Consumer Perspectives on

National Consumer Voice
for Quality Long-Term Care
2012

PRODUCED BY

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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.

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Introduction

This report, part of a three-year, "Consumers for Quality Care, No Matter Where" advocacy initiative of the National Consumer Voice for Quality Long-Term Care (Consumer Voice), seeks to understand quality care from a unique perspective; the individual receiving or accessing paid care services and support in their own home. The Consumer Voice convened interviews, surveys and a national focus group over the course of six months to: determine how consumers define quality care, pinpoint needed care improvements and recommend policy actions to strengthen and provide more access to quality home care.

In 1985, the Consumer Voice (then named the National Citizens' Coalition for Nursing Home Reform or NCCNHR) published the seminal report, "A Consumer Perspective on Quality Care: The Residents' Point of View." This report was proof that nursing home residents' voices can and will be heard. Now nearly 30 years later, through this report on home care, the Consumer Voice provides an opportunity for another population of consumers to have their voices heard at the decision-making table.

This report comes at an important and active time in long-term care history; federal programs such as "Money Follows the Person" are helping to support a shift to home care, state governments are enacting policies and programs to transition people out of nursing homes back into the community, both as a cost saving measure and to increase independence among consumers; health care costs are still on the rise; the population of aging Americans is growing rapidly; the federal Medicare and Medicaid programs, which provide public financing support for long-term care, are under enormous economic and political pressure; a Baby Boomer generation next in line for long-term care is demanding to stay at home; and advocates are strongly supporting home care as an alternative to institutional care.

While much is being done and discussed at federal and state levels to support home care, the basis for all efforts should start with asking consumers what they want and need. Not only has this report gathered important information for policymakers and the entire aging advocacy network to use as a basis for decision-making, but like the 1985 report, the process of seeking input has in itself provided consumers with an opportunity to speak out and contribute to shaping the policies that so greatly impact their lives.

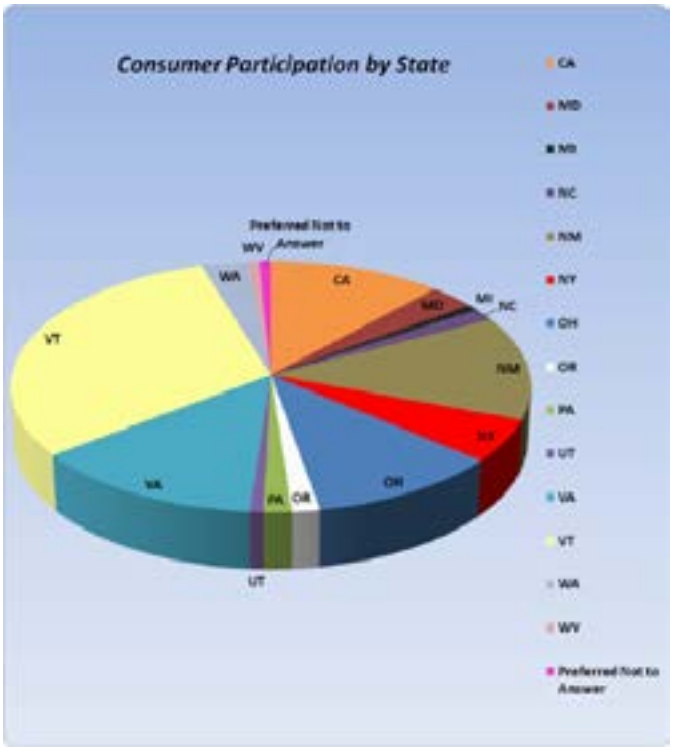
Methodology

The information contained in this report was gathered through a three-tier outreach process. The bulk of the consumer input came from one-on-one telephone interviews. The Consumer Voice set out to do both interviews and focus groups, but quickly learned that focus groups are very hard to arrange in the home care setting. Unlike nursing home care, where residents could join a discussion in a common area at one time, bringing home care consumers together physically in one space proved to be difficult. In the future, it would be interesting to try to pull individuals together for a focus group in senior centers or other community settings where consumers may frequent.

Interviewees - Consumers

This report includes the voices of 212 consumers from fourteen or more states (some consumers chose not to identify in which state they reside). The Consumer Voice contacted over 300 individuals and of those, 212 were "eligible" to participate. In order to participate in an interview, the consumer needed to: 1) reside in their home, 2) receive paid care services (that is, not exclusively unpaid family caregiving) and 3) receive more than just home-delivered meals. Consumers who were ineligible to participate were given other opportunities to advocate with the Consumer Voice.

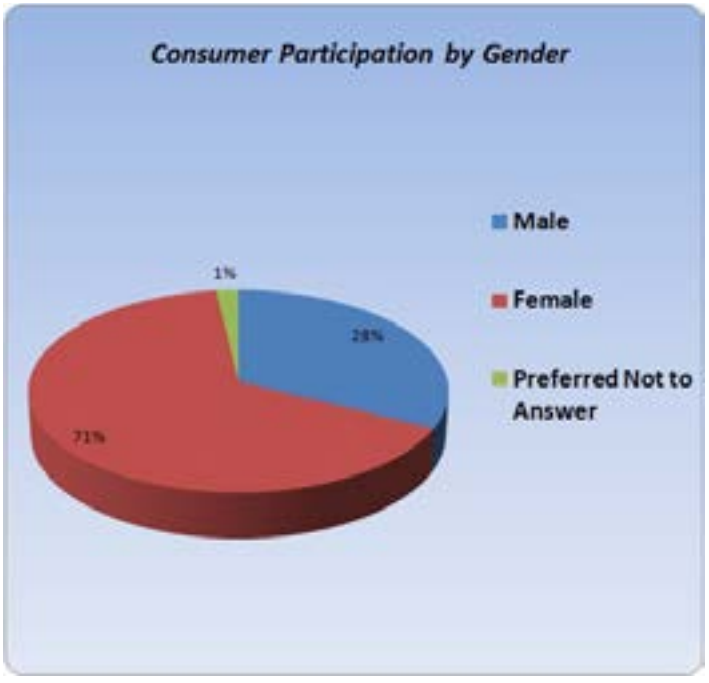
Interviewees were informed that their responses for the report would remain anonymous and that none of the information they provided would impact the care or services that they received.

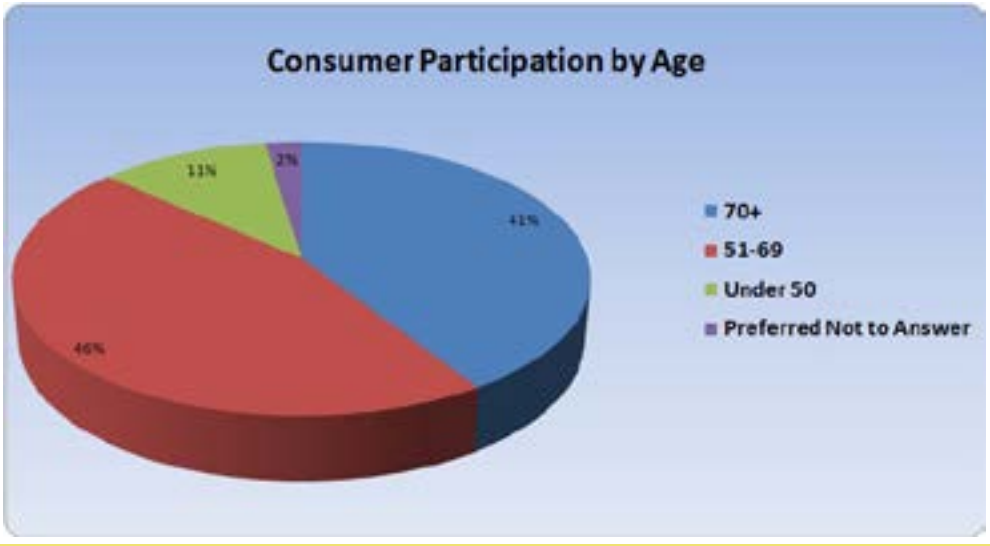


To identify home care consumers, the Consumer Voice sent out e-mails, involved various advisory councils and connected with partners across a number of states. Names of consumers (who, prior to submission, had already been contacted by people they knew to ensure they were willing to participate) were given to the Consumer Voice staff and then compiled. Since the goal of this project was to hear directly from the consumer, family members were not interviewed; however, the Consumer Voice is interested in conducting more outreach with family caregivers in the future.

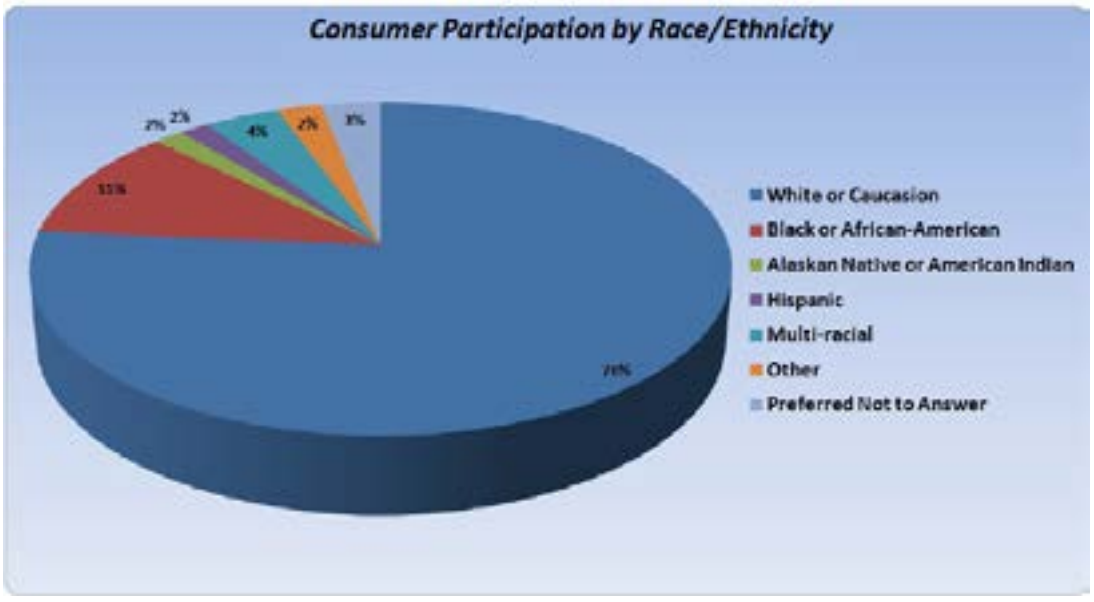
Of the 212 consumers interviewed, 71% were female, 28% male and 1% chose not to answer.

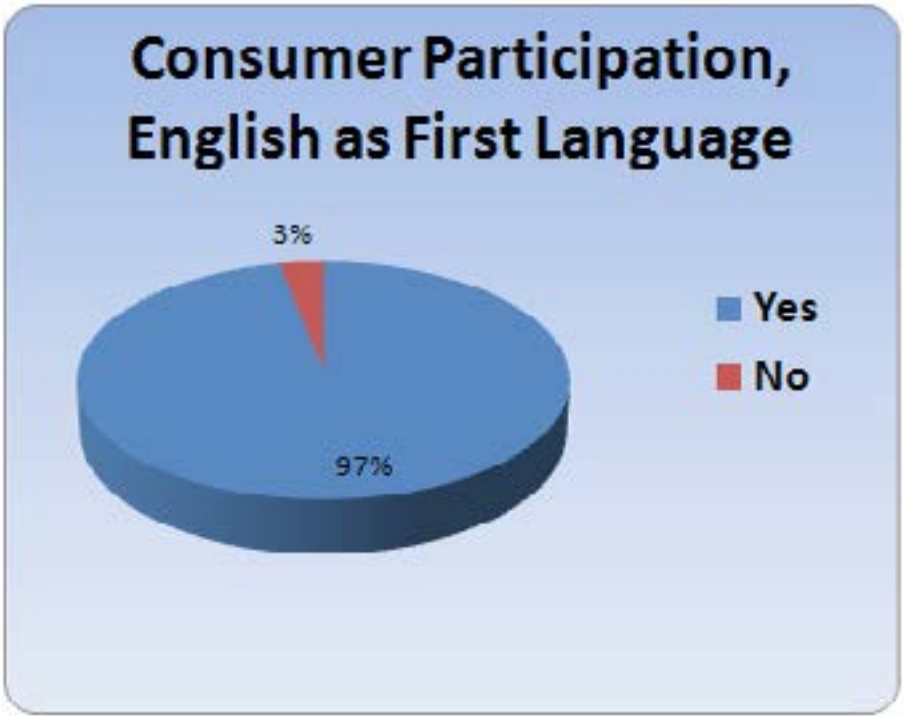
The consumers interviewed were almost evenly split in age; about half in the 70+ range and half in the 51 - 69 range. The report also reflects the voices of a number of consumers under 50 years of age, demonstrating the diverse range of individuals accessing long-term care, support and services in their homes.





The race and/or ethnicity of interviewees was predominantly White or Caucasian with Black or African-American as the second largest population of respondents. English was identified as the first language of over 97% of interviewees. The Consumer Voice made efforts to include a diverse group of consumers through outreach to advocates in a mix of states in different regions and by making promotional materials for the interviews available in multiple languages.





Interviewers

The Consumer Voice recruited volunteer interviewers from around the country: ombudsmen, family members, aging experts, other advocates, etc. The interviewers were found through national e-mail requests for help and through a five-state pilot project on home care quality, also part of the "Consumers for Quality Care, No Matter Where" initiative.

Volunteers were given written instructions on how to conduct the interviews and were "matched" by staff with a consumer or consumers to interview. The volunteers started by calling their interviewee to ensure that the individual still wanted to participate and to select a date and time for the interview. If the consumer was no longer interested in participating, the volunteer interviewer reported this to the staff of the Consumer Voice. If they were able to proceed with the interview, the volunteer did so at the set time, following both an instructional guide and questions developed by the Consumer Voice.

Upon completion of the interview, volunteers documented their interview notes and submitted them to the Consumer Voice staff for compilation.

Project Goals and Interview Questions

The questions posed in the interviews were developed by the Consumer Voice staff to achieve the goals of this report:

- How do individuals receiving care in their homes perceive the quality of their services?
- Why do consumers want care in their homes versus in a nursing home?
- How could home care be improved?
- What do consumers see as the role of government in ensuring quality home care?

Prior to launch, the interview questions were reviewed by a national advisory council and two researchers and then tested with several consumers. A complete list of all interview questions can be found in Exhibit A at the end of this report.

Other Methods

In addition to one-on-one telephone interviews, the Consumer Voice collected feedback in two additional ways: an online survey and a national telephone focus group. The online survey mirrored the instructions and questions given to volunteer interviewers, but was made available for consumers to complete directly through a web tool, SurveyMonkey.

The Consumer Voice also conducted a national conference call focus group of home care consumers, held in July 2012. The call was moderated by two Consumer Voice staff, and carried out in a question and answer format. The call covered the questions presented in the

phone interviews and online survey as well as additional follow up questions; 49 consumers participated. This format had an added benefit of enabling consumers to hear directly from each other. While the Consumer Voice has convened nursing home residents on national conference calls several times, this was the first time it brought consumers in their homes together by phone. It is anticipated that this will be the first of many similar calls offered in the future.

Why Home Care?

Why home care versus other kinds of long-term care?

Nursing homes have come a long way since the "almshouses" of the nineteenth century. The laws and regulations governing nursing homes have improved vastly over the years so that today, regulations stemming from the landmark Nursing Home Reform law mandate quality of care and quality of life for each and every resident. All nursing homes participating in the Medicaid and/or Medicare programs must "provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that…is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." This means a resident should not decline in health or well-being. Residents are also given the right to dignity, choice and self-determination.

In addition, culture change, a transformation of traditional institutions and practices into communities in which each person's capacities and individuality are affirmed and developed, has strived to make nursing homes truly "home" for residents (Pioneer Network). There are some great examples of good nursing homes that have truly embraced culture change at all levels; however, as you will read from this report, consumers prefer to receive care in their home over care in *any* nursing home, even in the best facilities. Home care is to many the ideal form of long-term care, preserving independence and shifting the power dynamic back into the hands of the consumer.

The Consumers' Perspective: Why I Want to Be At Home

Government makes the case that care in the home versus in an institutional setting is less expensive; and the potential for higher quality and personalized care at home is appealing to the advocacy community. But why do consumers want to be at home? The most frequent consumer responses to, "why home care?" centered around fear of poor care and being out of one's own element in a nursing home, desire to stay independent and wanting to make one's own decisions.

• Care at home gives me choices

The consumers reached felt strongly that home care is more personalized; for instance, many can set their own schedules and tell their worker(s) what they want and do not want. A number of people said it was very important to them to keep their pet(s), which they could only do at home. Other consumers were living with their spouse or other family member (who did not need long-term care) and would not want to leave that person/people to enter a facility.

• Care at home keeps me active in the community

A number of consumers interviewed felt that receiving support in their home enabled them to get out in the community, such as visiting with other people at an adult day center, volunteering at church or simply going shopping at the mall. On the flip side, a number of consumers felt confined to their homes and wished they could venture out more, as discussed later in the section on ways to improve home care.

• Care at home gives me a feeling of hope

Consumers frequently said that they felt hopeful staying at home; that it gave them a sense that they were actually getting better and not just maintaining or on the downhill path that they believed they would have experienced in a nursing home. One individual also said, "The worker can focus on just me and not on all the other people they have to take care of in a nursing home."

• Care at home is better than a nursing home

Some home care consumers had a very negative perception of nursing homes, "My father was in a nursing home, and I don't like them because of his time there. Workers would steal his money, his medications and his personal belongings." Another individual told us, "I was in a nursing home for seven weeks and nearly lost my mind because it wasn't the place for me to be."

It is unclear from the interviews how many consumers may have once been in a nursing home and now receive care at home. Regardless, consumers expressed a general sentiment across the board that they would do anything possible to stay out of institutional care. Some consumers based this strong feeling on personal experience; while others based it on the experience of people they know or a general perception of what care in a nursing home would be like.

Workers

Home Health Care Workers

Workers are essential to the quality of life and quality of care for long-term care consumers. The experience of the older adult receiving care at home is determined by his or her interactions with direct care worker(s). In the Consumer Voice's 1985 report on the resident perspective of nursing home care, residents explained that the most important elements of quality in their day-to-day lives were the accessibility and attitude of the worker(s). The Consumer Voice can say from experience with this most recent project, that the same critical importance of workers to consumers is true in the home care setting.

The Consumers' Perspective: How I Feel About My Worker(s)

"She treats us like family and we treat her like family. We only have sons, so we feel that God gave us a daughter in [our worker]." This is a great summary of how the majority of consumers who provided input felt about their in-home care worker or workers. A rewarding element of this project was hearing from consumers and their many, many wonderful stories of dedicated workers who provide quality care and who frequently go above and beyond in their duties.

• My worker makes a difference

Consumers described their workers as optimistic, honest, kind, gentle, etc. One interviewee said, "[My worker] listens to what I have to say. For example, I tell her to clean the toilet with Comet and she does it." Another consumer shared how her worker helps her to match up her clothes each morning, which makes her feel better about herself when she goes out. It appears that it is often the "little things," like cleaning the house in the way the consumer used to do themselves, that make a big difference for people.

• My worker is like family

When asking consumers how a worker should get to know them, one individual said, "ask me, what is your philosophy in life?" The relationship between the consumer and the home care worker seems to transcend other healthcare settings in terms of the worker(s)' knowledge about the consumer's preferences and needs as well as the relationship that can develop between worker and consumer; the worker is in the individual's home, where the interaction can happen at a deeper level, sometimes to the point where the worker becomes part of the family unit; "We are best friends, more like sisters, I can't think of how we could be any closer. Just through casual conversation that built trust."

• My worker could do better

Of course, not all consumers reached were happy with their worker(s). One individual said: "workers need to pay close attention to their client's physical needs and talk to us like adults – they should not talk down to you or call you 'sweetie.' I say 'call me by my name.' Also, they need to learn to listen and learn. Don't get preconceived ideas and don't be afraid to ask. I tell them that you won't look stupid if you ask me questions."

A number of consumers said that workers are not fulfilling their potential or that the agency was not able to recruit the right kinds of workers because direct care work is an unattractive job (in pay, benefits, etc.). One individual shared, "Maybe if care givers were paid more for the job, it would attract more intelligent and skilled workers. There are a lot of people without any common sense working in consumers' homes or with no understanding of disabled constraints."

To address concerns with worker(s) abilities, most consumers interviewed cited the need for additional training, although one consumer noted there are some skills which do not require additional training, saying "…all the home care workers who come in know housework well – how to clean and cook. They have known how to do this since they were 'knee high to a grasshopper'."

Does Care Planning Play a Role in Home Care As It Does in Nursing Homes?

The 1987 Nursing Home Reform Law requires nursing homes to establish a written plan of care with the resident, the resident's family or legal representative. This care plan has been an important part of advocating for quality long-term care in an institutional setting. Not only is this established in law, but the care plan and a dialogue in the first hours of admittance into a nursing home can make a huge impact on communicating (and fulfilling) a resident's needs and preferences.

Written plans for medical care in the home are required in the federal regulations for Medicare-certified home health agencies, though they only pertain to medical care and not the full range of services that are often provided in that setting (Section 484.18 Condition of Participation: *Acceptance of patients, plan of care, and medical supervision.* "Care follows a written plan of care established and periodically reviewed by a doctor of medicine, osteopathy, or podiatric medicine."). When services and supports are funded through a Medicaid Waiver, a service plan must be developed. Given the importance of the care plan in the nursing home setting, the Consumer Voice wanted to know - does a comprehensive written care/service plan have a place in home care?

The Consumers' Perspective: I Do or Do Not Want a Care Plan

Interestingly, most consumers were not aware that they actually had a formal plan of care in place. When asked about care plans, the majority focused on the idea of some type of agreement or plan between them and their worker. Consumers were very mixed on this issue. In general, those who were not in favor of any type of written plan seemed to be very concerned that writing it down would mean they would lose all flexibility. "A written plan is not a good idea as nothing is ever set in stone and workers and consumers need to be flexible." Some consumers were concerned how too much planning would be perceived by their worker(s); "I think it is important to have an agreement in place, but it is almost offensive to the worker to give them a schedule once they know how to do their job well." Another individual said, "I do not believe having preferences in a written plan is necessary because I can communicate what I want. We all change our likes and dislikes over time, and I prefer to 'go with the flow'."

Some individuals did not want to be bothered with standardized forms or questions, but had their own style or way of communicating their needs and preferences to the worker(s). For example: "I have a board that I write down things that I see that need to be done. This works out really well, because my worker is able to prioritize what tasks are most important. This way she gets the most important things done before she leaves."

Other consumers welcome a more formalized written plan of care: "My daughter currently sees little things that need to be done and writes them down. I think this would be a wonderful idea." These individuals also felt the plan of care should be reviewed by the consumer and worker(s) regularly, such as every six months.

Regardless of how consumers want to communicate their needs and preferences, it is clear that a plan is only as good as those who read and carry it out: "We already have a written plan, and it really works. Unfortunately when we don't have our usual home care worker we never know what we are going to have to deal with. It's like the box of chocolate from Forrest Gump: you never know what you're gonna get. The new person disregards the plan and does not show any professionalism."

Getting Help

Who do consumers turn to for help?

Consumers repeatedly said that they go right to the home care agency if there are concerns with their worker or overall care and support (and then, with mixed results). Consumers listed the following individuals and organizations as those who they would turn to if they needed assistance with their care:

- Home health care agency (workers employer)
- Family
- Case worker
- Disability lawyer
- Council on Aging
- Visiting Nurse Association
- State ombudsman or ombudsman transition specialist
- 911
- Patient advocacy group
- The worker him or herself
- Adult Protective Services
- Primary Care Physician

• Consumers had mixed results in getting help

Many consumers felt they received a good response when asking for help: "If I have a problem with my worker, I call the home health agency and they replace the person immediately." Other individuals have had a very difficult time addressing their situation, "There is no one responsible or efficient to contact. No way to reach an ombudsman and have significant change with a situation. Whenever a complaint is made to the agency the issues are not resolved and I simply receive a new caregiver. This does not give me any confidence that the previous worker will be fired or receive any new training."

• Consumers were concerned for their worker

Some consumers also expressed concern that asking for help might negatively impact their worker. They expressed a fear of retaliation against the worker versus a fear of personal retaliation (as advocates hear about time and time again in institutional care settings). Consumers said fear of getting the worker fired (if the problem they are encountering does not rise to

that level in their minds) prevents them from reporting issues. One individual shared: "The person that came [to help me] asked me when [my worker] came and I told her about 10 minutes after the hour. Then she reported [my worker] for being late and she is never late - she just comes here from another client's house. I was so upset because[my worker] got in trouble. Since then I have been careful about saying anything. That person was looking for something negative and asked questions to try to get a negative answer about home care."

• Consumers may need an advocate

Currently, approximately thirteen state long-term care ombudsman programs advocate on behalf of home care consumers. In the future, it would be very helpful to talk with consumers in these states to determine how the consumer views the role and effectiveness of the ombudsman as a source of help.

Government's Role

What is the Government's Role?

Government has been involved in both creating access to home care and working to ensure quality of services.

• Access

In 1983, Congress amended the Social Security Act, giving States the option to receive a waiver of Medicaid rules governing institutional care. This formally created "home and community-based services" as we know today. Later on, in 2005, these services were offered as a formal plan option for state Medicaid programs (Centers for Medicare and Medicaid: HCBS).

Since that time, there have been numerous developments on the federal and state levels to provide home care as a long-term care option to individuals across the United States. For example, "the 'Money Follows the Person (MFP)' Rebalancing Demonstration Program helps States rebalance their long-term care systems to transition people with Medicaid from institutions to the community. Forty-three States and the District of Columbia have implemented MFP Programs" (Centers for Medicare and Medicaid: MFP). Under the Affordable Care Act, two new programs, the Balancing Incentives Payment Program (BIPP) and the Community First Choice (CFC) options were created. BIPP provides funding to states that spent less than 50% of their Medicaid long-term services dollars on non-institutional care in fiscal year 2009. States must agree to make certain structural changes to their long-term care systems that will enhance access to home and community-based services. CFC is a Medicaid state plan option that provides funding to increase consumer access to home and community attendant services. The Affordable Care Act also created the Federal Coordinated Health Care Office under CMS, now known as the Medicare-Medicaid Coordination Office, which is charged with improving the integration of Medicare and Medicaid benefits for individuals who are eligible for both Medicare and Medicaid benefits ("dual eligibles"). Twenty-six states are seeking approval of demonstration projects to test use of a capitation or managed fee-for-service model. This would involve managed long-term services and supports.

At the state level, there are programs in some states that are funded through state dollars rather than Medicaid or Medicare.

• Quality

Home health is regulated at the federal level by the Medicare Home Health Conditions of Participation and Guidance to Surveyors. There are additional federal standards for care in the home, including the OASIS-C standardized assessment tool for all Medicare and Medicaid patients. The Centers for Medicare and Medicaid Services (CMS) also operates "Home Health Compare," a basic online tool to compare the services of home health agencies by geographic location. While voluntary to agencies, CMS and the Agency for Health Research and Quality (AHRQ) developed a "Consumer Assessment of Health Providers and Systems," which are surveys to evaluate the "interpersonal aspects" of Medicare-certified home health care. Furthermore, federal Medicaid Waivers require states to have in place a quality management system for overseeing and improving the quality of home and community-based waiver services. This system is referred to as Quality Frameworks.

Many states also license home health agencies and a few are starting to regulate "personal services" agencies, which provide non-medical home care services. Finally, legislation has been introduced in Congress that would create a "home care consumers bill of rights" and a home care ombudsman demonstration project.

• Cost of care

The cost of 24/7 care in a skilled nursing facility can be astronomical. For a private room in a nursing home, the annual cost can be $80,000+ (MetLife); home care from a licensed agency might cost the consumer (or the payor of the services) an average of $21/hour; with only a few hours of care a day, there is a significant incentive for states to shift support and services to in-home care.

So how is this care paid for? Medicaid is the primary payor for long-term care, covering a range of services in the home, community and in institutional settings. Many of these critical services, such as personal care or homemaker services, are not covered by Medicare or private insurance. However, to qualify for Medicaid coverage of home and community-based services, individuals must meet strict eligibility requirements. In general, consumers must have very little income and minimal assets; be a senior or person with a disability; and have a nursing home level of care needs.

Private long-term care insurance can be an option, but it is very costly, provides limited benefits and has long waiting periods for coverage. In addition, many companies previously providing insurance options have left the industry, leaving consumers with few ways to formally save for home care services.

Moreover, home and community-based services are limited in many states because these services are not mandated like nursing home services are. For that reason, 70 percent of nursing home residents receive Medicaid coverage, while only 42 percent of Medicaid spending on long-term care covers people in their own homes or in the community.

When only a few hours of care a day are needed at home, the cost is far less than nursing home care. Consequently, the annual cost savings for transitioning consumers out of nursing homes or keeping them in their homes can be compelling, particularly for states looking to reduce their budgets. However, we need to consider that consumers in a home care setting are most likely not receiving 24 hours paid care or supervision -- even when they may need it.

Paying for home care services is therefore an enormous challenge for states and for consumers and their families. As part of the Affordable Care Act, Congress passed the CLASS Act, which would have created a national voluntary insurance program for long-term care. People who participated in the program would pay premiums for five years before they were eligible to collect benefits. If they met the eligibility criteria, they would then be able to collect a cash benefit that would allow them to pay for a choice of long-term services and supports. At the time of the writing of this report, the CLASS Act has been suspended.

The Consumers' Perspective: How and Should Government Be Involved in Home Care?

Consumer responses to this question varied greatly from not wanting any government involvement in home health care whatsoever to a desire to have much more government oversight and support. A number of the consumers stated that they want the government to fund additional hours of in-home care; better coordination of services; choice in hiring their worker; and they want flexibility for their worker in carrying out his/her tasks.

In addition, consumers saw many other ways that government could and should be helping:

• Require caseworker assessment of the workers (not only to help with problems, but to give support and credit to the workers who are doing their jobs well);

• Set standards for and oversee home health agencies;

• Conduct surveys of the care provided;

• Ensure contractors are fulfilling their obligations;

• Better inform consumers and workers of their rights;

• Be more inclusive of consumers, families and workers on government committees and in decision-making processes;

• License home care workers;

• Provide additional services in the home, such as podiatry and dental care;

• Require training and certification of workers;

• Provide dispute resolution services;

• Pay workers better wages and offer benefits;

• Enforce existing regulations; and

• Provide better screening of workers, such as criminal background checks.

Overall, the most common answer to this question was: we need FUNDING, FUNDING, FUNDING! Consumers expressed great concern not only that the government continue to make Social Security, Medicare and Medicaid available to pay for home care services, but that the amount of money to fund these services be increased.

Those consumers who do not want government involvement, or feel that the government's role should be limited, felt passionately so: "I don't feel that the government is competent," "I am not sure the government is able to do anything; there needs to be a national outcry for better quality care for the elderly and disabled," and "I really don't want government in my home."

The Consumer Voice is interested in digging deeper into the reasons some consumers do not want government involved in their home care. Are these consumers more able or capable of speaking out on their own behalf, or more willing to do so? Are they concerned about having someone come into the home to assess that services are being provided and delivered in a quality and timely way? Is there fear of having the services taken away or of being told they need more than is being provided and will have to go to a nursing home? Perhaps there are general privacy concerns as well?

The Consumers' Perspective: What Is Lacking?

Consumers' experiences with home care as expressed in this project were overwhelmingly positive. That said, consumers were encouraged to be honest (without repercussion) about any ways in which their home care quality might be lacking and how care could be improved. Consumers pointed to seven core areas that need improvement:

• Consumers want more care hours

Many of the people reached said they were not receiving enough support in terms of total number of hours of care or frequency of visits. Several individuals said that at a point in the past they were receiving more care, but it was cut back due to budget constraints. "I am approved for help three days a week for two hours each day, but unfortunately they only provide me with two hours twice a week. I have complained to the Ombudsman about the service cutback, but nothing has happened so far to improve the situation."

It would be an interesting study to compare the amount of support individuals with nursing-home-level of care needs receive at home versus what they would receive in an institutional setting. National data show that nursing home residents often get less than four hours of nursing care per day, but a big difference between the nursing home and home care settings is that help is available on-site in a nursing home if a resident needs it. In home care, people come and go based on the number of hours of care approved, which can be just a few hours a week.

Other people want more support, but either do not know how to get it or have not asked. It is unclear to the Consumer Voice whether the individuals need more care (that is, if doing an assessment would show they require more care) or if the desire for more is a feeling of insecurity or loneliness (or all of the above). Regardless of the reason, consumers definitively said that more care would increase their quality of life, as well as support their family members with the stress of unpaid caregiving. One consumer told the interviewer, "My spouse would like additional assistance at night. I still share a room with my husband and he often gets up with me 3-4 times per night for toileting, etc."

• Consumers want workers to have flexibility

Whether it is to change a light bulb, fix a curtain rod, take the consumer for a stroll around the neighborhood or have time carved out to just sit and visit, consumers want workers to have much more flexibility in their jobs. There was a sense from the interviews that workers may want this too, but that agency rules inhibit flexibility and limit work to whatever is on the care "list." At a minimum, consumers suggest that scope of work must be better communicated, "It would be helpful if they were clear about the things that they can and cannot do for me. I think that they should be able to provide services that are needed by the client. For example, if I need to have lotion applied, but they tell me I have to do it myself. It is prescription medicine and I have limitations regarding what I am able to do."

• Consumers want a role in choosing workers

"Sometimes I don't feel comfortable with the person that they send over. Some people do not do a good job and others are not very honest. They are coming into your home and this is very important." Again, the relationship between the worker and the consumer is paramount to success; consumers want some way to assess whether a worker is a good fit for them and their household from the outset.

• Consumers do not want to be told how personal their relationship can be with the worker

"The agency told me that the relationship with the homemaker should not be personal. That we cannot be friends." As discussed earlier, the relationship (whether very close or just a generally good rapport based on communication and trust) between the consumer and the worker appears to be one of the biggest factors influencing quality of care. As one consumer said, "It's really a problem that workers are encouraged to NOT form a bond with the consumer, as that special bond is what makes for good care; it's also unrealistic."

• Consumers want to get out of the house

Consumers are happy to live in their own homes, but they can still feel confined at home. Many interviewees said that they wish they could leave the house more frequently, for shopping trips, or to get fresh air. Some of these individuals are not getting out because the agency does not allow the worker to assist the consumer in that way. Other individuals just do not have enough hours of support to receive the assistance they need to get out of the house regularly. One individual said, "I wish I could go do the grocery shopping with my worker. I am blind and I like to feel and smell what I am going to buy to eat."

• Consumers want workers to have more training

The individuals interviewed identified two key areas for additional worker training: 1) the "soft" skills like house-keeping and meal preparation, and 2) advanced medical skills, such as wound care. Coursework in cooking, interpersonal skills, house-keeping, cultural sensitivity, English and conflict management were some of the most frequently stated responses. Consumers also asked for more training of workers in medical and advanced medical care. Specific requests include: accurately taking and reading blood pressure, using assistive devices correctly, CPR certification, skin and wound care support, medication management, knowledge of how to handle special situations like a seizure and managing conditions of dementia.

This raises an interesting question: Do we need advanced care aides?

A number of consumers said they would like to see their worker better trained to provide better quality care and to enable the worker to make a higher wage.

• Consumers want workers to be better compensated

"If I could change one thing, I would offer night time workers benefits to keep them around because they have kids and families which makes it very hard for them to continue work. Low levels of pay for the night workers also affect this, causing lots of turnover in workers that I have had over the years. My daytime caregiver has been working with me for nine years now, but turnover is really high at night. They should be offered vacations and/or benefits." As will be discussed later in the policy recommendations, the Consumer Voice heard over and over again that consumers think home care workers deserve better pay and benefits and that increased compensation would mean better care (less turnover, a more educated/trained workforce, etc.).

• Consumers want better scheduling of workers

"It would be great if I could have more flexibility in terms of scheduling my worker's days and hours. Having her come out two times a week instead of one would be better. I so enjoy the companionship, but the agency has many clients and they have indicated to me that this is not an option. I live in a rural area and I know that this makes things more challenging as well." Some consumers indicated that the schedule they were placed on prevents them from partaking in other activities, such as volunteering in the community. Consumers want some level of input in setting their worker's schedule.

• Other care concerns

Additional points made by the consumers include lack of care coordination (among agencies, caregivers, family), rude or disrespectful workers, poor management at the home health agency and frequent turnover of workers.

Conclusion & Policy Recommendations

What Was Learned From This Project?

• Consumers have a voice and want to be heard

Policymaking, program development and advocacy should always start from a dialogue with the population impacted (the consumer); better yet, give consumers a seat at the decision-making table. Long-term care consumers across settings, including those receiving support in their homes, have a voice and want to be heard.

• There is a different power dynamic at home

Individuals living in their own homes feel more control over the situation they are in because of the location. The power dynamic is different than in other long-term care settings. Consumers at home often see themselves as the "boss" and are less hesitant to speak up (though some are still hesitant) than the Consumer Voice's experience with individuals in other settings.

The physical location of the consumer being in their own home appears to raise the level of quality in itself, in shifting power back into the hands of the individual. Even in the best culture change nursing home, an individual is living in a community setting where personal wishes and desires have to be balanced with the wishes and desires of others.

• The bases are yet to be covered

Lack of care hours and frustrating scheduling issues are reflective of where the United States is in supporting home and community-based services today. Consumers are still struggling to get the basic services they need at home, and this remains the major focus of most individuals. Some consumers are so grateful to have any service once they get it that quality of care may not be on their radar screen. That said, the interviewing was a wonderful way to engage consumers in conversations about quality they may not have yet had or know they could have.

• Home is viewed as better than a nursing home

Whether or not you can make an "apples-to-apples" comparison between institutional care and home care in terms of cost, services, physical environment, etc., what is ultimately important is the consumer's experience and perception of quality care. Consumers in this report perceive the quality of care at home as much better than nursing home care. They will do anything - including living without the hours of care they need or want - in order to stay out of a nursing home.

• Flexibility in a worker's tasks is critical

Worker flexibility is imperative to quality in the home care setting. Yet, flexibility is a challenging, double-edged-sword. Flexibility can be good and improve quality of care and quality of life by meeting both the anticipated and unanticipated needs of the consumer. It can also give the worker great satisfaction to be able to help the consumer with whatever she or he needs. At the same time, too much flexibility can mean the worker might not be providing the services she or he is required to perform or taking on tasks that are dangerous to him or her. Too much flexibility can also mean the worker is expected to do things for the consumer that are not compensated, are out of his or her skill set or training and/or are potentially hazardous to the worker. Boundaries can be fuzzy and hard to set; this is a topic that needs continued exploration.

Policy Recommendations

• Ensure adequate, continued funding of critical programs like Medicare and Medicaid

The majority of interviewees are concerned for the funding of the services they receive. Without this support, many individuals could not receive care in the home (or even in a nursing home for that matter). Many individuals believed it is the government's role to ensure that the Nation's most vulnerable individuals have access to the care they need. Advocates must continue to make a strong case to Congress, the White House and to their state policymakers that these programs are essential in order to provide long-term care to those who cannot afford it privately.

• Make home and community-based services a mandated Medicaid service

Funding for home and community-based services is at the top of the list of consumer concerns - funding not only to maintain the service they have, but to allow them to access additional services. Eliminating "institutional bias" by requiring that home and community-based services be covered under Medicaid would help achieve both goals. This approach would ensure that more Medicaid dollars are available to help people get the care they need at home.

• Enact policies that increase training, wages and benefits for home care workers

Federal and state governments need to set training requirements for home care workers and create opportunities for workers to receive additional training to advance in their field. Furthermore, increasing wages for home care workers is an important step toward improving the quality of the job. Consumers themselves believe that improving the quality of the job attracts better people to the work, decreases turnover and makes the workers' lives better by increasing job satisfaction, and improving morale - all which mean better care for individuals.

"Demand for home health care workers is soaring as baby boomers — the 78 million Americans born between 1946 and 1964 — get older and states try to save money by moving people out of more costly nursing homes. But filling more than 1 million new home care positions over the next decade will be a challenge. Most home health aides are paid about the same as maids and manicurists and don't get sick days or health insurance themselves. Many who are self-employed must pay for their own gas for driving to appointments and cover their own medical bills if they're hurt on the job (Associated Press)."

• Require that consumers have the right to choose their workers and schedules for care and services

Consumers were very clear that they wanted a say in who their worker is and when their services are provided. These choices are fundamental to person-centered care. Allowing consumers the choices in these areas makes care and services more responsive to consumer needs and improves not only quality of care, but quality of life as well. Without these choices, we are in essence "institutionalizing" people in their own homes.

• Carry out background checks on all home health workers

"Although most states require that home health care agencies perform criminal background checks on their workers and carefully screen job applicants for these positions, the actual regulations will vary depending on where you live. Therefore, before contacting a home health care agency, you may want to call your local area agency on aging or department of public health to learn what laws apply in your state (Administration on Aging)." The consumers in this report placed a lot of trust in the home health agencies to assign appropriate people into their home; to protect the safety of consumers and continue to build this trust, the Consumer Voice believes background checks should be required for anyone providing paid services to people at home.

• Support home care ombudsman demonstrations

Although a number of consumers are able to resolve their concerns directly with the home health agency, others experienced the need for an advocate. In listening to consumers, we identified a number of areas in which ombudsman assistance could be helpful, such as advocating for more care, speaking up for those who cannot address a problem on their own or promoting better care coordination. The Consumer Voice recommends demonstration projects to explore the potential benefits of long-term care ombudsman coverage of home care clients, as well as a study to analyze how the ombudsman has helped consumers in states that currently conduct home care advocacy (including talking directly with consumers in those states) and what is needed for an effective home care ombudsman program.

The time is ripe to explore whether the ombudsman model, which has been long-established in nursing homes, might translate well into the home care setting. "The problem is that the health care system is really fragmented. If someone doesn't have a real advocate on their side who's putting all the pieces together, it's going to be so hard to develop the system for how [living at home] is going to work (Ramnarace)."

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Exhibit A: Interview Questions

Background Questions

Name: _____
State: _____
Today's Date: _____

1. Please select your gender.
Male Female Prefer not to answer

2. Please select the race or ethnicity with which you most closely identify.

White or Caucasian
Black or African American
Asian
Native Hawaiian or Pacific Islander
Alaskan Native or American Indian
Hispanic
Multi-racial
Other _____
Prefer not to answer

3. Is English your first language?

Yes
No. What language is your first language? _____
Prefer not to answer

4. What is your age? _____
Prefer not to answer

Main Survey Questions
* *Please note: throughout this survey we use the term "homecare workers" to mean personal attendants, PAs, aides, providers, etc.*

1. What services do you receive at home? Please list all.

How often do you receive these services?

2. What are some things you like about receiving services and care in your own home?

3. If you could change anything about the home services and care you receive, what would you change?

4. Does your home care worker listen to what you have to say about your care and services?

   If yes, can you give an example? (For example, does your home care worker get you out of bed the way you've told him or her to do it?)

5. If there were a school that home care workers could go to, to learn their job, what classes would you want them to take?

6. What kind of person makes a good home care worker?

7. What should your worker ask you to get to know you?

8. Would it be helpful to create a written plan for your care with your worker? (For example, the plan could include what tasks the worker will do, what you like/dislike, the way you want things done, the times the worker will do things, etc., or anything else that would be important to agree on.)

9. What can your worker do to make you feel comfortable and safe at home?

10. If you have a problem with your care and services, who do you turn to for help?

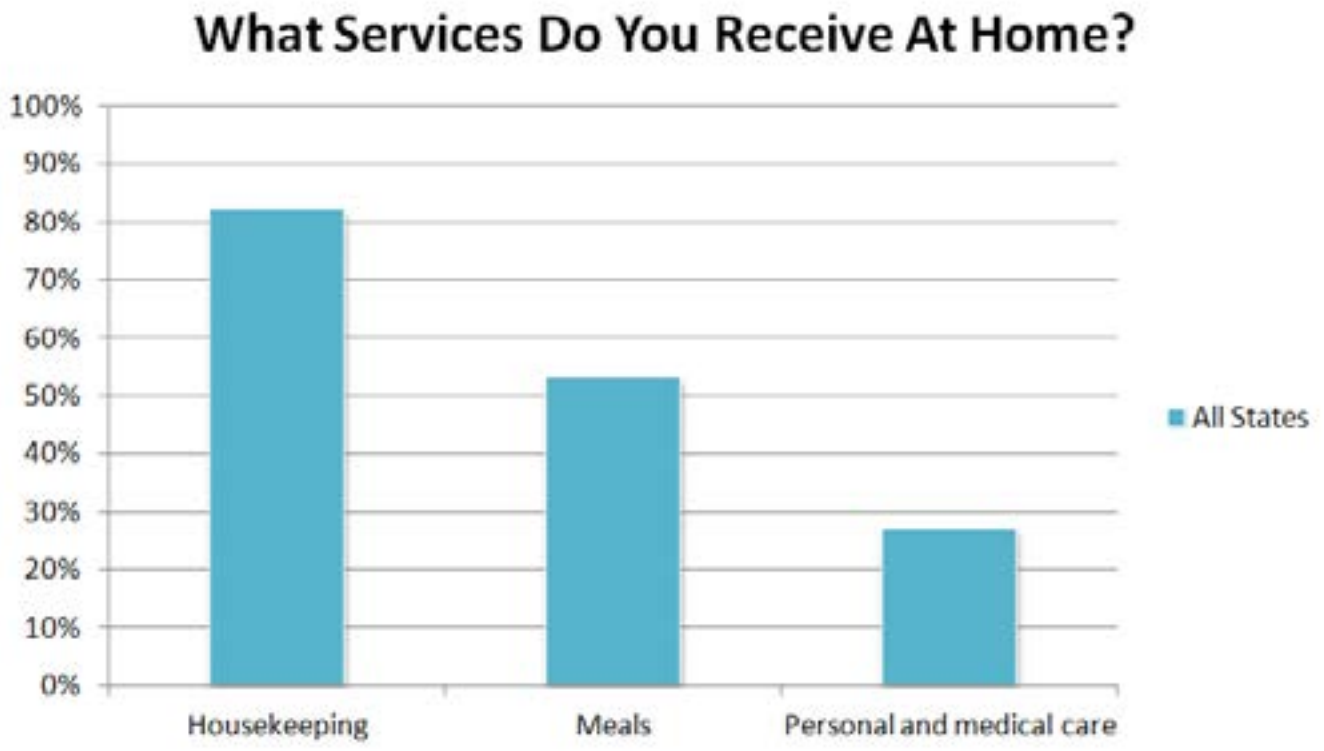
    Do you know anywhere else you could go for help?
    What kind of help should be available to you if you have a problem with care and services?

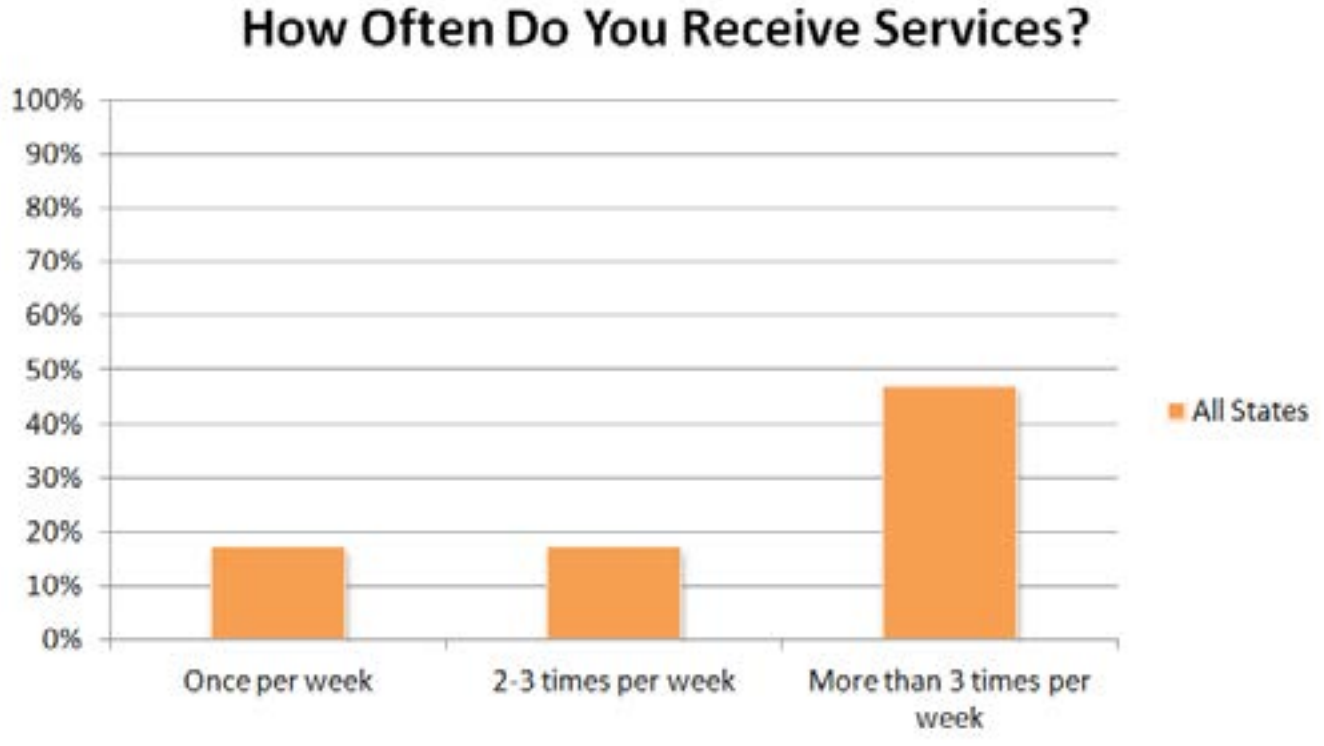
11. What do you like about receiving care at home rather than at a nursing home, or another location?

12. Do you the think the government can do things to ensure that you receive good care and services at home?

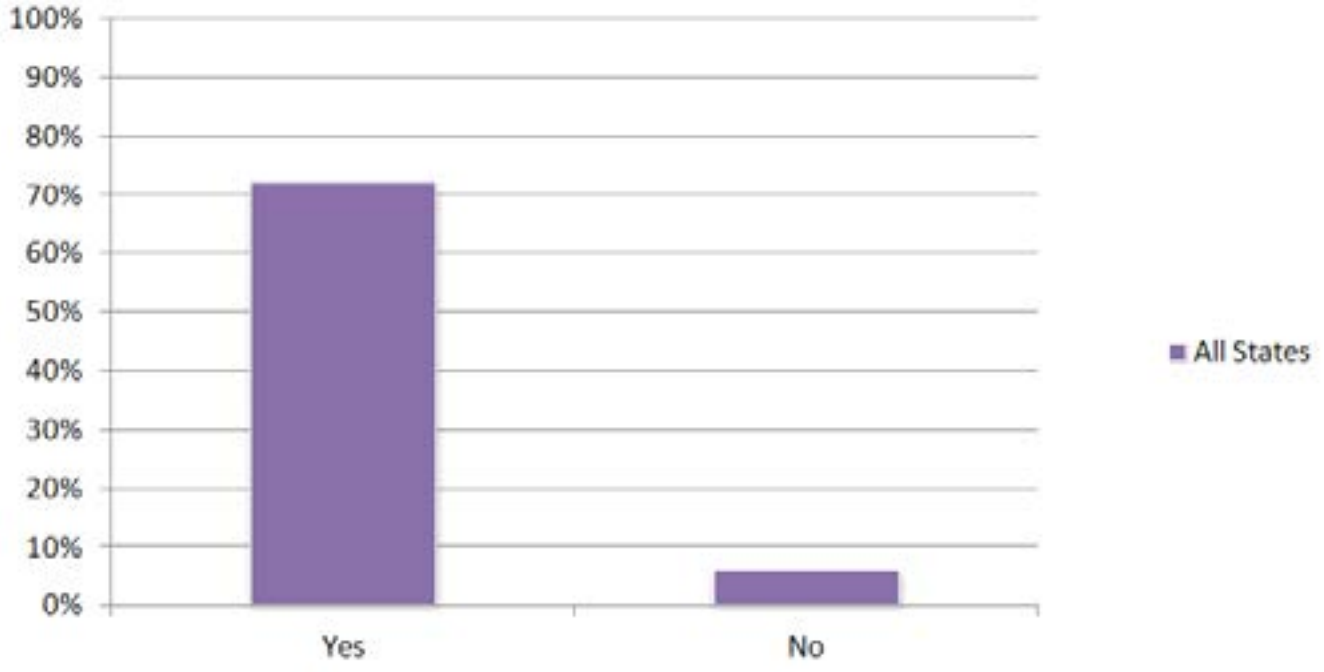
    If yes, what kinds of things might they do so that you receive good care?
    If no, why don't you think the government can do anything to help you get good care?

Exhibit B: Additional Interview Data

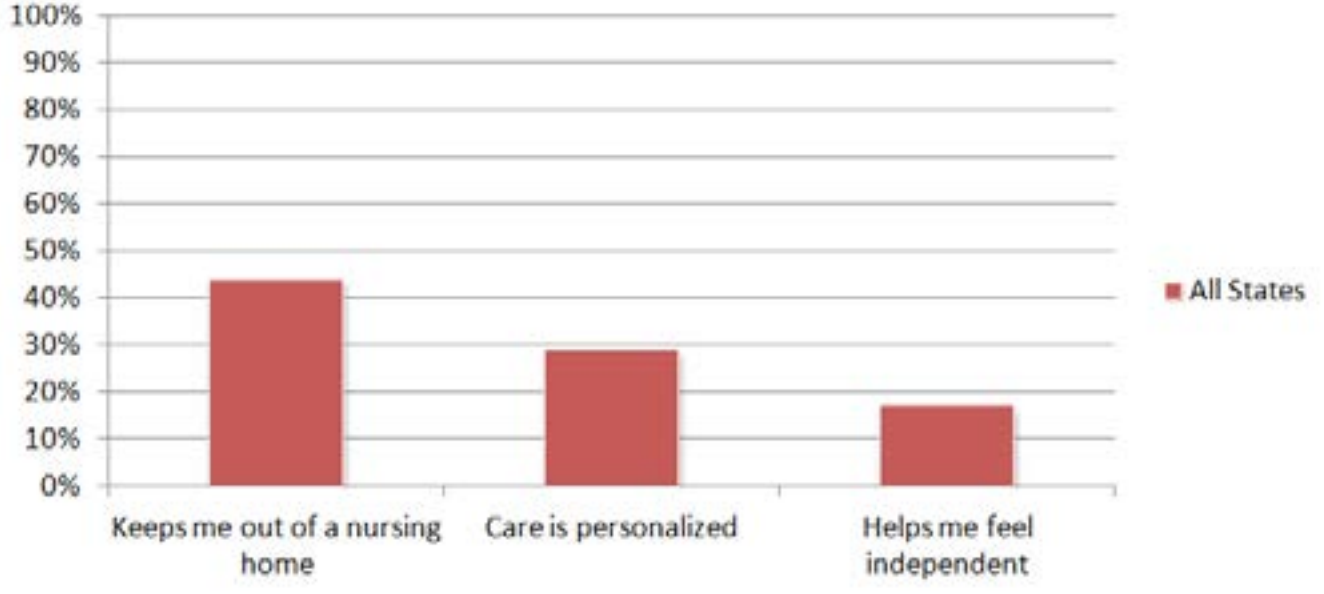




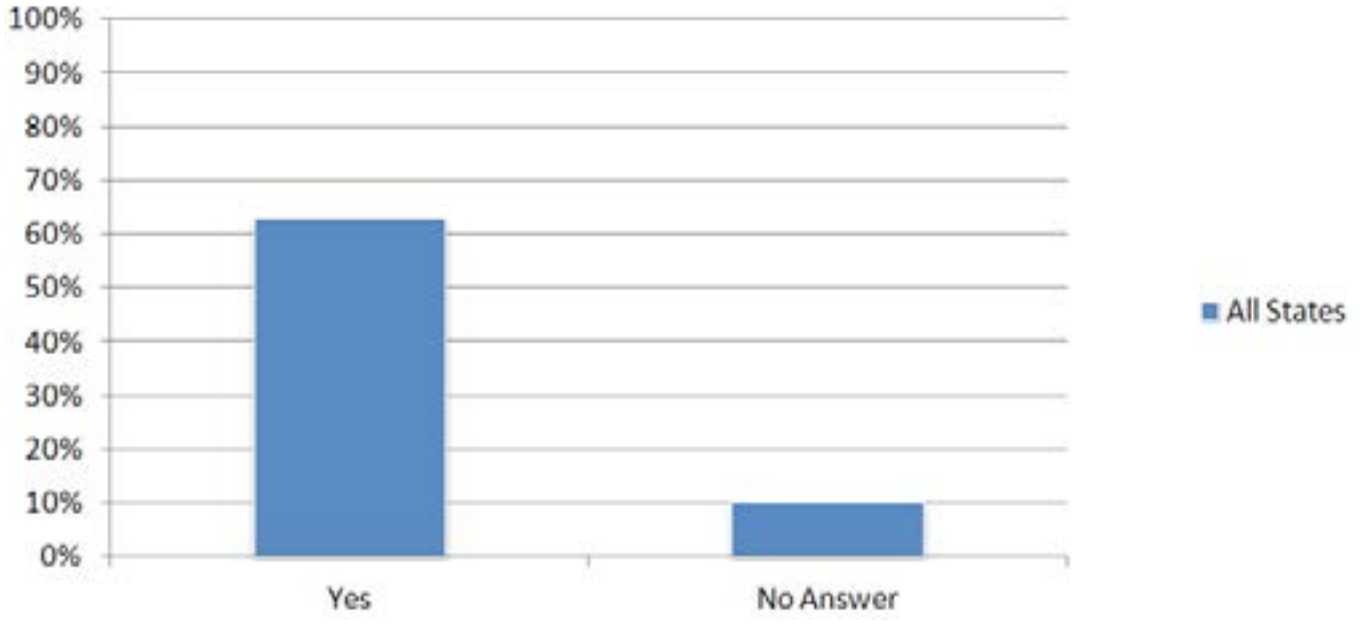
Does Your Home Care Worker Listen to You?



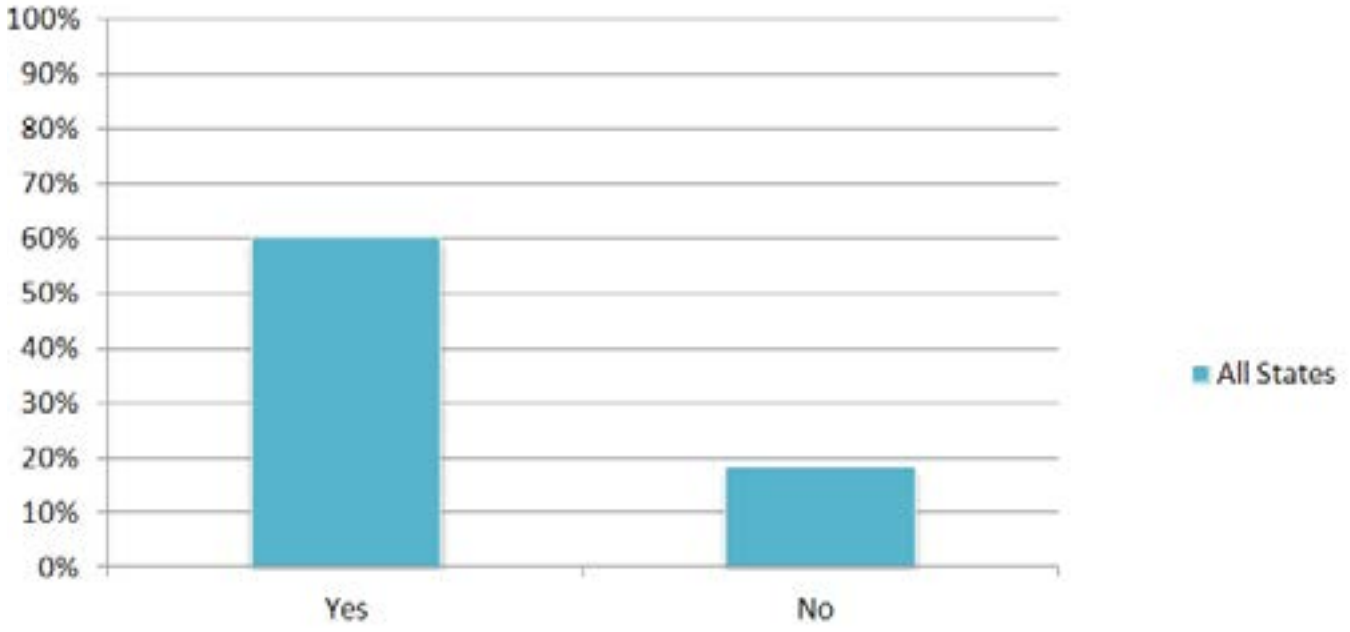
What Do You Like Most About Care In Your Home?



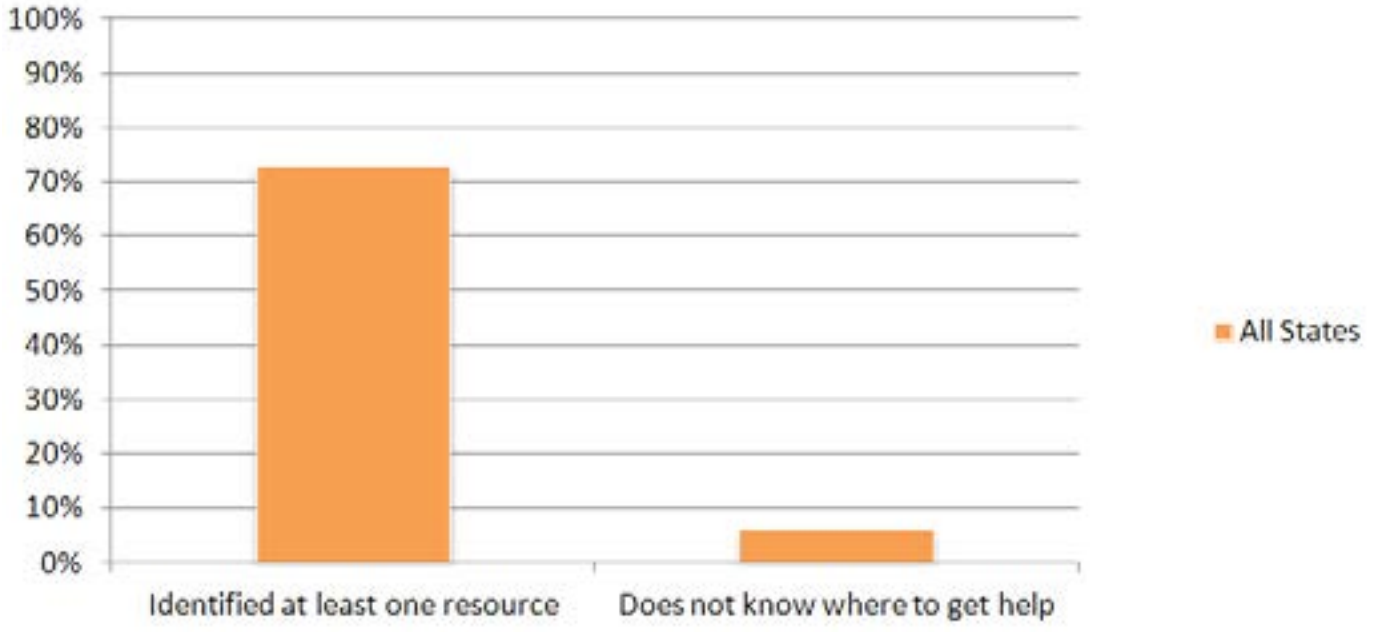
Should Home Care Workers Receive Additional Training?



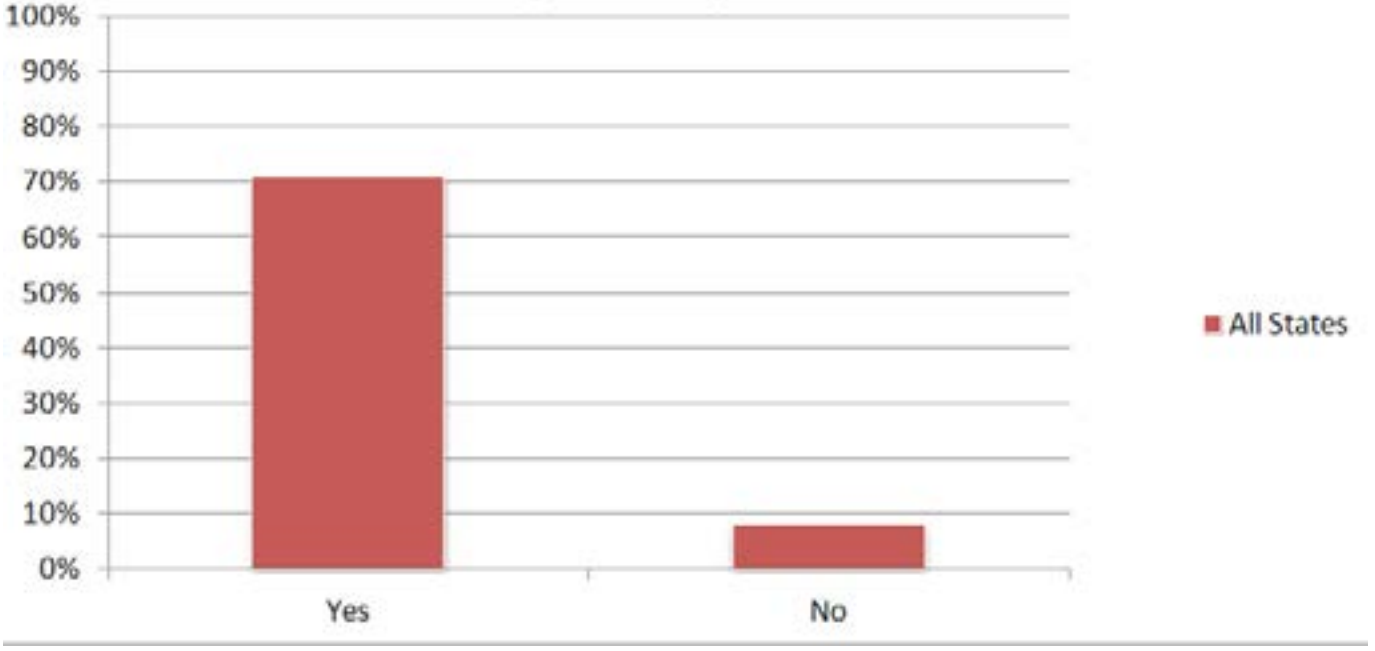
Do You Want a Written Care Plan?



Where Do You Turn to For Help?



Should the Government Be Involved in Ensuring Quality Home Care?



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