



***Quality Care, No Matter Where:
Successful Nursing Home Transitions***

Produced By



1001 Connecticut Avenue, NW, Suite 425

Washington, DC 20036

Tel: (202) 332-2275

Email: info@theconsumervoice.org

Website: www.theconsumervoice.org

July 2015

The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. We are a primary source of information and tools for consumers, families, caregivers, advocates, and ombudsmen to help ensure quality care for the individual.

Please send any questions or comments to info@theconsumervoice.org

ACKNOWLEDGEMENTS

The Consumer Voice would like to graciously thank the long-term care consumers who were kind enough to speak with us about their experiences transitioning out of a nursing home. We also extend our gratitude and appreciation to the countless individuals and groups, including long-term care ombudsmen, nursing home transition coordinators and staff at Centers for Independent Living, who connected us with consumers willing to share their story, promoted the project to their networks, and gave their personal and professional perspectives on transitions.

In addition, we would like to thank the following members of our staff, volunteers, consultants, interns, and individuals who assisted in this project:

Richard Gelula, Executive Director

Robyn Grant, Director, Public Policy and Advocacy

Lori Smetanka, Director, National Long-Term Care Ombudsman Resource Center

Amity Overall-Laib, Manager, Long-Term Care Ombudsman Program and Policy

Alia Murphy, Associate, Long-Term Care Ombudsman Program and Policy

Marybeth Williams, Associate, Public Policy

Amanda Celentano, Associate, Program and Research

Jeni Coyne, Consultant

Christina Steier, Consultant

Alejandra Ona, Accountant

Sara Cirba, Associate, Advocacy and Development, 2012-2014

Jenica Martin, Intern, 2014-2015

Tracey Katz, Intern, 2015

Leslie Ossim, Volunteer, 2015

Autumn Campbell, Director, Public Policy & Advocacy, National Association of Area Agencies on Aging

[Consumer Voice Governing Board](#)

[Consumer Voice Leadership Council](#)

National Nursing Home Transitions Project Advisory Council

Ed Ahern, Nursing Home Transition Specialist, California

Tara Bailey and Lisa Cooper, Long-term care consumer and mother

Donna Gillette, Policy Analyst, Resource Center for Independent Living

Phyllis Sadler, Long-Term Care Ombudsman Coordinator, Community Ombudsman Program,
Georgia

John Saulitis, Regional Ombudsman Program Director, Ohio

This project was supported by a grant from The Milbank Foundation for Rehabilitation, whose primary mission is to realize Jeremiah Milbank's vision of integrating people with disabilities into all aspects of American life. For more information, please visit www.fdnweb.org/milbank

INTRODUCTION

This is an important time in long-term care as individuals with disabilities and older adults increasingly wish to receive services and supports while remaining in the community. A growing number of federal programs are helping to support a shift to home care. One such program, Money Follows the Person (MFP), was authorized in 2005 and is designed to assist nursing home residents who wish to leave the nursing facility and transition back into the community. Initially authorized to be funded through Fiscal Year 2011, MFP was extended to September 30, 2016 through the passage of the Patient Protection and Affordable Care Act in 2010.¹

In 2013 Consumer Voice published a report that examined how individuals who had moved out of nursing homes in California believed the transition process could be improved and recommended policy actions based on what we learned from consumers. In that project we learned that moving from a nursing home into the community can be difficult, particularly if an individual has been in the nursing home for many years and/or if the person is living with a disability for the first time.

In order to learn more, Consumer Voice then built on the success of the California project to look at transitions nationwide from the perspective of both the individuals who had moved back into the community and the programs that assist them. The findings are presented in this report, along with policy recommendations from consumers; state MFP Directors and state long-term care ombudsmen; and local transition coordinators and ombudsmen.

¹ <https://www.cfda.gov/index?s=program&mode=form&tab=core&id=608884168116eecaef45984edbb48594>

PART I. OVERVIEW OF NURSING HOME TRANSITIONS

There's no place like home. Consumers want to age in place and sustain their independence, dignity, and freedom of choice. In our report, *Nursing Home Transitions in California*, the consumers' perspective was that care at home gave individuals more choices, kept them active in the community, and was generally better than care in a nursing home. In addition to consumer preference, government has made the case that in-home care is less expensive than care in an institutional setting and has created options for those who wish to receive services in their home and community.

Home and community-based services (HCBS) waivers can be part of a state's Medicaid program and provide options to older adults and persons with disabilities. The Centers for Medicare and Medicaid Services (CMS) defines HCBS as "person-centered care programs that are delivered in the home and community setting and address the needs of persons with functional limitations and in need of assistance with activities of daily living." A model example of a national HCBS program is the Money Follows the Person Rebalancing Demonstration.²

The MFP Demonstration is a federal initiative designed to help reduce the number of individuals receiving long-term care in institutional settings. One of the program's goals is to augment home and community-based services while reducing the use of institutional settings. Strengthened in 2010 by the Affordable Care Act, there are currently forty-four states and the District of Columbia that offer MFP programs to their residents.³ According to a 2013 national report on transitions, over 35,000 Medicaid recipients had applied for MFP while nearly 6,000 more were in the process of applying.⁴

According to a report by Mathematica Policy Research, "MFP programs had cumulatively transitioned 40,693 individuals" and over 10,000 had enrolled in 2013 alone.⁵ The success of the program varies by state, but has been relatively high overall. According to Mathematica's 2013 report, "reinstitutionalization rates among the first MFP participants suggest that between 3 and 11 percent of participants return to institutional care within six months of the transition." A similar report done in 2011 found that "9 percent of MFP participants had been reinstitutionalized, another 6 percent had died, and 85 percent had remained in the community" in the 12 months following a transition.⁶ The report goes on to say that the majority of MFP participants that re-enter facility living do so within the first three to six months of being back in the community; the authors speculate that this is due to a shift from

²<https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Roadmap/Resources/LTSS-Models/HCBS.html>

³<http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/money-follows-the-person.html>

⁴<http://kff.org/report-section/money-follows-the-person-a-2013-state-survey-of-transitions-services-and-costs-key-findings/>

⁵http://www.mathematica-mpr.com/~media/publications/pdfs/health/mfp_2013_annualrpt.pdf

⁶<http://www.mathematica-mpr.com/~media/publications/PDFs/health/mfpfieldrpt7.pdf>

“transition experts to care coordinators” and suggest states work to make the acclimation period smoother for individuals.

Mathematica surveyed state officials in 2011 and asked them to identify the biggest obstacles they found to the transition process in their state. The number one response was finding affordable and accessible housing. Having “effective transition coordinators, ability to cover one-time moving expenses, and extra support from transition coordinators or extra HCBS beyond what regular Medicaid programs typically cover” were listed as the top three crucial elements to a successful MFP program.⁷

⁷ <http://www.mathematica-mpr.com/~media/publications/PDFs/health/MFPfieldrpt8.pdf>

PART II. METHODOLOGY

Consumer Voice identified and then interviewed consumers from across the United States.

Identification. To identify former nursing home residents, Consumer Voice reached out to: State Long-Term Care Ombudsmen (SLTCO); Local Long-Term Care Ombudsmen (LLTCO); Money Follows the Person (MFP) Directors; State and Local Transition Coordinators (TCs); Local Centers for Independent Living (CILs); a National Nursing Home Transitions Project Advisory Council formed for the purposes of this project (members are listed on p.3); and partners from various states. *Help Wanted* ads were placed in our weekly electronic newsletter that reaches 3,605 individuals and groups, and social media sites were utilized to seek potential interviewees. In addition, the Consumer Voice Governing Board and Leadership Council were asked to assist.

Interviews. Based on responses from our requests, sixty-three interviews were conducted primarily via one-on-one telephone interviews with consumers that had transitioned out of nursing homes. In some cases, family members or caregivers were given consent by the consumer to complete the interview on their behalf. Consumer Voice staff, interns, volunteers, and members of the Advisory Council conducted the interviews.

Interview questions were developed by Consumer Voice staff in consultation with the Advisory Council.

All interviewees were informed that: 1) they did not have to answer any questions they did not want to; 2) there were no right or wrong answers; 3) participation in the interview was completely voluntary; 4) the information they provided would not affect their care or benefits; and 5) all participants would remain anonymous.

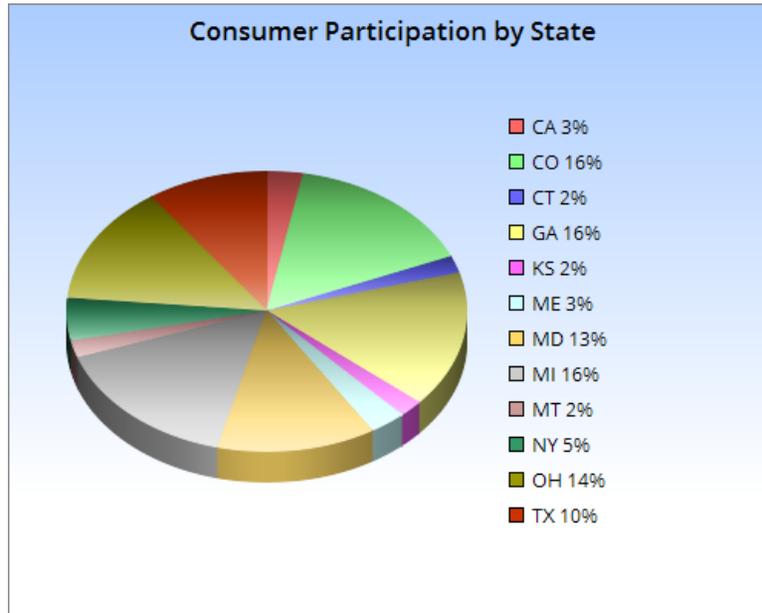
Information was also collected from SLTCO, LLTCO, MFP Program Directors, State TCs, and Local TCs through electronic survey and phone interview. The Advisory Council assisted in creating these interview questions as well.

All interview/survey questions can be found in Appendix 1.

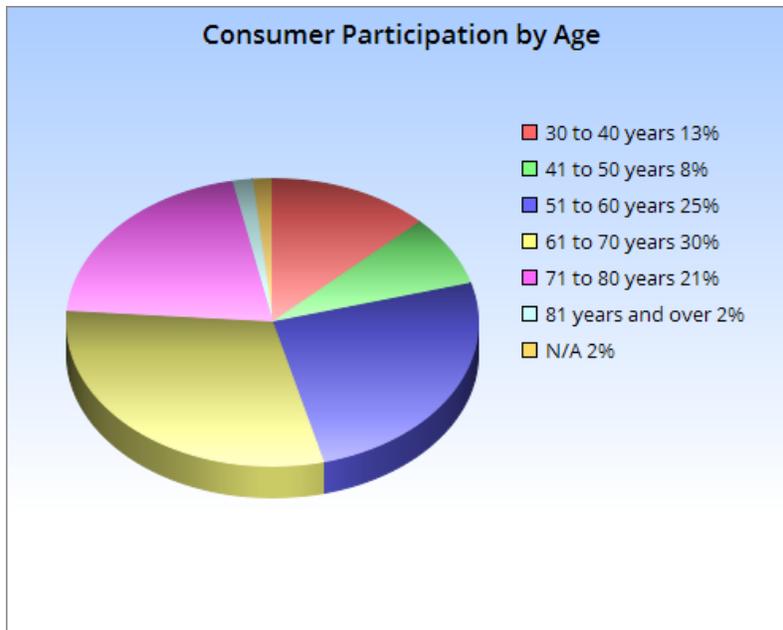
Data were collected from December 2014 to April 2015.

PART III. CONSUMER PROFILE

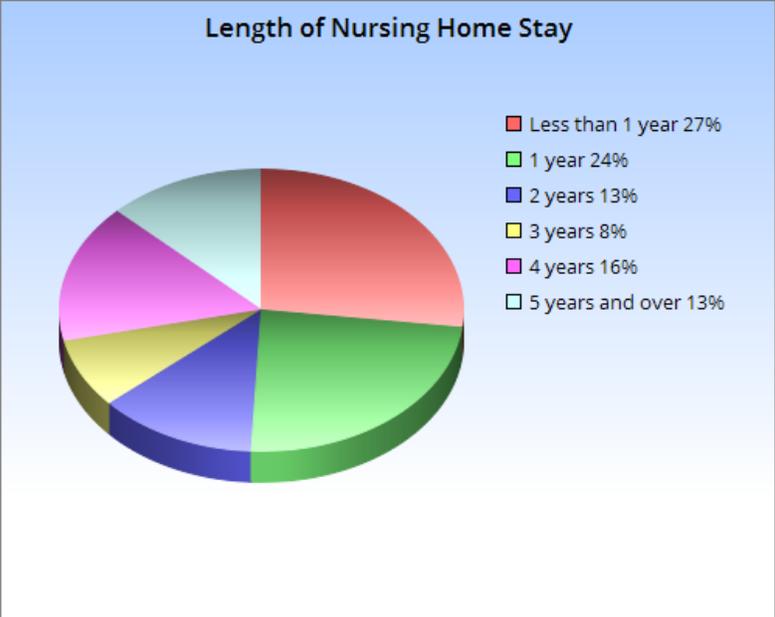
Sixty-three consumers are represented in this report from twelve states: California (CA), Colorado (CO), Connecticut (CT), Georgia (GA), Kansas (KS), Maine (ME), Maryland (MD), Michigan (MI), Montana (MT), New York (NY), Ohio (OH), and Texas (TX). The greatest numbers of consumer participants were from Colorado, Georgia, and Michigan.



Of the consumers interviewed, 56% were female; 44% were male. Ages varied from thirty-one to ninety-one years old. Over half of the people interviewed fell between the age of fifty-one and seventy with a median age of sixty-one.



Slightly over half of the consumers interviewed, 51%, spent less than two years living in a nursing home before transitioning back to the community. One resident spent fourteen years in a nursing home; this was the longest length of stay among interviewees.



PART IV. CONSUMER PERSPECTIVE

Consumers were asked about three aspects of the nursing home transition: *preparing for transition*, *the transition day*, and *after the transition*. Key questions and responses for each of the three parts are highlighted below.

PREPARING FOR TRANSITION

❖ *How did you learn about the possibility of moving out of the nursing home? How did the nursing home respond?*

Learning about moving out

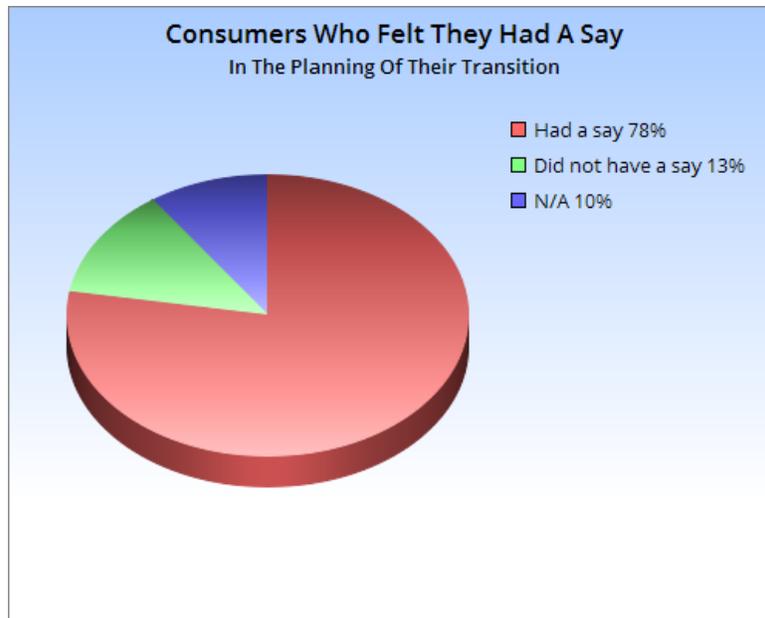
The three primary ways interviewees found out about their option to transition were through Medicaid waiver programs, Centers for Independent Living (CILs), and other nursing home residents. Local advocacy groups, Area Agencies on Aging (referred to as “AAAs,” these are agencies that play a key role in planning, developing, coordinating, and delivering a wide range of long-term services and supports to consumers in their planning and service area), and MFP programs were the second most common sources of information. Four individuals learned they had the right to transition from nursing home staff.

Nursing home response

Nursing home responses and actions varied from cutting corners on care prior to the discharge day (one consumer reported, “My physical therapy sessions were cut two weeks prior to moving out, and I could not get my insulin injections”) to seeing the residents’ transition “as an achievement” for the individual. In general, most consumers found the nursing homes to be only minimally involved in the information and preparation phase of their transition. One consumer said the nursing home he lived in never informed him of alternatives, “They would ask how they could make my stay better but they never ever mentioned the option of leaving.” This consumer went on to say that once he got involved in the transition process, he had to educate the social worker at the nursing home about the waiver program.

❖ *Do you feel you had a say in planning your move?*

The majority of consumers, 78%, felt they had a say in planning their transition and knew what to expect of the process thanks to the transition programs and agencies that helped them navigate the steps. “I was slightly familiar with the process and they (HOME Choice of Ohio) walked me through it” said one individual who felt his voice was heard in the planning process and was heavily involved in decision making around his transition. Other consumers responded to this question unfavorably, but did not share examples as to how they felt unheard.

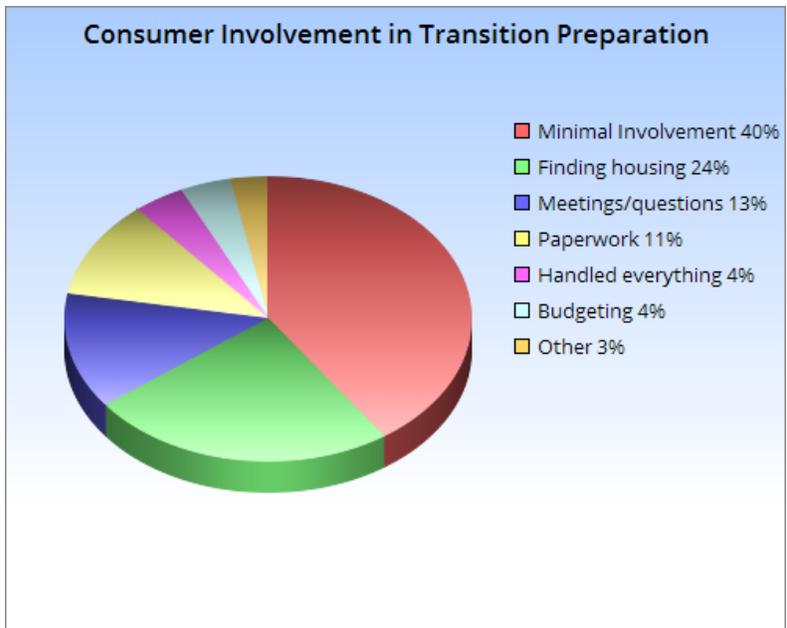


❖ *How did you get involved in the process while you were still in the nursing home?*

Consumers said they often participated in regular meetings to discuss the transition which helped them feel heard and let them know what steps they needed to take. One individual, who had monthly phone meetings initially, then more frequently as the move drew closer, said that during this part of the process he was able to “find my own apartment, plan how I wanted to live independently, and get myself ready physically.”

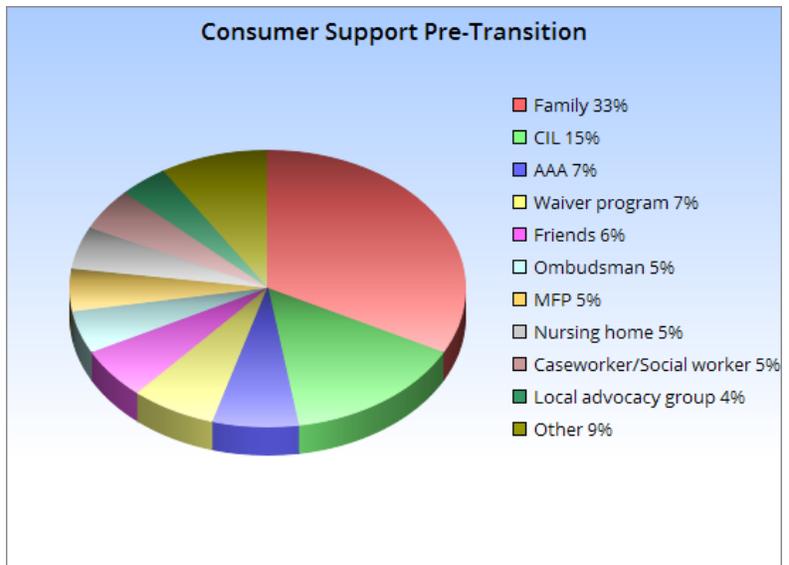
Numerous consumers interviewed said their biggest involvement, and biggest problem, was finding a place to move. “People don’t realize they have choices and take the first place available” said one consumer, “but you need to feel comfortable where you live and be able to get out. Otherwise you might as well stay in the nursing home.” Finding a place to live while still living in a nursing home was difficult for many consumers – especially for the few that had to find housing with little to no assistance.

Residents generally were pleased with their level of involvement in coordinating the transition, even those who had minimal involvement. “Not much I had to do. The waiver program and family did everything for me” said one consumer when asked about her involvement in the transition preparation.



❖ *Who helped you the most while you were preparing to move out of the nursing home? Who provided support?*

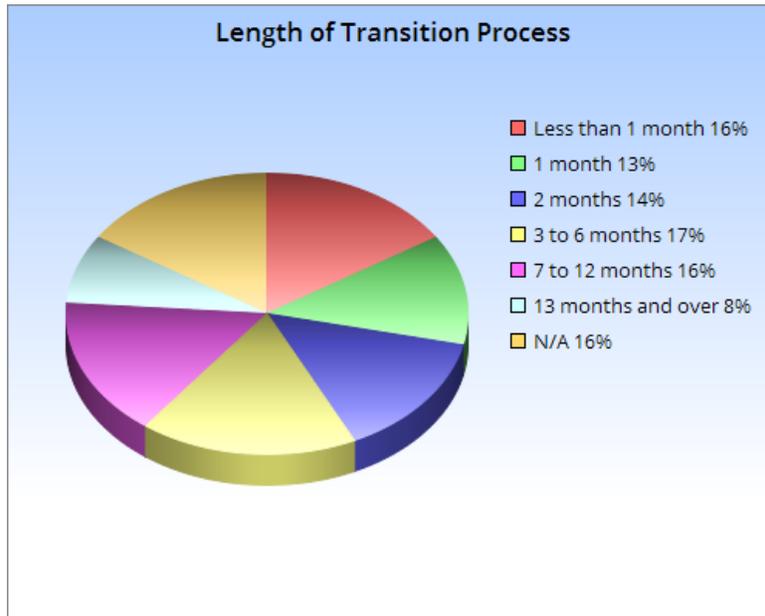
Family members provided the most support to interviewees. CILs also ranked highly as a source of support.



❖ *What was the length of time of the entire transition process?*

The total length of time varied from a matter of days to years. Some of the consumers were unsure of the length. Difficulty finding suitable housing was the main reason for an extended transition process. Many interviewees discussed housing as one of their biggest struggles due to a lack of accessible locations and/or they were tasked with finding housing themselves while

in the nursing home – without access to transportation to view housing options in person or a readily available phone to call potential housing options.



❖ *What should people think about as they prepare to move?*

Reflecting back on their experiences, 23% of consumers noted that being able to get around - both in the household and in the community - were very important considerations. One consumer indicated that an individual needs to think about stairs and “getting in and out.” Another interviewee noted that the person relocating has to consider in advance how much space they will need in the apartment in order to maneuver a wheelchair freely. This particular consumer ended up with very little furniture in order to accommodate her wheelchair.

Public transportation was also a great concern for many interviewees. “Fill out the application for the mobility van and free transportation while still in the nursing home,” suggested one individual, while another advised that the “transportation process doesn’t happen overnight. Get all the help you can and start early.”

Furthermore, 23% of consumers identified the need for a support system as a top priority. Support can come from family members, friends, aides, peers, and support groups. An interviewee stated that people transitioning should have a support group because “independence after a nursing home is not the same as it was before the nursing home.”

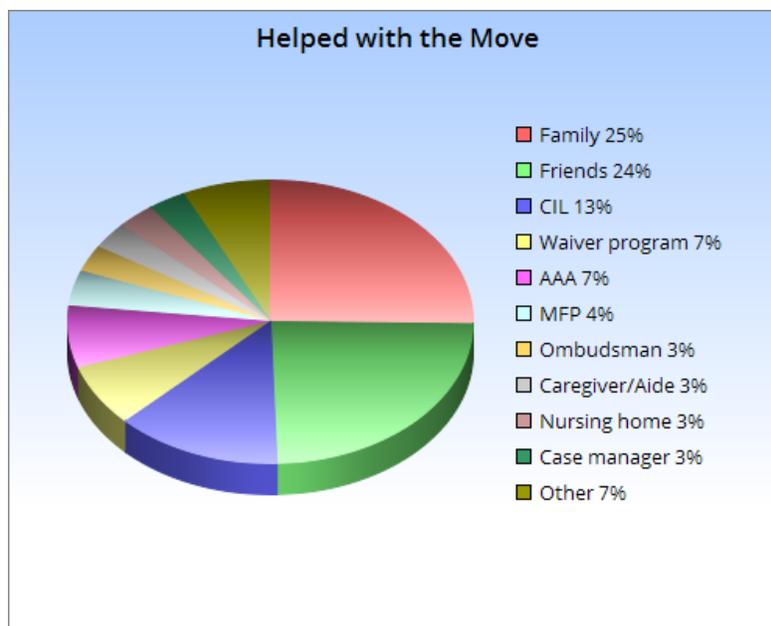
THE TRANSITION DAY

❖ *What type of housing did you move into?*

Seventy-seven percent (77%) of consumers moved into an apartment, while only 20% went to live in a house with family and/or roommates. Many of these apartments were in senior living complexes and some were Section 8 public housing units.

❖ *Who helped with the actual move?*

Family was the biggest help when it came to the actual move; friends came in closely behind. CILs were also active and assisted on the day of the move. Several consumers indicated that they thought the nursing home should have been more hands-on during the move by helping them pack their belongings.



❖ *What problems did you face during the actual move?*

Almost all the interviewees said the move itself went smoothly.

However, a few consumers reported problems:

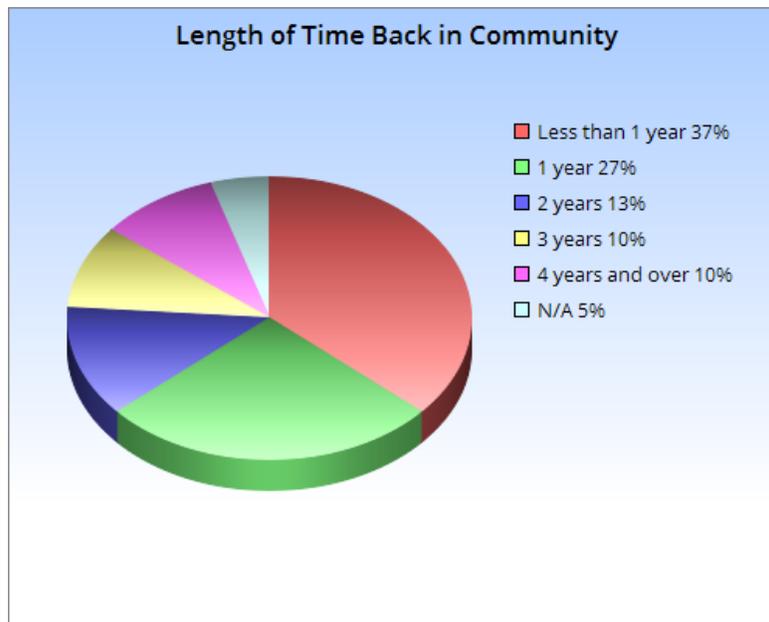
- Four consumers had difficulty obtaining what they needed from the nursing home on the day of the transition. One of these individuals had problems getting the paperwork from the nursing home for their Supplemental Security Income (SSI) checks, this individual said the facility also destroyed prescriptions written by {sic} doctor.
- Two people did not receive their new wheelchairs at the time of relocation.

- One consumer experienced complications with home modifications. He needed both a wheelchair ramp and a walk-in shower, but neither were ready when he moved out of the nursing home.
- Two individuals said that critical furniture was not in the apartment when they moved in. One consumer stated there was no bed or chair in her apartment upon her arrival. For two nights she had to sleep by pulling in a chair from the hallway and sitting on it with her legs up on her walker. Another consumer had to spend the first night on the couch because her bed had not been delivered.

AFTER TRANSITION

❖ *How long have you been living back in the community?*

The majority of consumers had been living in the community just under or over one year. A few individuals had been out of the nursing home for over ten years.



❖ *What should a person think about after moving out of the nursing home?*

The top four points consumers believed a person should consider once they transitioned are described below.

- Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)**

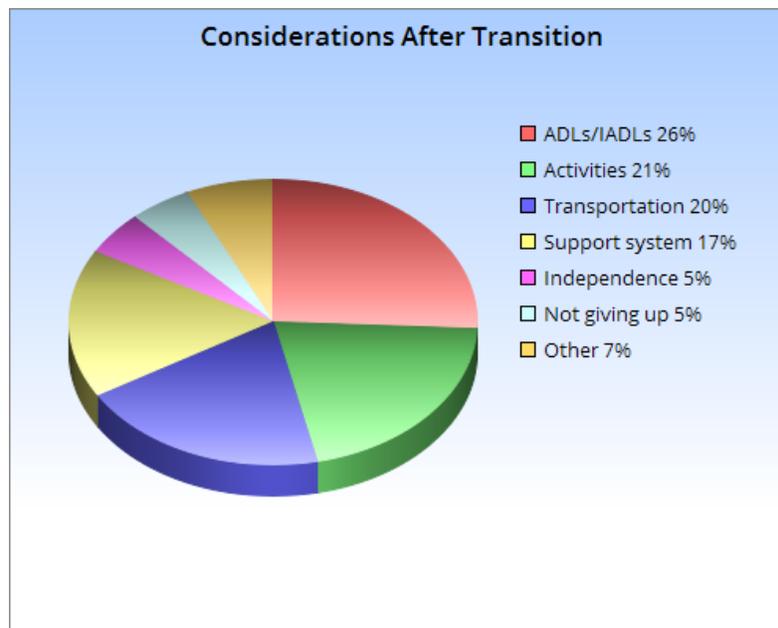
Consumers noted that they needed to think about daily routines and being able to handle activities of daily living (ADLs- tasks such as bathing, dressing, eating, getting in and out of bed) and instrumental activities of daily living (IADLs- tasks such as paying bills, budgeting, shopping, cooking, and managing medication). “I had to learn how to get up and get dressed with no assistance,” reported one consumer, while another said, “I had to learn how to clean myself and cook for myself.” Consumers identified laundry and cooking as being particularly difficult. “Meals on Wheels wasn’t right away. Trying to cook for myself was difficult,” explained one man when talking about his experiences since being back in the community. A few others explained that doing laundry was one of their hardest tasks living alone. One individual described having to wash her clothes in the sink and said that because doing laundry was so difficult, she often wore clothes until they were very dirty. She then threw them away and bought new clothes at a nearby thrift store. Budgeting money was also mentioned frequently in interviews. After living in a nursing home where most items were supplied, consumers said it was important to think about money and to watch spending habits to ensure they would have enough to pay their bills.
- Activities/staying active**

Many of the sixty-three consumers felt that finding ways to stay active in the community was important. One individual, a former president of his resident council while in the nursing home, continued to stay social and active in the community by going to everything available to him at his senior living complex – even things that did not apply to him specifically, like diabetes workshops. Another interviewee said he found out that “after a certain age I could take college courses just for my own personal needs for free except for labs.”
- Transportation**

Getting to these activities in the community was another issue that consumers needed to consider because transportation is so problematic. One individual admitted that things were not perfect, but that she was still grateful for transportation options, “[The paratransit vehicle] is not always on time but I still enjoy the freedom of not being locked up at home.” The Americans with Disabilities Act (ADA) requires that free paratransit services be available to people in areas where fixed route public transportation is available. Paratransit operations run the same days and hours as fixed route transportation, but offer door-to-door services to qualifying people with disabilities.⁸ “I use Mobility [paratransit service] and I praise them because they are the only thing I can use; but they are just so late!” said another individual. He added that the service was “over worked” and did not have enough drivers.
- Support system**

⁸ <http://ftawebprod.fta.dot.gov/ContactUsTool/Public/FAQs.aspx?CategoryID=4>

“Having a support system is the greatest asset when transitioning” said one consumer, and many others agreed. Everyone interviewed needed support in some shape or form and to various degrees. Many said they received support from their family and from transition programs and home care aides. However, some individuals did not have family or could not rely on them for support. One consumer said he gets a lot of support from the members of a motorcycle club he belongs to as well as his aides.



While not at the top of the list, consumers nevertheless said that a positive attitude was essential.

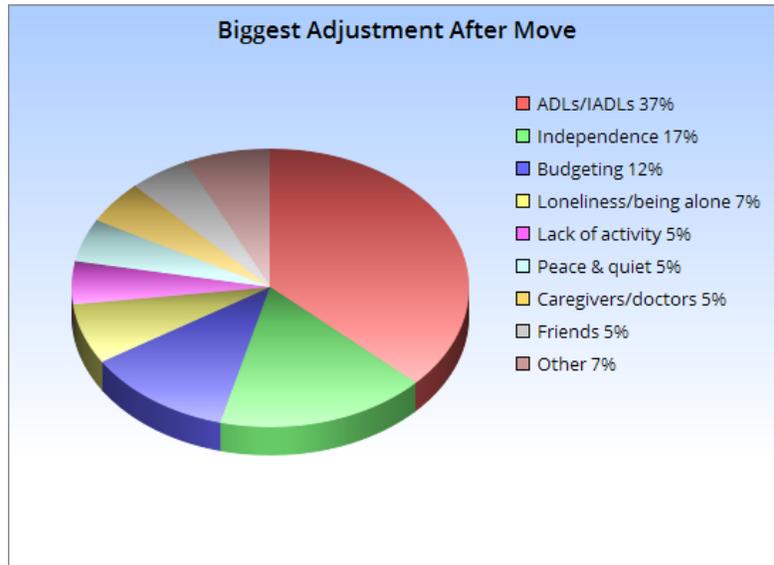
One consumer found that “being courageous while I am independent” was at times overwhelming as well as empowering. He remarked that it is “important to be mentally prepared to be independent.” Another individual commented that she sometimes has trouble motivating herself. Her advice to others in similar situations is to, “Stay focused on becoming independent. The more you do it, the easier it becomes.”

❖ *What was the biggest adjustment you went through once you were out of the nursing home?*

“At first, I thought I came home too fast” replied one consumer, “but I just needed time to adjust” she continued.

Taking care of daily tasks themselves was the biggest adjustment consumers noted. Activities such as getting in and out of bed, transferring to and from their wheelchair, and simply moving inside their home and out, were difficult. It was also hard to adapt to “getting up to do dialysis and getting dressed with no assistance” and cooking for themselves. Although he’s lived in the

community for three years, one interviewee said that getting ready at nighttime was still hard for him.



A number of consumers were surprised that they had to become accustomed to silence and “peace and quiet.” They had to adjust to call bells not going off and not being woken up for toileting in the middle of the night.

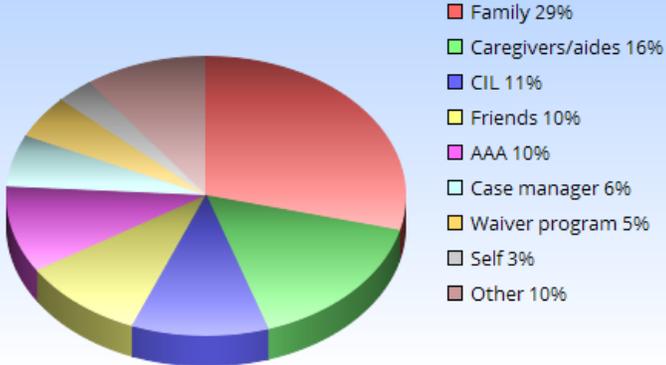
Some interviewees were unashamed to admit there were things they missed from their nursing home stay – such as friends and someone cooking for them.

❖ *Who do you turn to for help?*

Family members were the primary source of support and assistance. Caregivers and home health agencies were also found to be extremely helpful.

One consumer moved in with her daughter, but requires minor help around the house and cherishes her independence; “You lose so much when you live in a nursing home. You forget what it’s like to be normal and you must abide by rules. But now you can set your own rules. I have more independence and make my own decisions.”

People That Help



PART V. LONG-TERM CARE OMBUDSMAN &

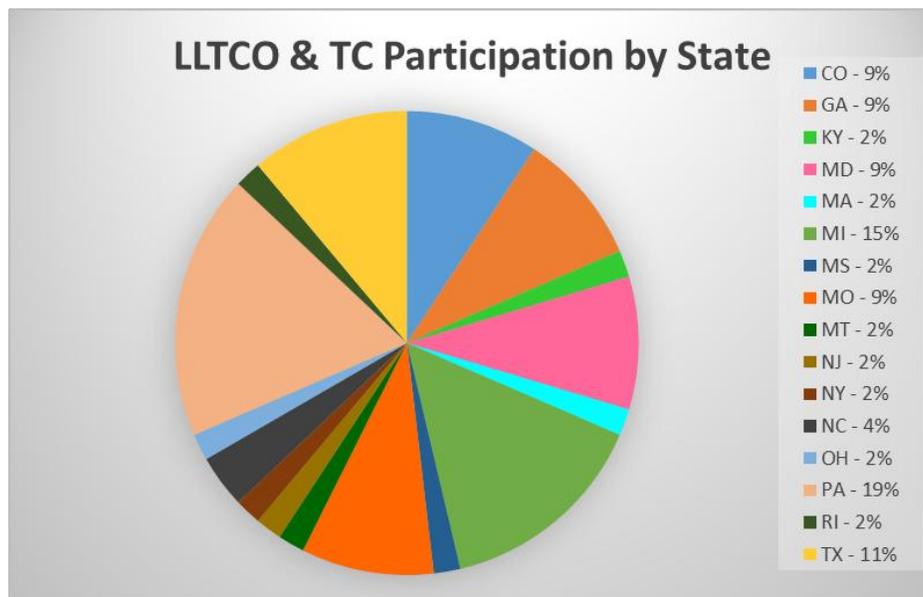
MONEY FOLLOWS THE PERSON PROGRAM PERSPECTIVE

In order to obtain as broad a perspective as possible regarding successful transitions, Consumer Voice also surveyed and/or interviewed individuals working for two programs that assist nursing home residents in returning to the community: the Long-Term Care Ombudsman Program and the Money Follows the Person Program. Information was collected from staff at both the state and local levels. For how participants were selected, see Methodology on p. 7; interview/survey questions are listed in Appendix 1.

LOCAL LEVEL

Electronic surveys were completed by fifty-four (54) Local Long-Term Care Ombudsmen (LLTCO) and Local Transition Coordinators (TCs) who are part of the Money Follows the Person program. Staff from sixteen states participated: Colorado (CO), Georgia (GA), Kentucky (KY), Maryland (MD), Massachusetts (MA), Michigan (MI), Mississippi (MS), Missouri (MO), Montana (MT), New Jersey (NJ), New York (NY), North Carolina (NC), Ohio (OH), Pennsylvania (PA), Rhode Island (RI), and Texas (TX). The survey was divided into three sections: preparing for transition, the day of the transition, and after the transition. The questions were very similar to those asked of consumers so that the answers could be easily compared.

Responses and highlights from key questions follow.



PREPARING FOR TRANSITION

❖ *Based on your experience, what should consumers consider when planning to move?*

Ninety-six (96%) of local ombudsmen and transition coordinators stated that consumers should work with their transition team to create a thorough transition plan that carefully considers their home and community support needs. The transition team and consumers should discuss the consumers' goals outside the facility, what they will be able to do for themselves, and what assistance they will require. Examples of specific issues to consider include:

- Is the transition plan a realistic plan that will meet health/social/medical needs?
- Is there a reliable support network?
- What type of setting can best meet the consumer's needs (own home, live with a family member or friend, home sharing, residential care facility, senior apartment or apartment for persons with disabilities)?
- Is affordable and accessible housing available in the desired location? Are home modifications needed?
- Are financial matters, such as income and budget addressed? Is money management assistance needed?
- Is durable medical equipment required? Can it be ordered and delivered on transition day?
- How will medication be administered? Is training needed?
- Will the nursing home provide a 30-day supply of all medications? How will refills be obtained?
- What are the transportation needs? Is transportation readily available and accessible?
- Have all the necessary identification documents been obtained, such as photo ID, Birth Certificate, Social Security card, Medicaid and Medicare cards?
- Has home safety been evaluated? Is there a back-up plan for care, including emergency contact information?
- How will day-to-day activities, such as food preparation, household cleaning, laundry, shopping, etc. be handled?
- Are social needs addressed to prevent isolation and promote social interaction?

❖ *What are some typical issues that consumers experience during the preparation phase?*

Approximately two-thirds of the LLTCO and TCs - 62% - stated that lack of affordable and accessible housing in consumers' preferred location is a major issue. Related concerns were the inability to find housing due to income limitations, past delinquent debt, criminal history, and loss of identification documents.

Numerous ombudsmen and transition coordinators (26%) also commented that consumers may experience anxiety, fear, a lack of family support, and a sense of being overwhelmed by all the decisions that need to be made during the preparation phase. Consumers often endure long wait periods without knowing the status of their case.

In addition, 12% of LLTCO and TCs felt there is often a lack of communication between the supports planning agency and the nursing facility staff.

❖ *In general, what do you think could be done to make the preparation part of a transition better for consumers who want to move out of the nursing home?*

- 33%: Involve consumers in the planning process and include family and friends who have offered to help to create a realistic, workable plan. One respondent believed that consumers may have unrealistic expectations of what they are able to do independently. For that reason, they recommended having consumers “demonstrate their ability to do ADLs.” A transition coordinator wrote, “The consumer needs to be involved 100% and accountable,” and stressed that the coordinator must be “aware of all of their medical needs including the ones the consumer doesn’t tell you about.” This information is essential for coordinating the supports the consumer needs in the community.
- 21%: Provide on-going education (training and materials) for nursing facility social workers, discharge planners, consumers, and family members on the transition process, including resources and community living options.
- 21%: Develop more community resources, including affordable and accessible housing, transportation, and mental health services.
- 20%: Maintain open communication between all parties involved so the consumer is not getting mixed messages. A LTCO suggested having more planning meetings so that “everybody is on the same page.”
- One respondent: Ensure consumer access to computers so they can search for resources, evaluate services and learn about their community.

ACTUAL TRANSITION

❖ *Based on your experience, what is necessary for a move to be successful (i.e. what needs to happen, what needs to be in place)?*

More than a third (76%) of LLTCO and TCs indicated that proper planning, communication and coordination among the entire transition team is necessary for a successful move. This includes developing a transition plan which defines home and community support needs and ensuring

these supports are set-up prior to move out. One person summed this up by calling for a “well thought out discharge plan in writing for the consumer to take with them.”

❖ *What problems do consumers typically face during the move?*

Over half of respondents, 55%, reported that adequate services and supports are not always in place. This includes durable medical equipment, a 30-day supply of all medications, furniture, food, assistive technology, house appliances and household items. Consumers are excited to leave the facility and move back into the community but it can be very stressful if equipment and services are not set up.

Another 22% said consumers often experience problems with managing their medication, including learning how to self-administer them and obtain refills.

One respondent indicated that consumers frequently need guidance and assurance on the day of transition because nursing facility staff have not followed through on agreed upon actions, such as providing filled prescriptions or assisting them with packing their belongings.

❖ *In general, what do you think could be done to make the actual move of the transition process better for people transitioning out of the nursing home?*

The primary recommendation for improving the move (38% of LLTCO and TCs) was full cooperation and coordination among all persons involved in planning the transition, including the consumer, transition coordinator, facility social worker, ombudsman, case manager, and family. One transition coordinator suggested checking in one week in advance of the move with everyone working on the transition, such as the nursing home social worker and managed care ombudsman (where appropriate) to ensure that the transition goes smoothly. Another said that the “transition coordinator has to be the support for the consumer moving to be available for any concerns or issues. Make sure all assistance needed for the move is set in place before the move date.” An ombudsman recommended “better coordination among everyone involved to make sure that everything is set up prior to the person leaving.”

Other suggestions included:

- Hiring the home care staff before transition (16%)
- Utilizing a navigator/transition coordinator to work through issues and access resources (16%)
- Providing support and assistance with packing of personal belongings from facility staff (13%)

AFTER TRANSITION

- ❖ *What have you seen to be the biggest adjustments and problems for a consumer after leaving the nursing home?*

Transition coordinators and ombudsmen alike (78%) commented that consumers often feel anxiety and shock in their new environment. For some consumers, it is a big adjustment to leave the nursing home environment and become accustomed to their new living arrangements and responsibilities.

In addition, among LLTCO and TCs:

- 94% said consumers may feel overwhelmed from adapting and adjusting to being independent and responsible for decision making and day-to-day management of their budget, medications and transportation needs.
- 30% indicated that the availability of and on-time delivery of durable medical equipment can be quite challenging.
- 18% felt consumers may lack support from family and friends or find that promises to help are not kept.
- 15% stated that home care staff not showing up for work, broken equipment, and unreliable transportation were problems.

Lack of access to round-the-clock care was also noted as an adjustment. One TC remarked, “Not having a call button and instead having to wait for caregivers to come on scheduled times.”

Specific comments about adjustments and problems included:

- “Returning to the responsibility of managing his/her affairs/money, etc.; lack of community, isolation, etc. Overall, I would say for most people it is a positive change but may take a few months to adjust to the new environment, etc.”
- “One of the biggest for some of the clients is the fact that their social interaction lessens due to the environment into which they move.”
- “Sometimes difficulty managing their own finances/affairs.”
- “Feelings of loneliness (if not living with friends or family).”
- “At first, everyone and everything is in place and working effectively. However, the longer the time passes, the more the resources are depleted and the energy levels diminish.”

❖ *What do you think could make those adjustments easier, address consumer problems, and make life after the transition as successful as possible?*

Responses and the percentage of LLTCO and TCs for each response are as follows:

- 76%: Thorough planning with cooperation and coordination among all persons involved in planning. Utilize a strong support team comprised of transition coordinator, ombudsman, case manager, family, and friends to assist with addressing issues and concerns.
- 41%: Ensuring access to resources, such as utilities assistance, a discount cell phone, transportation, and prescription refills. This includes community resources and tools for being successful at home. A calendar and schedule for medications are examples of two tools that can help.
- 20%: Consumer engagement in creating the life they want. Consumers should be proactive, advocate for themselves and deal with any problems that arise quickly. One respondent said, “Be a part of your own process. Work with your team to make your life look as close to what you want it to be as possible from the beginning.”
- 12%: Modify the plan of care as needed. One ombudsman noted, “Care managers are typically responsive and recognize when people need more service hours, to adjust their plan of care, etc.”
- 12%: Providing consumers with the opportunity to connect with a mentor, peer support and/or support group to help them adjust after transitioning back into the community.
- 9%: Consumer involvement in their community, attending worship services, engaging in volunteer and social activities.
- 9%: Asking family and friends to fill support gaps.

Survey comments to this question included:

- “Some counseling on the reality of the situation. But that should be presented beforehand, to minimize the impact of the change. This also includes family/friends involved.”
- “Connecting/reconnecting with family and friends who can offer support.”
- “Thinking about and talking frankly about what is needed to be happy in the community - what are their goals? Why do they want to leave? What are the things in the community they're hoping to enjoy, etc.?”

One respondent gave this advice to consumers, “Don't expect that everything will go perfectly, don't develop an attitude that you don't need help, we all do. Remember workers coming into your house may not do things exactly as you would but don't shut off your access to help.”

Some transition coordinators and ombudsmen made recommendations for their own work:

- “Share past experiences, what worked best and what didn't” and “have transition peers talk to others interested in program.”
- Have some type of consumer check list to give to consumers so they “can go along with the process and make sure everything is complete as well. That would be a tangible way for consumers to be involved and provide some sense that this is a controlled process.”

NOTE: See *Consumer to Consumer: Tips for a Successful Nursing Home Transition* for a checklist and tips on transitioning for consumers.

STATE LEVEL

While local ombudsmen and transition coordinators provide help directly to consumers, SLTCO and MFP Program Directors work to coordinate and collaborate with partners, access resources, and create a system responsive to consumer needs. To gain their perspective, electronic surveys were completed by twenty SLTCO and MFP Program Directors. States represented included: Alaska (AK), California (CA), Georgia (GA), Idaho (ID), Iowa (IA), Maine (ME), Michigan (MI), Missouri (MO), North Dakota (ND), New Jersey (NJ), New York (NY), Ohio (OH), Rhode Island (RI), Vermont (VT), Virginia (VA), Wisconsin (WI), and Wyoming (WY). The survey questions can be found in Appendix 1.

❖ *Does your state have a statewide advisory group for Nursing Home Transitions?*

Fifty-three percent (53%) of the respondents reported that their state had a Nursing Home Transition Advisory group comprised of state agencies responsible for Medicaid, Disability Services, Aging Services, Developmental Disabilities, and Mental Health, as well as advocacy groups, Long-Term Services and Supports (LTSS) provider agencies, representatives of the State Long-Term Care Ombudsman Program, Centers for Independent Living, consumers, family members of consumers, and caregivers.

❖ *What parts of the transition process are working well for consumers in your state?*

The majority of SLTCO and MFP Program Directors (89%) stated that collaboration with partners in a team-based process was positive and an asset. They reported that collaboration and on-going communication regarding policy development, sustainability planning and coordination of services contributed to the success of nursing home transitions. Several respondents specifically mentioned the importance of having a good working relationship between the state Medicaid agency and State Long-Term Care Ombudsman program. One SLTCO reported that their State Medicaid Agency notifies their office of problems and seeks local ombudsman program assistance.

The ombudsman role as advocate and educator was mentioned as a natural fit for successful nursing home transition work. Ombudsmen have always been involved in assisting consumers with transitioning into the community. They are available to help consumers resolve problems that can arise during the transition process.

Several state leaders pointed out the importance of ombudsmen, transition coordinators, AAA options counselors and advocates from the CILs serving as resources for both consumers interested in transitioning and nursing facility staff. They felt this was a factor in successful transitions.

❖ *How could the transition process be improved?*

Thirty-two percent (32%) of respondents indicated that one of the biggest challenges was a serious lack of affordable and accessible housing in both urban and rural communities. The process of finding and securing housing can take quite a while; this slows down the transition process. Additional housing options are needed, including small residential care homes.

SLTCO and MFP Program Directors also identified a need for education:

- Nursing home staff need to be educated on community living options and the transition process. High turnover of nursing facility staff means that new employees lack information and makes the jobs of ombudsmen and transition coordinators more difficult. Fifteen percent (15%) of SLTCO responding specifically mentioned that ombudsmen are frequently re-educating and training nursing facility staff due to high turnover.
- Home health staff and case managers need to learn that “it really is possible for people to live in the community.” Respondents commented that consumers transitioning back into the community “hit much bias and distrust” and are frequently referred to Adult Protective Services (APS).

PART VI. CONCLUSIONS AND RECOMMENDATIONS

Our findings show that in general, consumers returning to the community from a nursing home and those helping them through the Money Follows the Person and Long-Term Care Ombudsman programs believe the transition process is working relatively well. This is in line with the 2013 Mathematica report conclusion that the success rate was high overall.

Nevertheless, our data show that significant barriers impact the success of a nursing home transition back into the community. Across the board, affordable and accessible housing was identified as the number one obstacle. This again corresponds to the Mathematica report results.

To address this and other barriers, as well as to improve the transition process from beginning to end, Consumer Voice makes the following recommendations based on what we learned from consumers, SLTCO, MFP Program Directors, local ombudsmen, and transition coordinators.

RECOMMENDATIONS FOR IMPROVEMENTS

Advocates should refer to the companion publication, *A How-To Guide for State and Local Advocates*, to find strategies and approaches for implementing these recommendations.

1. Form a state advisory group for nursing home transitions

Collaboration, coordination and on-going communication with partners in a team-based process was reported to contribute to the success of nursing home transitions. Several SLTCO and MFP Program Directors who were interviewed or surveyed noted that their state has a Nursing Home Transition Advisory group. A strong advisory group should be comprised of state agencies responsible for Medicaid, Disability Services, Aging Services, Housing, and Developmental Disabilities and Mental Health, as well as advocacy groups, LTSS provider agencies, representatives of the State Long-Term Care Ombudsman Program, Centers for Independent Living, representatives from the Aging and Disability Resource Connection (ADRC), consumers, family members of consumers, and caregivers. In order to ensure that the voice of consumers is heard and well-represented, a significant number of consumers should serve on the state advisory group. The focus of the advisory group should be on policy development, sustainability planning, and coordination of services.

In response to a question about what aspects of state coordination have worked well, one SLTCO stated, “Having the stakeholders group means you always have those resources available if you need them.” This strengthens the transition process at every level.

2. Create and disseminate to nursing home staff written information about community options, resources, and programs that assist consumers to transition

Not only are residents and family members often unaware of their options, nursing home staff are as well. Facility staff need to know where consumers who want to return to the community can go for assistance. They also must have at least an understanding of the local housing and service options and resources in order to provide consumers with general guidance. The need for distributing such information to nursing home staff was clearly illustrated by one consumer's statement that "it felt like the blind leading the blind" when talking about the lack of information her social worker had on community options. Another consumer was forced to learn about the state's waiver program himself and then explain it to his facility's social worker.

We recommend that the lead contact agency (the agency the state contracts with to provide transition services in the community) develop and regularly update a written list of community transition options and distribute that list to the director of social services in each nursing home in their area on a monthly basis.

3. Require nursing homes to post in a public and easily visible place information about programs that help residents transition

Consumers were clear that they needed information about transition services. Many consumers said they had problems getting any information from nursing homes. According to one consumer, "The nursing home didn't offer any information on transitioning to independent or home care living. They wanted me to stay and never leave. They should offer a way for residents who don't need to stay in the home to find the programs that help them leave."

One woman suggested, "Post information in the nursing home about transitioning and who you can call for information and help."

To that end, we recommend that information stating that consumers can transition, along with contact information for transition programs, be posted in facilities in public places where residents, family members, and visitors can easily see it.

4. Increase affordable and accessible housing options

Consumers, long-term care ombudsmen and transition coordinators alike listed the lack of affordable and accessible housing as a problem that slows down and complicates the transition process. One ombudsman stated, "Increase available housing! If we're advocating for people to remain in the community, there needs to be housing for them to live in." One consumer expressed frustration that he had to remain in the nursing home for an additional two to three months solely because he could not find housing. One individual said looking for accessible housing was a challenge because a place may be listed as accessible but sometimes that "just meant you could get through the door; it didn't guarantee the bathroom was handicap accessible."

One possible strategy is to leverage the Medicaid HCBS rule to increase affordable housing options. This rule defines home and community-based settings to ensure that Medicaid’s home and community-based services programs provide full access to the benefits of community living and offer services in the most integrated settings. Another option is to work with the state agency responsible for safe and affordable housing to assign housing vouchers specifically for persons transitioning from a nursing home into the community. This could be accomplished using the Section 811 Project Rental Assistance Voucher Program.

5. Increase transportation options in the community

As described in this report, transportation was one of the biggest problems faced by consumers after their move back into the community. “Transportation is of the essence. People need to be free to go and not sitting at their home,” explained one consumer. Another individual reflected that she was fortunate that the public bus stop was near her home because she could get out to talk to and meet new people. She said that without access to transportation, “she didn’t know how she could cope.”

In order for consumers to successfully live in the community, they must have access to readily available transportation. The Medicaid HCBS rule, mentioned in recommendation #4, could be leveraged to develop and expand transportation options in the community.

6. Provide greater support to individuals returning to the community

Connecting with someone who has already successfully transitioned to the community or others who are in the process of doing so can be a particularly powerful source of support and assistance. Approaches include:

- Peer mentoring. A peer mentor can provide the consumer with suggestions and ideas based on his/her own personal experience and first hand experiences – something a transition coordinator cannot do. Peer mentors can also provide knowledge, information, and understanding, while creating a meaningful and supportive relationship during this transitional process. This relationship can be particularly important following the move out of the nursing home since a number of interviewees reported feeling isolated and lonely after being around many other people in the facility.
- Buddy System. If a paid peer-mentoring program is not feasible, a type of one-on-one “buddy system” could be created to connect a consumer who is transitioning to a person who has already transitioned.
- Support group. Instead of a one-on-one approach, support groups bring a number of people together who are going through similar experiences. This gives them the opportunity to share their own experiences, compare notes about resources, talk about their feelings, and improve coping skills.

- **Community Support Coaches.** Although Community Support Coaches are not mentors or peers, they provide services and supports to consumers who have transitioned. Coaches work to assist consumers as they adapt and adjust to being independent and responsible for their daily lives.

All four approaches would provide skills building, guidance, emotional support, and encouragement to the person leaving the nursing home.

7. Establish local groups of peers/advocates

One way to both inform consumers in nursing homes about their options and support them during the transition process is through the creation of a group consisting of individuals who have already moved out of a nursing home. Former nursing home residents who are now living in the community are the true “experts.” Such a group is exactly what one consumer recommended; she felt there should be a program where people who have lived in a nursing home and transitioned go into nursing homes to 1) talk to residents about moving out; 2) connect them to a program to help them; and 3) keep in contact with residents who want to move out to see if they are receiving the help they need.

8. Seek written guidance about the role of nursing home staff from CMS and/or the state survey agency

Several consumers, as well as ombudsmen and transition coordinators, reported having problems with the transition process because nursing home staff did not provide the necessary assistance. Examples include failing to prepare and make available at the time of discharge the necessary resident paperwork and medications. One consumer said, “The nursing home was no help.”

Under federal nursing home regulations (§483.12(a)(7) Orientation for Transfer or Discharge), a facility must provide *sufficient preparation and orientation to residents to ensure safe and orderly transfer or discharge from the facility*. It must also *assure that sufficient and appropriate social services are provided to meet the resident’s needs* (§483.15(g) Social Services), which includes discharge planning services.

We recommend that CMS issue a Survey and Certification (S&C) letter to state survey directors detailing what the nursing home must do to comply with these requirements as part of the discharge planning process. The S&C letter should specifically address the facility’s role in transitions, including keeping residents informed, assisting residents with phone calls, packing, having medications and paperwork ready upon discharge, etc.

Should CMS fail to write an S&C letter, state survey agency directors should provide such guidance directly to nursing home providers.

9. Identify and/or develop creative, flexible funding to ensure that housing, services, and supports are in place prior to transition

As mentioned in the report, several consumers had problems with services and supports not being set up prior to their move, often because services cannot be paid for while the person is still in the nursing home. This creates a stressful and possibly dangerous situation.

Transition programs at both the state and local level should actively explore ways to cover these expenses. Potential resolutions include: developing state and local funding sources and creating a repository for used medical equipment and household items.

10. Provide residents, based on their choice, with a team to support them from the time they decide to transition through, at a minimum, the first 90 days after the transition

Consumers should have the option of working with a well-defined, formally recognized transition team to create a thorough transition plan that carefully considers their home and community support needs. The composition of the support team would change as the consumer progresses through the transition process. During the planning phase, the team might consist of the consumer, transition coordinator, ombudsman, nursing home social worker/discharge planner, family, and friends. After the move, the consumer's team members would likely include the case manager, transition coordinator, home care ombudsman (if available), peer mentor, family, and friends. The team would provide assistance with addressing issues and concerns, including modifying the consumer's plan of care and advocating for more service hours if needed. The team would support the consumer for at least ninety (90) days post-transition.

APPENDIX 1

[Consumer Interview Questions](#)

[State Long-Term Care Ombudsman Survey Questions](#)

[MFP Program Director/State Transition Coordinator Survey Questions](#)

[Local Long-Term Care Ombudsman Survey Questions](#)

[Local Transition Coordinator Survey Questions](#)