



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 2nd 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