

APPLICATION FORM

All applications must include the following information. Separate applications must be submitted for each eligible program. **Deadline: June 3, 2019.** Please include this application form with electronic entry. If you do not receive an email confirming receipt of your entry within 3 days of submission, please contact <u>Gage Harter</u>.

PROGRAM INFORMATION

County: County of Henrico
program Title: Life Enrichment for those Aging with Developmental Disabilities
Program Category: Health and Human Services

CONTACT INFORMATION

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Program Overview

Since 1985, the Life Enrichment program (LEP) has served individuals with intellectual disabilities who have high personal care needs and who were interested in learning and experiencing their community. As the individuals aged and their needs changed, it became clear that the program needed to change too. Since 2016, the Life Enrichment Program has made a commitment to support individuals to age in place. The program focuses on providing person centered services for individuals who are aging with Intellectual Disabilities accommodating the physiological and psychological changes that occur in these individuals. Many individuals with Down Syndrome experience dementia symptoms starting between ages 40 - 50 years. The program focus was changed to allow these individuals to attend with their friends as long as they are physically able and to assist with their more intensive need for activities focused on maintaining skills and more intensive personal assistance.

Problem/Challenge/Situation Faced by Locality

The average life expectancy for people with a developmental disability was 22 years in 1931, compared to 62 years for the general population. Now, average life expectancy is 70 years for most people with developmental disabilities, quickly approaching that of the general population. As these individuals have aged, many begin demonstrating behavior that is seen with dementia or Alzheimer's as early as age 40-50. Recent studies have shown that as many as 90% of individuals diagnosed with Down's syndrome (one type of developmental disability) will experience Alzheimer's-like symptoms. Programs for individuals with developmental disabilities are often large, noisy and very "busy" with activities ranging from work to sports to community. Individuals began to indicate their dislike of noise and were often unable to manage what had previously been routine for them. In the past, individuals would choose to leave a familiar setting due to their inability to be active, often staying at home and declining rapidly. As

more individuals expressed the need for retirement services, our agency began to change the focus of the program. It was determined that individuals who could stay where they are familiar, allows them additional support with people they know and decreases the impact of change and the speed of their decline.

Our philosophy for working with these individuals is to provide services until they are no longer able to benefit from the supports provided, while recognizing that engagement in activities leads to longer lives. This is commonly called helping a person "age in place". The number of individuals we serve aging into this group went from just a few to now almost 20 individuals. The focus of one program changed and the ideas were adopted within other parts of the programs to assist all aging individuals.

How Program Fulfilled Awards Criteria

The program is innovative in that we did not reinvent the wheel, however, we did identify ways to change the services already provided to better meets the needs of the individuals we serve. Many traditional day programs simply move people out of their programs when the needs get too intrusive or they do not meet all of their needs. The LEP Aging program actually changed our environment, our activities and our staff knowledge without changing the basic familiar place and people that interact with these individuals.

The program partnered initially with the local Alzheimers Association and continues to utilize their resources. We coordinate with the Area Planning and Services Committee on Aging and Disability to ensure we are trained and current on the most innovative practices available. We encourage partnership with each individual's family and support system such as their group home provider, to ensure that we are all working together and using similar techniques with the individual. This allows the individual to feel more comfortable and remain familiar with what is expected in all of the places they associate and where they live.

This model is easily replicated and can be adopted by other providers or localities.

How Program Was Carried Out

Our current staffing is 3 full-time training specialists, 2 full-time training assistants and 2 parttime training assistants in order to maintain no more than a 3 to 1 client to staff ratio. Activities occur with small groups, normally 3 to 5 individuals or one-on-one and at times, 2 staff with one client. Our current capacity is 15 individuals.

Staff partnered with the local Alzheimer's Association to provide training for staff throughout the region supporting individuals with Intellectual Disabilities as they age. Training included symptoms and triggers, behavioral concerns, providing routines and structures, environmental guidelines and providing care. Each staff member completed at least one full day of training and receive refresher training annually. Based on the training, the environment in LEP has been designed to support these individuals to include lighting, music, sound control, and encouraging environmental efforts. The Program also provides comfortable chairs and extra staffing to ensure health and safety. Individualized care is provided based on where a person is in their dementia journey.

Staff continuously finds creative activities to encourage skill maintenance and a stimulating environment: music activities, reminiscence activities including youthful tasks such as tossing paper air planes, playing ball toss, and during a snowy day, playing bean bag toss or having a snowball fight. Staff is very flexible and dedicated to meeting each person where

they are in the moment. This includes keeping in contact with care givers and family members to help plan the best and most efficient way to help a person through the progression of their disease, including accommodating a shortened schedule when it becomes apparent that a full day is too taxing for individuals who may become confused when tired. Individuals are supported to maintain their connection to their community through outings that invoke a sense of joy and reminiscence (going out to eat with friends, buying items).

Individuals who were already in the program began to show signs of engagement. We offered others the opportunity to participate and over the dedicated course of two years, have developed the current situations and activities. Barriers are overcome such as providing red plates to encourage eating, assisting with getting individuals on and off of vans when they feel unsure, being creative about where individuals go in the community to accommodate visual processing issues. Program activities in the center may include work (generally for short periods of time), crafts, exercise, skill building such as word matching and name recognition, problem solving skills such as following more than one step directions and peer recognition are often the focus of games played. Activities involving music are often used to engage individuals in their surroundings. Music and videos are often used as a means of reminiscing and maintaining understanding of the current day. Community activities may be similar to those in other programs but are generally more individualized and of short duration -under 1 hour, and include leisure activities, completion of personal errands, participation in local events, and exposure to favored community activities. For some, volunteering with local organizations has also been found to be helpful.

Financing and Staffing

Since we took an existing program and changed the focus, there was no start up costs or outstanding capital costs. The costs of the program are demonstrated below. There may be additional costs depending on the needs of the program. For example, the need for a Hoyer lift to assist changing an individual and allowing them to be out of their wheelchair for 45 minutes each day. Hoyer lifts costs between \$3,000 and \$4,500, depending on the style. We also have a changing table which, if purchased new, could cost between \$2,000 and \$3,000.

For intentional programming, we have included a budget for client activities which allows us to pay for expenses incurred when joining community activities. These activities could include admission fees to museum exhibits, coffee and donuts when visiting coffee shops, purchases at thrift stores or collectable shops or other community activities of choice. Generally individual expenses are kept under \$10.00 per month per person. If a person can pay, they are asked to contribute towards personal purchases. Having this in the budget assures that no one is denied services based on their ability to pay. The primary cost is staffing.

Salaries FT \$202,633

PT 15,000

Benefits 86,896

Operating budget including cell phones for community activities, travel and staff training, food, client activities, program supplies and miscellaneous, expenses such as admission costs for staff, parking, tolls.

Operating Budget 3,200

Total expenditures - \$307,745.

Program Results

Outcome measures were monitored for the last two fiscal years. Building staff competency was the first outcome achieved with all staff having completed competency based training and continued learning on a quarterly basis.

The next outcome increased the types of activities and generated new and better ways of engaging the individuals. This outcome produced at least two new activities each quarter.

Additional outcomes were more personal to each individual. Three individuals were able to remain in the program until they went into hospice care. Three individuals transferred from the work program to enjoy the quieter setting while still working part time each week. Two individuals have increased their ability to communicate because of the more individualized, specific interventions in the quieter setting with more targeted activities. Success is in the stories. One individual demonstrated signs of "sundowning" or late day confusion. If someone has dementia, their confusion and agitation may get worse later in the day. For this individual, these symptoms began after lunch. Staff began planning calming events with him, showing him pictures of people and places, he is familiar with and worked with his team for a reduced schedule. Another individual had medical issues which precipitated his staying home from the program. As he improved, staff worked with his group home staff for visits and gradual return to the program to assist in his transition.

Two stories stand out to demonstrate the value of this program and the continued need for it.

BS was demonstrating a decline due to dementia in his work program. He would get confused, angry and at times, seemed scared. He was offered the opportunity to spend time in both the LEP program and his vocational program. After about a month, his behavior demonstrated his preference for LEP by reporting there each morning. Staff have been committed to ensuring BS continues to have the opportunity 2 - 3 times per week to complete the paid tasks he enjoys which offers extra support in the vocational program. His day has been individualized by going to his preferred places in the community, enjoying his Elvis Presley music, and playing his harmonica at a local Assisted Living Facility – all of which continues to help him retain his work skills and the relationships with his peers and staff he has built over the years.

KG came to LEP over a year ago. When he arrived, he was recovering from hip surgery and had not been an active participant in his physical therapy. He arrived with a walker and an unwillingness to do his exercises because they were boring. Staff worked with him little by little to increase his stamina and confidence by using games and fun activities to get him started. He is a jokester and loves having fun. When he first started going out in the community, he was going out for a cup of coffee on very short walks. As time went on, he went to other places and was able to walk behind a shopping cart as part of the experience. As he began to walk further distances, staff encouraged him to push his limits by going to an art gallery. One gallery was the Virginia Museum of Fine Arts, where he noticed the special exhibition on African masks. He walked all the way to the back far side of the museum, watched a film, and had long conversations with staff. KG began to use American Sign Language (ASL) rather than his own dialect of signs and gestures, something that had been unsuccessfully tried in the past when done in a "classroom" format. As he became more mobile, he has increased his activities. KG has gone to Feed More (the local food bank) to assist with taking backpacks to Falling Creek Elementary School to help children have meals on the weekends. His ability to move has been

reinforced in the program by encouraging him to move around through walking, ball toss, ring toss, and various interactive forms of exercise. KG continues to make progress and slow his aging process.

Brief Summary

Adults with developmental disabilities are living longer than ever before and many experience early onset dementia or Alzheimer's Disease. This creates challenges for those with developmental disabilities due to many of their inherent functional limitations and understanding of their health conditions. For individuals at or near the retirement age, with this added complication a traditional habilitation program no longer meets their needs. As one study in Today's Geriatric Medicine noted, "providers and care team members need to learn about the characteristics, health care needs, and common clinical issues in this population." The Life Enrichment Program seeks to do that while assisting individuals in maintaining their skills while enjoying their retirement years. The goal is to offer activities that may emphasize improvements in memory, sensory ability and/or physical health. Partnerships with Senior Connections and other groups who specialize in services for those who are aging is one component. The environment has also been adapted to include smaller tables for group work, more comfortable lighting, and community activities that are of shorter duration due to the lowered stamina of some individuals. Staff receives specialized training in working with older adults, particularly those with symptoms of dementia or Alzheimer's. This change in program has allowed individuals to be active participants far longer than traditional day programs.