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Money Follows the Person Rebalancing Demonstration

Unmet Needs in the Connecticut Home Care Program for Elders

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Background

The Money Follows the Person (MFP) Program benchmarks are designed to address gaps in Connecticut's long term care system. The intention in achieving MFP benchmarks is to use the enhanced federal match (FMAP) in the future to decrease these identified gaps and move the state further forward in its rebalancing efforts. This report addresses Benchmark 3: proportion of people receiving care in Home and Community-Based Services (HCBS) versus in institutions. The aim of this work is to identify unmet needs and service gaps in the current Connecticut Home Care Program for Elders (CHCPE) through a study of individuals who discontinue participation in the CHCPE and enter a nursing home.

This study set out to address the question: what are the unmet needs and associated service gaps for individuals in the CHCPE who transition to nursing homes? Approximately 50 percent of the CHCPE participants who discontinue the program enter a nursing home for long term care at the time they leave the CHCPE. This report explores the full range of reasons for relocation to a nursing home, including change in functional or health status, inability of available formal and/or informal supports to meet the care needs of the individual in the community, challenges in securing and retaining reliable formal home health care, housing instability, and/or need for services not available through the CHCPE such as personal care assistants. We track the full range of transition trajectories, including individuals who are admitted to hospitals and/or visit emergency departments for an acute episode or exacerbation of a chronic health condition, and subsequently move to a nursing home for either a short or long term stay.

The study has three components: 1) review of CHCPE administrative data for a retrospective cohort of CHCPE clients, 2) review of care manager notes for a 15% subsample of the retrospective cohort, and 3) focus groups with access agency care managers to address broader aspects of systems gaps leading to nursing home admission. This assessment received approval from the University of Connecticut Health Center's (UCHC) Institutional Review Board.

PART 1. CHCPE administrative data

Methods

The CT Department of Social Services provided a statewide database including all CHCPE clients who were discontinued from CHCPE during calendar year 2008, as well as a subset of clients who were discontinued for the following reasons: “entered LTC (long term care) due to health” or “entered LTC due to client choice”. Clients who have a temporary nursing home stay may continue on the program until they have been in the facility for 90 days or they or their families decide they will remain in the nursing home as a long term resident. The database is divided by the five service regions of CT: Bridgeport, Hartford, New Haven, Norwich and Waterbury. Three access agencies manage all CHCPE clients, based on these regions: The Agency on Aging of South Central Connecticut (AASCC) manages the New Haven region, the Southwestern Connecticut Agency on Aging (SWCAA) manages the Bridgeport region, and Connecticut Community Care, Inc. (CCCI) manages the Hartford, Norwich, and Waterbury regions. Table 1 displays the number of discontinued clients in each region and the percentage in one of the LTC discontinuance categories.

A total of 3,529 clients were discontinued from CHCPE in 2008 and 49 percent (1745) of these clients were discontinued because they had entered LTC. Bridgeport had the lowest proportion of discontinued clients entering LTC (44%) and Norwich had the highest (52%).

Table 1. 2008 discontinued CHCPE clients who entered a LTC facility, by region

	Bridgeport	Hartford	New Haven	Norwich	Waterbury	Total
Total 2008 discontinued from program	463	1075	939	340	712	3529
Total sample discontinued because entered LTC	204	544	469	177	351	1745
% of discontinuances going to LTC	44%	51%	50%	52%	49%	49%

Drawing from data systematically collected annually in the Modified Community Assessment, each of the three access agencies provided administrative data for their CHCPE clients discharged to a nursing home in 2008. After removing duplicates and a few cases with incorrect identifying data, the DSS data sample size was reduced to 1721. The three agencies were able to find matches in their data systems for 1468 (85%) of the 1721 people on the cleaned DSS list. Mismatches most likely occurred due to data entry error of social security numbers, dates of service, or region. Administrative data included demographics, programmatic data indicating program category and length of time participating, medical diagnoses, and emergency room use and hospitalizations in the year preceding program discontinuance.

Results

Tables 2-4 summarize the administrative data for the 1468 matched CHCPE participants who left the program and went to a nursing home. Ages ranged from 65-102, with a mean of 83. About three-fourths of participants were female and 78 percent were white.

Table 2. Demographic Data for 2008 discontinued CHCPE participants who entered a LTC facility (Total N = 1468)

	N	%	Mean	Range
Age			83.1	65-102
65-74	220	15		
75-79	230	16		
80-84	349	24		
85-89	332	22		
90+	337	23		
Gender				
Female	1077	73		
Male	391	27		
Race				
White	1148	78		
Black	173	12		
Hispanic	115	8		
Other	25	2		

Two-thirds of participants had been enrolled in Level 3 of the CHCPE, the Medicaid Waiver portion of the program. Just over one-fourth were in Level 2, the state-funded portion for people with three critical needs who do not meet the Medicaid financial eligibility criteria. Only seven percent were in Level 1, for people with one or two critical needs. The number of months in the program was calculated by subtracting the month of enrollment from the month of discontinuance in 2008. Some people had multiple episodes of program use; in these cases the month of first enrollment was used for the calculation. Participants had been in the CHCPE between 1 month and almost 20 years, averaging 35 months. The length of time in the program is distributed fairly evenly between short, medium and long-term users: 18 percent had enrolled within the previous 6 months, and 16 percent had used the program for between 6 months and 1 year, 19 percent used it for between 1 and 2 years, 26 percent had participated for between 2 and 5 years, and 21 percent had first enrolled more than 5 years before discontinuing.

Table 3. Program Data for 2008 discontinued CHCPE participants who entered a LTC facility (Total N = 1468)

	N	%	Mean	Range
CHCPE category				
Level 1	107	7		
Level 2	394	27		
Level 3	965	66		
Months in CHCPE (N=1577)			35	1-237 (=19.75 yrs)
<6	286	18		
6-11	255	16		
12-23 (1 – 2 years)	301	19		
24-59 (2 – 5 years)	411	26		
60+ (5 years or more)	324	21		

Table 4 shows the five most common diagnoses for this group of CHCPE participants. Most diagnoses come from participant and family self-report to the access agency care manager; a small number come from clinician report when the assessment is done in an institutional setting. These numbers may be slight undercounts, as one access agency provided only primary diagnoses (N=261). Half of the participants had either a primary or secondary diagnosis of hypertension, 46 percent had rheumatoid or osteo- arthritis, and just over one-third had a visual impairment. One-third had a dementia diagnosis and one-fourth had diabetes. In addition to the multiple physical health conditions, 16 percent of participants had a mental health diagnosis. The assessment form does not specify specific mental health diagnoses.

Visits to the emergency room and overnight hospitalizations were common in this sample, with about three-quarters of the participants having an ER visit and three-quarters having a hospital stay in the year before discontinuance. Participants had between 0 and 6 visits to the ER, with 1.3 visits on average and between 0 and 12 hospitalizations, also with 1.3 hospitalizations on average.

Table 4. Health and Health Service Use Data for 2008 discontinued CHCPE participants who entered a LTC facility (Total N = 1468)

	N	%	Mean	Range
Common Diagnoses				
Hypertension	734	50		
Rheumatoid/Osteoarthritis	669	46		
Visual impairment	496	34		
Dementia	465	32		
Diabetes	362	25		
Mental Health diagnosis	240	16		
Any ED visit (AASCC only, N=414)	321	78		
# ED visits (AASCC only, N=414)			1.3	0-6
Any Hospitalization (AASCC & CCCI only, N=1207)	919	76		
# Hospitalizations (AASCC & CCCI only, N=1207)			1.3	0-12

PART 2: Review of care manager case notes

Methods

Selection of cases to review

The CHCPE program comprises several program types including case management, personal assistance services, and assisted living. Each access agency maintains detailed case notes for participants in the case managed program type, but not those in the assisted living or personal assistance services programs because the latter programs do not use agency care managers.

All information regarding discharge decisions is recorded by the case managers in the client's case notes. Case notes for CCCI and SWCAA clients are computerized; case notes for AASCC are kept in paper files. The research team selected five sample cases from the DSS client list for each access agency to become familiar with the format of the case notes and to develop a preliminary coding list. After removing clients from non-case managed programs, a fifteen percent random sample was drawn for each region. The access agencies provided case notes to the research team for review. SWCAA and CCCI case notes were sent via secure email to UCHC. Three research team members reviewed AASCC case files on site at the New Haven office. Table 5 shows that of the 252 clients in the random sample, 20 had no match at the agency, eight were ineligible for various reasons, and 224 files were reviewed and coded.

Table 5. 2008 discontinued CHCPE clients who entered a LTC facility selected for case file review, by region

	Bridgeport	Hartford	New Haven	Norwich	Waterbury	Total
Total sample discontinued because entered LTC	204	544	469	177	351	1745
Case managed	196	484	427	172	344	1623
15% random sample	31	74	58	30	59	252
No file match	2	5	6	2	5	20
Ineligible*	2	2	4	0	0	8
Total files coded	27	67	48	28	54	224

*reasons for ineligibility: not discontinued in 2008, died with no LTC admission, moved out of state, illegible notes

Procedure

Five members of the UCHC research team reviewed and coded client case notes. At least one researcher read the care manager's case notes to identify contributing factors and reasons for the client's discontinuance from CHCPE and entrance into LTC, which was typically into a LTC bed in a skilled nursing facility (SNF) or nursing home. Researchers read all the case notes beginning six months before program discharge, or further back as needed, to gain a complete picture of that client's experiences. A code list was developed and utilized by all coders to ensure a standardized procedure. Coders were trained by the project principal investigator (JR).

Each coder's first three cases were also coded by another member of the research team and then the codes were compared and agreed to by consensus, ensuring that they applied codes uniformly.

Code list development

The principal investigator (JR) and the project consultant (LC) developed an initial code list based on the initial review of the 15 sample case files provided by the access agencies. The initial code list was also informed by results from the three care manager focus groups, described in Part 3. The entire research team reviewed and refined the code list. After each coder had used the code list with three to five case files, the code list was refined again resulting in the final list of 25 codes (28 including sub-codes), displayed in Table 6. The codes identify issues that came up during the six months preceding program discontinuance. All but one code describe situations specific to the client. Code 21, "At time of discharge from CHCPE, no discussion of additional CHCPE services noted", was used to distinguish between cases where care managers documented suggestions of additional CHCPE services that might have addressed the other issues, and cases where this discussion was not noted.

Table 6. Code list for CHCPE discontinuances due to entering LTC

1. Needs more services than can be provided (e.g., 24 hour supervision)
2. Fall
3. Acute illness onset leading to need for more assistance
   3a. hospitalization (includes ER visit)
4. Chronic illness worsening leading to need for more assistance
5. Lack of family/informal supports
6. Family requests initial or continued placement
7. Family fear of client being alone
8. Family cannot continue to provide care (burned out)
9. Family cannot provide additional care needed (after a health status change)
   9a. client's health status change
   9b. family member's health status change
10. Family refuses services – doesn't want staff in home
11. Client requests placement
12. Client refuses existing services
13. Client refuses new services
14. Client isolation/loneliness
15. Paid help unreliable (no shows, etc)
16. Dissatisfaction with services (e.g., doesn't like Meals on Wheels food)
17. Need for assistive technology/medical equipment
18. Need for PCA – e.g., one person to do multiple levels of care (e.g., companion & HHA)
19. Need for other services not available in CHCPE
20. Client goes to NH for rehab/short term recovery
21. At time of discharge from CHCPE, no discussion of additional CHCPE services noted
22. Care manager recommends NH placement
23. Mental health/substance abuse issues
24. Client not compliant with meds
25. Legal issues (e.g., issues with conservators, criminal charges)

Analysis

All applicable codes were assigned to each case reviewed. The total number of times each code was assigned out of the total 224 cases reviewed was tallied and a percentage was calculated. Percentages were also calculated for each code by region.

Results

All of the codes from the code list were utilized for at least one case. On average, each case received 6 codes with a range from 2 to 13 codes per case. Table 7 shows the codes assigned from most common to least, and the percent of cases that received each code. Appendix 1 shows the regional breakdown of the assigned codes.

Table 7. Contributing factors for CHCPE discontinuances due to entering LTC

Code description	Percent of cases with this code
Hospitalization (includes ER visit)	80
Needs more services than can be provided (e.g., 24 hour supervision)	62
Client goes to NH for rehab/short term recovery	62
Family requests initial or continued placement	54
Chronic illness worsening leading to need for more assistance	53
At time of discharge from CHCPE, no discussion of additional CHCPE services noted	47
Fall	35
Client's health status change	31
Acute illness onset leading to need for more assistance	30
Mental health/substance abuse issues	20
Lack of family/informal supports	18
Family cannot continue to provide care (burned out)	18
Family cannot provide additional care needed (after a health status change)	17
Family fear of client being alone	14
Client requests placement	14
Family member's health status change	13
Care manager recommends NH placement	11
Client not compliant with meds	8
Client isolation/loneliness	7
Legal issues (e.g., issues with conservators, criminal charges)	7
Client refuses existing services	5
Client refuses new services	4
Dissatisfaction with services (e.g., doesn't like Meals on Wheels food)	4
Need for other services not available in CHCPE	4
Paid help unreliable (no shows, etc)	3
Need for PCA – e.g., one person to do multiple levels of care (e.g., companion & HHA)	3
Family refuses services – doesn't want staff in home	2
Need for assistive technology/medical equipment	2

A wide range of factors contributed to a move to a long term care facility and subsequent discontinuance from the home care program. While these factors include changes in health status, as might be expected, other influential conditions include family availability and attitudes as well as CHCPE program limitations. In a large majority of cases (80%), clients had gone to the emergency room or stayed overnight or longer in a hospital in the preceding few months. About two-thirds (62%) of care managers noted that the client needed more services than could be provided by the program, typically 24 hour care or supervision. Further, a few care managers specifically noted that the client would benefit from having a flexible care provider who could do varying levels of care, such as a personal care assistant (PCA), which was not an available service in the program. About two-thirds (62%) had had a short term rehabilitative stay in a nursing home in the preceding months. Over half of the case files (54%) noted that a family member had requested either an initial move to a nursing home or that the client remained long term in a nursing home following a short term stay. Over half of the case files (53%) also noted worsening of a chronic illness.

Other frequent triggers to discontinuing the program and entering long term care include falling and the acute onset of a health problem or illness which both occurred in about one-third of the cases reviewed. Twenty percent of clients had mental health or substance abuse issues. In addition to mental health diagnoses and substance abuse issues, some clients had behavioral symptoms of dementia such as aggression or delusions, which care managers and families found particularly difficult to handle. Care managers and families both need more training and resources to work with clients with these conditions.

Almost one-fifth of clients lacked any family support and care managers noted family members were burned out or overwhelmed by the caregiving demands in another 18 percent of cases. In an additional 17 percent of cases, family members were not able to provide care after a significant change in the client's health status. Fourteen percent of clients' family members expressed fear about the client living alone, and 13 percent of clients' family members could not provide support due to a change in their own health.

A handful of factors were relatively rare in the cases reviewed, at least as noted by care managers. Fewer than five percent of cases described clients or families who refused either new or ongoing services, or who were dissatisfied with services. Problems with unreliable care providers were noted in only three percent of cases. The need for unavailable medical equipment or assistive technology only arose for two percent of clients. Because it is not currently a covered service under the program, it is likely that care managers are not familiar with the wide range of assistive technology that could potentially benefit their clients, and therefore did not refer to it in their case notes. However, if the program did allow for assistive technology and provide training to care managers, this service could potentially enhance care plans significantly.

Care managers have to balance myriad factors for each client to put together a care plan which can support that client in the community. In 11 percent of the reviewed cases, the recommendation to move to a long term care facility came directly from the care manager. Yet more often, care managers continue to work to keep clients in the program by arranging services that will allow them to return to the community even after they have gone into a nursing home. About half of the case notes document discussions held with clients or family members at the time of discharge from the program. These discussions explained either additional CHCPE services that could be put in place to keep the client at home or bring them home from a short term nursing home stay, or procedures for re-applying to the CHCPE when the client was ready. In cases where no such documented discussions took place at the time of discharge from the

CHCPE (47%), it was often clear why the client could no longer benefit from home care or why the family could no longer support them at home. In some cases, however, it was unclear why care managers did not note additional services that might assist a client in remaining eligible for home care. It is possible that if these discussions occur in all cases poised for discharge to enter LTC, more clients would stay in the program. Care manager training could include strategies focused on identifying and problem-solving for clients at risk of discontinuance, based on the triggering factors identified in this study.

PART 3. Views and Experiences of Access Agency Care Managers

Methods

Recruitment

Participants were recruited in collaboration with each of the three access agencies which are contracted by the Department of Social Services to provide care management services to participants in the CHCPE: CCCI, AASCC, and SWCAA. Directors from each access agency were contacted via email and telephone and invited to participate.

All three access agencies agreed to participate in the study, including hosting their agencies' focus groups and recruiting the participants. The agencies were each asked to recruit six to eight care managers and at least one care manager supervisor, and were encouraged to include regional and ethnic diversity. One focus group was held at each agency.

Three focus groups were conducted during June and July, 2009, with a range of 7-9 participants per session, for a total of 24 participants. This number of participants (the "sample size") is consistent with established standards for focus group research (Morgan, 1998), and represents the experiences of the three access agencies that serve the entire state of Connecticut.

Description of participants

Over half of the participants in each focus group were care managers or care manager team leaders, lead coordinators, or supervisors. One agency regional supervisor also attended. Other participants included those in nursing, mental health, and clinical care quality assurance. They were highly diverse with respect to their professional background and expertise, with bachelors and masters level training in human services, social work, gerontology, sociology, psychology, nursing, education, recreation, substance abuse counseling, and public health. Their work experience included home health care, hospitals, nursing homes, engineering, human service agencies, mental health care, and care management. Longevity of employment at the current agency ranged from 9 months to 21 years.

Table 8. Strata and sample size for focus groups

Site	Total participants per program type					
	Care manager	Care manager team leader or lead coordinator	Regional supervisor	Nurse or clinical quality assurance	Mental health consultant	Total participants
SWCAA	4	2		1	1	8
CCCI	5		1	1		7
AASCC	6	2		1		9
Total participants	15	4	1	3	1	24

Procedure

Focus groups were conducted in accordance with established methods (Morgan and Kruger, 1998; Kruger and Casey, 2000) at the access agency office locations at a time convenient for participants. They were approximately one hour in duration. All groups were led by an

experienced focus group moderator (LC), and experienced co-facilitator (MP) who managed all logistics, note taking, and recording observational data. An audiotape was made of each session to allow for clarification of points and preparation of transcripts for computerized analysis. Participants were assured that their participation was voluntary, data would only be reported in the aggregate, and they would not be identified in any way. All protocols were reviewed and approved by the University of Connecticut Health Center Institutional Review Board.

Data collection tool

A series of guiding questions with structured probes was developed, used a "tunnel" format, opening with an introductory, non-threatening question and moving to increasingly more substantive issues, following the approach defined by Kreuger and Casey (2000). Participants were asked to recall two of their most challenging cases during the prior year (one client who was cognitively intact and the other with cognitive impairment), who they felt might have been able to remain in the program but ultimately had to move into a nursing home. They were asked to describe what occurred as they tried to arrange necessary services and supports. Subsequent topics for discussion included perceived obstacles to keeping clients in the community and program supports that would be most useful in being able to support clients in the community (Appendix 2).

Analysis

Recorded data were transcribed and formatted as a single transcript per session. Systematic, verifiable analysis was accomplished through a number of strategies, including consistent use of the discussion guide, audio taping and independent professional preparation of the transcripts, standardized coding and analysis of the data, use of researchers with diverse background for analysis and the creation of an analysis audit trail to document analytic decisions (Curry et al., 2009; Mays and Pope, 1995; Miles and Huberman, 1994). Emergent themes were compiled to characterize core issues regarding participant experiences and perceptions. *Please note that participants have been assured of the confidentiality of their statements; information reported here must be protected accordingly.*

Results

The results of the focus groups are presented as follows. The first section includes three composite vignettes in order to illustrate some common scenarios described by the care managers in the group. The next section reports unmet needs of clients who entered LTC and left the CHCPE. This section is organized by themes and presents quotes from the focus groups to illustrate the identified themes.

Composite Vignettes

The following three vignettes describe various circumstances and trajectories experienced by CHCPE clients who were discontinued from the CHCPE program because they moved into a nursing facility. They represent a composite of CHCPE client characteristics and situations, as described by focus group participants, but none are real individual clients. The vignettes are intended to illustrate both the complexity and diversity of service needs, as well as the critical role of both formal and informal supports in maintaining CHCPE clients in community settings.

Cognitively intact

At age 86, Mary still lives by herself. She is unable to drive or do physical chores due to her physical health problems. She is obese, diabetic, and has high blood pressure, and finds it very taxing to even get around her home.

Her daughter has been coming by at least once a week, bringing groceries, doing household chores, and taking her to appointments. One day she finds her mother on the floor, where she had been since falling the day before. After going to the hospital for assessment, Mary is discharged to a nursing home as she now cannot walk, and her home is not wheelchair accessible. During this time, she is prescribed insulin, as the oral medication is no longer controlling her diabetes.

Mary is very upset to be in a nursing home and calls her daughter every day, saying she just wants to go home. Distressed by the situation, the daughter brings Mary home to live with her, with care provided under the CHCPE. Now using a walker, Mary also needs supervision with walking and assistance with transferring. However, Mary's daughter works during the day and has two children, so she is not available to assist Mary during the day, and finds it difficult to do so in the evening. The care coordinator arranges for a nurse to come in two times a day to give Mary insulin and change her bandage and also provides a Lifeline service. However, the local home care agency cannot provide the full amount of intermittent support that Mary needs for hands on, supervision, and companionship care. Mary falls two more times during the day when she is alone, and each time is taken to the hospital for evaluation by the emergency medical responders. The home care agency and care manager agree that given the lack of sufficient supports, it is not safe for Mary to continue living in the community, and Mary is placed in a nursing home on a long term basis.

Mental health problems

John is 65 years old with bipolar disorder and severe COPD. He has difficulty breathing without oxygen, and needs medications for his mental and physical health problems. Currently he is living independently in an apartment on Medicaid and SSDI.

His sister keeps in touch with him sporadically. She called DSS when she visited and found that he was not taking his medications or taking care of himself. DSS referred him to the CHCPE. The waiver assessment indicated a need for medication management and supervision, especially regarding taking psychotropic medications, as well as assistance with homemaker tasks, groceries, and getting prescriptions. The care manager arranged for a nurse to come in once a week to fill up medications for the week, and homemaker services three times a week.

This arrangement worked fairly well at first. He was still finding it difficult to live independently without other structure in his life. John then stopped taking his psychiatric medications, because he "felt fine." Without these medications, he became easily agitated, verbally abusive, and threatening to his neighbors and home care staff. Eventually his nurse and homemaker both refused to go into his home for fear of their safety. His care manager worked with several agencies in the area, but could not find replacements who were willing to take his case. The apartment manager called police when he found John physically threatening another resident. John was taken to the ER. After finding no appropriate residential options which could provide the structure and daily assistance he needed, he was placed into a nursing home.

Cognitive impairment

Frank is 74 years old and has moderate dementia. Recently he has lost a lot of weight, and is now very thin and frail. He lives with his 77 year old wife, Sarah, who has osteoarthritis which makes it painful for her to walk. Their only adult child lives in another part of the country. Frank needs cueing and directions for almost all activities, and hands on care for others, like getting dressed or taking a bath. He is also becoming more incontinent, and is very active at night, pacing round their apartment.

Their current CHCPE services include a daily morning home health aide (HHA), who helps Frank bathe and get dressed, provides continence care, gets his breakfast, and goes with him for a daily walk if possible. He is also eligible for HHA services 5 evenings a week. However, due to a shortage of HHAs in the area, the local home care agency can only provide this service to him two evenings a week. Instead, Frank has a companion for the other 3 evenings. The companion tries to engage Frank and distracts him if he begins to pace or tries to wander outside. However, she cannot provide incontinence care, nor can she help him get into his night clothes when he needs assistance.

When the home health aide is not there, Sarah takes care of her husband, and also does the grocery shopping, cooks the meals, pays the bills, and takes care of other household duties. It is difficult for her given her osteoarthritis, but she does the best she can.

One day when grocery shopping with Frank, Sarah slips and falls, breaking her hip. The ambulance takes Sarah and her husband to the hospital. While Sarah is having emergency surgery, Frank, totally disoriented, wanders off. A police officer finds him and takes him back to the hospital. The hospital determines that he would not be safe alone at home and arranges for him to go to a nursing home with a dementia unit.

Sarah is discharged to the same facility for short-term rehabilitation. She goes to see her husband, but he seems to have declined since she was hospitalized, and she cannot engage him in conversation. One week later, she is ready to go home with outpatient physical therapy. However, Frank now needs more hands on help than before. He now is totally incontinent and has become more withdrawn and less responsive, even with Sarah. Sarah now has limitations to the care she can give him and the waiver services do not provide for 24 hour care. Consequently, Frank cannot come home, and becomes a long-term resident at the nursing home.

Unmet needs

Participants described a wide range of unmet needs for clients, including both formal and informal supports, as well as related considerations such as housing and quality of care (see Table 9). Certain issues were discussed at greater length and with comparatively more intensity. Although these narrative data cannot be quantified or ranked, they are presented in an order that reflects the relative urgency or importance from the participants' perspectives.

Table 9. Unmet needs identified by access agency care managers

Inadequate or no informal support
Inadequate availability of home care personnel for shifts other than regular day hours, such as evening, overnight, weekends, or personnel available for short, intermittent care
Lack of more flexible, intermediate service provider to provide mixed level of care
Inadequate mental health and substance abuse services and supports
Inadequate supportive housing that is affordable, accessible, and available to client
Inadequate resources to manage increasing number of highly complex cases
Inadequate adult day programs and family member respite services
Inadequate or lack of transportation, especially assisted transportation
Shortage of homecare agencies, home health aides, and a high quality, diverse workforce
Limited funding

Informal supports

The role of informal supports in providing care for individuals living in the community and vulnerable to potential relocation to a nursing home cannot be understated. However, because this report is intended to inform program and planning efforts for formal services, the informal care section is presented following the formal care section.

Formal supports

Challenges in accessing formal supports were discussed at length and in detail. Most pressing was the inadequate availability of home care personnel (especially home health aides) for nights or weekends, as well as for intermittent or quick care. Care managers also shared frustrations regarding the lack of home care staff who can provide a mixed, intermediate level of care. Participants also reported an insufficient supply of specific types of services, including mental health services, supportive housing, adult day programs, respite services, and transportation. Finally, in each group, care managers reported feeling at times overwhelmed trying to address the complexity of client needs with limited services and funding constraints.

A. Inadequate availability of home care personnel for shifts other than regular day hours, such as evening, overnight, weekends, or personnel available for short, intermittent care.

In describing their most difficult client cases, care managers unanimously agreed that a core challenge is to secure agency-based care in general, particularly for shifts outside of regular day

hours. They experienced difficulty finding evening, nighttime, and weekend care, and found no services available to provide short intermittent care.

> "When you work in a hospital [or] you work in a nursing home, the workers are mandated weekends and nights. There isn't that same mandate in the community. So there is a huge gap in trying to give someone evening hours and weekend hours – and that is something that people need. Care doesn't stop… the agencies draw their employees by how flexible they are – you tell us the hours you want to work, you tell us the hours when you are available. So everyone works 7 'til 3 or 9 to 4 – no weekends no nights. But, we're getting people who are having increasing needs, and we need people to work weekends, we need someone to go there and help them to get to bed, and then they would be fine. But, you know, families are not always available. That and the fact that there are such a limited number of people in the agencies."

B. Lack of more flexible, intermediate service provider to supply a mixed level of care.

The need for an additional level of provider to deliver a diverse array of hands on care also emerged as a recurrent issue. Care managers identified a need for a new caregiver category with pay and training at least commensurate with home health aides which would combine activities currently limited to different types of care providers. The exact care needed would differ throughout the day, and might include assistance such as personal care, assisted transportation, physical assistance, homemaker, companion, and money management.

For example, this type of provider could help the client get up, bathe, and dress; cook breakfast and clean up; physically assist the client into the car and provide transportation to the doctor's, errands, etc.; perform personal care even if not at home; and provide companionship and supervision. The care managers described this role as something offered through agencies, rather than self-managed Personal Care Assistant (PCA) services. However, PCA services might be another alternative solution for this issue.

> "I was just thinking of a case that I had last year, a very difficult one… She had severe COPD, continuous oxygen, could not manage her medications regime. Her son was retired and lived locally, but did not want his life to be focused on taking care of his mother. So we tried to provide her with a care plan, and she was just so afraid where she couldn't stay at night. She would call in the middle of the night. She would fall out of bed, sometimes intentionally. Back and forth to the ER, back and forth to facilities for short-term rehab – she just couldn't do it. That was with available help. And it just didn't work out. She was State also. Sometimes, you need more than that one thing. Home health aides are limited. She would need a PCA during the day. Two hours every other day, and mornings, usually can't come in the evening.
>
> *So if you had had a blank check for this person, what would you have tried to put in place to keep her home safely?*
>
> [She could] get 12 hours a day, with that blank check. Most of the money would be spent on a PCA where they could do the cooking, transferring, personal care. Let the family do the overnight, if her son was still willing to do the night care, checking in on her."

Care managers recounted having clients whose care needs fluctuate throughout the day, presenting a challenge to arrange for the most suitable caregiver to be able to meet the client's differing needs.

> "There are not a lot of full service agencies anymore and for people who have multi problems. They need a home health aide for hands on care, they need homemaking for cooking, cleaning, laundry, shopping, and they need companion for being there. And if somebody needs hands on care intermittently during the day, you need a full service agency. You can't split up and have one agency send in somebody for an hour an hour and a half to do a bath.
>
> Nor do you want three people running in.
>
> Exactly. For an Alzheimer's client it's very problematic."
>
> "I have a male in a nursing home right now who needs hands on. His family wants him home, but he will only get one to two hours of home health aide care, but he needs eight hours hands on. If can't get enough services, he cannot go home. And now under Medicare he will be getting less services. That is a problem. They need so much hands on, but nobody can do it. "

And this exchange reflects the frustration of care managers trying to piece together level-appropriate services within budget constraints and limited availability of providers:

> "I have a client right now with kind of the same issue that's in a nursing home right now for short term. The family wants to take him home, but they're saying, 'Well how much help can he get?' And he needs hands on, and I said, 'Well he's going to get an hour, maybe two a day.' And they're saying, 'Well what about the rest of the day?' And I said, 'I can do a companion. That's all I can do.' You know, we can't do eight hours of home health aide, and that's what he needs, is hands on.
>
> *So what will happen with that case do you think?*
>
> Well, he may end up staying, you know, if we can't get him home with enough services in place. And if he got on to Medicare, he'll probably get even less than what I was able to give him, so that's the problem. They need so much hands, on nobody can do it. What good is a companion sitting there if they can't help him? And we have a few agencies who will split services for us so they will put in one person who will be half home health aide, half companion, half homemaker, but those are very few."
>
> *Describe that. You mean they do an hour at a home health aide rate?*
>
> Well, say we put in a five hour block. Maybe two hours is a homemaker, and one hour, and so, you can save money that way. But the person is certified so they can do some personal care. But that's only a few agencies.
>
> *That varies by agency?*
>
> Yeah, because it wastes the home health aide's time really.
>
> But see, I think we should. I think it would us help if we had more personal care assistants, and I don't necessarily mean PCA as we use it now, but more people that can do hands on, and not hands on at $24 or $25 dollars an hour. That's very expensive for us you know."

> "It's always different according to where you live, too. I have a client who just recently within the last couple weeks has declined dramatically... I called [for] the home health aide and companion split, and they couldn't help me because they didn't have it available where he lived. And they don't want to take that home health aide that could go to multiple cases and leave them at somebody's home all day as a homemaker/companion [who] could provide that care all day. But that's definitely somebody you could probably keep home if he could have that, and then his son could come home later. But they end up being institutionalized because you can't get the fluctuation and availability of the home health aide to provide the care, and it's very limited agencies that will cover a split... we only have some that do."

Another expresses the need for an intermediate provider for safety reasons to prevent a fall for a client who is unsteady:

> "My client she can toilet independently, but needs someone to watch her as she walks. Needs some hands on to guide her to the bathroom. Some type of intermediate level of care... [who] could do some hands on care. With a private aide, they will do this. Because if this client falls, she will not recover. If she breaks one bone, that is it. It could be avoided by that."

One care manager described one of her client's need for supervision, which prompted an observation from another:

> "And if we had had kind of a service that was half way between a home health aide and a homemaker where – because she didn't always need the personal care, but she needed the supervision. She needed somebody to grab her elbow when she was getting out of the chair...
>
> *What do others think about this, intermediate provider?*
>
> They do it in other states and it works. It's kind of like our PCA program. It's a PCA service where it's done through a contract agency and it's that middle of the road kind of person. Even for someone like that gentleman. That would work."
>
> "We do have agencies that try to accommodate that, like having a home health aide and homemaker – like having the home health aide there all of the time. But they don't have a lot of motivation, because the people who are providing the services would want a higher rate for more period of time and than a lesser rate. And we are limited to the number of homemaker hours that we can put in, and some agencies don't do companion hours, which would also allow us to extend it. So a lot of times, what you are trying to do is to provide enough care so that families can work, daughters and sons can work during the day. And they maybe only need some supervision, and intimate and personal care, like to help transfer – because you're tied with the fact that the homemaker is not supposed to touch them at all – you need to be able to provide that home health aide in there for the toileting during the 8 hour day."

C. Inadequate mental health and substance abuse services and supports

There were intense discussions regarding increasing mental health needs among clients of all ages. Agencies do not have staff trained to work with clients with mental health needs, and in certain instances, agencies or individual providers refuse to go into a client's home due to fears

for their safety. Unmet mental health needs mentioned included a lack or inadequate supply of community-based detox and short-term treatment facilities, structured day programs for older adults with mental illness, and age-appropriate support programs, such as support groups for older adult addicts.

> "... we have had a huge increase in mental illness clients and [elderly] clients with... psychiatric issues."

> "It's really [a] problem, and if you have somebody who has like a mental illness or if they [have] Alzheimer's dementia, or if they have the behavioral aggressive or confused, then certain aides get very – they don't want to go to those homes, and then [the clients] get stuck without anybody. It's difficult to try to find a consistency."

> "With mental health issues – we can identify the mental health problem but it is often masked with substance abuse. Elderly clients drinking and doing drugs. We can't change that behavior. We can get providers, services. Then when the home health aide got there, he was intoxicated and exposed. The home health aide would not stay, so then he goes without care. The agencies will stop their care because he is noncompliant [still drinking]…. A big behavior piece is missing – substance abuse and psychiatric issues. One man almost assaulted a pregnant nurse.... There are not enough mental health counselors who will contract with us because our reimbursement is too low. Big issue right now..."

> "Mental health has always been difficult to find.... They have to be very careful about offering it – is this, would they benefit from it? One person, we offered it, but then we did not hear from him.... I've heard of other care managers running into the same issue. "

> "There are not therapeutic programs for elderly people with substance abuse. There are also a couple of groups – there's one in Bridgeport, there's one in Stamford – that they can go to, but if you have somebody who is a frequent flier, you know, they can't. They go to the hospital and they get detoxed, and they get sent back home. And then they go to the hospital and then they get detoxed, and then they get sent back home. And this keeps happening until, like, with one of my clients that is currently in the nursing home, she fell and that was the end of it. But there's no thirty-day program or anything…."

D. Inadequate supportive housing that is affordable, accessible, and available for clients with more complex situations

Participants noted a range of challenges related to housing needs and availability for their clients. They observed a lack of available and appropriate housing, including limited low-income assisted living or residential care homes with supervision which can provide medication management, including giving injections; personnel trained in mental health, cognitive, and behavioral issues; and the 24/7 availability of staff. Settings such as these also can provide the structure needed by clients with substance abuse or mental health issues. They also described problems in getting their clients accepted into housing settings, due to poor credit, legal problems, or safety concerns.

> "I had one case that came to mind. It was – he was a young, 67 or 68-year old man with mental illness, schizophrenia, and he was living in an independent apartment and had to [be] placed because of lack of structure, the lack of the homemaker being knowledgeable about the disease, and him refusing when he really needed the service.

He had the locked med box to allow him to take his meds; the nurse would help with that. He did accept a health aide a couple of times, but he would just wander – and we would pick him up. He would see his therapist, but there was no other structured groups. He didn't like adult day care because he was high functioning, cognitively intact. But then he had to be placed – and he was placed for over six months. [Now I'm] trying to bring him back home again. And once again, the lack of structure there, so again he's back in a nursing home. So he gets better, and now he's back out in the community in a structured environment and getting total case management. There was actually a mental health agency in the area."

"... the housing issue is also big....I have people that I have kept out of nursing homes because they're in a residential facility where they get their meds dispensed. And if it's insulin, it's a lifesaver; and if it's a mental health, you know a psychotropic drug, it's also a lifesaver. It's just because of that."

"In our area, we are lacking rest home supervision - or living type homes, where there is more staff involved. We have a meals on wheels, but if we had the meal site, you could free up that money to do other things."

"About half of the referrals are on hold...because of lack of housing. They don't have any housing available. Because they have been in a nursing home for five years or so, they don't have a home to go home to.... I know one example of a client who has been in a nursing home for six months, but she is a felon and she didn't pay all of her utility bills for years. So for anybody to accept her, give her a lease – it's a long shot. And she's addicted to prescription drugs."

"But there's also a lot of waiting lists at the good places. You know some towns two years; or some aren't even taking applications. So even if you have a client that's willing to make the move, the places, some of the places that are available, you wouldn't want to put them, you know, they're just horrible places"

"This gentleman who has been in a nursing home is a registered sex offender. They can't find any place for him to live because nobody will take him. So it's all those kinds of things where they get evicted and then nobody wants them you know what I mean?"

"There is also senior housing. One of my clients had a fire. He was in a high rise. He was drinking and smoking... He's been paying privately for the Red Roof Inn which is like $376 per week. He had $5000 and now he's down to $1000. He was hospitalized for suicidal ideation – they had a mental health nurse up there, meals on wheels, homemaking, counseling – also filled out numerous applications for assisted living, thinking that that would be better. We filled out all of these applications, and nobody wants him. Nobody wants to take that risk, for that to happen in another building... So I am now looking for shelters. And that too becomes an issue, because there aren't that many shelters in my area, and they're only open at night, which gives him no place to go during the day. So I haven't even got that far."

"The client I mentioned who is now in a nursing home for short term rehab, she's living in senior housing. She is a fall risk. She really is not appropriate for the residential care facility I was talking about because she's not chronically mentally ill, even though she is chronically depressed. She's dynamic, she's creative, she's alert, and she would not fit in, so that's not appropriate... [She needs] assisted living component where they can

send people in several times during the day and have that, you know, ability to provide intermittent support. Because she doesn't need 24 hour support, she needs intermittent, and she needs a lifeline that will call somebody from right in the building not get the fire department there."

E. Inadequate resources to manage increasing number of complex and highly challenging cases

Participants also described feeling overwhelmed by the scope and amount of work associated with providing care management for specific clients. Increasingly, they are seeing older, frailer clients with more intensive medical needs. They also described having greater numbers of clients with a combination of mental health, substance abuse, serious physical health, and/or cognitive or behavioral issues. They talked about the difficulty finding community-based services for these clients, and the time intensive care coordination associated with them.

"I think we would all say that the cases are much more difficult…. I have been doing this 13 years and the difference in the client you got when I started and the difference in the client you have now is they're older, they have more health issues, they're ten times more complicated, [the] family dynamics are incredible. I just came from a case conference on a client that has serious, serious wounds, and the family was supposed to be providing a whole bunch of care and they're not. They're... not turning him, and now the wounds are infected. They sent him to the hospital. The hospital sent him back. The family is saying we're not going to do it. You don't even know where to go from there, so he's probably going to end up in a nursing home but there's no way we can put a home health aide in the number of hours he needs."

"[One client] went in...for surgery [for a broken leg], and not even two days later she discharged herself against medical advice from the hospital. She wanted to go home. She had been noncompliant with medications before her hospitalization, and we had a nurse that was in there daily to give her her medication because she had overdosed at one point in time on sleeping pills... The agency wouldn't take her back because she had left the hospital AMA, so they couldn't get medical clearance... So we now have a schizophrenic client who doesn't want us, who is not compliant with medications, and [is drinking] alcohol... Her daughter told us she was going to provide care. And the day after they went [home], the daughter took off. So she's home with a broken leg and nobody to help her."

F. Inadequate adult day programs and family member respite services

Care managers described adult day programs as filling an important need for particular clients. They spoke with disappointment and frustration about the recent closings of multiple programs and the implications of such closings for their clients.

"We've also had a lot of day care centers that have closed. Even if we could do something to expand – to get that back to where it used to be – where you had a pretty good group of day care centers in any area. We had three that closed in the Northwest corner. That was a huge gap in service. And a lot of this all goes back to reimbursement, unfortunately. So if the day care can't afford to stay open, then it's a big, big break in service."

> "[One client] had informal support, that was family, that would provide evening care. And she was not incontinent – so she needed no hands-on care, so you could have used a homemaker. [She] couldn't get on the PCA program because there was a waiting list. They could not send her to adult day care because there wasn't an adult day care facility in that area. So there was nothing to do for the day – so they had to place her."

One care manager also noted the challenges of transportation rules that prevented one client from attending adult day care:

> "Now there is only a 12 mile radius for transport. We have one [adult day program] in Canaan and one in Torrington, so if you live in the outer part of Barkhamsted, then you can't get to any of them. McLean in Simsbury is outside the limit. So we don't have a day care facility. "

The limited hours of adult day programs also limits their effectiveness:

> "The family could bring their family member to the day care. But the day care doesn't start until 9 and that person has to be at work at 7 AM. [There's] no way of coordinating that. And then you can't depend on a homemaker because she needed the hands-on help to get out of a car."

The importance of family and informal caregivers was stressed in each group discussion. Care managers also perceive that there is inadequate respite for families and informal caregivers. They note the strong potential for family 'burnout' and note the consequences often include transition to a nursing home.

> "If you can let your family work and then [you can] have them available in the evening when it is incredibly hard to get any kind of service – evenings and weekends – which is a huge factor in trying to keep someone at home. Then you have a better a chance for maintaining somebody in the community for an extended period of time. Because you're giving the family member the opportunity to do things with their kids. Because it's that sandwich generation, where they've got the parents and the growing kids. So it gives them the ability to go out and work and do things with their kids in the evening and still provide the supervision, the follow up with doctors, and doing the doctor thing. That would be such a huge benefit to be able to have that for everybody, not just a PCA program."

> "My lady I guess she was diagnosed with dementia, and it kind of progressed... she has no children, and it was her niece taking care of her and pretty much...it would be at night that she'd need the most. And she would call the niece all the time because she was afraid to be alone. The niece had to take care of her mother as well as her aunt, and she couldn't do both, so she had to place her".

The need for additional family caregiver support services and how to connect the family with these resources was also discussed. Others talked of a need to educate family about the limits of public programs and care managers:

> "I mean if we could just offer something for the family. I don't know what, but something, out there to let them know what is expected, what they can do... I know I am just pulling straws, but they want the impossible."

> "[Families need] some type of you know support and resources out there other than ourselves. As a care manager, sometimes I feel that the expectation from family and clients are so high... it gets sometimes very, very difficult, and I wish that would be something, you could say... there is this program... that will talk about [resources], a one night seminar... something that will give you some teaching about... what the programs are out there so that we don't have be the only bridge.
>
> Right, we're counselors.
>
> Well, we are to the families as well.
>
> We do, we have two clients... when I have a client with family involved, that's how it is... I have two clients: the family and the client."

G. Inadequate or lack of transportation, especially assisted transportation

Care managers described the lack of transportation, for both medical and non-medical needs, as problematic for clients and their family members. There is potential for the lack of transportation to precipitate admission to a nursing home, if the client ultimately goes to a hospital emergency room for care and is subsequently referred to a nursing home. In particular, participants emphasized the need for *assisted* transportation.

> "[Transportation] may not preclude a transition to nursing home, but certainly it would keep people healthier at home. There is just no transportation for people who don't have Title 19 transport. Or rural areas that have primary care physicians outside of the radius that Title 19 will provide for. There is just no way to get them to their regular scheduled appointments."
>
> "Well, I think [transportation is] a huge a problem. A lot of these care agencies' homemakers or companions they are not allowing the companion or homemaker to transport these[clients] to their medical appointments because, I guess, they feel it's a big liability or something, and then you have to rely on Title 19 or LogistiCare and sometimes they're not reliable at all... There's a few programs like down in Stamford, but then you still have to pay for a taxi and most of them can't afford, you know, even if it's at a discount."
>
> "These people need transportation. They have only medical transportation, and it takes five to six hours for them to come back to get him after an appointment. There are many problems with that. The clients hate the wait. Sometimes the family member or companion going with them cannot wait. One of my clients had an accident [incontinence] waiting for transportation at the doctor's, and the companion could not help her."

Limitations in scope of transportation services were also discussed, such as companies not crossing town lines, or the need for services which provide assistance along with the transportation. The variation among agency provider rules regarding geography and assistance also presents a challenge for coordination and access to transportation.

> "Only a companion can accompany a client out of the house. The home health aides are not allowed to do that. But companions can't do any hands on. They can't help to get

them in and out of the van. The drivers also not supposed to help. The companion is not supposed to help the person – so they do not."

"I have two agencies that don't allow their homemakers to transport. Some agencies allow their homemakers to transport within a radius. Some agencies will allow their homemakers or companions to go and some have a ten mile radius, some have a five mile radius. It is ultimately at the discretion of the homemaker."

H. Shortage of homecare agencies, home health aides, and a high quality, diverse workforce

Participants described other considerations that pose challenges in providing adequate, high quality care in the community, including a shortage of agencies and skilled, diverse workers. Compounding this is the tendency of agencies to not take on or discontinue clients they consider unsafe – clients are often the ones with the most needs.

"There was a gentleman who had COPD and he had serious wound issues on his legs. He did have a son that was living next to him in a duplex, who was working. But [we] couldn't provide enough nursing services – his COPD got worse. So he ended up going into the nursing home and stabilizing – and then there were not enough services in the area to bring him back home."

"... it's getting better now, but there was definitely a shortage of agencies that had a contract to administer services through CHCPE. Down in Greenwich we had a very hard time finding non-skilled agencies and even skilled agencies in Greenwich. The past year we have gotten a few more contracts but it's been very difficult."

"Where my clients are is a pretty rural area. We have limited agencies and those agencies have limited time slots..."

Participants also expressed concerns with the quality of the provider workforce, referring to instances of theft from clients or inappropriate behaviors. Some attributed it to the low wage and benefit structures for home care professionals. Others found that experienced caregivers with great skills move on to more professional careers.

"But finding people who are really, really good, and get the kinds of training they need, and that last, and that have the kind of experience that you need for coping – I mean that's front line work. It's extremely difficult work and for very low pay, so people who have any kind of ambition tend then to move on... not too many will stay. I have found a lot of home health aides that... started going to nursing school or whatever. They don't stay in those front line positions."

The increasing diversity of clients receiving care in the community requires caregivers with a range of language skills. The lack of providers with these unique skills presents challenges to communication and caregiving in a variety of service areas.

"Some people who speak Turkish [and we] can't find help. Language can be a constraint. And they want nurses and any other caregivers to be able to speak their language. I have Italians that want Italians, and I can't even find Italian caregivers."

"Mental health counseling is an issue in English. Try to find a Spanish speaking, that's huge."

I. Funding limitations

Limitations in funding and, therefore, program services were also identified as contributing to unmet needs. Specific types of funding and services included: inadequate reimbursement for mental health services, lack of coverage for 24-hour live-in care, availability of comprehensive care restricted to Medicaid, and implications of monetary or hourly caps, e.g., causing a shortage of paid caregiver hours.

> "If there was a service that was allowed to do minimal care assist for that four-hour block, then she could have stayed at home because the rate would have been lower than the three hours for the home health aide – and you could have provided more time for that service, and she would have had that minimal personal care that she needed. So were it not for the cost caps of the program and her not having the more comprehensive care plan of Title 19, she could have stayed at home."

> "What would be helpful? Usually it ends up being a funding issue. It's a funding issue to get people into a short term treatment facility for substance abuse. [It's] not covered through Medicaid funding – and with the co-morbidity it's harder."

> "We get a lot of referrals from DSS [for] people that are 65 that just, you know, had been with them, and then they come to us for the home care program..." . A lot of those clients have a lot of behavioral health issues with substance abuse. We get them and we have to take them.
>
> And they get a lot of services.
>
> And they get mad when you don't get them as much.
>
> Well, they've had a lot of services, and then they come to us. I had one [say], 'I don't know why I have to call you all the time.' She didn't want a case manager. She didn't want to have to call me to get permission for her services. Her expectations were very unrealistic, but she was like, 'I was on this program for 10 years before. I don't know why I have to go and put up with this now.'"

> "An issue for me is, my client recently passed away that's on the PCA [CHCPE pilot program], but for her she had her each worker can only work a max of 25 ¾ hours so if somebody who has total care..., they are going to have to have multiple workers... I mean the budget's not a problem, but... if you have somebody that needs a lot of care, you are automatically going to get probably at least three workers, and there's not back up workers or anything."

Some care coordinators expressed frustration at not being able to provide all the services needed by the client to stay in the community.

> "It's like you said before, you end up being the bad guy because you only have a certain amount of resources, and...you end up banging your head against the wall. You can't do anything."

Informal supports

Participants also described a lack of informal supports, primarily in the form of families, but also neighbors and others. They noted multiple reasons for insufficiency of informal support for some clients. Families may not be able to devote the necessary time due to competing demands such as work and children. A second major issue is that some family members may be available but are unable or unwilling to provide the type or amount of care needed. Other clients simply have no family or do not have family living nearby. Finally, families may prefer that their family member live in a nursing home.

A. Family not available enough hours due to competing demands

Participants were very sensitive when talking about the role of family in providing care and supports essential to keeping the client living safely in the community. Competing demands are a major impediment for some families, who, despite sincere intentions, are unable to devote the necessary time to their family member. There are family members who would prefer to stay at home and provide care, yet must work due to the need for income.

> "I was thinking of a case that I have, and she's not in a nursing home, but... that is where she is unfortunately going to at some point in her life. She is a very young female client...early 70's, but she suffers from rheumatoid arthritis. So... all her joints are basically contracted, so she is bedridden. And she lives with a family who... has to work. So we are trying... to do our best to cover for these periods of times when they are at work. But it's very challenging, because home health aides can only be there, you know, for this long, and then... you try to have a companion... supervising, because she is really bedridden. If there was an emergency in the home... yeah, she has a lifeline that she could press, but... it's not safe to have somebody that is not able to really pick up the phone or do anything else. So I worry a lot about her, because I feel that home health aides are so limited and the time that they have is limited... It took us months to talk to the agency so that she could have somebody twice a day because she needs that. She's in bed all day, and the family doesn't... come in until the afternoon.... And she is cognitively intact, and ... [when I say] have you ever thought about a facility, and she will tell you, 'No way, Jose' is what she says every year when I go ask the same question. She does not want it. She wants to remain at home and... to me it's really hard, because I don't know how to... maintain her. And... it is big burden to... the family, and so I always wonder if the family one day [will say], 'This is it.'"

> "I think that there are families who would like to stay home and take care of their aging parents, but financially they have to go to work. One case I know of, the family is just exhausted – his wife, his daughter, son-in-law is very nice and caring. Absolutely caring family. And the wife, now that he is in a nursing home, she visits him every day. But she's 87 years old, and she has a lot of physical problems."

B. Families available but unable or unwilling to provide care

Even in cases where the family is available, members may be either unable or unwilling to provide sufficient care to keep the client in the community. A circumstance that arises frequently is when a spouse caregiver becomes sick or too frail to continue to provide the care. In other cases, the gender of the caregiver makes certain tasks awkward, such as a male child providing personal care for his mother.

> "The spouse who is the caregiver gets sick in the process. The client was… totally dependent on her husband for everything. They did accept home health aide for a couple hours every day. And she had life line… He drove her to all appointments. The daughter actually lived on the same property, lived next door, but worked full time. But actually I never spoke to the daughter that much. Mostly talked to the husband who did everything. The husband kept refusing to get some kind of heart surgery and that eventually made his heart condition get worse. He could not care for her physically, he could give her transport during the night, he got her breakfast, did her meds, did everything – so when his health status started to decline, the client pretty much could not remain there."

C. Client has no family available

One care manager cautioned that some clients simply do not have family or other informal supports available.

> "There are a lot of elderly people out there with absolutely no one to take care of them. That just reinforces the need for all of this. I think we all think that everybody has somebody who cares. And that is not the case."

> "The services are there, he's managing fine. He's safe. But it's getting everything done. Like cataract surgery, getting him prepared for that. Making the arrangements, the transportation, making sure that we know when he's going into the hospital. It's just a lot for the nurse and myself to coordinate all of that – and that will be on-going as long as he is at home. So it's not really a service problem. It's more the lack of supporter – a backup support, like a daughter, who could take charge and talk to the doctors. We had to make the schedule for cataract surgery, and something happened and the Dr. said he would cancel it, and we had him all ready for the surgery – and the Dr. cancelled on us. And so we started the process again. We really have to monitor him very closely and that's difficult to do sometimes."

D. Family requests nursing home placement

In some instances, the family may request the client be transferred to a nursing home. Participants offered several reasons for this, including feeling the client is safer in an environment with close supervision and care. In some instances, this arrangement is considered optimal for both the client and the family.

> "I offered them many services because she was also a waiver client but was not using many services and didn't want to use many services because the husband would do everything. So she went into respite at Countryside and then she actually stayed there. The client had come from there. Now her social life was better, the husband could visit her there, and she actually liked Countryside and wanted to stay there because she understood that the husband could not longer help, and the two of them did not want more services from CCCI and so she was placed back in nursing home. It was good for her."

<u>Innovative programs</u>

Participants were asked if they knew of any innovative programs in the State which address these gaps in services in a new or creative way. A few initiatives were cited which focus on evening and overnight adult programs, assisted and cross-town transportation, substance

abuse counseling, money management, and a full services ethnically-specific agency (see Appendix 3).

Conclusions

This study is intended to provide insights into gaps in services for participants in the Connecticut Home Care Program for Elders (CHCPE) who are vulnerable for transition from community to nursing home. This report summarizes findings from a review of CHCPE client administrative data and case notes in addition to a series of focus groups with care managers in each of the state's access agencies.

Examination of administrative data provided by the three access agencies provides an overview of client demographic, programmatic, health and health services. A random sample of case notes covering the period up to and including program discontinuance were coded to identify contributing factors for client moves from community to nursing home residence. In the focus groups, care managers shared their views and described experiences regarding the care and supports they arrange for clients in the community through the CHCPE.

Administrative data were provided for the entire group of CHCPE clients discontinued in calendar year 2008 due to entering LTC. Due to the random sampling procedure, findings from the case note review represents this entire population. Focus group participants were drawn from each access agency and provide a reasonable representation of experiences for the entire state of Connecticut. Although the focus group data cannot be generalized statistically, the findings are based on high quality conversation among expert care managers. The clear and recurrent themes that emerged independently in each group discussion parallel many of the findings from the case note review, which strengthens the reliability and importance of these findings.

The administrative data demonstrate that the majority of these clients were white, female, and over 80 years old. About two-thirds received services through the Medicaid waiver portion of CHCPE. On average, they had spent about three years in the program before leaving, but the length of stay varied widely between 1 month and almost 20 years. Participants' most common medical diagnoses were hypertension, rheumatoid or osteoarthritis, visual impairment, dementia and diabetes. Sixteen percent had a diagnoses mental illness. Three-fourths of the group had visited the emergency room and three-fourths had been hospitalized in the year preceding program discontinuance.

The case note review identified a wide range of factors that contributed to a move to a long term care facility and subsequent discontinuance from the home care program. While these factors include changes in health status, as might be expected, other influential conditions include family availability and attitudes as well as CHCPE program limitations. Focus group participants further provided rich and detailed descriptions of cases for clients who ultimately transitioned off of the CHCPE and into a nursing home. They reported a diverse range of challenges in both formal and informal care supports and types of care. Certain issues, such as the lack of home care providers available on nights and weekends and limits of covered services, have been identified as persistent and pressing issues for some time. Several additional concerns emerged that were unanticipated, including the need for an intermediate type of homecare worker who could provide a wide range of care, from hands-on to homemaker; increasing presence of substance abuse and mental health needs; and the lack of appropriate housing available for these clients, whom we may assume to have a range of residence options since they are living in the community. Importantly, the lack of housing and limited covered services were also

described as a barrier to community-living in a focus group conducted in August, 2009, at AASCC regarding obstacles encountered in the Money Follows the Person program.

These findings can be used to inform current efforts to redesign the CHCPE in several ways.

1. **PCA Services -** Program administrators should consider the potential role of a personal care assistant benefit in addressing this recurrent and major impediment to keeping clients in the community. Making PCA services available not only would address one of the most severe unmet needs (lack of evening/weekend care), it would also respond to the preferences of family members to remain at home as caregivers. In 2009, the addition of PCA services to the CHCPE has been approved by the CT Legislature and will be added under the next renewal of the HCBS waiver.

2. **Expanded adult day programs & Foster care -** There are other potential models to consider that could help with the need for overnight supervision and lack of a sufficient nighttime workforce, such as evening or overnight programs parallel to adult day programs and foster care.

3. **Flexible home care provider -** Care managers described the potential value of developing a new level of agency-based home care provider, similar to a personal care assistant, who would be able to provide a mixed level of care, including intermittent hands-on care. This level of provider would be paid at a wage between a homemaker and home health aide, allowing for more precise alignment of care needs and providers.

4. **Mental health and substance abuse services and training -** The availability of mental health and substance abuse services targeted for older adults should be examined and strengthened. One possible avenue could focus on specific mental health and substance abuse training for care managers and other providers as well as for families.

5. **Transportation -** The need for transportation, in particular assisted transportation, is also significant and should be considered in the program redesign. An immediate potential transportation solution for residents in 20 Connecticut towns and cities in the central part of the state are two affiliates of the national, non-profit organization Independent Transportation Network (ITN*America*™). In Connecticut, the affiliates are called ITN*NorthCentral Connecticut*™, based in East Windsor, and ITN*CentralCT*™, based in Middletown. These affiliates provide door-through-door, automobile-based transportation by appointment for older adults, including those with assistive devices. There is a fee, but discounts are available. Funding to help start this transportation program has been provided by the State of Connecticut Department of Social Services Aging Services Division, and by the Hartford Foundation for Public Giving. More information about this new transportation alternative, including the two current Connecticut-based affiliates, can be found at the website: http://www.itnamerica.org. Plans are underway to establish ITN*America*™ affiliates in other regions of Connecticut.

6. **Care manager training –** Care managers could benefit from increased training in a number of areas such as use of evidence-based protocols for managing specific health conditions (e.g., dementia or osteoarthritis), the availability of assistive technology, and fall prevention. It is conceivable that additional training could help care managers be even more proactive in problem-solving and working with families to increase community supports after such triggers as a hospitalization or short term nursing home stay.

7. **Coordination with hospital and nursing home discharge planning –** Based on the very high incidence of hospital and nursing home stays in this group of discontinued CHCPE clients, clearly more structured coordination with hospital and nursing home discharge planners marks a key intervention point to maintaining people on the CHCPE.

Future research on this topic should take a broader approach and compare the incidences of the factors identified here across CHCPE clients who remain in the program as well as those who discontinue for reasons other than entering LTC.

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Appendix 1. Contributing factors for CHCPE discontinuances due to entering LTC, by region and overall

Code	Description	Bridgeport		Hartford		Norwich		Waterbury		New Haven		Total	
1	Needs more services than can be provided (e.g., 24 hour supervision)	18	67%	46	69%	10	36%	35	65%	30	63%	**139**	**62%**
2	Fall	9	33%	23	34%	9	32%	17	31%	20	42%	**78**	**35%**
3	Acute illness onset leading to need for more assistance	5	19%	31	46%	3	11%	25	46%	4	8%	**68**	**30%**
3a	Hospitalization (includes ER visit)	19	70%	57	85%	26	93%	44	81%	34	71%	**180**	**80%**
4	Chronic illness worsening leading to need for more assistance	17	63%	26	39%	15	54%	32	59%	28	58%	**118**	**53%**
5	Lack of family/informal supports	2	7%	10	15%	5	18%	13	24%	11	23%	**41**	**18%**
6	Family requests initial or continued placement	18	67%	38	57%	5	18%	35	65%	24	50%	**120**	**54%**
7	Family fear of client being alone	4	15%	8	12%	1	4%	15	28%	3	6%	**31**	**14%**
8	Family cannot continue to provide care (burned out)	5	19%	8	12%	3	11%	13	24%	11	23%	**40**	**18%**
9	Family cannot provide additional care needed (after a health status change)	0	0%	19	28%	5	18%	14	26%	1	2%	**39**	**17%**
9a	Client's health status change	9	33%	19	28%	5	18%	30	56%	7	15%	**70**	**31%**
9b	Family member's health status change	8	30%	7	10%	3	11%	6	11%	4	8%	**28**	**13%**
10	Family refuses services – doesn't want staff in home (specify)	1	4%	0	0%	0	0%	2	4%	2	4%	**5**	**2%**
11	Client requests placement	4	15%	9	13%	3	11%	10	19%	5	10%	**31**	**14%**

12	Client refuses existing services	0	0%	4	6%	0	0%	4	7%	3	6%	**11**	**5%**
13	Client refuses new services	0	0%	4	6%	0	0%	1	2%	3	6%	**8**	**4%**
14	Client isolation/loneliness	0	0%	2	3%	4	14%	6	11%	3	6%	**15**	**7%**
15	Paid help unreliable	2	7%	1	1%	0	0%	2	4%	2	4%	**7**	**3%**
16	dissatisfaction with services	3	11%	2	3%	3	11%	1	2%	0	0%	**9**	**4%**
17	Need for AT/medical equip	0	0%	0	0%	1	4%	1	2%	2	4%	**4**	**2%**
18	Need for PCA	0	0%	1	1%	1	4%	2	4%	3	6%	**7**	**3%**
19	Need for other services not available in CHCPE	4	15%	2	3%	1	4%	1	2%	0	0%	**8**	**4%**
20	Client goes to NH for rehab	22	81%	48	72%	16	57%	37	69%	15	31%	**138**	**62%**
21	At time of d/c from CHCPE, no discussion of additional CHCPE services noted	16	59%	31	46%	10	36%	21	39%	27	56%	**105**	**47%**
22	Care manager recommends NH placement	5	19%	8	12%	1	4%	8	15%	3	6%	**25**	**11%**
23	Mental health/SA issues	2	7%	15	22%	5	18%	17	31%	5	10%	**44**	**20%**
24	Client not compliant with meds	0	0%	6	9%	4	14%	4	7%	4	8%	**18**	**8%**
25	Legal issues	1	4%	3	4%	6	21%	3	6%	2	4%	**15**	**7%**

Appendix 2

CHCPE Gaps
Discussion guide

Thank you for joining us today. We appreciate you taking the time to talk with us. This project is being done as part of the evaluation of the Money Follows the Person program. We are interested in understanding the unmet needs and service gaps in the current Connecticut Home Care Program for the Elderly (CHCPE). We want to learn about the experiences of individuals who discontinue participation in CHCPE and enter a nursing home. As you know, a large number of CHCPE participants who discontinue the program enter a nursing home at the time they leave the CHCPE.

We understand that it is sometimes difficult to disentangle increased needs from insufficient home and community-based services to meet those increasing needs. So the more detail you can give us on a given case, the better. These complexities are exactly what we are trying to understand. As we are talking today, please think about the full range of transition trajectories, including clients who are admitted to hospitals and/or visit emergency departments for an acute exacerbation of chronic health conditions and subsequently move to a nursing home for either a short or long term stay.

1. Let's start with having you introduce yourself and tell us your background, your current role and how long you have been in this role.

2. Now we are going to ask you to think about the clients you have helped over the past year, and recall two of your most challenging cases: the first, where the individual was cognitively intact and the second where the client had cognitive impairment. Let's start with the cognitively intact person. Focus on a client who you felt might have been able to remain in the program but ultimately had to move into a nursing home. What kinds of support did that client need, and what happened when you tried to arrange those supports? (repeat for client with cognitive impairment).

Moderator: Elicit multiple cases, and only use these probes if not addressed initially by the group

- change in functional or health status,
- inability for available formal and/or informal supports to meet the care needs of the individual in the community (e.g., money management, transportation availability and/or cost and/or requirements for mobility),
- challenges in securing and retaining reliable formal home health care,
- housing instability,
- unmet need for additional services and supports such as personal care assistants.

3. Based on your experience, what do you consider are the biggest obstacles to keeping clients in the community?

- Lack of supports (defined above)
- Language barriers

4. Also based on your experience, what kinds of program supports would be most useful in being able to support clients in the community?

5. We are very interested in cataloguing innovative programs, even small ones, that may be in place around the state. What kinds of creative programs can you describe for us (e.g. transportation, workforce recruitment and retention)?

6. We have been talking about the unmet needs and associated service gaps for individuals on the CHCPE who transition to nursing homes. Is there anything else you think we need to know in order to understand this issue?

Appendix 3

Innovative programs described by Care Managers during the focus groups

Evening adult care programs

- Evening adult day programs, 6-10 pm, which would allow family caregiver to work full day, and have after work activities or go out to dinner and movie. None currently in state, but being discussed at one assisted living facility.
- Overnight 12 hour adult day programs – 7pm-7 am; to let family get rest. Especially helpful for "sun downing" and nighttime pacing. Currently a program in NYC.

Transportation

- Regional level transportation, across town lines. The Veteran's Administration (VA) in one area providing this for VA patients.
- Some towns offer transportation which can fill in gaps of other transportation systems, such as for other than medical appointments.
- One area Cancer Treatment Center has own transportation system – provides free assisted transportation for patients receiving treatments.
- Cancer Society uses volunteers to provide this type of service.
- One area adult day program provides assisted transportation across town and regional lines.

Substance abuse

- Liberation House grant to send substance abuse counselors into homes of elderly to do substance abuse counseling.

Other programs

- Some churches or synagogues provide voluntary assistance with bill paying or money management. Currently no formal support is allowed to assist with money management.
- CT's own CHCPE PCA pilot program. PCA can provide intermittent, mixed level of care; wait list is an issue.
- Culturally and ethnically specific home care agency and adult day services. For example, in one area, a home care agency provides Russian home care workers, Russian Meals on Wheels, and has an adult day center open to all, but specializing in Russian older adults – all staff are Russian speaking.