

Administration on Aging Alzheimer's Disease Demonstration Grant to States

Evaluation of State Programs to Provide Supportive,
Educational and Direct Service Interventions for Caregivers
of People with Alzheimer's Disease or a Related Disorder



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SECTION I: Executive Summary

The incidence of Alzheimer's Disease or a Related Disorder (ADRD) is expected to increase significantly as the population ages. In Vermont more than 20% of the state's population will be over the age of 65 by 2020, making it the second "grayest" state in the nation. As such, Vermont will be disproportionately impacted by aging related diseases such as ADRD. (1) It is not well understood how the estimated increase in people with ADRD will be met with a corresponding increase in the number of resources including caregivers, specialized dementia care units, workforce, respite etc.

It is estimated that in Vermont, there are 11,000 individuals or 9% of the population over age 60 affected by ADRD. Of the 6,789 total nursing home residents in Vermont, 25 percent have no cognitive impairment, 29 percent have very mild to moderate impairment and 47 percent have moderate to severe impairment.(2) The prevalence of ADRD in younger populations is also increasing, perhaps due to improved diagnostic ability. According to the Centers for Disease Control and Prevention, National Center for Health Statistics, the death rate in Vermont due to Alzheimer's disease was 27.6 per 100,000. This is compared to the United States rate of 21.8.(3)

From 2004 to 2007 DAIL implemented a three year grant from the Administration on Aging (AoA) with matching dollars from the State of Vermont to provide supportive, educational and direct service interventions for caregivers of people with ADRD with the goal of helping those with ADRD remain in their homes and communities. The evaluation of these programs funded under Vermont's Alzheimer's Disease Demonstration Grant to States is an important way for us to understand how to further improve our use of resources to enrich the lives of our constituents as well as provide insight to the AoA regarding the use of federal resources to improve the systems of ADRD care in Vermont. We believe this document also presents important considerations for other states which may be planning the development of similar interventions and programs. For all of these audiences, this report will play a key role in defining a common understanding of:

- What succeeded, including the strengths and weaknesses of each program component.
- The extent to which caregiver well-being has been addressed by the program including gaps and outstanding caregiver needs.
- The extent to which new programs have been integrated into our current system of care.
- The extent to which training and education programs offered to paid caregivers and professionals was effective.

Evaluation Focus Area #1: Dementia Respite Grant Program

The Dementia Respite Program was a key component of Vermont's 2004-2007 ADDGS activities and continues to play an important role in supporting the Department's efforts to help family caregivers so they may continue in their caregiving roles and delay or prevent admission of their loved ones to long-term care facilities. The 2004-2007 Dementia Respite Program was funded by the AoA ADDGS (\$196,150 annually) and an annual appropriation of \$250,000 in State General Funds. The program, which is coordinated through Vermont's Area Agencies on Aging (AAA), served 1101 families during the grant period. Dementia respite grants are available to individuals with dementia and their family caregivers who are not eligible for other home and community based programs. To be eligible for a dementia respite grant, the care recipient must be a community-dwelling permanent resident of Vermont, have a formal diagnosis of dementia and meet certain income eligibility requirements. On average, dementia respite grants range between \$1,000 and \$1,500 annually per household. Dementia respite grants can be used to pay for services that provide family caregivers with a break from their caregiving responsibilities such as homemaker services, substitute in-home caregiving or Adult Day services.

Goals:

- ◆ To understand the ease of access to respite care/respite care programming.
- ◆ To understand the extent to which existing respite care resources and programs are responsive to the needs of the target population.
- ◆ To understand the quality of and satisfaction with respite services.
- ◆ To understand the outstanding need or demand for respite services.

Findings and Recommendations:

1. *Maintain the current program flexibility and scope of respite services.*
2. *Increase outreach and education strategies to bring caregivers into respite care services during early stages of ADRD. Activities can include heightened outreach by existing Dementia Respite Grant Coordinators and engaging other traditional and nontraditional stakeholders (clergy, doctors, family and friends).*
3. *The network of respite care providers is inadequate to meet the needs of caregivers even when resources are available.*

4. *Given the current state of attention to healthcare workforce distribution and quality in Vermont, it is important to assure that the workforce needs of the Dementia Respite Grant Program are represented in existing strategic planning.*
5. *Increase service providers (hospitals, memory center, doctors etc) who are knowledgeable and referring to the program.*
6. *Increase funding available to families to obtain respite services.*

Evaluation Focus Area #2: Caregiver Bridges Project

The Caregiver Bridges Project was another important component of the 2004-07 ADDGS activities. Using the National Association of Area Agencies on Aging (n4A) Making the Link Program as a model, partnerships were established between primary care practices and other community providers to improve services to support individuals with ADRD and their family caregivers. This project was supported with \$140,000 of AoA ADDGS funds. Project implementation was coordinated by the Memory Center at Fletcher Allen Health Care. Partnerships were formed between seven primary care practices in four areas of the state, the Council on Aging for Southeastern Vermont (COASEV), the Area Agency on Aging for Northeastern Vermont (NEVAAA), Champlain Valley Agency on Aging (CVAA), the Middlebury Project Independence Adult Day Center, two community mental health centers (HowardCenter and Counseling Service of Addison County) and two private mental health practitioners. AAA case management staff and/or a mental health counselor were co-located at the primary care practices to provide on-site screening for cognitive impairment, screening for depression and caregiver stress, information and referral services, case management and/or mental health counseling. All project partners were provided with training on ADRD-related diagnosis and treatment. In addition, primary care practitioners were offered regular consultation with geriatric psychiatrists from the Memory Center at Fletcher Allen Health Care (FAHC) during the project period. A total of 51 individuals with ADRD and 69 family caregivers obtained services through the Caregiver Bridges Project.

Goal:

- ◆ To develop recommendations regarding further implementation of the Caregiver Bridges/Making the Link Project as well as support of existing practice sites.

Objectives:

- ◆ To understand the professional value (community and primary care practice) with the Project.
- ◆ To understand the enabling factors contributing to thorough implementation.

- ◆ To understand the barriers to thorough implementation.
- ◆ To understand the critical components of practice “readiness”.
- ◆ To understand the consumer satisfaction and consumer value with the Project.

Findings and Recommendations

1. *Dedicate external staff to supporting the implementation of the project who focus upon transfer of skills and expertise to the practice staff.*
2. *If similar initiatives are going to occur they should continue to replicate this model.*
3. *Provide more frequent physician team support.*
4. *When implementing, develop strategies to address the unique features of how the practice operates in order to facilitate adoption of new practices.*
5. *Efforts need to focus equally on increasing practice capacity for change as well as supporting adoption of specific care models.*
6. *Sustainability requires implementing individualized strategies with primary care practices to change the system of care in addition to implementing models or protocols designed to improve patient outcomes.*

Important system change for Caregiver Bridges Project practices included:

- Funding – in order to promote lasting change funding streams in either ongoing grants or billable services would be required.
- Organizational Goals – while seemingly simplistic, stating the organizational goals (and setting realistic goals) for improvement of care for individuals with ADRD is important in gaining organizational and professional commitment.
- Provider Education – ongoing support of development opportunities by peer professionals specifically targeting difficult areas of practice change or patient treatment.
- Feedback on Practice Performance – providing practices an opportunity to reflect on their activities and the extent to which they are meeting their pre-determined goals.
- Feedback on Community Programs – assuring that the level of information exchange and communication between primary care providers and community providers occurs in a manner that is efficient, accurate and timely enough to inform patient care.

Evaluation Focus Area #3: ADRD Training

In addition to the training provided in conjunction with the Caregiver Bridges project, seven other training opportunities were provided to more than 400 community providers. Participants included case managers from AAAs and Home Health Agencies, developmental services providers, elder mental health counselors, the Alzheimer's Association of Vermont and DAIL staff.

Goal:

- ◆ To understand the relative ease or difficulty of training participants to apply their knowledge to the system of care in which they practice.

Findings and Recommendations

1. *Consider providing training on development and monitoring of organizational goals related to ADRD.*
2. *Improve the ability of professionals to provide standardized screening and assessment for individuals with ADRD.*
3. *Develop a statewide training plan which identifies strategic skill building, core professional competencies and content which improves care of individuals with ADRD.*

SECTION II: Introduction

The Department of Disabilities, Aging and Independent Living's (DAIL) mission is to make Vermont the best state in which to grow old or to live with a disability – with dignity, respect and independence. To achieve this goal, the Department is committed to fostering the development of a comprehensive and coordinated approach to the provision of community-based systems of services for older adults and people with disabilities. Our goal is to enhance the ability of these Vermonters to live as independently as possible, actively participating in and contributing to their communities. As we approach this work, we are guided by the following core principles:

- **Person-centered:** the individual is at the core of all plans and services.
- **Respect:** individuals, families, providers and staff are treated with respect.
- **Independence:** the individual's personal and economic independence are promoted.
- **Choice:** individuals will have options for services and supports.
- **Self-determination:** individuals direct their own lives.
- **Living well:** the individual's services and supports promote health and well-being.
- **Contributing to the community:** individuals are able to work, volunteer and participate in local communities.
- **Flexibility:** individual needs guide our actions.
- **Effective and efficient:** individuals' needs are met in a timely and cost effective way.
- **Collaboration:** individuals benefit from our partnership with families, communities, providers, and other federal, state and local organizations.

We are proud of Vermont's history of consistently re-evaluating the system of aging and long-term services and supports and in developing innovative approaches to using our limited resources to respond to the needs and preferences of Vermont's aging population.

From 2004 to 2007 DAIL implemented a three year grant from the Administration on Aging (AoA) with matching dollars from the State of Vermont to provide supportive, educational and direct service interventions for caregivers of people with Alzheimer's Disease or a Related Disorder (ARD) with the goal of helping those with ARD remain in their homes and communities. The evaluation of these programs funded under Vermont's Alzheimer's Disease Demonstration Grant to States is an important way for us to understand how to further improve our use of resources to enrich the lives of our constituents as well as

provide insight to the AoA regarding the use of federal resources to improve the systems of ADRD care in Vermont. We believe this document also presents important considerations for other states which may be planning the development of similar interventions and programs. For all of these audiences, this report will play a key role in defining a common understanding of:

- What succeeded, including the strengths and weaknesses of each program component.
- The extent to which caregiver well-being has been addressed by the program including gaps and outstanding caregiver needs.
- The extent to which new programs have been integrated into our current system of care.
- The extent to which training and education programs offered to paid caregivers and professionals was effective.

In order to assist in understanding the answers to these questions a variety of evaluation methods were used including key informant interviews, focus groups with professionals, focus groups with caregivers, audits of provider practices and survey administration. Detailed information regarding each of these methods and how they were applied to the evaluation questions are described later in this document.

SECTION III: Overview of Alzheimer's Disease and Related Disorders in Vermont

Based on existing data sources as well as findings from interviews with key Vermont stakeholders, this section provides a context of the current state of Alzheimer's Disease and Related Disorders in Vermont (ADRD), an important but limited backdrop to the evaluation findings and recommendations. The backdrop provided is limited due to the lack of ADRD-specific data, a key finding in that future evaluation activities may benefit from well documented information that forms baseline data from which to measure change.

A. Definitions and terms

Dementia refers to a significant intellectual decline or impairment that persists over time. To be classified as a type of dementia, a disorder must meet both of the following criteria:

- a. "It must cause decline in at least two of the following four essential cognitive functions:
 - i. memory;
 - ii. ability to generate coherent speech or understand spoken or written language;
 - iii. capacity to plan, make sound judgments and carry out complex tasks; and
 - iv. ability to process and interpret visual information.
- b. The decline must be severe enough to interfere with day-to-day life."(3)

Approximately 1% of dementia cases are caused by a physical or psychological condition that can be successfully treated, therefore a thorough medical history and physical examination is necessary to make an accurate diagnosis.

Alzheimer's disease accounts for 50 to 70 percent of cases and is the most common form of irreversible dementia. In addition to Alzheimer's disease, other types of dementia include:

- Vascular dementia
- Mixed dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
- Dementia due to Parkinson's disease
- Dementia due to Creutzfeldt-Jakob disease
- Substance-Induced Persisting dementia

B. Demographics

The incidence of ADRD is expected to increase significantly as the population ages. In Vermont more than 20% of the state's population will be over the age of 65 by 2020, making it the second "grayest" state in the nation. As such, Vermont will be disproportionately impacted by aging related diseases such as ADRD.(1) It is not well understood how the estimated increase in people with ADRD will be met with a corresponding increase in the number of resources including caregivers, specialized dementia care units, workforce, respite etc.

There are more than five million individuals living with ADRD in the United States. It is estimated that in Vermont, there are 11,000 individuals or 9% of the population over age 60 affected by ADRD. In 2005, of the 6,789 individuals who spent any time in a nursing home in Vermont, 25 percent had no cognitive impairment, 29 percent had very mild to moderate impairment and 47 percent had moderate to severe impairment.(4) The prevalence of ADRD in younger populations is also increasing, perhaps due to improved diagnostic ability. An estimated 500,000 Americans younger than 65 have ADRD.(4) According to the Centers for Disease Control and Prevention, National Center for Health Statistics, the death rate in Vermont due to Alzheimer's disease was 27.6 per 100,000. This is compared to the United States rate of 21.8.(3)

National research shows that Alzheimer's disease is more prevalent among African-Americans than among whites (with estimates ranging from 14% to almost 100% higher), but there are no Vermont-specific statistics on Alzheimer's disease by race. There is a greater familial risk; and genetic and environmental factors may work differently to cause Alzheimer's disease in African-Americans.(5) A report by the National Alzheimer's Association also suggests that Hispanics may be at greater risk to develop dementia than other ethnic or racial groups. The burden of disease is falling heavily on Hispanic/Latino families, particularly daughters and other female relatives, in part because of the strong sense of responsibility and the role of women in these communities but also because of the lack of culturally and linguistically appropriate and responsive health and community services. Given the rising racial and ethnic diversity of Vermont's population there may be cause for developing culturally responsive programming to serve this population.

Alzheimer's Disease and the Developmentally Disabled - Diagnosis of ADRD is becoming increasingly common among those under the age of 65 in the general population, and among those with developmental disabilities, particularly Down Syndrome. Twenty-five percent of individuals with Down Syndrome over the age of 35 have Alzheimer's disease. The prevalence of dementia in this group is expected to greatly increase over the next 20 years as medical interventions prolong their lifespan. (6)

C. Screening, surveillance, and epidemiology

Screening for cognitive impairment is the first step to a diagnosis of ADRD. While there are standardized screening tools and protocols, anecdotal information suggests older Vermonter's are not routinely screened for cognitive impairment by their primary care practitioners.

The Vermont Department of Health, Health Surveillance Division regularly reports Alzheimer's-related mortality in their annual Vital Statistics Report. This data is based upon death certificate records and is projected to underestimate the Alzheimer's-related mortality because of commonly made mistakes in documenting primary and secondary causes of death. Alzheimer's Disease ranks 7th for cause of death in Vermont (Figure 1) and exceeds national Alzheimer's mortality rates (Figure 2).

Figure 1: Leading Causes of Death – Vermont Residents, 1988 - 2003(7)

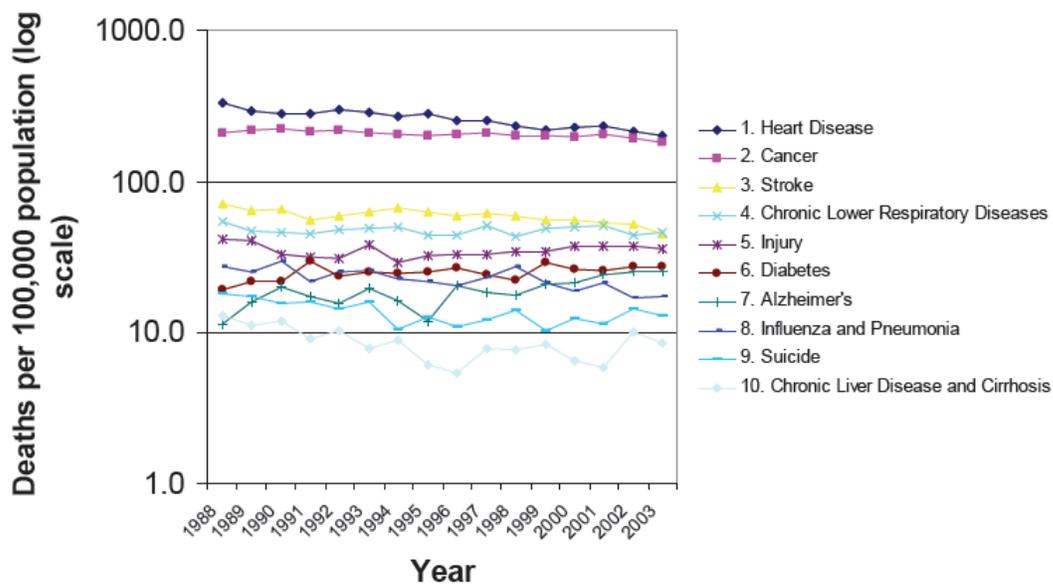


Figure 2: Leading Causes of Death (age-adjusted rates per 100,000 population) – Vermont and U.S. Residents, 2003(7)

| | Vermont | | U.S. |
|------------------------------------|---------|---|-------|
| | 2003 | | 2003 |
| Heart Disease | 199.6 | ↓ | 232.3 |
| Cancer | 181.8 | ↓ | 190.1 |
| Stroke | 45.2 | ↓ | 53.5 |
| Chronic lower respiratory diseases | 45.6 | | 43.3 |
| Injury | 35.5 | | 37.3 |
| Diabetes | 27.2 | ↓ | 25.3 |
| Alzheimer's disease | 25.3 | ↑ | 21.4 |
| Influenza and pneumonia | 17.2 | ↓ | 22.0 |
| Suicide | 12.9 | ↓ | 10.8 |
| Chronic liver disease | 8.5 | ↓ | 9.3 |

↓ = Rates have decreased over the past 8 years in Vermont
 ↑ = Rates have increased over the past 8 years in Vermont
 Data Source: Vital Records, age-adjusted to the standard 2000 U.S. population

D. Cost of Care

Costs to provide care for individuals with ADRD are substantially higher than health care costs for persons with other chronic illnesses and threaten to deplete long-term care resources.

The cost to federal and state government and business was more than \$148 billion in 2005. During that year, Medicare spent \$91 billion on beneficiaries with ADRD (projections: to \$160 billion by 2010, \$189 billion by 2015). State and federal Medicaid spending for nursing home care—\$21 billion in 2005 (projections: \$24 billion by 2010, \$27 billion by 2015). Costs to businesses with employees who are caregivers are estimated at \$36.5 billion as a result of lost productivity, missed work and costs to replace workers who leave the work force due to caregiving demands.(7) Another source, Koppel, R. Alzheimer's Disease: The Costs to U.S. Businesses in 2002, shows the following total business costs for Alzheimer's disease in 2002 (in billions of dollars):

2002

| | |
|---|----------|
| For workers who are caregivers of people with Alzheimer's | \$36.512 |
| For health care for people with Alzheimer's | \$24.634 |
| Total business costs for Alzheimer's disease | \$61.146 |

While Vermont-specific information regarding the costs of ADRD is not available, a lot is known regarding the costs of care for individuals needing nursing home or home based

care. The average annual cost of a Medicaid beneficiary in a nursing home is \$54,000 and the cost of home-based care is estimated at \$28,000. Medicaid pays for approximately 68 percent of the long-term care beds in Vermont. Given the complexity of ADRD we can reasonably expect higher per person costs. (8)

Families and friends provide the majority of long-term care to people with ADRD. During 2005 in Vermont, 17,981 caregivers provided more than 15.5 million hours of unpaid dementia care valued at \$151,796,652 dollars (Alzheimer's Disease Facts and Figures 2007). A Health and Retirement Study found that in 1995, average annual out-of-pocket expenditures for individuals and families of individuals with ADRD for hospitalization, nursing home care stays, outpatient treatment, home care and prescription medications were between \$2,150 and \$3,010 as compared to \$1,350 for people with no dementia.(2)

E. Long Term Care Infrastructure

1. Funding

Vermont has been described by national and state leaders as a trail blazer in the field of long-term care. First in the nation to implement the Choices for Care (CFC) Program under an 1115 Long Term Care Medicaid Waiver, the state has expanded Medicaid Long Term Care entitlement to individuals beyond nursing homes, to include those who are seeking home and community-based services and to demonstrate that by providing preventive services, the need for more costly services can be delayed or prevented. Under CFC, Vermont has implemented an option for spouses to be paid as caregivers; implemented Flexible Choices, a cash and counseling option providing individuals with flexibility in how they use their long term care allocation to best meet their needs; opened its first PACE (Program for All-Inclusive Care for Elderly) center and is piloting options for providing 24 hour care in home and community-based settings. Through other initiatives, Vermont has been an innovator in providing flexible, consumer-driven ways for individuals to "age in place".

Through a CMS Real Choice Systems Change Grant, Vermont is in the process of developing MyCare, an integrated approach to service delivery and financing of primary, acute and long-term care for individuals who are not yet nursing home eligible. This innovative approach will establish a core reimbursement system for integrated care organizations with the goals improving access to services, permitting more consumer-focused flexibility in what services are provided and how they are provided, and ensuring that the services provided are of high quality.

The premise of these reform efforts is to shift the balance of long-term care expenditures to a less costly environment and serve more people in the setting of their choice. As a result, demand for home and community-based services continues to increase. Since

implementation of Choices for Care; between October 2005 and December 2007 nursing facility residents decreased by 9.5%, home-based participants increased by 47.3% and Enhanced Residential Care (ERC) usage increased by 89%. (13)

2. Long term care facilities and supports

a. Residential Care Homes and Assisted Living Residences

Vermont's residential care homes offer a less restrictive living environment than nursing facility care, in a community-based setting. There is great diversity among Vermont's providers with a range of options in setting, size and types of services. The 102 Level III facilities offer 24-hour on-site staffing. As of January 2008, there were 110 Level III and IV residential care homes in the state, with 2,277 licensed beds. Occupancy for residential care homes has averaged between 82% – 86%; however, there is noticeable variation in the occupancy from home to home. (14)

b. Nursing Facility Occupancy and Utilization

As of January 2008 there were 42 nursing facilities with 3,331 licensed beds. Ninety-three percent of Vermont nursing facility residents are 60 years of age or older and 66 percent are 80 years of age or older. (15) While 4% of Vermont residents over the age of 65 are likely to use nursing care facility, the prospect increases with age, to approximately 13% by age 85. While many people live in nursing facilities, there are also many who receive nursing facility services for shorter stays as nursing facilities continue to expand their ability to provide both inpatient and outpatient (for prior residents) rehabilitative services, respite and palliative care. In 2005, the leading reasons for admission to a Vermont nursing facility were to receive short-term rehabilitation or skilled care (64%) and/or case needs related to a significant change in functional status (27%). In State Fiscal Year 2005, 68% of public expenditures for long-term care in Vermont were spent on nursing facility care compared to 32% for home and community-based services. The impact of Act 160 is clearly evident when comparing these figures to the breakdown in 1996, before the implementation of the Act. At that time, an estimated 88% of public expenditures for long-term care were spent on nursing facility care compared to only 12% for home and community-based services. (12) Projected expenditures for the 2007 State Fiscal Year indicate that 65% of public expenditures for long-term care in Vermont will be spent on nursing facility care compared to 35% for home and community based services.(15)

c. Home and Community Based Care

According to the Vermont Assembly of Home Health Agencies (VAHHA), Vermont's 12 member home care agencies served fewer people, employed fewer full-time equivalent (FTE) caregivers, and the number of home care visits decreased only slightly between 2000

and 2003. The number of people served declined from 21,726 to 21,375, a 1.6% decrease. Home care visits declined 5.6%, from 920,906 to 869,441. VAHHA reports that these decreases are due to the more restrictive Medicare eligibility requirements and changes in the Medicare reimbursement from fee-for-service to an Interim Payment System. Medicare comprises 50.3% of all home health agency revenues in Vermont, as compared to 31.3% for Medicaid. The remaining 18.4% of revenues come from "other" sources such as private insurance, self-pay, homemaker and town funds. In fact, town funds comprise only 1% of Vermont's home health agency revenues.

Vermont's five AAAs report an increasing demand for home-delivered meal services. In Federal Fiscal Year 2006, the AAAs provided 661,472 meals, nearly a 13% increase from the Federal Fiscal Year 2001 level of 574,910. As more of the 'old-old' (age 85+) population ages in place, we anticipate an increase in the population of older adults in Vermont who will need to access this service. In Federal Fiscal Year 2006, AAAs provided case management to 8,627 individuals who needed more than information and assistance or brief contact assistance. This represents nearly a 5.4% increase from the Federal Fiscal Year 2001 level of 8,160.

d. National Family Caregiver Support Program (NFCSP)

Family caregivers provide most of the needed care to older adults and children and contribute their own funds to the care for their family member, often giving up or limiting employment, personal goals, and other interests. The NFCSP provides an array of services and support specifically designed for family caregivers. Family caregivers have long been described as the "backbone of long-term care" with nearly two thirds of older persons with long-term care needs relying exclusively on family and friends. Family caregiver support services allows AAA's to meet the unique needs of family caregivers for which there is no other available resource.

Vermonters Served: (FFY '06) 5,402 caregivers, in addition, general caregiver information services were provided to an estimated 153,000 Vermonters statewide through Vermont's AAA Senior Helpline staff.

Services include:

- Information for caregivers about available services
- Assistance for caregivers in gaining access to services
- Individual counseling, support groups and training to help caregivers make decisions and solve problems relating to their caregiver roles
- Respite care to temporarily relieve caregivers from their caregiving responsibilities

- Supplemental services, on a limited basis, to complement care provided by caregivers

e. Adult Day Services

Adult Day Services Provide an array of services to help older adults and adults with disabilities to remain as independent as possible in their own homes. Adult Day Services are provided in community-based non-residential day centers creating a safe, supportive environment where people can access both health and social services. Services include professional nursing services, respite (including support and respite for family caregivers), personal care, therapeutic activities, nutritious meals, social opportunities, activities to foster independence, support and education to families and caregivers. In FY07, Vermont's 13 Adult Day providers served 1,063 people.

f. Mental Health Elder Care Clinician Program (ECCP)

The Elder Care Clinician Program provides mental health services to older adults, aged 60 and older, through the collaboration of Vermont's AAAs and Community Mental Health Centers. Elder Care Clinicians include social workers, psychologists, qualified mental health professionals and mental health outreach workers. Psychiatrists may be part of the treatment team for consultation and prescribing and monitoring medications. An Elder Care Clinician can meet with the person in his/her home or in an office setting. The frequency and duration of treatment depends on individual needs. In FY07, 500 older Vermonters were served through this program.

Services Include:

- Community mental health outreach
- Mental health screening and clinical assessment
- Supportive counseling
- Medication monitoring

3. Long term care capacity

The 2015 Projected Use Rate was derived by taking the 2015 projected use (i.e. number of participants) and dividing it by the 2015 projected number of non-institutionalized people with disabilities, 18 years of age or older in Vermont. Using this approach, a 2015 Projected Use Rate state average was calculated for each of the eight services/programs and then applied to each county. In order to achieve the vision of a more balanced long-term care system, each county would have to perform at either the state average or the county's 2015 Expected Use Rate, whichever is higher. According to the forecast, all counties would need to increase their capacity, some more dramatically than others. Many

home and community based providers reported that the current reimbursement rates make it difficult to meet the current needs and that expanding services would be very challenging. (9)

4. Health Professionals and Caregivers

While dementia specific health professional and workforce data is unavailable there has been significant interest in defining the demand and shortages of health care professionals (including personal care providers). The resulting Vermont research on health professionals indicates that the state is undergoing wide health care shortage in many professions with high turnover in the more low paying - high hands-on care sector. Even with increased efforts to recruit and retain health care professionals it is expected that shortages will continue and potentially worsen as the population of Vermont continues to age. It is reasonable to expect that the shortages and turnover rates for the general healthcare workforce are similarly true for the workforce of professionals caring for individuals with Alzheimer's and their families.

Personal care attendants and licensed nurse's aides are in short supply. The problem is exacerbated by increasing demand for the services, low wages and poor or non-existent benefits. Staff shortages and the frustration felt especially by nursing facility caregivers who had insufficient time to provide quality care create additional barriers to recruiting and retaining people to provide these important services. Shortage of available and well-trained caregivers is also an ongoing problem, and is critical to supporting long-term care in home-based settings. There is an increasing need for home care providers who can offer nighttime and/or weekend respite care, and an apparent shortage of caregivers to provide this type of assistance. The importance of supporting and encouraging family caregivers, including the need to provide them with information they need to hire and manage paid caregivers, is noted by advocates and family caregivers themselves. (12)

F. Public Education and Outreach

The ***Aging and Disability Resource Connection*** (ADRC) Project currently underway (funded by a grant from the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) is assisting the state to establish highly visible and trusted places where people in need of long term services and supports can access comprehensive information, referral and assistance and a streamlined process to access needed services and resources. ADRC specific information will be available for individuals with ADRC and their family caregivers. Area Agencies on Aging are playing a lead role in the Vermont initiative.

SECTION IV: PROGRAM EVALUATION

FOCUS AREA #1 DEMENTIA RESPITE GRANT PROGRAM EVALUATION ACTIVITIES

The Dementia Respite Program was a key component of Vermont's 2004-2007 ADDGS activities and continues to play an important role in supporting the Department's efforts to help family caregivers so they may continue in their caregiving roles and delay or prevent admission of their loved ones to long-term care facilities. The 2004-2007 Dementia Respite Program was funded by the AoA ADDGS (\$196,150 annually) and an annual appropriation of \$250,000 in State General Funds. The program, which is coordinated through Vermont's Area Agencies on Aging (AAA), served 1101 families during the grant period. Dementia respite grants are available to individuals with dementia and their family caregivers who are not eligible for other home and community based programs. To be eligible for a dementia respite grant, the care recipient must be a community-dwelling permanent resident of Vermont, have a formal diagnosis of dementia and meet certain income eligibility requirements. On average, dementia respite grants range between \$1,000 and \$1,500 annually per household. Dementia respite grants can be used to pay for services that provide family caregivers with a break from their caregiving responsibilities such as homemaker services, substitute in-home caregiving or Adult Day services.

Evaluation of the Dementia Respite Grant Program was accomplished using qualitative methods, primarily conducting focus groups with both caregivers and Dementia Respite Grant Coordinators. Focus group interview guides were developed to elicit caregiver and coordinator feedback to understand the effectiveness of the program which is defined by the following evaluation goals:

- ◆ To understand the ease of access to respite care/respite care programming.
- ◆ To understand the extent to which existing respite care resources and programs are responsive to the needs of the target population.
- ◆ To understand the quality of and satisfaction with respite services.
- ◆ To understand the outstanding need or demand for respite services.

One focus group was held with Dementia Respite Grant and NFCSP Coordinators at their regularly scheduled meeting through the assistance of the DAIL Dementia Project Director. The focus group lasted approximately one hour with six coordinators in attendance. Two additional focus groups were held with caregivers, one in St. Johnsbury and one in Burlington. Caregivers were recruited with assistance from Area Agencies on Aging and Home Health Agencies who had direct contact with the target population. In each instance, recruitment was performed by sending out a letter to agencies respective mailing lists and

requesting that participants contact the evaluator to confirm their attendance. Each focus group was convened for two hours during which participants were provided a meal. Participants were queried as to whether respite care would be needed for their participation in the focus group. At the end of each session participants were provided a \$25 stipend, filled out a short survey to collect demographic, socioeconomic and other data, and were asked to indicate their interest in participating in future planning events related to ADRD. Those individuals who were interested in future participation were asked to provide additional information so they could be contacted directly in the future.

A total of 13 caregivers participated in focus groups, 85% were women, 15% men with an average age of 64 years. Average household income of participants was \$55,000, however after calculating incomes based upon family size participants ranged from just under 100% of the Federal Poverty Level to 500% of the Federal Poverty Level (FPL). Financial eligibility for participation in the Dementia Respite Grant Program is 300% FPL, the focus group participants represented current and past users of the Program as well as individuals who never accessed the program. The following Charts provide additional insight to participant characteristics and diversity:

Chart 1: Caregiver Relationship

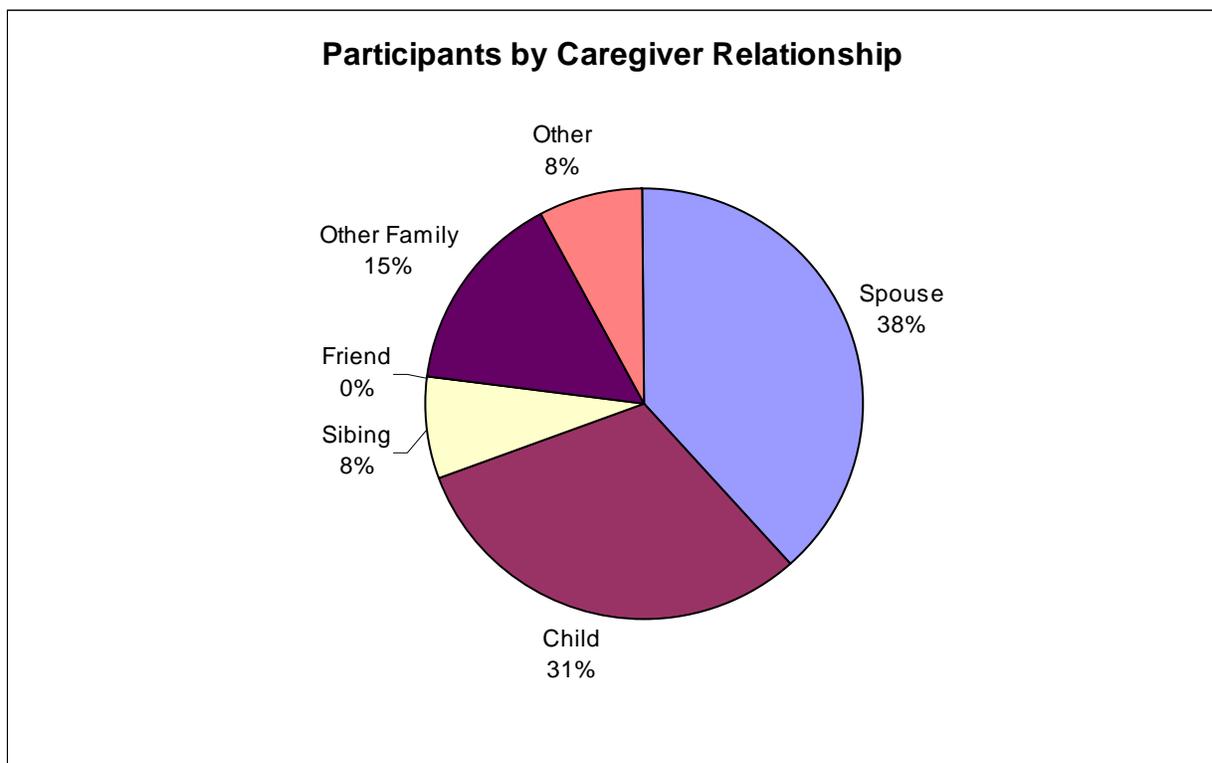


Chart 2: Educational Attainment

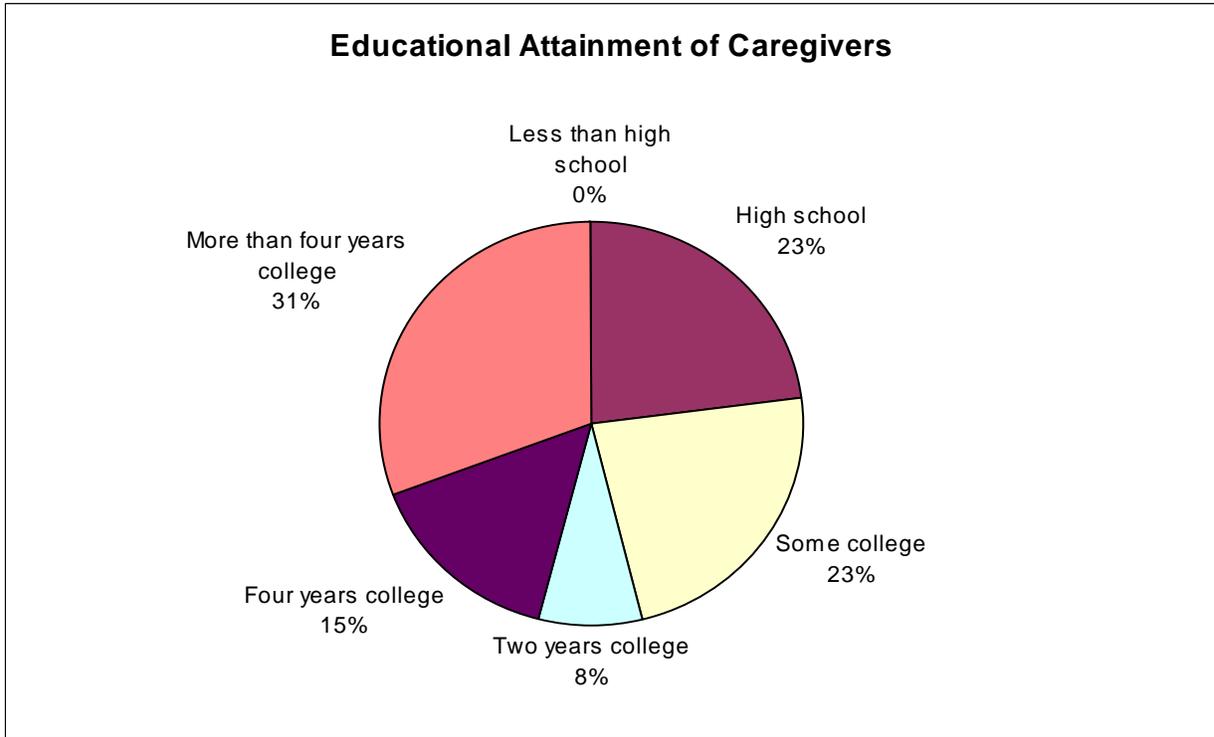


Chart 3: Experience with Program

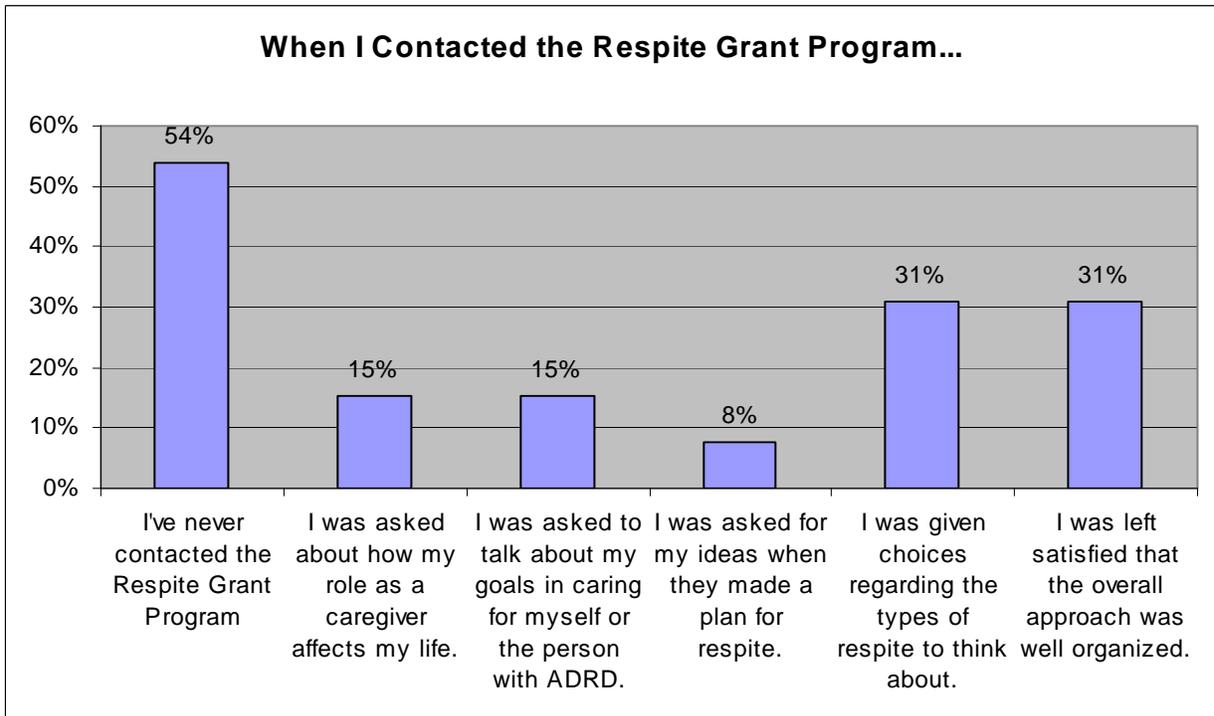


Chart 3 represents data collected regarding participant experience with the Program. Participants were instructed to circle all answers which applied.

While meaningful analysis of this information would require further discussion with participants to understand their responses, given the consistent message regarding the burdensome nature of caregiving by participants, it is remarkable that 54% of individuals participating in the focus group had never contacted the Area Agencies on Aging about the Dementia Respite Grant Program. During the focus group, six of the thirteen disclosed that they did not know about the Program's existence. There were little differences in responses from those who accessed the program and from those who did not.

I. Findings and Lessons Learned

a. Responsiveness to needs of target population

1. Maintain the current program flexibility and scope of respite services.

Given the broad scope of respite services that are provided under Vermont's Dementia Respite program, the general impression is that the types of services which are available are conducive to the respite needs of caregivers. This level of flexibility was seen as a strength of the current program in addressing the needs of a broad group of caregivers. Given the variability in age, relationship to person with ADRD, work status, income level etc. this flexibility is seen as a keystone in the current and future success of the program. There is a general concern that reductions in funds or other programmatic changes could decrease this flexibility.

2. Increase outreach and education strategies to bring caregivers into respite care services during early stages of ADRD. Activities can include heightened outreach by existing Dementia Respite Grant Coordinators and engaging other traditional and nontraditional stakeholders (clergy, doctors, family and friends).

While the broad scope of services provided an opportunity to be responsive to caregivers' needs, it is also widely recognized that there are caregiver barriers to having needs met. Specifically, some caregivers feel that they have a personal commitment to their loved one to provide their care and that accepting respite care would be in breach of that commitment. Others may be concerned about having people in their home and given that performing background checks on respite providers may be the responsibility of the caregiver this is an added deterrent. Other caregivers are reluctant to use what may be seen as public assistance. Irregardless of the type of caregiver deterrent, they are very powerful barriers to assuring program responsiveness to caregiver needs and require outreach, support and education.

The urgent nature of caregiver needs can make accommodating requests for respite services difficult. Many times, caregivers access the program only after they have reached their personal limits. Their first call to the program may occur after they have exhausted their own personal resources and are essentially “burnt out”. Once connected with the program,

*My father and I take care of my mother and he doesn't leave the house and doesn't do social things. No matter who comes to the house he doesn't like them, it is a combination of how much money it costs, not trusting that people will do a good job or feeling that taking this money (Respite Grant) is like taking charity. **Burlington participant***

caregivers often continue their participation in the program. Having said this, there was resounding concern that in order to be the most supportive and effective, caregivers need to be engaged before they find themselves in a crisis. This feedback from key informants and focus group participants is further supported by literature indicating that engagement in caregiver respite programs when a loved one is in early stages of ADRD is an important predictor of caregiver health and wellbeing as well as a predictor of delay of entry into nursing homes.

*I felt guilt the first time I used it and it was heavy. I made arrangements for someone to come and to pay for the care (using Respite Grant) and had to push myself. After a while I had to think, I've donated so much money and time to organizations and charity, now it is time for me to receive a little back. It was hard to do.
Spouse St. Johnsbury*

3. *The network of respite care providers is inadequate to meet the needs of caregivers even when resources are available.*

While the Dementia Respite Grant Program may pay for services responsive to caregiver needs, those services are not readily available to the individual. Many caregivers would greatly benefit from respite services short in duration (such as two hour respite) so they can go to the grocery store, exercise, or engage in outings and social events, however, getting a respite care provider for these events and with one to two week notice is not feasible. There are often minimum requirements for the number of hours that respite services can be provided or the supply of respite providers is such that it requires significant advanced planning. As a result, caregivers feel they are often becoming more socially isolated by nature of the system limitations.

*First, can you get someone, then can you get them for the time that you need them, then the thing with dementia, if you have a different person each time it is confusing and we find it takes a lot of time for folks (respite providers) to feel comfortable and know the routine. It just isn't worth the disruption (to the person with ADRD). **St. Johnsbury Caregiver***

b. Quality and satisfaction with respite services

1. Given the current state of attention to healthcare workforce distribution and quality in Vermont, it is important to assure that the workforce needs of the Dementia Respite Grant Program are represented in existing strategic planning.

It feels like we always need to make compromises, if you want someone available at a rate you can pay, you don't have many choices. If I was paying a lot I would expect a lot but those of us in this room don't have the luxury, we are at the mercy of whomever is coming. St. Johnsbury Caregiver

Given the broad scope of respite services that are covered and the relative ease of participating in the program, the general sentiment is that there is a sense of satisfaction among caregivers. Having said this, concerns with quality and satisfaction were often times outside the purview of the respite coordinator staff and Program itself. Variability with the

quality of staffing – those individuals providing direct respite services – was of concern. While respite service providers employed by agencies were seen as being of more consistent quality, there were significant concerns that family members, neighbors as well as staff of private agencies need specialized training to improve quality and that the existing capacity of respite providers greatly differed from provider to provider.

c. Ease of access

1. Increase service providers (hospitals, memory center, doctors etc) who are knowledgeable and referring to the program.

Once a caregiver connects with the Dementia Respite Grant Program it was felt that access to the program resources was relatively easy. AAA Dementia Respite Coordinators indicated that upwards of 90% of individuals who requested assistance from the program received it and those individuals who did not (which was most commonly because of financial eligibility) were still assisted in identifying other resources. Adult Day Programs, Home Health Agencies, Area Agencies on Aging and memory centers were seen as important referral sources which helped to facilitate and ease access to the program through outreach and education. Several sources of referrals were seen as underutilized including primary care practitioners, the Alzheimer's Association of Vermont, hospital discharge planners and general public/self referrals. Ease of access is predicated upon the assumption that caregivers understand that this program and its resources are available to them. Similarly, the availability of staffing to provide respite is an important predictor of ease of access. The Dementia Respite Coordinators indicated that between 20%-50% of the time even while caregivers gained financial access through participation in the program, they were not always able to access services because of the availability of respite staff. The impact lack of available staff has on ease of access can be compounded

by administrative burdens such as background checks for which caregivers are often responsible.

d. Outstanding need

1. Increase funding available to families to obtain respite services.

In both consumer and coordinator focus groups, participants indicated that in addition to changes in the system (such as increased workforce, flexible scheduling etc.) there still needed to be an increase in the amount of resources available to the Program. The need for expanded services ranged from providing resources to help caregivers who want to continue to work, to those who desired to be caregivers part time and full time. In all instances, participants were concerned that there were other families and caretakers in Vermont that were not accessing the program, who if they began to access the program would overburden it further.

In an attempt to quantify the need for additional resources, three models to define need for respite services were developed, these include:

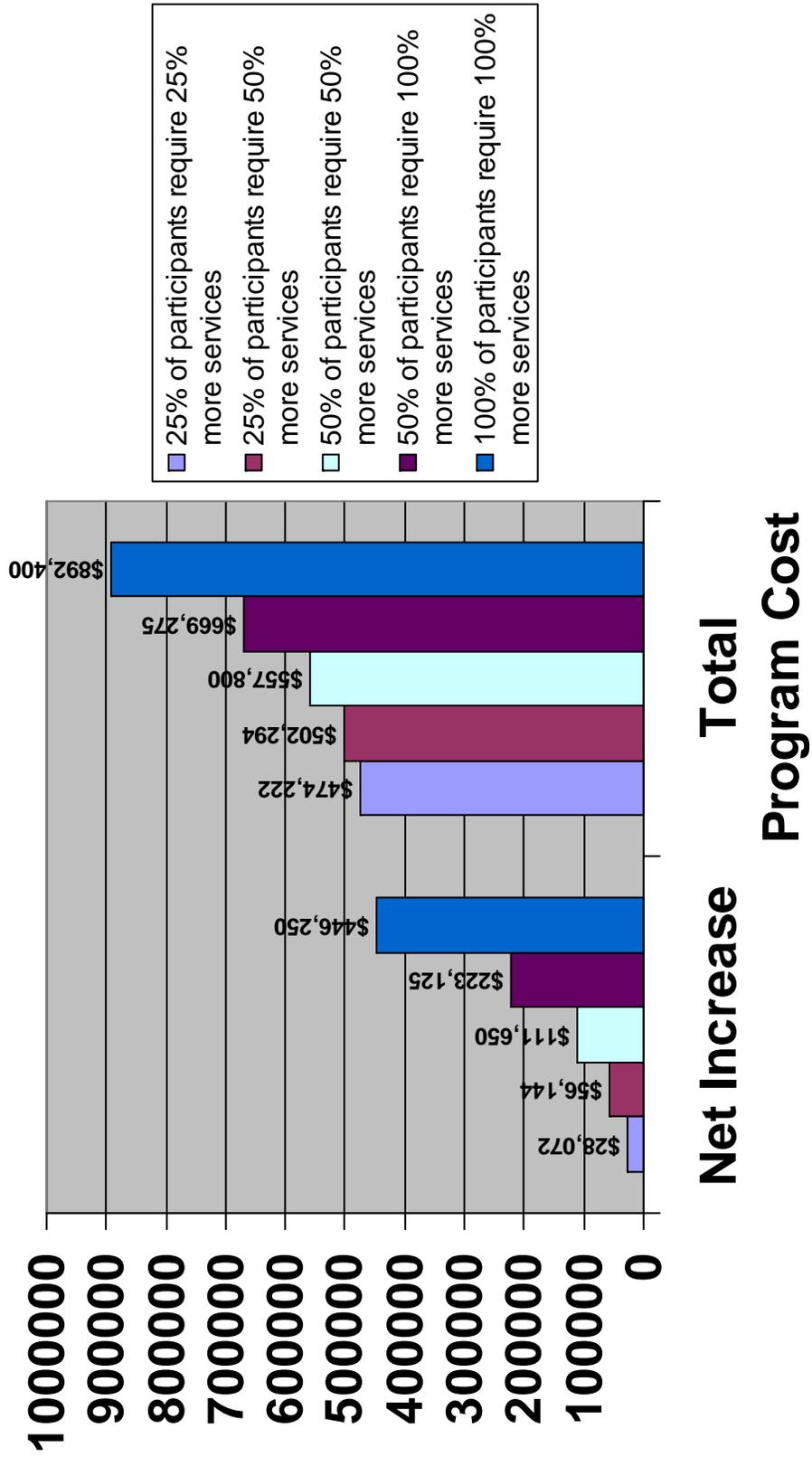
1. Projecting need based upon expanding the volume of services available to current program participants;
2. Projecting need based upon expanding the number of program participants and keeping the volume of services steady and;
3. Projecting the need based upon both expanding the volume of services and the number of participants.

In addition one model for projecting potential cost savings was developed. This model was developed using data from a study funded by the Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy *Does High Caregiver Stress Lead to Nursing Home Entry?* by Brenda Spillman and Sharon Long. In this article the authors profile the personal and informal care characteristics of caregivers reporting high stress “Relative to lower stress caregivers, highly stressed caregivers provide larger amounts of care, are far more likely to be caring for elders who require near constant supervision or exhibit behavior problems, to report that caregiving is a physical strain and to report that caregiving is a financial hardship. They are also more likely to report having used paid help with caregiving, assistive devices, or home modifications and to need help, respite or financial assistance.” Their research suggests that caregiver stress is an important and highly significant predictor of nursing home entry and a reduction in stress can result in a reduction of nursing home placements by 17% over a two year period. Given that 40%-80% (10,11) of caregivers report high physical and emotional stress, provision of respite care to alleviate such stress would result in considerable long term care savings.

Model #1: Need: Providing more services to existing participants

Assumptions:

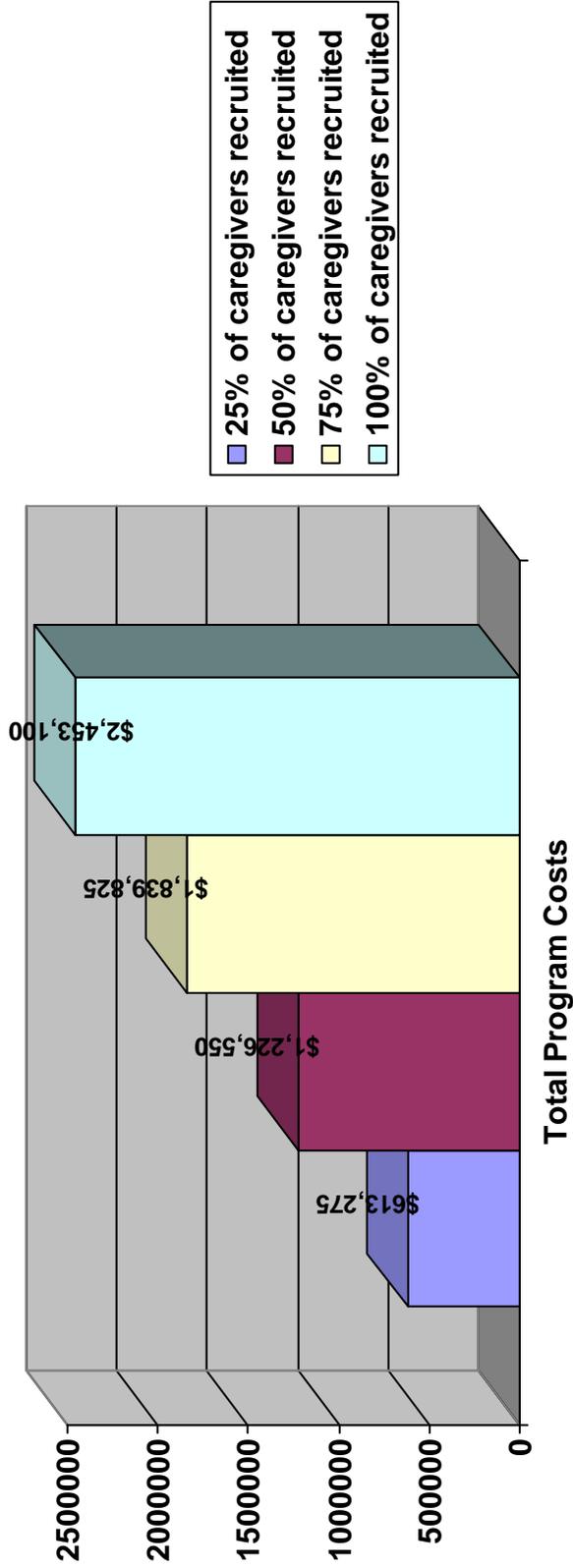
- Average of 350 participants annually
- Original budget of \$446,150 (\$1275 per participant)
- Number of participants remains static, services increase.



Model #2: Need: Increasing the number of caregivers participating in the Program

Assumptions:(2)

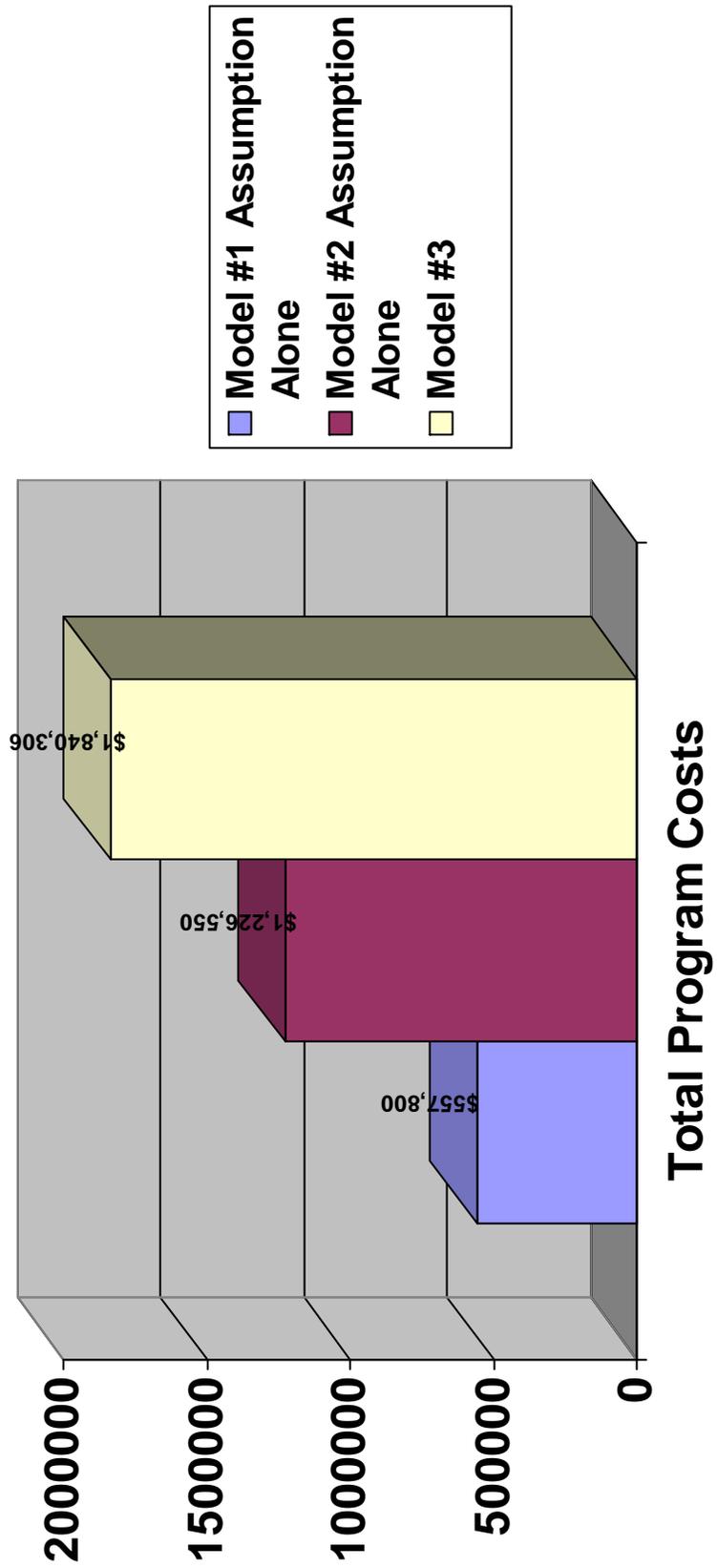
- Original budget \$446,150 (\$1275 per participant)
- Estimated 11,000 persons in Vermont with ADRD
- 70% of individuals with Alzheimer's reside at home = 7700 persons at home, of those persons:
 - 25% of the caregivers have resources to self pay
 - 25% of the caregivers/individuals with ADRD qualify for other programs or have insurance coverage
 - 25% of the caregivers will not use Dementia Respite Grant Program for personal or cultural reasons
 - 25% of the caregivers would use the Dementia Respite Grant Program = potential need for 1460 caregivers/persons with ADRD
- Assume the ability to recruit 25%, 50%, 75% and 100% of those caregivers (481,962,1443, and 1924 participants respectively)



Model #3: Need: Providing more services to a larger number of participants

Assumptions:

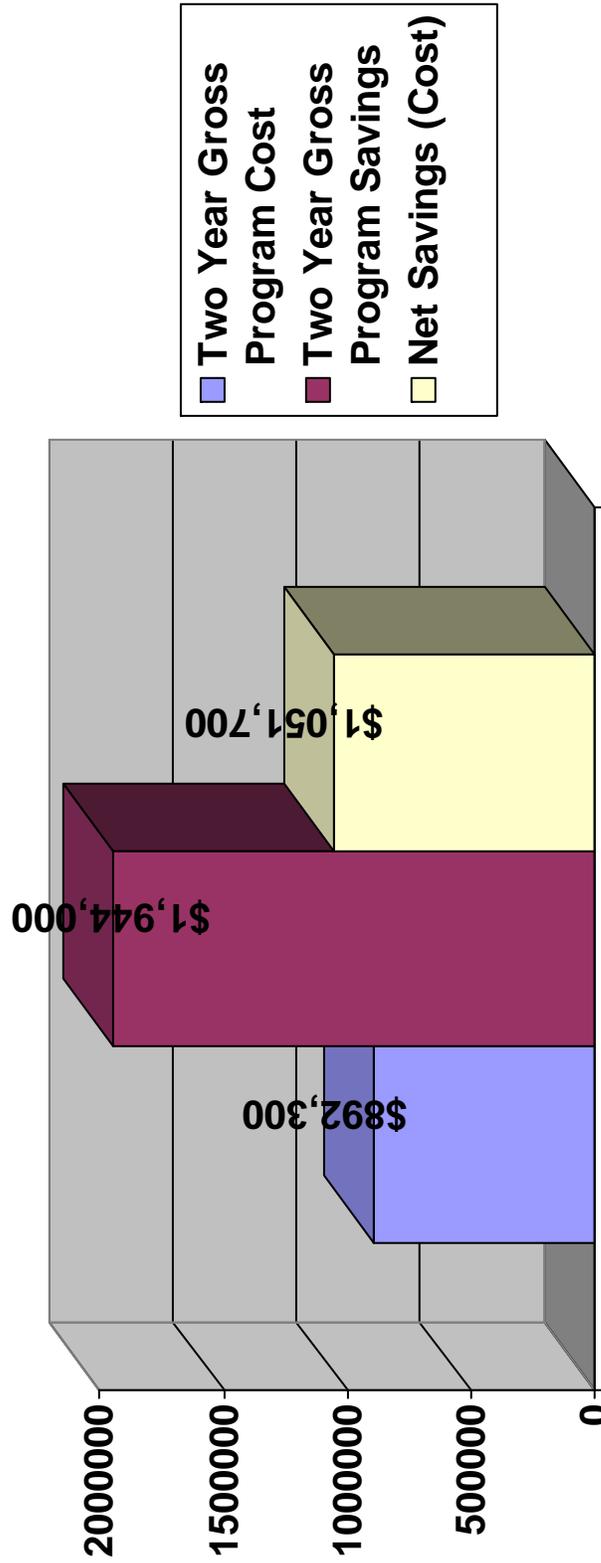
- Original budget \$446,150 (\$1275 per participant)
- From Model #1: 50% of the participants get 50% more services (increased costs for 50% of participants to \$1,913)
- From Model #2: 50% of the potential users (962) are recruited into the program
- Model #3: 50% of the potential users are recruited into the program and use 50% more services (962 participants at \$1,913 per participant) i.e. blended Model 1 and Model 2



Model #4: Program Potential Savings

Assumptions:

- Original budget \$446,150 (\$1275 per participant) per year (\$892,300 two year cost)
- 350 current program participants
- 40% of the caregivers highly stressed physically and emotionally = 140 program participants
- Elimination of stress results in 1.7% reduction in nursing home entry over a two year period = 24 program participants
- 24 program participants diverted for 1.5 years each
- \$54,000 average Medicaid cost for nursing home



Need for additional services:

Utilizing conservative assumptions regarding service utilization and the number of individuals who could likely benefit from the program, still projects resources which are significantly higher than the 2004-2007 program budget. Expansion of the program should be thoughtful and consider the extent and nature of expansion that would provide a meaningful impact to the target population. For example in addition to expansion of the resources given directly to program participants, additional consideration for funds to administer the program – such as outreach, education, developing referral patterns from new sources etc – will impact the resources necessary to improve the program.

Potential program savings:

Holding all assumptions as true, the potential savings is approximately 1 million dollars given current program parameters. This figure is most likely not accurate, primarily because the current program funds less than one hour of respite care per week (1 hr private respite care provided by Licensed Practical Nurse is \$27, \$1275 average grant would fund 47 hours per year) and while evidence regarding the appropriate “dosage” of respite care was not found, it seems reasonable to assume that one hour per week of respite would not adequately support those caregivers with high physical and emotional stress.

e. Other outstanding issues

As with much qualitative research, convening stakeholders and consumers of services to discuss their needs and the systems of care often provides insight to issues outside the primary research questions of the project. Additional issues discussed included:

1. Lack of insurance options for caregivers

There were instances where caregivers felt that they had enough resources to stay at home part time or full time to provide care, however, doing so would leave them with no insurance or having to pay for insurance out of pocket, thus making it unaffordable. This was a deterrent to fulfilling a more prominent role as a caregiver and participants felt that the cost/benefit of providing resources for insurance was good.

I love doing it, I can't explain the feeling that I have when I do it. I would do it full time if I could make a living out of it, but I have a job and a health and retirement plan. If I could quit my job tomorrow and do it I essentially would. Burlington, Child of person with ADRD

2. Addressing the health and wellness of individuals with ADRD.

Age is a risk factor for a number of illnesses, many chronic in nature. Providing respite care

for individuals with ADRD and a chronic disease, such as diabetes, is a challenge. Given the nature of some chronic diseases, services that could have been provided by a neighbor require the services of a registered nurse. Given the expenses for higher technical staff, respite care becomes increasingly cost prohibitive, even with support from the Program. Similarly, the training and technical requirements to provide this level of care results in a smaller pool of professionals available to provide respite.

3. Lack of public awareness and support.

There was an overarching sentiment that networks of caregivers and services were generally lacking and that caregivers increasingly retreated and socially withdrew. As they retreated and their loved one's disease progressed, the stressors dramatically increased. Being in public and having to explain why their loved one is acting the way they are acting; further separation from their friends because they did not know how to respond to their loved one's behaviors; isolates caregivers. Focus group participants themselves said they knew very few if any persons with ADRD or caregivers before they themselves became caregivers, and yet still they did not know many of the other people in the focus group who lived in their own community and dealt with the same issues they did.

Focus Area #2 CAREGIVER BRIDGES PROJECT EVALUATION ACTIVITIES

The Caregiver Bridges Project was another important component of the 2004-07 ADDGS activities. Using the National Association of Area Agencies on Aging (n4A) Making the Link Program as a model, partnerships were established between primary care practices and other community providers to improve services to support individuals with ADRD and their family caregivers. This project was supported with \$140,000 of AoA ADDGS funds. Project implementation was coordinated by the Memory Center at Fletcher Allen Health Care, Partnerships were formed between seven primary care practices in four areas of the state, the Council on Aging for Southeastern Vermont (COASEV), the Area Agency on Aging for Northeastern Vermont (NEVAAA), Champlain Valley Agency on Aging (CVAA), the Middlebury Project Independence Adult Day Center, two community mental health centers (HowardCenter and Counseling Service of Addison County) and two private mental health practitioners. AAA case management staff and/or a mental health counselor were co-located at the primary care practices to provide on-site screening for cognitive impairment, screening for depression and caregiver stress, information and referral services, case management and/or mental health counseling. All project partners were provided with training on ADRD-related diagnosis and treatment. In addition, primary care practitioners were offered regular consultation with geriatric psychiatrists from the Memory Center at Fletcher Allen Health Care (FAHC) during the project period. A total of 51 individuals with ADRD and 69 family caregivers obtained services through the Caregiver Bridges Project.

The evaluator was able to elicit information from four of the seven practices as well as their partner community based organizations regarding their experience with the Caregiver Bridges Project. Information was gathered to accomplish the following goal and objectives:

Goal:

- ◆ To develop recommendations regarding further implementation of the Caregiver Bridges/Making the Link Project as well as support of existing practice sites.

Objectives:

- ◆ To understand the professional value (community and primary care practice) with the Project.
- ◆ To understand the enabling factors contributing to thorough implementation.
- ◆ To understand the barriers to thorough implementation.
- ◆ To understand the critical components of practice “readiness”.
- ◆ To understand the consumer satisfaction and consumer value with the Project.

In order to understand the full impact of Caregiver Bridges and the practice experience implementing it, a certain amount of “deconstruction” needed to occur in order to be able to gain insight and accomplish the evaluation goal. Given the nature of primary care practices and implementing new models, the evaluation methodology included an approach which first analyzed the impact and level of satisfaction the model produced within the practice and second gauged the impact that operationalizing such a model in a primary care practice had on the program success. More simply stated, did the practice staff feel that: 1) the model and model components accomplished the objectives of the program to identify individuals with ADRD and their caregivers and link them with necessary community resources and 2) was the model able to be operationalized into the practices existing clinical and administrative systems in order to fully function and continue into the future in the absence of ongoing grant funding.

a. Qualitative Review of the Model and Model Components

Interviews were conducted with practice staff as well as community based organizations regarding the model.

1. Dedicate external staff to supporting the implementation of the project who focus upon transfer of skills and expertise to the practice staff.

Practices felt that while implementation of the model was difficult at times, there was inherent value to participating in the project. Each practice and the community based partners were dedicated to implement changes to improve care for their patients and their communities. They felt that there was value in having FAHC Memory Center staff supporting this work in that the staff continued to push the model and implementation forward and provide technical expertise. Having said this, they were concerned that once the project ended there would not be an internal drive and resources (both expertise and person power) to continue the project.

2. If similar initiatives are going to occur they should continue to replicate this model.

Interviewees consistently felt that the model components were helpful, effective and did not suggest changes or alternative arrangements or components. They also felt that caregivers and patients experienced the value of having Caregiver Bridges services available on-site at the primary care practice.

Given the importance of evidence based interventions, continued attention to model outcomes should also be an important consideration in continuing to promote this model. As part of the Project implementation FAHC Memory Center staff was able to collect limited outcome data, however, this evaluation focuses mainly on process measures versus outcome measures.

3. Provide more frequent physician team support.

Sites consistently indicated that more frequent physician team support (in the form of inservices, trainings or professional consultations) would be recommended if Caregiver Bridges was to be replicated.

4. When implementing, develop strategies to address the unique features of how the practice operates in order to facilitate adoption of new practices.

When asked regarding the most difficult and easiest components of the model to adopt, no one thematic area emerged. Each practice indicated that they had different experiences with other projects that prepared them in some ways, as a result, each practice was unique in the challenges and strengths that they brought and their ability to implement the model components.

When asked what practices would do differently, they indicated that they would have addressed issues that would facilitate or deter implementation which were known to the practice in advance. Issues such as having practice leadership buy-in, increasing communication and dedicating a contact person to work with FAHC Memory Center staff (who was delegated time, not just responsibility) and developing an implementation strategy that was incremental and phased in over time. Similarly, practices responded very differently when asked where the model (or system supporting the model) broke down most frequently and least frequently. Given the variation in system strengths and weaknesses, implementation of the model should be tailored to the individualized practice system.

5. Efforts need to focus equally on increasing practice capacity for change as well as supporting adoption of specific care models.

When discussing the longevity or sustainability of the Caregiver Bridges Project, interviewees were concerned that without the external help, in terms of the technical assistance, regular check-ins, prompting and encouraging that the Caregiver Bridges Project may not continue. While Memory Center staff provided the much needed support to keep the project functioning during the grant period it is not realistic that such an approach is sustainable. Similarly, in the absence of grant funding the practices felt that they would be challenged to be able to provide the services ongoing because of the lack of funding from private or public payers. While payment policies are outside of the purview of the practice, they are important components of the overall health care system which enables projects such as Caregiver Bridges to function.

b. Practice Readiness Assessment and Qualitative Review of the Practice Systems

A practice readiness assessment was chosen as an important tool in the evaluation. Given the qualitative nature of the data collected, the assessment provided a more objective view of the practice's ability to effectively implement the Project. Conventionally, primary care practice systems and staff are equipped to treat acute health care issues. From a quality improvement perspective, the Caregiver Bridges Project was attempting to improve the quality of dementia care by shifting the practice focus from one designed to treat acute illnesses to one designed to treat more chronic illnesses such as ADRD. Applying both a quality improvement and chronic disease perspective was critical to this evaluation. The practice readiness assessment was adapted from an existing tool which was developed by the MacColl Institute for Healthcare Innovation, Group Health Cooperative. Since the mid-1990s, the Institute has focused on research and quality improvement efforts to improve the quality of care for the chronically ill, with the goal of bridging the gap between patients' needs for comprehensive chronic care and health care delivery systems originally designed mainly to treat acute illness. The Institute is the national program office for The Robert Wood Johnson Foundation's program on Improving Chronic Illness Care. The survey was designed to help systems and provider practices move toward the "state-of-the-art" in managing chronic illnesses such as ADRD which includes the support of patients' families and caregivers. The tool has been used to help teams identify areas to improve the readiness of their practice to improve quality of existing services as well as inform policymakers regarding the programmatic improvements, policy issues and financial considerations to improve and spread improvements in chronic disease care.

The practice readiness assessment examines the practice systems from seven perspectives including:

System Level Adoption

Connection with Community Supports.

Systems to Support Self-Management

Clinical Decision-Making

Administrative Systems and Workflow

Information Systems

Continuity of Care Activities

For our purposes, the tool was significantly scaled down to reduce the number of questions required of the practice staff. Rather than serving as a desk-top audit of the practice it provided an opportunity to discuss the practice systems and understand the difficulties and ease to changing the systems to accommodate the objectives and model components of the Caregiver Bridges Project. This was accomplished by completing the tool in person and discussing the results.

1. Sustainability requires implementing individualized strategies with primary care practices to change the system of care in addition to implementing models or protocols designed to improve patient outcomes.

The ability or inability of a practice to adopt new models, protocols or processes is not necessarily indicative of the quality of care or competency of the professionals in the practice. Excellent care can be provided by organizations which are less adaptable to change. Interviews with practice staff underscore the difficulty and resource intensiveness of changing practice patterns and behaviors. Given the body of research that has provided insight to evidence-based methods of practice behavior change, it is imperative that projects such as the Caregiver Bridges Project pay careful attention to not only what they want to change regarding practice behavior but also how to promote sustainable behavior change. Just as an individual requires goal setting, commitment, trial and error and personal reflection before becoming proficient and adopting long lasting behavior change, a practice follows similar developmental processes. Of particular interest in this evaluation are the areas where practices felt that their readiness to change systems could be improved, these included:

- Funding – in order to promote lasting change funding streams in either ongoing grants or billable services would be required.
- Organizational Goals – while seemingly simplistic, stating the organizational goals (and setting realistic goals) for improvement of care for individuals with ADRD is important in gaining organizational and professional commitment.
- Provider Education – ongoing support of development opportunities by peer professionals specifically targeting difficult areas of practice change or patient treatment.
- Feedback on Practice Performance – providing practices an opportunity to reflect on their activities and the extent to which they are meeting their pre-determined goals.
- Feedback on Community Programs – assuring that the level of information exchange and communication between primary care providers and community providers occurs in a manner that is efficient, accurate and timely enough to inform patient care.

The evaluation underscores the complexity and resource intensive nature of engaging in activities to change primary care practice behavior. While the Project was very thoughtful about adapting best or evidence based practices to change outcomes of individuals with ADRD and their family caregivers, there needed to be further exploration of the types of systems changes that would be necessary to support the Project activities. In the absence of efforts to change the practice system, the Project risks that the investment made does not have a long lasting effect and essentially, practice behavior reverts to it's original form; to a place it was before the Project began.

FOCUS AREA #3: PROFESSIONAL EDUCATION EVALUATION ACTIVITIES

Training on ADRD-related issues and interventions to support family caregivers were essential to the 2004-2007 ADDGS activities. In addition to the training provided in conjunction with the Caregiver Bridges project, seven other training opportunities were provided to more than 400 community providers. Participants included case managers from AAAs and Home Health Agencies, developmental services providers, elder mental health counselors, the Alzheimer's Association of Vermont and DAIL staff.

Given the diversity of participants as well as content of the dementia trainings, it was unlikely that an evaluation of participants and their information retention was a viable approach to understanding the impact and value of these events. In order to maximize evaluation efforts the evaluator attempted to identify an approach that would unify the evaluation of the disparate participants and content and provide insight for DAIL regarding future training opportunities. While the participants and the content varied, upon completion of the training each participant returns to their place of work where it is hoped that they would apply what they have learned in that environment. Similar to other evaluation activities, the approach was to examine the systems and the relative ease or difficulty of training participants to apply their knowledge to the system of care in which they practiced. Once again, instruments which measured organizational readiness to change, (with a particular focus on changing organizational systems) were used to develop a survey of training participants.

In order to implement the survey, a database of survey recipients was developed from training registration information obtained through DAIL. An unduplicated list of entries was created, surveys were sent with a self addressed return envelop requesting a two week return date. To encourage a high response rate and quick return, a drawing for \$100 was offered for all individuals who replied within a two week timeframe and then another \$100 for all individuals who replied within a four week timeframe (essentially doubling the drawing chances for early responders). The survey instrument included a tear off sheet at the end so that responses were separated from identifying information which was used only for the drawing.

Of the 285 unique individuals, eight surveys were returned for incorrect address. Of the 277 remaining surveys, 72 were returned for a 26% response rate. Data was input into an Excel database and simple univariate analysis was completed. Surveys results were analyzed for the entire cohort of respondents, for respondents identifying as Management/Administrative staff and for respondents identifying as Direct Care/Caregiving staff. Surprisingly, no significant differences were observed between responses from Management vs Direct Care staff. As a result, analysis focuses on all respondents.

1. Consider providing training on development and monitoring of organizational goals related to ADRD.

As demonstrated in the following charts, respondents indicated that 29% of their organizations do not have goals or do not actively review goals regarding providing or improving care for individuals with ADRD, furthermore 15% of respondents indicated that they did not feel they had an adequate understanding of how to do goal setting within their organization. Engaging in goal setting develops a two-way dialogue and helps to get all stakeholders on the same page, clarifying assumptions and bringing to the surface misunderstandings in what you are to accomplish. Staff of organizations who contribute to setting goals are engaging in a participatory process which gives staff a genuine “stake” in accomplishing the goals because the process of joint decision-making builds trust and mutual respect. Finally, setting goals makes your planning easier in that it breaks down challenging tasks that might seem overwhelming to manageable, measurable activities.

Chart 4: Goal Setting in Organization

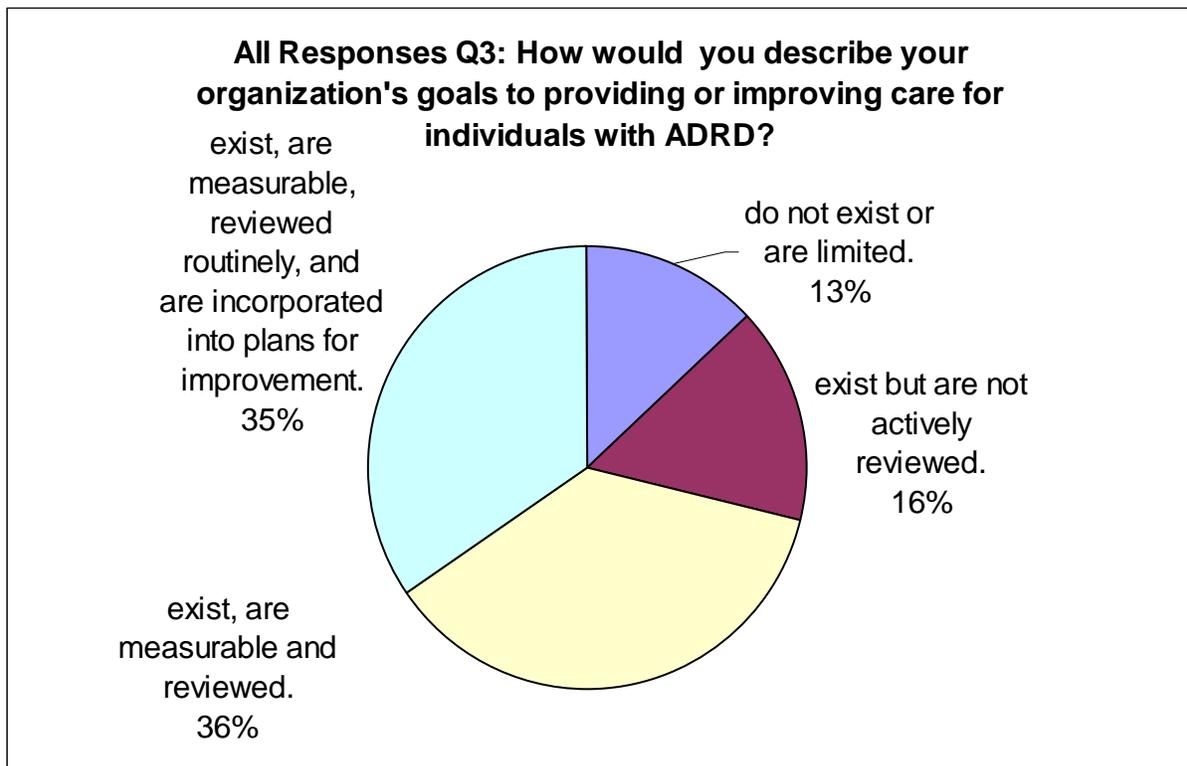
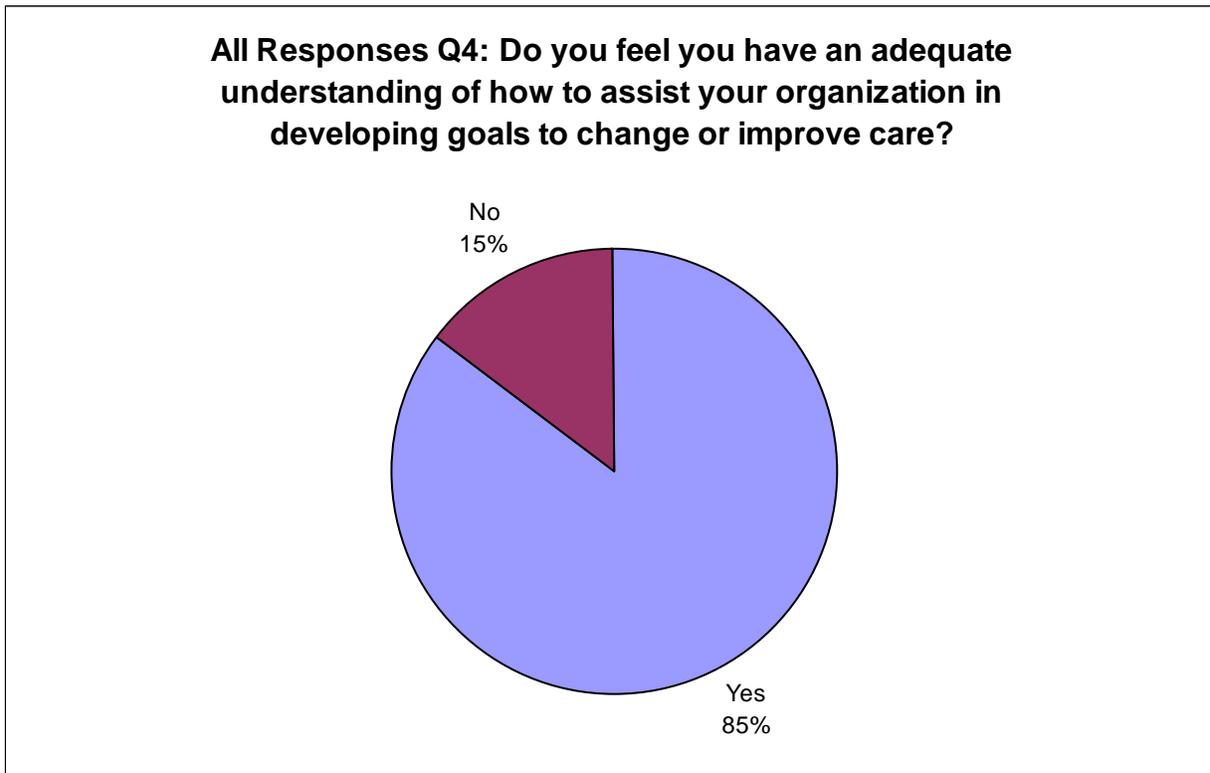


Chart 5: Respondent Understanding of Goal Setting



2. *Improve the ability of professionals to provide standardized screening and assessment for individuals with ADRD.*

Forty percent of respondents felt that standardized screening and caregiving guidelines were either not available or not integrated into care delivery, as demonstrated in Chart 6, similarly 38% of respondents felt that they did not have adequate understanding to change this within their organization (Chart 7). Standards of care provide assurances to the people served that the care provided is based upon objective guidelines versus socioeconomic or demographic characteristics. Ideally, caregiving decisions are based on explicit, evidence based guidelines supported by professional research. The guidelines should also be readily available for discussion with patients and families so that they can understand the principles behind their care and become more engaged as care partners.

Chart 6: Presence of Standardized Screening and Caregiving

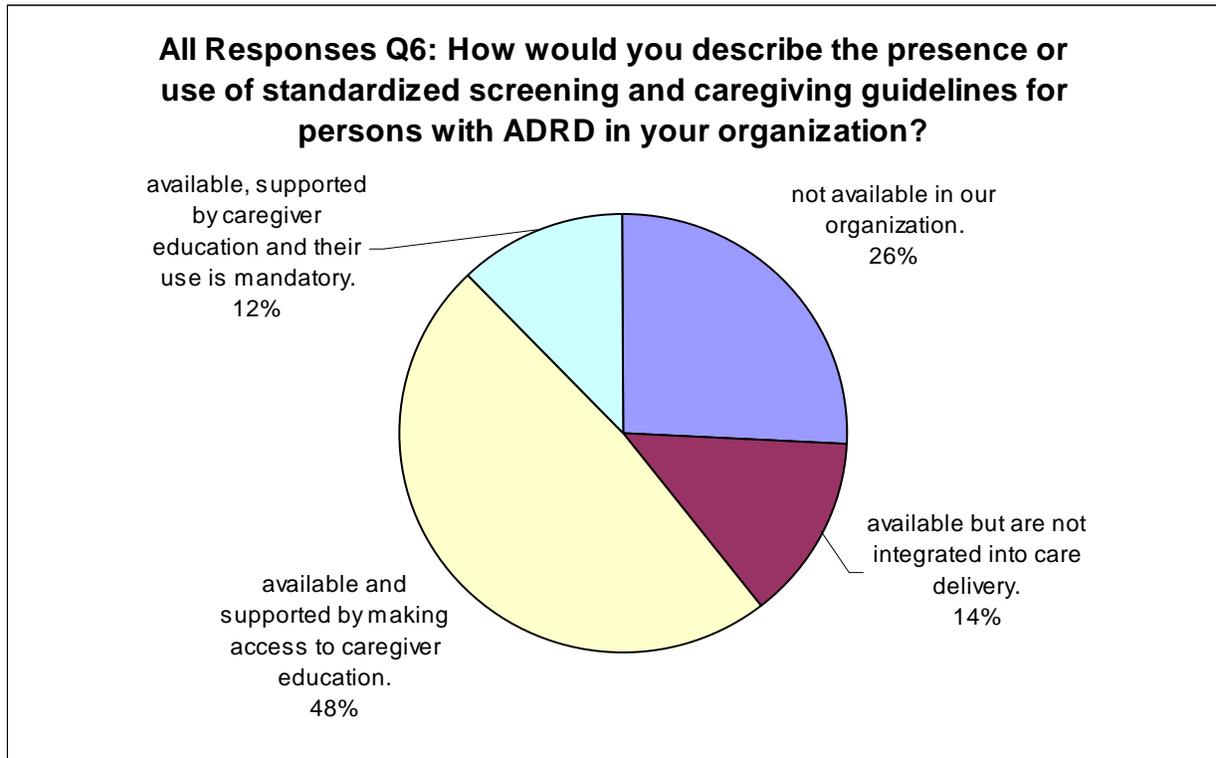
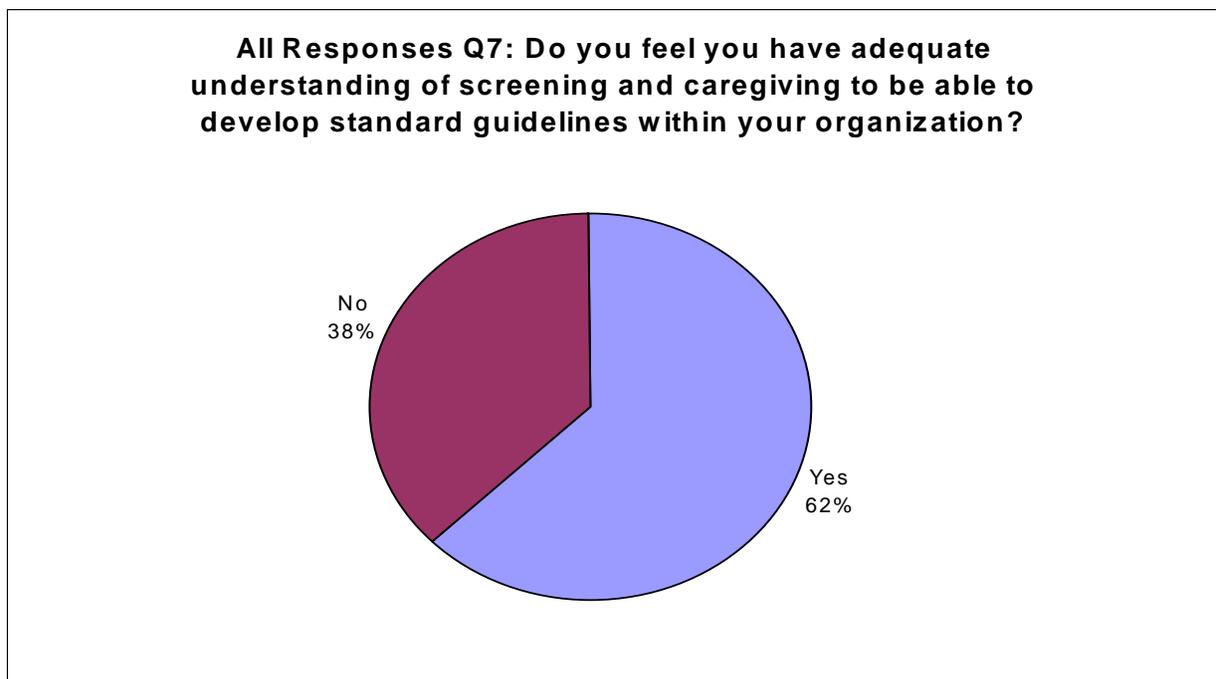


Chart 7: Staff Development of Standard Guidelines



3. *Develop a statewide training plan which identifies strategic skill building, core professional competencies and content which improves care of individuals with ADRD.*

Forty one percent of respondents indicated that their organization's approach to providing professional education is sporadic and 30% feel that they do not have adequate training available to support their work (see Charts 8 and 9). Staff is a critical ingredient for quality elder-serving organizations. Those who make caregiving decisions need ongoing training to stay up-to-date on the latest evidence, using new models of provider education that improve upon traditional continuing education and assure that the core competencies expected of caregivers are met. Programs often attribute their success to effective staff, and research shows that professional development can enhance the skills of both new and longtime staffers. Professional development is a broad term that can refer to a variety of education, training, and support opportunities including:

- Higher education training, such as continuing education courses and degree programs;
- Pre-service training and orientation for new staff;
- In-service training provided by programs to current staff;
- Training seminars and resource centers provided by external organizations;
- Local and national credentialing systems and programs;
- Local and national conferences;
- Mentoring programs; and
- Ongoing informal resources, such as newsletters, online discussion boards, and "brown bag" lunches for staff members to share ideas and expertise.

Chart 8: Approach to Providing Professional Education

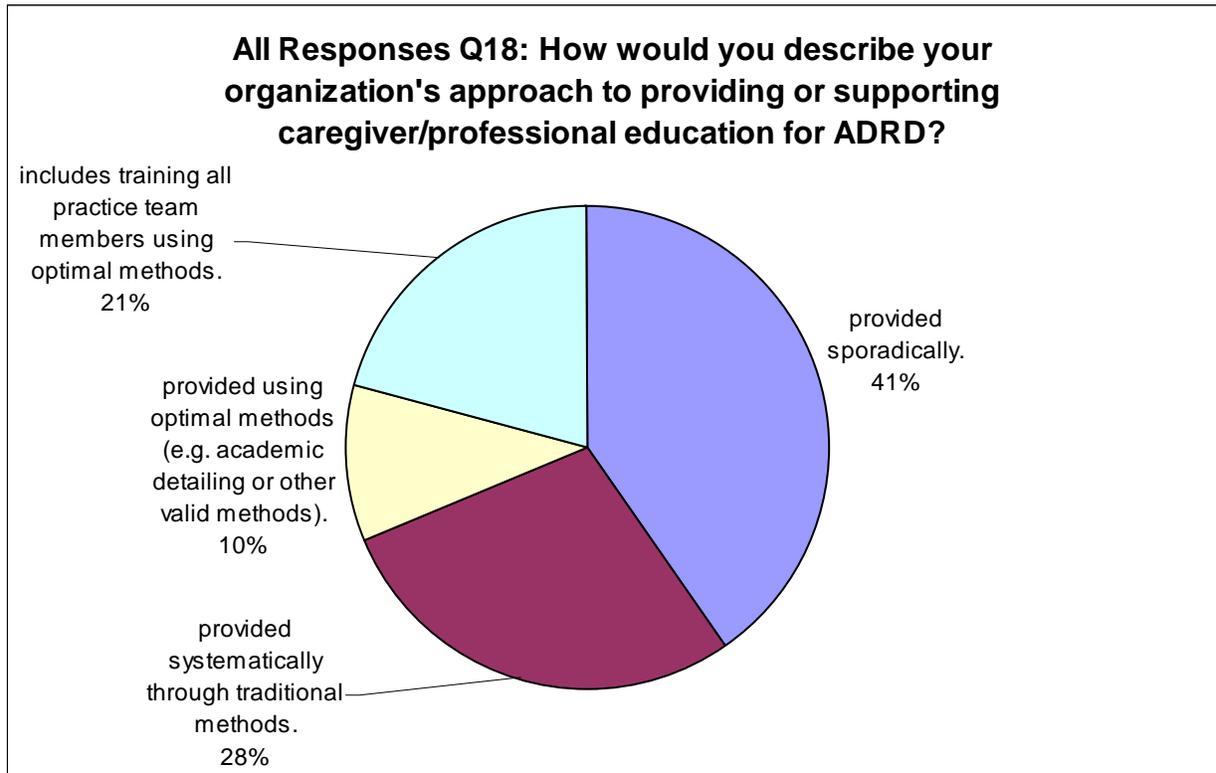
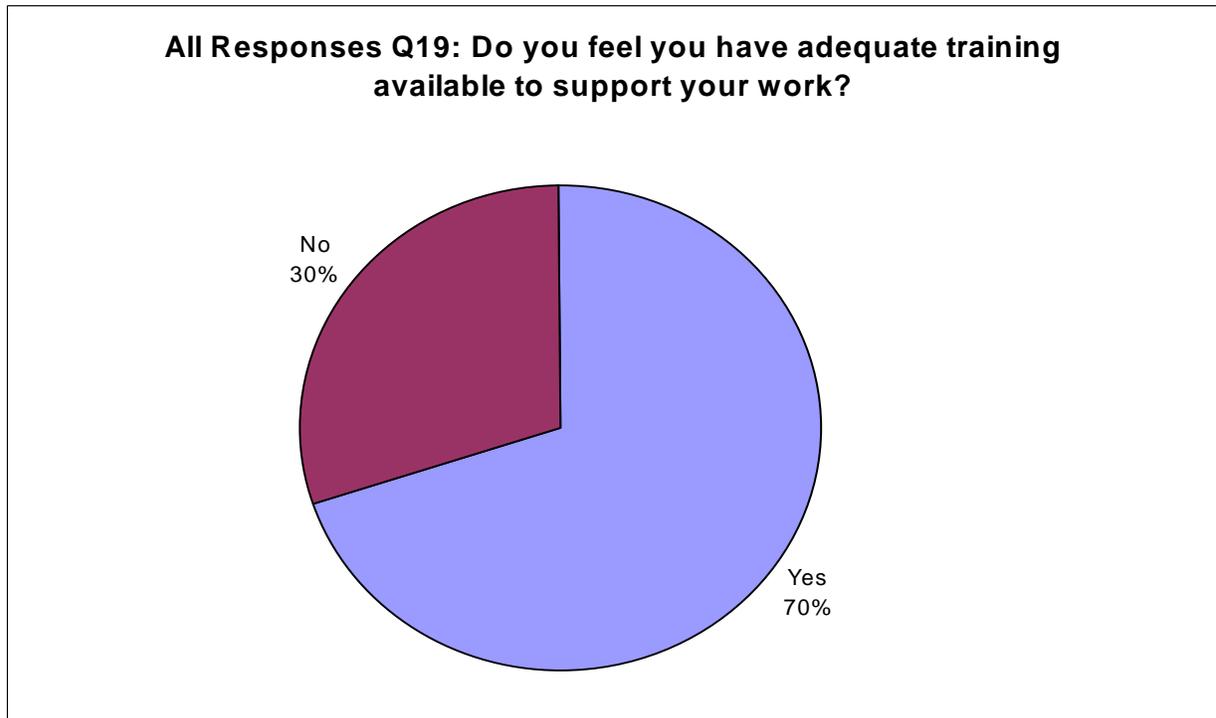


Chart 9: Adequate Training to Support Professional Work



SECTION V: DISCUSSION

DAIL has had a longstanding history of developing programs which address the most outstanding issues of aging Vermonters and their families. Their efforts to develop innovative systems of care have made them recognized as trailblazers in the aging services community both on a national and local level. The results of this evaluation underscore the importance of creating a balance between development and promotion of excellent and innovative programs to support individuals as well as integration of these programs with each other and all parts of the long term care system.

As the state moves towards the development of a State Plan for Dementia, findings of this evaluation will help drive an approach which identifies areas for systematic improvements, integration and helps create a vision for continuity across programming. It will also assist DAIL in the future development of programs, particularly those which assure a strong safety-net for our priority populations by aligning both the function of new programs and the systems in which they operate to assure full integration and operation within the long term care system.

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