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**Current Living Situation and
Service Needs of Former
Nursing Home Residents:
An Evaluation of New Jersey's Nursing
Home Transition Program**

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Current Living Situation and Service Needs of Former Nursing Home Residents: An Evaluation of New Jersey's Nursing Home Transition Program

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EXECUTIVE SUMMARY

Introduction

As part of its evaluation of the New Jersey Senior Initiatives Community Choice Counseling Program, the Center for State Health Policy at Rutgers conducted an evaluation of former nursing home residents who were discharged through the Community Choice Counseling Program. This report addresses clients' current living situation, use of informal and formal assistance, service deficiencies, satisfaction, and quality of life.

Methods

All 1,750 clients discharged from January 1, 2000 through December 31, 2000 were asked to participate in the survey approximately six to eight weeks after discharge. In total 859 former nursing home residents or their proxies were interviewed. Excluding the deceased and those who were unable to participate due to physical or mental impairment, our response rate was 56.6 percent (859/1,519).

Results

Current Living Situation

The majority of clients (77%) are now living in a home-based setting¹, with more than half living in their own home or apartment. One-third are living alone, while almost two-thirds are living with a relative (spouse, child, or other relative). Almost one-fourth of clients are in a community-based facility setting,² with most in an assisted living setting (11.6% of the total). Only a few clients (3.7%) are living in nursing homes again.³ Eighty-

six percent reported being satisfied with their current living situation and an additional seven percent were somewhat satisfied.

Demographics and Physical Health Characteristics

Clients include more females, and almost all are English speaking. About half were widowed and about one in five are married. One-third of the clients had completed high school, with about one-fifth having either some high school or some college. About ninety percent are over 65 years of age, with a third between 75 and 84; a quarter are over the age of 85. Most of the respondents reported no difficulty with having their speech understood (83.3%), hearing normal conversation (70.9%), and seeing normal print (55.7%). The majority reported difficulty with lifting up to ten pounds (61.6%), walking three city blocks (71.7%), and climbing a flight of stairs (61.3%).

Ability or Inability to Perform I/ADLs

On average, the home-based respondents are able to do 3.8 (s.d.=1.7) of the five ADLs and 4.3 (s.d.=2.7) of the 9 IADLs. Facility-based clients could perform significantly more ADLs (ave.=4.3, s.d.=1.3) and IADLs (ave.=4.2, s.d.=2.3). They had significantly less difficulty with bathing (30.4%), dressing (16.1%), shopping (64.3%), and getting in and out of bed (8.9%), but significantly more difficulty with managing finances (57.1%), managing medications (62.5%), and preparing meals (64.9%) than their home-based counterparts.

Informal vs. Formal Care for I/ADLs for Home-Based Clients

On average, home-based clients reported receiving informal assistance with 1.32 (s.d.=1.8) ADLs and 4.9 (s.d.=3.1) IADLs. Home-based respondents reported formal or paid assistance with an average of about 1 ADL ($t=-.98$, s.d.=1.61) and 1.5 IADLs (s.d.=2.3). Most home-based clients received informal care from a relative (53.3%) usually a child (29.3%) or spouse (13.9%). About one quarter said they cared for themselves, some (16.1%) indicating solely and others (7.4%) in combination with family, friends, or paid caregivers.

Unmet Needs and Potential Impact of Living Situation

Four out of five (79.4%) of the home-based seniors did not need any (additional) help, while approximately one in ten (9.8%) reported needing assistance with all five ADLs. Few facility-based clients (or their proxies) reported needing help (or more help). Additionally, most clients or their proxies (85.2%) said that they have the help and

services they need to stay where they are. Approximately ninety percent (n=749/827) responded that they had the help and services needed to avoid injury.

Quality of Life

Significantly more facility-based clients (81.5%) said they enjoyed life more than their home-based counterparts (68%). Those in a facility setting were significantly more likely to visit with family than those living in a home-based setting (74% vs. 66%). Facility-based clients were also significantly more likely to visit with friends than were home-based clients (68.3% vs. 59.5%). Regarding activities that they could now do, home-based clients mentioned caring for one's self, cooking and eating better (preferred) foods, watching TV, driving, shopping, and walking. When asked why they were not able to do these activities in the nursing home, most cited being too frail or the restrictiveness of the nursing home. Activities they had been able to do in the nursing home, that they now could not included: physical therapy or rehabilitation treatment, socializing with others, playing bingo, or doing arts and crafts.

Conclusions

In light of these results, there are several conclusions, mainly:

- Most former nursing home residents are very satisfied with their current living situation.
- Quality of life is also improved with most able to do things that make life enjoyable and visit with family and friends.
- Of those former nursing home clients interviewed, most are able to perform almost all of the activities and about half of the instrumental activities of daily living.
- Although most clients were able to perform the ADLs, between 10 and 20 percent of the clients indicated a need per activity.
- Most people who reported unmet needs were already receiving assistance usually from an informal caregiver.
- In spite of unmet needs, most people did not feel that their ability to remain in the community setting was jeopardized.

In conclusion, the Community Choice Counseling program seems to be successfully assisting nursing home seniors to return to the community with the

appropriate set of services. More importantly, seniors are benefiting from an enhanced quality of life.

- ¹ Home-based settings include the client's own home or apartment, a shared private home, and senior subsidized apartments.
- ² Facility-based settings include assisted living facilities, residential health care facilities, and group home. These settings are differentiated from home-based settings because they offer a package of support services such as meals, housekeeping, etc.
- ³ These clients were removed from further analysis since they are no longer residing in a community setting.

Current Living Situation and Service Needs of Former Nursing Home Residents: An Evaluation of New Jersey's Nursing Home Transition Program

Sandra Howell-White, Ph.D.

Introduction

In August 1998, the New Jersey Department of Health and Senior Services (NJDHSS) initiated the Community Choice Counseling Program to provide counseling for Medicaid-eligible nursing home residents identified as candidates for discharge. Counselors provide these residents with information about housing and service alternatives available in the community, help them make informed choices about their living arrangements and other needed services, and they provide emotional support to ease the transition from the nursing home to the community.

As part of its evaluation of the New Jersey Senior Initiatives, Rutgers Center for State Health Policy conducted an evaluation of the Community Choice Counseling Program.¹ This report addresses clients' current living situation, their use of informal and formal assistance mechanisms, service deficiencies, and client satisfaction, and quality of life.

In the following sections, we describe our research methods, including the respondents, and the questionnaire design. We conclude with a discussion of the survey results, addressing implications for the Community Choice Counseling program, and recommendations/considerations for further study of the program.

Methods

All 1,750 clients discharged from January 1, 2000 through December 31, 2000 were asked to participate in the survey. Using information obtained from the discharge summary forms supplied by NJDHSS, we contacted the former nursing home clients approximately six to eight weeks after discharge. When possible, the nursing home dischargee was interviewed; however, a proxy was used when the mental or physical condition of the client prevented his/her participation, or the client preferred the proxy be interviewed.² When a proxy was used, the client (if able) was asked to confirm the

proxy choice. In a small number of cases, both clients and their proxies completed the interviews (see Appendix A for further details).

The interview consisted of a series of closed and open-ended questions, and took approximately 20 minutes to complete (see Appendix B).³ The survey instrument included questions about preventive health characteristics, physical ability characteristics, quality of life indicators, service use and needs, safety concerns, and respondents' current living situation.⁴

In total, 859 former nursing home residents or their proxies were interviewed (see Table 1). One hundred people refused to participate, 245 were unable to participate due to a physical or mental impairment and had no caregiver, family member, or friend to serve as a proxy respondent. We were unable to contact 560 clients.⁵ In addition, another 211 clients were deceased. Excluding the deceased and those who were unable to participate due to physical or mental impairment, our response rate was 56.6 percent (859/1,519).

A comparison of respondents and non-respondents showed that the groups have significantly different nursing home lengths of stay. In particular, those who refused to participate had significantly longer lengths of stay than participants. These groups are not significantly differentiated by gender.

Table 1. Sample Disposition

Results	Total Sampling Frame	Average Length of Stay Days in NH (s.d.)^{6*}
Surveyed	859	109.9 (229.7)
Unable to Participate	245	111.6 (299.6)
Refused**	100	230.7 (429.7)
Deceased	211	86.6 (178.1)
Unable to Reach/Locate	560	129.3 (247.2)
TOTAL	1975	119.1 (254.1)

* Significantly different ($p < .01$) between the groups $F=5.9$

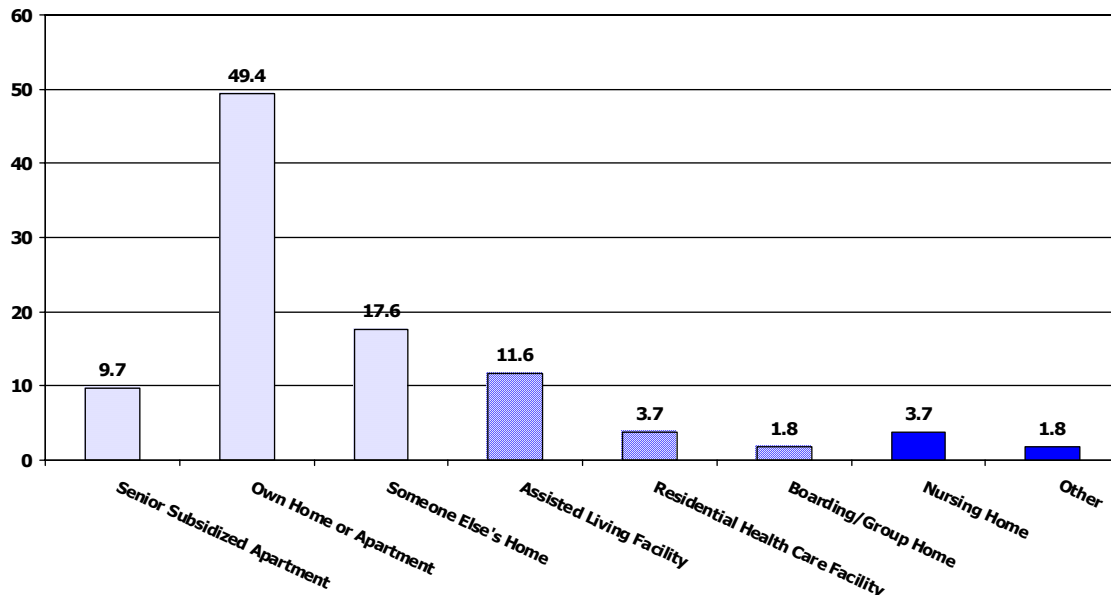
** Significantly different ($p < .01$) from the average length of stay of those who participated.

Results

Current Living Situation

The majority of clients (77%) are now living in a home-based setting (see Figure 1). More than half are living in their own home or apartment (49.4% of the total), while one in ten live in a senior-subsidized apartment (9.7%) and one in six are living in someone else's home (17.4%). Of those living in a home-based setting, one-third (34.4%) are living alone. The majority of home-based clients (57.6%) are living with a relative – most often a spouse (22.2%), a child (24.6%), or another relative (4.9%). Only a few are living with friends (4.0%), paid caregivers (4.0%), or someone else (0.9%). Nearly one-fourth (23.0%) of clients are in a facility-based setting, with the majority in an assisted living setting (11.6% of the total). Only a few clients (3.7%) have returned to living in a nursing home setting.⁷

Figure 1: Seniors' Current Living Situation



Total Home-Based=76.7% Total Facility-Based=17.1% (not including NH and other)

n=874

The overwhelming majority of respondents were satisfied with their current living situation. Eighty-six percent (n=716/831) of the clients (or their proxies) reported being satisfied with their current living situation, and an additional seven percent (n=60) were somewhat satisfied. Only seven percent (n=51) were dissatisfied. Of those living in home-based settings, thirty-four people were dissatisfied. Most of these clients were dissatisfied either because of some issue with their home (e.g., size, expense, or lack of privacy) or a safety concern such as living in an unsafe neighborhood or in an environment that makes it difficult to use a wheelchair or walker. Those living in a facility-setting who were dissatisfied also commented that they disliked their living situation, would rather be at home, didn't like the food or the staff, or they wanted additional privacy.

Although there were no significant differences between how clients and proxies rated their living situation, clients living in home-based settings were more satisfied than those living in facility-based settings ($X^2 = 12.9, p < .01$). There were, however, no significant satisfaction differences within the home-based or facility-based settings. With regard to client satisfaction, there were no significant differences among those living in their own home, a senior subsidized apartment, or another person's home. Similarly, there were no differences between those in a residential care facility or an assisted living facility.

Demographics and Physical Health Characteristics

To understand the characteristics of those seniors who participated in the study, we asked a number of questions about their social and physical characteristics. In general, the clients include more females than males and almost all are English speaking (see Table 2). About half were widowed and about one in five are married. Married clients are more likely to be in a home-based situation than in a facility, while those never married are more likely to be in a facility than in a home-based situation. Regarding educational level, one-third of the clients had completed high school, with about one-fifth having either some high school or some college experience. About ninety percent are over 65 years of age, with a third between 75 and 84 and a quarter over the age of 85. Proxies were more likely to respond for the oldest group ($O^2 = 27.99, p < .01$) and the lowest educational group ($O^2 = 47.52, p < .01$).

Table 2: Client Characteristics

Characteristic	Percentages
Age (n=689) (ave.=74.7, s.d.=14.2) range=22 through 101	2.8% <40 8.7% 40 through 54 8.3% 55 through 64 21.8% 65 through 74 33.5% 75 through 84 25.0% 85 and older
Gender (n=787)	32.3% Male 67.7% Female
Primary Language (n=755)	94.8% English 1.0% Spanish 4.2% Other
Education Level (n=755)	19.6% Elementary but not High School 20.9% Some High School 35.2% Complete High School 16.4% Some College or Trade School 7.7% Completed College or higher
Marital Status (n=779)	21.2% Married 47.9% Widowed 15.8% Divorced 15.1% Never Married

In addition to their demographic characteristics, we also asked seniors about their preventive health behaviors (see Table 3). Not surprisingly, almost all of them had seen a physician in the previous 12 months, had a regular check-up in the previous year, and tried to eat a healthy diet. Most of the clients reported taking vitamins or dietary supplements on a regular basis, and about two-thirds said that they exercise daily. The clients' tobacco and alcohol use also reflect these healthy behaviors. While one in eight is currently using tobacco, half of the respondents reported never having used tobacco. Likewise, only one in ten are currently using alcohol, with more than two-thirds having rarely or never used alcohol in the past.

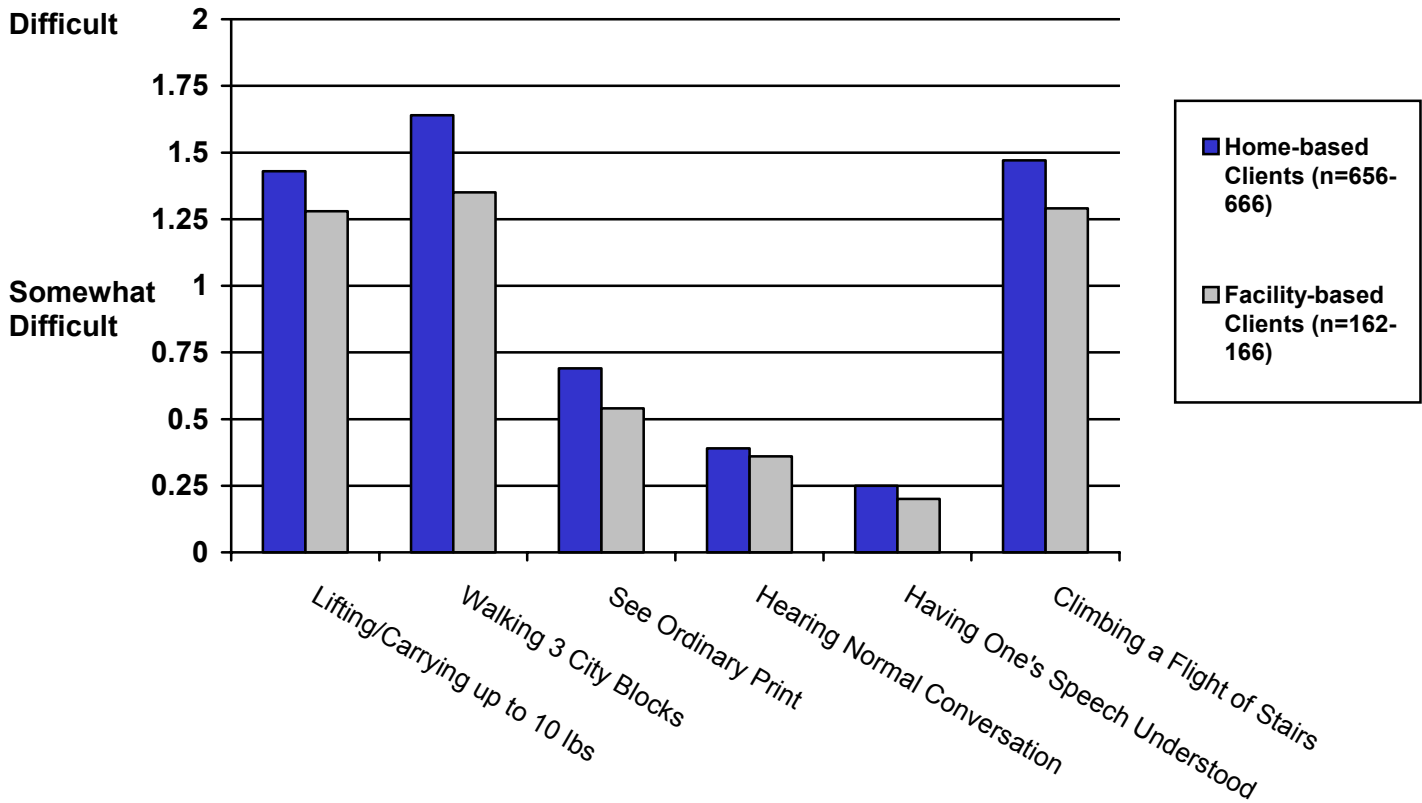
Table 3: Preventive Health Characteristics

Preventive Health Characteristics	Percentages
Seen a Physician in the previous 12 months (n=783)	99.6% Yes .4% No
Had a regular check-up in the previous 12 months (n=772)	95.3% Yes 4.7% No
Tries to eats a healthy diet (n=782)	92.7% Yes 7.3% No
Takes vitamins/dietary supplements regularly (n=783)	71.1% Yes 28.9% No
Frequency of Exercise (n=772)	20.6% Never 3.1% Once per Week 4.6% Twice per Week 9.2% Three times per Week 60.8% Everyday 1.7% Other
Tobacco Use (n=780)	48.3% Never 38.5% Former User 13.2% Currently Using
Current Alcohol Use (n=781)	89.7% Rarely or Never 7.2% Sometimes 3.2% Often
Past Alcohol Use (n=699)	64.9% Rarely or Never 22.9% Sometimes 12.2% Often

In addition to preventive health behaviors, we also used an assessment tool to gauge the clients' physical abilities and limitations (see Figure 2) (Nagle, 1976). While most of the respondents reported no difficulty with having their speech understood (83.3%), hearing normal conversation (70.9%), and seeing normal print (55.7%), the majority reported difficulty with lifting up to ten pounds (61.6%), walking three city blocks (71.7%), and climbing a flight of stairs (61.3%).

Since our sub-analysis indicted that clients may respond differently than proxies, we compared the client and proxy responses to these health characteristics. Indeed, clients reported significantly less difficulty than did proxies across all measures. At least two factors may account for these differences. First, having a proxy respondent indicates that the client is less able either physically or cognitively to respond, and therefore we would expect these clients to be less physically able. Secondly, some clients may

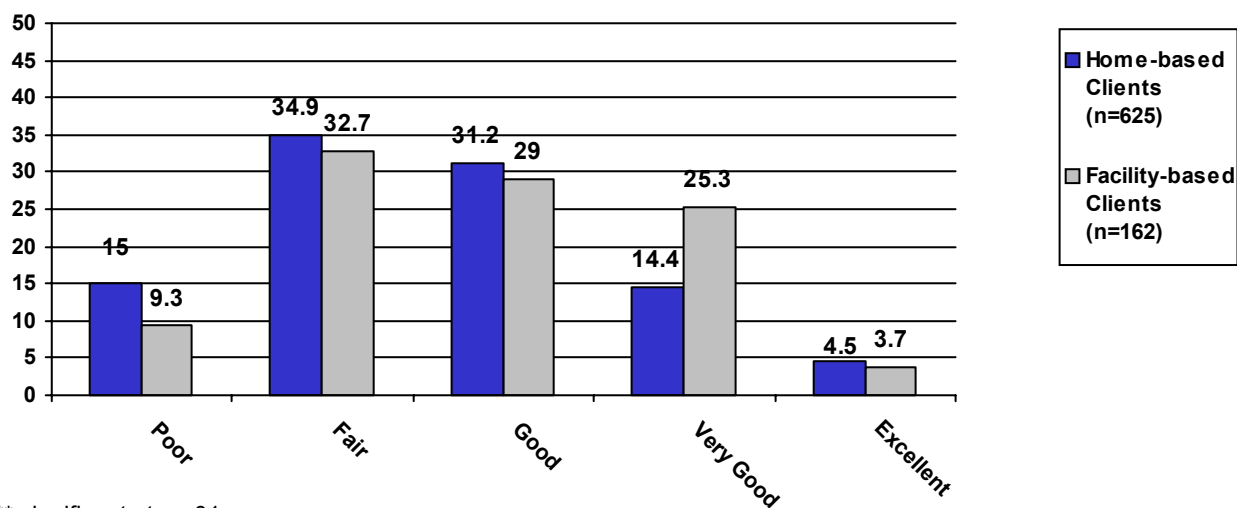
Figure 2: Physical Limits and Abilities



overestimate their abilities while proxies may be more conservative in their evaluations. Another factor which may be interrelated is whether the client is living in a home-based setting (such as a private home) or in a facility-based setting (such as an assisted living facility). Indeed, current living situation was significantly related to lifting, walking, seeing, and climbing, but with those in a home-based reporting more difficulty than those in a facility-based setting.

Found to be a predictor of mortality and morbidity (Greiner, 1999; Idler et. al., 1997; 1999), respondents were asked to assess their own (the clients) health (see Figure 2). Two-thirds of the clients (or their proxies) reported having good (30.6%) or fair (34.6%) health. These results were compared to results of the 2000 Behavioral Risk Factor Surveillance System (BRFSS) for New Jersey . The BRFSS data includes a random sample of persons 65 and older living in the community. In general, those discharged through the CCC program rate their health slightly lower than do the respondents in the BRFSS data. For instance, 11.1 percent of the BRFSS respondents rated their health as excellent, compared to 4.3 percent for the CCC group, while only 7.1 percent of the BRFSS rated their health as poor compared to 13.9% for the CCC group.

Figure 3: Self-Reported Health**



** significant at $p < .01$

To further examine the influence of respondent type (i.e., the client vs. proxy) and current living situation, we compared how clients rated their health to how proxies rated the clients health and how those living in a home-based setting compared to those in a facility-based setting. There were no significant differences between client's and proxies in rating the client's health. There is, however, a significant relationship between self-reported health and current living situation ($O^2 = 12.86$, $p < .01$). The differences appear to be in the poor and very good rating level, with home-based clients more likely than expected to rate their health as poor, while facility-based clients are less likely to rate their health as poor. The opposite holds true in the very good rating; fewer home-based clients rated their health as very good, while more than the expected number of facility-based clients rated their health as very good.

Although it is impossible to determine if these differences are due to the unique perceptions of clients vs. proxies or if they are attributable to true physical differences, respondent type is clearly related to these self-reported physical health characteristics and self-rated health. Therefore, further analysis will continue to consider the effects of respondent type.

Activities of Daily Living

In addition to seniors' physical limitations, their ability or inability to perform particular activities of daily living often influence the type of services they need and the

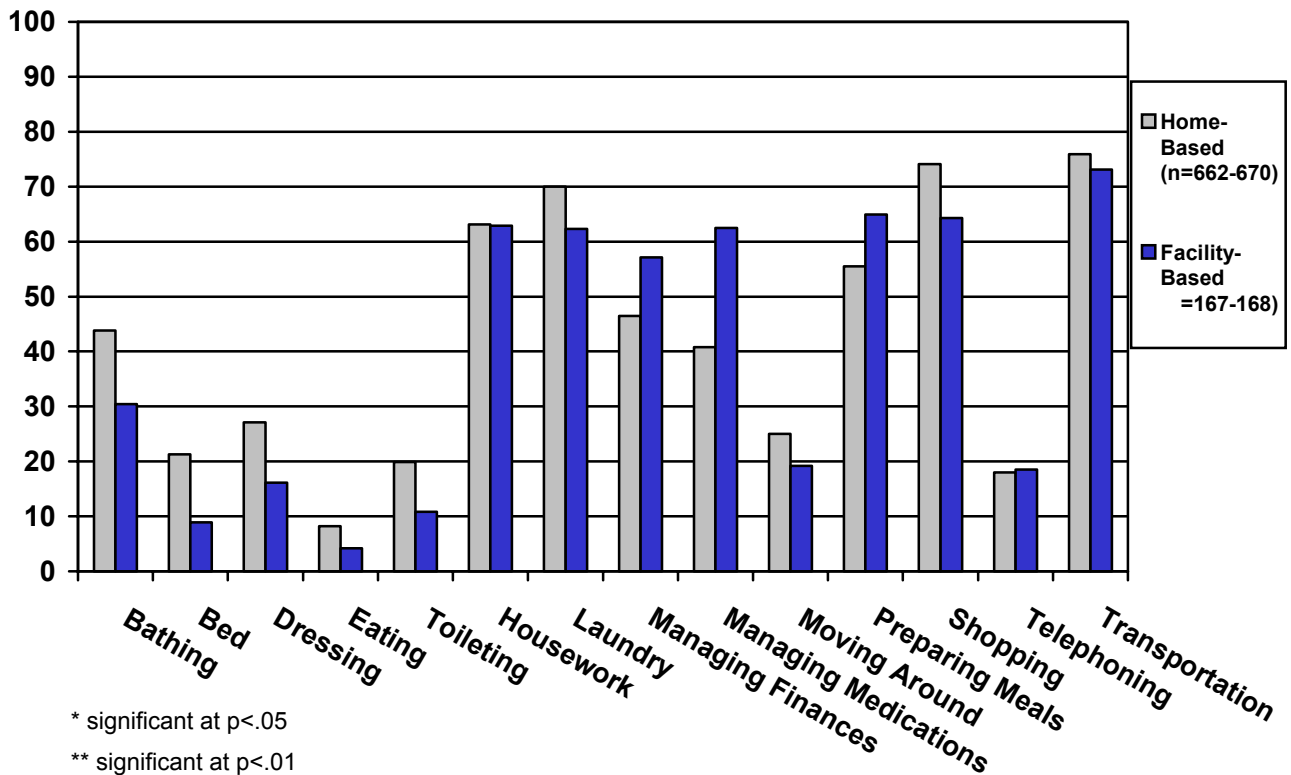
quality of their life. Thus, the client's ability to perform five key activities of daily living (ADLs) and nine instrumental activities of daily living (IADLs) indicated an individual's level of independence. For example, although an older adult may be able to prepare a light meal or snack, they may also be receiving assistance with the activity, perhaps having a relative prepare the main meals. Therefore, we also considered whether clients were receiving help from informal caregivers, such as family and friends, and/or from paid caregivers; e.g., home health aides. Since facility-based living situations often provide a package of services, we only considered receiving help from formal and informal caregivers for the home-based population. Although some individuals may be able to perform these activities of daily living or receive assistance with their care, they still may have additional unmet needs. Therefore, we asked whether they needed (or needed more) assistance with the five activities of daily living and the nine instrumental activities of daily living. Although a person may report an unmet need, having unmet needs does not necessarily indicate how these unmet needs may impact their life. For instance, a person may need more help with such IADLs as doing laundry and shopping, but these needs may not impact their ability to stay in a home-based setting. To fully understand the impact of having unmet needs, we also asked whether they felt they had the services they needed to remain in their community setting and to avoid injury. Although facilities provide services, we did examine whether facility-based, as well as home-based clients perceive themselves as having unmet needs.

Ability or Inability to Perform I/ADLs

We considered the individual's ability to perform activities of daily living separately for home- and facility-based seniors since one's ability to perform I/ADLs can often influence (as well as be influenced by) one's living situation. On average, the home-based respondents are able to do 3.8 (s.d.=1.7) of the five ADLs and 4.3 (s.d.=2.7) of the 9 IADLs. About half (52.9%) were able to perform all five ADLs, while only seven percent were unable to perform any of the five activities. Regarding IADLs, one in eight are able to perform all nine IADLs, and again only 7.5 percent were unable to perform any of the IADLs. Activities which presented the greatest difficulty for home-based seniors were bathing (43.6%), housework (63.1%), laundry (70.0%), managing finances (46.5%), managing medications (40.8%), preparing meals (55.5%), shopping (74.1%), and transportation (75.9%) (see Figure 4).

Facility-based clients could perform significantly more ADLs (ave.=4.3, s.d.=1.3). However, they were not significantly different than home-based clients in terms of the

Figure 4: Percent of Seniors Unable to Perform Activities of Daily (ADLs) and Instrumental Activities of Daily Living (IADLs) (by Type of Activity and Current Living Situation)



number of IADLs they could perform (ave.=4.2, s.d.=2.3). Similar to the home-based clients, about two-thirds of facility-based clients (68.3%) can perform all five ADLs. Like their home-based counterparts, facility-based clients also had difficulty with housework (62.9%), laundry (62.3%), and transportation (73.1%). Facility-based seniors, however, had significantly less difficulty with bathing (30.4%), dressing (16.1%), shopping (64.3%), and getting in and out of bed (8.9%), but they did have significantly more difficulty with managing finances (57.1%), managing medications (62.5%), and preparing meals (64.9%).

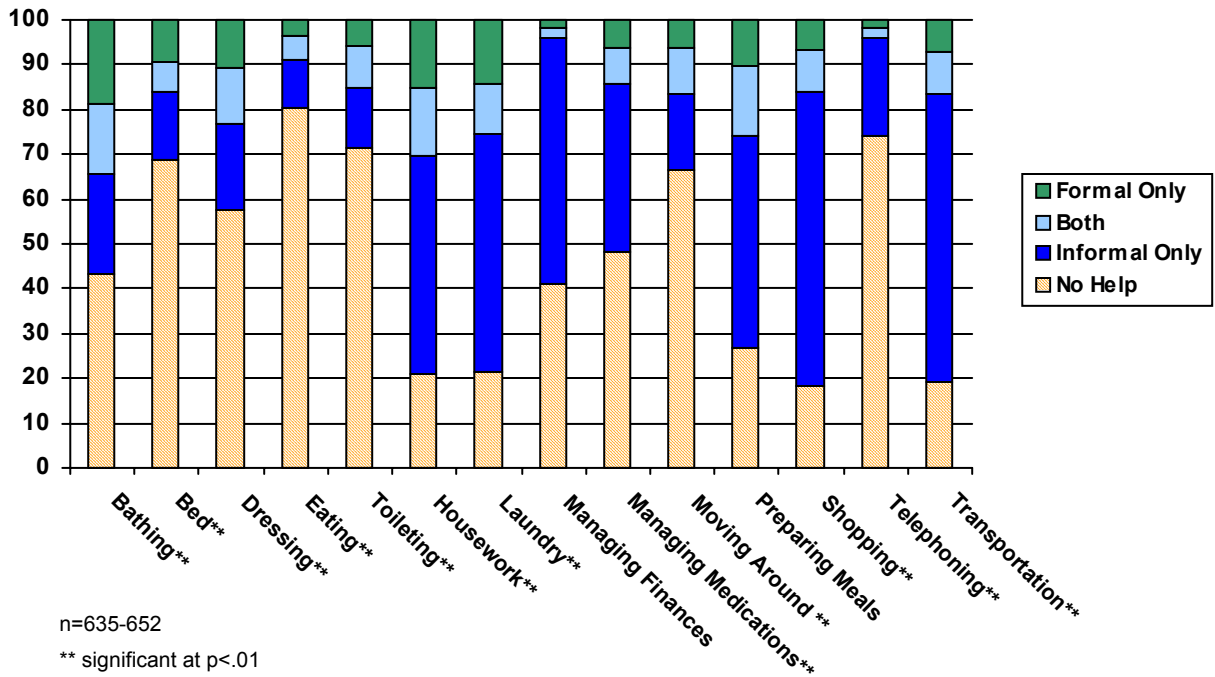
Informal vs. Formal Care for I/ADLs for Home-Based Clients

Since home-based seniors can receive services from informal and/or formal care providers, we compared the level of care received from each type of caregiver.⁸ On average, home-based clients reported receiving informal assistance with 1.32 (s.d.=1.8) ADLs and 4.9 (s.d.=3.1) IADLs. About half do not receive any informal care with ADLs, while one in eight (13.3%) report informal assistance with all five ADLs. About one in seven (14.3%) receive help with all nine IADLs, while about an equal number (14.6%) do not receive any informal help. With respect to formal or paid assistance, home-based

respondents reported help with an average of about 1 ADL (O=.98, s.d.=1.61) and 1.5 IADLs (s.d.=2.3). About two-thirds of clients did not receive any formal assistance with ADLs (64.5%) or IADLs (56.8%). Only a few clients received formal help with all five ADLs (7.7%) or all nine IADLs (1.9%).

Although a majority of home-based clients received no assistance with ADLs, when they did receive assistance, it was more likely to come from informal sources, such as family and friends, rather than paid caregivers (see Figure 5). Help with bathing was the most common type of ADL assistance, with 22.6 percent of clients receiving informal help only, another 15.4 percent receiving informal and formal help, and 18.9 percent receiving only formal help. In contrast to help with ADLs, the majority of clients did receive assistance with IADLs. In particular, clients received the majority of assistance with housework (78.9%), laundry (78.5%), shopping (81.6%), and transportation (81.0%). The overwhelming majority of assistance came from informal caregivers. For instance,

Figure 5: Percent of Home-Based Seniors who Receive No Help, Informal Help, Paid Help, and Both Informal and Formal Help



over half of the clients received all of their assistance with laundry (53.1%), finances (54.9%), shopping (65.4%), and transportation from informal caregivers. Only about ten percent reported receiving IADL assistance solely from formal caregivers with most getting help with housekeeping (15.3%) and laundry (14.1%). Between 10 to 15 percent of

respondents received both informal and formal help with the IADLs. The exception was managing finances for which less than four percent of the clients or their proxies reported using formal caregivers.

Main Caregiver

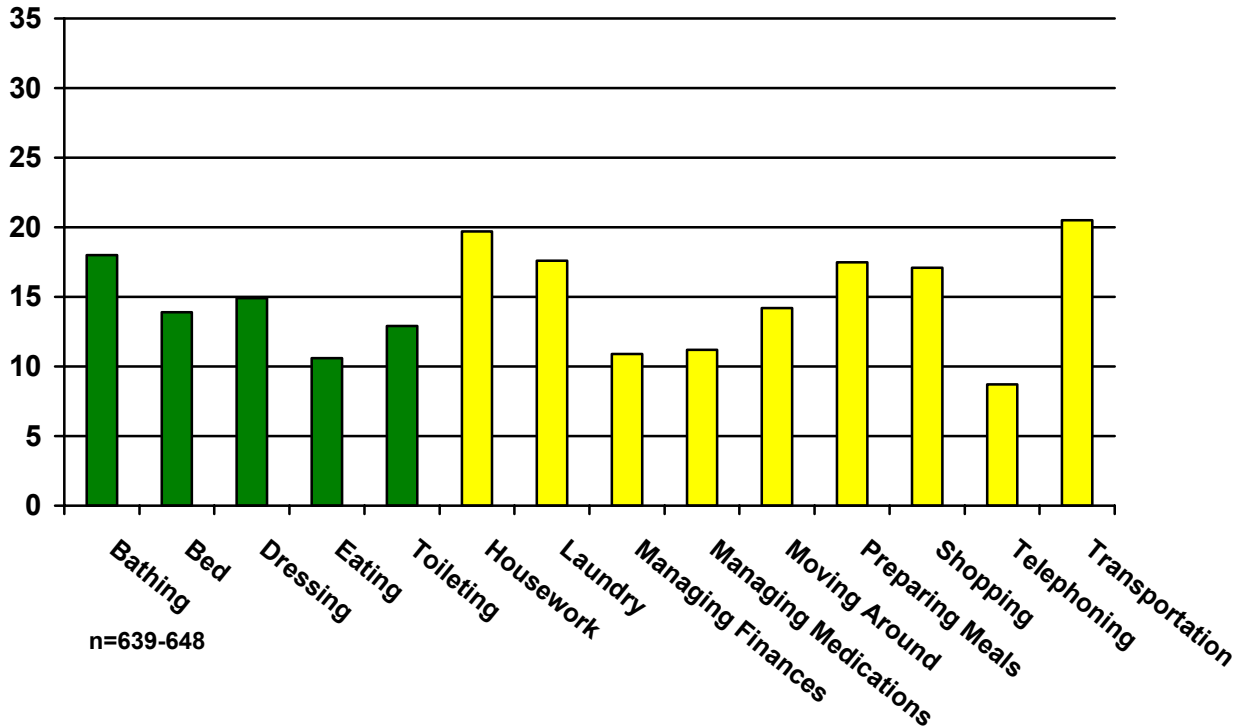
When asked about their main caregiver, most home-based clients received informal care from a relative (53.3%), usually a child (29.3%) or spouse (13.9%). About one quarter said they cared for themselves, some (16.1%) indicating solely and others (7.4%) in combination with family, friends, or paid caregivers. Less frequently mentioned caregivers included friends, grandchildren, multiple family, and combinations of family and paid caregivers. While informal help from family and friends usually means unpaid, that may not always be the case. Therefore, respondents were asked if they paid their informal caregiver. Almost all informal care was provided without pay, with only twenty-eight (4.6%) home-based seniors paying for help with shopping and twenty-seven (4.5%) paying for help with transportation.

Unmet Needs and Potential Impact of Living Situation

Independent of how much assistance a person maybe getting with the activities of daily living, they may still need additional assistance. To measure unmet need, clients (or their proxies) were asked if they needed any (or more) assistance with the five ADLs and the nine IADLs. To understand the effects of unmet needs, clients were also asked if their unmet needs could potentially impact their living situation, either by threatening their ability to continue to live in their current environment or whether they had the help and services they needed to avoid injury.

As one's current living situation, a home-based or a facility-based setting, influences the assistance one receives, it can also effect the level and type of unmet needs one may have. This was true for both unmet ADL and IADL needs. The average home-based client needed help (or more help) with less than one (.71, s.d.=1.6) ADL and two (1.4, s.d.=2.5) IADLs. Four out of five (79.4%) of the home-based seniors did not need any (additional) help, while approximately one in ten (9.8%) reported needing assistance with all five ADLs. Slightly more than two-thirds (72.3%) did not indicate needing help (or more help) with any of the nine IADLs, while 8.3 percent indicated needing help with all nine IADLs. The most prevalent areas of need include: bathing (13.9%), dressing (14.9%), housework (19.7%), laundry (17.6%), getting around (14.2%), preparing meals (17.5%), shopping (17.1%), and transportation (20.5%) (see Figure 6).

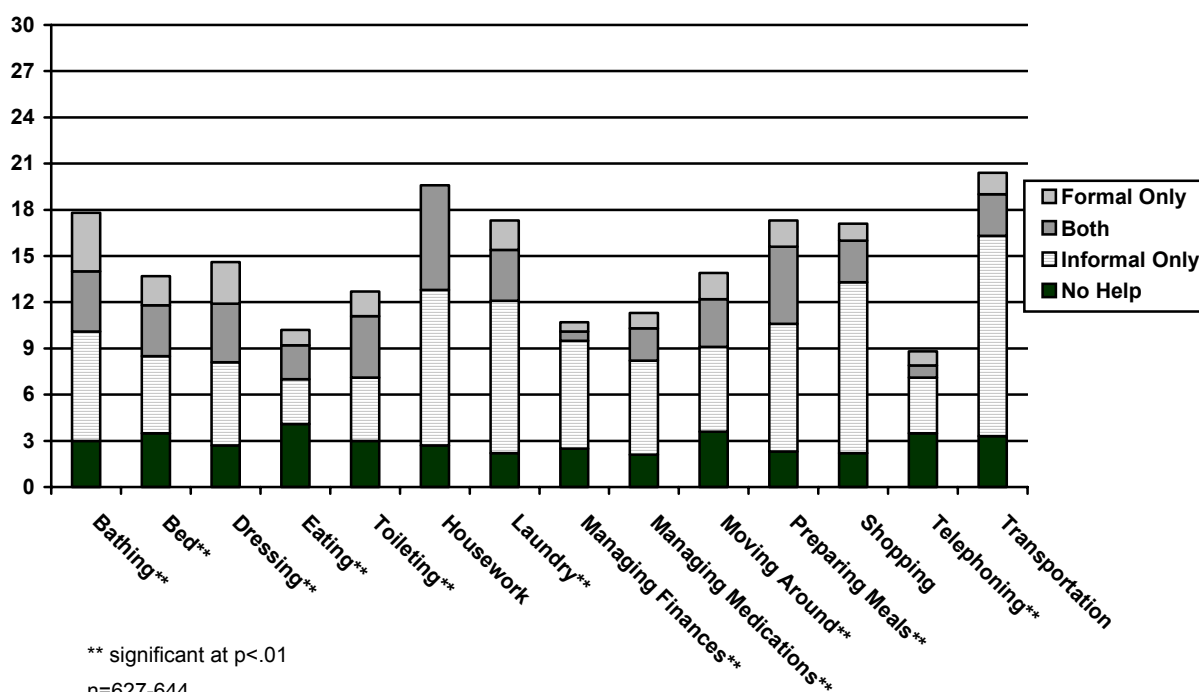
Figure 6: Percent of Home-Based Seniors Who Need (More) Assistance with Activities of Daily (ADLs) and Instrumental Activities of Daily Living (IADLs) (by Type of Service)



Although facility-based clients typically receive a package of services, facilities may not necessarily fulfill all of a client's needs. Few facility-based clients (or their proxies) reported needing help (or more help), with the average respondent indicating an unmet need in less than one area ($O=.10$, $s.d.=.62$ for ADLs, $O=.25$, $s.d.=1.25$ for IADLs). In fact, almost all of the facility-based seniors (96.8%) reported no unmet ADL needs or IADL need (reported by 93.0%). Additionally, facility-based clients were less likely to report having an unmet ADL need ($O^2=27.0$, $p<.01$) or an unmet IADL need ($O^2=33.2$, $p<.01$) than those in home-based settings.

The impact of respondent type on level of need was also considered. Proxies were significantly more likely to cite unmet needs than were client respondents. Several factors could account for these differences. First, having a proxy respondent was related to less healthy or able clients. In turn, these clients would probably have greater needs and might therefore be more likely to have higher levels of unmet needs. Second, the proxy may be providing assistance, and therefore might be more likely to indicate needing assistance. To test the relationship between getting help (and from whom) and

Figure 7: Percent of Home-Based Seniors who Need Help by Receipt of Help from Informal and Paid Caregivers



further unmet needs, we compared receiving help (and the source of the caregiving assistance; i.e., formal vs. informal) and whether these clients required additional help (see Figure 7). The greatest amount of unmet need was indicated by those who already received assistance from informal caregivers, such as family and friends. For instance, of the twenty percent that said they need help with housework, half (10.1%) of these already receive help from informal caregivers. In contrast, only 2.7 percent of those indicating unmet needs currently receive no help and 6.8 percent receive help from both an informal and formal sources. No one who receives help from formal sources indicated further unmet needs.

Apart from their needs with activities of daily living, most clients or their proxies (85.2%) said that they have the help and services they need to stay in their current living arrangement. Home-based respondents were significantly more likely to report that they had unmet needs that could impact their continued living situation than did facility-based respondents ($O^2=14.47, p<.01$). Of those home- and facility-based clients who said they (or the client) did not have adequate help (128/862 or 14.8%), most mentioned the need for a home health aide or 24-hour care. Only a few people mentioned needing financial

help, a particular form of therapy, or a different living situation. Reasons given for not having these services include lack of finances (42/128) and not knowing whom to contact (14/128).

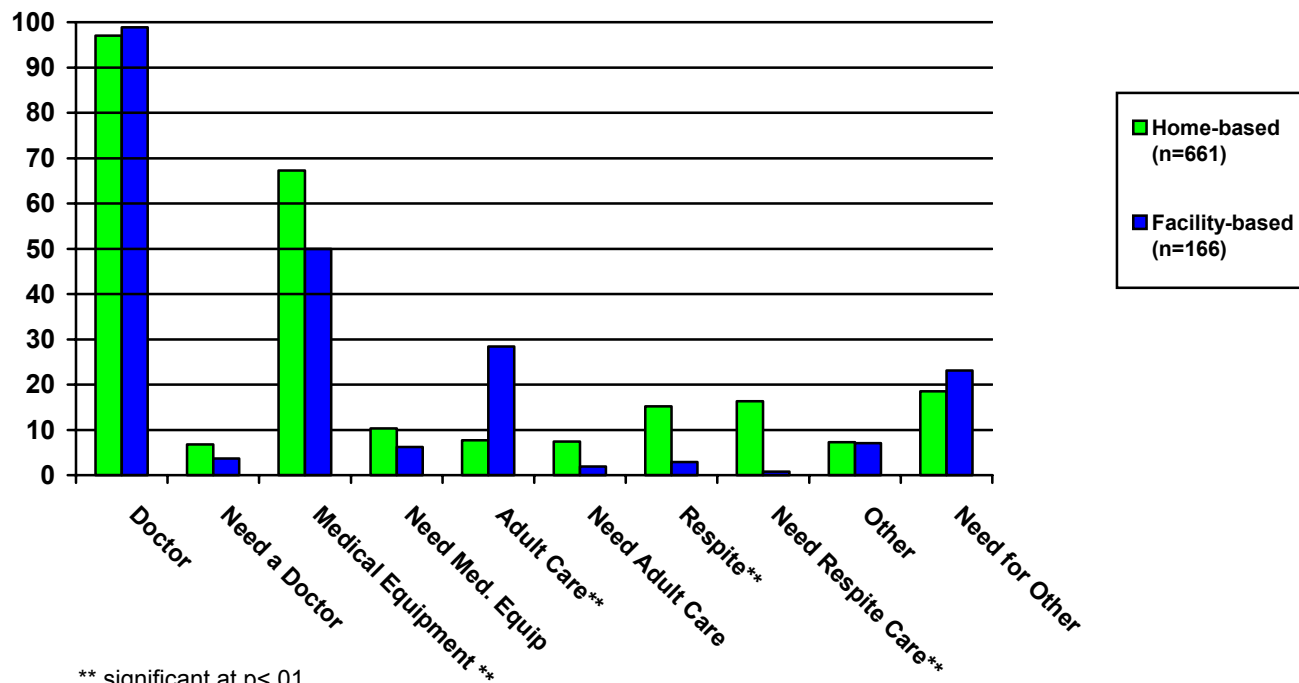
Another important factor influencing whether an elderly person is able to remain in the community is their vulnerability to injury. Approximately ninety percent (n=749/827) responded that they had the help and services needed to avoid injury. Although few people indicated they felt they did not have the services needed to avoid an injury, those living in facility-based settings were significantly less likely to feel vulnerable to injury than those in home-based settings (2.4% vs., 11.2%). Those who felt they did not have the services necessary to avoid injury most often mentioned needing a home health aide, 24-hour care, or a specific service or piece of equipment such as a wheelchair. Again, the chief reasons given for not having these services included lack of finances and not knowing whom to contact.

Each of these approaches (needing assistance with ADLs or IADLs, having the services available to avoid injury, and having the services to remain in one's current living situation) provides specific detail about the type of assistance needed. Across these measures, one-third of all respondents expressed an unmet need in at least one of these four areas. There is, of course, some overlap of need areas. For instance, individuals who felt that unmet needs jeopardized their living situation often perceived a threat of injury (55/152 or 36.2%). However, the same people do not always report multiple needs. For instance, about half (58/124 or 46.8%) of the individuals who reported needing help or services in order to remain in their living situations reported no unmet ADL needs. Likewise, about half (40/78 or 51.3%) who considered themselves at risk for injury did not report needing any (further) help with ADLs. This relationship also held true for needing help with IADLs, with forty percent reporting a threat of injury (31/77), or needing services to remain in one's current living situation (58/124), but no unmet IADL needs.

Professional Services

As might be expected, almost all respondents reported seeing a physician (see Figure 8). More than half of the respondents reported using medical equipment, with significant differences between those living in home-based settings (67.3%) and those in facility-based settings (50.0%). Although few people reported needing these services, home-based clients were significantly more likely to need respite (15.2% vs. 2.9%) and adult day services (82.9% vs. 29.0%) than were those in a facility-based setting. These differences are expected as facilities often provide the same social and medical

Figure 8: Percent of Seniors Who Receive Formal Services and Who Need Formal Services (by Type of Service)

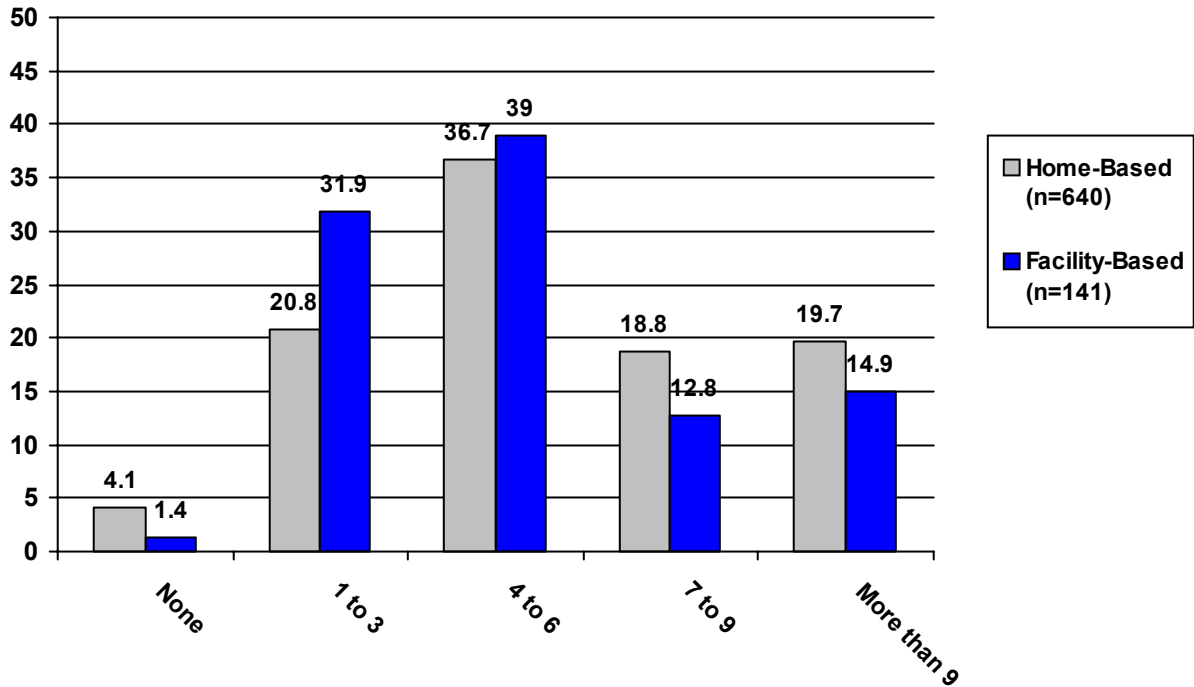


services as adult day care facilities and families of those in facilities do not require respite services.

With both groups having a range of zero to thirty prescription medications, the average number of prescription medications for home-based clients 6.30 (s.d.=4.18) was significantly higher than that for facility-based clients 5.73 (s.d.=4.23). While the average number of prescriptions falls below the MDS indicator that stipulates nine or more medications for nursing home residents as a risk factor to quality of care, 15 to 20 percent reported more than nine prescriptions (see Figure 9). About one-fifth to one-sixth of the clients reported between seven and nine prescriptions. Just over one third reported between four and six medications, and about 20 to 30 percent reported between one and three medications.

Having multiple prescriptions might be somewhat of a concern if the type of medications are not monitored for interactions. New Jersey does have a monitoring system in place for persons enrolled in the state's pharmaceutical assistance plan for the aged and disabled (PAAD)(Hare GT, et.al., 1999 and 2000). This system is designed to alert pharmacists about potential problems; however, only 95 (12 %) clients or their

Figure 9: Number of Prescription Medications by Current Living Situation**



** significant at $p < .01$

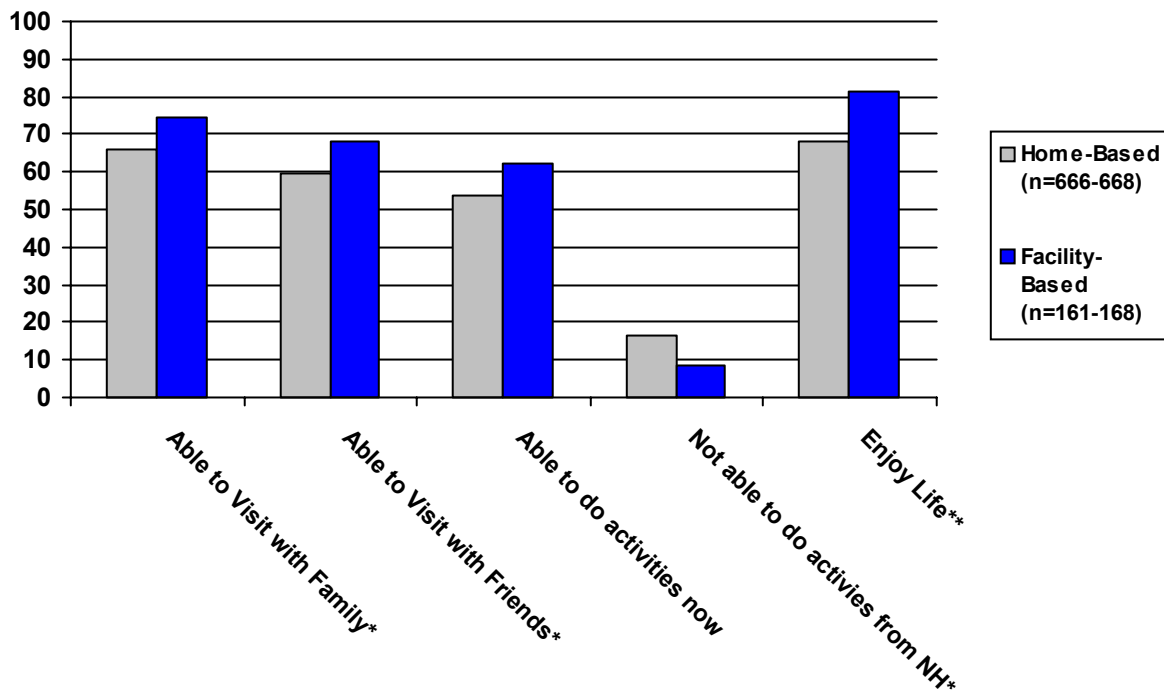
proxies specifically mentioned having PAAD. This number probably under-represents those on PAAD, as many did indicate that Medicare or other forms of coverage such as Medicaid and private insurance paid for their prescriptions.

Quality of Life

A primary goal of the Community Choice Counseling program is to enhance quality of life of nursing home residents by providing them with the choice to return to a community setting. Ultimately, it is the individual's perceived quality of life that is important. If individuals are happy about returning to the community and feel that they have an improved quality of life, then the program has realized an important goal. To this end, clients (or their proxies) were asked if they were able to do the things that made life more enjoyable, whether they were able to visit with family and friends, and what they were able to do in the community that they could not do while in the nursing home (see Figure 10).

While most people said they are able to do things that make their lives enjoyable, significantly more facility-based clients (81.5%) said they enjoyed life than their home-based counterparts (68%). Of the 213 seniors living in a home-based setting who said they missed things that made their life enjoyable, almost half (n=94) mentioned poor health, especially lack of mobility, as the reason. Other problems included needing assistance to

Figure 10: Quality of Life



ambulate or the lack of transportation to go out and socialize. Health and mobility were also the primary concerns among those (n=19 of 28) in facility settings. Only three people mentioned needing to live in a different setting.

Contact with friends and family is also an important aspect of quality of life. Those in a facility setting were significantly more likely to visit with family than those living in a home-based setting (74% vs. 66%). Both groups said that visiting with family was very important to them (78.7%), with only ten percent saying that it was not important. Facility-based clients were also significantly more likely to visit with friends than were home-based clients (68.3% vs. 59.5%). Again, this activity was considered very important by most clients (69.5) with one in eight (14.8%) saying that visiting with friends was not important.

While most of these clients said they are able to visit family and are able to visit friends, some were less fortunate. Ninety-nine former home-based residents (43% of those who said they could not visit) said they were not able to visit family because of transportation or mobility problems such as being bedridden, not about able to drive anymore, or not being able to leave the home. One in three cited transportation or mobility as a barrier for seeing friends. Distance was also a barrier to visiting family (n=54, 23.7%) and friends (n=114, 44.5%) for home-based clients. Not having anyone to

visit was also a problem, one in ten home-based clients (n=25, 10.9%) reported not having any (or any nearby) family, while one third (28.9%) said they have no (or any nearby) friends. Of the forty-three facility-based clients who said they were unable to visit with family, half (53.5%) cited either lack of family or distance to family as why they could not see them. Lack of friends (or lack of friends nearby) was also mentioned by 65.4% (n=34/52) clients. These facility-based clients also mentioned lack of transportation as why they could not visit with family (16.3%) and friends (11.5%).

Clients divided evenly on whether they can now do activities that they could not do in the nursing home. Facility-based clients, however, were significantly more likely to report being able to do activities that could not do in the nursing home ($O^2 = 4.4, p < .05$). Home-based clients reported now being able to perform many different activities such as caring for one's self, cooking and eating better (preferred) foods, watching TV, driving, shopping, and walking. In essence, these people reported being able to lead a more independent life. In addition to these activities, facility-based clients also noted being able to socialize more. When asked why they were not able to do these activities in the nursing home, most cited being too frail or the restrictiveness of the nursing home. The overwhelming majority of both groups (89%) said that now being able to do these activities was very important to them.

Although most felt they were able to do more in their community setting, one in eight (n=125, 14.9%) said there were activities they had been able to do in the nursing home that were no longer possible. Half of these clients (50.8%) said these activities were very important to them. Another one-third (35.%) said they were somewhat important. Both home- and facility-based clients mentioned physical therapy or rehabilitation treatment, socializing with others, play bingo, or doing arts and crafts. These activities were lost because they were no longer able to get in-home therapy or had difficulty leaving the home. Home-based clients were significantly more likely to say they could no longer perform some activities than were facility-based clients (16.5% vs. 8.3%, ($O^2 = 7.1, p < .01$). This difference is not surprising as facility-based settings, such as assisted living facilities, often offer similar social activities.

Discussion

At approximately eight weeks after discharge from a nursing home, almost all of the clients who were assisted back into the community by the New Jersey Community Choice Program were living in a home-based setting or a community-based facility setting

such as an assisted living residence. Less than five percent had returned to a nursing home. More importantly than where they reside, the overwhelming majority of the respondents were satisfied with their current living situation. Most felt they were more able to visit with family and friends and more able to do the things that made life more enjoyable.

The clients who participated in this study exhibited fairly healthy life styles with high levels of regular check-ups, healthy eating habits, and low rates of smoking and drinking. Additionally, the average senior was able to do about four of the five activities of daily living and four of the nine instrumental activities of daily living. Home and facility-based seniors had the most difficulty with physically and logistically challenging activities such as bathing, housework, managing finances and medications, and transportation.

Although most seniors are able to do a fair number of activities of daily living, many are receiving assistance especially with IADLs. Informal caregivers, typically a family member, provided most of this assistance. Less than ten percent of clients received all of their assistance from formal or paid help. Another one in ten received assistance from both informal and formal sources. Although many clients were able to perform I/ADLs, a number reported needing (or needing more) help. Only a few of the home-based clients who were currently receiving no assistance expressed need in I/ADLs. The majority of those who expressed needing assistance were already getting help from informal sources, or a combination of informal and formal caregivers. Again, the most prevalent areas of unmet need include: bathing, housework, laundry, preparing meals, shopping, and transportation. In spite of their unmet needs, the majority of clients (or their proxies) were confident that their current level of help is adequate to remain in the community and felt they had the help and services needed to avoid injury. Those who didn't have what they needed, usually mentioned needing a home health aide, 24-hour care, and financial help. Although the respondents reported these needs, Medicaid does not provide for all types of services, such as 24-hour care.

While only minimal information was available to compare respondents to non-respondents, respondents were significantly different from non-respondents in terms of length of stay in the nursing home. For the most part respondents were more likely to have had shorter lengths of stay in the nursing home. Therefore, these results should be considered with caution. Nonetheless, the results from these former nursing home

residents do provide an appropriate picture of the living situation of those discharged through the Community Choice Counseling program.

Conclusions

In light of these results, several conclusions can be drawn, primarily:

- Most former nursing home residents are very satisfied with their current living situation.
- Quality of life is also improved with most able to do things that make life enjoyable; e.g., visiting with family and friends.
- Of those former nursing home seniors interviewed, most are able to perform almost all of the activities and about half of the instrumental activities of daily living.
- Although most clients were able to perform the ADLs, between 10 and 20 percent of the clients indicated some limitation per activity.
- Most people who reported unmet needs were already receiving assistance, usually from an informal caregiver.
- In spite of unmet needs, most people did not feel that their ability to remain in the community setting was jeopardized.

In conjunction with the Community Choice program, DHSS also provided several community programs, the Caregiver Assistance Program (CAP), CCPED, the Assisted Living (AL) Waiver program, Alternate Family Care (AFC), and Jersey Assistance Community Caregiving (JACC). These programs provide community services for both Medicaid (CAP, CCPED, AL waiver, and AFC) and non-Medicaid populations (JACC). Although these community programs are available to assist seniors, they still receive the bulk of assistance from informal caregivers. Additionally, these programs have eligibility requirements as well as coverage limits for the services. Clients and their families should be well educated about the type and scope of resources available in the community and whether they are covered under the Medicaid program. Additionally, clients and their families should also be educated to detect changes in the client's situation that may warrant re-examining whether their setting is the most appropriate.

In conclusion, the Community Choice Counseling program seems to be successful in assisting nursing home seniors to return to the community with the appropriate set of services. More importantly, seniors are benefiting from an enhanced quality of life.

Endnotes

- ¹ From August 27 to October 11, 1999, the Center conducted a pilot study of 107 former nursing home residents who had been counseled through New Jersey's Community Choice Counseling (CCC) program and subsequently discharged. Our current study is an expansion of that pilot project to include all clients discharged from January 1, 2000 through December 31, 2000.
- ² When proxies answered the survey, interviewers were instructed to ask for proxy views on subjective questions (rather than for proxy estimations of clients' views).
- ³ The original questionnaire was developed with input from Community Choice Counselors and other program staff, the Advisory Committee of the Senior Initiatives Evaluation, Center for State Health Policy staff and an external reviewer with expertise in long-term care.
- ⁴ The survey instrument also includes questions about the experience with the Community Choice Counselors and selected health episodes, but these areas are not reported in this report.
- ⁵ Clients were deemed unable to locate if we could not reach them after successive attempts. A detailed protocol specified the number of attempts, variation in times and days, and number of interviews before a client was deemed unable to locate. Additionally, this category includes persons for whom we had no contact information.
- ⁶ This information was not available for all clients.
- ⁷ These clients were removed from further analysis since they are no longer residing in a community setting.
- ⁸ Since services are provided as a package for those living in facilities, we only report on assistance received by home-based seniors.

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Appendix A

Sub-Population Analysis

Due to concerns regarding potential memory and cognitive ability, as well as differences in knowledge and perceptions between proxy and client, we conducted several sub-population analyses. First, differences in responses between respondent type (client, proxy, or both), cognitive understanding, and knowledge were considered. Approximately 43 percent of our interviews were answered by clients, 52 percent by proxies, and 4 percent by both a proxy and client (see Table A). Using a three-point scale, interviewers were asked to assess respondents' knowledge of what was asked and their level of confusion about questions they were asked. Almost all respondents seemed knowledgeable (93.5%) and were not confused (92.6%). None of the respondents were either totally confused or had no knowledge. Using the knowledge and confusion questions, a cognitive index rating of the respondent's ability to answer questions with full understanding was created. Most respondents (89.2%) seemed knowledgeable and were not confused when answering the survey questions (see Table A).¹ Although almost all respondents scored high, significantly more caregivers were knowledgeable and not confused (93.3%) than clients (85.5%).

TABLE A: Sub-Population Factors

Respondent Type	Percentage of Sample
Interview completed by client	42.7 (n=372)
Interview completed by proxy	52.2 (n=455)
Interview completed by both client and proxy	5.1 (45)
TOTAL	100% (872)
COGNITIVE INDEX RATING	
Knowledge/No Confusion	89.3 (766)
Some Confusion or Lack of Knowledge	8.7 (75)
Some Confusion and Some Lack of Knowledge ²	2.0 (17)
TOTAL	100% (858)

Table B: Analysis of Sub-Population Difference³

Survey Question	Respondent Type
“How satisfied would you say you are with your living situation: satisfied, somewhat satisfied, or not satisfied?”	$\chi^2=3.2$
“Do you feel that you have the help and services you need to continue to live where you are?”	$\chi^2=2.6$
“Do you feel that you have the help and services you need to avoid injury?”	$\chi^2=0.2$
“Do you feel safe with family, friends, neighbors, and paid caregivers?”	$\chi^2=0.03$

To determine whether we should analyze sub-groups separately, we tested the effect of type of respondent on several key survey questions. The questions were chosen because they required subjective responses, addressed crucial issues (such as client safety), and/or could threaten seniors' living situation.

The questions were:

How satisfied would you say you are with your living situation?

- Do you feel that you have the help and services you need to continue to live where you are?
- Do you feel that you have the help and services you need to avoid injury?
- Do you feel safe with family, friends, neighbors, or paid caregivers?²
- The distribution of responses for our sub-populations was quite similar, and analysis showed no significant difference for any of the pairings (see Table B).⁴ Therefore, a disaggregated analysis was not required by respondent type for certain elements.

¹No composite score was computed if one or both of the ratings was missing.

²Only two respondents (one proxy and one client) said they did not feel safe (or feel the client was safe) with family, friends, neighbors, caregivers. Therefore, significance testing for this question was unnecessary and inappropriate.

³Since only five percent of the surveys were answered by a combination of client and proxy responses, we analyzed differences by respondent type using only the categories of "client only" and "proxy only."

⁴Interviewers were also asked to assess the client's memory of the Community Choice Counseling experience in particular, but this was not considered an indication of general functioning, and was therefore not included in the index. Overall, this assessment supported the validity of answers to the Community Choice questions.