

2008 CSG Innovations Awards Program
Application

ID# (assigned by CSG): 08-S-43WV

State: West Virginia

Assign Program Category: Health and Human Services: Aging

1. Program Name(s): FAIR (Family Alzheimer's In-Home Respite) and Lighthouse
2. Administering Agency: West Virginia Bureau of Senior Services
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9. Please provide a two-sentence description of the programs.

In an effort to meet the underserved respite needs of Alzheimer's caregivers as well as the in-home service needs of individuals who do not qualify for Medicaid, the West Virginia Bureau of Senior Services created the FAIR and Lighthouse programs. The programs complement each other and are presented together due to their unique funding source (table games licensing fees) which has created/expanded both programs at no cost to state taxpayers, and their focus on seniors requiring support to remain in their homes and communities.

10. How long has this program been operational (month and year)?

FAIR was created in July 2006 and served its first clients in August of that year. Lighthouse was created in April 2007 with the first participants qualifying in July 2007.

11. Why was this program created? What problem(s) or issue(s) was it designed to address?

Individuals with Alzheimer's disease are often cared for by their family members. These caregivers often neglect their own mental, physical, and emotional health. According to the National Family Caregivers Association, elderly caregivers with a history of chronic illness, who are experiencing caregiver stress, are 63% more likely to die in any given period than their non-caregiving peers. Those providing at least 36 hours of care per week are more likely to suffer from depression, and the stress of caring for persons with dementia may impact a person's immune system for up to three years after caregiving ends. Through the FAIR (Family Alzheimer's In-Home Respite) Program, caregivers are provided up to 16 hours of respite weekly.

The Lighthouse Program was created to meet unmet needs of seniors by providing in-home assistance to maintain independence. The participants meet medical requirements but are not eligible for Medicaid. This program acts as a stopgap for people who do not qualify for traditional programs and prolongs their ability to remain in their own homes and communities.

Both the FAIR and Lighthouse programs were created to meet the needs of unserved and underserved populations. They were also designed to reduce assisted living and nursing home placements through respite and/or in-home services, adding to the state's long-term care rebalancing efforts.

12. Describe the specific activities and operations of the program in chronological order.

The FAIR program concept began in 2002 with the West Virginia Bureau of Senior Services being awarded two successive three-year Administration on Aging Alzheimer's Disease Demonstration Grants, which provided in-home respite care to caregivers of individuals with Alzheimer's disease or a related dementia. Respite was originally provided in eight of our 55 counties through county aging providers, and eventually the number of counties served was increased to 16. This

original grant established the need for respite care and was the impetus for the statewide FAIR Program.

In March 2006, the West Virginia Legislature appropriated \$800,000 of Lottery proceeds to expand respite statewide. In June of that year, a consultant was hired one day per week to help with the start-up. Guidelines were developed and meetings were held with providers to educate them regarding the new program. In August 2006, the first caregivers began receiving respite through FAIR. By September, the need for a full-time staff position was recognized, and in October, the part time consultant became the full time Director of Alzheimer's Programs.

In 2007, the West Virginia Legislature approved increased funding for FAIR to \$1,795,000 for FY08. FAIR is available in all 55 counties. Technical assistance is ongoing, and annual reviews began in January 2008, focusing on the quality of care in the program.

The Lighthouse Program began in March 2007. A written policy and procedures manual, training materials, and a brochure were developed by the Bureau of Senior Services. County aging directors received information on Lighthouse as well as training for administration of the program at a statewide meeting held in June 2007. Training was held for county aging provider employees working on the Lighthouse Program in four regional meetings during July and August 2007. Media campaigns to enlist participants started in the summer of 2007. On-site peer review monitoring began in January 2008 and technical assistance is available to providers on a continual basis. The demand for service has continually risen as word of the program spreads.

Both FAIR and Lighthouse are being marketed through the local county aging programs. A statewide television campaign (financed by the West Virginia Lottery) has also been implemented. In addition, published information on both programs is available on the Bureau of Senior Services website, www.wvseniorservices.gov.

13. Why is the program a new and creative approach or method?

The West Virginia Legislature passed a table games referendum bill. West Virginia Governor Joe Manchin supported such legislation, provided some dollars generated were set aside for in-home care services. All

licensing fees (\$1,500,000 first year and \$2,500,000 year two and every year after) were dedicated to the Bureau of Senior Services for in-home services. In June 2007, voters in two counties passed the referendum allowing table games, voters in one county defeated the proposal, and the fourth county had an election delay, passing the referendum in August, although the final vote count did not occur until September 2007. The Bureau of Senior Services has received \$3,000,000 through two paid licensing fees. The third racetrack, with a passed referendum, delayed requesting a license due to late start-up, but did make a \$1,000,000 donation to the Bureau for the provision of in-home services. The dollars for FY09 will rise from \$3,000,000 to \$6,500,000 and by FY10 the amount will be \$7,500,000, and at that time the remaining racetrack will hold a second referendum to seek passage. If successful, FY10 could see \$9,000,000, and then by FY11 \$10,000,000 would be an annual payment for in-home services for seniors.

Both programs are being marketed through the local county aging programs. A statewide television campaign (financed by the West Virginia Lottery) has been implemented. Published information on the Bureau's web site, www.wvseniorservices.gov, is available. This is especially beneficial to family members living away from their senior relatives requesting information on programs and/or available services.

While providing respite and in-home services are not new ideas, the funding mechanism is a creative approach with no cost to the state's taxpayers. In addition, both programs utilize a sliding fee scale based on the income of the care recipient, with proceeds incorporated back into the FAIR and Lighthouse programs.

14. What are the state's startup 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 Lighthouse Program incorporated existing Bureau staff for direction and oversight. There was no additional administrative cost for manual development, brochure development, and data collection, as it was all handled by staff at the Bureau of Senior Services. There was a cost

of \$2,000 involved for printing of brochures. Minimal cost was accrued to complete the training sessions for providers. One new laptop computer was purchased for on-site monitoring reviews.

For the FAIR program, the Bureau paid the WV Chapter of the Alzheimer's Association \$1,000 to provide two one-day dementia care train-the-trainer sessions in 2006. There were also some additional costs for participant workbooks and instructor's manuals for each trainer to use in his/her county. Training is now conducted by the Bureau's Director of Alzheimer's Programs. A brochure has been developed and printed in-house, and data collection is also handled in-house. Total startup costs were \$9,000. Originally a consultant was hired one day per week, beginning in June 2006, to assist with the start up of FAIR, and in October of that year the full time position was created.

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

Annual operating costs are \$173,470, which includes three full time staff positions, travel, and related office expenses.

16. How is the program funded?

The programs are funded through the table games licensing fees. Year one fees are \$1,500,000 per track; year two and every year afterward the fees are \$2,500,000 per track. Two tracks have paid year one fees; one track will pay their fees July 1, 2008; and one track will hold a vote in 2009 (the referendum initially failed in 2007). Additional funding is through our annual budget. The Bureau of Senior Services is totally funded through Lottery proceeds; no state tax dollars are used to provide any senior program through the Bureau.

17. Did this program require the passage of legislation, executive order or regulations? If yes, please indicate the citation number.

Yes. §29-22-18

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

Information for both programs is published on the Bureau's web site, www.wvseniorservices.gov. Data collection is accomplished through the Bureau's Client Tracking Data System, which is utilized by all programs operating under the auspices of the Bureau. The software utilized is Aging F/A/C/T/S (Family and Child Tracking System), which has been upgraded by in-house staff to meet the reporting needs of these programs at no additional cost to the Bureau.

19. To the best of your knowledge, did this program originate in your state? If yes, please indicate the innovator's name, present address, telephone number and e-mail address.

To the best of our knowledge there are no other programs like the Lighthouse Program and the funding mechanism for both programs originated in West Virginia. While several states use lottery proceeds to fund senior programs, we are not aware of any other states that fund direct services to seniors through table games licensing fees. The innovation for both programs was a collaborative effort by several staff members of the West Virginia Bureau of Senior Services. The contact person is Dr. Sandra Vanin, Commissioner, West Virginia Bureau of Senior Services, 1900 Kanawha Blvd., E., Charleston, WV, 25305. She can be reached at 304-558-3317 or svanin@wvseniorservices.gov.

20. Are you aware of similar programs in other states? If yes, which ones and how does this program differ?

Research has shown that though there are in-home care programs in other states, there are none that are either operated or funded in the same manner as the Lighthouse Program. There are in-home respite programs for caregivers of individuals with Alzheimer's disease in a number of other states, including Ohio, Pennsylvania, Florida, Maine, New Hampshire, New York, New Jersey, North Carolina, and Wisconsin, but the difference is in the funding mechanism. Lighthouse and FAIR programs use table games licensing fees, which are a steady income stream regardless of casino revenue.

21. Has this program been fully implemented? If NO, what actions remain to be taken?

Both programs are currently fully implemented and exceeding expectations regarding numbers served. With the start of FY09, an additional \$2,500,000 will be added, based on the increase at year two of the licensing fees and the third track paying first year fees. The new dollars will be used to provide additional hours of service throughout the state and to eliminate waiting lists created by the high demand for the programs in their initial year.

22. Briefly evaluate (pro and con) the program's effectiveness in addressing the defined problems(s) or issue(s). Provide tangible examples.

The most significant benefits relating to these programs is the ability to reduce the amount of time someone may need to live in either an assisted living facility or nursing home. It also allows services to seniors who fall outside the parameters of other federal/state funded in-home care programs.

The great need for personal care for seniors outside the parameters of other federal/state funded programs was recognized by our staff working with the Medicaid in-home care programs. Lighthouse is meeting and exceeding this need as the following examples show:

- Monroe County: A senior was discharged from rehabilitation care (after a below-the-knee amputation on one limb and the amputation of two toes on the other) to home in August 2007. In October 2007, she saw an advertisement for Lighthouse in her local paper and placed the call that probably saved her life. When the nurse from the local county aging provider arrived at her home, she found that this lady had not had any of her medications (including insulin) since her discharge, and had already formed new ulcers on her remaining foot. The lady was referred for appropriate services, received immediate in-home care, and arrangements were made with local agencies and her physician's office to obtain her medications.

- Nicholas County: The wife of a gentleman with terminal brain cancer found the number for Lighthouse services through a television ad and called the Bureau office. She had been caring for her loved one alone for over two years and he had become a total care individual. The couple had long-term care insurance, but there were no providers in her area. Her call to Hospice services was refused because he was still being treated for his cancer. The nurse from the local county aging program arranged for immediate in-home care to begin, worked with the local Hospice to have services started and gave them both some assistance in his last weeks of life.

There are more than 42,000 individuals with Alzheimer's disease in West Virginia, with more than 70% of them living at home. Nearly 30,000 of those individuals may have sufficient informal supports or the financial resources to pay for private care. The remaining families struggle to meet the needs of their loved ones and, at the same time, continue to live their own lives as well. FAIR is one piece of the puzzle to help meet those needs, as the following indicate:

- Calhoun County: "The caregiver I work for doesn't get out, because she can't leave her family member with Alzheimer's. She used to take him with her to the store and lock him in the car."
- Grant County: One client has to work and says she doesn't know what she would do without FAIR. She can see a difference in her mother's attitude. Her mother looks forward to the worker coming.
- Pendleton County: FAIR has identified new families that they haven't served before. They feel the service is invaluable and they need to be able to serve more families. "So many have no one to help. We try to serve the neediest."

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

The Lighthouse Program has rapidly increased since its beginning on July 1, 2007. At the end of the first six months of the program, more than 1,500 seniors had been served. Monitoring is currently being done to assess the need for any changes in policy in the future.

Three changes were instituted in the FAIR Program during its first year of operation. First, the hours of respite a family could receive per week were increased from eight to 16. Families receiving other services through their county aging providers were also in need of respite care services and the policy was changed to allow families to receive FAIR in addition to other aging provider services. The third change was made in this current fiscal year. Originally, the FAIR sliding fee policy was based on household income and is now based on the individual income of the care receiver. The biggest change has been in the number of people served through these programs. In December 2006, the program served 85 families statewide but with additional funding and increased awareness of the program, 273 families were served in the month of December 2007.

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

Obstacle: Challenges from outside the senior provider network regarding the creation of another in-home service program.

Response: These programs serve individuals not covered by Medicaid and often not able to pay for private care. These programs are designed to meet the needs of seniors with no affordable in-home care available.

Obstacle: Program costs and effect on taxpayer dollars.

Response: Through the passage of table games legislation and funding through the Lottery Commission, these programs are provided at no cost to state taxpayers.

Obstacle: Legislative control of the usage of the dollars generated.

Response: Through the creation of a new line item in the Bureau of Senior Services budget, the dollars directive was clearly defined.

Obstacle: Finding both quality and quantity of in-home caregivers to meet the needs of both programs.

Response: Increased funding to include a minimum hourly rate of pay and if possible health care benefits. Currently, in collaboration with community and technical schools, the Bureau is working to develop a curriculum for certification of professional in-home caregivers, giving the position additional credibility and providing a framework for advancement through a career ladder.

The largest obstacle to FAIR and Lighthouse appears to be that the need is exceeding the dollars available. Despite the increased funding, many counties have waiting lists for respite and personal care services. As word of the success of FAIR and Lighthouse spreads, and as our state population ages (27,000 baby boomers each year), the need and demand for services continues to grow. The challenge is to continue to serve individuals with the resources available.