



**Community
Catalyst**

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The Future of Long-Term Service and Supports: Centering the Voices of Older Adults in Massachusetts

A Summary of Findings and Policy Recommendations

Authorship and Acknowledgements

Authorship

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Introduction

Shortcomings in the long-term services and supports (LTSS) system for older adults and persons with disabilities in Massachusetts, and around the country, have led to widespread discontent with the system.^{1,2,3} During the recent COVID-19 pandemic inadequate policies, oversight, and provider practice resulted in high rates of infection and death among older adults in nursing homes and other congregate living communities. These problems persist today. Additionally, the system does not meet the needs of older adults with functional and/or cognitive impairments due to greater awareness of the inadequacy in the LTSS financing and service delivery system has led to a growing number of policy discussions among advocates, policymakers, academics, and industry leaders about ways to improve the system. After the temporary policy changes put in place by the Center for Medicare and Medicaid Services during the pandemic, like the increase in funding for home and community-based services (HCBS), policy discussions across the country are gaining momentum. Older adults and their family caregivers have the most to both gain and lose, in any major system changes, making it critical that their voices be front and center of discussions regarding policy reform. This means making sure that the goals and preferences of these individuals are known, taken into account, and reflected in the policy choices that are offered at the state and federal level.

Purpose

The purpose of this study is to bring the voices of older adults and caregivers to the front and center in policy discussions around LTSS reform. Our goal is to ensure that the system better serves these individuals and is responsive to their needs and desires and understanding and documenting their views about policy options for reform is a critical first step. To that end, this project is designed to

¹ Long-Term Services and Supports: What are the Concerns and What are People Willing to do? (2016). ASPE Issue Brief. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation Office of Aging, Disability and Long-Term Care Policy. Washington, D.C. September. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//171616/LTSSconcern-IB.pdf

² Fix needed now: America's long-term care financing system is broken. (2023). The Hill. <https://thehill.com/opinion/congress-blog/4354596-fix-needed-now-americas-long-term-care-financing-system-is-broken/>

³ Are older Americans getting the long-term services and supports that they need? (2019). The Commonwealth Fund. Issue Brief. January. <https://www.commonwealthfund.org/publications/issue-briefs/2019/jan/are-older-americans-getting-LTS-they-need>

accomplish the following objectives:

- To elevate the voices of Massachusetts older adults and family caregivers through ongoing conversations about improving the LTSS system and incorporate their ideas and feedback to help shape decisions about system reform.
- To learn from, complement, and inform other state and national efforts to improve the LTSS system.
- To underscore the importance of meaningful consumer engagement in delivery system reform and other health innovations.

To accomplish these objectives, the project team engaged in two activities including: (1) conducting a survey of Massachusetts older adults, and (2) organizing listening sessions with older adults and caregivers. Beginning in June 2021, Community Catalyst and the Massachusetts Senior Action Council held a series of listening sessions with older adults throughout Massachusetts to understand their experiences with, and views about, long-term services and supports. At the same time, a paper and online survey was distributed to a group of older adults to obtain more detailed information on views and opinions which could support more quantitative analyses.

The primary focus of this report is to summarize the results of these two information-gathering activities and to offer policy options and recommendations based on what was learned. These learnings reflect older adults' and caregivers' LTSS needs and wants for Commonwealth system reform.

Sources of Information

Survey of Older Adults and Caregivers

The LeadingAge LTSS Center at UMass Boston conducted a survey of Massachusetts older adults and/or caregivers and sought to over-sample respondents from typically under-served communities—that is, Black and Hispanic populations. Through Massachusetts Senior Action Council leadership, they distributed surveys to community centers and congregate housing facilities throughout the Commonwealth; they also provided an online

option. 975 surveys were returned, coded, and put into the analytic database. Of those surveys, 547 (56%) were from paper surveys and 428 (44%) were completed online. For the majority of questions, item response rates were above 90%.

Listening Sessions

We completed seven two-hour listening sessions with 59 older adults from Boston, Lynn, Watertown, Cambridge, and Somerville. Their ages ranged between 70–95 years old. The participants came from a variety of backgrounds and were culturally and racially diverse. Six sessions were in English, one in Spanish. All participants were living in the community at the time of the listening session and had either personal experience living in a nursing home, for rehabilitation, or had cared for a family member or friend who lived in a nursing home. Several participants had previously worked in nursing homes as direct care workers while others had received supportive services in their home; very few of the participants had family members that they could count on to help with long-term services and supports needs.

This report summarizes information that is presented in more detail in two other reports:

1. The Future of Long-Term Service and Supports: Centering the Voices of Older Adults in Massachusetts. [Results of a Survey of Massachusetts Older Adults and Caregivers.](#)
2. The Future of Long-Term Service and Supports: Centering the Voices of Older Adults in Massachusetts. [Results of Listening Sessions with Massachusetts Older Adults and Caregivers.](#)

Key Findings

Survey of Older Adults and Caregivers Findings

The key findings from the paper and online survey included the following:

- More than two-in three respondents rated losing independence and self-determination, having to move to a nursing home, not being able to get to places, and losing the ability to enjoy things as issues that they are most

concerned about as they age.

- The single greatest concern cited by a plurality of respondents was having to move to a nursing home; people did not want to have to do this.
- More than half of respondents were very concerned about the potential of not having enough money to get the care they need (57%), not being able to choose where and how to receive services (55%), becoming socially isolated from family or friends (48%), and not having adequate transportation to get places (49%).
- Compared to Black and White respondents, Hispanic respondents were much more worried about not knowing where, or how, to get services due to not having the information they needed.
- Two-in-three respondents said that if they needed LTSS services, they would choose to receive the services in their own home. Slightly less than one-third of respondents indicated a willingness to move to an assisted living facility or senior housing to receive services there, if needed. Cost was a key barrier to their doing so.
- Hispanic respondents were much more likely to want to receive care in senior housing compared to White and Black respondents — 44% versus 19% and 16% respectively.
- Most people believed that having the resources to pay for care was “most important” for being able to age with dignity, should they require long-term care.
- Hispanic respondents were more than twice as likely as White and Black respondents to cite “being able to maintain connections” as the most important condition to be able to age with dignity while having their long-term care needs met.
- The two most cited actions that respondents felt the government should take to help people pay for LTSS included, expanding income eligibility for home and community-based services (HCBS) so that more people could qualify for such services (78%) and putting in place a social insurance program, similar to Medicare, that would pay for long-term care for everyone over a certain age (77%).

- Hispanics were most likely to say that providing financial support for family caregivers, including a spouse, was “most important”.
- A high proportion of survey respondents also supported ideas designed to ensure that their care needs and preferences were being taken into account.
- Investments in the training of caregivers, assuring that care is focused on a person’s quality of life as well as length of life, and paying workers a living wage were cited most often as important quality initiatives; all of which are tied to workforce needs.
- Among all policy options, the one cited most frequently was ensuring that people have the ability to pay for services; roughly three-in-five people cited this.

The survey analysis shows that the issues, challenges, and desires identified by this sample of individuals are consistent with those documented in other studies about the functioning of the LTSS system.^{4,5} The implication is that regardless of economic status, there are a consistent set of issues affecting almost all individuals engaging with the system; if the issues addressed by this convenience sample are addressed, the benefits have the potential to affect a much broader population. Additionally, how people want to see the system perform, and to what end, is remarkably similar. They want to see a system that is affordable to those who require paid care, a delivery system that provides high quality care to all who need it, and a service infrastructure that supports people’s desire to age in place — be that in their current home, in their community, or in senior housing. Second, while there are multiple areas for improvement, those related to paying for services are top on people’s minds. Whether it be expanding income eligibility criteria for HCBS, or putting in place a new public insurance program, the vast majority of respondents cite financing issues to be of paramount importance. Third, there is a relatively high percentage of individuals who indicate a willingness to move to senior housing as they age. And so, for these individuals, while individuals, aging in place is about “aging in community ”. Other research shows

⁴ Travers, J. L., Hirschman, K. B., & Naylor, M. D. (2022). Older Adults’ Goals and Expectations When Using Long-Term Services and Supports. *Journal of Applied Gerontology*, 41(3), 709–717. <https://doi.org/10.1177/07334648211033671>

⁵ NORC (2016). Long-Term Care in America: Expectations and Preferences for Care and Caregiving. <https://www.longterm-carepoll.org/long-term-care-in-america-expectations-and-preferences-for-care-and-caregiving/>

the positive effects of using senior housing as a platform for providing supportive services to older adult populations,⁶ and therefore, investments in senior affordable housing need to be incorporated into policies.

Finally, while some have touted support for new technologies as a way to address many of the shortcomings of the system, most respondents here do not view such investments as a panacea. At most, this option is viewed as secondary solutions to the larger problems that plague the system. Other financing and service delivery improvement options should be viewed as higher priority issues for this population.

It should not be forgotten that when thinking about policy direction, views can vary significantly by socio-demographic characteristics, such as race/ethnicity and income. In particular, the views of Hispanic older adults, who tend to use less formal (paid) service systems than other groups, have a very different set of policy priorities and tend to want to see more investments in technology and the unpaid family caregiving network. Additionally, more middle-income older adults who have a major concern with how to pay for care, are supportive of policies designed to improve the financing of care and make it more affordable. The implication of these statements are that whatever policy approaches are chosen, they are likely to be aligned with some, but not all, groups' needs and desires.

Listening Sessions with Older Adults and Caregivers Findings

Key findings from the listening sessions include the following:

- **Respect should be the guiding light of care providers.** Participants all talked about the need to be respected by care providers and emphasized ideas about what it means to live and age with dignity. Respect was defined as honoring personal privacy and dignity in health care settings, the need to exhibit empathy and cultural competency, and compassionately supporting independence by encouraging them to continue to engage in the things that mattered most to them. Many people said having health care providers who

⁶ Tavares, J, Simpson, L, Miller, EA, Nadash, P, Cohen, M. The effect of the right care, right place, right time (R3) initiative on Medicare health service use among older affordable housing residents. Health Serv Res. 2022; 1- 12. doi:10.1111/1475-6773.14086. <https://pubmed.ncbi.nlm.nih.gov/36270972/>

listened and communicated well was a priority.

- **Nursing Homes are always a last resort for care.** People do not want to go to nursing homes due to quality concerns and fears about inhumane conditions. Participants pointed to chronic staffing shortages, exemplified by the lack of time and respect, that perpetuate a cycle of inadequate care.
- **More accountability in nursing homes for complaint handling is needed.** The issue of accountability if, or when, things go wrong in a nursing home, along with confusion around steps to take when reporting a problem, is a concern for people. Transparent processes for complaint handling, without fear of retaliation, is an example of the type of change people would like to see.
- **Home Care is essential to have, but confusing to get.** A repeated concern was the lack of clarity around how to access home health care due to limited knowledge around the steps to take to secure services; this was especially true for integrated care programs like the Program for All Inclusive Care of the Elderly (PACE). Many people talked about unpaid family caregivers as being the most trusted providers of home care and discussed unreliability as being an issue with some home health workers. Many participants had stories about rushed and poorly trained workers who left them, or their loved ones, without adequate treatment.
- **Workforce issues abound.** Workforce concerns were a consistent topic during all of the listening sessions. Issues raised included: low pay for home health care workers, low pay and poor training issues leading to high turnover rates and poor quality of care, and the fact that training for home health workers does not focus, but should, on soft skill sets like relationship building.
- **Nursing Home alternatives are needed.** People do not want to be forced into a binary choice of living at home or in a nursing home, when they do not want to do either. Many people are looking for affordable housing with support, but out-of-pocket rates are impossible to cover. They are therefore looking for Medicaid to explore covering housing with services and/or assisted living arrangements.

The analysis of information gleaned from the multiple listening sessions highlights that the nature of provider interactions is critically important to how people

perceive their quality of care. That is, being treated with respect, having caregivers listen to their preferences and desires, and honoring the dignity of the individual are what matters most to people. People also want to age in place with enhanced access to home and community-based services. Their desire for a more robust service system is motivated both by (1) the desire to age in place and (2) the significant antipathy towards having to move into a nursing home. Finally, people understood that a poorly compensated and trained work force creates a number of serious problems; they were clear about their desire to see training focused on relational skills designed to support the building of meaningful relationships between themselves and the caregiver. Only in this way can the overriding goal of being treated with dignity and respect be met.

Policy Recommendations

The following high level policy recommendations stem from what we learned by listening to older adults in Massachusetts: those that responded to a detailed survey about their views and opinions, and those that participated in the listening sessions. These policy recommendations are all designed to accomplish one, or more, of three important objectives that were shared by almost all of the study participants: (1) a system that is more affordable, across a broad continuum of care options; (2) a service infrastructure that supports people's desire to age in place and in a way that promotes respect and dignity among both care receivers and care givers, and; (3) investments in coverage for additional senior housing options that will ensure that people can stay in the community and avoid having to select between the binary options of home or nursing home care. Specific recommendations include:

Relieving the LTSS Cost Burden.

1. Helping people pay for services, either through expansions in MassHealth coverage or through the development of a new source of financing such as a social insurance program for LTSS, were overwhelmingly cited by study participants as being critically important policy actions to explore. To that end, the Commonwealth should begin to examine the financial feasibility of

changes in MassHealth eligibility criteria for home and community-based care and support and should explore the research and stakeholder engagement costs, benefits, and desired structures for alternative social insurance approaches for LTSS.

Work Force Investments

- 1. Relational Skills Training.** The Commonwealth should require all direct care workers, whether in the home or in a skilled nursing facility, to undergo mandatory training on a core set of skills and competencies; with a particular emphasis on a range of relational skills including:
 - The ability to listen and communicate effectively
 - Eliciting and respecting the needs and preferences of older adults
 - Perceiving and interpreting older adults' verbal and nonverbal communication
 - Managing relationships with clients' family members
 - Strategies for avoiding miscommunication
 - Handling conflict effectively and with respect
 - Providing culturally and linguistically competent care
 - Coping with stress by learning and adopting self-care strategies
 - Finding ways to effectively express compassion to the person being cared for
- 2. Increase Wages for home care workers.** The Commonwealth should raise the hourly wage for direct care workers to a minimum of living wage, dependent on family size; for example, the living wage for a single adult with no children would be \$21.35 while for two working adults with two children, the wage would be \$32.46.⁷

Aging in Community

- 1. Support for Staying in the Community.** The Commonwealth should provide older adults with information on, and direct assistance to secure, all supports

⁷Massachusetts Living Wage Calculator for Massachusetts, 2023. <https://livingwage.mit.edu/states/25>

and services needed for people to age in place in their communities for as long as possible.

- 2. Support for Transitioning Out of Nursing Homes.** The Commonwealth should provide nursing home residents that are able, and want, to leave their facilities with information and direct assistance in creating a plan to do so – including securing all of the supports and services that will allow them to live in the community.
- 3. Nursing Home Alternatives.** The Commonwealth should invest in the creation, or expansion, of alternatives to skilled nursing facilities such as “small homes” or “rest homes”. They should also find ways to use alternative housing and support models – including assisted living and senior housing with services; which are affordable to older adults who need LTSS, but who do not necessarily need a nursing facility level of care.

Although much of the focus was on ways to support individuals in the community and improve the infrastructure and eligibility for home and community-based services, there were discussions about specific quality-related challenges in nursing homes. Specifically, there was concern about a lack of transparency regarding the steps to take when things go wrong. To address this, there needs to be improvement around the processes that assure accountability in nursing homes. To that end, the Commonwealth should ensure that there are transparent processes for complaint handling in nursing homes so that residents know that if there is a problem, they have a clear path to resolution.

Conclusions

The themes and recommendations from the listening sessions and the survey are mutually supportive and lead to the three broad categories of the policy recommendations summarized above. They also align with a number of initiatives put forward by state policymakers such as: [H2752](#), the Act to Improve Long-Term Staffing and Dignity for Caregivers; [S1408](#), an Act to Strengthen the Direct Care and Dementia Workforce; and [H0623](#), an Act to Improve Quality and Safety in Nursing homes. Moreover, Massachusetts has taken the first steps in exploring the potential financial implications of alternative social insurance approaches;

they have amended the recent state budget to provide up to \$500,000 for an [actuarial study](#) of the issue.⁸ This is a necessary first step to ensure that informed policy discussions among key stakeholder groups can occur, should the state decide to move in this direction.

Implementing even one of the recommendations above could significantly impact how older adults in need of LTSS, experience the system. We know this because it is exactly what they told us. Making sure that their views and opinions about LTSS priorities are top of mind during policy discussions, and that they have a seat at the table when specific proposals arise, will assure that system transformation is focused on the right issues to address people' most pressing needs. In order to ensure the system is designed to meet the needs of the people it serves; these changes are necessary.

⁸ The actuarial study is the last provision in line item 4000-0300 of the FY24 budget, which is chapter 28 of the Acts