ABSTRACT

EXPANDING ADULT DAY SERVICES FOR LOW INCOME SENIORS

AND THEIR FAMILIES: A GRANT PROPOSAL PROJECT

By

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With the rapidly increasing older adult population in our nation and around the world, the number of people diagnosed with Alzheimer's disease (AD) and other related dementias also increases. Alzheimer's disease and other related dementias are devastating illnesses. The most important risk factor for dementia is advanced age.

Adult day care programs are valuable services that assist people diagnosed with AD and their families. The purpose of this project was to obtain funding to support the expansion of an existing adult day care service so that older adults with limited resources can access services. After exploring different avenues, this grant writer found that the Alzheimer's Foundation of America would be the best potential funding source for this project.

The actual submission and/or funding of this grant was not a requirement for the successful completion of the project.

EXPANDING ADULT DAY SERVICES FOR LOW INCOME SENIORS AND THEIR FAMILIES: A GRANT PROPOSAL PROJECT

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CHAPTER 1

INTRODUCTION

Statement of the Problem

Aging is inevitable regardless of who you are, where you came from and what you believe (Shankar, 2010). Aging is a reflection of the changes in life; as people grow old, these changes may eventually lead to declining abilities and vulnerability to chronic diseases (National Institute on Aging, 2011a). The world population is growing exponentially. It is estimated that in approximately 30 years, the ratio of older population worldwide will double from 7% to 14% (National Institute on Aging, 2011b). In 2005, the world population was estimated at 6,514.7 million; approximately 90 million are over 60 years old, and 0.6 % of these are 80 years old and above (Shankar, 2010).

In the United States, the Center for Disease Control and Prevention (CDC, 2013) reported that the population for persons aged 60 and is predicted to be 89 million by the year 2050. The reason for this is driven by two factors. First, is the large number of aging baby boomers and second is the increasing number of people living beyond 80 years old. The growth of the aging population has been attributed to the advances in medical technology, which has allowed people with chronic conditions to live longer lives (CDC, 2013).

The Administration on Aging (2013) reported that about 43.1 million people in the United States are 65 years and older, or about 1 in every 7 of the population. From

2002 to 2012, the older adult population increased by 21%. The Administration on Aging (2013) also predicts that the number of older adults will increase twofold by 2060, totaling 92 million. Furthermore, the population of people 85 years and older is expected to increase threefold, from 5.9 million in 2012 to 14.1 million by 2040. Due to the rise in number of older adults in the United States, there are vast implications, including increased numbers of people with dementia, as well as issues with finances, housing, and quality of care (Administration on Aging, 2013).

Definitions of Terms

Adult day care centers: Provide a coordinated program of professional and compassionate services for adults in a community-based group setting. Services are designed to provide social and some health services to adults who need supervised care in a safe place outside the home during the day (National Adult Day Services Association, 2014).

Alzheimer's disease (AD): A condition that causes abnormal changes in the brain mainly affecting memory and other mental abilities; the most common form of dementia in older adults (Alzheimer's Association, 2014a).

Caregiving: Refers to attending to another individual's health needs. It often includes assistant with one or more activities of daily living (Alzheimer's Association, 2014a).

Caregiver Burden: A multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual (Kim, Chang, Rose, & Kim, 2012).

Dementia: An overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities (Alzheimer's Association, 2014a).

Older Adult: For this project, a person who is age 55 or older since this is the target population of adult day care.

Increased Number of Older Adults with Alzheimer's Disease

Approximately 24 million people around the world are suffering from dementia. The type of dementia most commonly diagnosed is Alzheimer's disease (AD). Memory loss due to AD is caused by the accumulation of plaques and tangles, which eventually leads to the deterioration of brain cells (Ballard, Gauthier, Corbett, Brayne, Aarsland, & Jones, 2011). Alzheimer's disease is a devastating and heartbreaking disease that robs a person of his or her memories, judgment and independence; it also robs the family and loved ones of the person they care about (Alzheimer's Association, 2011). Additionally, financial factors such as the higher costs of health care, loss of income and general costs of providing care impact the quality of life of both the caregiver and the person receiving the care (Family Caregiver Alliance, 2006). It is also costly for the government to provide for long-term care when families can no longer take care of their loved ones (Alzheimer's Association, 2011).

According to their most recent report, the Alzheimer's Association (2014b) stated that AD is the leading cause of dementia and memory loss in older adults, and age is the most important known risk factor for AD. Alarmingly, it is estimated that 1 in 8 baby boomers will get AD after they turn 65 (Alzheimer's Association, 2011). The risk of AD increases to nearly 1 in 2 at age 85. By 2030, the United States population aged 65 and

over is expected to double, which indicates that more people in this country will likely to have AD or will be caring for someone with the disease (Alzheimer's Association, 2011). There are currently an estimated 5.2 million people in the United States diagnosed with AD; 5 million of those are age 65 and older, and about 200,000 people with young-onset AD (i.e., those diagnosed with AD under age 65). Also, about 82% of people with AD are age 75 years and older (Alzheimer's Association, 2014b). In fact, AD is typically diagnosed after age 60, but AD has been seen diagnosed as early as 30 years of age (Family Caregiver Alliance, 2006).

The Alzheimer's Association (2014b) also reported that over 15 million family members and other unpaid caregivers provided an estimated 17.7 billion hours of unpaid care to people with AD in 2013. Of these, 65% of caregivers were women, 64% were employed outside the home, and 21% were 65 years or older. As the disease progresses, the stress of caregiving can result in physical and mental health impairments, as well as financial problems for caregivers (Alzheimer's Association, 2014b).

The Family Caregiver Alliance (2006) has stated that most caregivers are not prepared to take on the demands of caregiving responsibilities, and receive minimal to no support. Caregivers often continue to carry on their caregiving responsibilities even while their own health suffers. The overwhelming responsibilities of caregiving can put the caregiver's own health at risk. Caregivers' poor health status is one of the main reasons why an impaired loved one is placed in a long-term care facility (Family Caregiver Alliance, 2006).

Adult Day Care Services

The Alzheimer's Association (2014a) indicated that adult day care centers are a very beneficial service for caregivers who are in need of respite from their caregiving duties. These types of services are perceived to not only relieve caregiver burdens, but also help the person suffering from dementia (Alzheimer's Association, 2014a). Adult day care centers can assist in helping caregivers balance their responsibilities. The availability of hours and services varies at each center, but are typically open from 7 to 10 hours per day. Some may offer extended hours and provide transportation and meals. Adult day centers provide opportunities for participants to engage in social and other meaningful activities such as art, music and exercise programs. They may also offer other valuable services to the participants and their families such as counseling, nutrition and other supportive education (Alzheimer's Association, 2014a).

While organizations like the Caregiver Resource Center and the Alzheimer's Association offer respite services, many caregivers are still reluctant to use these services. Lack of awareness of these resources is one reason why caregivers do not use respite services. Another reason is that it is hard for many family caregivers to trust a non-family member with the care of their older adult relative (Alzheimer's Association, 2014a).

Goal of the Project

The goal of this project was to write a grant to fund a scholarship program in order to extend the availability of Orange County Care Connections Outreach (OCCCO) adult day care service program to low income older adults and their families in need of the service in the surrounding areas. The OCCCO program specifically serves older

adults suffering from mild to moderate stages of dementia. The services offered provide stimulation to maintain or enhance physical and mental status, as well as increase social interaction. The program also provides support to caregivers by alleviating stress and providing much needed respite from caregiving duties.

Social Work and Multicultural Relevance

The Alzheimer's Association (2014b) reported the physical and emotional impact of dementia caregiving is estimated to have resulted in \$9.3 billion in health care costs in the United States in 2012. It is projected that by 2030, the United States will need an additional 3.5 million health care professionals, including social workers, to address the needs of the growing older population (Alzheimer's Association, 2014b). The expansion of adult day care service is vital to address the needs of older adults affected by dementia and their family members (MetLife, 2010). Social workers who assist families dealing with a dementia diagnosis need proper training to be effective in identifying their needs, coping with losses, providing emotional support, assisting families in coordinating care and providing resources (Adams, 2006).

According to Administration on Aging (2013) in the year 2012, minority older adults ages 65 and over constituted approximately 21% the total population. Of these groups, 9% were African American, 4% were Asian or Pacific Islander, 5% were Native Americans, 1% were Native Hawaiian/Pacific Islander, and 0.7% indicated having two or more races. Persons of Hispanic origin represented 7% of the older population (Administration on Aging, 2013). With AD affecting all older people regardless of ethnic background, this project has multicultural relevance.

CHAPTER 2

LITERATURE REVIEW

Biology of Aging

Biological aging is not entirely linked to chronological aging; some diseases which cause cognitive impairments may occur at a younger age (Shankar, 2010). The human brain's structure begins to decline at a rate of about 5% per decade after the age of 40 years and continues to decline increasingly with age over 70 years (Shankar, 2010). A healthy human brain has tens of billions of specialized cells called neurons which use electrical and chemical signals to process and transmit messages to the different parts of the body. While the healthy brain may lose some neurons as part of the aging process, it does not lose a significant amount. With AD, there is a disruption in critical brain cell function and the cells are eventually destroyed. The progression of neuron destruction first affects the memory, and then later affects communication, reasoning and behavior. Ultimately, AD takes away a person's abilities and awareness of the world around him or her (National Institute on Aging, 2011a).

It is believed that aging results from a lifetime accumulation of damage to the human body's complex system; aging is also associated with changes to the brain (Clegg, Young, Iliffe, & Rockwood, 2013). "The hippocampus has been identified as an important mediator in the pathophysiology of cognitive decline and Alzheimer's dementia and is a key component of the stress response" (Clegg, et al., 2013, p. 753).

Furthermore, Clegg et al. stated that the aging brain is also characterized by the changes in the structure and function of the brain cells, which are activated by injury to the brain. These cells become overly responsive to stimuli associated with aging, which may cause damage or death to the cell (Clegg et al., 2013).

The CDC (2013) indicated that the growth of the aging population has been attributed to the advances in medical technology, which have allowed people with chronic conditions to live longer lives. However, even with these advances, many chronic diseases still pose major health challenges in the United States. Specifically, heart disease is the leading cause of death in the nation since early 1900; cancer is the second leading cause of death. These two diseases represent the highest risk as people grow old (CDC, 2013). Older adults are also at higher risks for other chronic diseases such as stroke, chronic respiratory disease, diabetes, and AD (CDC, 2013).

The CDC also stated that common diseases in older adults include arthritis, high blood pressure, and pulmonary disease. Two out of 3 older Americans have multiple chronic diseases (2013). The United States health care expenditures are among the highest in developed countries. Specifically, the cost of providing care for a person aged 65 or older is 3 to 5 times higher than the cost for a person aged 65 or under. Health care costs will continue to rise significantly with the growing numbers of older adults with multiple chronic conditions. Medicare spending is projected to increase from \$555 billion in 2011 to \$903 billion in 2020 (CDC, 2013).

The Alzheimer's Association (2014b) reported that people with AD and other dementias are hospitalized more than 3 times higher than other older adults.

Furthermore, people with chronic diseases such as coronary heart disease, diabetes,

stroke, or cancer concurrent with Alzheimer's and other dementias have higher medical cost and service needs than people with these conditions, but without dementia.

(Alzheimer's Association, 2014b).

Aging Policies

Achenbaum and Carr (2014) stated that the provision of services to older adults in the United States has existed for centuries. Many early aging services were provided by informal entities such as family, friends, neighbors and public organizations (Achenbaum & Carr, 2014). Achenbaum and Carr also stated that the Great Depression brought significant attention to the risks of growing old. The crisis led to loss of jobs, family units, savings, and other future financial resources. The most important source of support for older adults during that period was the Veterans Administration. Two federal laws that were created to address the needs of vulnerable older adults have changed the system of aging services: the Social Security Act and the Older Americans Act (Achenbaum & Carr, 2014).

In 1935, President Roosevelt called on Congress to assist vulnerable members of society, including the elderly, and declared his plan to provide a social security program. On August 14, 1935, the Social Security Act was signed into law. The Act was designed to pay workers a continuing income when they retire at age 65 or older (Social Security Administration, 2005). Social Security funds are collected from workers through an income tax called the Federal Insurance Contributions Act (FICA). According to the Social Security Administration, approximately 55 million people are currently receiving social security benefits (Social Security Administration, 2005).

The Older Americans Act (OAA) of 1965 funded the development of organizations such as the Administration on Aging (AOA), as part of the Department of Health and Human Services. The AOA's primary concern is to provide services to vulnerable older adults such as those with low incomes, members of minority group, and rural residents. The AOA established services to assist the aging community, such as the ombudsman programs and assistance with transportation needs, as well as programs to meet family caregiver needs (Judd & Moore, 2011).

In 1965, President Johnson also signed Medicaid and Medicare into law (Achenbaum & Carr, 2014). In Title I of the Act, the following rights were bestowed older Americans: the rights to adequate income in retirement; to proper medical and mental health care; to secure adequate housing; pursuit meaningful activity; to access to affordable community services; to immediate benefit to proven research knowledge; and to freedom, independence, and autonomy (Achenbaum & Carr, 2014).

The National Institute on Aging (2011b) indicated that majority of the oldest-old lose their independence due to physical disabilities. Many of these older adults need some form of long-term care. This may include services from nursing homes, community care and assisted living, residential care, and long-stay at hospitals. A big portion of the financial responsibility associated with providing this type of care often falls to families and society. With the increases in life expectancy and the staggering number of growth of the older population, the demand for this type of care will greatly increase (National Institute on Aging, 2011b).

As a part of the amendments to the Social Security Act in 1972, Adult Day Services (ADS) were recognized as providers of long-term care services in the United States (Anderson, Dabelko-Schoeny, & Johnson, 2012). Corresponding to the growing cost of nursing home care in the mid-1980s, ADS received more attention for governmental funding through the OAA and Medicaid Waiver Programs in an effort to promote home and community-based services. Public funding continued to grow in the 1990s and 2000s as public awareness was heightened about the devastating effects of AD and related dementias. The negative impacts on the caregivers due to the challenges associated with caregiving have also gained increased public awareness (Anderson et al., 2012). While a few people with AD and other dementias have long-term care insurance, most do not. In 2012, about half of all Medicare beneficiaries had an average annual income of \$22,276 or less, and about a quarter of the beneficiaries had income of \$13,418 or less (Alzheimer's Association, 2014b).

Adult Day Services Overview

Adult Day Service programs meet the social, health, nutritional, and daily living needs of adults in community-based settings during daytime hours (Anderson et al., 2012). They are often seen as an alternative to home care or institutionalization. The purpose of ADS programs is to help older adults with physical and cognitive limitations to continue community-based living in the community. Also, ADS programs support family caregivers by allowing them to remain in the workforce and receive a break from providing care for a frail older adult (Anderson et al., 2012). Currently, ADS programs primarily operate based on a social model, medical model, or a combination of both. Social models typically focus on the psychosocial needs of participants and provide opportunities to interact and socialize with others. The medical model, known as Adult Day Health Care (ADHC), focuses on the physical needs of participants. With this

model, services such as behavioral management, nursing care, medical care, and variety of skilled therapeutic interventions are typically provided (Anderson et al., 2012).

Alzheimer's Disease and Related Dementia

Dementia is an overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities (Alzheimer's Association, 2014b). In AD, the damage to and death of neurons eventually impair one's ability to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease are confined to their bed and require 24-hour care. Alzheimer's disease ultimately leads to death (Alzheimer's Association, 2014b). Currently, AD is the most common form of dementia that has been identified. Other dementia-related diseases include vascular dementia, dementia with Lewy bodies, Frontotemporal lobar degeneration, mixed dementia, Parkinson's disease, Creutzfeldt-Jakob disease, and normal pressure hydrocephalus, just to name a few (Alzheimer's Association, 2014b).

Ballard et al. (2011) provided an overview of recent evidence regarding the epidemiology, pathogenesis, diagnosis, and treatment of AD. The researchers reported that an estimated number of people with dementia in the world are expected to increase to 42 million by the year 2020 and to 81 million by the year 2040 (Ballard et al., 2011). Specifically, AD is associated with the accumulation of Tau (microtubule-associated protein), which is the major component of neurofibrillary tangles. Tau is a soluble protein, but produces insoluble products which cause disruption with the structure and function of the neuron (Ballard et al., 2011). Several potential risk genes for AD have been identified; the most consistently associated risk gene is *ApoE*. At present, AD can

only be diagnosed after death and only probable diagnosis of AD is possible (Ballard et al., 2011). Furthermore, Ballard et al. stated that in order to perform a clinical diagnosis of AD, a detailed history of symptoms is obtained from the patient and their caregiver to assess cognitive impairment, and a neuropsychological assessment is done. It is also recommended that CT or MRI scanning should be done to examine the brain to help determine what is contributing to dementia syndromes (Ballard et al., 2011).

Ballard et al. (2011) also stated that the current pharmacological treatments only help to minimize symptoms of AD; these include treatment for improving cognition and challenging behaviors, as well as mood and social interaction. Simple non-drug treatments, such as social interaction, person-centered care training, and holistic therapy, can be effective alternative treatments in patients with AD. Some researchers have suggested that exercising and having an events schedule will help provide an effective alternative for treatment of mild depression in patients with AD. The most potentially beneficial approach to reducing the prevalence of the disease is to promote healthy living (Ballard et al., 2011).

Mavall and Malmberg (2007) conducted a study of 51 caregivers of family members with dementia. The study aimed to get a better understanding of the characteristics of those people with dementia who entered day care. The findings revealed that all study participants were reported to have had at least one behavioral problem. About two thirds were reported to have aggressive behaviors (e.g., screaming, threatening or violent behaviors). Over three fourths exhibited disturbing behaviors (e.g., keeping the caregiver awake at night). One third of the clients exhibited risky behaviors

(e.g., wandering away from home). These researchers also concluded that depression was a common problem reported by caregivers (Mavall& Malmberg, 2007).

<u>Impacts of Alzheimer's Disease and Related Dementias</u>

Financial, health, and emotional costs to caregivers have been well documented. Myers (2003) stated that caregivers often find it necessary both to leave their job and face increasing costs for services related to providing care. They also may experience deterioration in physical and mental health (Myers, 2003). Caregivers report physical stress and fatigue, exhaustion, a variety of medical conditions, and increased use of prescription drugs. Myers also stated that caregivers experience more chronic illnesses, rate themselves as having poor health, and may need to seek health care services more frequently than do non-caregivers (Myers, 2003).

Caregivers' Mental and Physical Health

Papastravrou, Kalokerinua, Papacostas, Tsangari, and Sourtzip (2007) conducted a study aimed at discovering the effects of providing care to a family member with dementia. A combination of 172 patients and their primary caregivers were recruited from different neurology clinics that treated patients affected by AD. Caregivers reported that the symptoms (e.g., sundowner's syndrome, wandering, and agitation) of dementia were the factors that led to increased stress. Papastravrou et al. found that the stress associated with caring for family members with dementia had a negative impact on the caregiver's physical and mental health such as lowered immune system and depression. Caregiver stress was also found to be the key reason participants reported for the institutionalization of the person suffering from dementia (Papastravrou et al., 2007).

Kim et al. (2012) analyzed secondary data collected by the National Alliance for Caregiving and American Association of Retired Persons in 2003. The participants (*N* = 302) were randomly selected adults from seven states and were surveyed via telephone. Kim et al. found that people with lower economic status perceived caring for a person with dementia to be of a greater burden compared to those with higher incomes. Poorer health was also found to be associated with higher caregiver burden. Additionally, the lengthy number of hours spent providing care was found to be associated with a higher perception of burden. Kim et al. concluded that low-income family caregivers were at the highest risk for negative health and mental health outcomes.

Myers (2003) also indicated that mental health consequences of caregiving have been linked to burden because caregivers often place the needs of the care recipients before their own needs. The negative effects on mental health associated with caregiving duties include increased distress, depression, demoralization, and anxiety. Caregiving also contributes to lack of sleep, discomfort, and irritability (Myers, 2003).

Gitlin, Reever, Dennis, Mathieu, and Hauck (2006) also found similar findings of their study of 129 caregivers from three adult day services to examine effects of ADS. These researchers concluded that providing care to frail older adults can be stressful and result in a range of well-documented negative consequences. Some of those consequences include clinical depression, health problems, social isolation, financial difficulties, and mortality. This is particularly the case for family caregivers of individuals with dementia, who experience greater distress in comparison to individuals caring for older adults without dementia. Utilizing adult day services contributed to the

improvement of quality of life for both the caregiver and care recipient (Gitlin et al., 2006).

Adams (2006) conducted a study involving interviews of 20 spouses and adult daughters of someone with early/mild dementia or mild cognitive impairment (MCI). These family members reported taking on many new responsibilities in a demanding caregiving process. These responsibilities were mainly comprised of assisting with making decisions and providing supervision. Many participants reported mixed feelings and negative reactions such as frustration, resentment, grief, and relational deprivation. Some reported a heightened sense of protectiveness and compassion towards their family member with dementia. Most of the participants reported being reluctant about seeking or accepting help from others, and preferred to maintain the way things were as long as possible (Adams, 2006).

Chen, Ngo, and Park (2013) conducted a qualitative study of 15 individuals to get a better understanding of caregiver experiences. The participants were recruited from an outpatient clinic, and were currently providing care for individuals with chronic conditions including dementia. The study findings revealed that caregivers experience multiple daily challenges. They have to constantly balance several caregiving tasks, while struggling to maintain their own needs. The study concluded that in caring for a patient with chronic conditions, a caregiver often devotes large amounts of time, energy, money, and emotional support to the patient. The more involved a caregiver is, the more impact she or he may experience from the caregiving demands (Chen et al., 2013).

Dementia caregivers are also more likely to visit the emergency department or to be hospitalized if the care recipient has depression, low functional status, or behavioral disturbances (Alzheimer's Association, 2014b). Clearly, dementia caregivers are a vulnerable population.

Socioeconomic Impacts of Alzheimer's Disease

Bynum (2014) provided an overview of the impact of AD and related dementias. The most prominent consequence associated AD and related dementia is the financial costs of providing medical care and long-term care to individuals affected with the diseases. As people with dementia outlive their assets, the costs of providing long-term care in a nursing home, assisted living facility, or similar site are often directed to Medicaid. The direct costs for dementia were estimated to be higher than the direct costs for heart disease or cancer. When the costs of informal care are included, the costs associated with dementia care are far higher than those for other chronic conditions (Bynum, 2014).

The Alzheimer's Association (2014b) indicated that AD is one of the most financially burdensome diseases to society. Medicare beneficiaries with AD and other dementias are more likely than those without dementia to have other chronic conditions. Total payments in 2014 for all individuals with AD and other dementias were estimated at \$214 billion. Medicare and Medicaid are expected to pay 70% of the total health care and long-term care payments for people with AD and other dementias. Individuals and families are expected to pay 17% out-of-pocket costs. Average Medicaid payments per person for Medicare beneficiaries with AD and other dementias are 19 times greater than payments for average Medicare beneficiaries without AD and other dementias. Despite other financial assistance, individuals with AD and other dementias still incur high out-of-pocket costs (Alzheimer's Association, 2014b). By 2050, the total annual payments

for health care, long-term care, and hospice care for people with AD and other dementias are projected to increase to \$1.2 trillion. Included in this projection is a six-fold increase in government spending under Medicare and Medicaid and a five-fold increase in out-of-pocket spending (Alzheimer's Association, 2014b).

Wimo, Ballard, Brayne, Bauthier, Handels, Jones... Kramberger (2014) reported that the socio-economic impact of dementia disorders is enormous. Specifically, the worldwide societal costs were estimated at \$604 billion in 2010. Given the high prevalence and cost of dementia, it is important to find financially effective solutions to address the problem (Wimo et al., 2014).

According to Jude and Moore (2011), people who are financially disadvantaged tend to have greater difficulties with their health, relational issues, and obtaining resources as they age. Older adults who live at or below the poverty level suffer greater physical, cognitive, and emotional impacts than wealthier older adults. The poverty rate for elderly women is higher than men, higher for persons living alone compared to those who live with a spouse, and it is the highest among ethnic minorities. Furthermore, older adults with low income have high rates of chronic disease, which places them at higher risk for institutional placement as they age (Jude & Moore, 2011).

The financial, social and personal costs of providing care for disabled elderly individuals will continue to increase as the number of elderly population increases. The United States population of adults aged 65 and older has been predicted to increase from 40 million in 2010 to 55 million in 2020 (Metlife, 2010). In 2008, approximately 38% of older individuals reported some type of disability; this number is expected to increase as

more people live longer. Cognitive disability, particularly AD and/or related dementia, presents an increasing concern among older adults (MetLife, 2010).

Prevalence of Abuse in Older Adults with Dementia

Elder abuse is the "physical, psychological, and sexual abuse; caregiver neglect; and financial exploitation of people ages 60 and older" (Dong, Chen, & Simon, 2014, p. 642). Dong et al. reported that an estimated 11.4% of adults in this age group in the United States experienced some form of elder abuse in 2008. Elder abuse may lead to adverse health outcomes such as physical disability and psychological distress; it has also been linked to increased risks of morbidity and mortality. Elder abuse imposes a great social and economic burden on society (Dong et al., 2014).

Based on a review of prior research, Dong et al. concluded that older adults with dementia often have psychological or behavioral symptoms such as agitation and aggression, which may intensify care giver-recipient conflicts and result in elder abuse. The researchers also found that lower levels of cognitive function were associated with increased risk for elder abuse and self-neglect. Older adults with dementia may experience higher burden of chronic illness and physical impairment, which heightened their risk of abuse, compared to older adults without dementia. Caregiver burden and stress are among the most common risk factors associated with elder abuse. Other factors such as depression, anxiety, alcohol abuse, social isolation, and poor relationships with the victim prior to the occurrence of dementia are also associated with higher risk of abuse by caregivers (Dong et al., 2014).

Dementia and Elder Abuse – Federal and State Health Policies

Dong et al. (2014) stated that the growing awareness of both dementia and elder abuse has led to policy responses. In most states, statutes require professionals to report injuries or cases of abuse or neglect to law enforcement officials, social services, or a regulatory agency (Dong et al., 2014). In California, the two main organizations are Adult Protective Services and the Long-term Care Ombudsman Program, authorized in 1975 under title VII (Vulnerable Elder Rights Protection Activity) of the Older Americans Act. The Ombudsman office is federally funded, but may also receive state and local funding. The Ombudsman's offices are charged with investigating and resolving complaints filed by or on behalf of residents of long-term care facilities, such as nursing homes and assisted living facilities. They are also charged with advocating for long-term care system changes on behalf of the residents and protecting their legal rights (Dong et al., 2014).

The National Alzheimer's Project Act of 2011 was designed to coordinate governmental efforts for preventing and treating AD. The Act directed the Department of Health and Human Services to release a national plan to address AD, and revise the plan annually. One of the most critical goals of the plan is to protect the dignity, safety, and rights of people with AD. The Elder Justice Act was enacted as a part of the Affordable Care Act in 2010. The Act established two advisory bodies: the Elder Justice Coordinating Council and the Advisory Board of Elder Abuse, Neglect, and Exploitation. The Act was designed to reduce elder abuse incidents and to improve quality of care for people who are affected with dementia (Dong et al., 2014).

Sandwich Generation

MetLife (2010) defined the sandwich generation as people who are holding down a full-time job while raising children and serving as a caregiver for older relatives simultaneously. The findings from MetLife's 8th Annual Employee Benefits Trends Study identified some of the burdens and continue to highlight the workplace as a potential source for assistance. The study indicated that about 1 in 5 full-time employees is a caregiver of an older relative and nearly three quarters of these employees also have children under the age of 18 (MetLife, 2010). The study also revealed the following with regard to savings, home ownership, college costs, and family time. Specifically, 42% of employees with minor children without elder caregiving responsibilities say they live paycheck to paycheck, compared to 64% of members of the working sandwich generation. About 37% of working men and women with minor children are worried about being able to afford to buy a home, but that percentage doubles for those who are providing elder care. Also, 55% of workers with minor children are uncertain if they can afford future college costs, but that percentage increases to 72% for those who are also caregivers. And finally, while 45% of working parents are concerned about not having more time to spend with their families, the percentage for working parents who are simultaneously balancing parental and caregiving is elevated at 72% (MetLife, 2010).

Do, Cohen, and Brown (2014) stated that many members of the sandwich generation are simultaneously providing care for their elderly parents and their children. Do et al. conducted a study to determine the factors associated with caregiving and the health of the sandwich generation. The researchers reviewed a publicly available data from the Behavioral Risk Factor Surveillance System (BRFSS), which is a national

survey of adults, aged 18 years and older living in the community. In 2009, one adult per household in all 50 states (plus District of Columbia and three U.S. territories) were randomly selected and interviewed for the BRFSS with 52.2% median cooperation rate. The study was focused on how the association between caregiving and health status of caregivers varied by sociodemographic factors, number of children in the household, race/ethnicity, and income. The researchers found that caregiving and poor health is associated with the number of children in the household; caring for under aged children and elderly family member simultaneously elevated caregiver stress (Do et al., 2014). The researchers also found that there was a significant association between caregiving and health among Whites and others. This association was not observed for African Americans, Asians, or Hispanics, indicating that cultural differences may play a part in caregiving beliefs and perceptions. With regards to income, the researchers found that the strongest association between caregiving and health are among the group with intermediate income ranging from \$50,000 and \$75,000. The researchers also suggested that these sociodemographic differences are important to consider when developing policies and programs to help maintain caregivers' health (Do et al., 2014).

Adult Day Services Outcomes and Roles

In attempt to examine the benefits of utilizing adult day services, Gustafsdottir (2011) conducted a longitudinal study by observing nine adult day care centers caring for elderly people with dementia. The researcher conducted direct observation of the participants and interviewed family and staff at nine different adult day care locations. The study began in 2003 and final data were gathered in 2009. Gustafsdottir found that adult day care provides structure, enhances self-worth, and a sense of normalcy for

people affected by dementia. Also, adult day care allows older adults affected by dementia to enjoy the company of others in a safe environment. Additionally, Gustafsdottir found that the caregivers of participants who attend adult day care reported that these services reduced their stress by giving them a break from their caregiving duties (Gustafsdottir, 2011).

In a longitudinal study, Schacke and Zank (2006) interviewed 77 caregivers of a person diagnosed with dementia, and currently utilizing adult day care services over a 9-month period. The researchers concluded that utilizing day care service did reduce caregiver stress. The caregivers reported that having their older adult relative in adult day care enhanced their ability to maintain a balance between personal, professional and caregiving responsibilities. Also, Schacke and Zank stated that caregivers reported that their older adult relatives enjoyed adult day services because they were able to engage in social activities with other people (Schacke & Zank, 2006).

Based on a review of the literature, Fields, Anderson and Dabelko-Schoeny (2012) evaluated the effectiveness of ADS from the year 2000 to the present. The researchers found that caregivers of older adults in ADS experienced significantly lower levels of hostility from their care recipient compared with caregivers in other treatment groups. Also, caregivers who used ADS spent less time addressing behavior problems in care recipients than caregivers who did not use ADS. The researchers also found that ADS attendance was associated with significantly lower caregiver burden and stress related to family conflict and employment (Fields et al., 2012).

Utz, Lund, Caseta and Wright (2011) conducted a study using semi-structured interviews and time-log diaries to explore both desired and actual time-use among

employed (N = 26) and non-employed caregivers (N = 22). The researchers found that employed caregivers were generally more satisfied with respite time use than non-employed caregivers. Employed caregivers were also more likely to do activities they wanted to do, utilizing respite service to temporary relieve them of their caregiving duties. Although most employed caregivers considered employment to be a valuable and as a form of respite, lack of free time outside of work and caregiving was stressful. Similarly, non-employed caregivers expressed a desire to do activities they wanted to do, rather than only those related to caregiving tasks. These findings suggest that both employed and non-employed caregivers might benefit from better respite time use (Utz et al., 2011).

Gaugler (2014) conducted a qualitative study to examine why and how families and older adults utilize adult day services. The current study included 3 months of participant observation in one rural and one suburban ADS program in an upper-Midwestern region of the United States, as well as semi-structured interviews with 14 family members of clients and 12 staff members from these programs. The findings revealed that ADS works for clients in several ways. The clients benefit from activities which enriched their abilities to be independent, to be physically stimulated, and to have increased opportunity for socialization. The variety of client activities at ADS also contributes to the ability for clients to live longer on their own. ADS benefits the clients' family by helping them feel reassured that their loved one is safe and being cared for while at the program. Families also benefit from support services offered by ADS to help them cope with their care giving responsibilities (Gaugler, 2014).

Anderson, Dabelko-Schoeny and Johnson (2012) reported on a secondary analysis of findings from the 2010 MetLife National Study of Adult Day Services. Anderson et al. highlighted the changes in the organization and service characteristics of the ADS industry to help us understand the current and future roles that ADS can play in meeting the challenges of an aging society. Over 4,600 ADS centers were identified across the United States in 2010, representing a 35% increase since the last census in 2002. Also, ADS centers reported serving an average of 34 participants in 2002 compared to 51 in 2010. It is estimated that the ADS industry now serves over 260,000 participants and family members, an increase of over 100,000 since 2002 (Anderson et al., 2012). These researchers also indicated that the most frequent health conditions experienced by ADS participants were reported to be dementia (47%), hypertension (46%), and physical disability (42%). ADS centers reported on average that 1 in 4 participants (25%) had some type of chronic mental health condition. Annual budgets for ADS centers were most frequently between \$100,000 and \$500,000. Furthermore, most ADS centers (70%) reported to be operating at a balanced budget, while 17% reported an annual deficit, and 13% reported an annual profit. ADS centers continue to provide respite services to family caregivers, offering educational programs, support groups and individual counseling (Anderson et al., 2012).

Barriers to Utilizing Adult Day Care Services

Phillipson, Magee, and Jones (2013) stated that many people with dementia live at home with family caregivers. These caregivers often become overwhelmed with their caregiving duties, and badly in need of a break. Although there is clearly a need, caregivers rarely utilize respite services. Phillipson et al. conducted a study of caregivers

(N = 294) to investigate caregiver beliefs regarding out-of-home respite care services and why caregivers choose not to such utilize services. The survey revealed that despite needing respite services, 44.2% of those surveyed were not utilizing day respite and 60.2% were not utilizing residential respite programs. The reason for not using the services was strongly due to beliefs that using the service would result in negative outcomes for the care recipient. The researchers recommended that to improve the use of out-of-home respite services, family members need to be better educated on the benefits of ADS for both the caregivers and care recipients (Phillipson et al., 2013).

In a study by Brown, Friedemann, and Mauro (2012), a random sample of 537 patients and caregivers were recruited from home care agencies. The study explored the perceived need for and use of ADS in a low-income population. While half of the caregivers reported that they had a perceived need for using ADS, only 19.1% of these caregivers used adult day services, mostly in the case of severe patient cognitive impairment. These researchers further revealed that although there was a perceived need for services by almost 50% of the caregivers, less than 20% of those with a perceived need used services. The reasons for not utilizing the services were attributed to cost, distance, availability of transportation, hours open, and as well as the family's lack of knowledge about available resources. Concerns about the availability of ADS center staff to provide care and supervision for person with dementia has been identified as a primary reason for stopping use of the service (Brown et al., 2012).

Preparing for the Baby Boomers

In a secondary review of the findings from the 2010 MetLife National Study of Adult Day Services, Anderson et al. (2012) concluded that while funding for ADS may

have risen in the past 10 years, the study revealed that ADS centers are not well funded or financially stable. Most ADS centers reported that they are barely surviving. Recent efforts to increase funding for ADS did not yield positive results, and it is uncertain that ADS will continue to grow with such financially dire circumstances despite the apparent need for services (Anderson et al., 2012).

On January 4, 2011, President Barack Obama signed the National Alzheimer's Project Act (NAPA) into law which instituted the Advisory Council on Alzheimer's Research Care and Services. It also requires the Secretary of the U.S. Department of Health and Human Services (USDHHS) to work collaboratively with NAPA to develop and maintain a plan to address the increasingly devastating effects of AD and related dementias in our nation. In May 2012, NAPA declared AD to be a significant national issue (USDHHS, 2013).

The CDC is currently expanding on their Healthy Brain Initiative. They are producing a document called "The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018." This document outlines the plan of how the state and local public health agencies, as well as collaborative partners will bring awareness and education to the community. The goal of the initiative is to promote cognitive functioning, address cognitive impairment for individuals living in the community, and provide assistance to individuals in need. The initiative also provides actions under the following four areas: monitor and evaluate, educate and empower the nation, develop policy and mobilize partnerships, and assure a competent workforce (USDHHS, 2013).

Multicultural Issues

The Alzheimer's Association (2014b) reported that older African-Americans are about twice more likely to have AD or another dementia as older White, European-Americans. Hispanics are about one and one half times more likely to have AD or another dementia as older whites. There are some indications that genetic factors may have an influence on the risk for AD and other dementias, but do not necessarily explain the higher occurrence among different racial groups. Other health conditions, including high blood pressure and diabetes that may increase one's risk for AD or another dementia, are more prevalent in African American and Hispanic people. Also, other risk factors, such as lower level of education and other socioeconomic characteristics may be indicative of increased risk in these minority groups. Furthermore, almost two thirds of those with AD in the United States are women (Alzheimer's Association, 2014b). The reason for the higher prevalence of AD in women may be because on average women have a longer lifespan than men, and are more likely to reach an age of high risk for AD (Alzheimer's Association, 2014b).

Gitlin, Reever, Dennis, Mathieu, and Hauck (2006) stated that the majority of frail older adults rely on family members to care for them. Family caregivers account for more than three quarters of the long-term care providers in the United States.

Approximately 16% of primary caregivers were employed (Gitlin et al., 2006). Family caregivers often serve in multiple roles. Their roles as caregiver of an individual with AD or related dementia often create a burdensome impact on their own situation and quality of life. While caregiving is the norm in many families, it is not consistent across all cultural groups (Wimo, et al., 2012).

Marquez, Losada, Izal, Montorio, Knight, Ruiz, and Robinson Shurgot (2006) conducted a study of 108 Hispanic dementia caregivers (48 who lived in Los Angeles, and 60 who lived in Madrid) recruited from different communities to determine the association of *familism* with burden and symptoms of depression in family caregivers. *Familism* was defined as "the strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity, and solidarity among members of the same family" (Marquez et al., 2006, pp. 69-70). The researchers stated that *familism* has an important value in many cultural groups, particularly in the traditional Latino or Hispanic culture. In this study, the researchers found that *familism* is associated with burden and depression in the Hispanic culture. Specifically, Marquez et al. found that *familism* was greatly associated with lesser burden among the Hispanic caregivers in the United States, but with higher levels of emotional disturbance in the Spanish caregiver sample (Marquez et al., 2006).

Yarry, Stevens, and McCallum (2007) reported that older African American and Hispanic individuals often live in multigenerational households. Yarry et al. highlighted that in able to help ethnic minority spousal caregivers, it is important to focus on helping older family members cope with the failing health of their spouse, supporting their religious beliefs, and enhancing skills to promote a healthy relationship and quality time together. Yarry et al. also stressed the importance of helping older spouse caregivers to accept their limitations in the type of care they can provide, and of supporting them by understanding the cultural meaning of caring for a spouse (Yarry et al., 2007).

In a national study of adult day services (N = 557), Metlife (2010) found that half of all adult day service participants were White, European-Americans. The other ethnic

groups that used adult day services were African Americans/Blacks (16%), Hispanics (9%), and Asians (9%). The participants' living arrangements were as follows: 27% living with an adult child, 21% with a spouse, and 20% living alone, and 18% residing in a community care facility (MetLife, 2010).

Conclusion

Alzheimer's disease (AD), the most common form of dementia, has an enormous impact on the people affected by the disease, as well as society as a whole. The symptoms of AD and related dementias have been proven to be very challenging.

Respite care services, such as ADS, have been found to be beneficial in maintaining symptoms of dementia, helps lessen incidents of challenging behaviors, and provides an opportunity those who are suffering from the disease to participate in meaningful activities. The ADS have also been found to be beneficial in assisting family caregivers in relieving caregiver stress. Family caregivers remain to be the main resource to assist with the needs of individuals with dementia. The ADS is a valuable service in supporting families care for their loved one at home and helping to enhance their quality of life (Anderson et al, 2012).

CHAPTER 3

METHODOLOGY

Description of the Proposed Project

Since older adults and their family members have to pay out of their own pocket for adult day services, low-income families often do not have the resources to pay for this care. This is because MediCal only covers the cost of Adult Day Health Care, which is based on the medical model. Currently, MediCal does not cover the cost of adult day care services because they do not offer health services. The social model of adult day care was developed for people with AD because they are typically strong physically; their primary deficits are in cognition. The purpose of this project is to acquire supplemental funding to help low-income older adults attend adult day care centers.

Host Agency

Orange County Care Connections Outreach (OCCCO) has agreed to be the host agency for this grant proposal. The OCCCO is a non-profit agency under the Internal Revenue Code 501(c)(3). It provides a social model (no medical interventions) adult day care program, which was established in 1997. The agency provides specially designed programs for older adults who have been diagnosed with mild to moderate dementia, have related disorders, or are frail and require additional care and supervision. The mission of OCCCO is to serve families in need of respite from their daily caregiving responsibilities by providing compassionate services regardless of race, ethnicity or

religious affiliation. The OCCCO offers meaningful activities designed to meet the creative, emotional, functional, and spiritual needs of the people they serve (OCCCO, n.d.).

Strategies for Identifying and Selecting Potential Funding Sources

Various sources were explored to discover potential funders to support the proposed enhancement of the existing adult day care program. The Google (www. google.com) internet search engine was a primary tool to locate potential funding sources. The following key words were used to assist in narrowing down the search results: "elderly services grants," "federal grants for senior services," "Alzheimer's disease community service grants," and "caregiver services grants." In addition, Google was utilized to identifying other organizations and potential funders committed to enhancing the quality of lives of the elderly population in need.

Governmental and organizational websites were ideal sources to begin searching for potential funders. Specifically, the availability federal grants directly related to supporting elderly services were explored through the Administration on Aging (www. aoa.gov) also now known as the Administration for Community Living (www.acl.gov), as well as state grants governed by the California Department of Aging (www.aging.ca. gov). Also, non-profit organizations identified to have strong commitment in supporting needs of older adult services such as the Alzheimer's Foundation of America (www. alzfdn.org), American Association of Retired Persons (AARP) Foundation (www. aarp.org), Archstone Foundation (www.archstone.org), and Harry and Jeanette Weinberg Foundation, Inc. (www.hjweinbergfoundation.org) were highly considered.

Grant Selection Criteria

After researching potential grant funders, specifically government agencies and/or organizations addressing the needs of people affected by Alzheimer's disease and other dementias, as well as caregivers' needs, several potential funders were identified. The Administration on Aging's Supportive Services and Senior Centers Program provides state grants to different services to help elderly people maintain independence in their own homes. These programs provide senior services such as transportation, case management, and in-home services. They also support community services such as adult day care (Administration on Aging, 2012).

The California Department of Aging has four grants dedicated to support senior services: the Aging and Disability Resource Center (ADRC) grant, Alzheimer's Disease Demonstration grant, Alzheimer's Disease Evidence Based Demonstration grant, and Evidence Based Health Promotion grant. Unfortunately, these grants appear to target culturally specific population and communities and it is thus likely that the proposed program would not qualify (California Department of Aging, 2014).

The Grantmanship (http://www.tgci.com) website was also utilized as a resource to locate potential funders. Under the top giving funders in California, the Weingart Foundation (http://www.weingartfnd.org) was identified to be compatible with the proposed program. The Weingart Foundation supports non-profit organizations in providing effective services which focus on health, human services, and education for people and communities in need. The highest priority is given to programs which serve people who are underserved and financially disadvantaged. Priority is also given to six Southern California Counties: Los Angeles, Orange, Riverside, San Bernardino, Santa

Barbara, and Ventura. The Weingart Foundation also funds programs that benefit the general community and improve the quality of life for all individuals in Southern California (Weingart Foundation, 2014).

The American Association of Retired Persons Foundation (AARP) has funding available to contribute to the enhancement of quality of lives of vulnerable, low-income older adults. The AARP's Isolation Impact Area grant (http://www.aarp.org/aarp) foundation/in particular, helps support diverse programs to help financially disadvantaged seniors address issues of isolation (AARP Foundation, 2012). The AARP Foundation is dedicated to helping vulnerable older Americans in meeting their daily essential needs such as food, housing, finances, and social connections (AARP Foundation, 2012).

The most promising funding source identified was the Alzheimer's Foundation of America (AFA). The AFA's mission is "to provide optimal care and services to individuals confronting dementia, and to their caregivers and families-through member organizations dedicated to improving quality of life" (AFA "Mission Statement," 2014). The AFA regularly provides grants to nonprofit organizations that develop or enhance programs which deliver services to address the educational, social, emotional, and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families. The AFA aims to fill the gap in services for these individuals and families, to ensure that they receive quality of care (AFA, 2014).

The AFA awards grants several times a year with three of the four grant opportunities in congruent the proposed program: the Bi-Annual grant, Brodsky Innovation grant, and Family Respite grant (AFA, 2014). First, the Bi-Annual grant is available for application during the spring and fall cycles. The grant funds programs and

services such as support groups, cognitive stimulation activities, prescription assistance program, rapid response system and professional training. The members of the AFA's Board of Trustees review the grant proposals. The following criteria must be met and are scored on a scale of 1-5: clear and effective descriptions; high community demand; creativity; best practice; and budget in sync with real costs (AFA, 2014). Secondly, the Brodsky Innovation grant is available for application once a year. It is designed to support innovative programs that improves the lives of individuals with AD or other related illnesses, and their families. The grant application must be submitted by May 15 of each year and must demonstrate innovativeness, greatest need and replication potential (AFA, 2014).

The Family Respite Care grant is intended to help fund respite care costs. Funds must be utilized to provide scholarships to clients with AD or a related dementia and/or their families with financial needs. The scholarships are for respite services, such as social model adult day programs, in-home aides, companion care or overnight respite, at the grantee's own organization or another organization. This grant is offered in the spring and fall of each year; for consideration, applications must be postmarked by June 1 for the spring cycle, and December 1 for the fall cycle (AFA, 2014). The grants have been beneficial to grassroots organizations and their communities by providing care for individuals with Alzheimer's disease and related illnesses, as well as their families (AFA, 2014). The specific dollar amounts available for the grants were not indicated at the AFA website. The proposed grant meets the AFA's eligibility criteria in terms of its philosophy and goals. The AFA is the most suitable funder for this proposed grant.

Needs Identification

To assess the need for adult day care services, this grant writer contacted local agencies (e.g. Orange Caregiver Resource Center and Alzheimer's Association of Orange County) to ask for information about unmet needs in the community. This grant writer also contacted the referral coordinators located at the Orange County Area Agency on Aging to get information on where they see a lack of adult day care services. Finally, this grant writer contacted other adult day care centers in the target area to find out if they have a waiting list.

CHAPTER 4

GRANT PROPOSAL

Executive Summary

The number of older adults with Alzheimer's disease (AD) and other dementias continues to grow alarmingly due to the exponential number of people aging in our population. Dementia is a devastating disease which slowly takes away memories and independence of the people affected; it also typically causes overwhelming responsibilities for the family who cares for them. Many of the elderly suffering from AD and other dementias do not receive adequate physical, mental, emotional and social stimulation. Adult day care programs provide compassionate and meaningful services, which help enhance the quality of lives of the people affected by the disease.

The overwhelming caregiver responsibilities can often lead to caregiver burnout and illnesses. Taking a break from caregiving duties allows caregivers to address their own needs, which helps contribute to a more positive attitude and relationship with the care recipient. Adult day care services also provide support to caregivers by providing them respite from their caregiver duties, emotional support, and other support to assist them in providing effective care for their loved ones. The purpose of this proposed program is to expand the adult day care service to the people in need of this type of program in the community.

Need for the Proposed Program

The United States population of people aged 60 and above is growing rapidly. This population growth is predicted to increase from 9.3 million in the year 2000 to 89 million by the year 2050. This increase is driven by the large number of aging baby boomers and the growing number of people living beyond 80 years. The growth of the aging population has also been attributed to the advances in medical technology, which have allowed people with chronic condition to live longer (CDC, 2013). The AOA also predicts that the number of older adults will increase twofold by 2060, totaling 92 million. Furthermore, the population of people 85 years and older is expected to increase threefold, from 5.9 million in 2012 to 14.1 million by 2040. Due to the rise of the aging population in the United States, there are vast implications affecting the lives of our society (AOA, 2013).

Approximately 24 million people around the world are suffering from dementia. The type of dementia most commonly diagnosed is AD, and age is the most important known risk factor. Alarmingly, it is estimated that 1 in 8 baby boomers will get AD after turning 65, and the risk of AD increases to nearly 1 in 2 at age 85 (Alzheimer's Association, 2011; Ballard, et al., 2011). Memory loss due to AD is caused by the accumulation of plaques and tangles, which eventually leads to deterioration of brain cells. AD is a devastating and heartbreaking disease that robs a person of memories, judgment and independence; it also robs the family and loved ones of the person they care about. By 2030, the United States population aged 65 and over is expected to double, which indicates that more residents will have Alzheimer's disease or will be caring for someone with the disease (Alzheimer's Association, 2011; Ballard, et al.,

2011). The Alzheimer's Association also reported that over 15 million family members and other unpaid caregivers provided an estimated 17.7 billion hours of unpaid care to people with AD in 2013. Of these, 65% of caregivers were women, 64% were employed, and 21% were 65 years or older (Alzheimer's Association, 2014b).

The financial, health, and emotional costs to caregivers have been well documented. Several researchers found that caregivers experience deterioration in physical and mental health. Caregivers report physical stress and fatigue, exhaustion, and a variety of medical conditions. Furthermore, studies showed that caregivers experience more chronic illnesses, and may need to seek health care services more frequently than do non-caregivers (Adams, 2006; Alzheimer's Association, 2011 & 2014; Myers, 2003; Papastravrou et al, 2007). The Family Caregiver Alliance (2006) stated that most caregivers are not prepared to take on the demands of caregiving responsibilities and receive minimal to no support. But caregivers often continue to carry on their caregiving responsibilities, while their own health suffers. The overwhelming responsibilities of caregiving can put the caregiver at risk for chronic health conditions. Caregivers' poor health status is one of the main reasons why an impaired loved one is placed in a long-term care facility (Family Caregiver Alliance, 2006).

Additionally, several sources indicated that financial factors, such as the higher costs of health care, loss of income and general costs of providing care, impact the quality of life of both the caregiver and the person receiving the care. It is also costly for the government, which pays for long-term care when families can no longer take care of their loved ones (Alzheimer's Association, 2011 & 2014; Family Caregiver Alliance, 2006).

Adult Day Care Services

The Alzheimer's Association (2014a) indicated that adult day care centers are a very beneficial service to caregivers who are in need of respite from their caregiving duties. These types of services are perceived to not only relieve caregiver burdens, but also to help the person suffering from dementia (Alzheimer's Association, 2014a). Adult day care centers can assist in helping caregivers balance their responsibilities. The hours and services vary at each center, but are typically open from 7 to 10 hours per day. Some may offer extended hours and provide transportation and meals. Adult day centers provide opportunities for participants to engage in social and other meaningful activities such as art, music and exercise programs. They may also offer other valuable services to the participants and their families such as counseling, nutrition education, and other types of support (Alzheimer's Association, 2014a).

While organizations like the Caregiver Resource Center and the Alzheimer's Association offer respite services, many caregivers fail to use these services. Lack of awareness of these resources is one reason why caregivers do not use respite services. Another reason is that it is hard for many family caregivers to trust a non-family member with the care of their older adult relative (Alzheimer's Association, 2014a).

Organization Description

The Orange County Care Connections Outreach (OCCCO) adult day program has agreed to be the host agency for this grant proposal. The OCCCO is a non-profit agency under the Internal Revenue Code 501(c)(3) and was established in 1997. The program is governed by Board of Directors which is made up of six community volunteers (a nurse, physical therapist, hospice chaplain, retired technology company vice president,

accountant, and pastor), a church liaison, and the program administrator. The mission of the OCCCO is to serve families in need of respite from their daily caregiving responsibilities by providing compassionate services regardless of race, ethnicity or religious affiliation (OCCCO, n.d.). The goals of the OCCCO adult day program are: (a) to provide respite to family caregivers from their daily care-related duties; (b) to provide meaningful activities for the care recipients in a safe and nurturing environment; (c) to help maintain dignity and self-worth of care recipients and their families; (d) to provide emotional, educational, skills training, other resources and support for family caregivers; and (e) to provide transportation to program participants who need it (OCCCO, n.d.). The agency operates at two different locations. Grace Respite Care is located in the city of Huntington Beach, Orange County, California. Redeemer Respite Care is located at the Leisure World senior community living facility in the city of Seal Beach, Orange County, California. Grace Respite Care is open Mondays through Fridays; Redeemer Respite Care is open on Tuesdays and Thursdays. The hours of operations for both centers are from 9:30 a.m. to 3:30 p.m. Both centers operate year round, closed only for a few major holidays. Support group sessions are provided for the family and/or caregivers on a monthly basis at the Grace location, with respite care staff available during the sessions as needed. Transportation service is available only at the Grace Respite Care location for the program participants who live in the surrounding area (OCCCO, n.d.). OCCCO adult day care program have compassionate staff and are experienced caregivers with specialized training in dementia care. The OCCCO team strives to provide their clients with quality care, and that each client receives individual attention (M. Klevos, personal communication, August 20, 2014).

Target Population

The OCCCO adult day program is available to older adults 55 years of age and older diagnosed with mild to moderate memory impairment or other related disorders that might benefit from special day care and supervision (OCCCO, n.d.). The older adult participant will be typically living in the community with a family member or in an assisted living environment. The target population for the proposed program is older adults meeting the above mentioned criteria who live in the surrounding cities near the two centers such as Fountain Valley, Garden Grove, Huntington Beach, Long Beach, Los Alamitos, and Seal Beach. The program is dedicated to reach out to the isolated seniors and caregivers in the community in hopes of enhancing their quality of lives.

Program Description

Adult Day Services meet social, health, nutritional, and daily living needs during daytime hours for older adults living at home. It is often seen as an alternative to home care and institutionalization. The ADS programs help older adults with physical and cognitive limitations to continue community-based living in the community. The ADS support family caregivers by allowing them to remain in the workforce and receive a break from providing care for a frail older adult (Anderson et al., 2012). The ADS primarily operate in social model, medical model, or a combination of both. Social models typically focus on the psychosocial needs of participants and provide opportunities to interact and socialize with others. Medical models focus on the physical needs of participants and provide nursing care, medical care, and variety of skilled therapeutic interventions (Anderson et al., 2012).

The OCCCO program is a social model (i.e., no medical services provided) adult day program which is tailored to provide compassionate care and meaningful activities for older adults diagnosed with mild to moderate dementia and other related disorders. The activities are designed to meet the creative, emotional, functional, and spiritual needs of the people they serve. The program also provides training and education, as well as counseling and support services to the participants' family and loved ones. The program participants enjoy a variety of daily activities which includes arts, crafts, music, physical and mental exercises, reminiscing and socialization (OCCCO, n.d.).

The OCCCO currently has a "Memories in the Making" program, which is an art program developed by the Alzheimer's Association, Orange County Chapter. They also offer seasonal and themed arts and crafts activities. Other stimulating activities include current events, games (such as puzzles, trivia games, ball toss, bowling and golfing), massage therapy, pet therapy, special guests, daily music sing-along, and exercise. The exercise program consists of stretching and gentle aerobic exercises, breathing, and strengthening exercises. The reminiscing and socialization activities provide the participants opportunities for self-expression, to share their stories, and to be acknowledged individually. An example of the reminiscing and socialization activity is an ice cream social. The participants may be asked to name their favorite ice cream flavor, play trivia games and/or tell stories about their favorite memories. The thoughtfully designed activities may provide added benefits for the participants such as opportunities to practice motor skills and functions. Also, ADS program participation offers opportunities to improve communication and social engagement with others (M. Klevos, personal communication, August 20, 2014).

Goals and Objectives

The goal of this project is to help enhance the quality of life of older adults and their families who are in need of ADS program in the surrounding areas. This grant will provide scholarships to approximately 15 low-income in a 2-year period. Because one of the barriers to participation in an adult day program is transportation, part of the funds will be allocated to secure a transportation service to provide participants a convenient way to attend the program. Funds will also be utilized to provide additional caregiver support, such as increasing the availability of support group meetings and educational opportunities to assist caregivers with effective caregiving and coping skills. The following are the objectives in correspondence with the proposed expansion of the program:

- Objective 1: To reach out to the families and caregivers who are involved in providing care to an elderly person affected with Alzheimer's disease or other dementia.
- Objective 2: To provide scholarship to 15 low-income older adults who might benefit from the adult day care services and cannot afford it.
- Objective 3: To carry out OCCCO's adult day care program mission by providing compassionate care and planned meaningful activities in a safe environment.
- Objective 4: To provide families and caregivers support services such as respite from their caregiving duties, counseling, educational and skills training, and support groups.
- Objective 5: To provide program participants with low- or no-cost transportation to and from the adult day care center.

Deliverables and Outcomes

By the end of the 6-month period, the program is expected to produce the following outcomes:

- 1. Enroll approximately 15 additional participants, expanding average daily attendance from 28 to 43 participants a day.
- 2. The participants will enjoy appropriate and meaningful activities. The staff will draw from participants' personal histories to create meaningful and enjoyable activities. Through the use of arts, crafts and other creative projects, participants will be encouraged to communicate and express their thoughts and emotions. The program will incorporate evidence-based practices, as well as age-appropriate activities to meet each participant's individual needs.
- 3. A trusting relationship between staff, participants, and their families will be established through a safe and nurturing environment.
- 4. The participants' caregivers will benefit from the program by receiving temporary relief from their caregiving duties, have an opportunity to catch up on other responsibilities, and relieve stress.
- 5. The program will provide caregivers opportunities to attend support groups where they can share their challenges and experiences with others who can relate to their situation.
- 6. Other support services will be available to caregivers such as caregiver skills training and coping techniques. The program caregiver support and services will help families to enhance and maintain a meaningful relationship with their loved ones affected with dementia.

Timeline

It is estimated that it will take approximately 6 months to achieve the expansion of the program. These includes reaching out to the families in need in the community and recruiting new participants; conducting assessments and enrollment of new participants; enhancing program plan to include a transportation and educational programs; enhance program activities and special events to meet the diverse participants' needs; and hiring additional staff.

Months 1-2

- 1. Prepare flyers, brochures and other marketing materials.
- 2. Complete mailings and deliveries.
- 3. Conduct community outreach activities such as an educational seminars and memory testing.
- 4. Hire additional qualified staff corresponding to the needs of the new participants.
 - 5. Ensure that program location will accommodate additional clients.
 - 6. Acquire a vehicle and insurance coverage.
 - 7. Create evaluation questionnaires.

Months 2-3

- 1. Conduct training for newly hired staff which will include dementia education and specialized dementia care training.
- 2. Conduct assessments to ensure that the program can appropriately provide service to meet applicants' needs.
 - 3. Establish program policies and fees with new participants and their families.

- 4. Ensure that equipment and supplies will accommodate additional clients.
- 5. Address the needs of each individual participant to ensure proper interventions.

Months 4-5

- 1. Provide service to new participants.
- 2. Ask new participants' family caregiver to complete a survey when first attending the program regarding their needs and their perceptions of the benefits utilizing the adult day program.
- 3. Familiarize new participants with new environment, staff and other participants.
 - 4. Encourage new participants to take part in activities.
- 5. Encourage families to participate in support programs available and to connect with other families in the program.
 - 6. Document a daily progress report for each participant.
 - 7. Evaluate appropriateness and benefits of program activities.
 - 8. Evaluate newly hired staffs' overall performance.

Month 6

- 1. Continue to implement and evaluate effectiveness of program.
- 2. Engage all participants actively in activities according to their level of ability.
- 3. Review participants' attendance and level of participation.
- 4. Determine any barrier in attending the program.
- 5. Conduct another survey regarding participants' needs and their family caregiver's perception of effectiveness and benefits of the program.

6. Evaluate the program's overall effectiveness. A progress and evaluation report will be provided to the funding agency by the Program Director.

Plan of Evaluation

To determine the effectiveness of the enhanced OCCCO day program for older adults with dementia and other related disorder, a thorough review and evaluation of attendance log, daily progress documentations, staff evaluation and survey results will be conducted. In addition to the surveys, families of participants will periodically be interviewed to acquire information about their satisfaction with the program and how utilizing the program has impacted their overall quality of life.

Budget Narrative

The estimated budget for the proposed expansion of the OCCCO adult day care program is \$390.072. The budget encompasses the cost of providing grants to 15 low-income participants to cover 50% of daily program fee, as well as transportation at no cost to the participants. The budget also includes personnel salary for five additional staff, activity and food supplies, community outreach, transportation, and other marketing. The line-item budget is attached as an appendix.

Respite grants: 15 low-income older adults will each receive a respite grant of \$23.50 per day which is 50 % of the daily program fee, totaling \$91,650 per year for a 2-year period.

Transportation grants: A transportation service to and from the center will be provided to the OCCCO program participants free of charge. This service typically cost \$10 per day. The cost for providing transportation service is \$31,200 per year.

Staffing Personnel

Program Assistants: The Program Assistants (PA) provide care with compassion and dignity, assist participants with activities and ADLs as necessary, assist with daily logistics, and work under direct supervision of the program supervisor. There are currently seven PA and will hire four additional PA with the proposed program enhancement. The staff to client ratio will be one staff to four participants (1:4 ratio). The average hourly rate for Program Assistants is \$13.00 per hour at 24 hours per week. The total annual budget for the additional four Program Assistants is \$64,896.

Driver: An experienced driver will transport participants from their homes to the program in the morning and will return them safely to their homes in the afternoon. The driver must have a clean driving record, have good customer service skills and experienced in operating wheelchair lift. The driver is also responsible for the maintenance and cleanliness of the vehicle. The hourly rate for a driver is \$10 per hour at 16 hours per week totaling \$8,320 per year.

Direct Program Expenses

Transportation: Approximately \$400 per month will be spent on fuel and vehicle maintenance. A vehicle will be donated for the Seal Beach center. The annual insurance cost is approximately \$2,600. The total annual transportation budget for the proposed program is \$7,400.

Activity supplies and entertainment: Approximately \$250 will be spent on activity supplies and special entertainment. The total cost is approximately \$3,000 per year.

Program food supplies: Approximately \$400 per month will be spent on participants' daily snacks, totaling \$4,800 per year.

Office supplies, duplicating, and mailing: Approximately \$100 per month will be spent on office supplies and mailing, totaling \$1200 per year.

Advertising/marketing: Approximately \$2,000 will be spent in advertising and recruiting participants for the first year of the proposed program enhancement, and will be lowered to \$1000 the seconde year.

Outreach events: Approximately \$1,000 will be spent on community outreach related expenses per year.

In-Kind Resources

To provide transportation service to OCCCO program participants, a vehicle equipped with handicap access will be obtained by donation through local business or healthcare agencies that has a vested interest in the population being served by the program. The approximate cost for the vehicle is \$40,000.

Revenues

The daily adult day program fee to the participants is \$57 per person. The projected yearly income for the proposed program is approximately \$117,780.

Line-Item Budget

See Appendix for Line-Item Budget.

CHAPTER 5

LESSONS LEARNED

Identification of Need for Proposed Program

Identifying the need did not present a great deal of challenge because of the current statistics and literature available related to the need of the target population for the proposed program. This grant writer has a great passion for assisting elderly adults suffering from dementia, as well as their family caregivers. Through education and working with this population for the past several years, this grant writer received better understanding of the impacts of Alzheimer's disease and other dementias in relation to health, social and financial burdens for the person suffering from the disease, their loved ones and the community. This grant writer also became an advocate for adult day care programs and believes that they are beneficial in engaging the people suffering from the disease in meaningful activities and providing caregivers much needed relief from their caregiving duties, which helps enhance their quality of lives.

Review of Literature

At the beginning of the research process, finding literature on adult day care centers proved to be challenging. This grant writer began by utilizing CSULB library online database to locate articles about Adult Day Care (ADC) services. It appeared that limited studies have been conducted on the subject, and there are only few current studies. Many of the studies also concluded that the benefits of such programs are

difficult to prove and mainly subjective. This grant writer took a different approach and widened the search topic to include key words such as dementia, Alzheimer's disease, and caregiver stress. It became apparent that there are much more current research studies available, specifically on Alzheimer's disease and caregiver burden. Utilizing the Google search engine to expand the research was very helpful in locating scholarly articles. Articles found through Google that not available free of charge are then located at the CSULB online library using the search tool by title. The review of scholarly literature on the overwhelming impacts of Alzheimer's disease and other dementias strengthened this grant writer's passion for working with this population and solidified the decision to pursue this grant proposal.

Location of Potential Funding Source

This grant writer explored the Grantmanship website (http://www.tgci.com), as well as several governmental and non-profit organizations websites, to identify potential funding sources. It was surprising to find multiple grants available to support programs designed to assist in meeting the needs of elderly adults affected by Alzheimer's disease and other dementia and their families. This grant writer found available potential funding from the Administration on Aging's Supportive Services and Senior Centers Program, Alzheimer's Foundation of America (AFA), California Department on Aging, Weingart Foundation, and American Association of Retired Persons Foundation (AARP). Unfortunately, the grants available through the California Department of Aging appear to support specific communities and needs; the need for proposed program is unlikely to be a priority. The most promising funding source identified was the Alzheimer's Foundation of America (AFA).

Strategies to Increase Likelihood of Funding

This grant writer learned that there are many aspects involved in increasing the likelihood of funding the proposed program. The first is to identify a need and know the population in need. The second is to explore the different organizations and services related to the subject, conducting extensive research of current scholarly literature, presenting a compelling argument of the needs, and providing evidence of the program benefits. It is also important to explore different sources and organizations to locate available grants and to conduct a thorough review of the eligibility and application requirements for each individual grant. This grant writer also learned that having a carefully planned budget to fund operational costs is crucial. Finally, it is important to consider the above to increase the likelihood of funding for this proposed program because the host agency has not been successful in securing funds in previous attempts.

<u>Implications for Social Work Policy and Practice</u>

The financial, social and personal costs of providing care for disabled elderly individuals will continue to increase as the number of elderly population increases.

Cognitive disability, particularly due to Alzheimer's disease and/or related dementias, presents an increasing concern to older adults, their families and the community (MetLife, 2010). Social workers will play an important role in identifying and addressing the needs of this growing and vulnerable population. It is imperative for social workers to acquire proper knowledge about Alzheimer's disease and other related dementias to provide effective resources and interventions to those in need.

The expansion of adult day care service is vital to address the needs of older adults affected by dementia and their family members (MetLife, 2010). Social workers

will need to be actively involved in advocating for programs such as adult day care services to help families address their needs with cost-effective interventions, help maintain independence and financial security, manage chronic illnesses, and prevent hospitalization or institutionalization. Community awareness, governmental involvement and professional advocacy are needed to ensure the dignity, rights, safety and quality of life of the vulnerable older adults in our society.

APPENDIX

LINE ITEM BUDGET

APPENDIX

LINE ITEM BUDGET

OCCCO Program Budget

	Year 1	Year 2
Respite Grants		
Program Fee Grant \$23.50 x 15 Participants		
(208 visits/year/participant)	\$73,320	\$73,320
Transportation Grant	\$31,200	\$31,200
Total Respite Grants	\$104,520	\$104,520
Salaries and Wages		
Program Assistants (4)	\$64,896	\$64,896
Driver	\$8,320	\$8,320
Benefits	\$0	\$0
Total Salaries and Wages	\$73,216	\$73,216
<u>Direct Costs</u>		
	\$7,40	
Transportation:	0	\$7,400
Activity/Supplies/Entertainment:	\$3,000	\$3,000
Foods Supplies	\$2,400	\$2,400
Office Supplies/Duplicating/Mailing	\$2,000	\$2,000
Marketing	\$2,000	\$1,000
Community Outreach/Education	\$1,000	\$1,000
Total Direct Costs	\$17,800	\$16,800
Revenues		
Program Fees (\$47/person/day)	\$109,980	\$109,980
Transportation Fees (\$10/day)	\$7,800	\$7,800
Total Revenues	\$117,780	\$117,780
	,	
In-Kind Support		
Mini-Van	\$40,000	
	, ,	
Total Program Costs Requested		\$154,512

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