2-2011

Massachusetts' Home Care Programs and Reasons for Discharge into Nursing Homes

Cathy M. Wong
University of Massachusetts Boston

Nina M. Silverstein
University of Massachusetts Boston, nina.silverstein@umb.edu

Massachusetts' Home Care Programs and Reasons for Discharge into Nursing Homes[1, 2, 3]

Prepared by:
Cathy M. Wong, M.A.
Nina M. Silverstein, Ph.D.
Gerontology Institute,
University of Massachusetts Boston

February 2011

---

[1] The authors gratefully acknowledge the contribution to data collection from the following University of Massachusetts Boston gerontology undergraduate and certificate students: Darleen Blood, Cynthia Duryee, Matthew Gauvain, Grace Mackinnon, Julia Nickrosz, Archana Patel, Paul Rinaldi, Amy Rippy, and Timothy Sheehan. In addition, the authors further thank Wey Hsiao, Joe Quirk, and Siobhan Coyle of the Massachusetts Executive Office of Elder Affairs for sharing aggregate data; Rachel Berry of Somerville Cambridge Elder Services; and the care managers from the Aging Service Access Points who shared their time and insights for this project.

[2] This report was supported, in part, by the Gerontology Institute, McCormack Graduate School of Policy and Global Studies, and the College of Public and Community Service, University of Massachusetts Boston; and by Mass Home Care.

[3] The authors acknowledge the assistance of Al Norman from Mass Home Care, the Community Partner for this research, for his contributions to the study and to the final report. The authors also acknowledge Robert Geary, Gerontology Institute, for his assistance in manuscript preparation.

Mass Home Care

UMASS BOSTON

TABLE OF CONTENTS

LIST OF FIGURES & TABLES

EXECUTIVE SUMMARY

INTRODUCTION

Home and community-based services (HCBS) are a range of long-term care services intended to enable older adults and persons with disabilities to "age in place" in their own homes and communities. Previous studies well document that older adults prefer receiving HCBS rather than institutional care at a nursing home (e.g., Walker, 2010; Fox-Grage, Coleman, & Freiman, 2006). One study concluded that 84 percent of older Americans, aged 50 years and older, want to remain in their homes for as long as possible (AARP, 2005). Medicaid is a major source of funding for long term care. Currently, a large proportion of Medicaid funds in most states has been spent on institutional care (National Conference of State Legislatures & AARP, 2009), and older adults and their families have relied on nursing homes to be the provider of long-term care (Miller, Allen, & Mor, 2009).

In 2006, the national average of the proportion of Medicaid long-term care spending for disabled older adults and persons with disabilities going to institutional care was 75 percent, while 25 percent was directed towards HCBS (Kassner et al., 2008). Similar to the national average, the proportion of Medicaid long-term care spending for institutional care in 2006 was greater than the proportion for HCBS in Massachusetts with 78 percent of Medicaid long-term care spending directed towards institutional care, and 22 percent going to HCBS (Kassner et al., 2008). Moreover, in 2007, Massachusetts had nearly 25 percent greater rate of nursing home utilization than the national average (Wallack et al., 2010). As of 2008, according to the Massachusetts State Profile Tool, approximately 60 percent of MassHealth (Massachusetts' state Medicaid program) long-term care spending is spent on nursing facilities.

Massachusetts' Home Care Program Services

This report is focused on and limited to three main programs in Massachusetts that provide HCBS: Home Care Basic, Community Choices Program (Choices), and Enhanced Community Options Program (ECOP). These three home care programs are not the full complement of HCBS in the Commonwealth. MassHealth's (Medicaid) role in HCBS is as a payer of services. The home care programs are administered by Aging Service Access Points (ASAPs) under contract with the Executive Office of Elder Affairs (EOEA). The EOEA is the State Unit on Aging. The EOEA provides home care services statewide holding contracts with 27 ASAPs throughout the Commonwealth. ASAPs are described as a single entry point for elders in the community, and services provided by ASAPs include care management, information and referral, nursing home pre- and post-admission screening, development of service plans, and monitoring of service plans.

The home care programs provide services to eligible elders who need assistance so they may continue to live independently in their homes and

communities. An interdisciplinary team that consists of care managers and nurses from ASAPs conducts an assessment in the elder's home to determine eligibility for the programs. Care managers assess clients' needs and provide service plans that meet their needs, incorporating informal supports, other available resources, and utilizing the home care funded programs as part of the service plan. Individual services needs and a personalized service plan are developed with elders and their family members.

Research Objectives

This study provides a snapshot of clients enrolled in three home care programs by examining the sociodemographic characteristics, health status, and unmet needs assessed among clients at one point in time in 2010. Additional qualitative data are used to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into institutional long-term care settings. The report concludes with recommendations to enhance the delivery of home care program services in Massachusetts.

METHODOLOGY

Three sources of data are used to address the research objectives of this study: qualitative data from in-person interviews with 17 care managers and one registered nurse in spring 2010; aggregate data provided by the Massachusetts Executive Office of Elder Affairs through their Comprehensive Data Set; and a sample of journal entry notes from care managers and nurses that were provided from one ASAP.

Care Managers' Perspectives

UMass Boston gerontology students enrolled in a spring 2010 Aging and Social Policy seminar, in partial fulfillment of the requirements of the undergraduate major in gerontology and Certificate in Gerontological Social Policy, conducted a research project titled, *Discharge from Home and Community-Based Services to Nursing Homes in Massachusetts: Care Managers' Perspectives*. The research objective of the project was to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into nursing homes.

After receiving approval from the Institutional Review Board (IRB) at UMass Boston, student researchers conducted in-person interviews with a convenience sample of care managers at eight ASAPs. A total of 17 care managers and one registered nurse were interviewed at their respective agencies. It should be noted that the registered nurse was interviewed due to the care management role she served at one ASAP that had few care managers to participate in the study. Care managers and the registered nurse were asked their perceptions about clients' barriers to remaining in the community that may lead to discharge into nursing homes. Herein, the data are presented for the total 18 care managers. The study prompted pursuing further data sources on examining the home care programs in Massachusetts, and this current report provides the additional data beyond the student research.

Comprehensive Data Set

The Comprehensive Data Set (CDS) enabled an examination of the clients enrolled in three home care programs in Massachusetts (Home Care Basic, Choices, and ECOP). The data were provided in aggregate form by the Massachusetts Executive Office of Elder Affairs. The CDS is a comprehensive questionnaire used by care managers and registered nurses for assessments with clients enrolled in the home care programs. Care managers monitor clients' needs and their service plans by conducting reassessments. Reassessments are performed at home visits in the clients' homes. For the Home Care Basic program, reassessment is required no less than every six months or as often as necessary when circumstances for a client changes. For the Choices and ECOP programs, reassessment is required no less than every three months or when a change occurs.

The data were provided for March 2010 and allow for a relative comparison of home care clients during the same period of time that the student interviews with care managers occurred. Caution should be exercised in generalizing these findings as these were not matched comparisons. The authors' intent is to provide some insights that may generate further exploration. During that time, a total of 32,417 clients were enrolled in the Home Care Basic program, 5,221 clients were enrolled in Choices, and 4,563 clients were enrolled in ECOP, which yields a total of 42,201 home care clients. This current study's analysis is presented as percentages and examines clients by each of the home care programs, which allows for program-to-program comparisons within the CDS.

Care Manager Journal Notes

To further explore reasons for discharge from the home care programs into nursing homes, a sample of 150 journal entries were reviewed for 15 clients during the months of February, June, and July 2010. Care managers and nurses document field notes of their clients and it was expected that these journal notes would provide more detailed information on reasons why clients are being discharged from the home care programs. The journal notes were reviewed and analyzed by identifying frequent themes mentioned for termination.

RESULTS

Comprehensive Data Set

The CDS was used to present a snapshot of clients enrolled in the home care programs in March 2010. Overall, home care clients are predominantly older women (75.4%) who are widowed (47.6%) and live alone (62.3%). Hypertension was the most prevalent disease diagnosis among the clients, with 80.4% of Choices clients reported as having the health condition. Clients from Choices and ECOP were much frailer and had more disease diagnoses than clients from the Home Care Basic program.

Doctors and hospitals account for very few referrals for home care services, 2.5% and 9.4% respectively. Over a third, 37.6% of total home care clients were taking nine or more medications. Also, 64.3% of total home care clients reported experiencing unsteady gait. A large proportion of Choices and ECOP clients,

66.3% and 67.6% respectively, report having limits in going outdoors due to fear of falling.

Critical Unmet Needs

Critical unmet needs are defined in the home care regulations (651 CMR 3:00) as a client's inability to perform or have someone else available to assist with any one or more of the following: any activity of daily living (ADL), meal preparation, food shopping, transportation for medical treatments, respite care, and home health services. An identified critical unmet need is required for eligibility for service on initial assessment or else clients are not enrolled in the home care programs. Clients from Choices and ECOP have more critical unmet needs. Over half, 52% of Choices clients and 47.9% of ECOP clients were reported as having critical unmet needs. Assistance with any ADLs, meal preparation, food shopping were the major critical unmet needs reported among Choices and ECOP clients. Caution should be exercised in interpreting these data in that they reflect one point in time and were provided in aggregate form, therefore it cannot be determined if these are ongoing unmet needs or the initial unmet need that determines eligibility and then was reduced or met through services later delivered.

The CDS has information on clients making trade-offs in purchasing prescribed medications, sufficient home heat, necessary physician care, adequate food, or home care during the last month due to limited funds. Almost all of the total home care clients, 97.9%, were noted as having made trade-offs.

Informal Support

More than two thirds (67.8%) of elderly home care clients do not live with their caregivers. The majority of caregivers for home care clients are a child or child in-law. Among the total home care clients, only 11.7% of caregivers are spouses, consistent with the majority of total home care clients being widowed females. A small proportion, 3% of Home Care Basic clients, 2.6% of Choices clients, and 1.6% of ECOP clients were reported as not having a caregiver. Concerning advance directives and responsibility, over half, 55%, of home care clients were reported as not having a health care proxy; 72% do not have a power of attorney; and 85% do not have advance medical directives in place.

Reasons for Termination from Home Care Programs

For fiscal year 2010, the major reasons for discharge from home care programs aside from transfer between programs were due to death and nursing home placement. About 13% of Home Care Basic clients, 17% of Choices clients, and 20.6% of ECOP clients were terminated from the home care programs and placed into a nursing home. Based on the total cases examined, 14.5% of cases were termination due to nursing facility placement, or 3,627 elders. Regarding death, 13.9% of Home Care Basic clients, 17.3% of Choices clients, and 21.4% of ECOP clients had passed away.

Care Managers' Perspectives

Overall, the majority (72%) of the care managers stated that clients are maintained longer in the community today than in past years. While they thought that more supports are available in their communities today, there were some notable exceptions.

This study found that addressing the need for 24/7 care in the home, in the opinion of several care managers, could potentially prevent or delay nursing home placement. Care managers were asked what additional services are needed to maintain clients in their homes. From the 18 care managers interviewed, 14 reported that 24/7 supervision could potentially delay institutionalization. One care manager expressed, "*… personal care services and people who need general supervision. So that can fall under companions if you need 24-hour supervision then it's very unlikely you'll be able to get it from the state."*

Another care manager stated, "*I think weekend services. It's easy to get services Monday through Friday. Weekends and night services, especially helping people get to bed. Overnight help to monitor clients."*

The care managers also noted a lack of informal caregiver supports and safety concerns, such as wandering among clients with Alzheimer's disease. Lastly, the majority of care managers reported that lack of exercise and poor nutritional habits are risk factors for their clients

Care Manager Journal Notes

Consistent with care manager interviews, the journal notes reveal that the need for continuous 24-hour care is a reason for discharge to a nursing facility. Often the need for 24/7 support and supervision is combined with other factors, such as the intensity of care required (e.g., two person assist). Frequent reasons for discharge into nursing homes noted in the journal entries were: the need for 24/7 care, risk and history of falls, a lack of informal support at home, the need for respite and support for informal caregivers, reaching a maximum of assistance with ADLs and IADLs, and the severity and number of medical conditions that are challenging to manage in the home.

CONCLUSIONS AND RECOMMENDATIONS

This study provide a snapshot of clients currently served by the three home care programs and insights from care managers as to reasons for discharge for HCBS to nursing home settings. We conclude by highlighting some of the findings and offering some recommendations to enhance the delivery of HCBS in Massachusetts.

Medication Administration: As reported from the CDS data, over a third, 37.6%, of total home care clients were taking nine or more medications. Because clients use multiple medications, and often have trouble keeping them straight or remembering to take their medications, improved services for medication management may be needed for clients. Future research might address concerns for polypharmacy and level of medications' compliance among home care clients. Programs might also explore enhancing assistance in the area of medications' management.

Evidence-Based Fall Prevention Programs: As reported from the CDS data, an estimated 64% of total home care clients were experiencing unsteady gait. A large proportion of Choices and ECOP clients, 66.3% and 67.6% respectively, were reported as having limits in going outdoors due to fear of falling. The care manager interviews also highlighted the need for increased fall prevention. Currently, interventions do exist on fall prevention. ASAPS are involved in the 'Matter of Balance' evidenced-based program. An assessment of the program and expansion if warranted should be considered due to the large proportion of home care clients experiencing unsteady gait and balance.

Improved Coordination with Medical Providers: As the CDS data indicate that doctors and hospitals account for very few referrals for home care services, 2.5% and 9.4% respectively, efforts should be explored to create better linkages with medical home providers and with hospital discharge staff. Improved communication may help reduce inappropriate or unnecessary admissions to hospitals and nursing facilities. Moreover, an estimated 52% of Choices clients and 41% of ECOP clients feel multiple periods of pain daily. Further, more than half of Choices clients, 56%, reported that the intensity of their pain disrupts performing usual activities. The home care programs currently do not provide services for pain management. Interventions in pain management should be available, as part of the chronic disease management program and better coordination with medical providers could address that need.

Risk Assessment: Safety was an important theme for the care managers interviewed. Safety of the client is seen differently by the client, the family, and the care manager. Tolerance for safety may also vary from client to client. Use of negotiated risk assessments with clients and family members might help to identify the risks, and clarify what the "safety" issues really are for all parties involved.

24/7 In-Home Supports: A major theme in the care manager interviews is the need for 24/7 care. Consumers who wish to remain at home need to have the ability to assemble care plans on short order, including coverage for overnight care and weekends. Community care plans need to be as straightforward to assemble as a nursing facility placement. This could include short-stay adult foster care placements, and special extended care response teams of homemakers and home health aides. Moreover, clients in home care could be maintained in the community if there were intermediate steps between care at home and care in a nursing facility. 24/7 supports can require combining housing with services such as supportive housing sites, or a small group home facility for individuals unable to live alone.

Self-Managing Chronic Conditions: Some clients terminated from the home care program and transferred to a nursing home have multiple medical conditions---which alone may not require discharge from home care, but in combination create the sense of overwhelming need. As a preventive measure, programming to provide individual, in-home chronic condition self-management support may help clients manage their chronic conditions with better outcomes. Hypertension (64.8%), arthritis (53.8%), and diabetes (30.6%) were the most prevalent health conditions among total home care clients noted in the CDS data. There are chronic disease self-management programs in the home care system today, but additional development of programs and interventions for these conditions may be warranted.

Care Manager Discharge Training: Care managers do not have a direct role in the decision to discharge, the decision resides with the older adult and family members. In the qualitative interviews, care managers were asked how much input they typically have in the decision to discharge clients from HCBS to a nursing home. The majority of care managers reported that they have some input, while "*the decision is from the clients' families*." Care managers were asked about what factors are considered by their clients and families in the decision to discharge from home care programs into a nursing home. One care manager explained that safety concerns and a lack of informal support at home are considerations for nursing home placement. A special curriculum designed to help care managers approach the discharge process would be helpful to better understand how to work with family dynamics; how to assess their own professional and personal attitudes towards safety; and how to ensure that the consumer's voice is given the weight it deserves.

Need for Additional Research: Additional study of terminations from home care should be conducted, focusing especially on service gaps identified in the journal notes. The journal entry notes provided insights into reasons for discharge among clients that may not have been captured from the CDS. Future studies focusing on service gaps could include a more comprehensive analysis using journal notes as well as interviewing clients and family members. In addition, future studies might be conducted in examining the role of the care manager, client, family members, and doctors in the decision making process. It is recommended that strategies be developed in working with healthcare

providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options.

A limitation of this study is the small sample of care managers who were interviewed for the applied research project. The nature of qualitative data is to use few subjects to collect in-depth data. Much was learned from these data. However, generalization is limited in that these care managers do not represent all care managers in the Commonwealth. Building on this current study, an electronic study of all care managers is planned for spring 2011. We look forward to collecting additional insights on this issue. Another limitation is the missing cases from the CDS data. We learned that the data needs are time consuming for the care managers and not all data are fully entered. Still, the study provided relevant information on reasons for client discharge. EOEA might revisit their reporting forms with the goal of minimizing missing data. It would be helpful to conduct additional studies on terminations from home and community-based care, focusing especially on service gaps identified in journal notes, and examining the role of the care manager, client, family members, and doctors in the decision making process. It is recommended that strategies be developed in working with healthcare providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options. It is hoped that ASAPs, other elder services groups, and policy makers will use this report to develop additional responses to address the identified service gaps in community-based programming.

INTRODUCTION

Home and community-based services (HCBS) are a range of long-term care services intended to enable older adults and persons with disabilities to "age in place" in their own homes and communities. Some services provided in the home and community normally include care management, personal assistance with activities of daily living (ADLs) and with instrumental activities of daily living (IADLs), home safety adaptations, transportation, and adult day health care (Muramatsu, Yin, Campbell, Hoyem, Jacob, & Ross, 2007). Previous studies well document that older adults prefer receiving HCBS rather than institutional care at a nursing home (e.g., Walker, 2010; Fox-Grage, Coleman, and Freiman, 2006). One study concluded that 84 percent of older Americans, aged 50 years and older, want to remain in their homes as long as possible (AARP, 2005).

Medicaid is the primary source of public financing for long-term care and the federal program that provides long-term care services for the elderly population (National Conference of State Legislatures & AARP, 2009). Medicaid is jointly funded by the federal and state governments, in which each state manages and administers its own Medicaid program while the Centers for Medicare and Medicaid Services (CMS), a federal agency, monitors the state programs (Clark, Burkhauser, Moon, Quinn, & Smeeding, 2004). Historically, a large proportion of Medicaid funds has been spent on institutional care (National Conference of State Legislatures & AARP, 2009), and older adults and their families have relied on nursing homes to be the provider of long-term care (Miller, Allen, & Mor, 2009).

One contributing reason for the large proportion of Medicaid funds spent on institutional care at nursing homes for disabled older adults is that Medicaid requires states to provide institutional care as a mandatory benefit to eligible persons, whereas HCBS is an optional benefit (Kaiser Commission on Medicaid and the Uninsured, 2004). As a result of this Medicaid requirement, the term "institutional bias" is used to refer to the limitations of alternatives in the development and provision of non-institutional services in home and community-based settings (Kassner, Reinhard, Fox-Grage, Houser, Accius, Coleman, & Milne, 2008).

However, with the recognition that older adults prefer to remain in their homes and desire more options for services provided in their communities, Medicaid spending on HCBS is increasing. It was estimated that in 1992 the total national Medicaid long-term care expenditures was $39 billion, with 15 percent of that total going to HCBS (Fox-Grage et al., 2006). In 2005, the total Medicaid long-term care expenditures increased to $94.5 billion, and 37 percent of that total was used to fund HCBS (Fox-Grage et al., 2006).

As each state administers and manages its own Medicaid program, there is variation among states on the proportion of funding for institutional care and HCBS. Regarding long-term care, the term "balancing" refers to the proportion of Medicaid long-term care spending and resources going toward HCBS as opposed to institutional care (Kassner et al., 2008). In 2006, the national average on the proportion of Medicaid long-term care spending for disabled older adults and persons with disabilities going to institutional care was 75 percent, while 25 percent was directed towards HCBS (Kassner et al., 2008). The proportion of Medicaid long-term care spending for HCBS at that time ranged from one percent in Tennessee to 54 percent in Oregon.

Similar to the national average, the proportion of Medicaid long-term care spending for institutional care was greater than the proportion for HCBS in Massachusetts. Specifically, 78 percent of Medicaid long-term care spending was directed towards institutional care, and 22 percent going to HCBS in 2006 (Kassner et al., 2008). Moreover, it was found that Massachusetts had a 25 percent greater rate of nursing home utilization than the national average (Wallack et al., 2010). As of 2008, according to the Massachusetts State Profile Tool, approximately 60 percent of MassHealth long-term care spending is spent on nursing facilities. These statistics provide a compelling reason to examine current issues regarding the provision of HCBS in Massachusetts for the purpose of providing greater choice on long-term care options for older adults and persons with disabilities in the Commonwealth.

The purposes of this study are to examine reasons clients are discharged from the home care programs into institutional long-term care settings; present a profile of clients enrolled in three home care programs in Massachusetts (Home Care Basic, Choices, and ECOP); and identify recommendations that may enhance the delivery of HCBS.

BACKGROUND

The Olmstead Case

Historical legislation has contributed to the recognition that older adults and persons with disabilities should have alternatives to institutional care. The Supreme Court decision from the case of *Olmstead v. L.C.* was influential in enforcing that older adults and persons with disabilities should be served in the most integrated and least restrictive settings possible to comply with the Americans with Disabilities Act of 1990 (ADA) (Keigher, 2006; Kaiser Commission on Medicaid and the Uninsured, 2004). The ADA is a comprehensive civil rights law that protects Americans with disabilities, and states are required to comply with the ADA by providing services in community-based settings when possible (Keigher, 2006).

The *Olmstead* case involved two women, Lois Curtis (L. C.) and Elaine Wilson (E. W.), diagnosed with mental retardation (Kaiser Commission on Medicaid and the Uninsured, 2004). Both L. C. and E. W. were institutionalized for a period of over two decades. Both women remained institutionalized despite the evaluation from their treatment team that their needs would be better served in a community-based setting (Kaiser Commission on Medicaid and the Uninsured, 2004). The *Olmstead* case was filed in 1995, and on June 22, 1999 the Supreme Court decided that “institutional isolation of persons with disability is a form of discrimination under Title II of the ADA” (Kaiser Commission on Medicaid and the Uninsured, 2004).

States are currently confronted with political pressure to expand alternatives to institutional care by increasing HCBS and the number of disabled persons served in home and community-based settings (Kassner et al., 2008). Currently, the number of disabled older adults receiving long-term care services in their homes and communities is gradually increasing (Kaiser Commission on Medicaid and the Uninsured, 2004). Massachusetts ranked 37th in the nation for the number of enrollees in its home and community-based waiver per 1,000 persons.

States have the option to provide services in the community through Medicaid HCBS waivers, also known as HCBS section 1915 (c) waivers. Under federal guidelines, states have the discretion to develop and implement their HCBS waiver programs with flexibility in the number of clients being served, type of services provided, and the duration of services offered.

Massachusetts Community First Olmstead Plan

In fall 2007, a planning committee convened to develop a framework and implementation strategies for Massachusetts Community First Olmstead Plan. Governor Deval Patrick's Community First Olmstead Plan provides a strategic outline of ongoing and future work in the development of more accessible and effective long-term care services and supports in the community. The six goals proposed in the Community First Olmstead Plan are to: (1) help individuals transition from institutional care, (2) expand access to community-based long-term care supports, (3) improve the capacity and quality of community-based long-term supports, (4) expand access to affordable and accessible housing and supports, (5) promote employment of persons with disabilities and elders, and (6) promote awareness of long-term supports.

The plan proposes strategic tasks and a timeline of completion dates in accomplishing the aforementioned six goals. The Community First Olmstead Plan has many objectives and is a work in progress. Tasks that were completed include, but are not limited to forming a Long-Term Care Financing Advisory Group and providing training to certified nurse aides and home health aides. Currently, some of the ongoing tasks as proposed in the plan are:

- educating clinicians in community practices, institutions, and hospitals about the availability and viability of community-based options,
- developing strategies to work with healthcare providers (e.g., physicians),
- determining options to support informal caregivers, and
- implementing programs for chronic disease self-management and healthy eating.

Massachusetts' Home Care Program Services

This report is focused on and limited to three main programs in Massachusetts that provide HCBS: Home Care Basic, Community Choices Program (Choices), and Enhanced Community Options Program (ECOP). These three home care programs are not the full complement of HCBS in the Commonwealth. MassHealth's (Medicaid) role in HCBS is a payer of services. The home care programs are administered by Aging Service Access Points (ASAPs) under contract with the Executive Office of Elder Affairs (EOEA). The EOEA is the State Unit on Aging. The EOEA provides home care services statewide holding contracts with 27 ASAPs throughout the Commonwealth. ASAPs are described as a single entry point for elders in the community, and services provided by ASAPs include care management, information and referral, nursing home pre- and post-admission screening, development of service plans, and monitoring of service plans.

The home care programs provide services to eligible elders who need assistance so they may continue to live independently in their homes and communities. An interdisciplinary team that consists of care managers and nurses from ASAPs conducts an assessment in the elder's home to determine eligibility for the programs. Care managers assess clients' needs and provide service plans that meet their needs, incorporating informal supports, other available resources, and utilizing the home care funded programs as part of the service plan. Individual services needs and a personalized service plan are developed with elders and their family members. Below is a description of the three main home care programs.

Home Care Basic: To be eligible for the Home Care Basic program, the elder must be 60 years or older unless the individual has a memory disorder such as Alzheimer's disease. The program also provides respite services to informal caregivers. The elder must be assessed to demonstrate the inability to perform a specified number of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Functional

impairment levels (FIL) are determined during eligibility assessments and reviewed at each reassessment. According to the home care program eligibility criteria, elders must receive one of the FIL levels listed below:

- FIL 1: 4-7 ADL impairments
- FIL 2: 2-3 ADL impairments
- FIL 3: 1 ADL impairments and 5 IADLs impairments OR 6-10 IADLs impairments
- FIL 4: 4-5 IADLs impairments

MassHealth recipients are eligible to receive services at no fee and no monthly co-payments. For elders who are not recipients of MassHealth but have low incomes, services are state-subsidized, and co-payment amounts are on a sliding fee scale based on annual gross income. As of 2010, to receive state-subsidized services, the gross annual income must be less than $24,838 for a household of one and $35,145 for a household of two. For elders who have an income above the income limits to qualify for state payment, services from the Home Care Basic program can be purchased.

Enhanced Community Options Program (ECOP): ECOP was implemented in 1993 and provides a higher level of service to elders who are ineligible for the MassHealth standard, but demonstrate medical eligibility requirements for nursing home services. ECOP was developed to address the needs of elders who meet the requirements for nursing home services but prefer to remain in their homes. To be medically eligible for ECOP, the elder must need at least one skilled nursing service on a daily basis, or the elder must need nursing services at least three times per week in addition to two other services for ADLs (Moschella & Winston, 2009).

Community Choices Program (Choices): Elders receiving services from the Choices program must be recipients of MassHealth and enrollees of the 1915 (c) Home and Community-Based Services Waiver. Similar to ECOP, Choices provides a higher level of services. The Choices program was developed to provide more intensive services to enrollees of the waiver program who are at imminent risk of nursing home placement.

Research Objectives

This study provides a snapshot of clients enrolled in the three home care programs by examining the sociodemographic characteristics, health status, and unmet needs assessed among clients at one point in time in 2010. Additional qualitative data are used to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into institutional long-term care settings. The report concludes with recommendations to enhance the delivery of home care program services in Massachusetts.

METHODOLOGY

Three sources of data are used to address the research objectives of this study: qualitative data from in-person interviews with 17 care managers and one registered nurse in spring 2010; aggregate data provided by the Massachusetts Executive Office of Elder Affairs through their Comprehensive Data Set; and a sample of journal entry notes from care managers and nurses that were provided from one ASAP.

Care Managers' Perspectives

UMass Boston gerontology students enrolled in a spring 2010 Aging and Social Policy seminar, in partial fulfillment of the requirements of the undergraduate major in gerontology and Certificate in Gerontological Social Policy, conducted a research project titled, *Discharge From Home and Community-Based Services to Nursing Homes In*

Massachusetts: Care Managers' Perspectives. The research objective of the project was to explore care managers' perspectives on the reasons home care clients in Massachusetts are discharged into nursing homes. The project was led under the guidance of Professor Nina Silverstein, Ph.D. with Cathy Wong serving as graduate teaching assistant. Al Norman, Executive Director of Mass Home Care, was the community partner for the project. Mr. Norman met with student researchers in class as a guest lecturer and provided substantial input throughout the research project.

Student researchers conducted in-person interviews with a convenience sample of care managers at eight ASAPs. Before initiating contact with ASAPs to ask for their participation in the study, an application to the Institutional Review Board (IRB) from the university was completed and approved as required for the protection of human subjects. Moreover, all students completed the on-line CITI training certification for participating in research involving human subjects (http://www.umb.edu/research/orsp/CITI_ training). A total of 17 care managers and one registered nurse were interviewed at their respective agencies. The structured interview was designed to elicit the care managers' perspectives on reasons why older adults are terminated from the home care programs. One registered nurse was interviewed due to the care management role she served at one ASAP that had few care managers. Herein, the data are presented for the total of 18 care managers.

Care managers were asked about clients' barriers to remaining the community. The main topics covered in the interview were health conditions among home care clients, physical functioning, mood and behavior, informal support services, and demographic background of the care managers. The average length of the 18 interviews was 40 minutes. Upon completion of the project, community partner, care managers, and directors of ASAPs were invited to attend an open-public presentation of the research findings held at UMass Boston in May 2010. (A powerpoint from that presentation is available upon request to the author.)

Comprehensive Data Set

The Comprehensive Data Set (CDS) was the second data source used for this current study. The CDS allows for examining a snapshot of clients enrolled in the home care programs in Massachusetts (Home Care Basic, Choices, and ECOP). The data were provided in aggregate form by the EOEA. The CDS is a comprehensive questionnaire used by care managers and registered nurses for assessments with clients enrolled in the home care programs. Care managers monitor clients' needs and their service plans by conducting reassessments. Reassessments are performed at home visits in the clients' homes. For the Home Care Basic program, reassessment is required no less than every six months or as often as necessary when circumstances for a client changes. For the Choices and ECOP programs, reassessment is required no less than every three months or when a change occurs.

The main modules of the CDS include physical functioning, cognitive patterns, social functioning, informal support services, and service utilization. As only aggregate data were available to the authors, the analysis for this study consists of descriptive statistics to examine the clients and their needs. The data for this study were provided in March 2010 and allow for relative comparison of home care clients during the same period of time that the student interviews with care managers occurred. Caution should be exercised in generalizing these findings as these were not matched comparisons. The authors' intent is to provide some insights that may generate further exploration. During that time, a total of 32,417 clients were enrolled in the Home Care Basic program, 5,221

clients were enrolled in Choices, and 4,563 clients were enrolled in ECOP, which yields a total of 42,201 home care clients.

As a comprehensive assessment tool, the CDS is a long questionnaire consisting of over 300 questions. Missing data were prevalent as not all answers were recorded for all questions. Upon inquiry, the authors learned anecdotally that when doing assessments, some care managers and registered nurses may not ask all questions due to time constraints during home visits. Therefore, the sample size (n's) varies throughout analysis of the data. This current study's analysis is presented as percentages, and examines clients by each of the home care programs, which allows for program-to-program comparisons with the CDS, but caution should be exercised in interpreting these data due to the limitations of the dataset provided.

Care Manager Journal Notes

To further explore reasons for discharge from the home care programs into nursing homes, a sample of 150 journal entries were reviewed for 15 clients during the months of February, June and July 2010. Care managers and nurses document field notes of their clients and it was expected that these journal notes would provide more detailed information on reasons why clients are being discharged from the home care programs. The journal notes were reviewed and analyzed by identifying frequent themes mentioned for termination. Not all of the 150 journal entry notes were on nursing facility referrals. Some of the entries were progress notes, on-site reassessments, program enrollment, and memos. From the 150 entry notes, an estimated 20 entries were on nursing facility referrals.

RESULTS

Care Managers' Perspectives

Care Management

Care managers were asked about the discharge rate of their clients now, compared to when they first started. The majority of care managers reported that clients are currently being maintained longer in the community. Specifically, from the 18 interviews, 72% (13) care managers reported that clients are being maintained in the community longer. One care manager stated,

> *"When I first started, we didn't have as much funding, and we couldn't maintain the consumers as long in the community for the lack of funds therefore the lack of available services that we could provide. Now we have the programs such as Choices and ECOP which do allow for additional services to maintain them safer at home."*

Another care manager stated, "*More people are able to stay at home longer with increased supports. The movement is growing. There is more awareness*." However, some care managers felt clients were being discharged sooner. From a care manager who reported that clients in her caseload are being discharged sooner to nursing homes, she explained,

> "*The difference I see now as to when I first started is that we are not able to fund services as much as we used to just because of our cut in funding and cuts for our home care services. So people aren't able to get what they need in the community so they end up in nursing homes."*

Care managers do not have a direct role in the decision to discharge, the decision resides with the older adult and family members. Care managers were asked how much input they typically have in the decision to discharge clients from HCBS to a nursing home. The majority of care managers reported that they have some input, while "*the*

decision is from the clients' families." Another care manager reported, "*Elders make the personal decisions.*" Some of the roles of the care manager when working with clients and families are to '*help clarify and give support to the family, educate on the aging process, and assist in home modification to keep elders in the home.*'

One care manager briefly stated, "*I have never recommended that someone go into a nursing home and have never attempted to get someone to go into a nursing home."* Another care manager reported, "*Well, we don't make that decision. The client makes that decision."*

Informal Caregiver Support

Care managers were asked about what factors are considered by their clients and families in the decision to discharge from home care programs into a nursing home. One care manager explained that safety concerns and a lack of informal support at home are considerations for nursing home placement:

> "'*A lot of times it is the family decision to place the loved one in that setting. It is very difficult for them but they are realizing safety concerns at home or just the lack of informal supports to keep the elder in their home setting. If I'm having reports of safety concerns, I certainly have to call the family and report any concerns so I might have some input. You know, that mom has wandered so many times and we don't want her to have a crisis so maybe institutional is safer at this point.*"

Twenty-four-hour and overnight care were also reported as factors in the decision to discharge from HCBS. One care manager stated,

> "*Overnight care is very difficult for an agency to provide and for the family to do so. So there is lack of family support, lack of funding. The elder may become too frail and sick to be safe at home. They may require more extensive medical treatments that you can't undergo while you are at home. Safety concerns about the elder being home if they have dementia and the dementia is progressing, they might need the 24-hour care in a locked facility unit."*

Another care manager stated,

> *"How much care they need usually is the main factor because we provide a lot of care but we cannot provide 24-hour care. So when it comes to that point and the family members are showing signs of burnout is generally when I start to talk to them about placement. Especially if the person lives by themselves, and the family member is back and forth, back and forth.'*

Care managers were asked what additional services are needed in maintaining clients in their homes, the need for 24-hour supervision for clients was frequently reported. One care manager expressed,

> "*.... personal care services and people who need general supervision. So that can fall under companions if you need 24-hour supervision then it's very unlikely you'll be able to get it from the state."*

Another care manager stated,

> "*I think weekend services. It's easy to get services Monday through Friday. Weekends and night services, especially helping people get to bed. Overnight help to monitor clients."*

Another care manager recommended that 24-hour care in the home can potentially prevent institutionalization:

> "*We can put in services to help but our services are not there 24-hours per day. So, if there isn't family support to supplement home care services, then they are more likely to be discharged to nursing home from a home and community-based setting. If we had a lot of money that we could spend to provide 24- hour care, we could prevent a lot of institutionalizations."*

Physical Functioning and Health Conditions

Care managers were asked to what extent their clients engage in the following behaviors that may promote future health problems: use of cigarettes, alcohol abuse, abuse of prescription or over the counter medications, lack of exercise, and poor nutritional habits. Of those, 78% (14) of care managers reported that lack of exercise is a concern they had for many of their clients. Furthermore, 22% (4) of care managers reported that poor nutritional habits are another concern for many of their clients.

In an open-ended question, care managers were asked what medical conditions are common among their clients. Diabetes was the most frequently reported medical condition. From the 18 interviews, 78% (14) care managers reported diabetes as one of the most common medical conditions among their clients. Several medical conditions were cited by care managers as particularly difficult for clients and often their families to manage at home. The most frequently reported medical condition was Alzheimer's disease, with 50% (9) care managers reporting Alzheimer's disease. Care managers expressed that later stages of Alzheimer's disease are especially challenging for clients to manage at home, "*Alzheimer's is very difficult as the disease progresses."* In addition, some care managers stated that caregivers of clients with Alzheimer's disease and other dementias have difficulty managing the disease at home, "*Dementia gets tricky with caregivers. There's not enough education or support. Families get overwhelmed when they don't know. Programs are not available any longer, and families burnout very quickly because of lacking supports*."

Care Managers' Perspective on HCBS and Institutional Care

Care managers were asked what community-based care can offer that nursing homes cannot, and vice versa. Care managers' perceptions are provided in Figure 1. To gage the value care managers put on HCBS they were asked, "*Should a client be maintained in the community at any cost?"* Over half, 56%, said yes. The following quote typifies the difficulty that the care managers felt in responding to this question: *"I want to say 'yes'. I say 'no' because I have worked in this field for so long that we would just be in a huger [sic] deficit than we already are because I know how costly it is to maintain an elder at home and the safety concerns."* The care managers were then asked about the level of spending to keep clients in their home versus a nursing facility. Over two-thirds (67%) of the respondents said that "as much" money should be spent in both environments; 33% said that "more money" should be spent in maintaining a client at home. No one said that less money should be spent at home.

Figure 1. Care Managers' Perspectives

Community-based care can offer....

- *"Greater sense of dignity"*
- *"People living in their own home with a familiar setting"*
- *"I think the home environment. Keeping them comfortable in a secure environment that they know and are familiar with. I think that helps a great deal. Moving them to a nursing home sometimes increases their confusion"*
- *"Trying to keep some of their independence as opposed to always having someone there to do every thing for them"*
- *"The socialization of having their friends and neighbors"*
- *'Privacy issues. When you are in a nursing facility, I think you lose a lot of your privacy, and at home you could maintain more of that"*
- *"Sense of freedom, maintain ones own lifestyle the way you want to*
- *"More opportunity for interaction in community, church, social independence, and go to the mall"*
- *"Autonomy and independence, pride, mental health, choice"*
- *"Quality of life. Seniors thrive in their own environment"*

Nursing homes can offer....

- *"24-hour care and medical monitoring of their medical conditions"* **
- *"Sense of relief to caregivers"*
- *"Safety is why everyone ends up in a nursing home pretty much, people think they're unsafe at home"*
- *"Safe facility for wandering issues"*
- *"Dependent care"*
- *"Exercise options that wouldn't be there"*
- *"Medical treatments in a nursing facility that can't be done at home, more extensive rehab or therapies"*

Note: *From the 18 interviews, 78% (14) care managers reported 24-hour care as a service that nursing homes offer that the community cannot.

Comprehensive Data Set

The Comprehensive Data Set was used to examine a profile of clients enrolled in the home care programs.

Sample Description

Table 1 presents sociodemographic characteristics of clients in the home care programs in March 2010. As seen in the table, clients from ECOP are older than clients from the Home Care Basic and Choices program. The mean age of ECOP clients was 84.2 years-old. A large proportion of the clients are non-Hispanic White. Overall, home care clients are predominately older women (75.4%) who are widowed (47.6%) and live alone (62.3%). The monthly average individual income for all home care clients was $1,361.52 ($16,338/yr) and the average household income was $1,622.32 ($19,468/yr).

Table 1. Sociodemographic Characteristics

	Home Care Total	Home Care Basic	Choices	ECOP
Mean age	80.2	79.8	79.1	84.2
Gender (n=42,196)				
Female	75.4%	74.7%	77.3%	77.9%
Race (n=41,461)				
White	85.0%	84.5%	84.0%	89.1%
Black	8.1%	8.0%	8.4%	8.4%
Asian	5.3%	5.8%	5.7%	1.5%
Native Hawaiian or Pacific Islander	0.4%	0.4%	0.4%	0.3%
American Indian or Alaskan Native	0.2%	0.2%	0.2%	0.0%[a]
Other	1.1%	1.1%	1.3%	0.7%
Ethnicity (n=41,461)				
Non-Hispanic	95.4%	95.7%	92.0%	98.1%
Hispanic	4.6%	4.3%	8.0%	1.9%
Understands English (n=42,228)				
Yes	89.0%	90.1%	76.0%	95.7%
No	11.0%	9.9%	24.0%	4.3%
Marital status (n=41,992)				
Widowed	47.6%	46.2%	44.9%	60.8%
Single	19.8%	21.0%	17.3%	14.7%
Married	19.1%	19.0%	21.7%	17.0%
Divorced or separated	13.4%	13.8%	16.1%	7.6%
Lives alone (n=41,461)	62.3%	64.3%	56.8%	54.7%
Education completed (n=24,684)				
Less than high school	31.8%	32.3%	33.9%	25.8%
High school graduate	39.2%	39.8%	31.1%	46.0%
Technical or trade school	5.5%	5.4%	5.1%	6.7%
Some college	12.0%	11.6%	13.3%	12.8%
Bachelor's degree	8.3%	8.0%	10.8%	7.1%
Graduate degree	3.2%	2.9%	5.8%	1.7%
Monthly average income				
Individual income	$1,361.52	$1,389.74	$1,199.89	$1,345.51
Household income	$1,622.32	$1,604.68	$1,755.58	$1,596.52

[a]1 client.

Table 2 displays disease diagnosis among clients. For nearly all of the health conditions, clients from Choices have higher rates of disease diagnoses than clients from Home Care Basic and ECOP. Hypertension was the most prevalent health condition among total clients and particularly prevalent among Choices clients. Specifically, 80.4% of clients from the Choices program were reported to have hypertension. In addition, arthritis and diabetes are health conditions that are high among total home care clients.

Table 2. Disease Diagnoses

	Home Care Total	Home Care Basic	Choices	ECOP
Heart/circulation				
Hypertension (n=27,020)	64.8%	61.3%	80.4%	63.8%
Coronary artery disease (n=25,209)	19.5%	16.7%	31.8%	20.0%
Cerebrovascular accident (stroke) (n=25,145)	14.2%	12.2%	20.9%	17.2%
Congestive heart failure (n=24,360)	13.5%	11.8%	20.9%	13.9%
Irregular pulse (n=24,919)	10.8%	9.3%	15.9%	13.0%
Peripheral vascular disease (n=24,767)	6.7%	5.5%	11.7%	7.2%
Neurological				
Dementia other than Alzheimer's (n=25,174)	12.6%	9.6%	20.4%	19.5%
Alzheimer's disease (n=24,861)	4.8%	3.8%	7.0%	7.8%
Parkinsonism (n=24,701)	2.8%	2.1%	4.9%	4.5%
Head trauma (n=24,718)	1.3%	1.3%	1.5%	1.6%
Multiple sclerosis (n=24,719)	0.9%	0.7%	1.6%	1.1%
Musculo-skeletal				
Arthritis (n=26,009)	53.8%	52.6%	75.8%	55.9%
Osteoporosis (n=25,111)	20.4%	19.4%	24.4%	20.4%
Other fractures (n=24,892)	10.5%	10.1%	10.8%	12.3%
Hip fracture (n=24,796)	5.7%	5.3%	6.3%	7.4%
Senses				
Cataract (n=23,553)	15.2%	15.4%	16.0%	14.1%
Glaucoma (n=24,180)	7.8%	7.1%	9.9%	9.7%
Other diseases				
Diabetes (n=25,779)	30.6%	28.0%	44.1%	26.9%
Any psychiatric diagnosis (n=25,090)	26.8%	23.4%	44.5%	22.8%
Emphysema, asthma, or chronic obstructive pulmonary disease (n=25,317)	21.2%	20.0%	29.5%	17.2%
Thyroid disease (hyper or hypo) (n=24,972)	15.3%	14.2%	19.9%	15.6%
Cancer, not including skin cancer (n=24,898)	12.3%	12.0%	13.8%	11.0%
Renal failure (n=24,819)	5.7%	4.9%	10.0%	5.2%

Urinary tract infection (n=24,720)	5.3%	4.6%	7.6%	6.1%
Pneumonia (n=24,728)	3.0%	2.8%	3.2%	3.6%
Tuberculosis (n=24,635)	0.3%	0.3%	0.3%	0.3%
HIV infection (n=24,047)	0.1%	0.0% [a]	0.3%	0.0% [b]

[a] 21 clients.
[b] 1 client.

As seen in Table 3, relatives comprise the largest referral source for total home care clients. Doctors and HMOs account for only 2.5% of the referrals to home care, and hospitals for only 9.4%.

Table 3. Referral Source (n=28,460)

	Home Care Total	Home Care Basic	Choices	ECOP
Relative	25.4%	24.4%	23.6%	35.1%
Certified home health agency	17.5%	17.0%	18.0%	21.3%
Self	17.0%	18.5%	13.9%	9.5%
Social service agency	12.6%	12.3%	17.4%	9.7%
Hospital	9.4%	9.4%	9.7%	8.5%
Other	7.0%	6.7%	9.1%	6.4%
MD/HMO	2.5%	2.6%	2.2%	2.1%
Housing authority	2.4%	2.6%	1.9%	1.8%
Council on Aging (COA)	2.1%	2.3%	1.4%	2.1%
Friend/neighbor	1.6%	1.7%	1.2%	1.4%
Protective services	1.4%	1.4%	1.0%	1.6%
Nutrition program	0.5%	0.5%	0.3%	0.3%
Aging service access point (ASAP)	0.3%	0.3%	0.0% [a]	-
Elder/risk	0.2%	0.2%	0.3%	0.3%
Transfer from ASAP	0.1%	0.1%	0.1%	-

[a] 1 client.

Table 4 displays the goals of care for clients. More than half of total home care clients, 58.1%, were being monitored to avoid clinical complications as their goal of care.

Table 4. Goals of Care

	Home Care Total	Home Care Basic	Choices	ECOP
Monitoring to avoid clinical complications (n=20,514)	58.1%	50.1%	76.8%	66.5%
Client/family education (n=20,343)	43.4%	37.0%	56.8%	52.0%
Family respite (n=20,371)	21.1%	19.7%	21.6%	26.2%
Skilled nursing treatments (n=20,471)	14.1%	12.2%	20.9%	13.5%
Rehabilitation (n=20,300)	8.7%	7.9%	11.6%	8.3%
Palliative care	1.2%	1.2%	1.5%	1.0%

(n=20,038)				

The CDS includes information on clients regarding making trade-offs in purchasing prescribed medications, sufficient home heat, necessary physician care, adequate food, or home care during the last month due to limited funds. Of the total home care clients, 97.9% were noted as having made trade-offs (n=35,532).

Health and Functional Status

Table 5 displays the functional impairment levels (FIL) among clients. Over half (52.1%) of Choices clients and close to half (48.9%) of ECOP clients were evaluated at the level of FIL 1. (An explanation of FIL levels is provided on page 4.)

Table 5. Functional Impairment Levels (n=41,132)

	Home Care Total	Home Care Basic	Choices	ECOP
FIL 1*	25.5%	17.6%	52.1%	48.9%
FIL 2	25.9%	22.3%	37.6%	37.6%
FIL 3	34.4%	41.7%	9.9%	12.8%
FIL 4	14.2%	18.4%	0.5%	0.7%

Note: *FIL 1 is defined as the frailest.

Table 6 demonstrates the count of ADLs and IADLs impairments. As illustrated in the table, clients from the Home Care Basic program have higher rates of IADLs impairments than ADLs. The percentages demonstrate that 39.3% of Home Care Basic clients have no ADLs impairments. However, 89.1% of these clients have 5 to 8 impairments in IADLs. IADLs impairments are more common than ADL impairments among Home Care Basic clients. For Choices and ECOP clients, they have higher levels of both ADL and IADL impairments.

Table 6. Count of ADLs and IADLs

	Home Care Total	Home Care Basic	Choices	ECOP
ADLs (n=42,228)				
No ADLs	30.7%	39.3%	2.0%	2.9%
1-2 ADLs	35.7%	36.6%	31.9%	34.3%
3-4 ADLs	16.0%	12.6%	27.4%	27.7%
5-6 ADLs	17.5%	11.5%	38.7%	35.0%
IADLs (n=41,132)				
No IADLs	1.2%	1.3%	0.6%	1.0%
1-2 IADLs	0.2%	0.2%	0.0%[a]	0.0%[b]
3-4 IADLs	7.6%	9.5%	1.2%	1.8%
5-6 IADLs	45.2%	50.4%	29.1%	27.5%
7-8 IADLs	45.8%	38.7%	69.0%	69.6%

[a]2 clients.
[b]1 client.

Tables 7 and 8 display services and support for assistance with ADLs and IADLs. Consistent with Table 6, the percentages demonstrate that Home Care Basic clients need less or no help with ADLs compared to clients from Choices and ECOP. The tables also display percentages on unmet services and support with ADLs and IADLs assistance. For all ADLs and IADLs, a large proportion of need is being met by services provided through the ASAPs, other formal services, or informal support services. No

definition for 'other formal services' was provided in the CDS. The results indicate that the highest percentage for unmet service need for ADL assistance is bathing, with 10.9% of total home care clients needing assistance with bathing. From Table 8, 10.5% of total home care clients have unmet needs for ordinary housework, 7.3% for meal preparation, and 6.7% for shopping.

The CDS also provides data on ADLs status decline among clients since their last assessment. Results demonstrate that 8.2% of Home Care Basic clients, 17% of Choices clients, and 15.1% of ECOP clients had a decline in their ability to perform ADLs since their last assessment (n=39,128). As previously noted, reassessments for the Home Care Basic program are required no less than every 6 months. For the Choices and ECOP programs, reassessment is required no less than every 3 months.

Table 7. Services and Support for Assistance with ADLs

	Home Care Total	Home Care Basic	Choices	ECOP
Transfer needs (n=40,650)				
Met by ASAP	3.5%	1.2%	13.1%	8.1%
Other formal services	15.2%	12.6%	23.7%	23.2%
Informal support	2.2%	1.8%	4.1%	3.1%
Unmet	1.7%	1.5%	2.2%	2.5%
No help needed	77.5%	82.9%	56.9%	63.2%
Indoor mobility (n=40,650)				
Met by ASAP	2.8%	0.9%	11.4%	6.3%
Other formal services	15.4%	12.5%	24.3%	24.9%
Informal support	2.1%	1.7%	3.4%	3.0%
Unmet	1.6%	1.4%	1.8%	2.4%
No help needed	78.2%	83.4%	59.2%	63.4%
Dressing (n=40,650)				
Met by ASAP	14.6%	6.8%	43.2%	35.9%
Other formal services	17.9%	15.4%	24.4%	27.5%
Informal support	5.1%	4.4%	7.8%	6.4%
Unmet	5.1%	4.7%	6.3%	6.4%
No help needed	57.3%	68.6%	18.3%	23.9%
Eating (n=39,123)				
Met by ASAP	2.3%	1.3%	7.0%	4.1%
Other formal services	1.3%	1.0%	2.5%	1.6%
Informal support	7.5%	5.7%	12.9%	14.4%
Unmet	0.7%	0.7%	0.8%	0.8%
No help needed	88.2%	91.3%	76.8%	79.0%
Toilet use (n=40,650)				
Met by ASAP	2.8%	0.7%	11.1%	7.9%
Other formal services	11.3%	9.0%	19.0%	19.2%
Informal support	1.9%	1.5%	3.4%	2.7%
Unmet	1.1%	0.9%	1.5%	2.2%
No help needed	82.9%	87.9%	64.9%	68.1%
Bathing (n=40,650)				
Met by ASAP	24.4%	15.2%	55.3%	52.6%
Other formal services	17.8%	17.3%	19.2%	20.4%
Informal support	7.7%	7.0%	10.7%	9.1%
Unmet	10.9%	11.3%	8.5%	10.8%

No help needed	39.2%	49.2%	6.4%	7.1%

Table 8. Services and Support for Assistance with IADLs

	Home Care Total	Home Care Basic	Choices	ECOP
Meal preparation (n=40,650)				
Met by ASAP	29.6%	26.8%	43.9%	33.3%
Other formal services	45.5%	45.8%	39.2%	50.8%
Informal support	6.7%	6.3%	9.1%	6.3%
Unmet	7.3%	8.0%	5.0%	5.7%
No help needed	10.9%	13.2%	2.9%	4.0%
Ordinary housework (n=40,650)				
Met by ASAP	61.5%	61.2%	66.9%	57.3%
Other formal services	23.5%	22.1%	23.8%	32.4%
Informal support	3.7%	3.6%	3.8%	3.7%
Unmet	10.5%	12.0%	5.4%	6.4%
No help needed	0.8%	1.0%	0.1%	0.2%
Laundry needs (n=39,777)				
Met by ASAP	54.1%	52.8%	64.8%	51.5%
Other formal services	3.2%	3.2%	3.9%	3.0%
Informal support	28.7%	27.8%	25.6%	37.9%
Unmet	9.2%	10.4%	5.0%	5.6%
No help needed	4.8%	5.8%	0.7%	2.0%
Money management (n=40,650)				
Met by ASAP	1.0%	0.9%	1.6%	1.4%
Other formal services	61.8%	57.8%	73.8%	75.9%
Informal support	2.2%	2.1%	2.9%	1.9%
Unmet	1.4%	1.4%	1.5%	1.3%
No help needed	33.7%	37.9%	20.2%	19.5%
Medication management (n=40,650)				
Met by ASAP	1.5%	0.7%	4.6%	3.1%
Other formal services	43.4%	38.7%	53.6%	63.5%
Informal support	8.1%	6.7%	17.9%	7.3%
Unmet	1.7%	1.6%	1.8%	2.0%
No help needed	45.4%	52.3%	22.2%	24.1%
Telephone use (n=40,650)				
Met by ASAP	0.4%	0.3%	1.4%	0.4%
Other formal services	18.8%	15.3%	28.8%	31.4%
Informal support	0.7%	0.7%	1.0%	0.6%
Unmet	0.5%	0.5%	0.5%	0.8%
No help needed	79.6%	83.3%	68.3%	66.7%
Shopping (n=40,650)				
Met by ASAP	30.7%	30.1%	37.0%	27.9%
Other formal services	57.2%	56.4%	54.6%	65.4%
Informal support	3.4%	3.4%	4.5%	2.3%

Unmet	6.7%	7.6%	3.6%	4.0%
No help needed	2.0%	2.5%	0.3%	0.4%
Transportation (n=40,650)				
Met by ASAP	4.7%	4.3%	6.6%	5.6%
Other formal services	70.4%	70.4%	64.4%	77.0%
Informal support	18.1%	17.5%	25.7%	13.8%
Unmet	2.3%	2.4%	1.7%	1.9%
No help needed	4.5%	5.4%	1.6%	1.6%
Outdoor mobility (n=40,650)				
Met by ASAP	2.6%	1.5%	7.7%	3.8%
Other formal services	66.9%	64.8%	69.9%	78.6%
Informal support	4.9%	4.1%	9.3%	5.6%
Unmet	2.4%	2.5%	2.4%	2.2%
No help needed	23.2%	27.2%	10.7%	9.7%

Table 9 displays critical unmet needs, which is defined in the home care regulations (651 CMR 3:00) as a client's unmet needs which include one or more of the following: any activity of daily living (ADL), meal preparation, food shopping, transportation for medical treatments, respite care, and home health services. An identified critical unmet need is required for eligibility for service on initial assessment or else clients are not enrolled in the home care programs. Clients from Choices and ECOP have more critical unmet needs. Over half, 52% of Choices clients and 47.9% of ECOP clients were reported as having critical unmet needs. Assistance with any ADLs, meal preparation, food shopping were the major critical unmet needs reported among Choices and ECOP clients. The data is taken from assessments of clients at one point in time and includes both initial assessments and on going assessments. A critical unmet need may be because the client is being initially assessed for what services they need, has deteriorated since the last assessment and therefore needs more services, or for some reason is not getting service they have an identified need for.

Table 9. Critical Unmet Needs (n=38,769)

	Home Care Total	**Home Care Basic**	**Choices**	**ECOP**
Food shopping	11.9%	12.1%	12.4%	10.5%
Meal preparation	10.6%	9.8%	13.3%	12.9%
Any ADLs	8.1%	5.9%	15.4%	15.4%
Transportation for medical treatment	4.2%	4.0%	5.9%	3.5%
Respite	2.6%	2.4%	2.8%	3.7%
Home health services	0.9%	0.6%	2.3%	1.8%

Physical Activity

Tables 10 and 11 provide data concerning pain among home care clients. Table 10 displays the frequency of which clients complain or show evidence of pain. More than half, 51.6%, of Choices clients feel multiple periods of pain daily. In addition, 40.6% of ECOP clients also feel multiple periods of pain daily. From Table 11, the majority of Choices and ECOP clients report that the pain is moderate. Approximately 13% of Choices clients report that the intensity of the pain is severe.

Table 10. Frequency of Which Client Complains or Shows Evidence of Pain (n=37,548)

	Home Care Total	Home Care Basic	Choices	ECOP
No pain	32.3%	33.8%	23.2%	32.7%
Less than daily	17.3%	17.8%	15.4%	16.9%
Daily- one period	10.8%	11.1%	9.8%	9.8%
Daily- multiple periods	39.6%	37.3%	51.6%	40.6%

Table 11. Intensity of Pain (n=36,473)

	Home Care Total	Home Care Basic	Choices	ECOP
No pain	30.9%	32.3%	22.1%	31.9%
Mild	21.3%	21.6%	19.8%	20.9%
Moderate	36.6%	35.6%	42.9%	36.0%
Severe	9.6%	9.0%	12.9%	9.6%
Horrible/excruciating	1.6%	1.4%	2.3%	1.6%

The CDS also contains data on problem conditions that cause pain. Clients were asked if they had problem conditions during the past three days. Among total home care clients, 16% have shortness of breath, 8.4% have edema, 8% have dizziness or light-headedness, 1.8% have chest pain, and 0.7% have no bowel movements during the last 3 days (n=37,548). In addition, clients were asked if their pain disrupts the ability to perform activities. 43.9% of Home Care Basic clients and 44.1% of ECOP clients reported that their pain disrupts the ability to perform activities. Concerning Choices clients, more than half, 55.9%, reported that the intensity of their pain disrupts performing usual activities (n=36,076).

Table 12 below displays the number of days clients went out of the house or building. Approximately 39% ECOP clients report going outdoors 1 day per week on average. Among Choices clients, 35.2% report going outdoors 2 to 6 days per week. As seen below, 13% of Home Care Basic clients, 26.3% of Choices clients, and 29.2% of ECOP clients report not going outdoors.

Table 12. Number of Days Client Went Out of House or Building (n=40,018)

	Home Care Total	Home Care Basic	Choices	ECOP
Every day	9.1%	10.5%	5.0%	3.6%
2-6 days a week	38.5%	40.5%	35.2%	28.2%
1 day a week	36.0%	36.0%	33.5%	39.1%
No days	16.5%	13.0%	26.3%	29.2%

Table 13 presents data on unsteady gait and fear of falling among home care clients. For Choices and ECOP clients, the percentages are the same with 84.8% of clients having unsteady gait. The proportion for Home Care Basic clients who have unsteady gain is lower, at 64.3%. Concerning clients who limit going outdoors due to the fear of falling, 66.3% of Choices clients and 67.6% of ECOP clients report having the fear of falling.

Table 13. Unsteady Gait & Fear of Falling

	Home Care Total	Home Care Basic	Choices	ECOP
Unsteady gait (n=38,794)	69.2%	64.3%	84.8%	84.8%
Limits going outdoors due to fear of falling (n=38,706)	49.3%	43.6%	66.3%	67.6%

Medications

A large proportion of home care clients are taking nine or more medications. Over a third, 37.6%, of total home care clients were taking nine or more medications. Specifically, 33.1% of Home Care Basic clients, 59.3% of Choices clients, and 44.4% of ECOP clients were taking 9 or more medications. Among total home care clients, a large proportion, 97.7%, report that their physician has reviewed their medications in the past 180 days (n=28,273). During assessments, home care clients are also asked if they take their medications as prescribed. Among the total home care clients, 86.8% report always being compliant in taking their prescribed medications (n=35,948).

Clients were asked what assistive devices they use for medication management. Among total home care clients, 77.5% use a daily-weekly pill box, 3.5% use pharmacy refill, and 1.4% use medication dispensing, and 9.1% report not using any assistive devices (n=26,684).

Table 14. Number of Medications Taken (n=32,866)

	Home Care Total	Home Care Basic	Choices	ECOP
0	8.1%	9.3%	3.0%	5.3%
1	1.9%	2.1%	0.6%	1.5%
2	3.1%	3.5%	1.2%	2.7%
3	4.9%	5.4%	2.3%	3.9%
4	6.3%	6.9%	3.7%	5.1%
5	8.2%	8.8%	5.2%	8.0%
6	9.6%	10.1%	7.3%	9.3%
7	9.8%	10.1%	8.1%	9.5%
8	10.5%	10.7%	9.4%	10.2%
9 or more	37.6%	33.1%	59.3%	44.4%

Cognitive Patterns

Table 15 presents memory recall abilities among home care clients. 47.1% of Choices clients and 47.5% of ECOP clients have problems in short-term memory. Among Home Care Basic clients, 23.9% have problems with short-term memory. For procedural memory, 15.7% of Home Care Basic clients, 33.5% of Choices clients, and 35% of ECOP clients have problems.

Table 15. Memory Recall Abilities

	Home Care Total	Home Care Basic	Choices	ECOP
Short-term memory* (n=39,835)				
Memory ok	70.5%	76.1%	52.9%	52.5%
Memory problem	29.5%	23.9%	47.1%	47.5%
Procedural memory** (n=39,726)				
Memory ok	79.9%	84.3%	66.5%	65.0%
Memory problem	20.1%	15.7%	33.5%	35.0%

Note: *Defined as ability to recall after 5 minutes.

Note: **Defined as ability to perform all or almost all steps in a multitask sequence without cues for initiation.

Table 16 displays how home care clients make decisions about organizing the day. The majority of Home Care Basic clients, 73.8%, are able to independently make decisions. A smaller proportion of Choices and ECOP clients are able to independently make decisions, 43.4% and 44.6% respectively. Further, clients were assessed if they had a decline in decision-making compared to their status 90 days ago. An estimated 7% of Home Care Basic clients, 15% of Choices clients, and 15% of ECOP clients had a decline in decision-making (n=39,475). Compared to Home Care Basic clients, Choices and ECOP clients were twice as likely to have a decline in decision making.

The CDS presents data on disorientation and agitation among clients such that safety is endangered. Among the total home care clients, 97.9% did not have disorientation or agitation such that their safety was endangered (n=31,436).

Table 16. How Client Makes Decisions about Organizing the Day (n=39,727)

	Home Care Total	Home Care Basic	Choices	ECOP
Independent	66.6%	73.8%	43.4%	44.6%
Modified independence	18.1%	15.5%	26.5%	26.6%
Minimally impaired	8.2%	6.0%	15.4%	14.8%
Moderately impaired	4.5%	3.0%	9.4%	8.5%
Severely impaired	2.6%	1.7%	5.4%	5.4%

Hearing and Communication Patterns

A small proportion, 2%, of the total home care clients are reported to have highly impaired hearing ability. From the total home care clients, 63.6% report hearing adequately.

Table 17. Hearing Ability (n=39,517)

	Home Care Total	Home Care Basic	Choices	ECOP
Hears adequately	63.6%	66.7%	58.1%	49.4%
Minimal difficulty	24.4%	22.7%	28.3%	31.3%
Hears in special situations	10.1%	8.9%	11.6%	16.6%
Highly impaired	1.9%	1.8%	1.9%	2.7%

Clients were assessed in their ability to express information and understand others. Compared to Home Care Basic clients, the proportion of Choices and ECOP clients who are able to express information and understand others is lower. Further, clients were

assessed in the status of their communication abilities compared to 90 days ago. 3.8% of Home Care Basic clients, 7.6% of Choices clients, and 7.6% of ECOP clients had a decline in communication abilities (n=39,218).

Table 18. Client's Ability to Express Information (Expression) (n=39,489)

	Home Care Total	Home Care Basic	Choices	ECOP
Understood	83.1%	87.0%	70.2%	71.4%
Usually understood	11.4%	9.3%	18.1%	18.1%
Often understood	2.0%	1.4%	4.4%	3.7%
Sometimes understood	0.7%	0.4%	1.8%	1.3%
Rarely/never understood	2.8%	1.9%	5.5%	5.5%

Table 19. Client's Ability to Understand Others (Comprehension) (n=39,406)

	Home Care Total	Home Care Basic	Choices	ECOP
Understood	80.4%	84.5%	67.9%	67.0%
Usually understood	13.7%	11.4%	21.0%	21.3%
Often understood	2.2%	1.5%	4.8%	4.6%
Sometimes understood	0.5%	0.3%	1.1%	1.0%
Rarely/never understood	3.1%	2.3%	5.2%	6.1%

Vision Patterns

In addition to hearing and communication abilities, Choices and ECOP clients have more impairment in vision. It was found that 35% of Choices clients and 31.1% of ECOP clients have impaired vision. Further, clients were assessed if they had a decline in their vision compared to 90 days ago. A larger proportion of clients in the Choices program had a decline in their vision abilities: 11.7% of Choices clients, 7.8% of Home Care Basic clients, and 9% of ECOP clients (n=38,888).

Table 20. Ability to See in Adequate Light and with Glasses if Used (n=39,389)

	Home Care Total	Home Care Basic	Choices	ECOP
Adequate	62.4%	65.8%	49.6%	53.9%
Impaired	26.4%	24.3%	35.0%	31.1%
Moderately impaired	6.1%	5.5%	8.1%	7.8%
Highly impaired	3.5%	3.1%	4.8%	5.2%
Severely impaired	1.5%	1.3%	2.5%	2.0%

Nutrition

The CDS included nutritional risk assessment. Nutrition risk was reported as highest among clients from the Choices program, at 37.3%. 29.6% of Home Care Basic clients and 31.1%ECOP clients were also reported to be at risk (n=39,891). Table 21 provides percentages regarding nutrition among home care clients. Approximately 19% of Choices clients, 15.7% of ECOP clients, and 15.4% of Home Care Basic clients consumes less than 4 servings of fruits or vegetables per day. A small percentage of clients, 4.7%, were reported as having a lack of money to purchase food that is needed. However, a large proportion of total home care clients, 75.2%, report not being physically able to shop, cook, and/or feed self. Further, more than half of total home care clients, 57.2%, report eating alone most of the time.

Table 21. Nutrition Screening

	Home Care Total	Home Care Basic	Choices	ECOP
Client has illness/condition that causes to change the kind/amount of food consumed (n=37,267)	35.6%	33.7%	45.8%	36.6%
Consumes fewer than 2 meals per day (n=37,236)	4.1%	4.0%	4.9%	4.3%
Consumes less than 4 servings of fruits or vegetables per day (n=37,131)	15.9%	15.4%	18.9%	15.7%
Consumes fewer than 2 servings of dairy products per day (n=36,806)	11.1%	10.7%	14.2%	10.5%
Consumes 3 or more drinks of beer, liquor, or wine per day (n=37,174)	0.8%	0.9%	1.0%	0.6%
Has tooth, mouth, or swallowing problems that make it difficult to eat (n=37,138)	7.4%	6.4%	11.2%	9.5%
Lacks enough money to purchase food that is needed (n=37,114)	4.7%	4.7%	5.9%	2.5%
Eats alone most of the time (n=37,217)	57.2%	59.5%	49.0%	50.3%
Takes 3 or more prescribed or over-the-counter drugs per day (n=37,121)	84.0%	83.4%	85.7%	86.0%
Has lost or gained 10 pounds in the last 6 months (n=36,884)	9.3%	9.2%	10.3%	9.4%
Not physically able to shop, cook, and/or feed himself/herself (n=36,884)	75.2%	73.7%	79.2%	80.1%

Informal Support

The majority of caregivers for home care clients are an adult child or child in-law. Among the total home care clients, 11.7% of caregivers are spouses.

Table 22. Caregiver's Relationship to Client (n=35,936)

	Home Care Total	Home Care Basic	Choices	ECOP
Child or child in-law	62.7%	62.4%	62.0%	65.9%
Other relative	16.7%	17.0%	15.0%	16.6%
Spouse	11.7%	11.2%	14.9%	10.9%
Friend/neighbor	8.9%	9.4%	8.2%	6.6%

As seen in Table 23, more than two thirds (67.8%) of elderly home care clients do not live with their caregivers. A small proportion, 3% of Home Care Basic clients, 2.6% of Choices clients, and 1.6% of ECOP clients were reported as not having a caregiver.

Table 23. Primary Helper/Caregiver Lives with Client (n=36,893)

	Home Care Total	Home Care Basic	Choices	ECOP
Yes	29.3%	27.2%	34.2%	37.6%
No	67.8%	69.7%	63.2%	60.8%
No such helper	2.8%	3.0%	2.6%	1.6%

The areas of support provided by caregivers are presented in Table 24. A large proportion of caregivers provide help with IADLs and emotional support. However, a smaller proportion of caregivers provide ADL care. It was estimated that 31.3% of Home Care Basic clients, 39.4% of Choices clients, and 44.8% of ECOP clients received ADL care from the caregiver.

Table 24. Areas of Help/Support Provided by Caregiver

	Home Care Total	Home Care Basic	Choices	ECOP
ADL care (n=35,935)	34.0%	31.3%	39.4%	44.8%
IADL care (n=36,028)	90.0%	89.8%	88.0%	93.1%
Emotional support or advice (n=36,016)	97.6%	97.6%	97.1%	98.1%

The CDS data note whether caregivers are in need of respite. Over a quarter, 27% in the Home Care total overall were reported as needing respite. Specifically, caregivers of ECOP clients, 35.9%, had the largest proportion in needing respite services, followed by 26% for Choices, and 25.6% for Home Care Basic.

Table 25 presents responsibility and advance directives among home care clients. Health care proxy comprised of the largest proportion. Over half, 55%, of home care clients were reported as not having a health care proxy; 72% do not a power of attorney and 85% do not have advance medical directives in place.

Table 25. Responsibility/ Advance Directives

	Home Care Total	Home Care Basic	Choices	ECOP
Client has health care proxy (n=34,309)	45.0%	44.5%	38.3%	56.3%
Client has power of attorney (n=34,221)	28.4%	27.3%	23.0%	42.4%
Client has advanced medical directives (n=31,638)	14.9%	13.9%	15.5%	20.6%
Client has a legal guardian (n=33,786)	3.9%	3.2%	5.2%	6.6%
Client has a rep. payee (n=32,344)	4.1%	3.5%	6.1%	6.1%
Client has a conservator (n=31,648)	0.9%	0.9%	0.9%	1.3%

Health Services Utilization

A large proportion, 94.7% of all home care clients appropriately seek primary care. Table 26 displays the time since last hospital stay among home care clients. 62.3% of Home Care Basic clients, 60.4% of Choices clients, and 60% of ECOP clients have no hospitalizations in the past 180 days. Table 26 also indicates that 19.2% of home care clients generally have been hospitalized within 30 days prior to their most recent care manager assessment.

Table 26. Time Since Last Hospital Stay (n=31,170)

	Home Care Total	Home Care Basic	Choices	ECOP
No hospitalization- 180 days	61.8%	62.3%	60.4%	60.0%
Within last week	5.5%	5.5%	5.6%	4.8%
Within 8 to 14 days	5.4%	5.9%	3.8%	4.7%
Within 15 to 30 days	8.3%	8.7%	6.9%	7.7%
More than 30 days ago	19.0%	17.6%	23.3%	22.8%

Home Environment Assessment

Table 27 displays whether home care clients and primary caregivers feel that the client is better off in another living environment. More than 90% report that client is not better off in another living environment. 93.3% of total home care clients do not have any hazardous conditions in their homes, such as hazardous conditions relating to flooring, heating, or bathroom. However, 3.3% of total home care clients do have hazardous conditions relating to access to their home.

Table 27. Client and Primary Caregiver Feel that Client is Better Off in Another Living Environment (n=38,721)

	Home Care Total	Home Care Basic	Choices	ECOP
No	97.4%	97.5%	96.9%	96.9%
Client only	0.7%	0.8%	0.8%	0.5%
Caregiver only	1.2%	1.0%	1.2%	2.0%
Client and caregiver	0.7%	0.7%	1.1%	0.6%

Social Involvement

More than half of total home care clients are not involved in social activities. Specifically, 56.9% of Home Care Basic clients, 66.3% of Choices clients, and 66.1% of ECOP clients are not involved in social activities. Table 28 demonstrates if clients' level of social participation has declined. The majority of clients had no decline in their level of social participation. Specifically, 87.5% of total home care clients had no decline.

Table 28. Decline in Clients' Level of Social Participation (n=38,925)

	Home Care Total	Home Care Basic	Choices	ECOP
No decline	87.5%	88.7%	83.1%	84.7%
Decline, not distressed	8.3%	7.6%	11.4%	10.1%
Decline, distressed	4.1%	3.8%	5.5%	5.2%

Table 29, displays the length of time the client is alone during the day. Among total home care clients, 43.4% report being alone long periods of time and an additional

19.9% report being alone all the time. Clients are asked whether he or she feels lonely. A large proportion of clients overall, 88.2%, report not feeling lonely.

Table 29. Length of Time Client is Alone During Day (n=39,212)

	Home Care Total	Home Care Basic	Choices	ECOP
Never or hardly ever	29.9%	28.5%	34.9%	33.7%
Alone one hour	6.8%	6.3%	9.0%	7.9%
Long periods of time	43.4%	43.6%	43.9%	42.1%
All the time	19.9%	21.7%	12.3%	16.3%

Reasons for Termination from Home Care Programs

Table 30 illustrates documented reasons for termination of client cases by the three home care programs for fiscal year 2010. As seen in the table, the major reason for discharge from Home Care Basic (19.8%) was transfer to Choices and ECOP.

The major documented reasons for discharge from the three home care programs aside from transfer between the programs were due to death and nursing home placement. As seen in the table, about 13% of Home Care Basic clients, 17% of Choices clients, and 21% of ECOP clients were terminated from the home care programs due to moving into a nursing home. Based on the total cases examined (n= 25,152) a total of 14.5% of cases were terminated due to nursing facility placement, or 3,627 elders.

Table 30. Reasons of Termination by Care Program

	Home Care Basic (n=18,218)	Choices (n=3,695)	ECOP (n=3,239)
Unknown Care Enrollment Status Reason	11.9%	12.8%	10.7%
Adequate Formal Support	4.3%	2.5%	2.8%
Adequate Formal Support (Cond. Deteriorate)	0.6%	0.3%	0.7%
Adequate Formal Support (Cond. Improved)	0.1%	0.0%	0.0%
Adequate Formal Support (Cond. Same)	1.0%	0.8%	0.7%
Adequate Informal Support	2.7%	0.2%	0.5%
Adequate Informal Support (Cond. Deteriorate)	0.1%	0.0%	0.1%
Adequate Informal Support (Cond. Improved)	0.3%	0.0%	0.0%
Adequate Informal Support (Cond. Same)	0.6%	0.1%	0.3%
Client Refused	12.5%	0.7%	1.4%
Cost Sharing Fixed	0.0%	0.0%	0.0%
Death	13.9%	17.3%	21.4%
Denial	0.2%	0.0%	0.1%
FIL Ineligibility	0.9%	0.1%	0.0%
Financial Ineligibility	1.0%	0.0%	0.2%
Moved From Service Area	4.8%	2.4%	3.8%
Non-Payment of Cost Sharing Fee	0.2%	0.0%	0.1%
Nursing Facility Placement	12.8%	17.0%	20.6%
Other Termination - Care Enrollment	0.8%	0.3%	0.3%
Transfer to Another Program	0.2%	0.9%	0.1%
Transfer to Case Management Only	0.2%	0.1%	0.1%
Transfer to Choices (from ECOP Waitlist)	0.0%	0.0%	0.0%
Transfer to Choices (from HCB Waitlist)	0.1%	0.0%	0.0%
Transfer to Community Choices*	8.3%	0.2%	11.8%
Transfer to ECOP*	9.3%	1.3%	0.4%

Transfer to ECOP (from ECOP Waitlist)*****	2.2%	0.1%	0.1%
Transfer to GAFC	0.3%	0.1%	0.0%
Transfer to HCB (from ECOP Waitlist)	0.0%	0.0%	0.0%
Transfer to HCB (from HCB Waitlist)	0.1%	0.1%	0.0%
Transfer to Home Care	0.7%	2.7%	1.6%
Transfer to Home Care Basic	6.7%	35.8%	21.9%
Transfer to Respite Over-Income	0.7%	0.1%	0.7%
Transfer to SCO - Commonwealth Care Alliance	0.4%	1.1%	0.1%
Transfer to SCO – Evercare	0.7%	1.3%	0.0%
Transfer to SCO - Senior Whole Health	0.9%	1.0%	0.0%
Transfer to Title III-c	0.3%	0.0%	0.0%
Withdrawn from WAITLIST-Other Reason	0.2%	0.1%	0.1%

Note: * The major reason for discharge from Home Care Basic (19.8%) was transfer to Choices and ECOP.

Care Manager Journal Notes

Consistent with the applied research project on care managers' perspectives that was conducted by the UMass Boston students, the journal notes reveal that continuous 24-hour care is a major reason reported for discharge. Often the need for 24/7 support and supervision is combined with other factors, such as the intensity of care required (e.g., two person assist). One care manager writes: "*Community options were explored. Because client needs 24/7, is a fall risk, and a 2-person transfer, there are no options for the client within the community. Family is no longer able to care for the client in the home*." For this client, the four reasons for discharge into a nursing home are: the need for 24-hour care; a fall risk; assistance with transfer that requires two people; and informal caregiver burn out.

Risk of falling was also documented by another care manager: "*Completed nursing facility referral. Consumer is being admitted today due to multiple falls at home.*" Another care manager writes:

> *"Client fell again today, which was the second time this week, and the family reports that client isn't able to ambulate the way she used to and that the client herself wants to go into a nursing home. The family is no longer able to care for her safely in the home. Client needs 24/7 care."*

A lack of informal support at home was also frequently cited as a reason for discharge into a nursing home. During a nursing home visit for a client who was recently discharged from a hospital, one care manager documents, "*Client states that she is doing okay. Client will be staying long term as she cannot get out of bed and does not have support at her home. Client feels safer where she can get 24-hour care."*

One journal entry describes in detail the experience of caregiver burnout:

> "*Caregiver states client has recently begun talking almost constantly at times, including at night. Client frequently calls caregiver for assistance at night to go to bathroom; caregiver and her husband getting little sleep because of this. Client up 4 times last night, about every 2 hours, for bowel movements. Caregiver expressed frustration with lack of sleep, increasing demands on her and her husband to respond to client's many needs. Client is less steady on feet. Caregiver needs more assistance with transfers and ambulation. Needs assistance with bathing, dressing, toileting, set-up with eating."*

The notes also reveal that the extent of the need for maximum assistance with ADLs and IADLs due to the severity of health conditions among clients could affect discharge into a nursing home. From another journal entry by a nurse who assessed a client with dementia, it describes the need for maximum assistance with ADLs:

> "*Client's dementia has progressed and she now requires 24-hour supervision, and requires maximum assistance of two for most of her ADLs care. After speaking with the family, a Long Term Approval [for nursing facility care] has been given due to lack of informal supports in the community."* For a client who had a stroke in 2008, one care manager documents, "*The client has required 24-hour care since suffering a CVA (stroke) with right-sided weakness 7/08. She needs assistance with all ADLs and IADLs, meds, incontinence and skin management, and care. The client is declining, eating less and sleeping most of the time. She has exhausted her money for private care."*

The number of medical conditions among clients may also influence nursing home placement. Clients with a larger number of chronic conditions may be more likely to be discharged into a nursing home. One care manager writes,

> "*The client is clinically eligible for nursing home approval. Diagnosis: dementia, other type, Alzheimer's disease, CVA, dysrthymia, hypertension, coronary artery disease, congestive heart failure, arthritis, diabetes, hyperlipidemia, cataracts, anemia, generalized weakness, colitis, infectious diarrhea, anxiety, and cancer. The client was an AFC client and her family was her primary caregivers. With her increasing needs (including chronic diarrhea), they had difficulty providing 24-hour care. The client needs skilled-monitoring and management of her many medical conditions. The client needs assistance with all IADLs, ADLs, diabetic, skin and nutrition monitoring and management, medication administration monitoring and management. Plan is for long term placement."*

For another client who had multiple medical conditions and was admitted into a nursing home, the journal entry states, "*Consumer was admitted with diagnosis of CVA, psychological problems, high cholesterol, seizure disorder, pacemaker, knee replacements, dementia, and history of falls."*

From the journal entry notes, frequent reasons for discharge into nursing homes noted were:

- ADL and IADL needs require 24/7 care that could not be sustained in the home setting,
- risk and history of falls,
- a lack of informal support at home,
- the need for respite and support for informal caregivers,
- reaching a maximum of assistance with ADLs and IADLs, and
- the severity and number of medical conditions that probably require 24/7 care that could not be managed in the home.

CONCLUSIONS AND RECOMMENDATIONS

This study provide a snapshot of clients currently served by the three home care programs and insights from care managers as to reasons for discharge for HCBS to nursing home settings. We conclude by highlighting some of the findings and offering some recommendations to enhance the delivery of HCBS in Massachusetts.

Medication Administration: As reported from the CDS data, over a third, 37.6%, of total home care clients were taking nine or more medications. Because clients use multiple medications, and often have trouble keeping them straight or remembering to take their medications, improved services for medication management may be needed for clients. Future research might address concerns for polypharmacy and level of medications' compliance among home care clients. Programs might also explore enhancing assistance in the area of medications' management.

Evidence-Based Fall Prevention Programs: As reported from the CDS data, an estimated 64% of total home care clients were experiencing unsteady gait. A large proportion of Choices and ECOP clients, 66.3% and 67.6% respectively, were reported as having limits in going outdoors due to fear of falling. The care manager interviews also highlighted the need for increased fall prevention. Currently, interventions do exist on fall prevention. ASAPS are involved in the 'Matter of Balance' evidenced-based program. An assessment of the program and expansion if warranted should be considered due to the large proportion of home care clients experiencing unsteady gait and balance.

Improved Coordination with Medical Providers: As the CDS data indicate that doctors and hospitals account for very few referrals for home care services, 2.5% and 9.4% respectively, efforts should be explored to create better linkages with medical home providers and with hospital discharge staff. Improved communication may help reduce inappropriate or unnecessary admissions to hospitals and nursing facilities. Moreover, an estimated 52% of Choices clients and 41% of ECOP clients feel multiple periods of pain daily. Further, more than half of Choices clients, 56%, reported that the intensity of their pain disrupts performing usual activities. The home care programs currently do not provide services for pain management. Interventions in pain management should be available, as part of the chronic disease management program and better coordination with medical providers could address that need.

Risk Assessment: Safety was an important theme for the care managers interviewed. Safety of the client is seen differently by the client, the family, and the care manager. Tolerance for safety may also vary from client to client. Use of negotiated risk assessments with clients and family members might help to identify the risks, and clarify what the "safety" issues really are for all parties involved.

24/7 In-Home Supports: A major theme in the care manager interviews is the need for 24/7 care. Consumers who wish to remain at home need to have the ability to assemble care plans on short order, including coverage for overnight care and weekends. Community care plans need to be as straightforward to assemble as a nursing facility placement. This could include short-stay adult foster care placements, and special extended care response teams of homemakers and home health aides. Moreover, clients in home care could be maintained in the community if there were intermediate steps between care at home and care in a nursing facility. 24/7 supports can require

combining housing with services such as supportive housing sites, or a small group home facility for individuals unable to live alone.

Self-Managing Chronic Conditions: Some clients terminated from the home care program and transferred to a nursing home have multiple medical conditions---which alone may not require discharge from home care, but in combination create the sense of overwhelming need. As a preventive measure, programming to provide individual, in-home chronic condition self-management support may help clients manage their chronic conditions with better outcomes. Hypertension (64.8%), arthritis (53.8%), and diabetes (30.6%) were the most prevalent health conditions among total home care clients noted in the CDS data. There are chronic disease self-management programs in the home care system today, but additional development of programs and interventions for these conditions may be warranted.

Care Manager Discharge Training: Care managers do not have a direct role in the decision to discharge, the decision resides with the older adult and family members. In the qualitative interviews, care managers were asked how much input they typically have in the decision to discharge clients from HCBS to a nursing home. The majority of care managers reported that they have some input, while "*the decision is from the clients' families*." Care managers were asked about what factors are considered by their clients and families in the decision to discharge from home care programs into a nursing home. One care manager explained that safety concerns and a lack of informal support at home are considerations for nursing home placement. A special curriculum designed to help care managers approach the discharge process would be helpful to better understand how to work with family dynamics; how to assess their own professional and personal attitudes towards safety; and how to ensure that the consumer's voice is given the weight it deserves.

Need for Additional Research: Additional study of terminations from home care should be conducted, focusing especially on service gaps identified in journal notes. The journal entry notes provided insights into reasons for discharge among clients that may not have been captured from the CDS. Future studies focusing on service gaps could include a more comprehensive analysis using journal notes as well as interviewing clients and family members. In addition, future studies might be conducted in examining the role of the care manager, client, family members, and doctors in the decision making process. It is recommended that strategies be developed in working with healthcare providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options.

A limitation of this study is the small sample of care managers who were interviewed for the applied research project. The nature of qualitative data is to use few subjects to collect in-depth data. Much was learned from these data. However, generalization is limited in that these care managers do not represent all care managers in the Commonwealth. Building on this current study, an electronic study of all care managers is planned for Spring 2011. We look forward to collecting additional insights on this issue. Another limitation is the missing cases from the CDS data. We learned that the data needs are time consuming for the care managers and not all data are fully entered. Still, the study provided relevant information on reasons for client discharge. EOEA might revisit their reporting forms with the goal of minimizing missing data. It would be helpful to conduct additional studies on terminations from home and community-based care, focusing especially on service gaps identified in journal notes, and examining the role of the care manager, client, family members, and doctors in the decision making

process. It is recommended that strategies be developed in working with healthcare providers (e.g., doctors, private physicians) and community-based providers to promote awareness of the availability and viability of community-based options. It is hoped that ASAPs, other elder services groups, and policy makers will use this report to develop additional responses to address the identified service gaps in community-based programming.

REFERENCES

AARP. (2005, April). *Beyond 50.05: A report to the nation on livable communities creating environments for successful aging.* Retrieved July 8, 2010, from AARP Web site: http://assets.aarp.org/rgcenter/il/beyond_50_communities.pdf

Clark, R. L., Burkhauser, R. V., Moon, M., Quinn, J. F., & Smeeding, T. M. (2004). *The economics of an aging society.* Malden, MA: Blackwell Publishing.

Fox-Grage, W., Coleman, B., & Freiman, M. (2006, September). *Rebalancing: Ensuring greater access to home and community-based services.* Retrieved August 14, 2009, from AARP Web site: http://assets.aarp.org/rgcenter/il/fs132_hcbs.pdf

Kaiser Commission on Medicaid and the Uninsured. (2004, June). *Olmstead v. L.C.: The interaction of the Americans with Disabilities Act and Medicaid.* Retrieved August 14, 2009, from http://www.wvdhhr.org/oig/olmstead/what%20is%20the%20olmstead%20decision/olmstead%20interaction%20with%20ada%20and%20medicaid.pdf

Kassner, E., Reinhard, S., Fox-Grage, W., Houser, A., Accius, J., Coleman, B., & Milne, D. (2008, July). *A balancing act: State long-term care reform.* Retrieved August 14, 2009, from the AARP Web site: http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf

Keigher, S. (2006). Policies affecting community-based social services, housing, and transportation. In B. Berkman (Ed.), *Handbook of social work in health and aging* (pp. 877-891). New York: Oxford University Press, Inc.

Miller, E. A., Allen, S. M. & Mor, V. (2009). Commentary: Navigating the labyrinth of long-term care: Shoring up informal caregiving in a home- and community-based world. *Journal of Aging & Social Policy, 21*(1), 1-16.

Moschella, A. L., & Winston, N. A. (2009). Community Medicaid programs: Alternatives to nursing homes. *Massachusetts Bar Association: Section Review, 11*(1), 35-37.

Muramatsu, N., Yin, H., Campbell, R. T., Hoyem, R. L., Jacob, M. A., & Ross, C. O. (2007). Risk of nursing home admission among older Americans: Does states' spending on home- and community-based services matter?. *The Journals of Gerontology, 62B*(3), S169-S178.

National Conference of State Legislatures and AARP. (2009, February). *Shifting the balance: State long-term care reform initiatives.* Retrieved August 14, 2009, from http://www.ncsl.org/documents/health/shiftingbalance.pdf

Walker, L. (2010, June). *Health care reform improves access to Medicaid home and community-based services.* Retrieved August 1, 2010, from AARP Web site: http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf

Wallack, S. S., Thomas, C. P., Flieger, S. P., & Altman, S. H. (2010, February). *Massachusetts health care cost trends: Part I: The Massachusetts health care system in context: costs, structure, and methods used by private insurers to pay providers.* Retrieved January 3, 2011, from http://www.mass.gov/Eeohhs2/docs/dhcfp/r/cost_trends_files/part1_system_in_context.pdf