

Update: Nursing Home Resident Input on the Moving Forward Coalition's Action Plans

Dear Coalition Friends & Colleagues:

When the Moving Forward Nursing Home Quality Coalition launched its efforts to prioritize recommendations from the National Academies of Sciences, Engineering and Medicine (NASEM) report on nursing home quality and turn them into action, we knew that residents had to be part of the conversation.

At first, we sought to include residents on all seven working committees. However, it became clear that challenges related to connectivity, variable resident schedules, and staff support needs made creating an inclusive and accessible space for residents challenging.

Some of those original resident committee members still participate on committees and workgroups. But we also realized we needed a way to engage a broader group of residents more directly and thoughtfully about their lived experience in nursing homes. We are still working to improve our approach to resident inclusivity through conversations with ombudsmen and advocates and with the help of many nursing home providers.

As a first step, Barbara Bowers, steering committee member, brought together a nationwide network of nursing home providers and staff, advocates, students and others to speak to residents both in informal one-on-one telephone calls and small group sessions about residents' experiences with nursing home daily life, care, policy, spaces and interactions.

In a first round of conversations, residents were asked to pick one or two NASEM report focus areas – person-centered care, staffing, transparency & accountability, financing, quality assurance, quality measurement & improvement, and/or health information technology – to share their experiences on. Following the Coalition's *action first* approach, residents were also asked to offer their suggestions about how to build on successful programs and improve identified issues.

In subsequent rounds, Bowers facilitated discussions about specific issues raised by the Coalition's seven committees with a similar framing and approach. Resident input was summarized and shared with committee members. Due to the informal nature of this approach,

we did not request demographic data and we do not plan to use this work as a basis for research. However, we estimate that we spoke to 90 residents across 14 states.

In the summary that follows, we group the personal experiences of residents as well as their recommendations for quality improvement by action plan focus area. Many of these recommendations align with best practices already taking place in nursing homes across the United States, and others offer exciting new ideas for quality improvement. Individual stories have offered Coalition members perspectives that ground our work and largely match existing evidence.

The Coalition does not endorse any specific suggestions in this summary. Instead, this document is intended to share resident input that our committees received as they've worked together. We hope that these comments will inspire others to work together to address areas of quality improvement that residents – as well as nursing home staff members, families, care partners, and others – have identified.

The Coalition is grateful for the ongoing input of nursing home residents. We are particularly indebted to the following nursing home residents for their generous contributions of time and effort to this input process and the Coalition more broadly: Cindy Napolitan, Frank Dornfest, Margarite Grootjes, Nancy Stevens, Pat Kallsen, and Sharon Wallace. We look forward to continuing to speak with more residents as we promote the goals outlined in our action plans. As always, we welcome any feedback, ideas or questions.

With gratitude,

The Moving Forward Nursing Home Quality Coalition Team



Person-Centered Care

*“Activities and relationships are so important
– they give life meaning!”*

Action Plan

Develop and/or adapt a data-supported, tech-enabled process for collecting goals, preferences and priorities (GPPs), documenting them in a care plan, and measuring the degree to which the care provided meets them.

Resident Input

Ensuring that residents’ goals, preferences & priorities are collected, implemented in care planning and successfully addressed is one of the Coalition’s top priorities. Many residents had a chance to share their care planning experiences with us and spoke about wanting to be more fully included in the care planning process.

In particular, residents spoke about the importance of scheduling care planning meetings well in advance and at times that are convenient for both the resident and any care partners. Residents also emphasized the importance of having the whole interdisciplinary care team participate in care planning – including and perhaps especially one of the clinical nursing assistants (CNAs) who works regularly with that resident. Similarly, residents stressed the importance of making standard processes and expectations for care planning clear in advance. For many, care planning was a source of more confusion than clarity about the sort of care they would be experiencing.

Residents also expressed interest in having opportunities to review their care plans and evaluate the success of the care plan’s implementation. The Coalition is focused on adapting or developing a measure of care concordance. Residents made clear that they should be able to participate in that process of determining concordance directly.

Future Resident Engagement

This action plan is one where the Coalition needs significant input from residents. In the spring, we spoke to a small group of residents about questions they’d like to be asked during care planning. The committee has used this input as it’s worked on filtering through existing care planning tools. For example, we found it very helpful to be reminded that words like “goal” may not be easily addressed by residents in specific conversations about care planning. The Coalition will continue to work with residents to refine its list of critical questions and categories to include our approach to goals, priorities & preferences.



Other Resident Perspectives

Person-centered care is also an issue of day-to-day quality of life and much of what the Coalition heard from residents on this topic could be relevant to truly person-centered care planning but was not directly related to specific elements in the action plan.

First, we were reminded of the importance of activities (therapeutic recreation). “Activities and relationships are so important – they give life meaning,” one resident said. Indeed, activities were both important to residents’ sense of continuity and important ways to build new social lives in the community. While some residents lamented their inability to continue treasured individual activities that required equipment, materials or assistance that was not available, others described the great lengths staff went to ensuring their ability to continue what was important.

We heard from many that they wanted more activity choice, more involvement in activities scheduling, and more opportunities to evaluate options and programming. Given the nature of outreach, most of the residents we spoke to were more active and socially inclined. That said, we did hear that attention may need to be paid to the balance of activities between more passive and more active, more and less intellectual, as well as outside and inside. Residents also emphasized the importance of and need for more activities team members.

Second, residents emphasized the importance of food quality. While most of the stories we heard about food were negative, some residents provided positive feedback. One resident said, “I was never able to cook like this!” Residents identified food temperature, flavor, coffee quality and choice as notable issues. One positive example described how the nursing home chef was also the independent living chef in the same community – perhaps an example of how to create consistent quality across settings such as continuing care retirement communities.

Staffing

“The importance of personal things should be part of [staff] training.”

Action Plans

Work with individual states and the Centers for Medicare & Medicaid Services (CMS) to expand and fully finance the inclusion of workforce compensation metrics in state quality incentive payment programs.

Work with workforce training and development leaders to design and pilot a standardized CNA career pathway reflecting the federal Registered Apprenticeship program framework.

Resident Input on Staff Training

Residents, in many cases, focused on some of the less tangible parts of staff training. For example, some residents emphasized the importance of training related to ageism and the value



older adults bring to communities. Similarly, some residents suggested that direct care staff, in certain cases, needed to be provided with additional time, opportunities and support to practice new skills and approaches. In that way, they reminded us that training isn't just about material presented but about how skills are practiced and continuously assessed in real time in the nursing home.

Similarly, residents shared observations about clinical team dynamics. While many residents emphasized the importance of consistent assignment, one resident shared that her nursing home's more team-based approach was largely successful in its responsiveness. "Sometimes I might have to wait up to ten minutes, but that's not too often," she said. In many cases, residents shared unfortunate stories about staff not working as well together. It's a good reminder that residents do notice team collaboration or breakdown, and teambuilding should be part of ongoing training and support in nursing homes.

In some cases, residents suggested that training should be provided to staff regarding the specific medical conditions of residents for whom they were caring. This suggestion was a reminder that just as nursing home care shouldn't be one-size-fits-all, staff training must also be individualized.

Residents emphasized how important they thought additional dementia training is.

Resident Input on Staff Compensation

Residents believed that staff deserve to be more fully compensated and that compensation is important to combatting staff turnover. They also noted the importance of providing extra support to "immigrant staff" as they settle into new communities.

Other Resident Perspectives

Residents we spoke with focused on the importance of sufficient and consistent staffing. The issue most frequently shared by residents is the insufficient numbers of direct care staff. The consequences of insufficient staffing were felt in long wait times for things like pain medications and using the bathroom. Other consequences of short staffing included showers being unscheduled, being unable to leave bed all day, having events get canceled and being unable to attend events. The impacts were felt most on weekends and during the night shift, which matches existing data on staffing in nursing homes.

Residents communicated that they felt staffing-related issues quite personally. Residents described the challenges of having to frequently rebuild relationships with new staff or feeling as if staff were too busy to take time for more psychological or emotional engagement. Residents felt particularly comfortable confiding in staff with whom they had longstanding relationships, and they saw these staff members as key contacts, particularly in urgent situations. "Otherwise, you are alone with your problem," one resident said.



Household Models and Physical Plant Improvements

“It’s awful when you know someone is waiting to get in and you just can’t go any faster. It’s embarrassing.”

Action Plan

Promote policies in one or more states and with one or more federal agencies to introduce incentives for and investment in nursing home physical plant improvements and conversion to household models.

Resident Input

Private space really matters to the residents with whom we spoke. Residents described disrupted sleep due to shared bedrooms – especially during roommate illness. Some also talked about the challenges of differing temperature preferences.

Shared bathrooms had the potential to compromise residents’ sense of dignity. Some residents felt embarrassed or even guilty about taking more time in the bathroom when they had to share. Some described the experience of being taken to a communal shower – in some cases, not fully dressed – as humiliating.

Where private space (single room, private bathroom) is not an option, residents encouraged the development of better systems for matching roommates, better approaches to bathroom privacy, and intentionally building fostering respect of privacy among staff and visitors.

Of note, some residents spoke about the importance of socioeconomic justice (particularly regarding public or private payment sources) in the distribution of private and shared rooms. This is a key consideration in the Coalition’s action plan.

Other Resident Perspectives

We took note of three other major environmental issues. First, recognizing that different needs have variable urgency, residents had concerns about the lack of ability for staff to triage call lights. As one resident said, there is “no way to know if I’m having a heart attack or [asking if] I have a glass of water.” Residents also described the importance of treating all call light uses and requests as meaningful.

Second, some residents had concerns about the way staff and administration responded to misplaced or lost belongings, especially during room changes, when these issues are often reported.

Third, noise, especially at night, was a serious concern. Overhead paging, loud conversations, and food carts were identified as particularly disruptive. Residents also mentioned the distress they felt when hearing others calling out.



Empowering Residents: Resident Councils

“Resident Council is a safe space where residents can share their feelings, positive and negative.”

Action Plan

Assemble and test a guide for nursing home teams to establish and sustain an engaging and inclusive resident council.

Resident Input

In our first year of work, we did not receive significant input from residents related to resident councils. However, since launching our action plans, we held a conversation with residents about an existing resident council guide we’re using as a foundation for our work. During that discussion, residents reminded us of the importance of resident councils not only in providing feedback, but in a number of other roles, including welcoming new residents, providing information to residents, organizing residents’ ability to advocate, celebrating community members and staff, and building a sense of community.

More broadly, residents spoke about issues related to providing feedback and advocating for themselves and others in nursing homes. First, we heard concerns about the way residents who provide input are “labeled” as “complainers” or “difficult.” Some residents even expressed concerns about retaliation. Interestingly and less evident in the literature, residents spoke about not wanting to get CNAs in trouble when they shared concerns or feedback.

Second, residents described struggling with the dynamics of advocating for others in nursing homes. While they recognized the importance of privacy, they shared the challenge of hearing someone else’s distress and not being able to help. When asked not to get involved, residents sometimes felt discouraged or helpless. Some residents suggested that an advocate should be present in every nursing home for residents to talk to in these circumstances – a suggestion which might be made possible through the expansion of the federal ombudsman program or through the increased empowerment of resident councils. Similarly, they suggested that residents should have a seat at major decision-making tables.

Third, residents talked about the importance of clear and consistent practices for informing residents about changing policies and about what they can expect regarding their care in the home.

Future Resident Engagement

We will continue to seek resident input on our resident council guide.



Other Resident Perspectives

Many residents talked about their ability to connect with the outside world. Some residents we spoke to were part of resident support or advocacy organizations. Others do volunteer work or engage in ongoing exchanges with young people who have volunteered to “adopt a grandparent.” Residents emphasized the importance of ensuring consistent connectivity and access to internet devices in nursing homes. Similarly, some residents shared concerns about the reliability of transportation and timely support for outings. Residents also advocated for non-restrictive visiting hours.

We also heard from residents about the importance of recognizing residents’ deaths and offering opportunities for remembrance. Residents shared that grief and mourning could be better integrated into community life.

Surveyors

“They should all go to a [household model] and find out what person-centered care is.”

Action Plans

To conduct a state demonstration project to pilot test and evaluate an enhanced surveyor training approach to resident-directed living.

Work with at least one state survey agency to develop a data-driven, two-day targeted recertification survey that will help agencies improve overall capacity, focus on nursing homes with a history of quality challenges or non-compliance, and respond to resident needs and specific complaints more promptly.

Resident Input

The Committee on Quality Assurance found resident input particularly helpful as they developed their two action plans. They were particularly keen to address residents’ experience of surveyors were not sufficiently attuned to their needs and perspectives.

Overall, there was a general uncertainty and lack of knowledge about the survey process and what residents could expect from surveyors. Some residents we spoke to perceived imbalance in who surveyors chose to speak with during visits. Residents spoke about wanting to have more opportunities to request to speak with surveyors during visits, about wanting surveyors to allow residents to lead conversations, and about having a spokesperson for residents who may not feel comfortable speaking to surveyors. We also heard about the importance of surveyors paying attention to activities and care plan implementation – both of which are part of the current survey process, but which residents felt could be more emphasized. Finally, we heard that



surveyor training could include more person-centered care elements, including visits to innovative nursing homes that excel in person-centeredness.

Future Resident Engagement

We will engage residents in developing and piloting surveyor training on person-centered care – with a focus on outlining key elements of the training and participating in dialogues with surveyors and other training participants.

Ownership Data and Transparency

“It’s chaotic.”

Action Plan

Design and pilot a nationally applicable blueprint for ownership transparency that makes meaningful data available and accessible.

Resident Input

Residents didn’t speak to a great extent on ownership – though the Coalition did get to speak separately with a group of care partners about their access to ownership and other nursing home data. Still, we heard from a few residents about experiences related to nursing home ownership. These residents reflected that ownership changes did lead to some degree of confusion in the home. They had particular concerns about staff turnover, changing ancillary providers, schedule changes, new policies affecting daily life, and a lack of early notification on all of the above. Residents emphasized the importance of ownership transitions as key junctures for quality assurance and oversight, as well as the importance of trying to maintain consistency in nursing home routines during these transitions.

Thank You

The Coalition is grateful for these and many other insights and ideas from nursing home residents, staff members, care partners and community members. We will continue to bring those groups and others together to help us create meaningful actions that will improve nursing home residents’ quality of life.

To provide additional feedback, please email us at info@movingforwardcoalition.org or submit feedback on [our website](#).

Thank you very much!

