

**Evaluation of
Alpha One Independent Living Center's
Home to the Community
Demonstration Program**

June, 2001

**Paul J. Saucier, M.A.
Elise J. Bolda, Ph.D.
Mark F. Richards, B.S.
Robert G. Keith, Ph.D.**



**Conducted with a grant from The Robert Wood Johnson Foundation through its
Building Health Systems for People with Chronic Illness Program**

Comments and questions about this report may be directed to Paul Saucier or Elise Bolda
at the Muskie School:

pauls@usm.maine.edu
eliseb@usm.maine.edu

Questions about the *Home to the Community* program may be directed to Dennis Fitzgibbons at
Alpha One Independent Living Center:

dennis_fitzgibbons@alpha-one.org

Contents

Charts	ii
Executive Summary	1
Background	1
Evaluation Approach and Limitations	1
Findings.....	2
Lessons and Implications	3
Terms Used in this Report	5
I. Background	7
II. Evaluation Approach and Limitations	8
A. Approach in General	8
B. Data Sources and Collection	8
C. Limitations	10
III. Findings	12
A. Did 40 or more participants move out of nursing homes during the project? ...	12
B. What were the notable differences between program participants and a comparison group of non-participants?	15
C. Did the health status of participants improve after they moved out of nursing homes?	21
D. Was physical function maintained by participants after they moved out of nursing homes?	26
E. Did quality of life improve for participants after they moved out of nursing homes?	29
F. What else was learned about participants who moved out of nursing homes?..	32
G. How did public expenditures for participants in the community compare to participants' public expenditures in nursing homes?	36
H. Did the attitudes of key nursing home staff about the ability of people with disabilities to leave nursing homes change over the life of the project?	38
I. Did the project have a lasting impact on public policy?	40
IV. Lessons and Implications	41
V. Summary	42
Appendix A. List of Data Instruments	43

Charts

Chart 1.	Number of People in Various Program Categories.....	14
Chart 2.	Age Distribution.....	16
Chart 3.	Admission Characteristics	16
Chart 4.	Presence of Selected Conditions.....	17
Chart 5.	Mobility.....	18
Chart 6.	Eating and Dressing	18
Chart 7.	Communication and Interactions	19
Chart 8.	Length of Stay in Nursing Home	19
Chart 9.	Able to be More Independent in Daily Activities.....	20
Chart 10.	Selected Outcomes.....	20
Chart 11.	Open Sores or Ulcers	22
Chart 12.	Seven or More Medications or Urinary Tract Infection	22
Chart 13.	Self-Rated Health.....	23
Chart 14.	Satisfaction with Health.....	23
Chart 15.	Pain (N=12).....	24
Chart 16.	Depression & Antidepressant Use	24
Chart 17.	"Downhearted and Blue"	25
Chart 18.	Sleep Patterns.....	25
Chart 19.	Independence in Activities of Daily Living.....	27
Chart 20.	Need Extensive or Total Assistance with Mobility	27
Chart 21.	Performance of Household Chores	28
Chart 22.	Active Homemaking for 21 or More Hours per Week	28
Chart 23.	Sense of Privacy.....	30
Chart 24.	Life Control.....	30
Chart 25.	Choice of Workers and Schedules	31
Chart 26.	Number of Movers with Medicaid Claims in 1 st Year Post-move, by Category of Service.....	33
Chart 27.	Days Enrolled in HTC Prior to Move (N=26)	34
Chart 28.	Living Arrangements of Movers (N=26).....	34
Chart 29.	Housing Subsidy	35
Chart 30.	Average Monthly Medicaid Expenditures per Mover (for Movers with Pre- & Post-move Claims	37
Chart 31.	Average Monthly Public Service Expenditures (for Movers with Other Public Service Expenditures).....	37
Chart 32.	Selected Pre and Post Responses of Nursing Home Staff Regarding Hypothetical HTC Participant.....	39

Executive Summary

Background

In March, 1997, Alpha One Independent Living Center began a statewide nursing home transition project in Maine named *Home to the Community*, funded by The Robert Wood Johnson Foundation through its Building Health Systems for People with Chronic Illness Program. The Muskie School of Public Service at the University of Southern Maine was awarded a grant by The Robert Wood Johnson Foundation to conduct an evaluation of the program. This report presents the findings from the evaluation.

The primary goal of *Home to the Community* was to assist 40 adults under 60 years of age to move out of Maine nursing homes over a 3-year period. Two years into the project, lower than projected program participation led to a decision to remove the age cap (which opened the program to adults of all ages) and to extend the program an additional year, through February, 2001.

Alpha One hypothesized that participants who moved would maintain function while enjoying improved health and quality of life, and that public expenditures would be no greater in the community than they were in the nursing home. Alpha One would identify potential participants, provide life skills training to them while still in the nursing home, and help arrange the housing and services they would need to self-direct their supports in the community.

Evaluation Approach and Limitations

The evaluation had several components and relied on multiple data sources, including nursing home resident assessments (Minimum Data Set, MDS), community service consumer assessments (Medical Eligibility Determination, MED), in-person participant surveys, a survey of nursing home staff, Medicaid claims, Alpha One project forms (including intake forms and progress notes), and key informant interviews with State officials and Alpha One staff. Changes in the health status, physical functioning and quality of life of participants were measured over time using a pre/post design with a comparison group. Although a wealth of information was collected regarding each person in the project, a significant limitation of the evaluation is the small number of project participants.

Findings

The answers to the following evaluation questions are summarized here and addressed further in the report.

1. *Did 40 or more participants move out of nursing homes during the life of the project?*

26 program participants moved out of nursing homes between March 1, 1997 and October 31, 2000. Alpha One provided services to an additional 24 participants who did not move.

2. *What were notable differences between program participants and a comparison group of non-participants?*

Participants who moved were more mobile, were more likely to eat independently, were less likely to be incontinent, had good expressive and receptive communication skills, had shorter nursing home stays, and were more likely to believe they could be more independent in the performance of daily activities.

3. *Did the health status of participants improve after they moved out of nursing homes?*

Health indicators were mixed but overall, a greater number of indicators improved than declined.

4. *Was physical function maintained by participants after they moved out of nursing homes?*

Functioning was maintained over time. Almost all measures of physical function showed little or no change over time.

5. *Did quality of life improve for participants after they moved out of nursing homes?*

Quality of life improved, with most indicators showing improvement or no change.

6. *How did public expenditures for participant services in the community compare to public expenditures for participants' nursing home care?*

Public expenditures decreased when participants moved into the community. Medicaid expenditures decreased in the first year of

community living, and fell further in the second year. Other public expenditures included housing subsidies, transportation, food assistance and fuel assistance. These went up in the community but were more than offset by Medicaid savings. A limitation of the expenditure study is that Medicare claims data were not available. At least 10 of the participants who moved were known to be Medicare beneficiaries.

7. *Did the attitudes of key nursing home staff about the ability of people with disabilities to leave nursing homes change over the life of the project?*

Surveys of directors of nursing and social services directors in nursing homes in 1997 compared with surveys in 2000 did not find any significant changes in attitudes toward independent living.

8. *Did the project have a lasting impact on public policy?*

Although Maine Medicaid policy has not changed to allow for full reimbursement of the nursing home transition activities provided in this demonstration program, there is some evidence that the program has influenced public policy. Most notably, the prior approval process for durable medical equipment was streamlined to ensure timely delivery of wheelchairs and other equipment to movers. As a very early nursing home transition project that pre-dated federally-sponsored programs in 12 states, *Home to the Community* may have had an influence on federal demonstrations and recent federal policy clarification in this area.

Lessons and Implications

A number of lessons may be gleaned from *Home to the Community* to inform policy makers and program designers. They include the following:

- The likelihood that someone will move out of a nursing home is related to the length of time the person has been in the nursing home;
- Availability of affordable and accessible housing is critical;
- Current federal Medicaid reimbursement policy for transition services falls short for some potential movers;
- The consumer-directed services model offered in *Home to the Community* appeared to work well for those who enrolled in the program, but it limits the target group for such programs;
- A nursing home transition program is more likely to enjoy a high participation rate if the program is well integrated into a State's existing long term care entry and reassessment mechanisms;

- Identification of participants is easier when a state initiates a project and can share confidential consumer information with its project contractors; and
- Nursing home staff should be engaged in transition projects.

These lessons are discussed further in the report.

Terms Used in this Report

Alpha One Independent Living Center (or Alpha One). Alpha One is Maine's only Independent Living Center and provides Independent Living Skills (ILS) services statewide. Alpha One is the agency that designed and administered the *Home to the Community* demonstration program.

Nursing Home Transition Program. A program designed to assist nursing home residents to move to more integrated settings. *Home to the Community* is a nursing home transition program.

Home to the Community (HTC). *Home to the Community* is the name of the demonstration program that was evaluated.

Participant. A person who enrolled at any time in Alpha One's *Home to the Community* project. Participants include those who moved into the community (movers) and those who stayed in the nursing home.

Mover. A participant who moved out of a nursing home while enrolled in *Home to the Community*.

Comparison Group. Nursing home residents in the Target Group, excluding *Home to the Community* participants (who moved or did not move).

Target Group. The universe of Maine nursing home residents who met the initial criteria established by Alpha One for the *Home to the Community* program. Initial criteria were:

- 18-59* years old;
- Acting as own guardian;
- No terminal prognosis; and
- In a nursing home for at least 30 days.

*The upper age limit of 59 was eliminated at the end of Year 2 in response to lower-than-projected participation.

A Note on the Quotations

The quotations that appear in boxes throughout this report are all from *Home to the Community* participants. They were taken from responses to open-ended survey questions.

I. Background

In March, 1997, Alpha One Independent Living Center launched *Home to the Community*, a statewide nursing home transition program in Maine. Funded by The Robert Wood Johnson Foundation through its Building Health Systems for People with Chronic Illness Program, the program's goal was to assist forty (40) people between the ages of 18 and 59 move out of nursing homes.¹ The Muskie School of Public Service at the University of Southern Maine was awarded a grant by The Robert Wood Johnson Foundation to conduct an evaluation of the program. This report presents the findings from the evaluation.

Home to the Community was designed to capitalize on Alpha One's long history of providing independent living services and peer support to people with disabilities in Maine. Using its statewide network of professionals and peers, Alpha One used grant support to identify nursing home residents who met the program criteria and to provide independent living services to them while they were in the nursing home and after they moved. Services provided included independent living skills training, identification and adaptation of accessible housing, and peer support. Also important was pre-move procurement of durable medical equipment, such as power wheelchairs. Alpha One had identified "Catch 22" Medicaid reimbursement policies that typically did not allow reimbursement for these services and equipment unless a consumer was already living in the community. Alpha One sought to demonstrate that providing the services and equipment to nursing home residents would enable them to move out. If the demonstration were successful, it would convince policy makers to change Medicaid reimbursement policy and make the approach sustainable after the grant period.

Since *Home to the Community* started in 1997, nursing home transition projects have been initiated in several other states. Beginning in 1998, the federal Health Care Financing Administration and the Office of the Assistant Secretary for Planning and Evaluation within the federal Department of Health and Human Services have awarded nursing home transition grants to 12 states, targeting a variety of population groups.² The federal agencies intend to award additional nursing home transition grants as part of a multi-pronged initiative to assist states with disability and long term care system improvements in light of the *Olmstead* decision. The Health Care Financing Administration has also been working to clarify the federal limits of Medicaid policy as it relates to nursing home transition services.

¹ The upper age limit of 59 was eliminated at the end of Year 2 in response to lower-than-projected participation.

² Projects have been funded in Arkansas, Colorado, Florida, New Hampshire, New Jersey, Pennsylvania, Rhode Island, Texas, Vermont and Wisconsin.

II. Evaluation Approach and Limitations

A. Approach in General

The evaluation was designed to assess whether or not a series of outcomes predicted by Alpha One at the beginning of the project were achieved. These included the following:

- At least forty (40) participants would move out of nursing homes during the project;
- Health status of participants would improve after they moved out of nursing homes;
- Functional status of participants would be maintained by participants after they moved out of nursing homes;
- Quality of life would improve for participants after they moved out of nursing homes;
- Public expenditures for participants in the community would be no greater than expenditures for their care in nursing homes;
- Greater awareness would be achieved among key nursing home staff about the ability of people with disabilities to move out of nursing homes; and
- The project would have a lasting impact on public policy.

To describe participant outcomes and changes in their health status, physical function and quality of life, we used a pre/post design with a comparison group. An analysis of Maine's nursing home resident assessment data from the federally mandated Minimum Data Set (MDS) at the start of the project identified 201 people in Maine nursing homes who fit the program criteria established by Alpha One. The comparison group was comprised of those who met the original program criteria but did not become HTC participants.

B. Data Sources and Collection

In order to minimize the intrusiveness and costs of data collection, existing data sources were used when possible. Maine's long term care system uses comparable items on automated assessment instruments used to describe nursing home residents' needs (Minimum Data Set, or MDS) and for determining eligibility for nursing home or community-based long term care services (Medical Eligibility Determination, or MED). A supplemental tool was created for use with existing assessment instruments to obtain data on other health and related items of interest for this evaluation.

The assessment tools do not include quality of life indicators, so we developed a participant survey that focused primarily on quality of life. This instrument drew heavily on the instrument development work of Phillip Beatty at the National Rehabilitation Hospital Research Center and included concepts developed by James Conroy at the Center for Outcome Analysis.

To assess public expenditures, we used a combination of Medicaid claims and, for movers, a separate consumer expenditure survey that asked participants to provide an inventory of their non-Medicaid public subsidies and services including housing subsidies, transportation, food stamps and fuel assistance. We also asked them to report earned income so that income and payroll taxes could be estimated and applied to offset public expenditures as applicable.

Nursing home resident assessment data were collected and reported by facility staff following routine reporting requirements. Monitoring the timeliness and reliability of these data are a function of the quality assurance program of Maine's nursing home case mix reimbursement system under Medicaid.

Medical Eligibility Determination (MED) assessments for nursing facility and community-based long term care services are conducted under contract with the State of Maine. Two statewide contractors conduct in-person assessments. Alpha One is the statewide contractor for persons seeking or receiving support for self-directed services under the Medicaid Home and Community-based Waiver for Adults with Disabilities. All MED data, and supplemental health and related item questions for this evaluation were collected from assessments conducted by Alpha One.

Participant surveys for quality of life information were conducted in-person by the evaluation team's interviewer (a single individual throughout the 4 year period). To maximize the likelihood of participation, we offered a \$25 gift certificate to L.L. Bean or a supermarket chain for each interview. (Our concerns of intrusiveness notwithstanding, every *Home to the Community* participant agreed to take part in the evaluation). In-person interviews were conducted with participants:

- at the time of enrollment in HTC;
- prior to moving out of the nursing home;
- 2 weeks following move to the community;
- 3 months post-move;
- 9 months post-move;
- 1 year post-move;
- 18 months post-move;
- 2 years post-move;
- 30 months post-move; and
- 3 years post-move.

For annual participant financial surveys, participants were mailed the survey and provided with suggestions on how to obtain needed information. The interviewer reviewed responses with participants during the annual in-person interviews. Review of these data suggest that participants were able to gather and report public expenditures with the guidance provided.

To assess whether the project influenced the attitudes of nursing home staff toward independent living, we conducted a pre/post mail survey of social service directors and

directors of nursing in all Maine nursing homes. The survey was first administered in 1997, the first year of the project, and again in 2000, near the end of the program.

Finally, to determine whether or not the program had an impact on public policy, we asked Alpha One to provide a list of targeted policy barriers when the program began in 1997. At the end of the program in 2001, we asked them to provide a self-assessment of their progress in addressing those barriers. We then conducted key informant interviews with State officials and reviewed State and federal documents to verify that certain policies had changed or not changed over the life of the project.

Before beginning the evaluation, we met with two groups of consumers who had lived through transitions to independent living. We asked what they had experienced at various points in their transitions, what factors had been most important to them, and what changes they had noticed in themselves. We also elicited their reactions to a preliminary list of indicators and proposed data collection approaches to ensure that the content of our evaluation was relevant to consumers and the process not overly intrusive.

The meetings influenced our approach in several ways:

- We changed our consumer interview schedule to add an interview when movers had been in the community for two (2) weeks. This was described to us as a difficult period, during which indicators might be likely to worsen. We had planned to conduct our first interview at the 3-month mark;
- We were encouraged to conduct in-person surveys, despite their intrusiveness. Consumers felt strongly that the challenge of completing a phone or mail survey would be too great, and that results could be compromised if personal attendants or others assisted in the survey;
- Consumers identified control and privacy as their major quality of life concerns. We were able to discuss with them quality of life indicators and fine tune our selections; and
- Consumers identified directors of nursing and social service directors as the most likely nursing home staff to influence a person's move to the community. We decided to target our nursing home survey at those individuals rather than administrators.

C. Limitations

While the findings offer an interesting picture of how participants and expenditures changed over time in the *Home to the Community* program, the numbers are too small to generalize the findings with confidence.

The public expenditure portion of the evaluation suffers from an additional limitation. Although ten (10) movers received Medicare services during this period (identified by Medicare crossover claims in the Medicaid claims file), Medicare claims data were not

available for the evaluation. Thus, a significant public expenditure is excluded from the analysis. The results should be of interest nonetheless to state policy makers, since the primary state cost (Medicaid) is captured in the analysis. We were also able to capture housing subsidy information, which is the largest and arguably the most important public subsidy in the community after Medicaid and Medicare.

III. Findings

A. Did 40 or more participants move out of nursing homes during the project?

Chart 1 provides the numbers of people in various program categories, with the 201 people in the original target group at the top of the chart. From the program start in March, 1997 through the end of the evaluation period (October 31, 2000), 26 *Home to the Community* participants moved out of nursing homes. During the same period, Alpha One provided services in nursing homes to an additional 24 participants who did not move (non-movers).

The target group was identified by the evaluators through analysis of Maine's nursing home resident assessment data files. The assessment files were used to select all nursing home residents who met Alpha One's program criteria at the beginning of the project. Those criteria were:

- At least 18 and no older than 59 years;
- Acting as own guardian;
- No terminal prognosis; and
- In a nursing home for at least 30 days.

The project had been planned originally to last three years. About halfway into the program Alpha One recognized that it was not meeting its projections and made two program changes in response. The age maximum of 59 was eliminated to allow older people to participate, and the program was extended by 1 year.

Three features of the *Home to the Community* model were undoubtedly factors in the program's struggle with participant recruitment.

- The contractor that conducts medical eligibility assessments and provides choice counseling to consumers in Maine's single entry point long term care system was not formally part of the project. Alpha One familiarized that agency with the *Home to the Community* program but did not receive any referrals. In contrast, the model developed in Colorado used the single entry point agency as a key contractor, paying them a supplemental fee for each person who moved out of nursing homes. In the Colorado program, 68 people moved in the first year.³
- Related to the previous point, *Home to the Community* was a project initiated by Alpha One. Unlike the initiatives that have followed in other states, *Home to the Community* was not a state-sponsored initiative, and Alpha One was not conducting the program as an agent of the State. Because Alpha One was not acting on the State's behalf, it could not have access to the names and locations of the target group

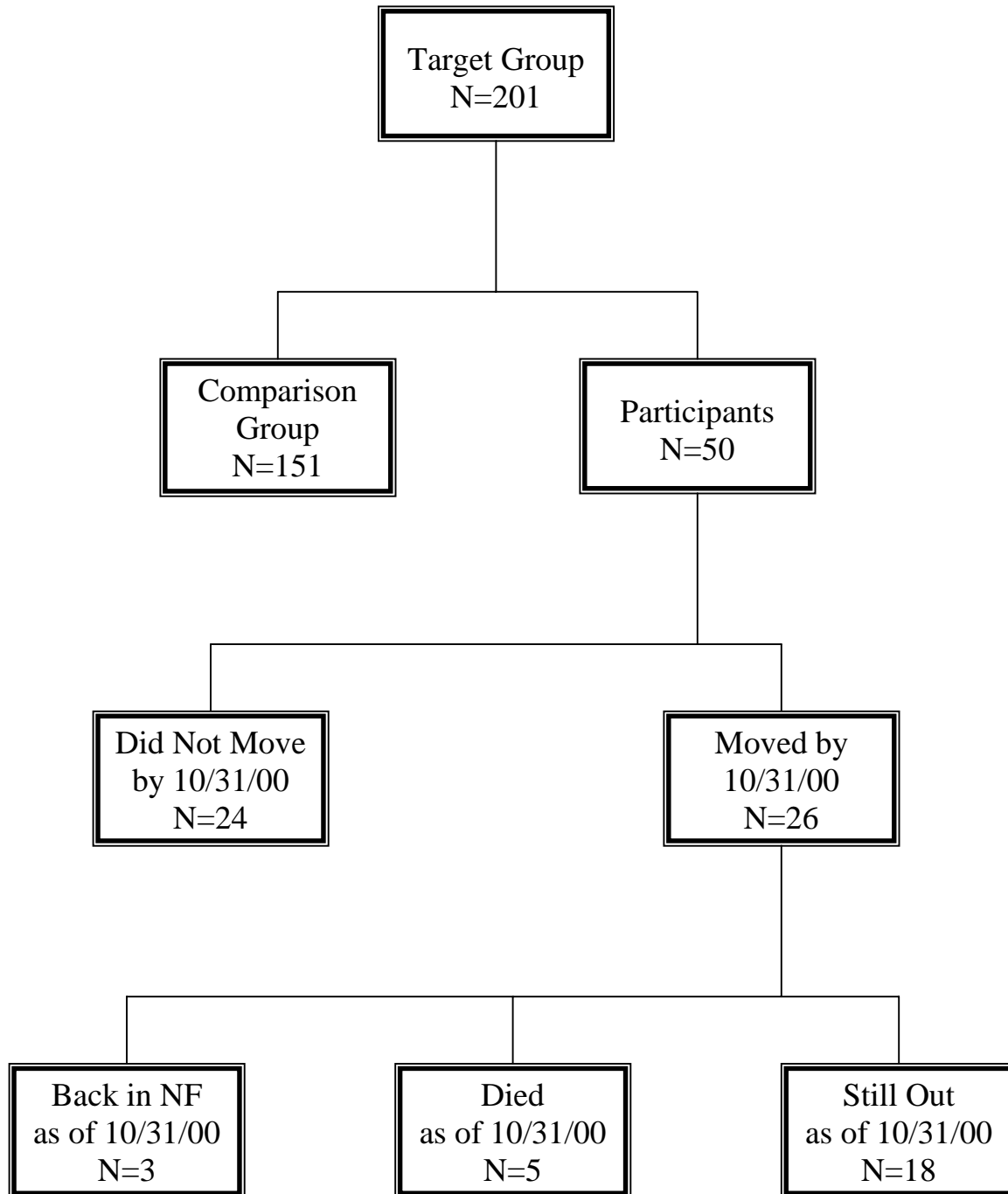
³ Colorado Department of Health Care Policy and Financing. *The Deinstitutionalization Pilot Project Evaluation and Report*. November, 1998.

members. The State authorized two blind mailings to target group members (in which Alpha One's marketing material was mailed for them but names and addresses were not shared), but Alpha One reported that they had no response from the direct mail efforts.

- A third feature of the program that may have made recruitment challenging was the consumer-directed services model being offered by Alpha One. There may have been eligible nursing home residents who did not want to self-direct their care but would have enrolled had traditional services been offered, including residential care options. Again, the Colorado project offers a contrast. Nearly two-thirds of those who moved in the first year of the Colorado project moved to an assisted living facility.

Finally, the numbers should be placed in context. Maine is a small state that has had considerable success in reducing its nursing home population over the last several years. The same program in a larger state or a state with a relatively larger nursing home population would have had a larger target group. Despite their lack of direct access to the target group, Alpha One provided services to 50 people, equivalent to 25% of the original target group of 201 people, and helped 13% (26) move into the community.

Chart 1. Number of People in Various Program Categories



B. What were the notable differences between program participants and a comparison group of non-participants?

Charts 2 through 10 compare the characteristics of the participants with those of the comparison group. Most of the data are taken from nursing home resident assessments (MDS). Although the program had 26 movers, most of the following charts report data on 24 movers. MDS assessments were not available for two participants.

Given that the two groups combined comprise the target group for *Home to the Community*, this comparison provides clues as to the type of person who would enroll in this voluntary program. Relative to the comparison group, participants:

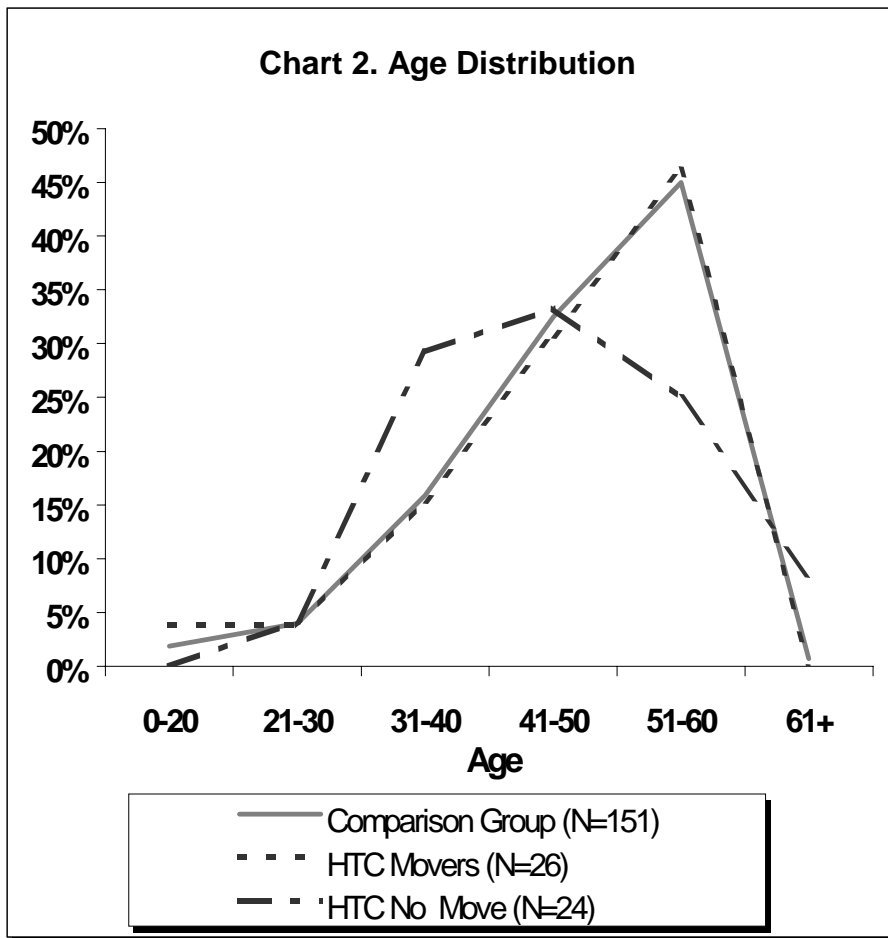
- had shorter stays in the nursing home;
- were more likely to believe they could be more independent in daily activities;
- were more likely to have diabetes or depression;
- were less likely to have short-term memory problems or incontinence;
- were more likely to understand and be understood by others; and
- were more likely to be comfortable initiating activities.

Participants had higher rates of discharges from nursing homes, lower rates of readmission to a nursing home, and lower death rates than members of the comparison group.

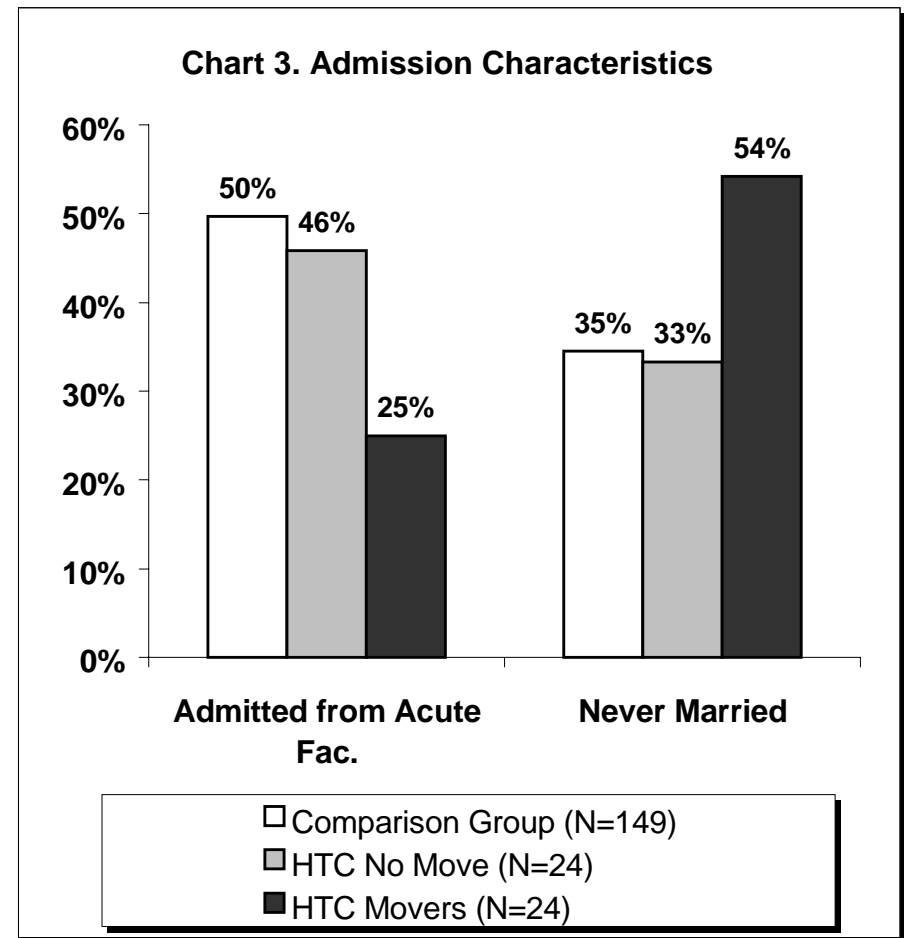
The analysis also compares those participants who moved with those who did not move. Compared to non-movers, movers:

- had shorter nursing home stays;
- were more independent in eating and dressing;
- were less likely to have been admitted from an acute care facility; and
- were less likely to need assistance with mobility.

**“A nursing home, for my age group,
is *not* where I want to be.
I’ve been here 7 months now.”**

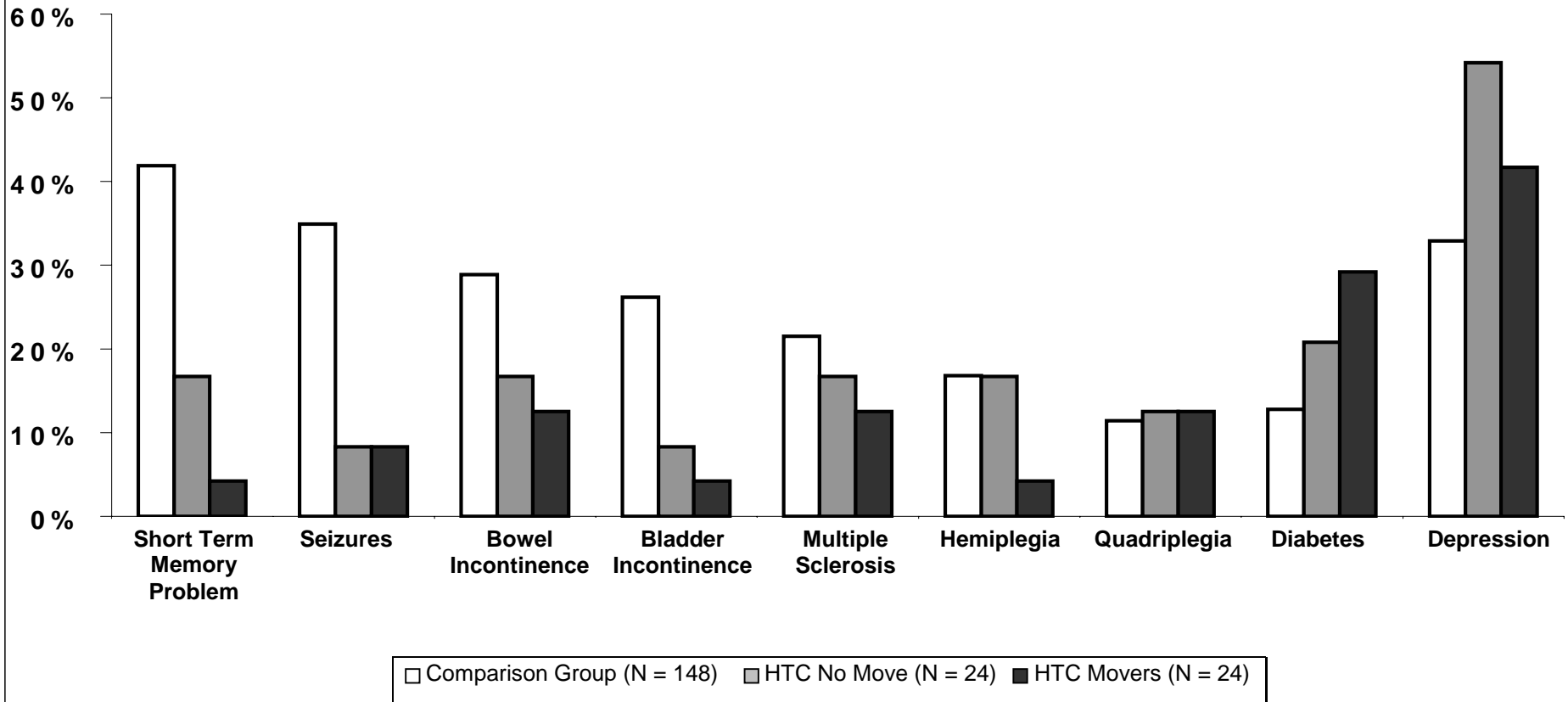


- The age distribution for movers and comparison group members was very similar.
- The largest cluster for these 2 groups was in the 51 to 60 year age range.
- Interestingly, participant non-movers were slightly younger than movers. Most non-movers were in the 31 to 50 year age range.
- It is not surprising that older people did not enroll, since the initial program criteria had a maximum age of 59.



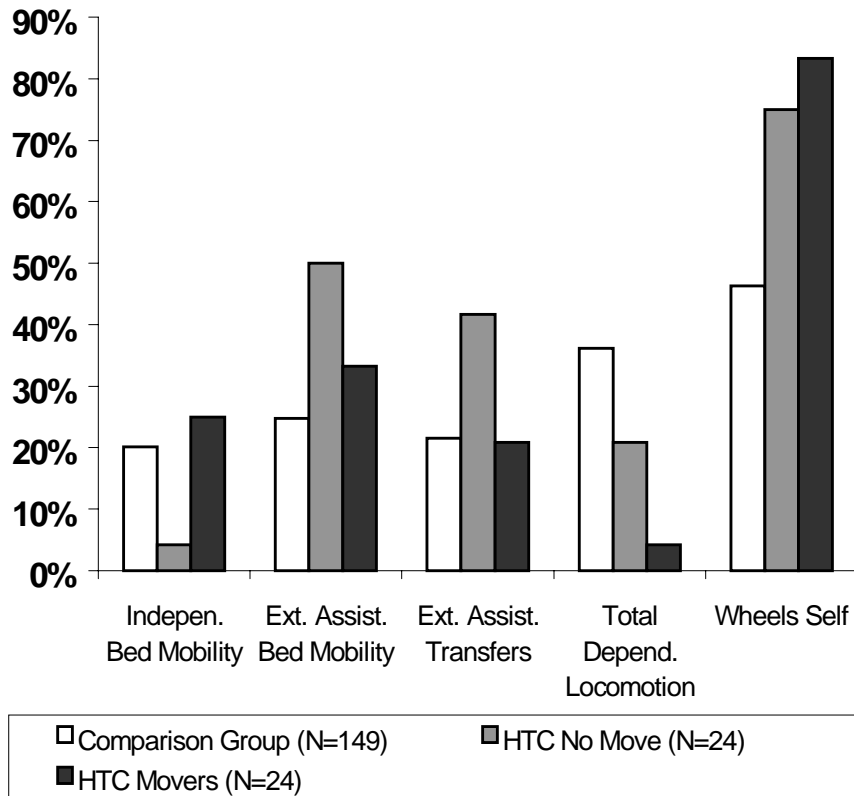
- Movers were less likely than comparison group members or non-movers to have been admitted to the nursing home from an acute care facility.
- Movers may have been admitted disproportionately from rehabilitation hospitals, but that category was not specified in our data.
- Movers were also less likely to have ever been married, suggesting that presence of a spouse did not increase the likelihood of moving.

Chart 4. Presence of Selected Conditions



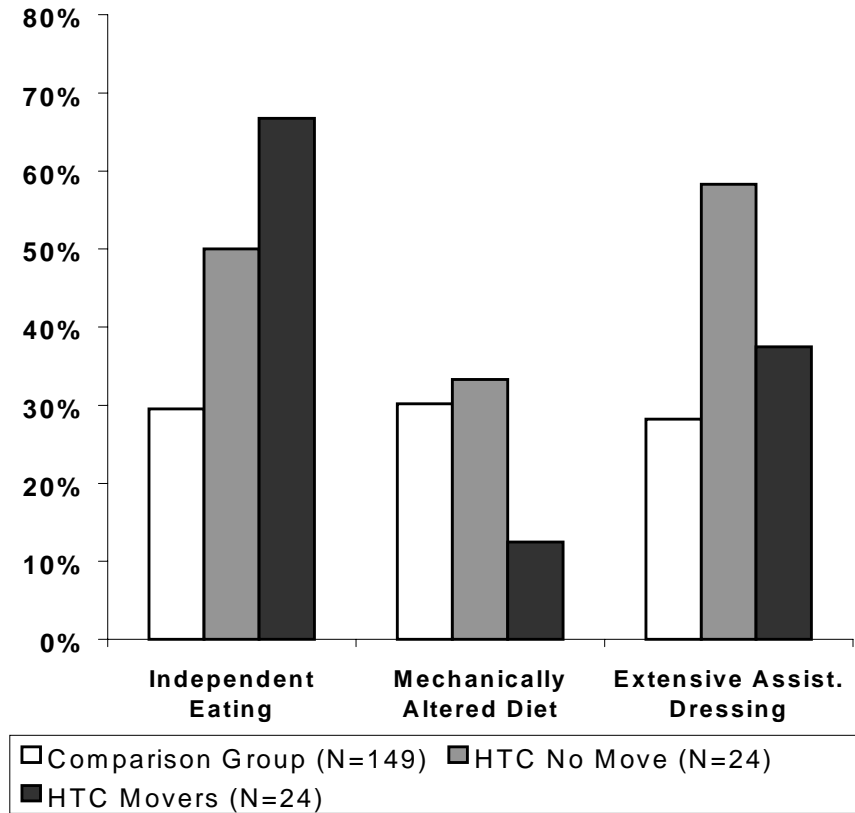
- Members of the comparison group were more likely than either group of participants to have short term memory problems, seizures, incontinence or multiple sclerosis.
- The prevalence of quadriplegia was similar in all three groups.
- Participants were more likely than comparison group members to have diabetes or depression.
- Among participants, movers were less likely than non-movers to have short term memory problems, hemiplegia or depression.

Chart 5. Mobility



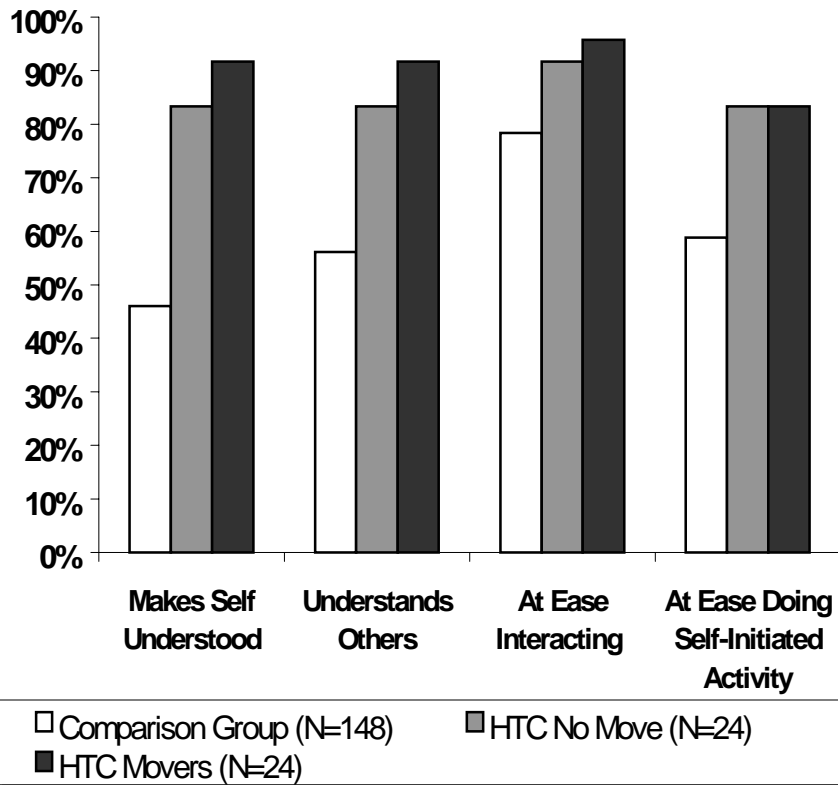
- Movers were most likely to be independent in bed mobility.
- Non-movers were most likely to require extensive assistance with bed mobility and transfers.
- Movers were more likely to wheel themselves and less likely to be dependent in locomotion than the other 2 groups.

Chart 6. Eating and Dressing



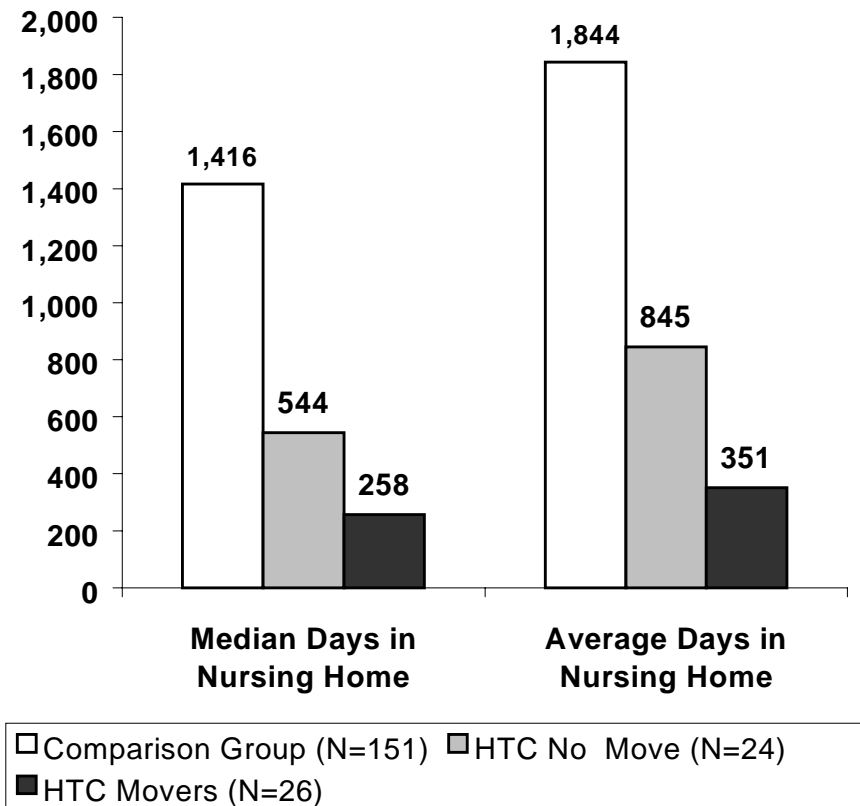
- More movers were independent in eating than either non-movers or comparison group members.
- Movers were less likely to have mechanically altered diets than either non-movers or comparison group members.
- Non-movers were more likely than either movers or comparison group members to need extensive assistance with dressing.

Chart 7. Communication and Interactions



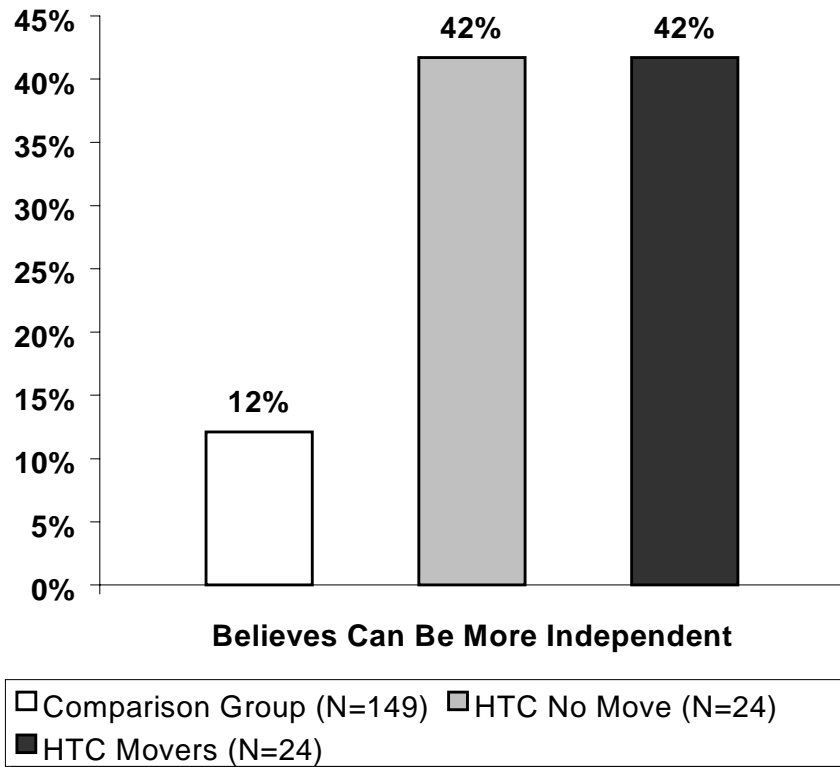
- Participants, particularly movers, were best able to make themselves understood and to understand others and were more comfortable in their interactions with others.
- Participants were more at ease with self-initiated activity.
- While these characteristics may be indicators of success at independent living, they may also suggest that people had to have good communication skills to enroll in the program. They may have had to overcome barriers in order to contact Alpha One.

Chart 8. Length of Stay in Nursing Home



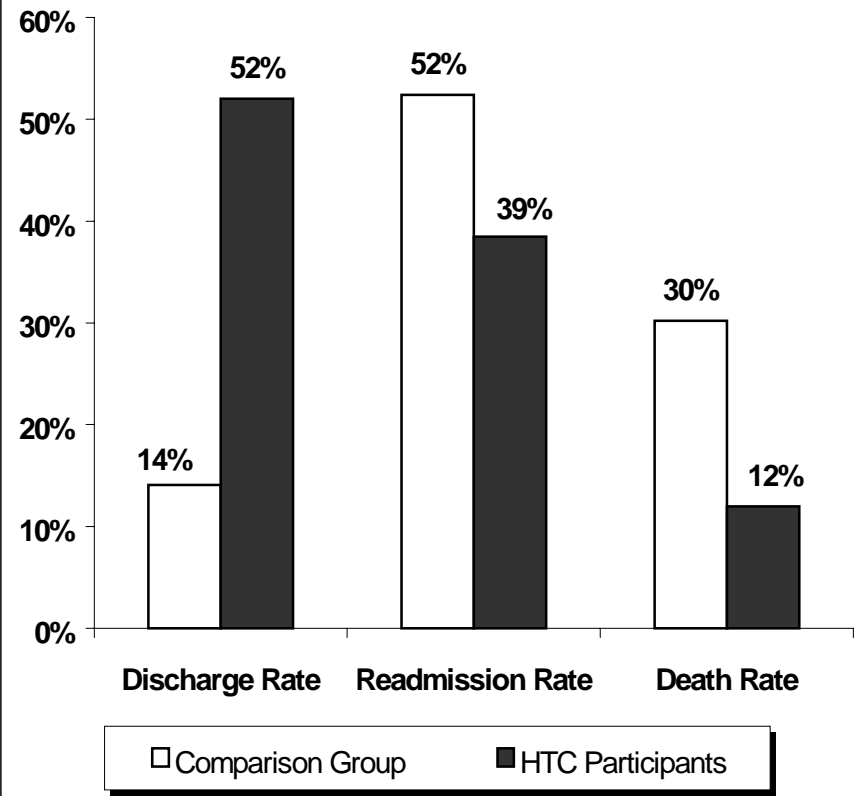
- Participants had shorter nursing home stays than members of the comparison group. Furthermore, movers had shorter stays than non-movers.
- This supports the longstanding presumption of policy makers that transition to the community becomes less likely when people have been in a nursing home for a long period of time.

Chart 9. Able to be More Independent in Daily Activities



- Participants were more likely than comparison group members to believe they could be more independent in the performance of activities of daily living.
- This is not surprising, since participants had to be willing to self-direct their care in the community.

Chart 10. Selected Outcomes



- Participants were more likely to be discharged than comparison group members, suggesting that the program had an impact beyond what would be expected without the existence of a transition program.
- Readmission and death rates were lower for participants than for the comparison group, addressing the possible concern that transition programs could lead to a “revolving door” pattern of readmissions, or result in severe trauma or death.

C. Did the health status of participants improve after they moved out of nursing homes?

The health status indicators reported in Charts 11 through 18 are taken from community long term care assessments (MED) and the consumer survey developed and administered for the evaluation. They include indicators of physical and mental health that were identified by consumers as having particular relevance to them. Sleep patterns are reported here, but might also have been appropriately reported with the quality of life indicators (E).

The indicators are mixed, with some showing improvement, others suggesting decline and still others showing no change over time. In the aggregate, however, this group of health indicators seems to paint a positive picture. Of the 16 indicators reported, 7 suggest improving health, 6 show no change, and only 3 suggest health decline.

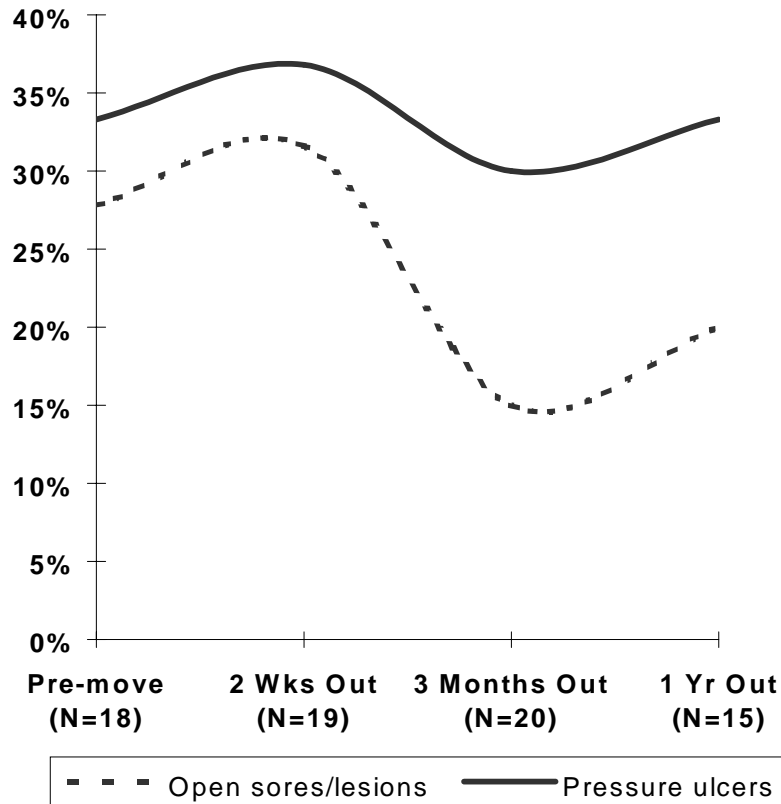
We report the percentage of movers who experienced each indicator. We have multiple years of data only for those who moved early in the program, so the number of participants drops dramatically after the first year. Accordingly, we have chosen to focus on the first year of community living.

As the consumers in our pre-evaluation focus groups had predicted, the 2-week post move time frame does appear to be a time of sudden and significant change, but not always in the direction predicted by our focus group participants. Whereas they had labeled this time “hell week” and associated it with declining well-being, many of the indicators show just the opposite. Some movers apparently experienced a sudden improvement upon leaving the nursing home, possibly as part of an initial euphoria, only to lose some or all of the improvement in the subsequent months.

**“Just get healthy, physically and mentally.
That’s it! You need [your health] to move on.”**

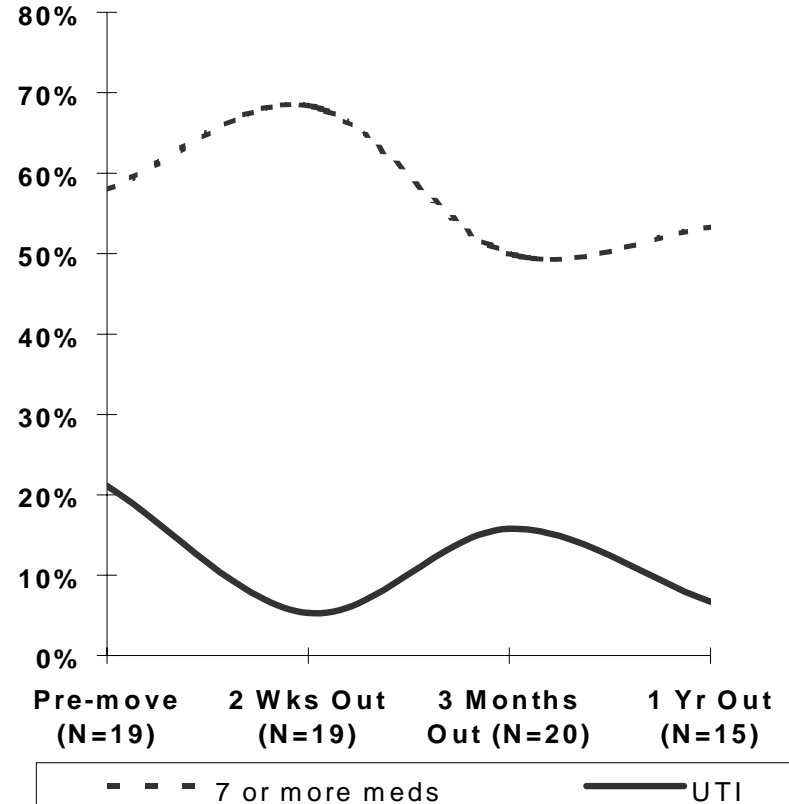
**“Let the doctors live in here for a couple of weeks
before they say we have to stay here.”**

Chart 11. Open Sores or Ulcers



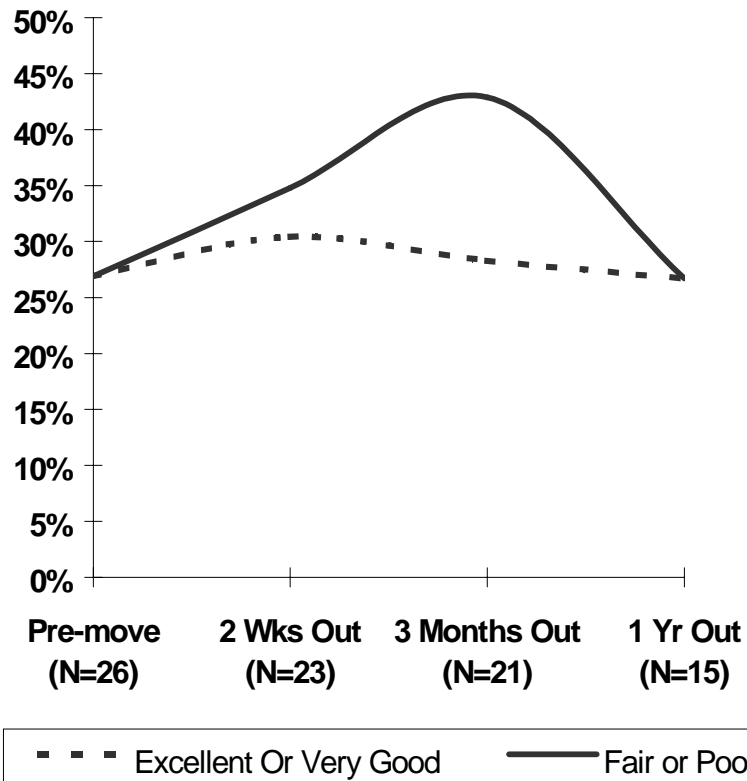
- The percentage of movers with pressure ulcers and open sores or lesions increased immediately following discharge, decreased at the 3-month point, then increased to at or below pre-move levels at the 1-year point.

Chart 12. Seven or More Medications or Urinary Tract Infection



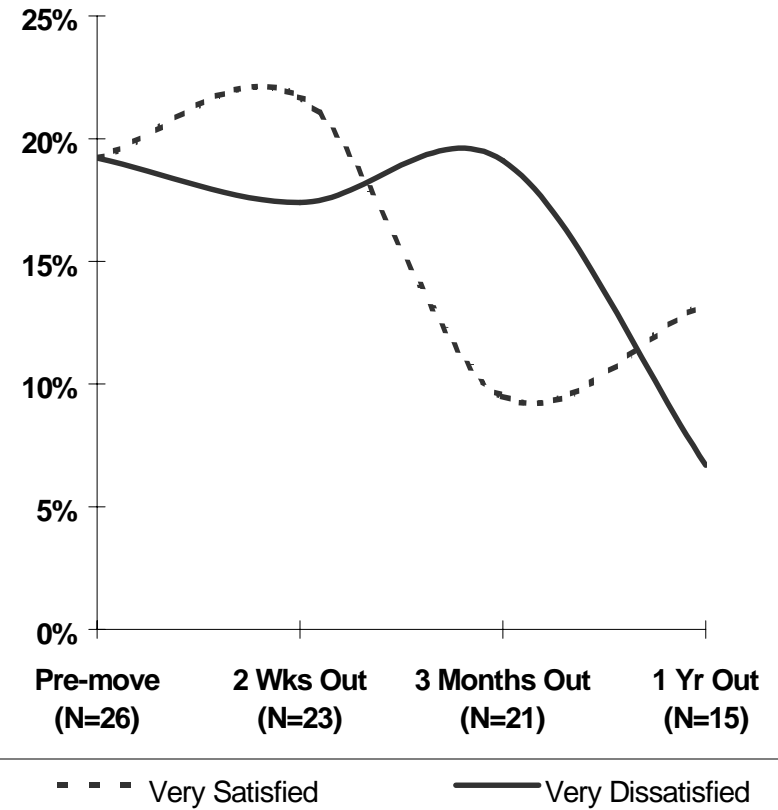
- The percentage of movers with 7 or more medications went up initially (at 2 weeks), then fell and was slightly below the pre-move level at the 1-year mark.
- Presence of urinary tract infection (UTI) had the opposite pattern (it decreased initially, then rose), but was also lower than the pre-move level at the end of year 1.

Chart 13. Self-Rated Health

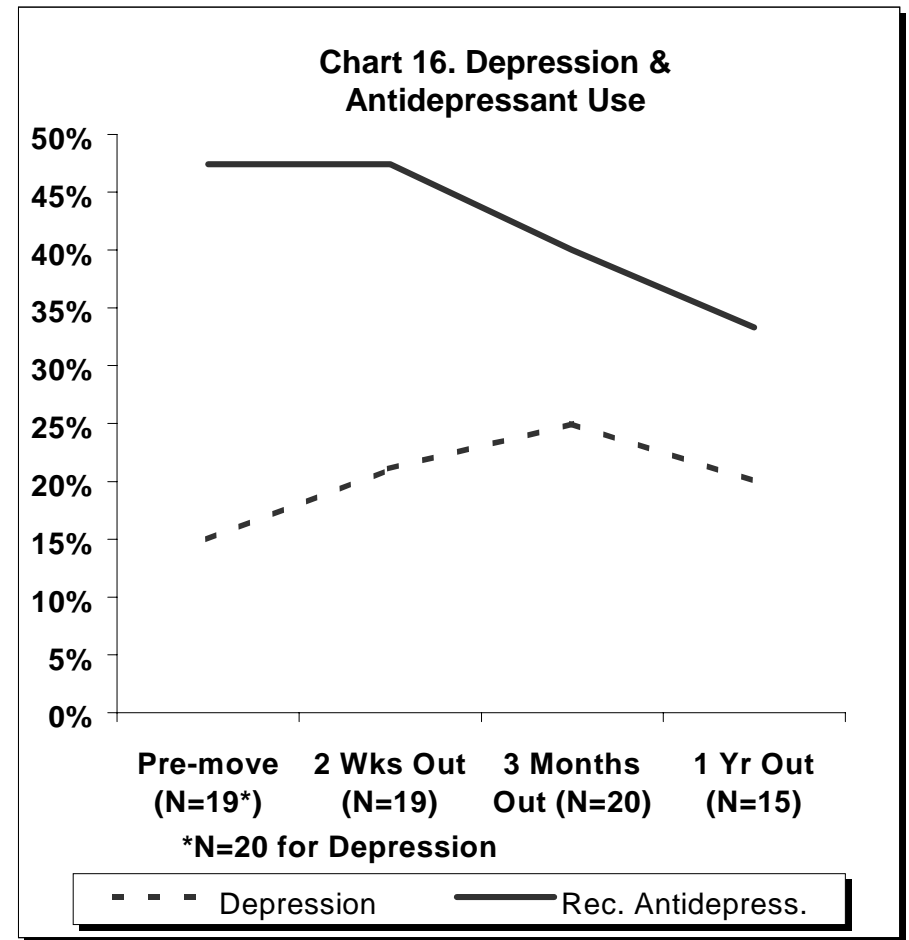
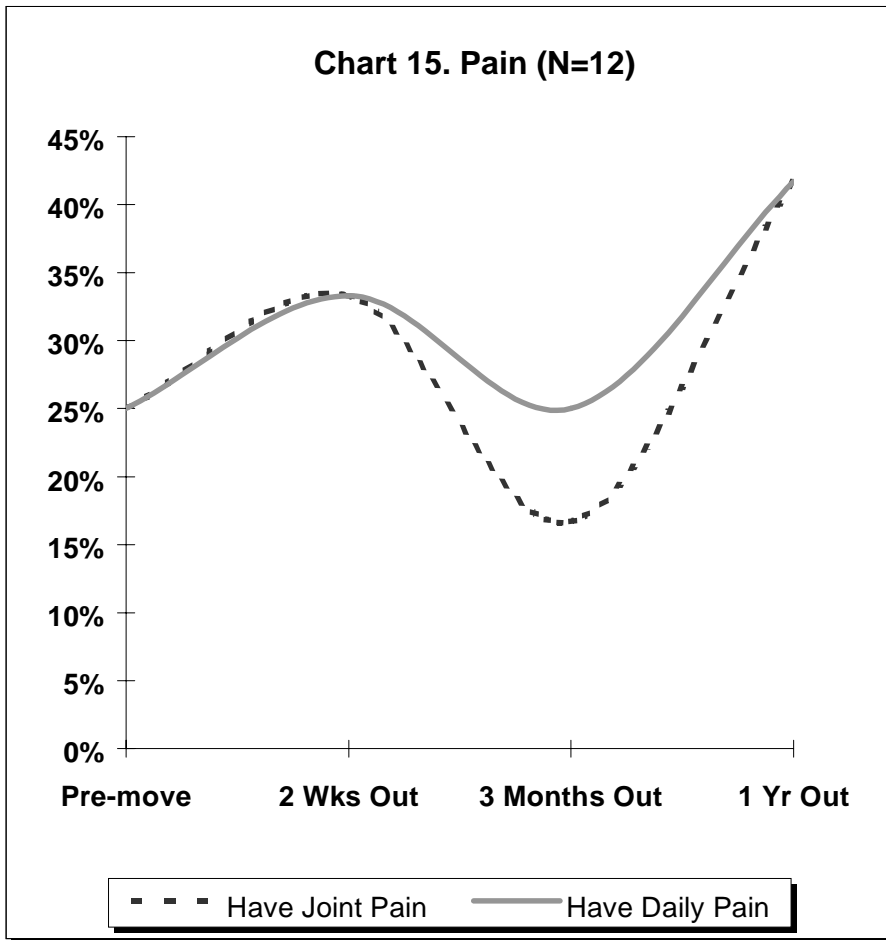


- The percentage of movers who ranked their health as “excellent or very good” was quite constant over time.
- The percentage ranking their health as fair or poor increased in the first 3 months but had returned to baseline levels by the 1-year mark.

Chart 14. Satisfaction with Health

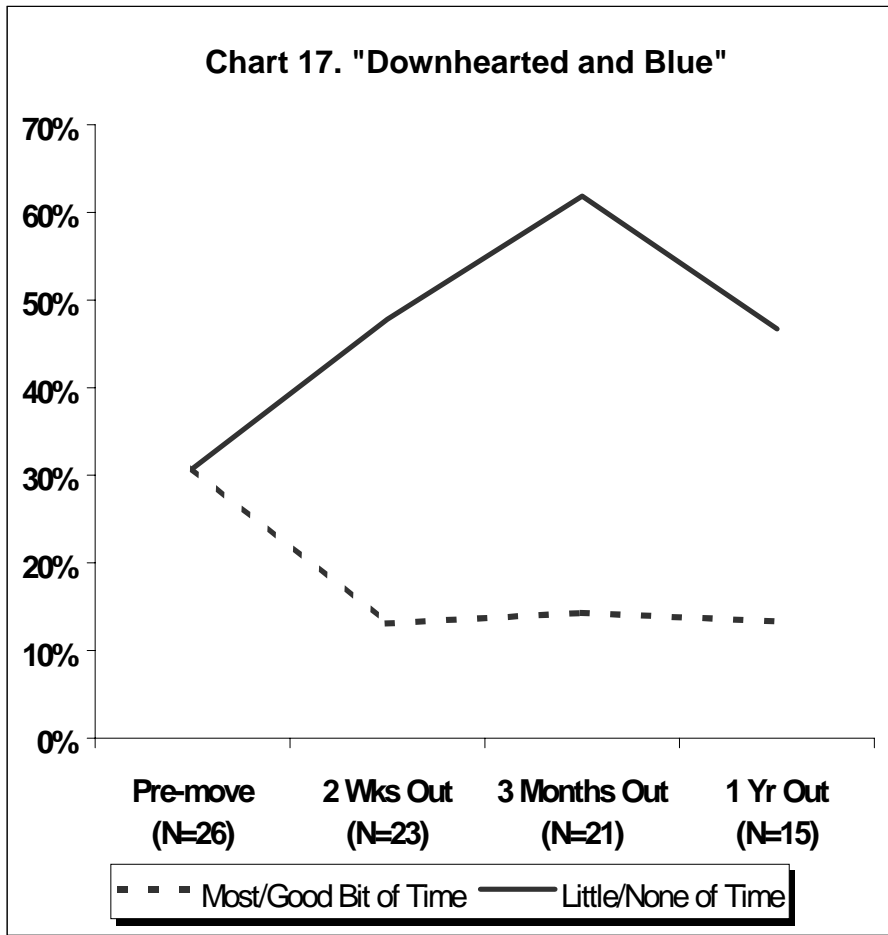


- The percentage of movers who were “very satisfied” and the percentage who were “very dissatisfied” with their health had both declined by the 1-year mark. Living in the community appears to have moderated participants’ satisfaction with their health.

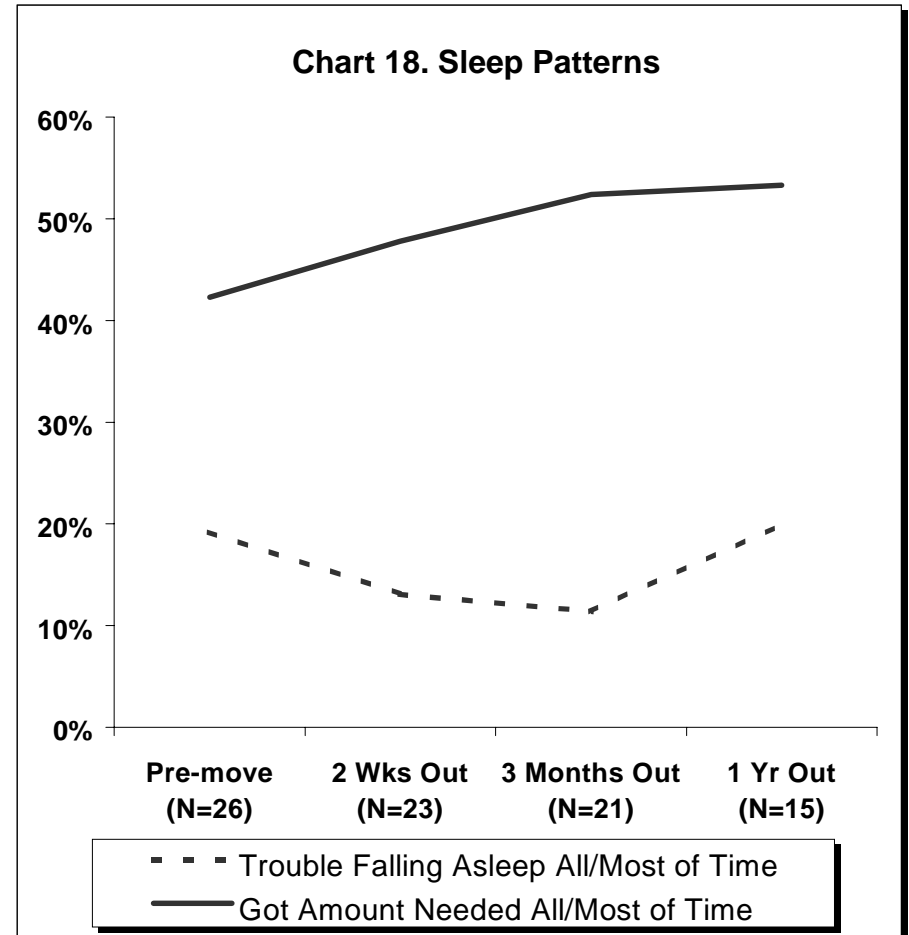


- This chart includes only those who were in the community for a full year to minimize distortion due to change in group size.
- While there is a reduction in reported pain at the 3-month point, both indicators of pain are higher at 1-year than at pre-move.
- Changes in medication regimen and increased physical activity are possible explanations for this observation.

- After an initial increase, the percentage of movers with depression at the 1-year mark was close to pre-move levels.
- Use of antidepressants decreased steadily during the first year.
- Together, these indicators may suggest that some pre-move use of antidepressants was unnecessary, or that declining depression resulted in less use of antidepressants in the community.



- This self-reported indicator offers a less ambiguous view of depression in the community. The percentage of movers who reported feeling downhearted and blue “most or a good bit of the time” fell post-move and stayed at the lower level throughout the first year.



- Sleep does not appear to have changed significantly as people moved out of the nursing home.
- Based on focus group reports we expected to see a short-term worsening of sleep patterns at the two-week mark, but none was observed.
- Movers appear to have “settled in” quickly.

D. Was physical function maintained by participants after they moved out of nursing homes?

With a few exceptions (bed mobility and homemaking) the indicators in Charts 19 through 22 suggest little or no change in physical function over time.

Indicators of functional capacity, including activities of daily living and instrumental activities of daily living were collected in much the same way as the health indicators in the previous section. These data are from the community long term care assessment data (MED), and the consumer survey developed and administered for the evaluation.

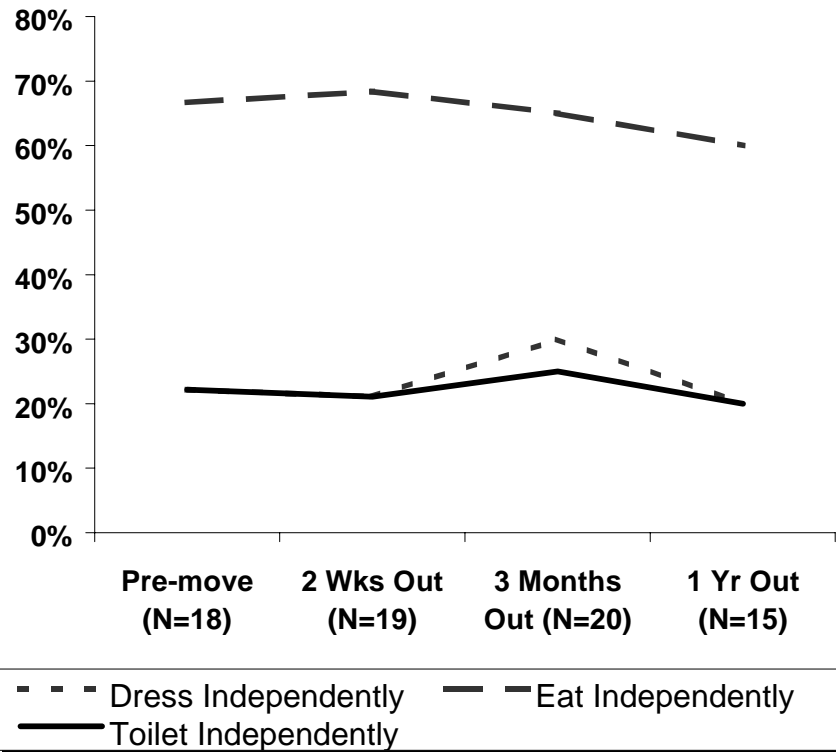
It should be noted that some indicators of function are highly dependent on environment. For example, movers in this study dramatically increased the amount of time spent on homemaking activities, but that very likely is because they did not need to perform homemaking in the nursing home. In other words, an increase in activity does not necessarily suggest enhanced physical ability, but may instead reflect changing opportunities and priorities.

As with the previous health indicators, we are reporting the percentage of movers who experienced the particular indicator at the time intervals shown.

**“When you have a dream, go for it.
Don’t let your disability stop you. It hasn’t been
smooth sailing, but that’s the way life is.”**

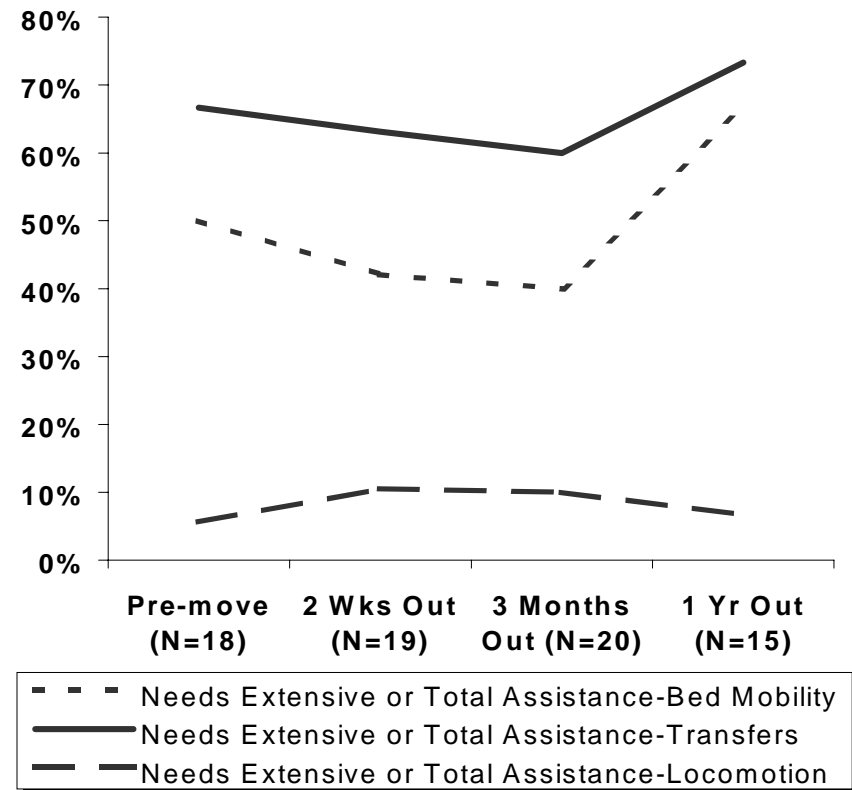
**“Right now, I’m looking for help.
There just isn’t anybody. People I interview are not
happy with the pay.”**

Chart 19. Independence in Activities of Daily Living



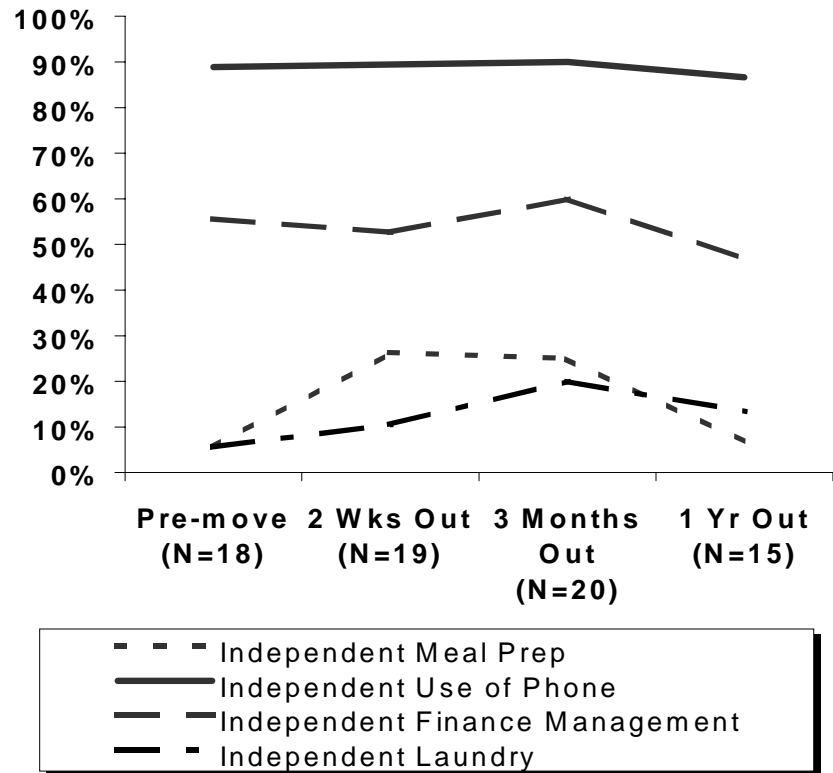
- The percentage of those who moved who were able to dress themselves, eat without assistance and use the toilet independently did not change significantly after moving to the community.

Chart 20. Need for Extensive or Total Assistance with Mobility



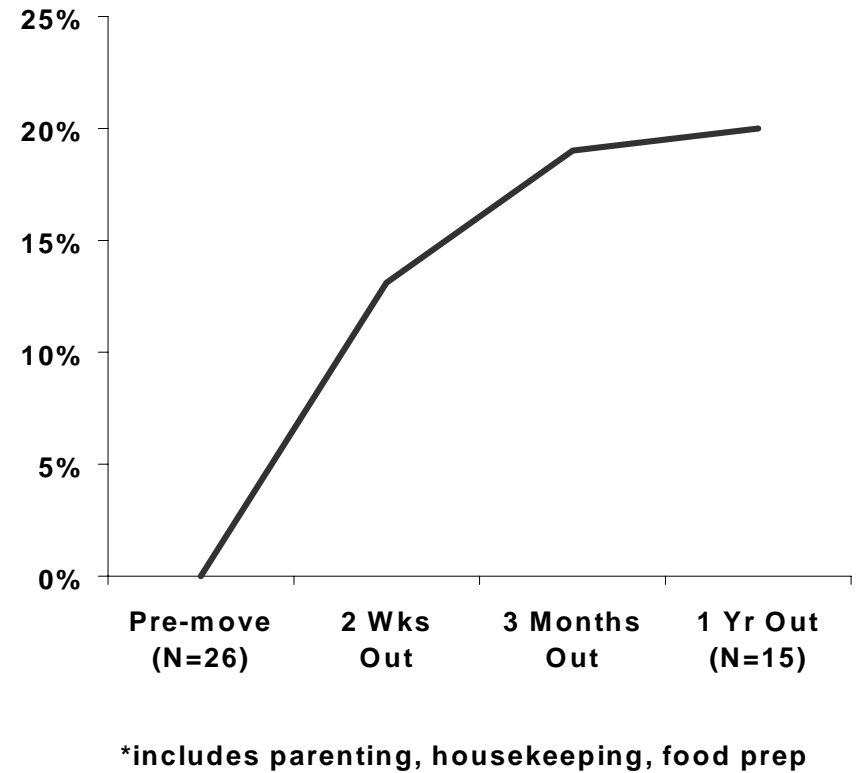
- The percentage of movers who needed extensive or total assistance with transfers and bed mobility decreased at 3 months, but by the 1-year mark, was slightly higher than in the nursing home.
- The percentage of movers who needed extensive or total assistance with locomotion was relatively stable over time.

Chart 21. Performance of Household Chores



- There was very little change over time in the percentage of movers who independently prepared meals, used the phone, managed personal finances, or did laundry (chores referred to as instrumental activities of daily living).
- Presumably, personal attendants replaced nursing home staff in assisting movers with many of these tasks.

Chart 22. Active Homemaking* for 21 or More Hours per Week



- By the end of Year 1, participation in homemaking for 21 or more hours a week was reported by more than one fifth of those who moved out of nursing homes.
- Increases in homemaking activity are probably related more to changing opportunities than to changing function.

E. Did quality of life improve for participants after they moved out of nursing homes?

With a few exceptions, this evaluation suggests improved quality of life for movers. Of the 8 quality of life measures reported in Charts 23 through 25, 5 showed improvement and 3 were unchanged following moves.

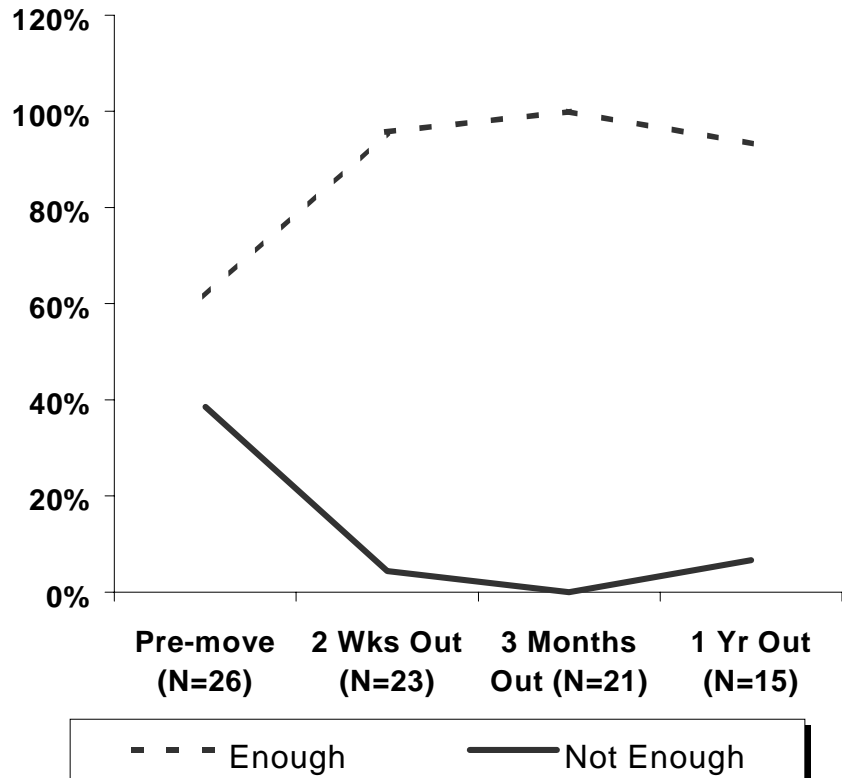
Interestingly, movers did not feel increased control over work, socialization or family relationships. None of the movers had obtained paid employment within the study period, which may explain their feelings of having no greater control over that area of life. Similarly, control over socialization did not increase for movers. This is not surprising in the short run, given the move from a group living situation, where others are in immediate proximity, to independent living, most often in a private home or apartment. An important quality of life question that requires a longer study period is whether socialization increases over long periods of time in the community, or whether isolation is a long term challenge for people living independently.

Quality of life measures were selected with input from consumers and collected through in-person interviews.⁴

“Just getting home, being home, is very satisfying. You don’t have to answer to people. I have more control of my life at home.”

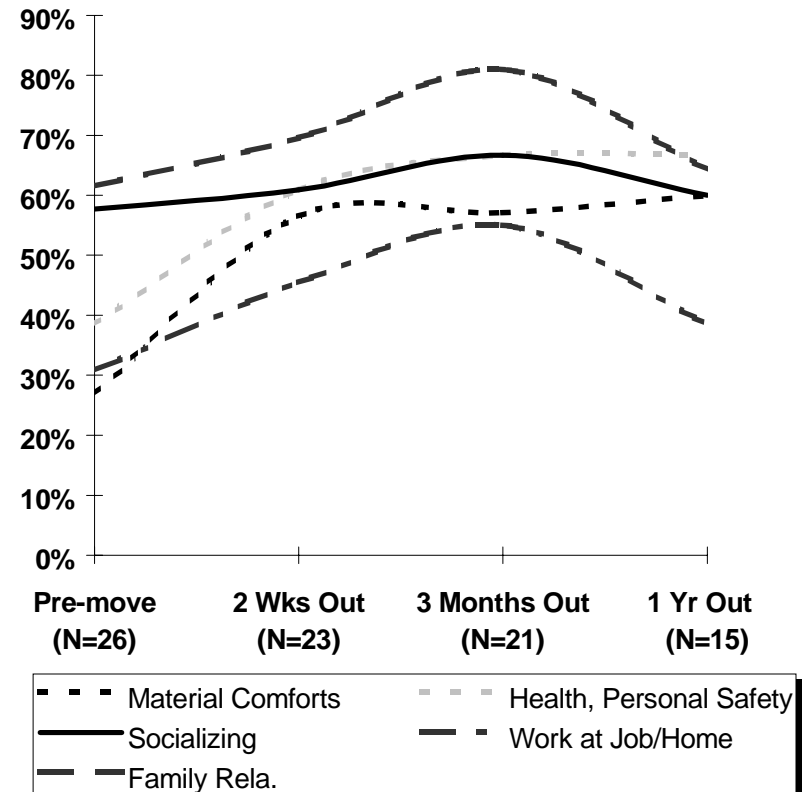
⁴ Phillip Beatty of the National Rehabilitation Hospital Research Center and James Conroy of the Center for Outcome Analysis provided helpful guidance and shared quality of life indicators that were adapted for our survey.

Chart 23. Sense of Privacy



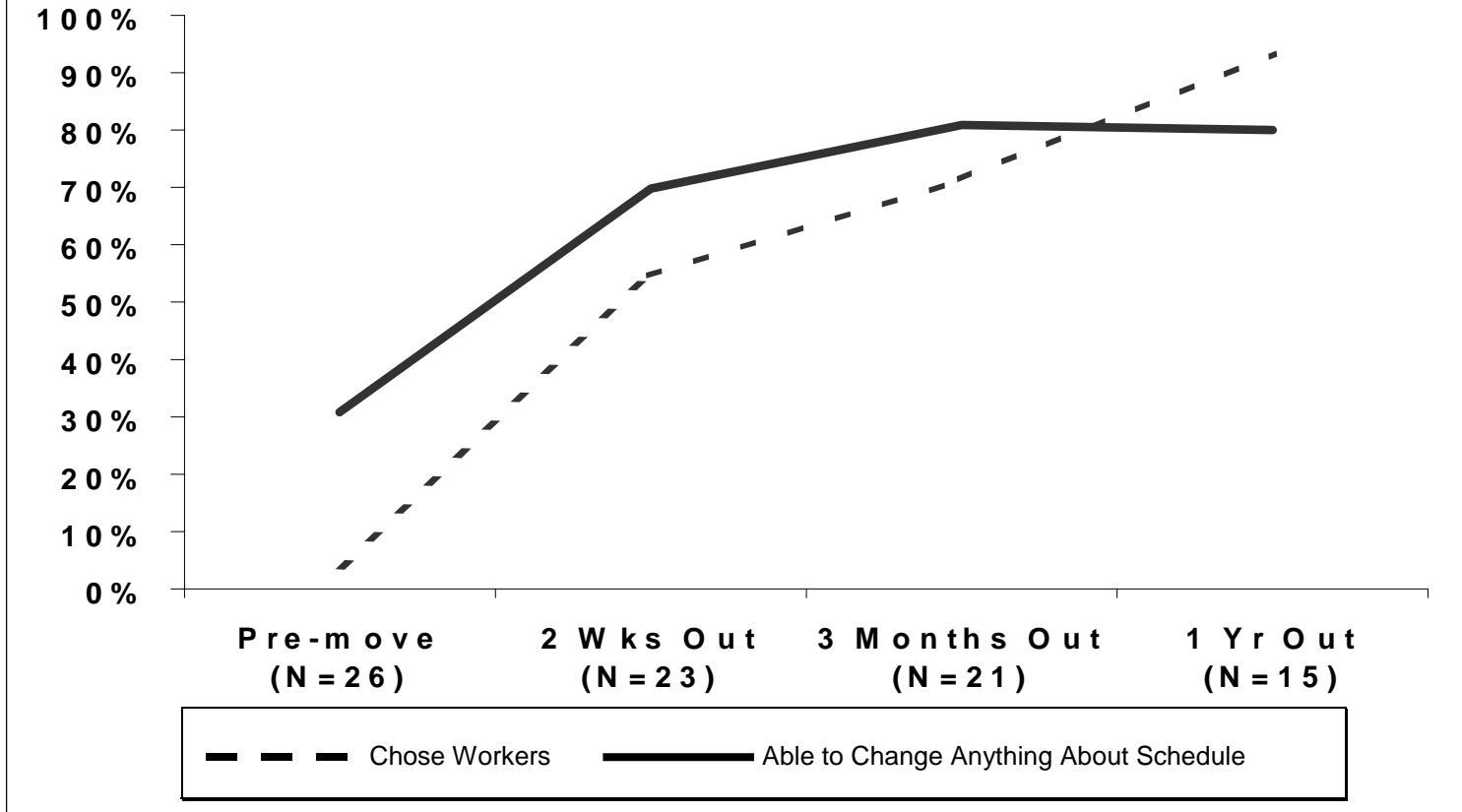
- Nearly 100% of movers reported that they had enough privacy in the community immediately following their moves.
- About 60% of movers reported having enough privacy in the nursing home.

Chart 24. Life Control



- The percentage of movers who reported having “complete” or “a lot” of control over material comforts and health and personal safety increased in the community.
- Reported level of control over socializing was quite constant over time.
- Control over family relationships and work increased for the first 3 months in the community, but had fallen back to near nursing home levels by the 1-year mark.

Chart 25. Choice of Workers and Schedules



- The percentage of movers who exercised choice over workers and schedules increased immediately following the move and throughout the first year in the community.
- This is related to the consumer-directed services model at the heart of *Home to the Community*. Had movers been going to alternative residential care settings or receiving traditional home care services, they may not have had as much control in these areas.

F. What else was learned about participants who moved out of nursing homes?

Charts 26 through 29 present additional information about movers that may be of interest to policy makers and program designers.

Medicaid claims were found for 16 of the 26 movers, fewer than anticipated. This is probably explained by loss of Medicaid eligibility following moves due to lower medical expenses available for spend-down calculations. Among movers who did have Medicaid claims, the categories of service accessed by the greatest number of movers were prescription drugs, home- and community-based waiver services, Medicare crossover claims, transportation, and durable medical equipment and supplies.

Nearly three-quarters of movers were enrolled in *Home to the Community* for 180 days or less before moving out of the nursing home. This length of program participation (180 days) is a significant time frame to examine because federal Medicaid policy was recently clarified to allow states the option of reimbursing certain case management services for up to 180 days prior to a move out of a nursing home.⁵ The remaining quarter of movers were enrolled in *Home to the Community* for more than 180 days. The transition services they received from Alpha One would not have been fully reimbursed under current federal Medicaid policy. As reported earlier in this paper, non-movers had a longer length of stay in the nursing home than movers. If transition programs are to successfully target people with longer nursing home stays, reimbursement policy may need to be extended beyond the 180 days currently available under federal Medicaid policy.

Most movers lived alone in apartments or houses when they left the nursing home. Though this might not be expected with other population groups, it is not a surprising finding for this program, since *Home to the Community* is a consumer-directed services model targeted at younger adults with disabilities.

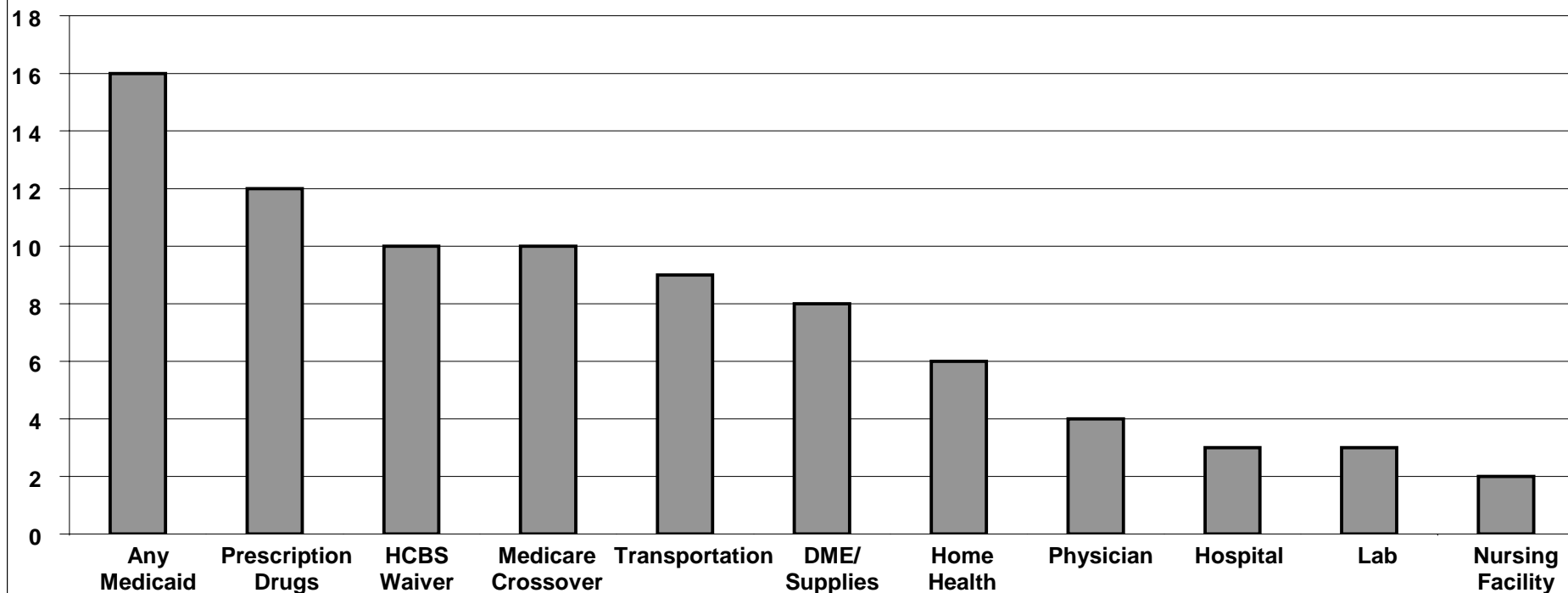
Two-thirds of movers had housing subsidies. Accessible and affordable housing is clearly critical to the success of transition programs. This finding supports the federal government's emphasis on housing as a critical component of nursing home transition programs.⁶

**“Try to find a house before you move out. It’s hard.
I found out the first time.”**

⁵ Health Care Financing Administration, Center for Medicaid and State Operations. Olmstead Update No. 3. (July 25, 2000).

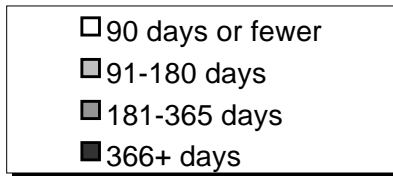
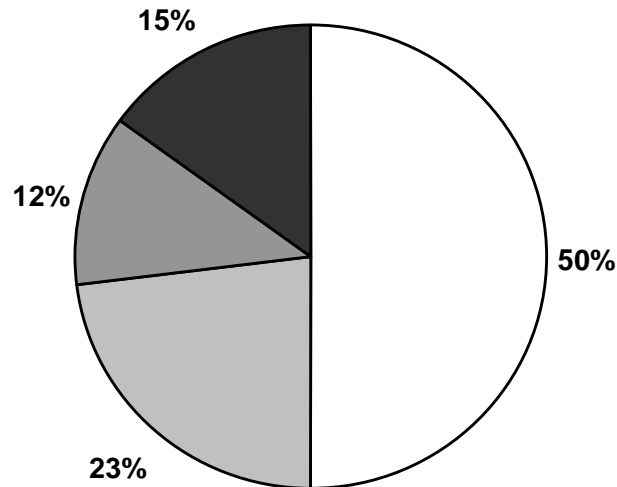
⁶ See HCFA's "Systems Change Grants for Community Living" (April 30, 2001).

Chart 26. Number of Movers with Medicaid Claims in 1st Year Post-move, by Category of Service



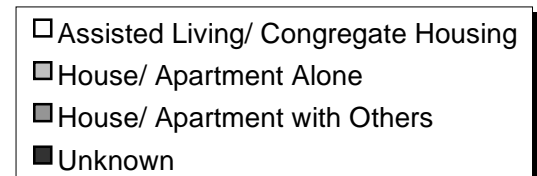
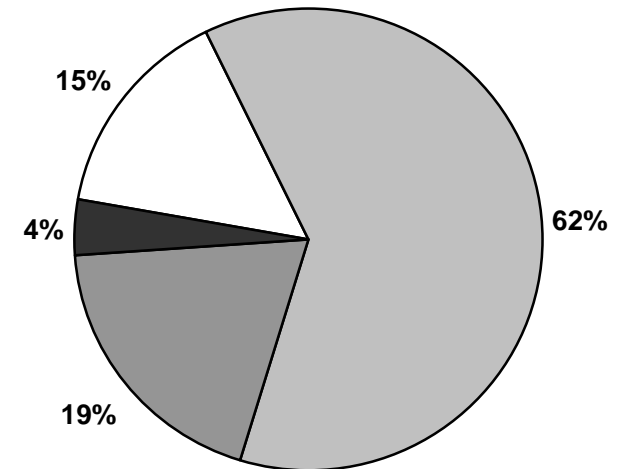
- The left-most bar represents the 16 movers with a Medicaid claim during the first year post-move.
- Following their move, fewer than half of movers with Medicaid claims used home health, physician, hospital, lab or nursing facility services billed directly to Medicaid. These low-use categories are services frequently covered by Medicare, and may have been used by dually eligible movers and billed to Medicare. Ten movers had Medicare crossover claims (fourth bar from left).
- Interestingly, 6 of the 16 movers covered by Medicaid while living in the community did not receive services billed under the Home- and Community-based Waiver program.

Chart 27. Days Enrolled in HTC Prior to Move (N=26)

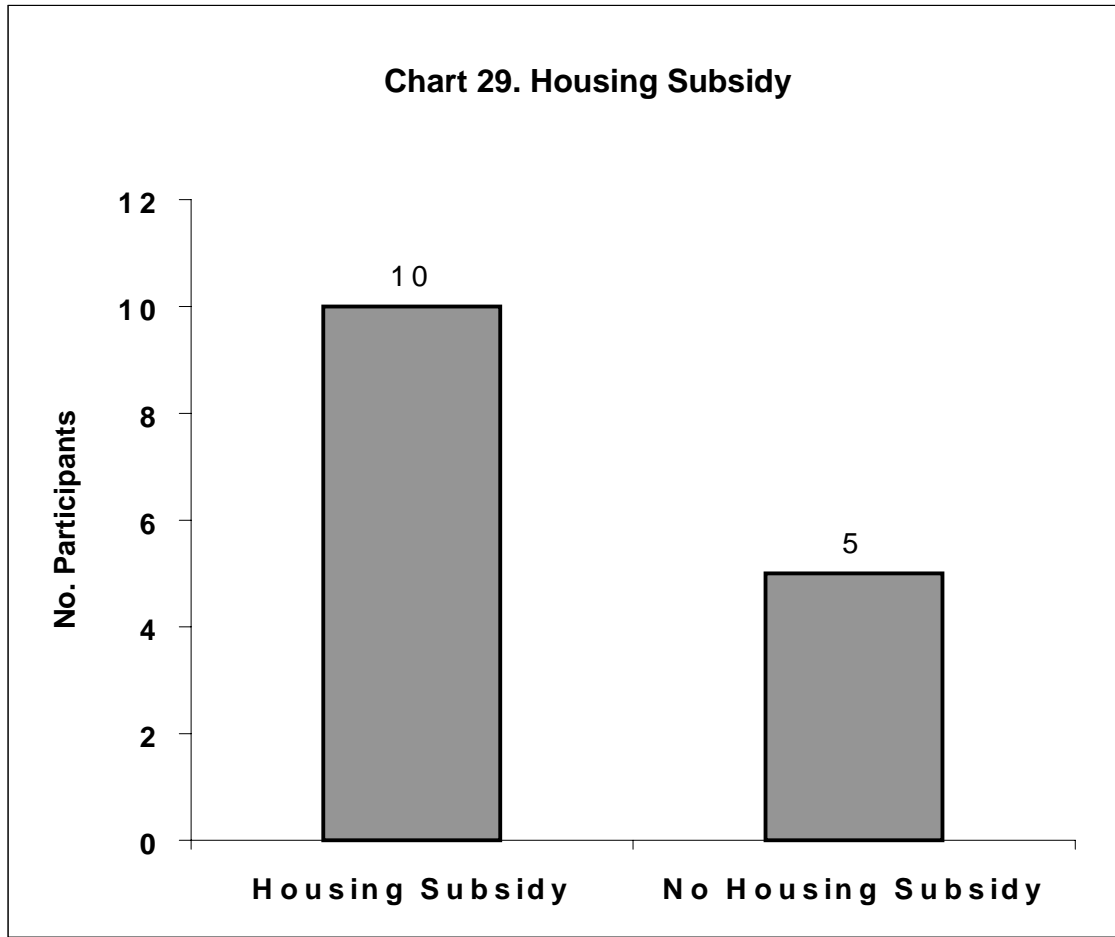


- Nearly three-quarters of movers were enrolled in HTC for 180 days or less before moving. States may elect to reimburse certain case management services for up to 180 days prior to a move out of a nursing home under current federal Medicaid policy.
- Current federal Medicaid policy would not have fully covered the pre-move period for the remaining 27% of HTC movers.

Chart 28. Living Arrangements of Movers (N=26)



- Nearly two-thirds of movers went from the nursing home into a house or apartment where they lived alone.
- 15 % of those who moved opted for assisted living.
- Nearly 20% chose to live with others (in other than an assisted living facility) when they moved out of nursing homes.



- Of the 15 people who completed the financial survey at the 1-year mark, 10 had a housing subsidy.
- Housing subsidies were generally easier for participants to obtain than accessible housing units.

G. How did public expenditures for participants in the community compare to participants' public expenditures in nursing homes?

Charts 30 and 31 provide information regarding certain public expenditures for participants. For this small group of people, the combined public expenditures of Medicaid, housing, transportation, food assistance and fuel assistance were lower in the community than Medicaid expenditures in the nursing home prior to moving.

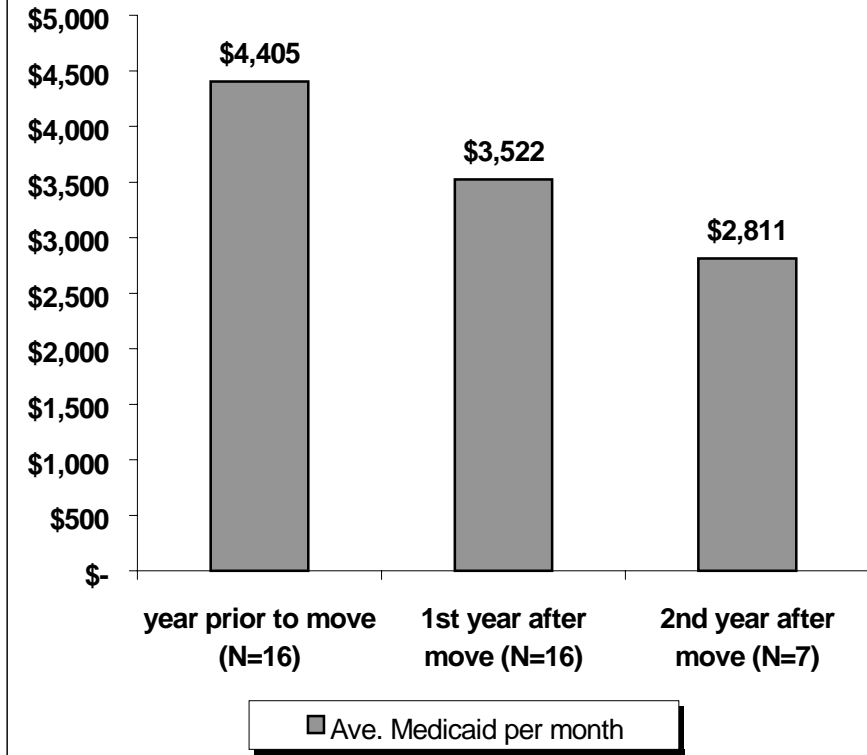
Although Medicaid claims were available on more than 16 people for the pre-move period, we are reporting for the 16 movers who had both pre- and post-move claims. We felt this was important to ensure a fair comparison of public expenditures between the nursing home and community services. Medicaid expenditures for participants decreased in the first year out of the nursing home, and decreased further in the second year. Only 7 of the 16 participants with pre- and post-move Medicaid claims were out of the nursing home for a full second year, so the average expenditure for the second year describes a very small group of movers.

Financial surveys were conducted annually in the community to determine what other public services movers were receiving, and whether they were receiving earned income that might have resulted in payment of offsetting taxes. Other public expenditures were calculated for housing, transportation food assistance and fuel assistance.

Although at least 10 movers are known to have been Medicare beneficiaries (through the presence of Medicare crossover claims in their Medicaid files), Medicare data were not available for this evaluation. This is a serious limitation, since Medicare expenditures for dually eligible beneficiaries (eligible for both Medicare and Medicaid) with long term care needs tend to be higher in community settings than in nursing homes.

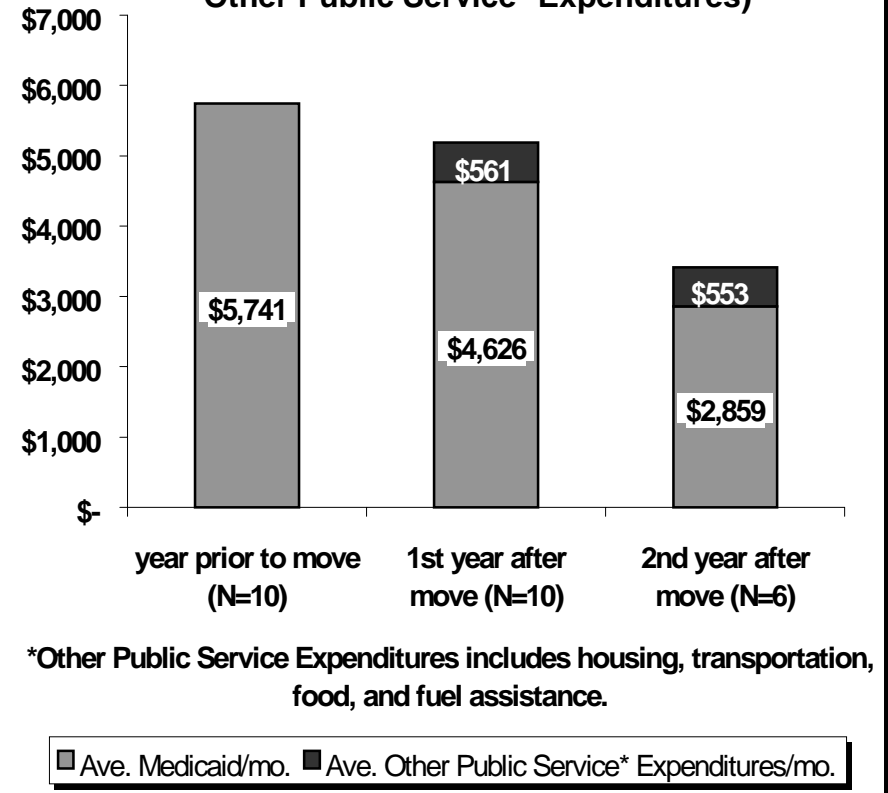
“Affordable housing is a very big plus. When I moved out, nobody warned me about the amount of money I would be sinking into laundry. \$20 per month is a lot for someone on a fixed income.”

Chart 30. Average Monthly Medicaid Expenditures per Mover (for Movers with Pre- & Post-move Claims)



- Average monthly Medicaid expenditures per mover decreased from \$4,405/month pre-move to \$3,522/month in the first year that movers lived in the community.
- Average monthly Medicaid expenditures per mover decreased further in the second year (to \$2,811/month), though data were available on fewer people.

Chart 31. Average Monthly Public Service Expenditures (for Movers with Other Public Service* Expenditures)



*Other Public Service Expenditures includes housing, transportation, food, and fuel assistance.

- When Other Public Service Expenditures (housing, transportation, food and fuel) were added to Medicaid, community expenditures were still lower than nursing home expenditures.
- Average Medicaid costs are higher for this subset of movers (those who had other Public Service Expenditures) than for all movers with Medicaid claims, shown on Chart 30.

H. Did the attitudes of key nursing home staff about the ability of people with disabilities to leave nursing homes change over the life of the project?

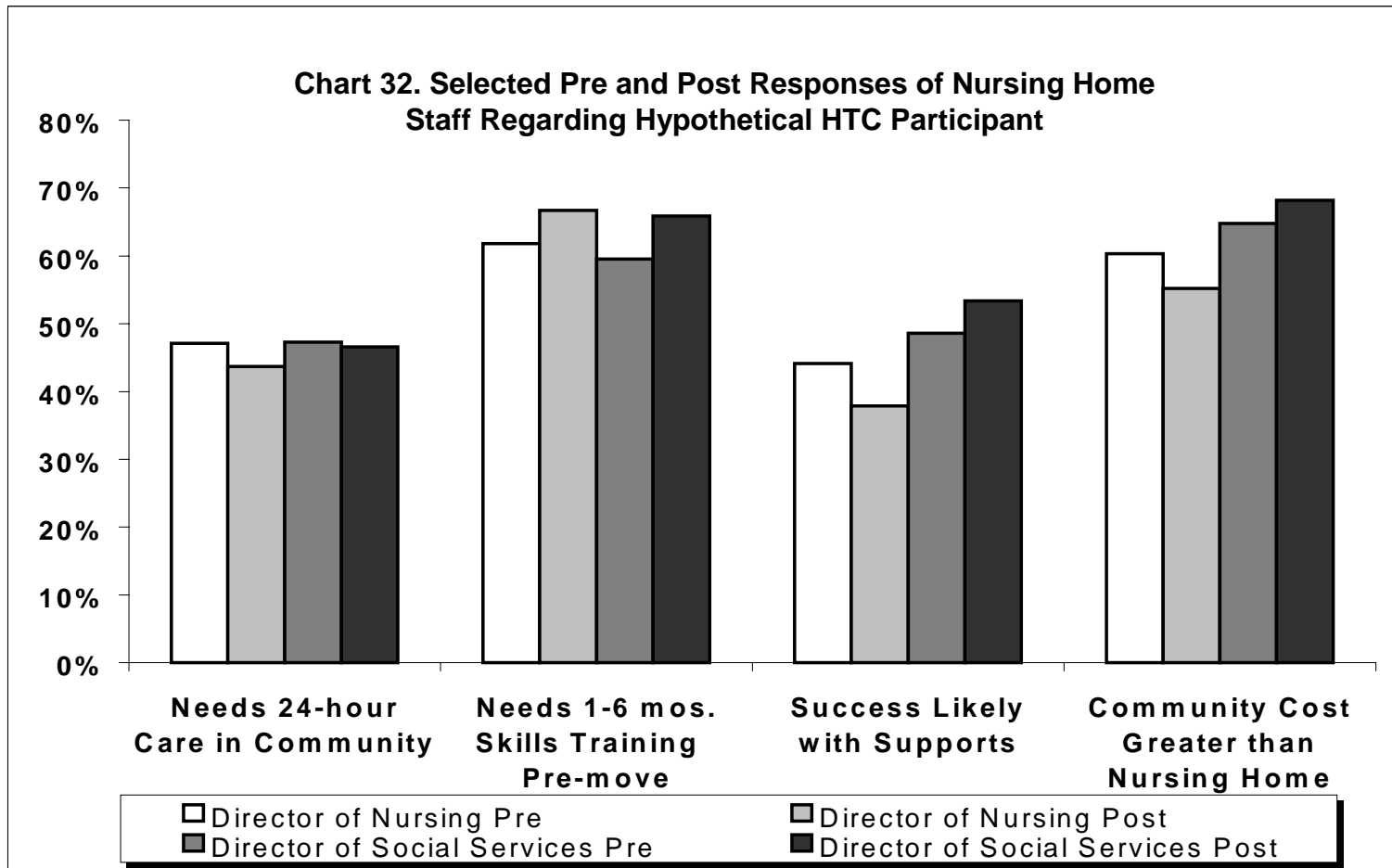
In order to determine whether the attitudes of key nursing home staff toward independent living changed during the project, we administered a pre/post mail survey at the beginning and end of the program. We found no significant changes in attitudes toward the ability of people with disabilities to leave nursing homes and establish independent living arrangements.

In consumer focus groups held before the evaluation began, consumers who had lived in nursing homes identified the directors of nursing (DONs) and the social services directors (SSDs) as the staff most likely to influence moves to independent living. Accordingly, we chose to survey those groups in all Maine nursing homes.

Responses did not change significantly over time, and the responses of DONs and SSDs were quite similar. We did not find any differences between nursing homes with *Home to the Community* participants and those with no participants. We also did not find any significant differences between nursing homes in urban areas and those in rural areas.

Although the responses of nursing home staff were more conservative regarding independent living than the actual experiences of *Home to the Community* participants, the survey responses suggested an openness to independent living when appropriate community supports are available. The gulf between nursing home staff and advocates of independent living may not be as wide as popularly believed. It may be fruitful for transition program designers to engage nursing home staff in program design and operation.

“Maintain contact with staff, both in the nursing facility and at Alpha One...It’s good to have someone to give you a hand. Find someone you can trust.”



Nearly half of the respondents felt that a hypothetical HTC participant described in both a pre and post survey:

- would require 24-hour-a-day care in a community setting; and
- was likely to succeed with the appropriate supports.

Nearly two-thirds of survey respondents felt that the participant:

- would need 1 to 6 months of life skills training before moving; and
- would have higher expenditures in the community than in the nursing home.

I. Did the project have a lasting impact on public policy?

To determine whether or not the program had an impact on public policy, we asked Alpha One staff to provide a list of targeted policy barriers when the program began in 1997. At the end of the program in 2001, we asked them to provide a self-assessment of progress in addressing those barriers. We then conducted key informant interviews with State officials and reviewed State and federal documents to verify that certain policies had changed or not changed over the life of the project.

Although Maine Medicaid policy has not changed to allow for explicit reimbursement of the nursing home transition activities provided in this demonstration program, there is some evidence that the program has influenced public policy in Maine and nationally.

- **DME Prior Approval.** Most tangibly, the Medicaid prior approval process for durable medical equipment was streamlined to ensure timely delivery of wheelchairs and other equipment to people moving out of nursing homes. This was done administratively as a result of discussions between the Maine Department of Human Services and Alpha One;
- **Influence on National Demonstrations.** As a very early nursing home transition project, *Home to the Community* may have had an influence on federal demonstrations in this area. For example, the Health Care Financing Administration's 2001 "Systems Change Grants for Community Living" includes additional nursing home transition grant opportunities, and specifically creates opportunities for states to partner with Independent Living Centers;
- **Clarification of HCFA Policy.** Although Maine Medicaid still does not cover nursing home transition services explicitly, there is evidence that the Maine Department of Human Services supports the program concept. In response to Alpha One's request to cover the service, DHS asked the Health Care Financing Administration for guidance on coverage. It may have been Maine's inquiry that triggered a clarification to be issued by HCFA in Olmstead Update No. 3 (July 25, 2000). In that letter, HCFA clarifies that transition services could be provided in the form of targeted case management or Home- and Community-Based Services Case Management for up to 180 days before discharge from the nursing home. The Maine Department of Human Services subsequently declined to support a bill before the Maine Legislature in 2001 that would have authorized Medicaid funding for transition services, but the Department's opposition was related to a large deficit in the State's Medicaid budget, rather than opposition to the concept. The Department consistently opposed all proposals before the Legislature that would have created new categories of Medicaid reimbursable services; and
- **Housing Inventory.** Alpha One is working with Maine State Housing Authority to improve the availability of accessible housing in Maine. Together, the agencies are creating an inventory of accessible housing that will provide a baseline for future expansion efforts.

IV. Lessons and Implications

A number of lessons may be gleaned from *Home to the Community* to inform policy makers and program designers. They include the following key areas.

- *The likelihood that someone will move out of a nursing home is related to the length of time the person has been in the nursing home. Movers in Home to the Community had significantly fewer days in the nursing home than non-movers. While targeting transition services to people with shorter length of stay raises valid equity concerns, policy makers and program designers should be aware that time appears to be a critical factor in transition programs.*
- *Availability of affordable and accessible housing is critical. After Medicaid, housing subsidy was the form of public support used by most participants. The average monthly housing subsidy was \$510.*
- *Current federal Medicaid reimbursement policy for transition services falls short for some potential movers. Current federal policy allows, at the option of states, reimbursement of transition services under case management reimbursement categories for up to 180 days prior to a move out of a nursing home. While nearly three-quarters of movers were enrolled in Home to the Community for 180 days or less before moving out of the nursing home, the remaining quarter of movers were enrolled for more than 180 days and would have exhausted their benefits.*
- *The consumer-directed services model offered in Home to the Community appeared to work well for those who enrolled in the program, but it limits the target group for such programs. Those who do not wish to direct their own care are not attracted to this program model. If states want to serve larger and more diverse target populations, they should consider offering a choice of transition program models to consumers.*
- *A nursing home transition program is more likely to enjoy a high participation rate if the program is well integrated into a State's existing long term care entry and reassessment mechanisms. Doing so makes it very easy to identify and discuss options with members of the target group. For example, county single-entry point agencies were key players in Colorado's project, and participation was relatively high.*
- *Related to the previous lesson, identification of participants is easier when a state initiates a project and can share confidential consumer information with its project contractors. In Home to the Community, Alpha One undertook the project independent of the State with grant funding. Because it was not acting as an agent of the State, Alpha One did not have direct access to the target group.*
- *Nursing home staff should be engaged in transition projects. Our survey of key nursing home staff and comments from participants suggest that nursing home staff could provide very beneficial support to potential movers if engaged in transition efforts.*

V. Summary

Following participant moves, changes in health status were somewhat mixed but showed greater improvement than decline on balance. Two health status indicators of particular interest suggested improvement. Urinary Tract Infections were less frequent; and use of anti-depressants was lower with no increase in diagnosed depression. These are both areas associated with avoidable decline in health and physical function. Conversely, self-reports of pain increased following moves. Increased pain may be attributed to changes in medication, changes in movers' preferences for more frequent medication, or increased physical activity.

For the most part, physical function did not change when participants moved to the community. One indicator that showed a dramatic increase, the number of hours spent on homemaking, probably reflects changing opportunities and priorities in the community rather than changes in function.

Perhaps most importantly, movers' reports of improved quality of life were sharp with regard to 3 measures: privacy, choice of workers and schedule control. These indicators of quality of life were identified as important to consumers during pre-evaluation meetings.

Finally, compared with pre-move Medicaid expenditures, public expenditures for care were lower for participants after they moved out of nursing homes. This conclusion does not consider Medicare expenditures, however. To fully capture and compare the public cost of nursing home residence and community living, Medicare claims data are essential. Nonetheless, from the vantage point of state policy makers with state budget responsibilities, it appears that a nursing home transition program can be a cost-effective strategy that makes community living options available to certain nursing home residents.

As previously noted, the findings from this evaluation are severely limited by the small number of movers and relatively short period of post-move observation. A longer observation period in future evaluations of this nature may provide additional insight regarding longer-term or "steady state" levels of homemaking involvement, employment, and socialization.

Appendix A. List of Data Sources

Data used in this evaluation came from the following sources. Copies of instruments are available on request from the Muskie School of Public Service, University of Southern Maine.

Quality of Life Indicators

- In-person Consumer Survey
- Minimum Data Set (MDS), versions + and 2.0

Health and Mental Health Status Indicators

- In-person Consumer Survey
- Participant Progress Notes
- Medical Eligibility Determination (MED)
- Minimum Data Set (MDS), versions + and 2.0
- Medicaid Claims Data

Physical Function Indicators

- In-person Consumer Survey
- Participant Progress Notes
- Minimum Data Set (MDS), versions + and 2.0
- Medical Eligibility Determination (MED)

Public Expenditures

- Medicaid Claims Data
- Participant Financial Survey

Attitudes of Nursing Home Staff

- Nursing Home Staff Survey

Policy Impact

- Key Informant Interviews
- Document Review



EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE educates leaders, informs public policy, and broadens civic participation. The School links scholarship with practice to improve the lives of people of all ages, in every county of Maine, and in every state in the nation.

EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE
96 Falmouth Street
PO Box 9300
Portland, Maine 04104-9300

TELEPHONE (207) 780-4430
TTY (207) 780-5646
FAX (207-4417

www.muskie.usm.maine.edu



**UNIVERSITY OF
Southern Maine**

A member of the University of Maine system