Biggest lessons learned is the shared humanity among all who attend the cafes, which is very gratifying to project leadership and volunteers since this was the objective from the beginning. Volunteers have commented over and over about how they have learned more about dementia by being with their guests, how they sometimes don't know which person in a couple has dementia and have to hold all assumptions, listen and use new discernment to figure it out. There has been great appreciation expressed for the opportunity to grow in understanding and compassion.

The project director shares, "We have had a number of calls from other churches with interest in hosting cafes. At this point we are encouraging them to support the existing Cafes. The exception was when we got a call from a church in Hendersonville. There was a strong call for a Memory Café in Hendersonville from members of caregiver support groups. We held a training at the First Baptist Church. They have a strong team which will produce a sustainable Memory Café for that community."

## **2. The Restorative Respite Outreach Program:**

Significant findings: This was a very interesting project, one that would be worth spending more time on in the future. Giving caregivers one-on-one attention and support in their homes to share their worries and concerns and then to talk with them about their needs and to encourage their consideration of what they might do right there in their home to restore themselves, refresh themselves in the midst of their hard work as caregivers was very engaging and seemed to have a lot of potential.

Challenges: The greatest challenge seems to be for the caregiver to hold on to the importance of the value of claiming time for themselves, to be off-task from caregiving. Once a little time opens up, the long list of "to-dos" seem to take over and the opportunity to do something fun/refreshing/relaxing takes a back seat. In some ways there is not a strong pattern of self-care for a lot of caregivers, so the practice of developing habits of self-care may seem selfish and are hard to develop.

"I met with the caregivers for two hours and in each case had a very engaging and satisfying session. With each client we made a list of what they would like to do in the follow-up visits. But, I was not in touch with them after those first sessions. If I had been in touch with each of the caregivers before their follow-up visits with the respite visits of their spouses with dementia, there might have been more success. Some followed up on the plans they made – it was about 50%... but, if they had been reminded beforehand and then encouraged the day of, they might have engaged in what they said they wanted to do each time. "

Lessons Learned: Caregivers need considerable encouragement and support to care for themselves. The project director shared, "The idea that they need restorative self-care was a new idea for EVERY client I spoke with. Once they understand that they need to do this and they need to plan it, it seemed to have appeal across the board. They probably need reminders ahead of time so that they can get the urgent "to do's" off their list so that they can actually carve out time to focus on themselves – and then have a trustworthy person to care for their loved-one with dementia so that they have the peace of mind to actually relax into focus on themselves. "

This effort required that the restorative care happen at home. Helping the caregiver think about how to use the space in and around their home – apart from their loved one - in ways that give them a break from caregiving was challenging in some cases. Some homes are very small and being in a separate area of the home "off-task" might require some creative thinking.

### **3. Conference, The Sacred Journey of Dementia**

Significant Findings: The response and evaluations for the conference were wonderfully positive – this was a successful conference. It was a conference in which those with a diagnosis had a major role and many felt “a new conversation” between those with a diagnosis and those who do not have a diagnosis was begun.

The director said, “We had almost 200 people in attendance. It was an inclusive event – those of any faith were welcome. And, we provided adult day care for those who could not attend the conference due to a progressed degree of their illness. Childcare was provided by the UU of Asheville. We tried to make it possible for all to attend who had interest.”

The project director shared that the conference planning came together with great harmony. That is in large part due to the great spirit among the women on the planning committee and the generosity of the First Baptist Church, which opened its doors and many of its resources to make the conference possible.

Challenges: The amount of time required to plan, market and execute the conference was significant. “In the end it was worth it as we were complimented on how well the conference was run. We had such a tiny budget that we paid for a lot of the costs ourselves. Without in-kind services by FBC we could never have done it. “

Lessons Learned: “As we talked about and planned this event, there was interest but a certain level of caution from a number of people who were only used to workshops and conferences that focused on the data about dementia.”

“We planned the day to invite attendees to tap into emotions. We realized after the conference that we had packed a lot into the day and will plan a shorter day next year, give more time in the breakouts for deeper sharing, spread out the program and include some lighthearted fun.”

One suggestion is to buy an audio system for the panelists and speakers – a lavalier system that does not require those on the panel to handle a microphone. It was found to be too difficult for them, is a distraction and causes them to lose focus.

“We will also work with Mountain Area Health Education Center next year (ahead of our planning process) to be able to offer CEU’s to professionals. That will increase the attendance of professionals significantly.

Regarding the “Setting Goals...” tool: The project director shared that how she used the tool. “I showed it to them, then we talked for a while about options of what they might like to do and after we talked for a while, I asked which of the ideas they thought would work best for this project. over the next two visits. I wrote them on the worksheet and I kept the sheet.

The problem was that I did not go back to the house with the person providing respite for their spouses. I talked with her about what the caregiver had planned, but am not sure if she talked with them on-site. I wish now I had coordinated with the respite provider on the schedule of her return trips so that I could have checked in with them and reminded them before her scheduled visit to encourage them to be ready for their restorative respite. I didn’t do that but I think it could be very effective to have that kind of phone-support after the initial meeting to reinforce not only the importance of their self care, but to give them permission to

claim the time. Also, with a little reminder, they might get the urgent tasks they might feel compelled to do out of the way, or scheduled for later – to clear the way for themselves to claim the time provided...to build a habit of restorative respite. I think this will take some intentional work over time...with support.”

**Project Sustainability:**

Most elements from each of the project objectives below are continuing beyond the mini-grant.

1) **Five Memory Café’s** were held at the First Baptist Church of Asheville, Unitarian Universalist Congregation of Asheville, Calvary Episcopal Church of Fletcher, Senior Resource Center of Haywood County, Waynesville, NC and the First Baptist Church of Hendersonville, NC.. 44 volunteers were trained to host these monthly events.

2) **The first conference, The Sacred Journey of Dementia**, that involved persons with a diagnosis of dementia in leadership at the conference – with strong urging from the community to hold a 2<sup>nd</sup> annual conference. Had an **attendance of approximately 200**, the majority of whom were caregivers.

3) A **new project of engaging caregivers in their own homes** in thinking through how to create restorative respite for themselves.

<b>Mini-Grant # 9: Land-of-Sky Senior Companion Program</b>	<b>Total # of Volunteers trained</b>	<b>Total # of Caregivers Served</b>	<b>Total Hours of Respite Provided</b>
<p><b><u>Completed Objectives:</u></b></p> <ol style="list-style-type: none"> <li>1) Provided at least 10 hours of respite care per week to qualified family caregivers.</li> <li>2) Created public awareness among volunteer stations regarding the Senior Companion Program.</li> <li>3) Matched senior companions with appropriate care recipients/family caregivers.</li> </ol>	<p><b>N/A Senior Companions are paid an hourly rate (\$2.65) plus mileage</b></p>	<p><b>22</b></p>	<p><b>1,753</b></p>

**Lessons Learned:**

When running a volunteer service, recruitment has got to be the best it can be. They are learning to take the time to get the right people and the right match for those they will be assisting. Someday they may use a survey tool to help match a companion with a person requesting help, but for now they ask a lot of questions and try to really listen to what the needs are for both the companion and the care recipient.

They continue to see the value in good training for their senior companions. The training must continue to change and be new and different and involve hands on skills, giving the companions tools to connect to and reach those they are assisting, and also how to practice good self-care.

It’s important to be flexible and serve where you can with what you have. During the project, new regulations from their primary funder were imposed that hampered their efforts to recruit new companions. They

adapted to this by adding more hours to the caseload of existing companions so they were able to serve new care recipients.

The “Setting Goals to Maximize Respite Time” tool was well received by family caregivers served by a senior companion. The majority of caregivers welcomed the goals worksheet/tool and was used as a discussion tool about caregiver self-help by a staff member who goes into each companion recipient’s home during a quarterly visit. They discussed the tool and it’s purpose and plan to keep using it in their interactions with family caregivers. They also are discussing making a follow-up tool to assess how well the goals worksheet is helping the caregiver to be used during the successive quarterly visits with the caregiver.

**Project Sustainability:**

One of the challenges with sustaining a program such as this is the need to constantly recruit new companions and serve appropriate care recipients. The senior companion program can only serve individuals who have been referred by a volunteer station staffed by a social worker. The project manager has worked to increase these referrals to the volunteer stations as well as doing additional education on how to make appropriate referrals. One aspect of making appropriate referrals is helping their referral sources and their community understand that senior companions are not able to provide a higher level of care than companion care unless the paid senior companion is a licensed professional. Many of their referrals are for people who are in need of some hands-on care or would have the potential to need hands-on care during a companion visit.

Even though the funding from this mini-grant concluded, the senior companion program was able to transition a majority of their new care recipients to other public funding sources, and three of them began paying privately for the companion service.

# Lifespan Respite Mini-Grant Program: Results from Caregiver Survey (Attachment B)<sup>1</sup>

## Data Collection Method

Upon registration into the Lifespan Respite Mini-Grant Program, caregivers completed a “Pre-Respite Form”. The form consisted of a demographics questionnaire and a 16-item Caregiver Burden Assessment. Scores on the 16-item form can range from 0 (no burden) – 16 (high burden). After the respite funds were used, the same caregivers also completed a “Post-Respite Form”. The post form contained the Caregiver Burden Assessment along with a 4-item satisfaction questionnaire that asked the caregivers how satisfied they were with the respite received through the program.

## Demographics

A total of 235 caregivers were provided respite paid for by the Lifespan Respite Mini-Grant Program, of those, 88 caregivers completed at least the Lifespan Respite Mini-Grant Program pre-respite form. There was a high return rate of the post-respite form, where 90% (n = 79) of the caregivers that completed the pre-respite form also completed the post-respite form. The age range of caregivers was 32 – 87 years old, with the average caregiver age of 56.61 years. The majority of caregivers were female (79%), white (72%), and married (65%). Furthermore, 63% had at least “some college” education and 53% had an annual household income greater than or equal to \$30,000. The relationship of the caregiver to the care recipient was primarily made up of a parent-child dyad, where 44% of the respondents were children caring for their parent and 22% were parents caring for their children. The care recipient age range was 4 – 103 years old, where the average age was 65.68 years.

## Outcomes

### *Program Satisfaction*

First we examined Program Satisfaction. All 100% of the caregivers who completed the post-respite survey indicated that they were at least “somewhat” satisfied with the respite services they received from the mini-grant program. Ninety-six percent of the caregivers said they were either “Very Satisfied” or “Extremely Satisfied” with the respite services. When asked if they would apply for the respite services again, all of the caregivers, except one, stated that, “Yes, they would apply again.”

For the following statement, “I used my respite to do something I enjoyed and it was time well spent”, 86% of the caregivers either “Agreed a little” or “Completely Agreed” with that statement. Finally, when asked the following question, “Did your respite provider talk with you about what you wanted to do with the respite and help with a plan?” 87% of the caregivers

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<sup>1</sup> Sarah Kennedy, PhD, Program Evaluator, DAAS, Alicia Blater, M.S., APR, Lifespan Respite Project Director, Family Caregiver Support Program consultant, DAAS. August 2013

said “Yes”. Overall, the caregivers stated that were satisfied with the respite services and they would apply for them again if available.

When examining the data, we noticed one particular “outlier”. Specifically, the one caregiver that said they would not apply for respite again also stated that they used the respite services so they could “Go to work”, rather than using the services to do something enjoyable. This same individual also stated that their provider who offered the respite did not talk with them and help them develop a plan of how to use their respite services effectively. They also were the only caregiver to “Completely Disagree” with the following statement, “I used my respite to do something I enjoyed and it was time well spent.” This begs the question that if the Service Provider spoke with this caregiver and instructed him/her on how to maximize your respite time towards something more enjoyable, rather than work, would their response have been different and more positive?

### *Caregiver Burden*

A Repeated Measures ANOVA was conducted to determine whether the changes in caregiver burden from pre- to post-respite was significant. A significant change was found where there was a 35% decrease in caregiver burden. Specifically, average burden at the pre-respite assessment was 7.02 and at the post-respite assessment it dropped to an average score of 4.53. Next we examined changes in scores from pre- to post-respite for each different type of caregiving dyad (e.g. spouse-spouse, parent-child, etc.). As can be seen in table 1, average scores for caregiver burden declined from pre- to post-respite across all caregiving types. A Repeated Measures ANOVA was run to examine whether there were significant differences in pre-post respite scores as a function of caregiving dyad. One of the caregiving types, Grandparent (CG) – Grandchild (CR), was excluded from the analysis because there was only one participant in this dyad and that participant did not complete the post-respite form, consequently there was no pre-post respite data. A second caregiver type, Friend (CG) – Friend (CR), was excluded from the analysis because only one of the caregivers completed the post-respite assessment.

Table 1  
Average Changes in Caregiver Burden by Caregiver-Care Recipient Relationship

Caregiver (CG) – Care Recipient (CR)	N	Pre-Respite Mean	Post-Respite Mean
Child (CG) – Parent (CR)	39	7.64	4.76
Parent (CG) – Child (CR)	19	4.47	2.77
Spouse (CG) – Spouse (CR)	15	8.67	5.20
Grandchild (CG) – Grandparent (CR)	5	9.00	7.00
Niece/Nephew (CG) – Aunt/Uncle (CR)	4	8.00	5.50
Sibling (CG) – Sibling (CR)	3	4.67	2.33
Friend (CG) – Friend (CR)	2	7.00	1.00*
Grandparent (CG) – Grandchild (CR)	1	0.00	-

**Note:** Scores on the 16-item form can range from 0 (no burden) – 16 (high

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burden), where a decrease in score equates to a decrease in caregiver burden

\*Only one caregiver in this dyad completed the post-respite form therefore it could not be included in the Repeated Measures ANOVA analysis

The next set of analyses examined changes in caregiver burden as a function of the caregiver-care recipient dyad. Demonstrated in Table 1, the sample size for the dyads Niece/Nephew-Aunt/Uncle, Grandchild-Grandparent, Sibling-Sibling, and Friend-Friend were relatively small compared to the other three dyad groups, consequently we collapsed these dyads into one group labeled "Other". The "Other" group (n = 13) had an average caregiver burden score of 7.00 at pre-respite and average score of 4.83 at post-respite. The subsequent analyses compared pre-post respite scores for the following four groups: Child-Parent, Parent-Child, Spouse-Spouse, and Other. The only significant difference between the four dyad groups was that the Parent (CG) – Child (CR) dyad has significantly lower pre- and post-respite burden scores.

The final set of analyses examined whether changes in scores on the Caregiver Burden Assessment were significantly different as a function of the self-report data on satisfaction of the respite service. A Repeated Measures ANOVA was conducted to examine whether or not the provider discussing respite planning with the caregiver had an effect on the caregiver burden scores. An effect was found such that average caregiver burden scores significantly declined from pre- to post-respite only for those caregivers that talked to their provider about respite planning. Burden scores did decline for those caregivers that did not receive consultation from their provider on respite planning, but the decline was not significant. Specifically, on average, those that received counseling had an average decline in burden of 3.10, while those that did not receive counseling had an average decline of only 0.60 on the Caregiver Burden Scale.

Given that there was not a comparison group in the study, we cannot say that the significant decrease in caregiver burden was a direct result of the respite program, but we can hypothesize that the respite service provided with these Lifespan Respite funds along with the "Consultation" has a positive effect on the caregiver.



## North Carolina Lifespan Respite Mini-Grantee **QUARTERLY REPORT**

**REPORTING PERIOD:** \_\_ Apr-Jun, 2012 \_\_ Jul-Sep, 2012 \_\_ Oct-Dec, 2012

**Grantee:** \_\_\_\_\_

**Date of Report:** \_\_\_\_\_

Individual(s) Completing the Report: \_\_\_\_\_

### **PERSONS SERVED AND UNITS OF SERVICE PROVIDED WITH THESE GRANT FUNDS:**

1. Total number of family caregivers served with these grant funds during reporting period: \_\_\_\_\_
2. Total number of respite hours provided to family caregivers with grant funds during reporting period: \_\_\_\_\_  
(If you are an adult day or volunteer program, please convert to hourly units)
3. Total number of **new** caregivers served with these grant funds during reporting period: \_\_\_\_\_
4. Total number of caregivers receiving emergency respite during reporting period: \_\_\_\_\_
5. Total number of volunteers trained during reporting period: \_\_\_\_\_
6. Total number of support groups held during reporting period: \_\_\_\_\_

### **DEMOGRAPHIC INFORMATION:**

Total numbers of caregivers serving the following populations with grant funds:

*(The total numbers should equal your total number above from question #1)*

- Adults 60+: \_\_\_\_\_
- Adults with disabilities 18 – 59: \_\_\_\_\_
- Children with special needs less than 18 years old : \_\_\_\_\_
- Other: Please describe: \_\_\_\_\_

Numbers of caregivers served that meet the following characteristics:

*(The total numbers here may or may not equal the total number from question #1)*

- Those with incomes slightly above NC’s Medicaid threshold, thereby disallowing them for a variety of publicly-funded resources: \_\_\_\_\_
- Those caring for someone with a traumatic brain injury or sudden disabling condition: \_\_\_\_\_
- Those whose family member requiring care is approved but on a waiting list for CAP services: \_\_\_\_\_
- Those who live in counties with few or no respite providers: \_\_\_\_\_

**PROJECT NARRATIVE REPORT:**

Please describe major activities and/or events related to your grant objectives:

Please describe significant problems, challenges, or lessons learned.

Please describe the ways in which this grant project is impacting family caregivers and care recipients. How do these funds enable you to provide “Just One More” new or enhanced service in your community(ies)?

Please comment on any other aspect of this grant project that you want the funder to know about:

Please provide comments or feedback about the restorative respite tool and your sharing this tool with family caregivers.



## **Setting Goals to Maximize Your Respite Time**

On this sheet of paper, please write down one to three specific goals of what you would like to accomplish during your respite time this week/month. Your goals can be anything (e.g., sleeping, cleaning, going to lunch with a friend), but they must be attainable during the respite time that is available to you. We recommend that you choose activities that:

- you have always enjoyed doing;
- you did before you became a caregiver but may not have been doing lately;
- have religious or spiritual meaning to you;
- may improve satisfaction with caregiving;
- may reduce the stress you might feel from caregiving;
- may increase your respite time;
- encourage you to use your respite more regularly.

### **Goals:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

At the end of the week/month, ask yourself whether you accomplished each of the goals and also whether you are satisfied with your effort at accomplishing each goal. Be honest with yourself, and use this information to revise your goals for the following week's/month's respite time. Caregivers who use their respite time to do what they intended to do may feel less burden and more satisfaction with their caregiving role.

### **Personal Reflections on Your Goals (notes):**

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