FROM THE FRONTLINES:

Home care workers voice COVID-19 challenges and ideas for change

JANUARY 2021

Research report

BETSY LEHMAN CENTER
for Patient Safety

ACKNOWLEDGEMENTS

The Betsy Lehman Center is grateful for partnerships with numerous agencies and organizations working to improve the quality of home care in Massachusetts. We are also thankful to the many individuals who helped us refine our survey and discussion questions, recruit focus group participants, and identify skilled facilitators and note takers to ensure that all participants' voices were heard and accounted for in our analysis. Our focus group discussions were very rich as a direct result of those efforts.

We offer our sincerest thanks to these individuals and the organizations they represent, including: 1199SEIU United Healthcare Workers East Massachusetts, Disability Policy Consortium, Executive Office of Elder Affairs, Heller School for Social Policy and Management at Brandeis University, Home Care Aide Council, Home Care Alliance of Massachusetts, Mass Home Care, and the Safe Home Care Project at the University of Massachusetts-Lowell.

INTRODUCTION:

Home care is an essential part of the health care continuum, especially during a pandemic

Home care workers are a large and diverse workforce. Collectively, they enable many thousands of the Commonwealth's older adults and people with disabilities to remain in their homes and communities, easing the burden on more intensive care settings like hospitals and nursing homes.

The state designated home care workers as employees delivering "COVID-19 Essential Services" early in the pandemic[1] and has prioritized them in its vaccination plan.[2] Yet the home care sector has not consistently been considered in federal, state, and health system strategies for mitigating the spread of COVID-19[3] at least, in part, because home care workers' roles in the continuum of care and the conditions under which they work often go unrecognized.

The COVID-19 pandemic has underscored both the need for a robust home care system and the challenges of delivering this care in ways that are safe and sustainable. Many of the tasks performed by home care workers, such as bathing, dressing and help with mobility, cannot be done without close physical contact. These tasks also require a basic understanding of safety principles and infection control, as well as access to resources that can help prevent the spread of infection, such as personal protective equipment (PPE), COVID testing and, now, vaccines.

Unique aspects of home care present additional challenges. Home care workers typically visit multiple locations each day, traveling by car or public transportation to care for people living in houses, apartment buildings, assisted living residences, nursing homes and other congregate living settings.[4] Low wages[5,6] lead many to take on extra shifts or work for more than one employer to make ends meet. Home care workers serve a population that is particularly vulnerable to COVID-19, with the highest prevalence of home care use among people aged 85 and older.[7] The workers themselves are often members of vulnerable populations[8] who live in communities with high rates of COVID-19.[9]

Together, these factors elevate home care workers' risk of contracting COVID-19, transmitting the illness among their clients and consumer-employers, and spreading it within their own families and communities. One recent study[10] in the United Kingdom found that COVID-associated mortality in home care is at least equivalent to that in nursing homes, though data on incidence of infection among those who either provide or receive home care in Massachusetts are not available.

RESEARCH QUESTION: HOW HAS COVID-19 IMPACTED THE HOME CARE SECTOR IN MASSACHUSETTS?

To better understand the effects of COVID-19 on the home care sector and to identify opportunities for improvement, the Betsy Lehman Center for Patient Safety conducted two studies. This report describes findings from a virtual focus group study with more than 80 frontline home care workers and a smaller number of home care clients and consumers during October-November 2020. In addition to gathering first-hand perspectives on home care service delivery during the current pandemic, the intent of this research was to elicit change ideas that could inform state programs and policies for strengthening this essential sector both during the pandemic and beyond. Earlier in the year, the Center worked in partnership with the Safe Home Care Project at the University of Massachusetts-Lowell to survey a representative sample of managers at home care agencies in the state. Some of the findings from that June 2020 survey, referred to as the "Home Care Agency Survey," are included in this report.

> *"In terms of why I'm proud of the work I do, I think there's two prongs to that. Number one is the fact that we show up. My peers show up and that just makes me so proud. And then the other part of that is I actually carry around a letter that's dated from the state of Massachusetts, the Commonwealth, that states that I'm an essential worker. And I just feel good that somebody says, hey, what we're doing is important, it's essential, and we're going to recognize that.*

METHODS:

Focus group participants, discussions and analysis

During October and November 2020, the Betsy Lehman Center hosted virtual focus groups with 83 home care workers who provided services in Massachusetts during the pandemic, including:

- 39 personal care attendants (PCAs). PCAs are hired directly by individual consumer-employers who qualify for coverage of these services through MassHealth*
- 44 workers affiliated with home care agencies (agency workers). These include home care aides, home health aides and more specialized workers such as physical and occupational therapists.

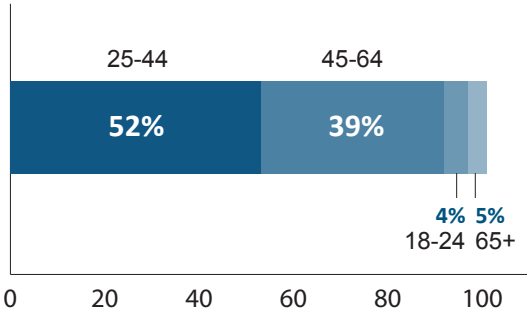
In addition, seven agency clients and PCA consumer-employers participated in sessions designed to elicit the perspectives of people who received home care services during the pandemic.

We conducted separate sessions for PCAs, agency workers, consumer-employers and agency clients. One PCA session was conducted in Spanish. Each 2.5-hour session included survey questions, followed by breakout discussion groups of about eight participants led by trained facilitators and note takers.

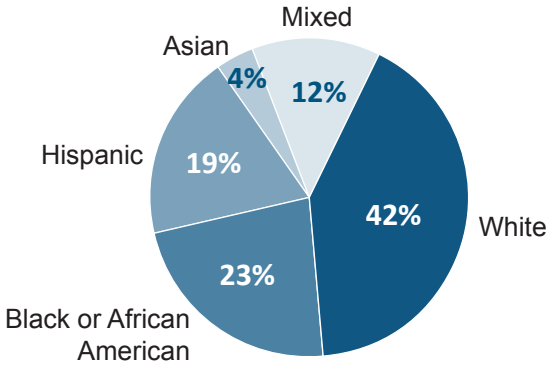
Survey questions captured information about the participants' experiences, explored general attitudes about COVID-19 challenges, and prompted thinking on topics, such as access to PPE, testing, and infection control information, explored in greater depth during the small group discussions. Discussions centered on hypothetical scenarios in which a fictional home care worker faced difficult COVID-related decisions as well as open-ended questions about challenges and change ideas (Appendix A). Because COVID-19 vaccines were not approved for use in the U.S. at the time, we did not explore the topic of vaccination.

FOCUS GROUP PARTICIPANTS

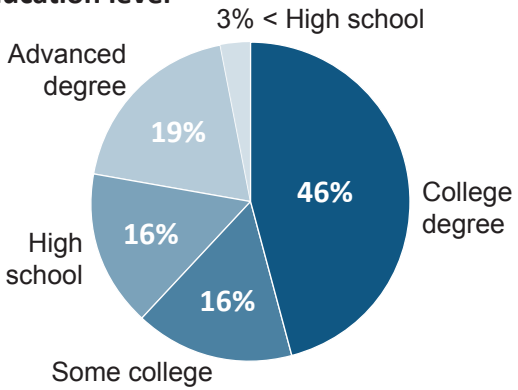
Age (Years)



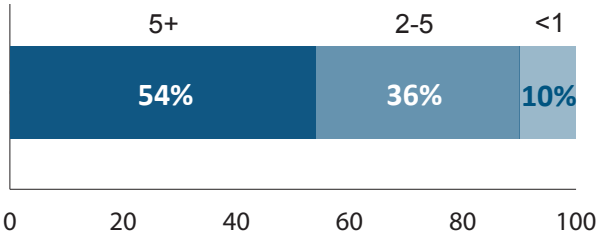
Race and ethnicity



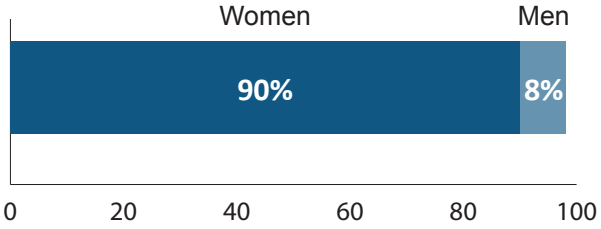
Education level



Tenure in home care (Years)



Gender



*PCAs are sometimes family members paid to provide care services to an eligible relative; almost 1-in-5 of the focus group PCAs lived with their consumer-employer.

Sessions were recorded with participants' permission. Two members of our research team independently reviewed a subset of session notes and transcripts to identify themes and reached consensus on preliminary themes. They independently coded transcripts in Excel based on these themes, iteratively revising during the coding process. A third researcher flagged and arbitrated discrepancies in coding, and the entire team reached consensus on major and minor themes. Researchers then selected exemplary participant quotes for inclusion in this report.

We recruited PCAs and consumer-employers through emails and text messages sent by their union* and an advocacy organization. We recruited agency workers and their clients through the state's home care associations and agencies. An online registration form collected demographic and work-related information (Appendix B). As a condition of participation, each person needed to be able to use the Zoom online meeting platform with video enabled. Individual coaching sessions on how to use Zoom were offered in advance of the sessions to anyone in need. Participants received $75 stipends for 3-4 hours of their time (including the registration process).

Participants were representative of the Massachusetts home care workforce in terms of race, ethnicity and gender. Workers under age 25 were underrepresented, while workers with college and advanced degrees were overrepresented.[11] Answers to survey questions were not significantly different for those without a college education except where noted in the report. Despite many attempts, we were not successful in recruiting larger numbers of clients and consumer-employers. The small number of participants were strong contributors, but may not be representative of all individuals who rely on home care services in the state.

FINDINGS: COMMON THEMES AND CHANGE IDEAS

This report is organized around eight findings about the characteristics of home care that impact the safety of workers, the people they serve, and the community at large, especially during the COVID-19 pandemic. Focus group participants identified challenges and opportunities for improvement in several areas:

- Allocation of scarce resources (e.g., PPE, COVID-19 testing)
- Access to information (e.g., training on infection control, consistent guidance on COVID-19 protocols, timely notification of potential exposure to COVID-19)
- Workforce retention and burnout (e.g., compensation, job security, decision making that requires safety tradeoffs, empowerment to act on safety protocols)

Participants also offered a number of change ideas to address these challenges during the pandemic and into the future, ranging from consistent, targeted infection control guidance to structural incentives for workers to stay home when sick.

Dominant themes that emerged from this work include home care workers' strong sense of dedication to their clients and consumer-employers, desire to conduct their work safely, and motivation to contribute to broader public health goals of stopping the spread of COVID-19 in their communities.

HOME CARE IMPACTS LARGE NUMBERS OF MASSACHUSETTS RESIDENTS

It is difficult to assign exact figures to the number of people who provide and receive home care services.

The Executive Office of Elder Affairs reported 63,104 older residents and people with disabilities received care through the State Home Care Program in fiscal year 2019.

The Personal Care Attendant Program served 35,000 in 2018, according to the PCA Quality Home Care Workforce Council.

Last month, the state included home-based health care workers in Phase 1 of its COVID-19 vaccination priority list and estimated the number of eligible individuals at 114,000.

None of these figures account for home care aides or recipients who make private-pay arrangements.

*1199SEIU United Healthcare Workers East represents the workplace interests of PCAs with MassHealth, which provides funds for PCA care to qualifying individuals in the state.

FINDING:

Concerns about the risks of COVID-19 in home care are shared by workers, agencies and the people they serve

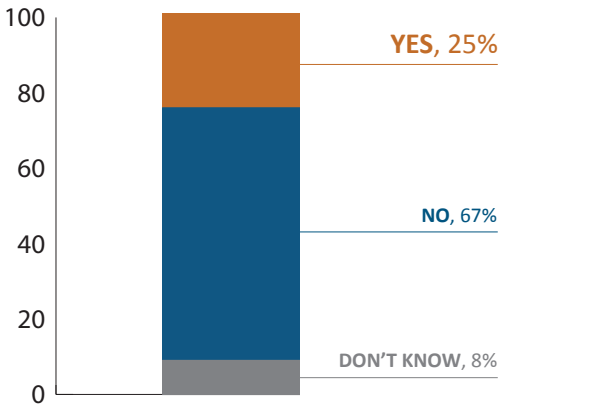
Many home care services require close and prolonged physical contact inside people's homes, making observance of social distancing protocols impossible. Not surprisingly, risk of exposure to COVID-19 was top-of-mind for most of the workers who participated in the focus groups.

Almost all of the participants agreed with a statement that people, in general, need to take COVID-19 more seriously. In addition, almost all said that the pandemic had an impact on their work and most worried about getting COVID-19 at work. One in four reported having provided care to someone with COVID-19.

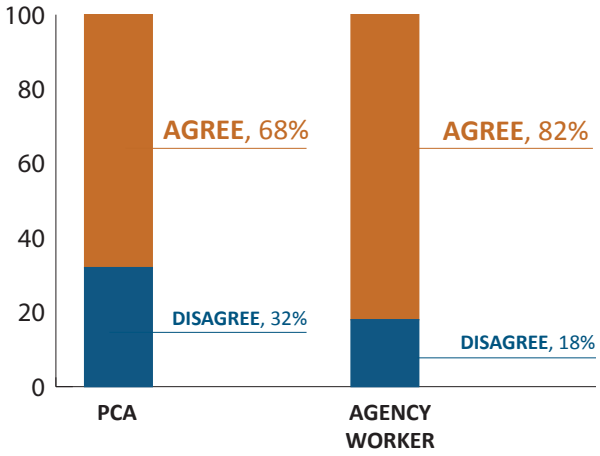
Home care workers are not alone in their perceptions of the risks of COVID-19 exposure and infection. Client and consumer-employer focus group participants also acknowledged the risks of COVID-19 exposure from workers.*

Home care agency managers expressed similar concerns in the Home Care Agency Survey earlier in the year.[12] Sixty percent of agencies had clients with COVID-19 or suspected of having the illness and 76% reported that at least one worker from their agency tested positive for COVID-19. In addition, 90% of agencies said at least some workers in their employ had to quarantine because of possible exposure to the virus.[13]

"I HAVE WORKED FOR A CLIENT/CONSUMER WHEN THEY WERE SICK WITH COVID-19"



"I WORRY ABOUT GETTING COVID-19 AT WORK"



> *I think we've all had cases where you've been in the house, and the patient may not be sick, but then somebody comes in and they go, 'Oh yeah, so-and-so, my neighbor, was over again this morning hugging me and she has COVID.' And they say it casually, like it's not a big deal. And then you're panicked because you don't have … It gives you a bad feeling.*

> *We're supposed to call our patients before every visit. And I have to say that … even with calling ahead, many times we go in and the patient is sick and does have COVID, even though they've said they don't have symptoms. You know. So it is pretty common.*

> *I'm the wrong person to ask because I'm really burnt out and I don't feel safe working in home care right now, so I just think there needs to be … a lot better communication and transparency. I feel like I'm not finding out that I've been exposed 'til five days later a lot of times.*

*Because of the small number of participants, data from the two sessions with home care clients and consumer-employers are not included in this report, but general takeaways of interest are noted where appropriate.

FINDING:

Home care workers travel between multiple residences, heightening the risk that COVID-19 will spread

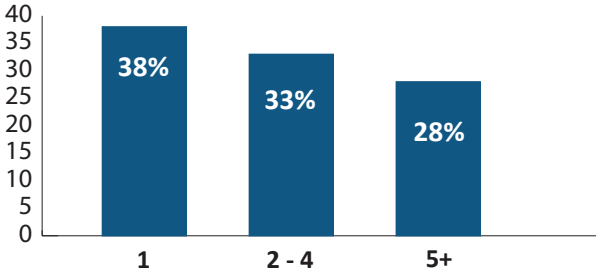
Many home care workers provide services in multiple settings each day, traveling between private homes and apartments, assisted living residences, nursing homes and other group settings. This is particularly concerning because many of the people for whom they care are especially vulnerable to complications from COVID-19.

Of the home care worker focus group participants,* more than a quarter provided services in more than one type of setting and one in 10 worked in three or more different types of settings.

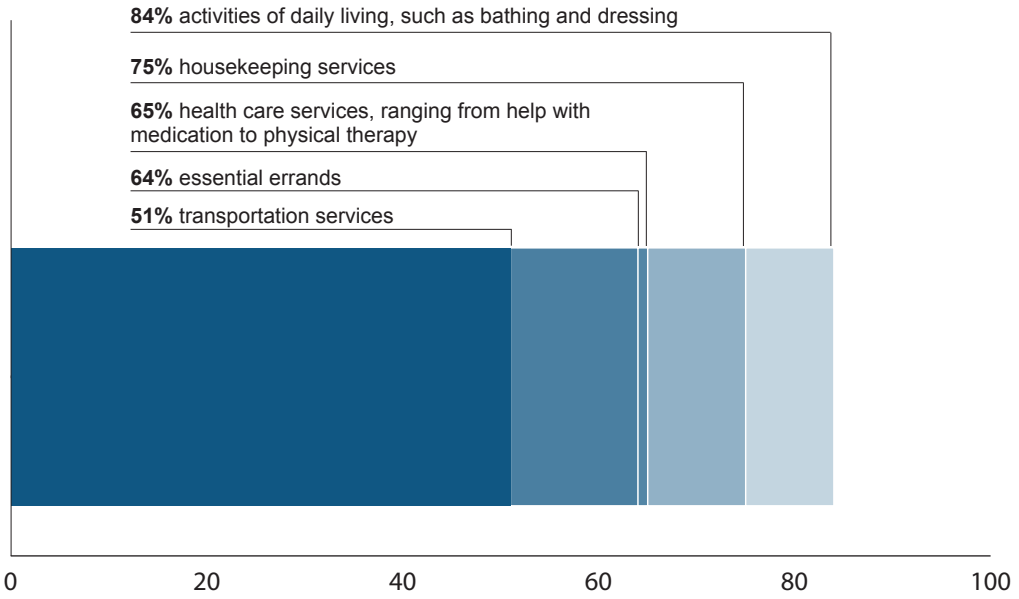
In addition, 6-in-10 home care workers provide services to two or more individuals on a typical day, with 28% of all home care workers caring for five or more people on a normal workday.

Home care clients perceive a risk of contracting COVID-19 through contact with home care workers. In the Home Care Agency Survey, agency managers indicated that demand for services declined early in the pandemic. Nearly all of the respondents reported that at least some clients were no longer willing to have home care workers come to their homes.

IN A NORMAL WORKDAY, HOW MANY CLIENTS/ CONSUMERS DO YOU SEE?



HOME CARE WORKERS PERFORM TASKS THAT REQUIRE CLOSE PERSONAL CONTACT



> *Right, so I have all different private clients that [I] have to go to and a couple of agency clients. I have a PCA client. It's like if this one person tells me that they have [COVID symptoms] and I have been in their house and I don't have the whole gear on me then those people will have to cancel for a day or two until I get tested.*

> *I think every agency needs to follow the same protocol. We need more guidance because everyone's doing something different.*

> *How do you move with two masks from three houses or four houses?*

*In this report, the survey question responses of PCAs and agency workers are presented separately when differences were noteworthy. In all other cases, the PCA and agency worker findings are combined and presented as the responses of "home care workers."

FINDING:

Access to appropriate PPE and training to prevent the spread of infection remains a challenge for home care workers

Because proper use of appropriate personal protective equipment (PPE) is an essential element of infection control and prevention for home care workers at all times but especially during a pandemic, we asked participants a series of questions about their PPE use, training and access.

Home care workers' ability to adequately cover their noses and mouths while at work is of utmost importance given current knowledge about the airborne spread of COVID-19 and the risk of asymptomatic and pre-symptomatic transmission.

For most participants, PPE during COVID-19 consists of some type of face mask and gloves; face shields and gowns are not widely used. Among PCAs, more than half regularly use cloth masks at work. While the vast majority of agency workers mainly use medical-grade masks (e.g., paper masks or respirators), one in five of this group rely on cloth masks.

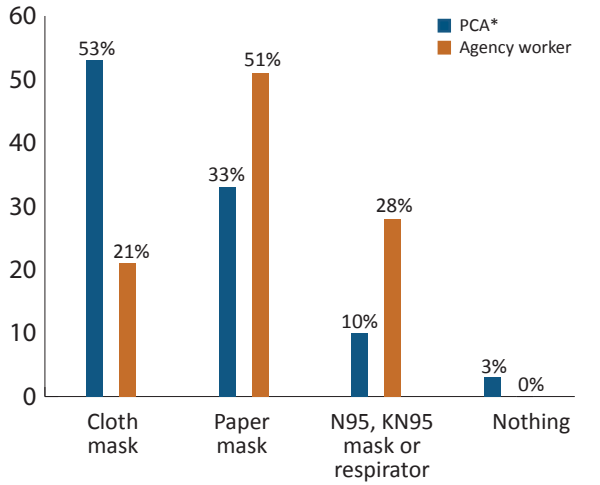
When working with clients or consumer-employers who have COVID-19, home care workers said they would feel safe with universal PPE including N95 masks, face shields or goggles, gowns that cover their clothing, as well as hair coverings and booties. Several participants noted that working in full PPE can be uncomfortable, but that they and their colleagues would use it when caring for individuals with COVID-19.

Several agency workers reported that their agencies organized specialized teams to provide care for clients with COVID-19, reserving the more protective PPE for use by those teams. While this seemed a good solution to many, it did not address workers' concerns about close contact with clients who might be asymptomatic or pre-symptomatic.

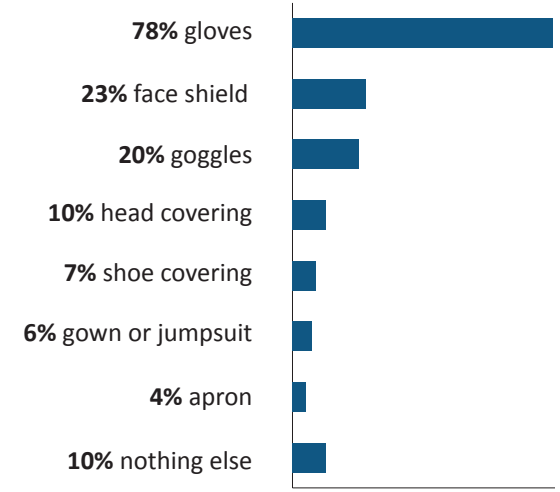
The vast majority of participants said they had been trained on how to safely don and doff PPE. But when asked if anyone had ever observed their technique — considered a best practice for evaluating competence in safe use of PPE[14] — fewer than half answered in the affirmative. This raises questions about the rigor of the training provided. Furthermore, some who did have access to N95 respirators questioned the adequacy of the fit testing and training they received.

Access to sufficient PPE, especially early in the pandemic, was also a concern. Most reported that they were able to get the PPE they needed. In discussions, however, they described the processes for obtaining PPE as confusing or inconsistent, especially for PCAs whose consumer-employers are expected to provision them with PPE and any other supplies they need to do their work.

"TO COVER MY NOSE AND MOUTH, I USUALLY WEAR … "



"IN ADDITION TO A COVERING FOR MY NOSE AND MOUTH, I USUALLY WEAR … "



> *I think I saw three or four different aides with different patients in different homes. We were at the point where we were all supposed to be wearing N95 Envo masks, every patient, every day, and none of them had them. And they didn't know they were supposed to have them. They weren't aware, you know?*

> *Nobody comes to tell you, 'This is how you're supposed to put the gloves, this is how you're supposed to put the PPE on.' And so unfortunately for those people who don't know, they go and then there's nothing they can do. They say, 'Oh, I'm just gonna work.'*

*Results limited to non-Spanish speaking participants due to translation error on this question in the Spanish focus group session.

FINDING:

Home care workers often lack access to timely information about COVID-19 exposure, safety protocols and other guidance

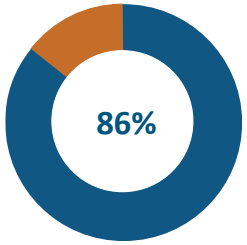
Among Massachusetts home care agencies surveyed earlier in the year, only 54% reported that they are always informed when a client has COVID-19.[15] This leaves workers especially vulnerable to contracting and spreading the virus while working in close contact with individuals who may be asymptomatic.

Access to frequent testing is especially important for workers who may not know the COVID status of the person for whom they are caring. A large majority said they are eager for easy access to COVID-19 testing post-exposure on a periodic basis, believing that testing will lower their risk of contracting the illness. Most said they would want to be tested regularly if they could do so free-of-charge. In discussions, client and consumer-employer participants mostly agreed that more frequent testing of workers and care recipients would be protective of all.

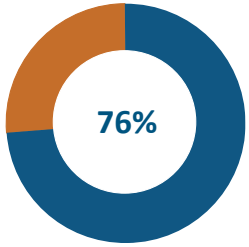
A number of participants expressed frustration at their inability to access testing promptly after possible exposure to a client or consumer-employer with COVID-19. The availability of testing sites, long lines or waits for test appointments, and turnaround time for results vary significantly by community and were, along with cost, cited by workers as barriers to more frequent testing.

Participants also noted that relevant, consistent guidance from authoritative sources including federal and state agencies was hard to access and implement, especially early in the pandemic.

PCAs, in particular, expressed frustration that they have to sift through conflicting guidance on their own and are often the sole decision-makers about what to do to keep themselves and their consumer-employers safe. Agency workers, who sometimes work for more than one agency, said that policies and protocols are not uniform and that some agencies have struggled to communicate updated guidance to frontline workers in a clear and timely way.



Workers agreed that regular COVID testing of the workforce would improve safety



Would want to be tested regularly if they did not have to pay

> *I feel like companies, agencies like most of ours, should be incentivized to test every employee. Ideally, it should be every day. … And I feel like testing is the part that we're really not doing enough of, especially for folks in our business. I know there are people in my agency that I work with that are clinicians that haven't been tested the entire pandemic. Not once.*

> *There's also the point of view of the client, because we've got clients asking us, Hey, what are you guys doing about COVID? Hey, what happens if you're not feeling well? Hey, how's your agency handling this? So it comes from a different direction at us too.*

> *If it was simple, [a potentially exposed worker] should just stay home and get tested for COVID and not expose any other clients in case it is COVID. But that said, I think it is not that simple because not everybody has the money to do that and you also care about your clients. But I think that when you need the money and you don't know if you are sick, you don't want to take the chance of staying home for nothing.*

FINDING:

Personal relationships and power dynamics play complex roles in home care safety

Unlike nursing homes and other congregate living settings that can implement policies to try to stop the spread of COVID-19 within their walls, home care providers lack control over precautions taken by the individuals in their care or by household members or visitors. Instead, workers rely upon building trusting relationships and open communication with their clients and consumer-employers to minimize their risk.

A sizeable majority of agency workers (82%) and PCAs (92%) believe that their client or consumer-employer would inform them if they had or might have COVID-19. However, despite good intentions, clients or consumer-employers might not always be forthcoming about their symptoms, several participants said. They may assume their symptoms stem from allergies or a cold. They may also be cognitively impaired and unable to accurately describe how they are feeling. They also may not have enough information to know if a friend or family member exposed them to COVID-19.

Participants said that acting in partnership with their consumer-employers or clients was the best way to protect both parties. For example, most said the people they care for would wear a mask when asked. But some participants also recognized that their long-standing relationships and familiarity with the individuals they care for might lead to incorrect assumptions about each other's safety practices or a relaxing of best practices.

Furthermore, while most home care workers believed any work-related safety concerns they reported would be taken seriously, they also said that many of their concerns are difficult to redress. For example, participants described learning about unsafe social distancing practices among family and friends at their client or consumer-employer's home, leaving them feeling unduly exposed to others who may be asymptomatically spreading the virus.Some participants called for restrictions or screening for visitors to their clients or consumer-employers' residences.

These themes were largely mirrored by the client and consumer-employer focus group participants. They expressed trust in the workers, while also acknowledging that they couldn't be sure how rigorously workers might follow COVID-19 public health guidance outside of the work setting. They also said they took notice of COVID-related precautions taken by their home care workers, understood that COVID protocols were unclear at times, and were selective in the questions or concerns they raised with their workers. Several said it was very important to them to avoid undermining the person taking care of them, whom they value immensely.

> *You could have a patient that has, like, six kids and grandchildren and they all have come to visit during the week. Or … or it could be the opposite — none have come to visit, you know? You just never know.*

> *And then you don't want to go in your patient's house because you don't know who used it. Yeah, it was a tough … It's been a tough few months.*

> *I see like 30 patients a week and none of my patients or any in their family have gotten sick and nobody at my house has gotten sick and I think that's because me and my clients, I've had them for a while, we're kind of on the same page. We appreciate helping each other, you know what I'm saying?*

> *I think as well as we, as a PCA, social distance and we limit our company and we're safe in our homes. I think the consumer should have some responsibility as well. They shouldn't be able to have whoever they want there without wearing masks. They should have a little responsibility to be safe for us too, not just themselves.*

> *But a clear policy either from the top down or arranged with each individual client about what to do in any given situation [can help]. If I wake up with a sore throat but no other symptoms, do you want me to come in? If I wake up with sinus pain so I am sniffly, but I am pretty sure it is not COVID, do you want me to come in? Do you want me just to check in every time I don't feel quite right and we evaluate it case by case? Or do you want me to just show up and be like 'Here's the situation'? I'd rather do that over the phone because that way I'm not passing germs if I have any. [It's about] having an understanding with each client about what their risk tolerance is so that nobody feels like they have been unreasonably exposed.*

FINDING:

Safety tradeoffs weigh on home care workers who feel a commitment to the people they care for

A strong theme among focus group participants was ongoing stress caused by the need to make decisions with limited information and resources. They are also acutely aware that many clients or consumer-employers are highly dependent on the services they offer, making it difficult to always follow safety recommendations.

For example, focus group participants discussed what a typical home care worker might do if she arrived to work and her client or consumer-employer acknowledged COVID-like symptoms and was awaiting test results. They described the pull they feel between what workers "should" likely do and what they "would" likely do. If the client or consumer-employer needed their help and there was no one else who could step in that day, they would find it hard to leave the home, even if that meant risking further exposure.

Similarly, if they awoke one morning with COVID-like symptoms, the participants said they would likely weigh concerns about how the needs of their clients or consumers would be met that day even though they know they "should not" go to work until they had more information about their condition.

Agency workers felt they had more options than PCAs under similar circumstances. Many home care agencies, they said, have policies about what to do in case of illness or if they suspect a client may be sick. These workers said they can usually call a supervisor for guidance in difficult situations. In addition, home care agencies have contingency plans for substituting workers in case of illness, though finding a sufficient number of workers during the pandemic has been a challenge.[16]

PCAs, who typically do not have an affiliation with an agency, described having a harder time arranging coverage on short notice when they are unable to provide needed services to their consumer-employers.

> *We haven't left the patients isolated. I am proud that I have continued to show up despite the chaos and risks.*

> *Because if they can't get out of bed without me coming in, I am gonna suit up in PPE and take care of them.*

> *Yeah, so the patients don't want to reveal [possible COVID symptoms] to you, or that they're sick or their family members are sick. 'Cause they're afraid you won't come.*

> *They are not going to get fed, bathed, they are not going to get their personal needs met if you don't show up. So it is a really, really tough situation especially now in this pandemic.*

> *Our agency is affiliated with a hospital and so in the hospital, you can't walk in without a mask or a face shield, you can't have visitors. In home care, I can ask my clients and their families to put a mask on and if they say 'no,' I'm not allowed to leave. I still have to stay there and provide care. That doesn't make any sense to me.*

FINDING:

Low compensation and job security concerns have safety implications

As noted earlier, low pay drives many home care workers to maintain multiple jobs. Benefits such as paid sick leave and employer-sponsored health insurance are often limited as well.

Focus group participants acknowledged that financial pressures and lack of clarity about paid leave policies had or might lead them or their colleagues to consider going to work even after a possible exposure to COVID-19.

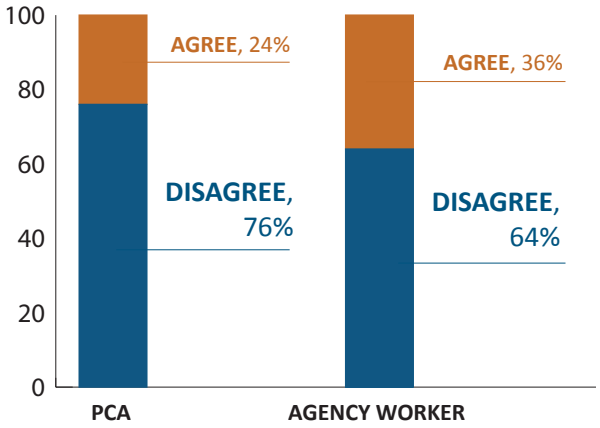
Three-in-four PCAs said they could not afford to quarantine without pay after a possible exposure to the virus and the same was true for two-thirds of agency workers.

More than two-thirds of PCAs but fewer than half of agency workers thought they would receive sick pay if they contracted the virus and had to stay home. Several noted that they had to use valuable paid sick time just waiting for COVID test results.

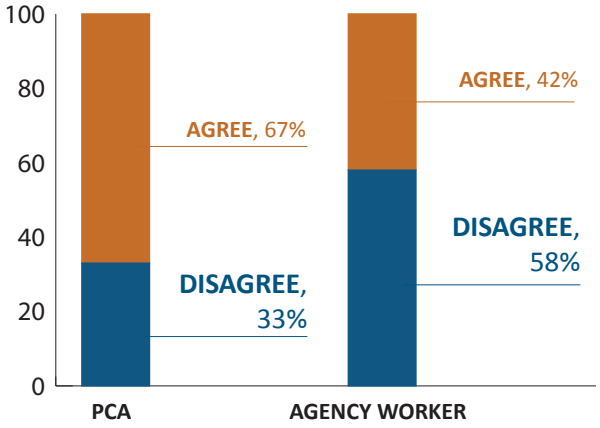
Focus group participants were generally aware that Massachusetts had taken steps to improve paid leave for frontline workers who need to quarantine and offered short-term "hazard" pay earlier in the pandemic. But they also expressed significant confusion over benefits and eligibility, often debating amongst themselves the terms of these evolving policies.

In addition to confusion about pay and benefits during the pandemic, workers harbored fears they might be permanently replaced if they had to quarantine. They also worried that they might lose a client or consumer-employer if they enforced safety protocols, adding to a general sense that they may have to manage in a compromised work environment in order to be paid.

"IF I HAD TO QUARANTINE, I COULD AFFORD TO STAY HOME WITHOUT PAY FOR TWO WEEKS"



"I WOULD CONTINUE TO BE PAID IF I WAS OUT SICK WITH COVID-19"



> *I know my employer says you have a choice. You can go in and take care of the patient and get paid, or you can refuse to go in and see the patient and not get paid.*

> *So it's kind of hard if there's no protection for the PCA. People can just fire you during these times when you're bringing up … valid reasons. So I think it's kind of hard that there's less protection for us as well, especially if you have multiple people you are assisting … where if we have valid concerns that are within the guidelines of our state and local officials and we're seeing someone not following them, that there is some sort of protection.*

> *A lot of health care workers are per diem, per visit, where they don't have benefits. So if you don't have those benefits to rely on, that makes you think twice about quarantining yourself as far as stopping the spread.*

> *I just know that I did have COVID in the beginning of all of this and payroll and HR basically had no clue what to do. I was out of work for a month and I did end up getting paid, but they told me I was not going to. It was a big, huge confusion.*

> *But when you call in that you don't feel okay, it seems you're exposed because you're not sure whether you were exposed or not. They will say, 'Okay, you don't go,' but to be paid, you have to use your sick time, which is, to me, I believe it's not fair, because we are fighting for people's lives and we do need our lives too.*

FINDING:

Low compensation and recognition for difficult, hazardous work jeopardizes home care workforce retention and development

Focus group participants believe home care workers are paid too little for high-hazard work. Hazard pay available earlier in the pandemic, they said, brought their take home pay closer to a living wage and incentivized them to continue working in home care.

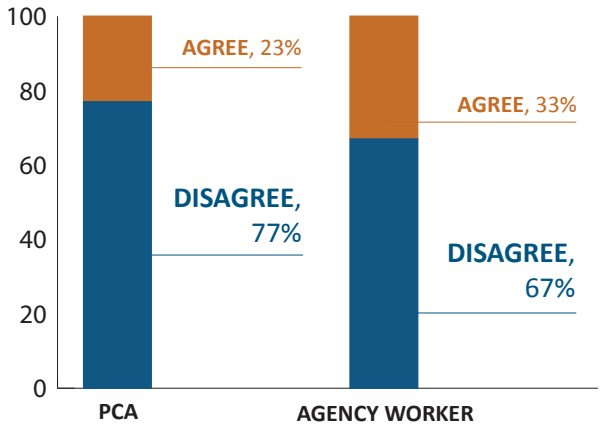
The pandemic has also stirred long-standing concerns about uncompensated hours for administrative tasks and care that sometimes take longer than expected. A recurrent theme was that unpaid overtime adds to a sense that their work is undervalued. This may be contributing to broader concerns about burnout in the home care industry.

Opportunities for professional growth are limited in home care. Focus group participants expressed some confusion over eligibility, costs and rewards associated with various certifications and other training and educational opportunities.

Participants further noted that they often feel undervalued and unrecognized as members of their clients or consumer-employers' health care teams. As frontline workers who spend extensive time with these individuals in their homes, home care workers often have observations that could be helpful to primary care physicians, nurses and other caregivers. Similarly, a better flow of information from the care team to the home care workers would help them provide safe and quality care they said.

Underscoring the challenges of worker retention, nearly 1-in-3 participants had considered stopping their work in home care because of concerns over COVID-19. That number was higher for workers with a college or advanced degree (31%) than it was for those who had not completed college (24%).

"I HAVE THOUGHT ABOUT STOPPING MY WORK IN HOME CARE UNTIL AFTER THE COVID-19 PANDEMIC"



"I was just thinking how to get more people into the field. Basic bottom line is better pay, better benefits.

"They shouldn't have stopped that hazard pay. COVID is still out there. We're still working and will be for a while.

"So people are quitting because an average 40 hour a week is never 40 hours. It's 50 plus, 55 plus, to get everything done, so it's not enticing to come work in home care.

"You have to make sure that everybody is respected and paid fairly. Because these corporation and businesses they get paid a lot of money per hour by the patient. But when it comes to the actual aides, they don't get the fair compensation. So, who would wanna work for something where you're busting your rear end and potentially getting yourself sick and mentally having a breakdown or close to a breakdown if you're not being adequately paid for your services and your knowledge and your caring?

"I personally would like to see that it be like a team effort of doing somebody's care plan. Like I'm just a CNA and I'm considered like the lowest of the totem pole. I'm to do what a nurse has made a care plan that has done nothing but sit at a table and ask the patient questions. They have no clue whether this person can walk to the bathroom or not. And as we take care of these patients, we see them declining, we see different things going on, and we should be able to have those care plans changed.

"A home health aide in the state of Massachusetts, you are certified but there is no licensure program so you don't have a license. So CNAs can work in home care but a home health aide can't work necessarily unless you work for a specific person in a nursing facility. There's a very big difference and so it almost feels like if you don't really have a license you don't fully have a voice, even though you can get training for things. You always feel like you're never going to be compensated fully for what you're worth even if you, like for me, I also work in the hospice sector of home care because that's still underserved and undervalued, dying with dignity.

CHANGE IDEAS:

Home care workers expressed change ideas for safety improvement and workforce retention

Focus group participants are acutely aware that, while home care services are essential, they are even harder than usual to deliver under COVID-19 and are associated with health risks to themselves, the people for whom they provide care, and their own communities. Participants shared the following ideas about what could be done to improve safety and support the home care workforce both during and after the pandemic.

1. **Consider home care workers as members of the broader health care team.** Home care workers believe they have more to contribute to conversations about care plans for their clients and consumer-employers but they seldom have a direct line of communication with the primary care physician, physical therapist or others on the care team.
2. **Prioritize home care workers in PPE allocation and distribution programs.** Participants are aware that home care agencies and the labor union that organizes PCAs have had to scramble to secure PPE, especially early in the pandemic. They expressed frustration that the home care sector had more limited access to PPE supply chains relative to other health care providers.
3. **Offer more frequent, robust training on use of PPE and other key infection control practices.** Participants said they are willing to participate in more intensive training, though expressed concern that home care workers are not always compensated for time spent on improving their knowledge base and skills. Most also said they had been trained on the use of PPE, but in further discussions they described inadequacies in that training.
4. **Make available regular COVID testing for home care workers and their clients and consumer-employers.** Frequent, accessible, cost-free testing of workers and the people they care for can help slow the spread of COVID-19 among vulnerable populations and reassure all that it is safe to continue delivering and receiving home care services.
5. **Improve communication between workers and the people they care for about safety practices.** Some home care workers described entering into written agreements with their clients and consumer-employers to come to a shared understanding of steps both parties can take to lessen their risk of contracting and spreading the virus. These might include provisions such as self-screenings for COVID-19 symptoms before visits or mask-wearing practices.
6. **Develop a worker backup system.** The availability of backup coverage would allow home care workers, particularly PCAs, to stay home from work when potentially infectious, knowing that their consumer-employers' needs would be met in their absence. This would both better protect consumers but also relieve workers of the moral dilemma they said they face when clients are depending on them for assistance with their most basic needs.

> *"The gratitude is overwhelming, but it's really nice to … most people have a lot of gratitude toward us anyway but especially in this unprecedented times, you know, to really feel that, how people really care about the work that you're doing, you know, makes you feel good, makes you want to keep doing it.*

> *"Well, if I can leave the house and they're smiling, they're happy, I made them laugh, I did everything that they wanted, and that they're happy with it, I leave happy myself because I feel I've made a difference in my hour or two, whatever, however long I'm there.*

> *"A lot of the clients they're isolated too. Their grandchildren don't come to see them now 'cause they don't want to give them COVID, they've been around other people. That was one of my biggest things I loved throughout the COVID, was just being there for them in that way, and being their granddaughter, being the one that they sit and talk to.*

7. **Develop direct, consistent guidance on COVID safety for the entire home care sector and improve communication about that guidance.** COVID-19 safety guidance offered by federal and state authorities was often difficult to understand or act upon in the home care setting, leading many home care agencies to develop and communicate differing interpretations of protocols. For home care workers and clients who engage with multiple agencies, these inconsistencies added to the confusion. Recognizing that protocols and guidance will continue to evolve over the course of the pandemic, home care workers would like to see improvements in the clarity and consistency of information they receive.
8. **Improve the compensation structure. Focus group participants believe current rates of pay are too low and will adversely affect the state's ability to attract and retain a capable home care workforce.** Low pay and limited benefits also influence risk-taking decisions by home care workers. Beyond addressing the overall low rates of pay, participants identified several structural adjustments they believe would make a difference in safety and workforce retention and development.
    - **Offer overtime pay.** Overtime pay could enable home care workers to put in longer shifts with a smaller circle of clients or consumers, thereby reducing the risk of spread. It also would allow workers to be paid for documentation of visits and other administrative tasks that they often are not able to complete within the time allotted for their shift, reducing burnout and staff turnover.
    - **Offer more generous paid sick leave and create a sick leave bank.** Home care workers called for adequate sick leave benefits to counter the financial pressures that might lead them to stay on the job while possibly infectious. Focus group participants also suggested that they could help one another through a "sick leave bank" option whereby those with unused sick time could donate it for use by other home care workers who have exhausted their own benefits.
    - **Continue hazard pay through the remainder of the pandemic.** Focus group participants were unequivocal in their appreciation for the temporary hazard pay earlier in the pandemic, reporting that it made a meaningful difference in their ability to make ends meet. Hazard pay also boosted morale by signaling recognition of the value of their service to some of the state's most vulnerable residents.
9. **Offer emotional support resources.** Home care workers said they face burnout issues similar to those experienced by other health care personnel. Some indicated that services typically offered to workers through employee assistance programs and other mechanisms could help retain the existing home care workforce.

> *"For me it was just like having them tell me like that they're so happy that I'm there providing that care for them and that they acknowledge like the little things I would do to just try to make them feel more comfortable because this is new for everyone, especially the elderly. They're not used to this type of stuff, like technology, all this stuff that's going on so just having them feel included and that you love and care for them means a lot to them and a lot to me.*

> *"It makes me proud that the work of PCAs is starting to get recognized. We are now considered "essential" workers. We are no longer just the women that show up at the house to care for someone. We are essential frontline workers supporting the most vulnerable populations. We have demonstrated the value of our work.*

POLICY AND PROGRAM IMPLICATIONS:

The pandemic underscores the need to ensure a robust, resilient home care sector in Massachusetts as demands for these services grows

Massachusetts has an abiding interest in a home care sector that has the capacity to safely serve tens of thousands of residents who rely on it to remain in their homes and communities. Yet home care is too often seen as operating on the periphery of the health care system.

For home care to realize its potential to improve quality of life while relieving pressure on other more intensive health care settings, its integral role in the continuum of care must be accounted for in state health care policymaking and prioritization.

The change ideas elicited through the focus groups are framed largely as responses to the pandemic. But many have roots in long-standing stresses to the home care workforce that, if alleviated, will position the state to meet the demands for these services as the percentage of older adults grows in the coming years.[17,18]

None of these change ideas are simple to execute, but some are within reach in the shorter term. They include better communication about COVID-19 status and access to timely testing, appropriate PPE and other resources to prevent workers and the people they care for from becoming infected—for their own sake and to stem the tide of hospital admissions. Other short-term solutions include the development of clear, consistent guidance on infection control protocols appropriate to home care settings. This not only would slow the spread of COVID-19, but could prevent illness from other viruses and bacteria that are spread through the close physical contact entailed by many home care services.

Change ideas that depend on major resource investments, resolution of complicated tradeoffs, or both will require more deliberation. For instance, the need for rigorous infection control practices could be addressed through additional education and training requirements for the largely uncertified, unlicensed workforce. This would empower home care workers to be on the front lines of preventing harms that diminish quality of life and lead to hospitalizations and readmissions. At the same time, additional education requirements may create entry barriers or drive existing workers out of the system. Striking the right balance will be of particular concern under the PCA model, intended as a highly flexible, low entry-barrier program to deliver compensated care to thousands who otherwise would be unable to live independently in the community.

The home care compensation structure looms large over all of these program and policy considerations. Focus group participants strongly concurred that the single greatest impediment to home care workforce retention and development is low pay. Home care may be more personally gratifying than other low-wage jobs for those who choose that path, but it is always demanding and sometimes hazardous even in non-pandemic times. Until wages and benefits account for these conditions, efforts to build the home care workforce are unlikely to meet with success.

CONCLUSION:

The focus group discussions elicited a strong sense of home care workers' dedication to providing safe and compassionate care to the individuals they serve as well as to strengthening the home care sector as a whole. Massachusetts has an opportunity to leverage this commitment to advance immediate and future statewide goals related to health care equity, quality, safety improvement and cost containment and to ensure access to essential home care services during the pandemic and beyond.

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