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2010 Innovations Awards Application

Deadline: March 1, 2010

ID # (assigned by CSG): **10-E-11NH**

Please provide the following information, adding space as necessary:

State: New Hampshire

Program Category (applicant): Health and Human Services – Aging

1. Program Name: Transitions in Caregiving
2. Administering Agency: New Hampshire Department of Health and Human Services, Bureau of Elderly and Adult Services
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9. Brief Description of Program:

Transitions in Caregiving is New Hampshire's program created from funding provided by the Administration on Aging through its Community Living Grants Program. Transitions in Caregiving addresses the needs of caregivers who are caring at home for an individual over the age of 60.

10. How long has the Program been operational?

The Program has been operating since 2007, beginning with two county pilot sites, expanded to additional counties in 2008, and will be operating statewide as of July, 2010.

11. Why was the Program created?

The Program was created to change and more effectively deliver services to family caregivers. Prior to 2007, NH's Family Caregiver Support Program was a centralized state-controlled model. Paper applications for respite funds were filled out locally but there was no mechanism for a comprehensive assessment of caregiver needs or ability to assist caregivers in long term planning.

12. Describe the specific activities of the Program:

The major objective of the Transitions in Caregiving Program is to shift the locus of control of the Older Americans Act, Title III-E caregiver support funds from a centralized state-controlled, provider driven model to a consumer-directed, locally managed model at the Aging and Disability Resource Centers (ADRCs) known as the ServiceLink Resource Centers (SLRCs) in New Hampshire. Another major objective is to assess whether intensive supports provided at the local level to caregivers can help them to sustain caregiving for longer periods of time. An additional objective is to enhance the ServiceLink Resource Center's ability to act as the single point of entry for family caregivers. The project was initiated in 2007 in two rural SLRC sites, Monadnock Region and Grafton County and will be expanded statewide as of July 2010.

In addition to the statewide ServiceLink Resource Center network, BEAS' other key partner in the development and implementation of the program has been the University of New Hampshire Institute on Disability (UNH IOD).

Each ServiceLink site has a dedicated Caregiver Specialist position. The Caregiver Specialist meets with the caregiver locally on site or in the caregiver's home to help identify his or her needs and develop support plans to alleviate their caregiver burden and challenges. The Specialist conducts a comprehensive assessment. The assessment was developed specifically for the program by the UNH IOD and formally approved for use as part of a research protocol by the University of New Hampshire's Institutional Review Board, allows us to obtain information that will evaluate the program's effectiveness in helping to support caregivers in meeting their goal of avoiding nursing home placement for the care recipient and subsequently avoiding spend down to Medicaid.

The assessment process can take one to three hours. Sometimes it is completed in one sitting; sometimes it takes a number of meetings. Progression through the assessment process allows the caregiver to begin to see the emotional and physical burden that comes with caregiving as the process evolves. The questions move from simple demographic inquiries about name, address, emergency contact to employment status information, impact on employment, out of pocket costs related to supporting the care recipient, to increasingly thought-provoking questions such as, "What qualities and strengths do you bring your caregiving role?" and "How are other family members involved?" and then into more formal clinical assessment tools.

Overwhelmingly, caregivers appreciate the assessment process itself and some have articulated that it was the first time they felt that someone was actually listening to them and focused on their needs rather than their care recipient's needs. Others have stated that the best part of the support is having someone to talk to regarding their situation and knowing that there is someone they can call to talk about their own needs.

The comprehensive assessment with the caregiver guides the development of a support plan. From the support plan the caregiver and Caregiver Specialist may develop a personalized budget for services of OAA Title III E and NH State supported respite and supplemental funds. Once the budget is developed, the Caregiver Specialist is authorized to approve the budget. Funds can be accessed immediately and the caregiver manages their budget through an Agency with Choice fiscal management service with ongoing support from the Caregiver Specialist.

While ServiceLink Caregiver Specialists support all caregivers, the target population for Transitions in Caregiving is caregivers who are at risk of spend down to nursing home placement. This is a unique approach, as the assessment tools are not targeted at screening people for financial or medical eligibility for federal or state funded programs. Financial and medical questions are included but responses are not required. The purpose for asking the questions is to help the Caregiver Specialist and caregiver to sort out more options and not to screen someone in or out of a program.

In order to facilitate comprehensive supports for family caregivers, trainings have been developed that aid the ServiceLink sites in supporting caregivers and include: a curriculum in consumer-directed services, planning and facilitation skills, administering the assessment tool, class leader training in the

evidence-based Powerful Tools for Caregivers, consumer-directed budgets and financial management services. An initial assessment instrument, a six-month follow up assessment and a follow up survey have been developed along with a financial management services packet. A Participant Guide has also been developed for family caregivers to explain the program and the meaning of consumer directed services.

Surveys of family caregivers who have taken part in the program have spoken loudly of the value of the enhanced level of support they have received and their ability to maintain the level of care they provide while taking care of themselves. One unintended benefit of the program is that by virtue of the support that they have received, family caregivers have actually expanded their circles of support. Isolated caregivers have become more comfortable advocating for themselves and asking for and receiving help.

13. Why is this Program a new and creative approach or method?

The Transitions in Caregiving Program has devolved a centralized, state-controlled part of the long-term care system into a community-based, person-centered, more accessible model. Two unique and outstanding aspects of this program: 1) It has developed an exceptional evidence-based, caregiver-centered assessment tool, which is providing important information about outcomes; 2) The target population for this program is caregivers caring for care recipients who are not eligible for Medicaid. The program has developed a successful cash and counseling model for those at risk of spend-down to nursing home placement.

14. What were the program's start-up costs? (Provide details about specific purchases for this program, staffing needs and other financial expenditures, as well as existing materials, technology and staff already in place).

The Transitions in Caregiving Program has built upon the existing infrastructure of the ServiceLink network as the single point of entry for services. All of the ten sites have a Caregiver Specialist on staff to interact with family caregivers caring for older adults. However, the skills and tools they had to work with previously were extremely limited. The primary focus of the program was to be able to provide a more comprehensive level of support to the family caregivers they serve. The development of a comprehensive assessment tool, person-centered planning, a flexible, consumer-directed budget for respite and other services and skills training were seen as critical interventions in supporting family caregivers. In particular, those that care for older adults at risk of nursing home placement and spend down to Medicaid. In addition, it was essential to provide additional skills training to the Caregiver Specialists giving them the tools they needed.

Initially, the project was piloted with two ServiceLink sites in the first year and was expanded to five sites the second year. Each ServiceLink Aging and Disability Resource Center participating in the project was given an annual budget of \$40,000 in addition to their contracted III-E funds (varied by site from \$27,000 to \$37,000 per year) to help build their operations and either boost the hours of their current Caregiver Specialist or hire on an additional part time individual. Additionally, the two initial pilot sites subsequently received a grant from the Weinberg Foundation, a national private foundation to expand the project even further into two neighboring counties.

Investment in staff trainings included \$650 per person (two from each site) to attend the Master's level Sociology course at the University of New Hampshire, Methods, Models and Tools, which focuses on person centered planning and facilitation. Over \$20,000 was invested to bring in two Master Trainers to teach class leaders the evidence-based curriculum Powerful Tools for Caregivers. In the first year of the project 19 individuals were trained in this curriculum. In the second year of the project another \$20,000 was spent to train another 20 individuals. As a result of these class leader trainings and the local trainings conducted in the communities three individuals in New Hampshire are now Master Trainers in this

curriculum and there is no longer a need to bring in Master Trainers from other states, part of the project's long range sustainability plan.

The Financial Management Services Agency received a start up amount of \$40,000 and thereafter received a 12% fiscal fee for their services. This enabled them to purchase laptops and portable copiers for the regional agents who do the face-to-face visits and paperwork for "family managed employees" hired under a co-employer relationship with the family caregiver and the agency.

The Bureau of Elderly and Adult Services has contracted with the University of New Hampshire, Institute on Disability (IOD) to provide the bulk of the project facilitation, and coordinate the events and trainings. Their contract was for \$231,000 for the first 18 months, and \$275,000 for the second 18 months of the project anticipated to end on September 30, 2010. The contract with the IOD includes the costs of the Methods, Models and Tools, Powerful Tools for Caregivers and other trainings conducted under the project.

15. What are the program's annual operational costs?

The program started in 2007 at an annual cost of \$333,333 in federal funds and \$111,111 in in-kind match. The program expansion in 2009 was increased to \$432,931 with a \$144,514 per year in-kind match.

16. How is the program funded?

The program is funded by a combination of Administration on Aging Community Living Program grant funds, Title III-E Older Americans Act funds and a portion of state general funded Alzheimer's Disease and Related Dementias Program service dollars.

17. Did the Program require the passage of legislation, executive order or regulations?

No, no legislative or regulatory changes were required.

18. What equipment, technology and software are used to operate and administer this program?

The program uses the existing Refer 7 database at the ServiceLink Aging and Disability Resource centers use. This database will be modified to include additional data of collection at the local level required of the Community Living Program and Title III-E. At present some of this data is collected manually and our goal is to automate the process by modifying existing technology.

19. To the best of your knowledge, did the Program originate in this state?

Yes, to our knowledge the program originated in this state and was conceptualized and developed by:

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20. Are you aware of similar programs in other states?

To our knowledge, Connecticut is the only other state that is developing a Community Living Program that is focused on family caregivers.

21. Has the program been fully implemented?

As of this writing seven of the ten ServiceLink sites in New Hampshire are participating in the program and will be expanded to the remaining three and operating statewide by July 2010.

22. Briefly evaluate (pro and con) the Program's effectiveness in addressing the defined problems or issues.

The details of the Program's effectiveness have been described above, and examples are as follows:

One woman who has been caring for her husband with Alzheimer's disease for the last 2 years wanted to go out to her regular book group two nights a week. She was unable to leave her husband alone at all. With help from Transitions in Caregiving she was able to identify a neighbor that she could pay to come in and care for her husband. As a result of this experience, she became empowered enough to realize that it was okay to ask her two grown children who lived nearby to take turns coming and sitting with their Dad -- something that she had been too proud and saddened to do before. This seemingly small thing has made a dramatic difference in not only her emotional but also her physical health as evidenced by decreased blood pressure. Additionally, this caregiver effectively used the combination of ServiceLink Caregiver Specialist support and a budget for respite services to provide enough relief to develop a plan of informal supports that allows her to avoid using her remaining retirement savings to private pay for help and thus avoid spending down to Medicaid.

Through Transitions in Caregiving we have been able to really look at respite from the caregiver's point of view. Ideally when the Caregiver and ServiceLink Caregiver Specialist are creating a support plan, they are developing a true picture of what a caregiver needs to feel healthy and able to better continue in their caregiving role. Respite for a woman with a husband with Parkinson's disease turned out to be a Kindle program because he could read without assistance. She stated: "I need a break from holding the paper and book and turning the pages so my husband can read for four hours a day because he has Parkinson's disease and he can't do it and it's his only source of enjoyment anymore". In order to pay for someone to sit with her husband to hold a paper and turn pages for just two hours/week, per year would cost \$2,300 at a standard companion care rate in the region. To have someone come in two hours a day, five days a week per year would cost the couple over \$11,500. The cost of the Kindle was \$495. For less than \$500, this family caregiver was afforded more respite than she could have wished for and her husband won some of his independence back.

23. How has the program grown and or/changed since its inception?

Transitions in Caregiving has implemented the systems change goals inherent in the AoA's vision for the ADRC/CLP following ways: The AoA envisions that the ADRC/CLP programs will create a person-centered, community-based environment that promotes independence and dignity for individuals. 1) Transitions in Caregiving has provided staff with intensive training from UNH IOD on person centered planning. 2) Care plans and budgeting are developed and managed by the caregiver with support from a Caregiver Specialist at the local level. 3) Caregiver grant funding that previously was being held aside but unspent by caregivers is now more creatively and effectively utilized, because the Caregiver Resource Specialist is providing ongoing contact and support to the caregiver and ensuring that the support plan is working. 4) Caregivers are able to control and expend their funds with the assistance of a financial management agency under the agency with choice model.

24. What limitations or obstacles might other states expect to encounter if they attempt to adopt this program?

The obstacle originally encountered was securing the "buy in" at all levels for a consumer directed option. Concerns were expressed that it could induce fraud and abuse of public funds and that it would

add additional layers that would cost more money. However, what is being demonstrated is that family caregivers are effective in making good choices with their service dollars and they are able to identify how to stretch them further. The customer service component of the Financial Management Services has enabled family caregivers in the project to get accurate and timely information on their budgets and expenditures, further empowering them in managing their own services.