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Living with Alzheimer's Disease: A Study of Adult Day Health Services in Massachusetts

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Living with Alzheimer's Disease: A Study of Adult Day Health Services in Massachusetts

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In Partnership with:
Alzheimer's Association-MA/NH Chapter
Massachusetts Adult Day Services Association

alzheimer's  association®



October 2008

Full Report available on the following web sites:
Alzheimer's Association-MA/NH Chapter (www.alz.org/MA/)
Massachusetts Adult Day Services Association (www.madsa.net)
Gerontology Institute, UMass Boston (www.geront.umb.edu)

Dedication

This report is dedicated to the hard-working staff from adult day health centers in Massachusetts who serve and support families, and participants with Alzheimer's disease and related dementias and other needs. We recognize the important work you do.

(Dedication by Susan Lubin representing the sentiments of the Spring 2008 Aging and Social Policy Seminar, UMass Boston.)

Acknowledgments

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EXECUTIVE SUMMARY

“If it’s a concern to the family, it’s a concern to us.”

ADHC Provider, March 2008

Introduction

The role of adult day health care (ADHC) is gaining increased attention as the nation prepares for the large cohort of baby boomers entering their later years. Many boomers are aging with physical and cognitive impairments, including Alzheimer’s disease and related dementias. Projections indicate that Massachusetts, along with the nation as a whole, is experiencing an increasing rate of older persons as baby boomers enter late-life. The Commonwealth can expect that persons with Alzheimer’s disease and their care partners will need community-based services that are specifically designed for adults with cognitive impairments. However, a report by the Robert Wood Johnson Foundation (2003) found that there is a serious lack of adult day care services for the state’s elderly population. The 2003 report found that Massachusetts is only meeting 62% of needs for adults with physical and cognitive impairments, and at least 78 more programs are needed in the state. Yet, programs in Massachusetts continue to close (Gottler, 2008).

Research Objectives

The specific objectives of the study were to: (1) describe existing practices of adult day health care services in Massachusetts for persons living with Alzheimer’s disease and related dementias, (2) explore programs that are specifically designed for participants who are in late-stage dementia, (3) address challenges that adult day health care services are now encountering, and (4) envision new paradigms for meeting the needs of persons with early-stage and early-onset dementia.

Methodology

This study was an applied research project conducted under the auspices of an Aging and Social Policy Capstone Seminar at the University of Massachusetts Boston, College of Public and Community Service, during Spring 2008. There were two community partner organizations for this research project, the Massachusetts Adult Day Services Association (MADSA) and the Alzheimer’s Association-MA/NH Chapter. Two methods of data collection were utilized in March 2008, an electronic survey and in-depth interviews.

A total of 155 adult day health care providers were identified as potential participants in the research project. The overall response rate was 60% (93) of the adult day care health providers either partially or entirely completed the survey. Slightly less, 43% (66), of the adult day health care providers entirely completed the surveys.

The second method of data collection involved qualitative interviews with eight adult day health care providers. The eight adult day health care providers were purposively chosen based on their location (convenience to the student researchers) and the known provision of Alzheimer's disease specific programs.

Results

The respondents to the electronic survey represented facilities from 11 of 14 counties in Massachusetts. Only Dukes, Franklin, and Nantucket counties were not represented. The average number of years in operation was 18 years and ranged from one to 33 years. The respondents were serving a total of 5,746 participants of whom 36% were male, 64% were female. Almost two-thirds, 61%, of responding sites served participants 65 to 84 years old. Approximately 22% reported serving participants aged 64 years and younger. Those aged 85 years and older were served by 17% of sites.

Participants attended adult day health centers from less than three months (9.6%) to more than 10 years (4.5%). Attendance between three months and three years was reported by 56% of sites; greater than 3 years and up to 10 years was reported by 29% of sites. Sites reported 67% of participants were subsidized, 17% pay out-of-pocket, and 17% use a combination of sources to make payments. Of the 15% with waiting lists, respondents reported a wait period ranging from two weeks to three months. At the time of the survey, therefore (March 2008), there were 219 persons who would have waited an average of 5.25 weeks for adult day health services in Massachusetts.

Responding sites (n=75) identified 1,609 participants as having been diagnosed with Alzheimer's disease or a related disorder. An additional 987 participants were reported as having cognitive impairments but not having formal diagnoses. Thus, in the sample, at least 45% of the persons in adult day health facilities in Massachusetts were reported to have cognitive impairments, with or without formal diagnoses. That percentage would likely be higher if all 93 sites responded with the specific data.

The major co-morbidities reported in order of prevalence were: diabetes (93%), mental illness (84%), mental retardation (68%), and blindness (55%). Also mentioned were Parkinson's disease, traumatic and acquired brain injury, multiple sclerosis, Huntington's disease, stroke, cancer, cardiac disease, and hypertension.

Many activities were reported as adaptable to varying stages of the disease: as the disease progresses, sites reported increases in counseling services for care partners and a focus on comfort for the participant. One respondent summarized their approach simply as: "*Remembering that behaviors are not intentional, that they are part of the illness, assists staff in dealing with situations appropriately.*" Another respondent stated, "*There are weekly support groups for*

only the participants as well as biweekly drop-ins for family members who require talking to licensed social workers. Furthermore once a month the Massachusetts Adult Day Care Association holds open support group meetings which is geared for anyone to attend.”

At the time of the survey, 32 sites reported that 541 participants were currently enrolled in the Safe Return® program (mean = 17 participants enrolled per facility). Just over a quarter of the sites (29) reported that the physical structure of the ADHC had purposely-designed spaces intended to serve participants with Alzheimer’s disease. Accommodations inside (e.g., calming décor, open environment, glassed ceiling, walking area for wandering, and large bathrooms) as well as outside the facility (e.g., fences, walking path in garden, raised flowerbeds, handicap accessible) were reported. Security factors were referenced as well: locked doors, alarmed doors, open-space floor plan, and small rooms to prevent over stimulation.

A variable was created to assess “dementia-friendliness.” Twelve characteristics were used to create low, moderate, and high categories. Sites were given one point for each service that was reported in the affirmative: Alzheimer’s-specific activities, support groups, five or more activities offered daily, staff trainings, MCI programming, early-stage programming, late-stage programming, end-stage programming, Alzheimer’s-specific services, care plans, Safe Return® registration checks at intake, and purposely-designed areas for participants with dementia. Results showed that 37% of centers scored between five and eight points and fell in the moderate-friendly category. Almost 25% scored greater than eight points and were considered “high-friendly.”

With the aging of the baby boom generation, the addition of younger participants is expected to increase. Respondents reported that they are preparing for such a situation by altering the services to reflect this generation. For example, one respondent recommended, “*playing Beatles’ music.*” Respondents had additional ideas to prepare for the potential baby boom generation: increased family education and involvement, additional facilities, partial hospitalizations, and a form of group home where multiple participants would share one residence.

Conclusions

Existing practices

Insights regarding existing practices were obtained from responses to both the electronic survey and in-depth interviews. Responses from the qualitative interviews include “*safety of participants and site,*” “*respect for individuality and autonomy,*” “*empathy for participants and families,*” and “*support for all.*” One respondent summed up their existing practice well: “*Offer appropriate, diverse, and quality programming.*” Another stressed placing families first: “*Listening to the concerns and needs of our patients and their families.*”

Stage-specific programming appears to be used to a certain extent by facilities. In fact, their ability to adapt services and activities provides some insights toward existing practices. The adjustment of physical environments increases safety and considers needs at an individual level. Specialized training, collaboration, consistent evaluations, and intergenerational involvement were also existing practices reported that should not go unnoted. It is apparent that no one model exists, and in fact implementing a variety of programming styles may result in increased success.

Late-stage Alzheimer's disease programming

The majority of respondents from both the qualitative and the quantitative questionnaires stated that services were available for the late-stage population (88% and 63%, respectively). Increased sensory stimulation and transportation adjustments (person-to-person versus door-to-door) were two services cited specifically. Response dealt with the adaptation of existing programming. For instance, ADL assistance is offered in many sites, but this assistance is increased as functioning decreased. In addition, from open-ended questions in the electronic survey that inquired about the provision of services for participants in late-stage and end-stage, there were four providers who reported working with hospice programs. One provider reported, "*We work with a hospice program to provide services both at the center and at the homes of the participants at end stage.*"

Challenges

Exploring the challenges faced by ADHCs resulted in a greater understanding of the overwhelming need for increased funding. Many responses referred to the maintenance of the facility, addressing the transportation needs, and paying the needed/required staff. In fact, 98% of sites completing the electronic survey reported funding concerns. Moreover, respondents cited concern for the finances of their participants with most falling below the state and national median incomes for their age category. Respondents believed that some could not afford to attend while others stated that reimbursement rates were an issue, particularly for participants under age 62.

Additional challenges arose regarding the ability to consistently provide activities and social encounters that "*cross the span of years.*" Respondents are aware of the changing demographics of their participants and are challenged to meet the needs of a population diverse in age, functional ability, economic status, and ethnicity. Their efforts at meeting these needs are constantly constrained as they report increases in paperwork requirements that erodes the quality and quantity of time spent with participants.

Envisioning new paradigms

The insights offered by respondents regarding new paradigms for those with early-stage or early-onset dementia were intriguing. Where so much financial concern was raised, it was inspiring to obtain ideas for the future that were often only indirectly related to money. Calls for expanding support groups into the evenings, additional exercise groups, outings (e.g., shopping, theatre, museums), and participant-volunteer opportunities were realistic and could likely be carried out with little increased cost. *“Intergenerational day services would allow participants to assist in child care offering a chance to give back to the community and feel a sense of belonging.”* Other visions did affect cost: public and staff education, increased space, kitchen facilities; however, they are no less critical. Education regarding early-onset for example would benefit all involved: staff, participants, family, and care partners.

Recommendations

As the population continues to age, such facilities or their next generation will become even more imperative, particularly for those older adults who choose to age in place. Studies that continue to explore best-practices will assist ADHCs in sharing knowledge regarding successful strategies of care. Continued exploration of ADHCs is warranted.

Public education was consistently a concern raised by ADHCs. Their desire for increased awareness in communities is on-going; however, their ability to educate is sometimes limited considering their present financial concerns. Although some organizations offer specialized workshops and trainings, often for little or no charge, getting the word out to the larger community is necessary. Individuals who know or care for an individual with cognitive impairment may be inclined to attend such a workshop; however, the education needs to reach greater audiences. An educated community is more likely to support financially its local ADHCs.

The population of future participants may be significantly different from the current population of participants. Specifically, the baby boom generation is projected to be more educated and financially better off. As a result, this group may expect different services and levels of care. Reaching this group now and offering education regarding the current abilities and limitations of ADHCs may be a strategy in altering the level of support these facilities currently receive. Baby boomers will be invested in securing the facilities that they will access in the near future. Without this increased public awareness, facilities will remain unnecessarily constrained.

INTRODUCTION

The role of adult day health care (ADHC) is gaining increased attention as the nation prepares for the large cohort of baby boomers entering their later years. Many boomers are aging with physical and cognitive impairments, including Alzheimer's disease and related dementias. Moreover, these boomers have a strong preference to age in place in their communities. It is estimated that 70% of persons with Alzheimer's disease and other dementias reside at home while receiving care from family members (Alzheimer's Association, 2007).

Alzheimer's disease is commonly known as a disorder that progressively deteriorates cognitive functioning. In addition, emotional, behavioral, and psychological symptoms are experienced as well (Shigeta & Homma, 2007). In the United States today, 5.2 million older persons aged 65 and older have Alzheimer's disease, which is the most common type of dementia (Alzheimer's Association, 2008). Since Alzheimer's disease is a disorder that most often occurs during later-life, the term early-onset dementia is used to refer to dementia that is diagnosed in persons under the age of 65 (Alzheimer's Association, 2008). An additional 500,000 persons who are younger than age 65 have early-onset Alzheimer's disease or another dementia (Alzheimer's Association, 2008).

Adult day health services are community-based services provided outside the home for adults with a variety of impairments (U.S. Department of Health and Human Services [HHS], 2006) and are the most commonly used form of out-of-home services (Montgomery, Rowe, & Kosloski, 2007). The first adult day services program opened in 1960 in Greensboro, North Carolina (HHS, 2006). The original program was similar to a geriatric day hospital program and then gradually evolved to become a community service to meet care partners' needs (HHS, 2006). Care partners of participants who had Alzheimer's disease recognized the effectiveness of adult day health services programs in providing personal care services and social activities for their family members. Moreover, the provision of adult day health services allowed for respite from demands of continuous care for persons with dementia. Care partners also had time for other obligations, such as employment (HHS, 2006). Currently, services provided from adult day health cares are recognized to be a realistic and promising approach to enhancing the well-being of persons with Alzheimer's disease and their care partners (Alzheimer's Association, 2007; Montgomery & Rowe, 2007; Zarit et al., 1998).

More research on adult day health care is warranted to document the effects of these programs (HHS, 2006). Given current treatment and estimates indicating an increasing prevalence of persons with Alzheimer's disease, learning more about the provision of adult day health services may contribute to improving the quality of life for persons with dementia in the community and their care partners.

BACKGROUND

Projections indicate that Massachusetts along with the nation as a whole is experiencing an increasing rate of older persons as baby boomers enter late-life (Gerontology Institute, 2008). The Commonwealth can expect that persons with Alzheimer's disease and their care partners will need community-based services specifically designed for adults with cognitive impairments. However, a report by the Robert Wood Johnson Foundation (2003) found that there is a serious lack of adult day care services for the state's elderly population. The 2003 report found that Massachusetts is meeting only 62% of needs for adults with physical and cognitive impairments and at least 78 more programs are needed in the state. Yet, programs in Massachusetts continue to close (Gottler, 2008).

Models of adult day services

There are three main models of adult day services: a social model, a health model, which is often combined with the social model, and a specialized model (HHS, 2006). A social model offers activities for physically and cognitively impaired adults. Activities include games, arts and crafts, and discussion groups (Montgomery & Rowe, 2007). The social model provides some assistance with activities of daily living (ADLs). A health model provides services and activities beyond a social model, and they often offer skilled nursing and rehabilitation services (HHS, 2006). A specialized model is designed to provide services for a specific group such as adults with mental illness, Alzheimer's disease and related dementias, or multiple sclerosis (HHS, 2006).

There is no federal oversight on adult day services, and each state establishes its own regulations. Massachusetts requires that adult day health providers offer the following services: ADL assistance; health education and counseling; health monitoring; medication administration; nursing services; physical therapy, occupational therapy, or speech therapy; skilled nursing services; social services; and transportation (HHS, 2006).

Reimbursement

In Massachusetts, adult day health services are subsidized in large part through the state Medicaid program, MassHealth (HHS, 2006). Adult day health services contract with and are regulated by MassHealth. Requirements are presented in the *Adult Day Health Provider Manual* for the MassHealth Program (HHS, 2006). In the manual, it describes two levels of care: adult day health basic and adult day health complex. The level of care given to participants is based on their needs (HHS, 2006). Complex care is given to participants who need more attention and additional services due to the severity of their condition. At the time when this research project was conducted, the reimbursement rate for basic care was \$53.41 and for complex care it was \$68.01.

Other sources for funding are from public programs, such as VA programs, the Social Services Block Grant, Older Americans Act, and state programs (HHS,

2006). In addition, adult day health cares depend on private pay and long-term care insurance for operating revenue (HHS, 2006).

Staffing requirements

There are regulations on staffing requirements for ADHCs. An ADHC must have a full-time program director and the designation of an assistant program director (HHS, 2006). Skilled nursing is a required service for adult day health centers. The adult day health center must provide skilled nursing services for a minimum of eight hours each day. A registered nurse must be on site for a minimum of four hours each day. A licensed practical nurse can provide nursing services for the other four hours (HHS, 2006). When the average daily census is 35 participants or more, the adult day health center must provide nursing services for a minimum of 12 hours (HHS, 2006). If the average daily census is 50 or more, the provision of nursing services is a minimum of 16 hours.

The employment of an activity director also is required. The activity director must be on site for a minimum of four hours each day (HHS, 2006). If the adult day health center has an average daily census of 24 participants or more, a social worker must be on site for a minimum of 20 hours each week. The availability of aides and consulting therapists for participants is at the discretion of adult day health providers (HHS, 2006).

To provide adequate, sufficient care for participants, there also are regulations on staffing ratios. For basic care, there must be a minimum staffing ratio of one direct staff member to six participants. Concerning complex care, one staff member to four participants is the requirement.

Dementia-specific characteristics

Understanding and assessing the symptoms of each stage in the course of Alzheimer's disease is important when providing services for participants in adult day health centers. Participants with Alzheimer's disease have functional capabilities in terms of their prognosis in the course of the disease. Alzheimer's Association experts stress that services offered by adult day health centers should be stage-appropriate and attention to the functional capabilities of participants should be taken into account when providing services. As seen in Appendix A (Brennan & Raia, 2008), persons who have early-stage Alzheimer's disease exhibit different behaviors and symptoms when compared to persons who are at later stages of the disease process.

Research objectives

Given that adult day health care services are vital for persons with Alzheimer's disease who desire to remain in their communities and that adult day health care supports family care partners by providing respite, the overall objective of this study was to begin to document the current state of adult day health services in Massachusetts, the services they provide, challenges they face, and visions for the future. Though previous literature concludes that adult

day health programs benefit impaired elders in the community, there is a lack of research on specific factors of adult day health care that addresses the needs of persons with Alzheimer's disease.

The specific objectives of the study were to: (1) describe existing practices of adult day health care services in Massachusetts for persons living with Alzheimer's disease and related dementias, (2) explore programs that are specifically designed for participants in late-stage dementia, (3) address challenges that adult day health care services are now encountering, and (4) envision new paradigms for meeting the needs of persons with early-stage and early-onset dementia.

METHODOLOGY

This study was an applied research project conducted under the auspices of an Aging and Social Policy Capstone Seminar at the University of Massachusetts Boston, College of Public and Community Service, during Spring 2008. Student researchers planned, developed, and implemented the study under the guidance of Professor Nina Silverstein and gerontology doctoral student, Cathy Wong, who served as the teaching assistant. There were two community partner organizations for this research project: Janet Gottler represented the Massachusetts Adult Day Services Association (MADSA), and Lindsay Brennan and Paul Raia represented the Alzheimer's Association-MA/NH Chapter. In the beginning of the research project, a discussion with Community Partners and student researchers took place at the University of Massachusetts Boston. The discussion was on the research objectives, methodology, and intended use of and dissemination of research findings. The Community Partners also provided substantive background to the students through guest lectures. An application was then submitted to and approved by the University of Massachusetts Boston Institutional Review Board (IRB) as required for the protection of human subjects prior to the commencement of data collection. Upon completion of the project, research findings were presented to the Community Partners and other interested health care professionals.

Quantitative data collection

The collection of data involved two methods. The first method was creating a survey that would be disseminated electronically. Survey Monkey was the software utilized for this purpose (visit www.surveymonkey.com). Survey topics in the electronic survey were: adult day health care services program profile, demographic characteristics of participants, dementia-specific characteristics, physical structure of adult day health care, transportation, funding, staffing, family interaction, collaboration with other organizations, background information of respondents, and "best practice," challenges, and future models. The electronic survey had a total of 78 questions; specifically, there were 42 closed-ended questions and 36 open-ended questions. The electronic survey was pilot tested with Community Partners and student researchers. When Community Partners

and student researchers pilot tested the survey, the pilot experience revealed that the electronic survey took an average of 30 minutes to complete.

The sampling frame for this research project was identified by MADSA. In addition, non-MASDA members were identified through MassHealth, Office of Long-Term Care. A total of 155 adult day health care providers were identified as potential participants in the research project. Before the actual dissemination of the electronic survey to adult day health providers, each adult day health care was sent a formal introductory letter from MADSA describing the research project and the confidentiality of their participation. The overall response rate was 60% (93) of the adult day care health providers either partially or entirely completed the survey. Slightly less, 43% (66), of the adult day health care providers entirely completed the surveys. These response rates reflect those reported in the literature of 65% or lower (Singleton & Straits, 2005).

Although respondents could begin the survey and return to it at later times to complete, actual respondents to the electronic survey expressed that the survey was too long and required information that was too detailed. This may have contributed to the partial completion of some of the surveys.

Quantitative analytic strategy

Analyses on the data from the electronic survey was done using the statistical software SPSS. Descriptive statistics were obtained to address the research objectives of this study. In addition to descriptive statistics, a summary variable was created to assess the level of “dementia friendliness” within the surveyed facilities. The specific survey questions utilized to create this measure are displayed in Appendix B. A possible score of 12 resulted from a count of variables considered advantageous to serving a population with diagnosed or undiagnosed Alzheimer’s disease. Sites that indicated offering Alzheimer’s disease specific services or activities, support groups, stage specific programming (MCI, early, late, end), or checking for registration in Safe Return® at intake were given a score of “1” for each positive response. Sites earned additional points for reporting that care plans were offered to caregivers and for employment of staff engaged in Alzheimer’s disease specific training. The number of activities offered daily was recoded into “1-4 activities” and “more than 5 activities.” Sites that reported offering “5 or more activities” earned an additional point. The last point was earned by those sites that “agreed” or “strongly agreed” that their facility housed a purposively-designed space intended to serve participants with Alzheimer’s disease.

The new variable was broken down into three levels of “friendliness.” Facilities scoring between 0 and 4 points were considered low-friendly, between 5 and 8, moderately friendly, and greater than 8 points, high-friendly.

Qualitative data collection

The second method of data collection involved qualitative interviews with eight adult day health care providers. The eight adult day health care providers were purposively chosen based on their locations (convenience to the student researchers) and the known provision of Alzheimer's disease specific programs. The topics covered by the qualitative interview were similar to topics from the electronic survey and were designed to obtain more explanatory, in-depth responses than possible in the electronic survey. The topics were: adult day health care services program profile, demographic characteristics of participants, family interactions, physical environment, funding, transportation, staffing, and "best practices" and future prospects. Before the qualitative questions were asked to staff members from adult day health cares, students were instructed to state a script that emphasized that confidentiality of responses, the voluntary nature of the interview, and the option to skip over questions. Completion times ranged from 50 minutes to two hours and 45 minutes, averaging 90 minutes. All interviews took place in March 2008.

Qualitative analytic strategy

Analyses on the data provided by the in-depth interviews involved a transcription of all responses from the qualitative interviews. Responses from the eight interviews were consolidated for each question. The grouping of responses for each question permits observing frequent, relevant words and themes that emerged from the interviews. The availability of qualitative and quantitative data allowed for more thorough analyses that would address the research objectives of this study.

RESULTS

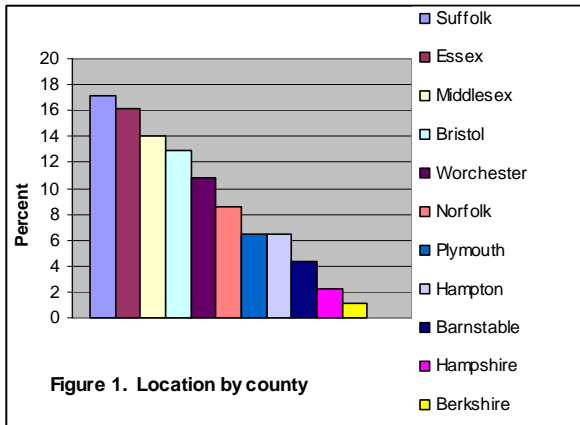
Quantitative Results

Respondent background for electronic survey

The demographic data for the respondents were asked at the conclusion of the survey. Therefore, background data were available for 66 of the 93 respondents. Program directors comprised 51 of 66 respondents (77%), and seven self-described as administrators (10.6%). The highest level of education reported by respondents was a Doctoral degree (1.5%), certification (6%), a Master's degree (20%), a Bachelor's degree (42%), an Associate's degree (24%), and a high school diploma (6%). Additional education specifically in Alzheimer's disease or related dementias was reported by 88% of respondents. This education was described as primarily through workshops and trainings offered by the Alzheimer's Association. Other forms of education mentioned included: college classes, self-education, and experience.

Sample description

The respondents represented facilities from 11 of 14 counties in Massachusetts. Only Dukes, Franklin, and Nantucket counties did not have



facilities included.¹ The counties with the greatest percentage of facilities responding, as seen in Figure 1, were Suffolk (17%), Essex (16%), Middlesex (14%), and Bristol (13%). Almost half (47%) of the respondents described their locations as suburban, 43% as urban, and 10% as rural.

Program profile

All sites operated at least Monday through Friday. A quarter of the sites were open on Saturday and five sites (5.4%) had Sunday hours. Weekend hours of operation ranged from zero hours to nine hours on Sundays and zero to 10 or more hours on Saturdays. Most sites reported between six to nine weekday hours of operation. The average number of years in operation was 18.46 and ranged from one to 33 years.

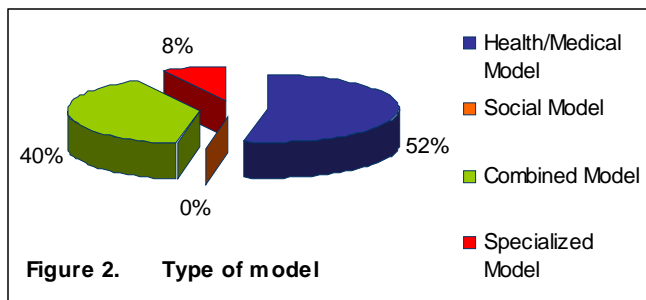


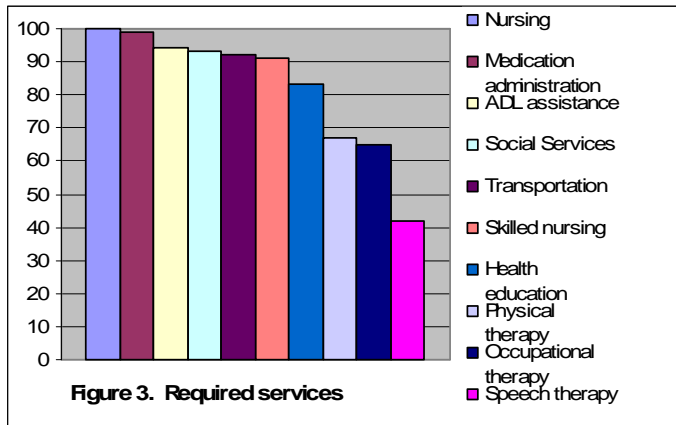
Figure 2 displays responses regarding the type of model followed at responding sites. Over half (53%) described their program as specifically a Health/Medical model; approximately 40% self-described as a Combined model of Social and Health, while 8%

defined themselves as following a Specialized model. Five of these seven specialized model sites specifically noted serving participants with memory impairments. One served participants with psychiatric diagnoses along with medical issues. And one site followed the PACE model (Program for all Inclusive Care to the Elderly). No program self-described as following a Social model only.

A range from 15 to 165 was reported as the maximum number of participants accommodated (average = 49). Current enrollment varied as well, ranging from 11 to 544 participants with an average of 67. A daily census of participants served was a lower average of 38. Most sites (85%) reported no current waiting

¹ Further examination revealed that the master list of sites compiled from the MADSA membership and the additional sites provided of non-MADSA members that was provided to us by MassHealth did not include providers from Duke or Nantucket counties. An additional search through phone and service directories did not reveal facilities in those two counties. A facility in Franklin County was among the non-respondents. We later identified three additional facilities in Franklin County that were not on either the MADSA or MassHealth lists but would have met our eligibility criteria to receive the electronic survey.

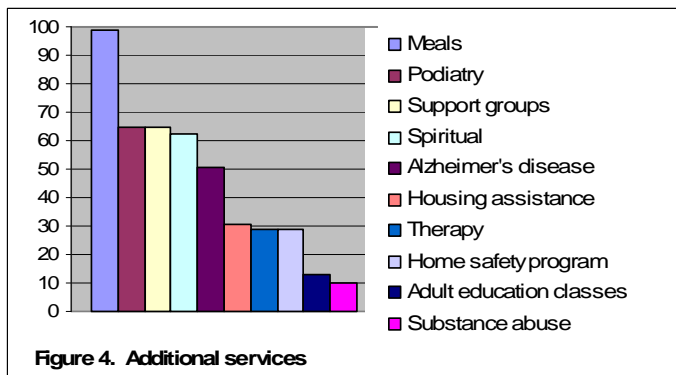
list. Of the 15% with a waiting list, respondents reported a wait period ranging from two weeks to three months. Thus, at the time of the survey (March 2008), there were 219 persons who would have waited an average of 5.25 weeks for adult day health services.



The services required by Massachusetts are displayed in Figure 3. Appendix C also lists required services. Most all of the responding sites (91 of 93) reported offering nursing services while 99% reported offering medication administration, and 95% offered ADL assistance. Other required services included social services (93%),

transportation (92%), skilled nursing (91%), health education (84%), and physical, occupational, or speech therapy (67%, 65%, and 42%, respectively). Such an “or” constraint explains why these services are not reported by 100% of ADHCs. For other services that did not reach 100%, however, the reason is less clear and not discernable with the data. The results may be due to the self-report nature of the study and reflect respondents’ misinformation.

Less frequently reported, though still offered by over half of the sites, were additional services not required by the state (Figure 4) including: meals (99%),



podiatry (65%), support groups (65%), spiritual support/counseling (63%), and housing assistance (31%). Services involving therapy (29%), home safety programs (29%), adult education classes (13%), and substance abuse (10%) were reported as well.

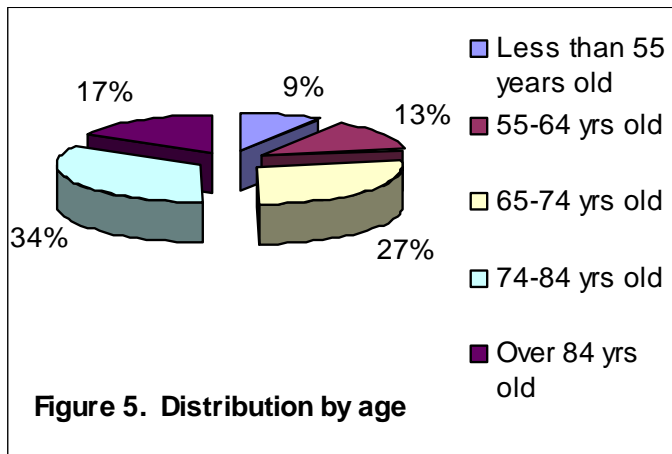
Services that were considered “Alzheimer’s disease specific” as operationalized by Brennan and Raia (Appendix A) were detailed by respondents in open-ended questions regarding different stages of the disease. Services included outings/field trips and groups games that often consisted of cognitive exercises. Respondents reported that services were adapted with changing levels of assistance depending on the needs of the participant. For instance, as the disease progressed, an increased need for one-to-one assistance was noted. Later stages further required a focus on comfort and sensory stimulation.

Most sites (43%) reported scheduling five to six activities daily. Approximately 35% of sites reported scheduling one to four activities daily, and 14% reported seven to eight daily activities scheduled. All respondents reported offering exercise, and 90% or more offered activities revolving around art, literature, and entertainment. Also popular were adaptive games (89%), music groups (86%), sports-related activities (82%), and day trips (78%). When asked to describe the most popular activity, several respondents (40%) specifically cited “bingo.” Additional popular activities included music, exercise, and live entertainment.

Demographics of participants

The respondents were serving a total of 5,746 participants of whom 36% were male, 64% were female. Over 96% reported serving White participants while 70% and 66% reported serving Black and Hispanic/Latino participants, respectively. Almost a quarter (23%) of the responding sites reported serving Asian participants, 20% serving Cape Verdean, 9% Middle Eastern, and 8% American Indian.

As seen in Figure 5, 61% of responding sites (n = 83) served individuals 65 to 84 years old. Approximately 22% reported serving participants aged 64 years and younger. Those aged 85 years and older were served by 17% of sites. Respondents (4%) reported that for most of their participants the highest level of education was a graduate degree, almost 5% reported a Bachelor’s degree, and 56% reported receipt of a high school diploma. The remaining 35% reported that most of their participants had received less than 12 years of education. More than half (52%) of responding sites stated that participants had income levels equal to or below \$10,400; 40% reported participants had incomes between \$10,401 and \$31,200. It is interesting to note that these respondent estimations differ significantly from 2005-2006 estimations of a Massachusetts median



income (\$56,592) and a United States median income (\$48,023) for this age group (www.census.gov). In fact, only the remaining 8% of participants in this sample have potential to reach the state and country median income levels with their estimated incomes greater than \$31,201.

Figures 6 and 7 display the duration and frequency of participant attendance. Participants (n = 4,680) attended adult day health centers (n = 77) from less than three months (10%) to more than 10 years (5%). Attendance between three

months and three years was reported by 56% of sites; attendance from 3 to 10 years was reported by 29% of sites.

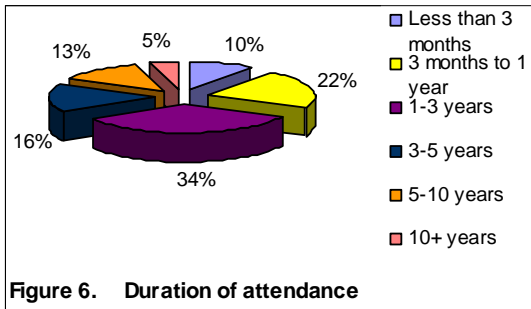


Figure 6. Duration of attendance

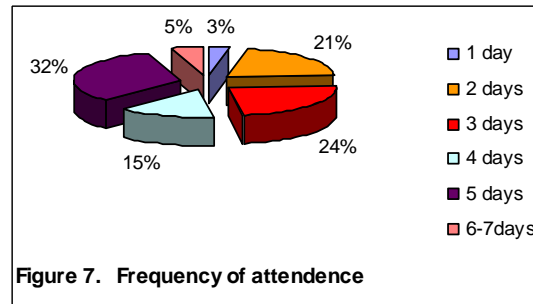


Figure 7. Frequency of attendance

Respondents were asked about the household composition of participants in order to understand the level of overall supports outside of the ADHC. According to respondents, 73% of participants lived with others; however, a large percentage (25%) live alone (2% were noted as an unknown household composition). Sites further reported that 31% of participants rely on an adult child caregiver. Assisted living settings (22%), home health aides (19%), and spouses (19%) were also cited as caregiving supports accessed outside of the adult day health facility.

To gain a sense of whether the respondents thought participants were attending the right number of days, respondents were asked whether they believed that participants were attending the right number of days, more days than needed, or fewer days than needed. Just over half (51%) reported that they believed participants were attending the center the “right” number of days, 49% reported participants should attend more often, and no sites reported that participants should attend less often. Figure 7 refers to participant daily attendance. Attending five days was most prevalent (33%) while only 5% attended more than five days. Participants attending only one day were reported by 3% of sites, attending seven days by less than one percent (0.1%).

Dementia-specific characteristics

Responding sites (n=75) identified 1,609 participants as having been diagnosed with Alzheimer’s disease or a related disorder. An additional 987 were reported as having cognitive impairments but not having formal diagnoses. Thus, in the sample, at least 45% of persons in adult day health facilities in Massachusetts were reported to have cognitive impairments, with or without formal diagnoses. That percentage would likely be higher if all 93 sites responded.

To provide a sense of where participants were in the disease process, Dr. Paul Raia and Lindsay Brennan created an explanatory handout of five stages of the disease from mild cognitive impairment through end-stage (Appendix A). These operational definitions were included in the electronic survey.

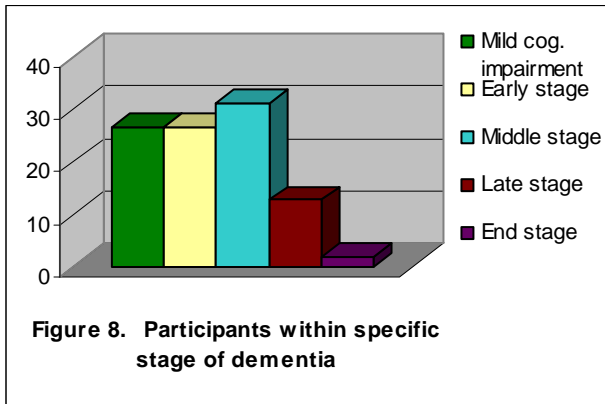


Figure 8. Participants within specific stage of dementia

impairment, an additional 27% for early-stage Alzheimer’s disease, and 32% for middle-stage Alzheimer’s disease. Late-stage was indicated for fewer participants (13%), and still fewer (2%) were considered to fall within end-stage Alzheimer’s disease.

Respondents were asked to indicate the number of participants that in their opinion fell within each of the five stages. As displayed in Figure 8, 74 respondents offered opinions on the stage of 2,206 participants with cognitive impairments whether or not a formal diagnosis was present. Of these participants, more than 27% were considered to have met criteria for mild cognitive

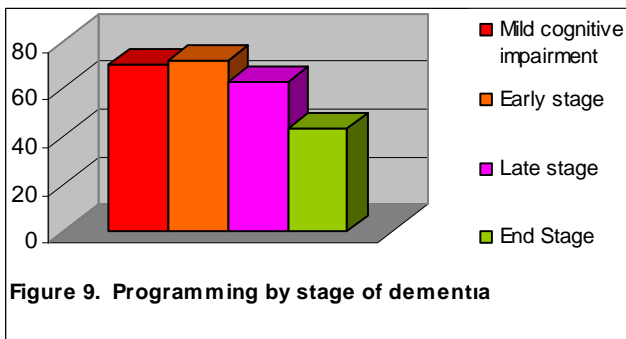


Figure 9. Programming by stage of dementia

cognitive impairment (physical and mental exercises, games with staff assistance). Although three sites reported they do not serve those with early-stage Alzheimer’s disease, 50 of 70 responding sites (71%) reported offering programming specific to these participants (increased assistance, cognitive stimulation). Ten of 72 respondents (14%) reported not serving participants in late-stage Alzheimer’s disease. Of the remaining 62 sites, 63% reported programs geared specifically to late-stage participants (sensory stimulation, smaller groups). The pattern continued as dementia symptoms became more pronounced: 21 of 72 responding sites reported not serving individuals in end-stage Alzheimer’s disease. Of the remaining 51 sites, 43% reported programming specific for these participants (focus on comfort, sensory). Of 72 responding sites, 52 reported serving or ever serving participants with early-onset Alzheimer’s disease (diagnosed before age 65) (72%). Responses were obtained for 54 sites regarding services specific for this group: Almost half, 44%, report having such programming. Many activities are reportedly adaptable to varying stages; however, as the disease progressed, sites reported increases in counseling services for caregivers and a focus on comfort for the participant.

Respondents were further asked about programming specific to each stage. These results are represented in Figure 9. Of 74 respondents, only one reported that his/her ADHC does not serve participants with mild cognitive impairment. Of those 73 sites remaining, 70% report programming specifically for mild

In addition, the respondents were asked to identify co-morbidities among their participants with cognitive impairments. The major conditions reported (n = 75) in order of prevalence were: diabetes (93%), mental illness (84%), mental retardation (68%), and blindness (55%). Also mentioned were Parkinson's disease, traumatic and acquired brain injury, multiple sclerosis, Huntington's disease, stroke, cancer, cardiac disease, and hypertension.

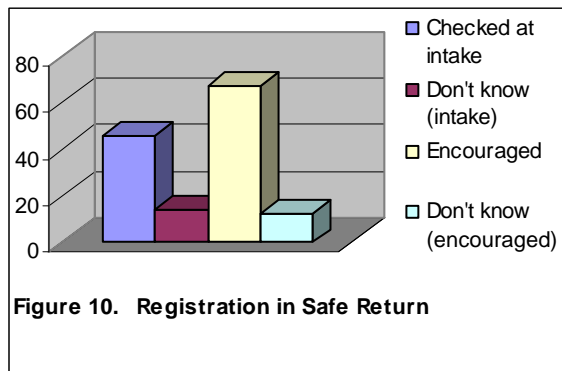


Figure 10. Registration in Safe Return

Safe Return® is a trademarked program sponsored by the Justice Department and administered by the Alzheimer's Association and now most recently, in partnership with Medic Alert. Participants are given Medic Alert jewelry that contains critical information regarding their medical conditions. Care partners/givers initiate a community network search with a single phone call that reports a

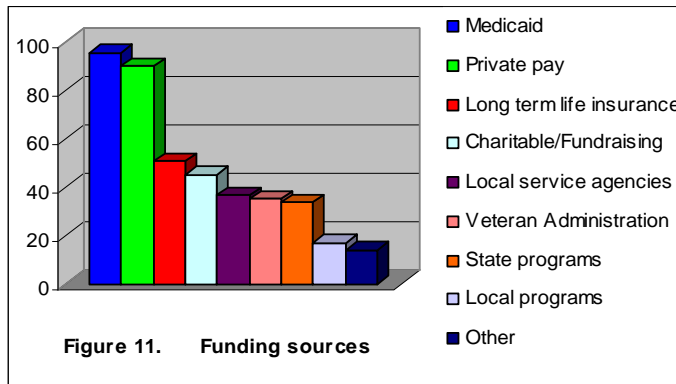
participant as missing. In addition, should a participant be located, this same 24-hour emergency phone number is called, and family members are contacted. The nearest Alzheimer's Association chapter offers support throughout a search effort to care partners/givers and families. As displayed in Figure 10, checking a participant's registration for Safe Return® at intake was reported by 46% of sites (n = 72); 14% however, stated they were unsure if this occurs. Should a participant attempt to leave the center unsupervised, an increased number of sites (67%) reported encouraging the Safe Return® program (13% remained unsure if this occurs at this time). At the time of the survey, 32 responding sites reported that 541 participants were currently enrolled in the Safe Return® program (mean = 17 enrolled participants per site).

Physical environment

Respondents reported (n = 71) a variety of characteristics that describes the physical structure of the ADHC. Being handicap accessible and housing a food preparation area were reported by 94% and 93% of sites, respectively. Other characteristics included maintaining an outdoor area (78%), creating a "home-like" ambiance (76%), and having space designed for the physically disabled (66%). In addition, 29 of 71 responding sites (41%) reported that the physical structure of the ADHC had purposively-designed spaces intended to serve participants with Alzheimer's disease. Accommodations inside (calming décor, open environment, glassed ceiling, walking area for wandering, and large bathrooms) as well as outside the facility (fences, walking path in garden, raised flowerbeds, handicap accessible) were reported. Security factors were referenced as well: locked doors, alarmed doors, open-space floor plan, and small rooms to prevent over stimulation).

Transportation

Transportation was reported as provided by or arranged by 64 of 68 responding sites (94%). Sites also reported arrangements created by family members (58%), alternative transportation vendors (31%), and volunteers (2%). Transportation costs appeared to be split fairly evenly by facilities and participants; daily costs for facilities were reported to range from \$0 to \$75 and averaged \$12.18; daily costs for participants were reported to range from \$0 to \$35 and averaged \$12.53. However, 37 of 64 responding sites reported that these fees are additional costs not included in their regular rates (58%).

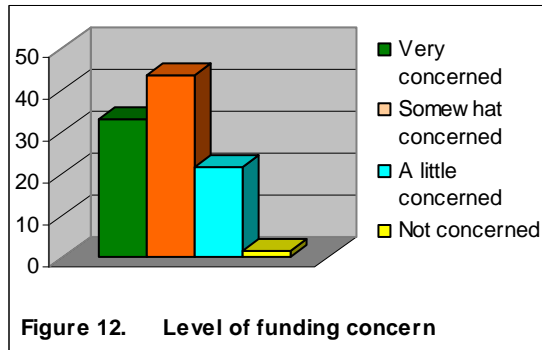


Funding

Figure 11 displays a variety of funding sources referenced by the respondents. Receipt of funding from Medicaid was reported by 68 of 71 responding sites (96%); however, private pay via out-of-pocket and long-term care insurance were also frequently reported (90% and 51%, respectively). Average

reimbursement rates through Medicaid were reported as \$51 for basic care and \$66 for complex care. Average private payer reimbursement was similar: \$56 for basic, \$65 for complex care. From MassHealth, the reimbursement rate for basic care is \$53.41 per day, and the complex reimbursement rate is \$68.01. The average reimbursement rates reported by adult day health care providers for basic and complex care were lower than reimbursement rates from MassHealth. Additional sources of funding were noted as well: charitable contributions (45%), local service agencies (37%), Veterans' Administration (35%), and state programs (34%). Less frequently reported was funding through volunteers (20%), local programs (17%), Older Americans Act (9%), and social services block grants (7%).

Sites (n = 69) offered information regarding 4,834 participants' payment status. They reported 67% of participants (3,217) are subsidized, 17% (811) pay out-of-pocket, and 17% (806) use a combination of sources to make payments.



As Figure 12 shows, "making ends meet" was a concern for 45 of 69 sites (65%) while 23 sites (33%) reported being very concerned. Only one site (1%) reported not having a concern regarding maintaining current operating expenses.

Staffing

Responding sites (n = 68) reported an average of 11 staff members (seven full time, four part time). Accessing an average of three volunteers was reported by 62%. Respondents were asked to describe the racial diversity among staff members. White employees were reported by 94% of sites, Black employees by 49%, and Hispanic/Latino staff members by 44%.

Table 1. Staff and Participant Racial Diversity

| <u>Race</u> | <u>Staff</u> | <u>Participant</u> |
|-----------------|--------------|--------------------|
| White | 96% | 94% |
| Black | 70% | 49% |
| Hispanic/Latino | 66% | 44% |
| Asian | 23% | 10% |
| Cape Verdean | 20% | 19% |
| Mid Eastern | 9% | 2% |
| American Indian | 8% | 2% |

Other race/ethnicities included Cape Verdean (19%), Asian (10%), American Indian/Alaska Native (2%), and Middle Eastern (2%). This diversity is mirrored in the respondents' reports of participant diversity (discussed in the section titled *Demographics of Participants*) and is displayed in Table 1.

Staffing included a variety of positions: 96% of sites (n = 63) reported employing registered nurses and 88% reported employing social workers. Registered nurses were employed by 96% of sites, social workers by 88%, program directors by 85%, and 71% employed activity directors. Regulations for adult day health cares require the employment of a program director, registered nurse, and activity director. The data from the electronic survey reveal that not all adult day health providers appear to employ the required positions for reimbursement.

Additional positions included certified nursing assistants (68%), aides (65%), licensed practical nurses (60%), and assistant program directors (44%). Less frequently reported were activities coordinators (41%), administrators (38%), consulting therapists (31%), and administrators (38%). Physical, occupational, and speech therapists were employed by 16%, 15%, and 12% of sites, respectively. Physical, occupational, or speech therapy is a requirement of adult day health providers that should be available for participants. Additional positions were noted by 23 sites (34%) and included drivers, cooks, and nutritionists, and five sites specifically stated that staff often hold more than one position. All 68 sites reported that a Criminal Offense Record Inspection (CORI) was required for their staff members, and 62 sites (91%) made this requirement of volunteers as well. [Note: The Commonwealth of Massachusetts requires CORI checks for all workers and volunteers who are in contact with children or elders.]

Training in Alzheimer's disease or related dementias was offered on site (48%), off site (6%), or via a combination of both (46%) by 78% of responding sites (n = 68). The Alzheimer's Association was frequently cited as a source of training whether through their materials, their workshops, or their speakers. Nurses, directors, and community resources are cited as well, however, less frequently.

Family interaction and collaboration with organizations

Although not specifically described, a written care plan was offered to guide caregivers by 41 of 66 (62%) responding sites. Some sites referenced more specific services that are offered to families of participants: Alzheimer’s caregiver support groups, referrals, and counseling. Over 70% of respondents reported collaboration with other organizations including the VNA and Alzheimer’s Association chapters.

Respondents were asked how the Alzheimer’s Association might further assist them. Requests consisted of needs in a variety of areas including mental health support, homecare, VNA, servicing of certified nurse assistants, and providing educational materials and training regarding Alzheimer’s disease and case management.

Table 2. Frequency of Dementia-Friendly Score

| <u>Variable</u> | <u>Frequency</u> | <u>Percent</u> |
|-----------------|------------------|----------------|
| Low | 36 | 38.7 |
| Moderate | 34 | 36.6 |
| High | 23 | 24.7 |

Note: Low= 0-4, Moderate= 5-8, High= >8
Note: n=93

Dementia-friendly summary variable

Analysis of the dementia-friendly variable resulted in a range of 0-11 of 12 possible points (mean = 5.83, SD = 3.16). Sites were fairly evenly dispersed (Table 2) into the three levels of “dementia friendliness.” Almost a quarter of the sites (24.75)

fell into the very-friendly category which, required offering more than eight of the selected services, 37% were coded as moderately friendly, and almost 39% were considered low friendly. A closer look at the individual variables is offered in Table 3.

Table 3. Frequency of Dementia-Friendly Variable Items

| <u>Variable</u> | <u>Frequency</u> | <u>Percent</u> |
|-------------------------|------------------|----------------|
| Alzheimer’s activities | 61 | 66 |
| Support groups | 59 | 63 |
| 5+ daily activities | 58 | 62 |
| Trainings | 53 | 57 |
| MCI programming | 51 | 55 |
| Early-stage programming | 50 | 54 |
| Alzheimer’s services | 46 | 50 |
| Care plan | 41 | 44 |
| Late-stage programming | 39 | 42 |
| Safe Return® | 33 | 36 |
| Purposively-designed | 29 | 31 |
| End-stage programming | 22 | 24 |

Although 66% of respondents reported offering Alzheimer-specific activities, only 42% and 24% appear to offer programming directed toward late- and end-stages. Reportedly, checking for registration in Safe Return® and having a purposively-designed area for individuals with dementia were low-scoring variables as well (33% and 29%, respectively).

**Qualitative Results
Program profile**

Of the eight respondents, seven carried a title of “director” in varying capacities (program director, center director, director of service). One

respondent did not supply a job title. Most respondents stated that they were currently satisfied with their hours of operation. Although not all sites specified hours of operation, some referenced hours during the week, others stated that regular Saturday and Sunday care was available. One respondent reported that weekend service occurred on a monthly basis. Those who were only partially satisfied or not satisfied referenced the need for increased weekend hours, stating that the respite time for caregivers was important. Over the past five years, respondents have noticed a change in their participant population. *“Clients are younger and often times more physically disabled and frail.”* *“An increase in male participants as well as male caregivers”* was noted. Respondents expect this trend to continue over the next five years. They expect as well that more participants will have diagnosed dementia and that families will expect increases in services. One respondent reported that *“waiting lists will increase due to a combination of increased referrals and participants utilizing sites for longer periods (into advanced stages).”*

- Half of the centers reported over 90%
- Three centers reported less than 35%
- One center reported 40%

Figure 13. Estimated percentage of participants with memory impairment, Alzheimer’s disease, related or suspected

Figure 13 displays a summary of responses regarding the estimated percentage of participants with memory impairments. Overall respondents estimated that an average of 70% of clients had memory impairments or diagnoses of Alzheimer’s or related

dementia. This average may be skewed due to some sites’ and/or funding sources’ requirement of a diagnosis in order to receive services, and therefore, reflects the purposive sample selection. Music therapy and physical exercise were noted most frequently as services provided for participants. Caregiver support and cognitive stimulation were cited as well. Also noted were activities including *“failure free activities, pet therapy, arts and crafts, transportation, and creative writing and life reviews.”* One site noted that, *“Special monthly activities occur as well: birthdays, religious activities, and outings.”*

According to most respondents, activities can be adjusted to serve early-, late-, and end-stage clients and as a result are often referred to as “specialized” for the particular group. One site did note that a specific curriculum was being created at the time of the interview that would serve early-stage participants. The overall recurring theme, however, was the adjustment of daily activities to suit the needs of individual participants at varying levels of abilities. Also of note was the increased assistance with ADLs that occurred as a participant’s functional capability declined (e.g., eating, toileting, bathing).

Responses regarding services for early-onset Alzheimer’s disease differed from those stages that describe severity. Many respondents reported that they do not currently serve this population yet believe activities could be adjusted for them as well. Others believe that allowing these participants to assist with specific tasks is helpful. Still others hope to create a more specialized model as

they expect this population to increase with the aging of the baby boom generation.

“The average stay for an ADHC participant is three to four years, with the longest person remaining for 8 years. They wouldn’t have lasted that long in a nursing home setting.”

“Adult day health centers have made it possible to help late-stage (participants) to age in place.”

“Allowing people to stay in their homes for as long as possible is best practice.”

“A client ...in late stage for 4 years. At the end, the lady would recline on a day bed, but she was still part of the group.”

Figure 14. Aging in place

Agreement was noted with the statement (Figure 14) that more elders are aging in place in adult day health care centers and that this results in benefits for individuals, families, and communities. Respondents referenced the changing roles of nursing homes, “*moving toward short-term care and rehabilitation*” and assisted living facilities, “*replacing longer-term care.*” One respondent believed that ADHCs fill in the gaps left behind; that it was due to their

involvement with the participant and his or her family that allowed individuals to remain in the community for longer periods. Another respondent told of a participant who utilized services until just days before her death. This respondent believed that such cases could occur more frequently if staffing ratios were sufficient.

Demographics of participants

Respondents reported that a variety of additional chronic health conditions exist among participants. Diabetes, Parkinson’s disease, and stroke were noted most frequently. Heart disease, mental retardation, and mental health issues, including bipolar disorder and schizophrenia, were noted as well. Respondents further reported, albeit less frequently, cases of COPD, hypertension, cancer, seizures, mobility issues, and traumatic brain injury.

Most respondents believed that participants were safe at home in the community when not at the ADHC. They reported that most live with caregivers or in other facilities where behaviors are monitored and ADL assistance is available. Although not specifically described, references were made regarding the willingness to follow procedures and the limits that exist should the ADHC feel a participant is unsafe at home. Limits regarding what an ADHC could do were a concern for some respondents. One respondent stated that, “*I would not hesitate to take these steps.*” Another expressed concern, fearing the steps were ineffective. They reported that the greatest behavioral challenges occur around concurrent mental health issues and choking (some participants often place items in their mouths). Other concerns revolved around sexual, wandering, and aggressive behaviors. Respondents reported that they have a variety of strategies in place to deal with difficult behaviors. Staff is trained in deescalating

situations, including pro-active security measures (locked doors and windows), avoiding expectations, and learning triggers for specific individuals. A respondent stated, “*Remembering that behaviors are not intentional, that they are part of the illness, assists staff in dealing with situations appropriately.*”

High staff to participant ratios and smaller physical spaces have assisted in the ability to recognize issues before they become too intense. Should unsafe behaviors continue, respondents reported that behavior plans were created or referrals were made to a psychiatrist for possible medication assessment. It is important to note that most respondents reported that using medication to deal with behavior was the least preferred method. One respondent noted that, “*It is often a family that pushes for medication, but ADHC staff was concerned about medication’s effect on safety (increased falls) and quality of life.*”

Wandering behavior was acknowledged by all sites, yet they reported that their strategies were successful in handling these participants. Alarms and locks were noted as well as the use of ID bracelets, but equally important was the staff’s ability to use gentle redirection in order to refocus participants onto a different task. A concern was raised regarding younger participants with cognitive impairments. These individuals, should they wander, may not be recognized in the community as impaired simply due to their younger appearance. Although ID bracelets were referenced, there were no direct comments made regarding the Alzheimer’s Association’s Safe Return program as a means of dealing with wandering behavior.

Due to the aging of the baby boom generation, the addition of younger participants is expected to increase. Respondents reported that they are preparing for such a situation by altering the services to reflect this generation. For example one respondent recommended “*playing Beatles’ music.*” Respondents had additional ideas to prepare for the potential baby boom generation: increased family education and involvement, additional facilities, partial hospitalizations, and a form of group home where multiple participants would share one residence.

Family interactions

Only one respondent reported limited interaction with family members. The remaining sites reported that their involvement was frequent and necessary in order to give/receive information important to sufficient care of the participant: “*Every time I deal with a family, I learn something new.*” Respondents claimed that they acted as a resource and a support to families regarding issues of long-term care decisions and referrals. One respondent noted: “*If it’s a concern to the family, it’s a concern to us.*” Although the frequency was not reported, one respondent stated that questionnaires are given to family members in order to assess their levels of satisfaction with the ADHC.

“Does not understand that the facility can only do so much”
 “Transportation demands”
 “Needing/wanting outside services”
 “...denial”
 “...educating (caregivers). Things their loved ones say or do is not deliberate ...it is a manifestation of the disease”
 “Poorly attended support groups”

Figure 15. Special issues arising with family interactions

Complications arose with family interactions and are summarized in Figure 15. Families, like participants, are at different levels of understanding and acceptance regarding the participant’s illness. Respondents reported that these differences must be recognized in order to properly serve these families. Further

challenges when dealing with families occurred due to a family’s potential misconception of the limits of an ADHC.

Physical environment

Respondents were asked to share any special features of the physical environment designed for the challenges of cognitive impairment. Safety devices on doors, windows, and even water coolers were noted. Additional safety features included the color coding of walls, doors, and furniture. One respondent noted that, “trash cans were colored in order to avoid a participant’s confusing them for a toilet.” Handicap accessibility and first floor locations were noted as key features. Another specified “the posting of Resident Rights, a reality calendar (displaying day of week), and the daily menu.”

“Conveniently located off a route ...easily accessible”
 “Easy off-on highway access”
 “Located in a nursing home ...access to doctors and referrals”
 “..variety of locationsstrategically located”
 “Great cookout space”

Figure 16. Advantages: Location of facility

The locations of the facilities had advantages (Figure 16) and disadvantages as well (Figure 17). Many respondents referenced the importance of easy access from highways and being in public view. The latter “Assists in community networking as well as familiarity for many participants.” One respondent stated, “We are connected to a nursing home and were able to access nurses and doctors readily.” Disadvantages were noted by those respondents without first floor facilities or public transportation. A steep driveway made access difficult for some participants. Further, being connected to a larger facility often caused confusion and one

respondent referred to the stigma of the area as “dangerous.” Similarly, outdoor environments were considered advantageous particularly when visually attractive and secure. Two respondents specifically referenced the importance of the plowing and shoveling that occurs at their ADHC. Those respondents that cited

*“Extremely large complex
...confusing”*

“Steep driveway in the winter”

*“Often confuse us with the nursing
home upstairs”*

*“One of our centers is located on the
second floor”*

*“Because of theft, we can not put
flowers on the outside patio”*

*“We can (not) take our residents
outside”*

“There is no outdoor environment”

**Figure 17. Disadvantages:
Location of facility**

disadvantages were from sites that did not have outdoor facilities and relied heavily on field trips.

Transportation

Transportation of participants to and from the facility was reportedly directed by ADHC staff and was comprised by a combination of third-party contracts, site vehicles, and participants' families. When asked about driver training, most sites reported that, *“Drivers are trained in CPR and first aid only.”* In addition, some respondents reported that, *“Drivers were trained regarding specific behaviors occurring with dementia patients.”* One site noted that drivers carried cell phones and were provided a list of three persons that are considered *“trusted drop off persons.”* Although the behavior of the participant

was cited as a special issue when considering transportation, other issues were reported. *“Language barriers”* and *“the need for increased driver training”* were concerns. According to one site, *“Transport is very labor intensive and involves much more than simply driving.”* Funding, vehicle maintenance, and consistent assistance from caregivers in loading and unloading participants were also of concern.

Funding

Medicaid was cited most frequently as a funding source with a range of reimbursement rates cited. Basic daily rates ranged between \$50.28 and \$72.00; complex daily rates ranged from \$63 to \$69. Private payments were also reported between \$70 and \$86. Other sources of funding included: Elder Services, PACE, the VA. To supplement funding concerns and make ends meet, respondents stated they rely heavily on fundraising, foundations, and grants. Two respondents reported the need to keep staff salary low and even cut staff back. Both actions are reported to have a direct effect on quality of care since salary may effect turn-over, and cutting staff affects the necessary ratio. Funding was a concern for all respondents.

Staffing

Staffing ratios of 1:6 and 1:4 were reported, which is consistent with requirements for staffing ratios, 1:6 for basic care and 1:4 for complex care. Although most reported this ratio was acceptable, they also stated that additional staff was always appreciated. In fact, one site stated, *“Extra staff should be present, they were never sent home as there was always something to do.”* Volunteers were utilized by most respondents and often supplemented the

staffing ratios. Volunteers reportedly enjoy helping in any way, but some preferred specific tasks, others preferred administrative duties that did not include direct interaction with participants. “*Children from local clubs*” and “*organizations and college students*” were noted as volunteers as well.

Most in-house staff training was provided utilizing training curriculum developed by the Alzheimer’s Association. Respondents reported that a staff member, often a nurse or social worker, completed the Association’s “Train the Trainer,” and would then bring this experience back to the ADHC. Most stated that all staff, including drivers and volunteers, attended trainings. One respondent stated, “*Staff was encouraged to independently locate and attend a workshop which was paid for by the facility.*” In-house trainings occurred in varying degrees of frequency and content. One site reported 12 hours every two years, another reported 20 hours yearly. Training topics ranged from hand washing and customer service to dementia-specific behaviors. One site reported trainings in diabetes that were useful for any aging-related field. Off-site trainings included CPR, first aid, and Alzheimer’s disease. Two sites referenced specific staff/positions that are required to complete trainings in order to fulfill CEUs for their specific field.

Respondents consistently reported they were pleased with the training opportunities available through the Alzheimer’s Association. They also stated however, that cost and redundancy were concerns, and “*more cutting edge techniques are necessary.*” One respondent stated, “*Trainings specific to the onset of dementias and best practices would be helpful.*” Another cited the importance of training in grant writing to obtain additional funding. A gap in education regarding exercise activities and trainings specific to nursing were also noted.² Additionally, the content of these trainings varied for their intended audience: Some focused on individuals who were interested in brain health; another was geared for individuals with MCI or early-onset dementia; yet another focused on assisting individuals in dealing with a recent diagnosis of dementia in the family.

All respondents reported having contact with the Alzheimer’s Association whether personally (participating in the Memory Walk) or professionally (referrals, access to web site, trainings). One respondent noted a concern regarding the Association’s hotline. No one was reached by phone, and the respondent was concerned that perhaps the hotline did not operate on weekends when it would be needed.³

² It is important to note that after hearing these responses, a check of the Alzheimer’s Association’s website (Massachusetts/New Hampshire chapter) was warranted. The search quickly located various trainings that were offered at no cost.

³ Note: The Helpline is serviced 24/7, and calls are answered by a personal counselor.

Respondents were asked to complete the sentence: Employees would like to work here because Replies included a “*stable commitment*” and “*strong mission*” as well as “*a rewarding experience in serving the underserved.*” Other respondents described employment at the ADHC as a “*labor of love,*” “*family oriented where opinions are valued,*” and “*the opportunity for laughter and professional growth are encouraged.*”

Existing practices and future prospects

A range of responses was obtained when respondents were asked to describe “something special” about their ADHC. Music therapy, outings, and outdoor facilities were cited as well as intergenerational opportunities, stage-specific programming, and home-cooked meals: “*Every facility should have an activity director who was a chef in a previous life.*”

| | |
|--|---|
| <p>“<i>Educational and intellectual programs</i>”</p> <p>“<i>Increase physical and outdoor programming</i>”</p> <p>“<i>Failure free activities</i>”</p> <p>“<i>Specialization of programs ...</i>”</p> <p>“<i>Small job or task oriented opportunities</i>”</p> <p>“<i>Day program that revolves around support group</i>”</p> <p>“<i>Community awareness</i>”</p> <p>Figure 18. Envisioning new early-onset programs</p> | <p>Similarly, respondents offered several insights into new models for those diagnosed with early-stage dementia (Figure 18). Due to the higher functioning capacity of this population, respondents reported that programs with increased opportunities for exercise, outings, and support groups will be necessary. Additional references were made to “<i>failure free activities that focus on intellectual and physical pursuits.</i>” One respondent reported, “<i>In the future, due to a younger Alzheimer population, sites may be more activity specialized. One facility may focus on arts and crafts while another may cater to physical exercise.</i>”</p> |
|--|---|

Challenges

“*Transportation*” and “*obtaining multi-lingual staff*” were cited as major challenges in delivering quality care. Funding and staffing (quality and ratio), however, were cited most frequently. One respondent referred to the money lost since accepting MassHealth, “*One day of MassHealth pays for two hours of staff.*” Another noted, “*If you charge too much, people might not come. If you don’t charge enough, you can’t cover your expenses.*” Surprisingly, when asked for a “wish list” for their ADHC, only two respondents cited money/funding directly. The need for funds was observed nonetheless in the facility upgrades that were frequently requested: carpeting, WEI, computers, televisions, sensory items. “*Increased community support and assistance from volunteers*” were requested by one site. Although not elaborated on, one respondent wished that ADHCs would lose their current stigma. It may be inferred that the reference was to preconceived notions regarding the “elderly” and their “physical and mental disabilities.”

The last question posed to respondents allowed them to make additional comments. Daily cost was referred to by two respondents. Both referenced *“the need to charge certain rates in order to cover expenses, and the relative inexpensiveness compared to other options, yet they continued to feel bad requiring these fees.”* They believed many participants and their families could not afford them. One respondent stated that all doctors should be required to be trained in Alzheimer’s disease and take classes in elder care: *“As people continue to live longer and longermore older adults will need to be taken care of.”* Responses also included *“The need for greater public awareness of both the population served and the roles of the facilities that serve them: ADHCs are the greatest things.”*

CONCLUSIONS

The current research focused on four goals of exploration: description of existing practices, late-stage dementia-specific programming, challenges, and new paradigms for meeting the needs of early-stage and early-onset participants. The exploration was undertaken via a wide range of questions that resulted in both quantitative and qualitative analyses. Due to the nature of the study, a purposively selected sample was obtained, and this, coupled with a high response rate, implies valid and important results.

Existing practices in ADHC

Information regarding current practices was obtained both directly and indirectly through both open- and closed-ended responses. Inferences made regarding specific physical characteristics, hours of operation, and popular activities resulted in a greater understanding of these concepts’ overall importance. However, when asked the question directly, responses, including *“safety of participants and site,” “respect for individuality and autonomy,” “empathy for participants and families,”* and *“support for all,”* dominated the qualitative analysis. One respondent sums up their best-practice well: *“Offer appropriate, diverse, and quality programming.”* Another stressed placing families first: *“Listening to the concerns and needs of our patients and their families.”*

Stage-specific programming appears to be used to a certain extent by most facilities. The adjustment of physical environments increases safety and considers needs at an individual level. Specialized training, collaboration, consistent evaluations, and intergenerational involvement were existing practices that should not go unnoted. It is apparent that no one model exists, and in fact, implementing a variety of programming styles may result in increased success.

Late-stage Alzheimer’s disease programming

The majority of respondents from both the qualitative and the quantitative questionnaires (88% and 63%, respectively) stated that services were available for the late-stage population. Increased sensory stimulation and transportation adjustments (person-to-person versus door-to-door) were two services cited

specifically. The remainder of responses dealt with the adaptation of existing programming. For instance, ADL assistance is offered in many sites, but this assistance is increased as functioning decreases. In addition, from open-ended questions in the electronic survey that inquired about the provision of services for participants in late-stage and end-stage, there were four providers who reported working with hospice programs. One provider reported, "*We work with a hospice program to provide services both at the center and at the homes of the participants at end stage.*"

Challenges

Exploring the challenges faced by ADHCs resulted in a greater understanding of the overwhelming need for increased funding. Many responses referred to the maintenance of the facility, addressing the transportation needs, and paying the needed/required staff. In fact, 98% of sites completing the electronic survey reported funding concerns. In addition, however, respondents cited concern for the finances of their participants, with most falling below the state and national median incomes for their age categories. Respondents believed that some could not afford to attend while other stated that reimbursement rates were an issue, particularly for participants under the age of 62. As the baby boom generation continues to age, financial concerns will only continue to increase. It is imperative to consider the important role that these institutions maintain in society and address their needs accordingly.

The challenges regarding the sometimes difficult behavior of participants was common, but it appears that most are satisfied with their strategies in which to deal with them. The reliance on prevention and proactive interventions as opposed to medication is further evidence of the successful work performed at these facilities. Public education is needed regarding the challenges faced by persons living with dementia. A greater understanding of the behaviors and needs of these individuals would increase their quality of life, particularly for those participants residing in the community, and would increase awareness as well regarding the work and the limits of local ADHCs. Ideally, such education would result in awareness that would lead to increased support and financing.

Additional challenges arose regarding the ability to consistently provide activities and social encounters that "*cross the span of years.*" Respondents are aware of the changing demographics of their clientele and are challenged to meet the needs of a population diverse in age, functional ability, economic status, and ethnicity. Their efforts at meeting these needs are constantly constrained as they report increases in paperwork requirements that erode the quality and quantity of time spent with participants.

Envisioning new paradigms

The insights offered by respondents regarding new paradigms for those with early-stage or early-onset dementia were intriguing. Where so much financial concern was raised, it was inspiring to obtain ideas for the future that were often only indirectly dependent on financial resources. Calls for expanding support

groups into the evenings, additional exercise groups, outings (shopping, theatre, museums) and participant-volunteer opportunities were realistic and could likely be carried out with little increased cost. *“Intergenerational day services would allow participants to assist in child care, offering a chance to give back to the community and feel a sense of belonging.”* Other visions did affect cost: public and staff education, increased space, kitchen facilities; however, they are no less critical. Education regarding early-onset for example would benefit all involved: staff, participants, family, and care partners.

Additional visions for the future included increased prevention strategies. Certainly these have become more common (brain stimulation), but studies need to continue in order fully to understand their significance. A respondent from the qualitative interview reported, *“Evening and weekend programming would allow for increased respite for caregivers who may positively affect the quality of care they are able to give, and therefore the quality of life for both participant and caregiver.”*

Although this study focused on four goals, much was learned regarding the important work of ADHCs. Overall, ADHCs are willing and able to offer participants and their families the respect, autonomy, and empathy that they deserve. They understand strategies that work best for them but are open to change and envisioning better services. They are successful at adapting services and activities to meet participants’ needs, and do this while funding concerns are ever present. They are aware of the increase in participants with cognitive impairments that will arrive in future, but they are hopeful for continued change in what they are able to offer. However, without increased public awareness, dementia-specific training, and funding, these facilities are unnecessarily constrained.

RECOMMENDATIONS

Continued exploration of ADHCs is warranted. As the population continues to age, such facilities or their next generation will become imperative, particularly for those older adults that choose to or find themselves aging in place. Studies that assess existing practices will assist ADHCs in sharing knowledge regarding successful strategies of care. For instance, many ADHCs currently report that they offer stage-specific programming; however, it appears to be more accurate to state that ADHCs are adept at altering activities in order to best meet a participant’s needs. Albeit impressive, a more structured system that enables access to core curricula would be beneficial. These curricula may be created jointly by ADHCs and dementia experts from organizations such as the Alzheimer’s Association and others within the aging network. ADHCs would then be able to share their current strategies with others while simultaneously considering new ones.

Public education was consistently a concern raised by ADHCs. Their desire for increased awareness in communities is on-going; however, their ability to do

so is limited considering their present financial concerns. Although some organizations offer such workshops and trainings, often for little or no charge, getting the word out to the larger community is necessary. Individuals who know or care for an individual with cognitive impairment may be inclined to attend such a workshop; however, the education needs to reach further. This would not only avoid learning about dementia because now “you have to,” but would result in an overall community with increased awareness. An educated community may be more inclined to support financially its local ADHCs.

The population of future participants is likely to differ from the current population. Specifically, the baby boom generation is more educated and financially better off. As a result, this group will likely expect significantly different services and levels of care. Reaching this group now and offering education regarding the current abilities and limitations of ADHCs may be successful in altering the level of support these facilities currently receive. Baby boomers will be invested in securing the facilities that they will access in the near future. Without this increased public awareness, facilities will remain unnecessarily constrained.

References

- Alzheimer's Association. (2008). *Alzheimer's disease facts and figures*. Retrieved September 11, 2008, from http://www.alz.org/national/documents/report_alzfactsfigures2008.pdf
- Alzheimer's Association. (2007). *Alzheimer's disease facts and figures*. Retrieved August 13, 2007, from http://www.alz.org/national/documents/Report_2007FactsAndFigures.pdf
- Brennan, L., & Raia, P. (2008, February). Operational definitions of Alzheimer's disease and related dementias. (*Prepared for current research project*).
- Gerontology Institute. (2008). *Changing age composition in Massachusetts and the United States: 2000-2006*. Retrieved June 15, 2008, from the University of Massachusetts Boston, Gerontology Institute Web site: <http://www.geront.umb.edu/inst/projects/docs/Age%20Composition%20UPDATE.pdf>
- Gottler, J. (February 12, 2008). (*Personal communication with Gottler during discussion*). Location: The University of Massachusetts Boston.
- Montgomery, R.J., & Rowe, J.M. (2007). Respite. In C. Cox (Ed.) *Dementia and Social Work Practice*. (pp. 339-360). New York: Springer.
- Montgomery, R.J., Rowe, J.M., & Kosloski, K. (2007). Family caregiving. In J.A. Blackburn & C.N. Dulmus, *Handbook of Gerontology*. (pp. 426-454). Hoboken, New Jersey: Wiley.
- Robert Wood Johnson Foundation. (2003). *Shortage of adult day services in most U.S. counties*. Retrieved February 12, 2008, from http://www.rwjf.org/files/newsroom/interactives/adult_day_centers/adult_day.jsp
- Singleton, R. and Straits, B. (2005). *Approaches to social research* (4th ed.). New York: Oxford University Press.
- Shigeta, M., & Homma, A. (2007). Alzheimer's disease. In J.A. Blackburn & C.N. Dulmus, *Handbook of Gerontology*. (pp. 333-366). Hoboken, New Jersey: Wiley.
- U.S. Census Bureau. (2000). *Household income estimates for two-year period: 2005-2006*. Retrieved August 12, 2008, from <http://www.census.gov/hhes/www/income/statemedfaminc.html>
- U.S. Department of Health and Human Services. (2006, July). *Adult day services: A key community service for older adults* (#HHS-100-03-0025).

Retrieved January 4, 2008 from <http://aspe.hhs.gov/daltcp/reports/2006/keyADS.pdf>

Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology*, 53B(5), S267-S277

Appendix A

Operational Definitions of Alzheimer's Disease and Related Dementias

*Prepared for current survey purposes by Paul Raia, PhD and Lindsay Brennan, LSW,
Alzheimer's Association, Massachusetts/New Hampshire Chapter, February, 2008*

Mild Cognitive Impairment:

Subtle but measurable memory loss and cognitive dysfunction greater than those associated with normal aging but not as severe as those associated with dementia.

- § Able to report his own memory loss
- § Memory loss that can be measured on assessment tests
- § Normal general thinking and reasoning skills
- § Ability to perform normal activities of daily living
- § Difficulty with word finding, naming of things, fluidity of speech and misuse of words.

Early Stage AD or related dementia:

Mild to moderate cognitive decline and memory loss

- § Short term memory loss, long term memory intact
- § Word finding / recall difficulty
- § Greater difficulty in social / work setting
- § Disorganized planning of routine tasks
- § Significant difficulty with executive functioning; ie. Finances
- § Mood dysfunction – depression, anxiety, withdrawal

Middle Stage AD or related dementia:

Noticeable memory loss, cognitive decline and physical changes

- § Changes in communication – speaking, listening, processing, & responding
- § Significant short term memory loss, and worsening long term memory
- § Key feature of this stage is that the person requires cueing and supervision with basic activities of daily living (dressing, showering, toileting meal prep, hobbies)
- § Progression in mood and behavior disturbances (anxiety, aggressiveness, sexually inappropriate, suspiciousness, agitation, limited attention span, pacing, repetition)
- § Requiring 24 hour supervision for safety - wandering risk
- § Visual-spatial dysfunction
- § Able to participate in group programming that is geared to AD clients
- § Requires regular refocusing and redirection

Late Stage AD or related dementia:

Memory and cognition continues to worsen, daily care needs increase significantly

- § Significant communication difficulties (speaking less, “word salad”, unable to follow commands)
- § Physical care needs are extensive (incontinence, unable to dress self, unable to feed self)
- § Changes in mobility – shuffling gate, if still walking
- § Require 24 supervision for safety and care

- § Limited ability to participate in traditional recreational activities, ie require sensory stim, 1:1 or, small group programs

End Stage AD or related dementia:

Final stages of disease with approximately 6 months or less to live

- § Little or no verbal communication
- § Totally dependent for all physical care
- § Sleeping more than 12 hours a day
- § Respond only to emotional or physical stimulation
- § Weight loss
- § Problems with swallowing and other basic reflexes
- § Compromised immune response

Appendix B

Questionnaire Items for Creation of “Dementia- Friendly” Variable

The following eleven questions were identified (a total of 12 points) in the questionnaire as having particular relevance to the successful care of individuals with Alzheimer’s disease.

1. My adult day health care offers these services (Please check all that apply):
- | | |
|--------------------------------------|--|
| Alzheimer’ Disease Specific Services | Assistance with Activities of Daily Living |
| Case Management | Classes for Adult Basic Education |
| Health Education and Counseling | Home Safety Programs |
| Housing Assistance | Information and Referral |
| Meals | Medication Administration |
| Nursing Services | Nutrition Counseling |
| Occupational Therapy | Physical Therapy |
| Podiatry | Private Pay Counseling Services |
| Psychological Therapy | Public Benefits Counseling |
| SHINE Health Insurance Counseling | Skilled Nursing Services |
| Social Services | Speech Therapy |
| Spiritual | Substance Abuse Services for Seniors |
| Support Groups | Transportation |
| Other (Please specify and describe): | |

One point received for each indication of “Alzheimer’s Disease Specific Services” and “Support Groups.”

2. My adult day health care offers these activities (Please check all that apply):
- | | |
|-------------------------------------|---|
| Adaptive Games | Alzheimer’s Disease Specific Activities |
| Art Groups | Books/Readings/Story Telling |
| Day Trips/Trips in the Community | Entertainment |
| Exercise | Hairdressing |
| Men’s Groups | Music Groups |
| Spiritual | Sports-Related Activities |
| Women’s Groups | None of the Above |
| Other (Please specify and describe) | |

One point received for each indication of “Alzheimer’s Disease Specific Activities.”

3. What is the typical number of activities scheduled daily?
 1-2 activities 3-4 activities 5-6 activities
 7-8 activities More than 8 activities

One point received for each indication of 5 or more daily activities.

The following six questions were scored one point for each 'yes' response:

4. Does your adult day health care offer training on Alzheimer's disease or a related dementia?
5. Does your adult day health care offer programs or specific services for participants who have mild cognitive impairment?
6. Does your adult day health care offer programs or specific services for participants who are in the early stage of Alzheimer's disease or a related dementia?
7. Does your adult day health care offer programs or specific services for participants who are in the late stage of Alzheimer's disease or a related dementia?
8. Does your adult day health care offer programs or specific services for participants who are in the end stage of Alzheimer's disease or a related dementia?
9. Is Safe Return®, the wanderers' alert program sponsored by the U.S. Justice Department and administered through the Alzheimer's Association, registration checked at intake for new participants?

One point received for Strongly Agree or Agree response:

10. The adult day health care where I work has purposively-designed spaces intended to serve the needs of my participants who have Alzheimer's disease or a related dementia.

Strongly Agree Agree Uncertain
 Disagree Strongly Disagree

One point received for 'yes' response.

11. Does your adult day health care offer a written care plan to guide caregivers?

Appendix C

Massachusetts Regulatory Summary

| Overview | | | |
|---|---|--|---|
| <p>Massachusetts provides adult day health services through its Medicaid state plan program, MassHealth. Provider services are governed by regulations published in the Adult Day Health Provider Manual under a contract between MassHealth and the provider.</p> <p>Massachusetts also offers and regulates a Supportive Day Program through the Executive Office of Elder Affairs Program for Councils on Aging and Senior Centers. Providers must agree to the Supportive Day Program requirements as an attachment to their provider agreement to provide services under state funding.</p> <p>The only requirements for adult day health services are those contained in the Adult Day Health Care Provider Manual for the MassHealth Program. These requirements are described in this profile.</p> | | | |
| Licensure and Certification Requirements | | | |
| Licensure Only <input type="checkbox"/> | Certification Only <input type="checkbox"/> | Both Required <input type="checkbox"/> | Other <input checked="" type="checkbox"/> provider contract |
| Definitions | | | |
| <p>Adult day health care. <i>Adult day health services</i> are all services provided at a MassHealth-approved adult day health program that meets the conditions of the <i>Adult Day Health Provider Manual</i>. The general goal of these services is to provide an organized program of services including nursing and supervision, therapy, nutrition, counseling, activities, case management. An adult day health program must operate at least Monday through Friday for 8 hours a day. There are two levels of care: adult day health basic and adult day health complex. Level of care is based on the member's care needs.</p> <p>Supportive day programs (SDP) provide support services in a group setting to help participants recover and rehabilitate from an acute illness or injury or manage a chronic illness.</p> | | | |
| Parameters for Who Can Be Served | | | |
| <p>Adult day health care. The definition of adult day health care above indicates the parameters for who can be served in these programs. Providers may serve anyone aged 18 or older. Providers may discharge an individual who develops behavioral problems that may endanger or seriously disrupt other members or staff, or requires increased services that the program is unable to provide, in which case the program must arrange for discharge to a more appropriate setting and may not discharge the member until appropriate services are available.</p> <p>Supportive day programs. Providers may serve individuals who are in need of supervision, supportive services, socialization, and minimal assistance with activities of daily living (ADL). Participants may have multiple physical problems, but must be stable and not need nursing observation or intervention. Participants may have some cognitive impairment but behavior problems must be able to be handled with redirection and reassurance. Participants must be able to communicate personal needs.</p> | | | |
| Inspection and Monitoring | | | |
| Yes <input checked="" type="checkbox"/> | No | | |
| <p>Adult day health care. A provider must agree to periodic inspections that assess the quality of member care and ensure compliance with the regulations.</p> <p>Supportive day program. The Office of Elder Affairs Program for Councils on Aging and Senior Centers may inspect providers but has no regular schedule or requirement to do so.</p> | | | |

| Required and Optional Services | | | | | |
|---|---|-----------------------|--|------------------------|--|
| | | Adult Day Health Care | | Supportive Day Program | |
| | | | | | |
| ADL Assistance | | X | | X* | |
| Health Education and Counseling | | X | | | |
| Health Monitoring/Health-Related Services | | X | | X | |
| Medication Administration | | X | | | |
| Nursing Services | | X | | | |
| Physical Therapy, Occupational Therapy or Speech Therapy | | X | | | |
| Skilled Nursing Services | | X | | | |
| Social Services | | X | | X | |
| Transportation | | X | | X | |
| *ADL assistance is limited to verbal or visual prompts. | | | | | |
| Provisions Regarding Medications | | | | | |
| <p>Adult day health care. Nursing services for all levels of care provided in adult day health care must include nursing services which administer medications and treatments prescribed by the member's physician during the time the member is at the program.</p> <p>Supportive day program. Participants are responsible for administering their own medications.</p> | | | | | |
| Provisions for Groups with Special Needs | | | | | |
| Dementia ü | Mental Retardation/ Developmental Disabilities | Other ü | medically complex members can continue to be served in ADH | | |
| Staffing Requirements | | | | | |
| <p>Adult Day Health Care</p> <p>Type of staff. The provider must employ a full-time <i>program director</i>. One professional staff person must be designated as an <i>assistant program director</i> and assume the responsibilities of program director as needed.</p> <p>There must be a <i>registered nurse</i> on site each program day that members are on site, for a minimum of 4 hours. The center must provide nursing coverage on site for a minimum of 8 hours total, four of which may be provided by a licensed practical nurse. When the average daily census reaches 35 or more, the center must provide nursing coverage on site for a minimum of 12 hours, of which 4 must be provided by a registered nurse. When the average daily census reaches 50, the center must provide nursing service for 16 hours a day, 8 of which must be provided by a registered nurse.</p> <p>The program must employ an <i>activity director</i> for a minimum of 4 scheduled hours each day. If the program's average daily census is 24 or more members, the program must employ a social worker on site for a minimum of 20 scheduled hours each week. Licensed staff may perform the social service requirements when the program's average daily census is 23 or fewer members. <i>Licensed practical nurses, aides, and consulting therapists</i> are to be hired as needed.</p> | | | | | |

Staffing ratios. Programs must have available sufficient direct-care staff to meet the needs of their members: for basic level of care services, a minimum-staffing ratio of one direct care staff person to six members and for complex level of care services, one staff person to four members. Programs offering both levels of care must maintain proportionate direct-care staff ratios to meet the needs of members based on the ratio of members requiring each level of care.

For the programs specializing in serving members with dementia, the program must maintain a staff-to-member ratio of at least one-to-four on site.

Supportive Day Program

Type of staff. The organization shall provide an adequate number of staff whose qualifications are commensurate with defined job responsibilities to provide essential program functions.

The defined positions are *administrator, program director, and activities coordinator*. The program director may also be the administrator.

Staffing ratios. There shall be at least two responsible persons, one a paid staff member at the center at all times when there are two or more participants present. The staff-participant ratio must be at least one-to-eight.

Training Requirements

Adult day health care. Programs must provide staff training appropriate to the mix of services provided. Programs must provide a minimum of 8 hours of in-service training sessions per year.

For programs specializing in serving members with dementia, staff training must include dealing with dementia, verbal and nonverbal communication skills, behavior management skills, group process skills, family functioning, dealing with difficulty in group participation, dealing with high anxiety, dealing with aggressive behavior, and dealing with wandering.

Supportive day program. Staff will be trained in signs and indicators of potential abuse. Orientation, in-service training, and evaluations shall be provided to all employees and volunteers, including the use of standard protocols for communicable diseases and infection control.

Relevant Medicaid Contracting Requirements for Adult Day Services Providers

The only requirements for adult day health services are those contained in the *Adult Day Health Care Provider Manual* for the MassHealth Program. These requirements are described in this profile.

Location of Licensing, Certification, or Other Requirements

1. http://www.mass.gov/Eeohhs2/docs/masshealth/transletters_2002/adh-15.pdf
2. http://www.mass.gov/Eeohhs2/docs/masshealth/transletters_2002/adh-16.pdf
3. http://www.mass.gov/Eeohhs2/docs/masshealth/transletters_2003/adh-17.pdf
4. http://www.mass.gov/Eeohhs2/docs/masshealth/transletters_2003/adh-18.pdf
5. http://www.mass.gov/Eeohhs2/docs/masshealth/transletters_2004/adh-19.pdf
6. Provided by the Executive Office of Elder Affairs. On file at RTI.

Citations

1. *MassHealth Transmittal Letter ADH 15. Adult Day Health Manual, Revised.* Commonwealth of Massachusetts, Executive Office of Health and Human Services, Office of Medicaid. [October 2002]
2. *MassHealth Transmittal Letter ADH 16. Adult Day Health Manual Revisions.* Commonwealth of Massachusetts, Executive Office of Health and Human Services, Office of Medicaid. [December 2002]
3. *MassHealth Transmittal Letter ADH 17. Adult Day Health Manual Revisions.* Commonwealth of Massachusetts, Executive Office of Health and Human Services, Office of Medicaid. [April 2003]
4. *MassHealth Transmittal Letter ADH 18. Adult Day Health Manual Revisions.* Commonwealth of Massachusetts, Executive Office of Health and Human Services, Office of Medicaid. [11/01/03]

5. *MassHealth Transmittal Letter ADH 19. Adult Day Health Manual Revisions.* Commonwealth of Massachusetts, Executive Office of Health and Human Services, Office of Medicaid. [September 2004]
6. *Supportive Day Program.* Attachment A to provider agreement. Executive Office of Elder Affairs. [FY 2003]

Source: U.S. Department of Health and Human Services. (2006, July). *Adult day services: A key community service for older adults.*