Policy Decisionmaking in Long-Term Care

Lessons from Infection Control During the COVID-19 Pandemic

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Initial responses to control the spread of coronavirus disease 2019 (COVID-19) at long-term care (LTC) facilities highlighted that residents, families, and staff are often excluded from policy decisions that affect them. These failings led to calls for dramatic reform. With no major legislative action on LTC quality for more than three decades, the opportunity now is to reimagine LTC in a way that is centered on the needs and preferences of those who receive care, their family members, and those who provide care.

To identify opportunities for improving LTC policy decisionmaking, RAND Corporation researchers examined policies on infection control in congregate LTC settings and interviewed a wide range of stakeholders. They collected input from residents, direct care staff, administrators, clinicians, and researchers, along with LTC consumer advocates and senior leaders in LTC policy and funding. The results identify the primacy of resident-centeredness in effective policy decisionmaking. Transforming LTC culture to elevate the needs of residents offers a way to improve policy, but this transformation will require attention to leadership within facilities, along with steps to increase inclusive decisionmaking and the transparency and accountability of decisions in LTC.

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The long-term care (LTC) industry is in distress. The coronavirus disease 2019 (COVID-19) pandemic made existing problems in LTC worse and introduced new challenges. With more than three decades since the last major LTC legislative action, new initiatives are overdue.

The pandemic also highlighted that residents, families, and staff are rarely represented in institutional LTC decisionmaking. Policies designed to minimize mortality and morbidity had negative consequences for physical and mental health. Initial policy responses to the pandemic across the LTC industry failed to account for what was important to residents. In other words, they were not resident-centered.

LTC consumer advocates, policy researchers, care providers, and residents and their families have all championed dramatic reform. A 2022 National Academies report, *The National Imperative to Improve Nursing Home Quality*, has strengthened the foundation for change. In promoting engagement and inclusion across the broad range of LTC stakeholders, the report could have a deep and sustained impact, spurring a reimagining of LTC on par with a 2001 Institute of Medicine report that made patient-centeredness a primary goal of U.S. health care quality reform. To fully realize the promise for change in LTC, the needs and well-being of care recipients must be at the center of both institutional governance and clinical care.

The COVID-19 pandemic can be a catalyst for establishing inclusive policy decisionmaking as the new cultural norm in LTC—decisionmaking that meaningfully involves residents, staff, and others. With input from a range of stakeholders, we identified opportunities to improve how infection-control and other policies are developed, communicated, and implemented and avoid a recurrence of the substantial harm that the pandemic caused to those who lived and worked in LTC settings:

- **Cultural change is essential.** Inclusive policy decisionmaking is not common in LTC.
- **Changes to LTC policy decisionmaking need to be sensitive to system-wide pressures.** The realities of regulation, financial management, and staffing must be acknowledged in any efforts to promote cultural change.
- **Leadership is critical to realizing change.** A consistent theme emerged on the importance of LTC facility leadership in setting the tone for staff action and, ultimately, ensuring resident well-being.
- **Resident-centered, inclusive policy decisionmaking balances community protection and individual well-being.**

These findings provide concrete steps for enhancing current efforts to improve LTC by changing the culture of policy development. We recommend adopting principles of resident-centeredness and participatory policy decisionmaking that includes input from those most affected by policy decisions.
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1. Introduction

Long-term care (LTC) in the United States is in crisis, with unacceptably poor care quality, avoidable mortality and morbidity, and diminished quality of life for both residents and frontline staff. The crisis deepened when the coronavirus disease 2019 (COVID-19) pandemic swept through LTC facilities, unleashing an unprecedented lockdown and isolation of residents from family and community supports, and as infection-control policies were put in place to limit infection spread (National Consumer Voice, 2021; Doty and Blanco, 2020; Levere, Rowan, and Wysocki, 2021). The impacts of these policies on residents are not yet fully known, but evidence is accumulating about severe physical decline; dangerous—sometimes fatal—anorexia; depression and delirium; and significantly reduced access to intensive care units, hospitals, and palliative care (National Consumer Voice, 2021; Schrack, Wanigatunga, and Jurachek, 2020; Inouye, 2021; Doty and Blanco, 2020). Recent decisions intended to control COVID-19 infection rates in LTC facilities highlight a stark imbalance of two important goals of care for the elderly and disabled: protecting health and preserving well-being. Federal and state officials and LTC organization leaders weighted the first goal heavily to shield residents from infection. However, these policies often do not address residents’ preferences or well-being.

The pandemic highlighted that residents, families, and staff are rarely represented in institutional decisionmaking within LTC facilities. Although patient-centered clinical practice and patient-centered outcome research have spread throughout most of the U.S. health care sector over the past two decades, uptake of patient-centered principles is less widespread in LTC. With low pay, demanding workloads, and poor working conditions, turnover among frontline LTC staff was high prior to the pandemic (Scales, 2018), and rates of turnover further escalated during the pandemic. Gender, race, and ethnicity are critical to examine in any study of LTC. Nearly 50 percent of LTC workers are people of color, and 82 percent are women. As with many outcomes in U.S. health care, examining outcomes for residents in LTC by race and ethnicity is illuminating in revealing disparities. COVID-19 deaths among residents in nursing homes with the highest proportions of non-white residents were over three times higher than those with the highest proportions of white residents (Gorges and Konetzka, 2021).

For the more than 2 million adults in LTC and their families, the pandemic led to substantial and avoidable suffering (Gardner, States, and Bagley, 2020). The LTC industry faces major and urgent challenges now (Silver-Greenberg and Gebeloff, 2021), and it will face surging demand for aging and dementia care in the coming decades. As the largest generations are now entering late life, the population needing LTC is expected to double by 2050 (Kaye, Harrington, and LaPlante, 2010). The medical acuity of residents in assisted living facilities is also increasing (Katz, Howd, and Rust, 2022). Meanwhile, the potential pool of caregivers and frontline LTC workers is expected to shrink relative to this growing need: The proportion of adults aged 45–64
to each person aged 80 and older was projected to decline from seven to one in 2010 to fewer than three to one in 2050 (Redfoot, Feinberg, and Houser, 2013). Solutions to improve LTC delivery for residents and families will inevitably require improvements in working conditions for frontline staff.

Lessons from the COVID-19 crisis offer a major window of opportunity to reimagine LTC. Fundamental changes could establish a path for residents, their families, and frontline staff to gain a seat at the policy decisionmaking table, a long overdue update to LTC institutions and operations.

For the purposes of this study, we included both skilled nursing facilities and assisted living facilities in our definition of LTC. Although we focus on these types of facilities, we recognize that LTC is provided in other settings, including through home- and community-based services.

Protecting Residents in Long-Term Care from Infection Risk

Challenges to infection prevention and control in LTC facilities include a congregate environment where infections are easily transmitted. Furthermore, evidence suggests that frequent transfers between LTC facilities and hospitals can worsen the disease burden in neighboring hospitals (Ricciardi et al., 2012). An older and frail population is more vulnerable to illness and death from infections that are not as much of a threat to younger people, such as seasonal influenza (Centers for Disease Control and Prevention [CDC], 2021).

Older adults in congregate housing are at extremely high risk of COVID-19 transmission and have the highest COVID-19 mortality rates among all age groups. Early in the pandemic, residents of nursing homes and assisted living facilities accounted for nearly half of COVID-19 deaths (Ouslander and Grabowski, 2020). Though much of the media attention was directed at nursing homes, assisted living communities also faced high rates of COVID-19 transmission and mortality. Infection rates in assisted living facilities were up to five times the national rate, and nearly one in three assisted living residents who tested positive for COVID-19 died (Ouslander and Grabowski, 2020; COVID-19 in Assisted Living Facilities, 2020).

As of July 2022, more than 150,000 nursing home residents had died of COVID-19 (Centers for Medicare and Medicaid Services [CMS], 2022a). Staff also suffered, with reports of more than 2,500 COVID-19 deaths among staff in nursing homes (CMS, 2022a). Initial high mortality rates slowed as SARS-CoV-2 detection improved and effective vaccines were introduced in early 2021. However, waves of variants continue to present a threat to those who live and work in LTC settings. The delta surge came after the introduction of vaccines, yet LTC residents and staff continued to experience excess deaths. Rates of illness and death in LTC settings rose again with the omicron surge. Much remains to be understood about COVID-19 and immunity and risk factors, but the risk to older adults is clear.

Attention to infection control appropriately increased in LTC facilities, with requirements for staff to wear personal protective equipment and policies to limit residents’ contact with each
other and with external visitors to limit COVID-19 transmission (Levere, Rowan, and Wysocki, 2021). Infection rates declined with these measures (Scales, 2018; CDC, 2021; Ouslander and Grabowski, 2020).

However, the months of isolation and restrictions on movement by residents in LTC facilities resulted in a range of unintended health impacts, including physical deconditioning, dangerous weight loss, and increased rates of delirium and depression (Schrack, Wanigatunga, and Juraschek, 2020; Inouye, 2021; Levere, Rowan, and Wysocki, 2021). Family and friends provide substantial care for residents even after a move from the community to an LTC facility (Coe and Werner, 2022). These “informal caregivers” provide functional assistance for physical needs, but they also address other care needs, including social connections. As noted in a 2022 National Academies report on the need for nursing home quality improvement, preventing family and friends from visiting residents resulted in a care gap and was linked to increased loneliness and social isolation (National Academies of Sciences, Engineering, and Medicine, 2022; Werner and Coe, 2021; Abbasi, 2020; Bethell et al., 2021; Veiga-Seijo, Miranda-Duro, and Veiga-Seijo, 2022).

Downstream consequences of social distancing and isolation policies are still being studied. There is initial evidence of an increased risk of dementia among those in social isolation (Shen et al., 2022; Lazzari and Rabottini, 2021). Isolation practices that were intended to control the spread of the virus may have led to excess cognitive decline and increases in neuropsychiatric symptoms (Curelaru et al., 2021). In some acute care settings, visitor exclusion was associated with an increased use of benzodiazepines and antipsychotics among older adults (Brown et al., 2022); this trend corresponded with anecdotal reports of lower medical care quality in LTC facilities. Grassroots efforts by advocates and family members led to state and federal legislative initiatives to address harms to residents when informal caregivers are denied facility entry as a result of infection-control policies (H.R. 3733, 2021).

The negative consequences of these policies for residents raise questions about what is necessary, what is negotiable, and who is deciding. Even absent the challenges posed by infection risks, living in LTC facilities requires trade-offs of autonomy and choice in exchange for care, protection, and safety. Choice may be limited foremost at the point when an individual, their family members, and caregivers are selecting an LTC facility; specifically, care needs and financial constraints can limit options. For older adults, frequent transitions from one setting to another can lead to a deterioration of mental and physical health (Callahan et al., 2012). Informal caregivers, such as family and friends, might not be able to provide the appropriate level of support for older adults in their communities (Helfenbaum, 2020; National Consumer Voice and National Center on Elder Abuse, 2020). Staff working in LTC settings can also have limited choice over their work setting. Pay and working conditions are similar and universally low in the majority of skilled nursing facilities (National Academies of Sciences, Engineering, and Medicine, 2022). Staff are primarily women with limited education; the relatively high proportion of immigrants among certified nursing assistants (CNAs), with attendant limited
English proficiency and financial stability, further limits job mobility (National Academies of Sciences, Engineering, and Medicine, 2022; Sloane et al., 2021; Campbell, 2018; Lee et al., 2020).

Once residents are in an LTC facility, their autonomy can be negatively affected both by organization-level policies in private-ownership settings and by federal and state regulatory policies. For instance, housing rights governing most landlord-tenant relationships do not apply to LTC settings. Privately owned assisted living facilities may have owner-favored rights related to evictions and due process. The last major federal legislation with a broad impact on LTC residents’ rights was the 1990 Patient Self-Determination Act (Pub. L. 101-508, sec. 4206 and 4751, 1990; Kusmaul, 2020; National Consumer Voice, 2020; Vervaecke and Meisner, 2021).

The tension between resident rights and resident protection, with the latter sometimes manifested as “compassionate ageism” (Vervaecke and Meisner, 2021), highlights the limits on resident self-determination in LTC; evidence suggests that self-determination has been sharply compromised by the pandemic (Kusmaul, 2020). Protecting residents from infection risk—the goal of infection-control policies—prioritizes community health over individual preferences. Prioritizing the presumed interests of the community over individual interests has led to a backlash regarding vaccine requirements and mask mandates in the United States. This de facto prioritization in LTC raises unique ethical issues in settings in which individual self-determination is compromised and among individuals whose risk tolerance may be informed by awareness of limited remaining length of life (Long-Term Care Workgroup, 2021).

A common viewpoint is that residents, family, and frontline staff form a triad that can contribute valuable individual and interdependent inputs (Koster and Nies, 2022; Holmgren et al., 2014). Families of residents are important stakeholders in LTC, and they can be empowered in some decisions and sidelined in others. Some family members may be formal decisionmaking proxies for residents, particularly for those with advanced cognitive impairment. Compared with staff in independent living settings, staff in LTC facilities have more decisional authority and power to implement decisions that can directly affect residents’ lives. While these LTC stakeholders—residents, families, and staff—share a focus on meeting residents’ needs, evidence suggests that they can hold starkly different views about what those needs are (Natan, 2008).

Reimagining Long-Term Care

The COVID-19 pandemic revealed breakdowns and failures in LTC, but it also offered lessons that can guide future policies to ensure the right balance of resident safety and autonomy. The failures opened a window of opportunity to actively challenge and change policy decisionmaking practices in LTC (Frank, 2021). The pandemic has raised awareness of the consequences of industry policies on resident survival. Federal policy is under increased scrutiny by LTC consumer advocates, clinicians, and policy researchers as challenges like high staff turnover and declining care quality accelerated after the start of the pandemic (Musumeci, 2021).
Delivery of LTC requires new solutions for balancing organizational demands, care quality, patient safety, resident quality of life, and decisional autonomy.

Rethinking How Policy Decisions Are Made in Long-Term Care

This report examines the possibilities for increased participation of residents, staff, and families in policy decisionmaking in LTC. Although shortcomings in current LTC policy in the United States are well known and long-standing, the ways in which the pandemic highlighted these problems have energized advocates, residents, families, and staff. Feasibility of positive change has increased thanks to the publication of a landmark report by the National Academies, *The National Imperative to Improve Nursing Home Quality*, reflecting the work of the research and advocacy communities (National Academies of Sciences, Engineering, and Medicine, 2022). Additional support for change comes from federal executive branch actions, the most recent of which, like the National Academies report, uses the term *resident-centeredness* (White House, 2022).

Small-scale nursing home models offer examples of how resident, family, and staff representation in decisionmaking can work. For example, in the Green House model, a small, self-managed team of CNAs cares for a stable set of ten to 12 residents. Residents have private rooms but congregate in a central living area, minimizing the architectural cues of an institution in favor of a homelike environment. Advocates of this model are aiming for higher staff retention rates than traditional nursing homes, in addition to improved quality of life for residents (Waters, 2021). Direct care staff are a focus for better working conditions, higher pay, and more decisional empowerment. The Eden Alternative model, also developed by the founder of the Green House model, emphasizes resident autonomy and includes as a core principle that those affected by decisions are involved in the decisions (Eden Alternative, undated). The cultural dimensions of these models offer important guidance for LTC reform on a wider scale.

Even with these positive examples, true resident-centeredness in LTC remains elusive. The field has not yet made the cultural shift to meaningfully elevate the roles of residents, staff, and families in policy-related decisionmaking. The current state of policy decisionmaking in LTC raises three interrelated questions:

- What changes would be needed to increase inclusiveness of policy decisionmaking?
- How could the structure of decisionmaking in LTC, referred to in this report as governance, be changed to facilitate this inclusiveness?
- What aspects of the relationship between those making LTC policy and those working and living in the facilities could facilitate this inclusiveness?

Rethinking Resident and Stakeholder Representation in Governance

To guide how this window of opportunity for change might be leveraged to improve LTC, a review of governance models of representation and participatory decisionmaking in LTC is
instructive. The top of Figure 1.1 shows *petitionary representation*, in which decisions about policy are top-down and affected stakeholders must petition the policy decisionmakers to effect change. The middle of the figure presents a model of active collaboration among stakeholders in policy decisionmaking through *participatory representation*. Although participatory decisionmaking may be seen by many as an ideal, current regulatory and private-ownership models make it unlikely to be realized in the short term. A feasible alternative at the bottom of Figure 1.1 combines petitionary and participatory representation. This hybrid model recognizes the authority of federal and state policymakers, with residents, families, and staff having a role and a voice in policymaking.

Participatory governance is intended to incorporate multiple and sometimes conflicting perspectives. The model is well suited, then, to balancing individual preferences and social group well-being. Weighing individual preferences for infection risk against protection of the facility community, for what are for many residents the last months and years of their lives, is the type of issue that this model can accommodate.

**Figure 1.1. Three Models of Stakeholder Representation in Long-Term Care Decisionmaking**

*Learning from the Past: How to Scale Participatory Policy Decisionmaking in a Complex Industry*

In 2001, the Institute of Medicine released *Crossing the Quality Chasm: A New Health System for the 21st Century*, a report that called for patient-centeredness and public participation in biomedical care and research (Institute of Medicine, 2001). This report, following on the heels
of a report that estimated the vast magnitude of low-quality care delivered in the United States (Institute of Medicine, 2000), introduced seismic shifts across biomedical care and research funders and research organizations. Inclusion of patient-centeredness as one of the six health care aims in the 2001 Institute of Medicine report dramatically changed research funding, leading to legislation that continues to drive advances in health care. The institute defined patient-centeredness as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001, p. 6). Across various definitions of patient-centeredness, a consistent theme is a focus on outcomes important to the patient (Frank, Basch, and Selby, 2014). Berwick elaborates on this concept in a way that is useful for operationalization:

- “The needs of the patient come first.”
- “Nothing about me without me.”
- “Every patient is the only patient” (Berwick, 2009, p. w560).

The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 established new clinical effectiveness research centers at the Agency for Healthcare Research and Quality (Pub. L. 108-173, 2003). In 2006, the Clinical and Translational Science Awards program was established with substantial funding through the National Institutes of Health, providing a powerful stimulus for clinical and translational science. In 2010, the impact of the 2001 Institute of Medicine report was still evident with the establishment of the Patient-Centered Outcomes Research Institute, the first major U.S. funder of clinical research requiring patient-centeredness and stakeholder engagement in the work it funds. All these initiatives have contributed to the cultural shift set in motion by the report (Concannon et al., 2021), and the shift toward stakeholder inclusion in evidence generation and implementation has demonstrably improved health care in the United States (Forsythe et al., 2019).

Maximizing the Success of Long-Term Care Reform

To ensure that the 2022 National Academies report on LTC quality is most effectively leveraged for transformational change, the analogy to the 2001 Institute of Medicine report is instructive. The 2022 report cites person-centered care as part of its first goal and first recommendation, but the authors note that the person-centered orientation is “not yet a reality for many nursing home residents” (National Academies of Sciences, Engineering, and Medicine, 2022, p. 5). Restructuring the culture of LTC toward inclusion of residents, families, and staff in policy decisionmaking, toward “resident-centered governance,” could bolster person-centeredness in care and expand its impact in a way that would mirror the role of patient-centeredness in health reform broadly. Funders are already committed to centering the consumer; transferring to “resident-centeredness” is logical. In the decades since the 2001 Institute of Medicine report was published, the empirical evidence base on the contribution of stakeholder participation in clinical and policy decisionmaking is maturing. There is currently a unique
window of opportunity to connect the now well-established patient-centeredness movement and its ethos of stakeholder representation to the unique needs of LTC (Concannon and Frank, 2020; Frank, Concannon, and Patel, 2020).

Path to Progress: Infection-Control Policies as an Organizing Principle

The focus of early COVID-19 pandemic infection-control policies was on reducing illness and mortality. The pandemic experience underscored that LTC residents and their families—those most affected by facility policies—were not well represented in decisionmaking about and in the development of those policies.

By early 2022, the pandemic entered a new phase, with vaccination and the potential for reduced community infection rates changing the infection-control landscape, along with widening recognition of the mental, physical, and social toll of isolation-based infection-control policies on residents and families. This new phase and the evidence base from earlier phases offer the potential to change infection-control policy for the better.

Infection-control policy in LTC provides a way to explore the current state of policy decisionmaking in LTC and to determine what is needed for a cultural shift toward inclusion of residents, staff, and families in consequential policy decisionmaking. We conducted interviews with and convened a range of LTC stakeholders to explore the feasibility and potential impact of this change. This project addressed the following questions in the context of pandemic-related infection control:

1. What specific changes are needed to increase inclusion of residents, staff, and families in policy decisionmaking in LTC settings? Which changes are best addressed within the facility, and which should involve LTC owners, payers, or regulators?
2. How could different governance structures for decisionmaking within LTC be used to advance inclusion of residents, staff, and families in policy decisionmaking?
3. What changes are required for the relationship between LTC facilities and policymakers to support residents’ voices in governance?

Following an overview of our methods, we summarize the key themes and subthemes that emerged from our stakeholder discussions and identify the action items to improve policy decisionmaking in LTC.
2. Methods

To address the research questions, we collected information through (1) a review of the literature on pandemic infection-control policies and the impact of the COVID-19 pandemic in LTC settings; (2) structured one-on-one interviews with relevant stakeholders; and (3) a small-group discussion with a panel of LTC researchers, clinicians, administrators, and advocates. In our interviews and panel meeting, we sought to obtain stakeholder perspectives on governance in LTC and opportunities to improve the inclusion of residents, families, and staff in policy development, implementation, and evaluation.

Literature Review

The literature review began with a focus on editorials and statements from professional societies, such as the American Geriatrics Society, regarding balancing of infection control and resident well-being in congregate LTC settings (American Geriatrics Society, 2020a, 2020b). A special issue of the journal *The Gerontologist* early in the pandemic collected empirical work and opinion pieces with a focus on health-related quality of life (Resnick and Zimmerman, 2021). Citation searches from those articles yielded additional empirical publications, supplementing the empirical studies and opinion pieces that we obtained through periodic searches of PubMed using the keywords *infection control* and *long-term care*, with the last search completed in February 2022, prior to qualitative data collection from our interviews and panel meeting.

Social media was an important part of early pandemic communications among those with an interest in LTC resident well-being. Ongoing monitoring of Twitter, for example, identified specific individuals working on the topic, including academic researchers, frontline clinicians, LTC facility leadership, and consumer and industry advocates. The literature review included an examination of these “gray literature” sources. Through the literature review, we identified types of stakeholders to provide input for this study, as described in the next section.

Selecting Interviewees and Panelists

To identify stakeholder types to contact, we began by considering different stakeholders’ relationships to LTC operational decisions and policies that are a focus of this work. We then listed stakeholder categories that represented the major constituencies affected by these decisions and policies. The initial categories were very broad: LTC residents, LTC consumer advocates and family members, facility administrators, LTC clinicians, and LTC researchers. We sought to involve participants from different geographic regions across the United States and from rural and urban and low- and high-resource settings.
Because this was the first formal, structured initiative with different LTC stakeholders asked to address governance and participation in relation to the pandemic, we prioritized the inclusion of clinicians and researchers with substantial experience with LTC issues. To ensure that we included the view of the LTC industry, an important constituency in the LTC ecosystem, we also sought out leaders in LTC industry advocacy and leaders working in private, for-profit LTC organizations, as well as those working in nonprofit organizations. We also sought to include prominent leaders in the field, including current and past presidents of professional organizations and leadership at major organizations that fund research and inform policy on aging.

Based on the number of discrete stakeholder categories we identified and our goal to recruit at least two to three participants from each prioritized stakeholder category, our target sample size was 12–15 interviewees and at least five participants in a panel-style discussion, for a total target sample of between 15 and 25 participants. A complete list of interviewees and panel meeting participants can be found in Appendix C.

A goal of this work was inclusion of a range of views across stakeholder types, levels of seniority, and race and ethnicity. For staff and residents especially, we anticipated that race and ethnicity would be meaningfully related to power relationships and interactions with administrators and policymakers.

Because interviews permitted focused questioning, we selected several representatives from consumer and industry advocacy organizations to be among the interviewees. We also selected residents for interviews only, rather than including them in the panel meeting, to ensure that we could query the full scope of their views without the distraction of a multistakeholder discussion. Finally, we included several clinician-researchers among our interviewees to ensure that we could identify and review relevant empirical research before referencing it during the panel meeting. We recruited participants through email, with the exception of LTC residents and direct care staff. Residents were identified through professional colleagues of the project team members. Despite multiple queries to researchers, clinicians, and advocates working in the LTC field, recruitment of direct care staff was only successful after we launched an outreach campaign through Craigslist.

Collecting Input: Interviews and Panel Meeting

We began collecting input through individual participant interviews scheduled for 30–60 minutes and conducted virtually via Zoom. For two residents, interviews were conducted via telephone to aid with accessibility. All interviews were conducted by one member of the project team with decades of experience in qualitative data collection.

Information collection, analysis, and output from the small-group discussion with stakeholders followed a “consensus panel” model (Fink et al., 1984). We sought to identify areas of consensus among the panelists and areas in which a lack of consensus indicated points of disagreement to examine in future research. We prioritized relatively senior stakeholders with
academic research and clinical care expertise, along with funders of research on LTC, but we also included some junior and midcareer stakeholders to capture a range of experience with LTC issues.

Because of pandemic restrictions on in-person gatherings, we held a virtual two-hour meeting with the panelists. We described the goals of the meeting and the larger research effort to invitees as follows: to hear from experts in the LTC field about possibilities for governance models within assisted living and skilled nursing facilities that could improve on the balance between resident well-being and facility requirements related to infection control. The pandemic provided a case study for examining this issue. We asked panelists for specific suggestions for making revised governance structures feasible and adoptable for use by state and federal policymakers.

**Interview and Panel Meeting Discussion Questions**

Table 2.1 provides an overview of the major topics for discussion with both our interviewees and panelists, along with specific discussion prompts for the interviews. See Appendix B for the full discussion guides, which drew on our literature review, a review of notes from informal discussions with colleagues in LTC clinical care, research that we conducted at the beginning of the pandemic, and discussions among the research team. The interview discussion guide was developed first. After we collected input from initial interview participants, we developed the panel meeting discussion guide. We sought to obtain input from at least five interview participants representing at least three stakeholder categories prior to developing the latter guide. This phased approach ensured that the panel meeting discussion would be informed by input from other stakeholders and not based solely on questions selected by the research team a priori. This approach also ensured that panel meeting participants were prompted to elaborate on the themes that emerged from our interviews, with a focus on novel input—the themes that were not expected by the research team. The major topics for discussion were the current situation in LTC and the feasibility of changes to governance structures; communication between administrators and staff about infection-control policy; communication with residents and families; the impact of resident and staff race and ethnicity on power relationships related to infection-control policies at LTC facilities; and pandemic policies’ impact on residents and staff. At the end of the meeting, participants were asked to share their recommendations for changes to improve the situation related to infection-control policy in LTC facilities.
<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
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</thead>
</table>
| Current situation and feasibility of governance changes     | Feasibility of resident, family, and staff engagement in management and related policy decisions:  
  - Describe current procedures for how administration communicates about new policies or policy changes to staff.  
  - Who is responsible for this communication?  
  - What channels for communication are used (e.g., staff meeting, email, online training with verification, other)?  
  - Who is responsible for implementing changes and ensuring adherence to policy?  
  - Is there evaluation of the policy adherence?  
  - Is there a review of impact of policy? If so, from what perspective:  
    o facility impact (e.g., cost for personal protective equipment); staff impact (e.g., training needs)  
    o resident impact (e.g., interaction with other relevant protocols for medication management)  
    o family impact (e.g., access to visits)? |
| Communication between administrators and staff             | Communication between administrators and staff:  
  - How do staff express concerns about the working environment to administrators?  
  - Can you give a specific example related to the last two years, during the pandemic? |
| Communication with families                                | Communication between administrators and residents and families:  
  - Do you have a family council? Do you have a resident council?  
  - How often does it meet?  
  - What sorts of items are discussed?  
  - Can you share some examples of issues raised by the council? What specific issues have they discussed regarding the pandemic? Have any changes in policy been made as a result of issues raised by the council? |
| Power structures and race and ethnicity                    | Impact of race, ethnicity, and gender:  
  - Now we have some questions to help us understand the demographics of residents, staff, and administrators in some specific long-term care settings. (For administrators and staff working in a limited number of facilities)  
    Approximately what proportion of staff are women? What proportion of residents are women?  
  - Do you have information you can share on race and ethnicity of staff and residents?  
  - (For researchers and others working across more than three facilities) LTC staff are disproportionately women, immigrants, and people of color. In your experience, what challenges do staff face when approaching the administration with concerns, and what role do gender and race play in this dynamic?  
  - In your opinion, are staff-administration relationships impacted by the race of staff and administration? What leads you to that answer? |
| Resident impact                                            | COVID-19 pandemic’s impact on residents:  
  - What impacts would you say the pandemic has had on residents (probe: physical health/stability vs. decline and rate of decline; mental health; social interaction; other)?  
  - What specifically led to the impacts you’ve identified (probe: social isolation, change in routine, other)?  
  - What changes would you suggest to mitigate or eliminate negative impacts? Why would you suggest these changes? What are obstacles to making these changes? |
<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff impact</td>
<td>COVID-19 pandemic’s impact on staff:</td>
</tr>
<tr>
<td></td>
<td>• In what ways did the pandemic impact staff in your facility (probe: staff attrition)? What led to staffing changes?</td>
</tr>
<tr>
<td></td>
<td>• What are specific and adoptable options for including resident, staff, and family members in policymaking in LTC when those policies impact the physical health and social and emotional well-being of residents, their families, and staff who care for them? What are obstacles—cultural, ethical, and legal—to inclusion of their views?</td>
</tr>
</tbody>
</table>
| Brainstorming opportunities | Recommendations:  
  • What groups or organizations should be part of discussions about infection-control policy in LTC?  
  • Do you have specific suggestions for incorporating different types of stakeholders in policy discussions? In policy implementation? In policy evaluation?  
  • Should staff be separated by groups for these discussions (e.g., by service type)?  
  • Is there anything we’re leaving out that needs to be addressed?                                                                 |

Data were collected between February and July 2022, following review and approval by RAND’s Institutional Review Board. Project team members joined interviews and took written notes, with one research team member leading the interviews. Accommodating schedule requirements for direct care staff interviews was more challenging. Because those interviews were scheduled with minimal lead time, only the lead interviewer participated. Research team members took written notes during the panel meeting as well, and that meeting was recorded. Transcripts were not generated, given availability of the recording and notes for reference and the intended use of thematic analysis that began with the discussion topics as the basis for theme identification. Team members’ notes were used as source material, with review of the recorded content as needed to ensure the accuracy of quotes. A team member created a collaborative online “key findings matrix” file to support the theme identification process and map participant input related to each theme.

Input from interview and group discussion participants was organized into six initial themes based on the question categories in the structured interview and panel meeting discussion guides; Table 2.1 provides an overview of the categories and questions, while the full guides can be found in Appendix B. We identified a final set of themes after an iterative review of the key findings matrix and analysis of the participant input we received. Themes emerged that were not directly related to topics in the structured interview and panel meeting discussion guides. For example, inclusion was mentioned by at least four participants, which was the threshold for considering it a theme. We listed and organized these additional themes topically. We also recorded subthemes to major themes as a way to organize detailed input and capture nuance in participants’ responses. Subtheme classification required supportive input from a minimum of two participants, and some subthemes exceeded this threshold. All but one interviewee agreed to be recorded; because of technical issues, we were not able to create a usable recording for an additional two interviews.
3. Findings

Twenty-three stakeholders provided input for this project. Seven individuals joined the panel meeting, and we separately interviewed 16 individuals. Interviewees included three assisted living residents and two nursing assistant care staff. The remaining interviewees included several senior leaders in aging policy research and clinical care, presidents or past presidents of major aging professional societies and funding organizations, senior administrators for multisite LTC providers, and representatives from multiple LTC consumer advocacy organizations. Figure 3.1 shows top-level stakeholder category and geographic region representation for all participants. Many participants represented multiple stakeholder categories—for example, clinicians working in LTC who were also researchers. Figure 3.2 provides detail on the range of perspectives within the three major categories (consumer advocate, provider, and policy/clinical researcher).

All project team members reviewed the major themes that emerged following the first nine interviews, identified through post-interview team discussions and a review of notes from the interviews. The initial nine interviews took place between February and May 2022. We developed the structured discussion guide for the panel meeting, held in June 2022, based on the major themes from the interviews. The final seven interviews followed the same format as the first interviews, but, in some cases, we added additional probes that incorporated input from the panel meeting participants. Those final interviews were conducted between June and July 2022.

**Figure 3.1. Stakeholder Characteristics**

<table>
<thead>
<tr>
<th>Stakeholder types</th>
<th>Interviewees (n = 16)</th>
<th>Panelists (n = 7)</th>
<th>Stakeholders by geographic region (n = 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LTC resident</td>
<td>3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Nursing assistant</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Clinician/researcher</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>LTC administrator</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>LTC consumer advocate</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>LTC professional society/funder</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
Figure 3.2. Stakeholder Subtypes

<table>
<thead>
<tr>
<th></th>
<th>CONSUMERS/ADVOCATES</th>
<th>PROVIDERS</th>
<th>POLICY AND RESEARCH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Industry advocate</td>
<td>Nursing</td>
<td>Clinical research</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Resident advocate</td>
<td>Medicine</td>
<td>Funder/policy/professional organization leadership</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>LTC industry</td>
<td></td>
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<td></td>
<td>5</td>
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</tr>
</tbody>
</table>

NOTE: Stakeholders could fall into more than one category in each subtype.

Note that we classified stakeholders according to all the subtypes and categories they represented. After reviewing input from the first nine interviews, we prioritized the inclusion of additional advocates, clinicians, and administrators among our interviewees. Our initial interviews suggested that many principles related to participatory policymaking were novel for these stakeholders. Early consistent themes emerged related to facility leadership and the role of the regulatory environment. Because these themes may link to the unexpectedly limited cultural familiarity with participatory policymaking among some stakeholders, we focused subsequent recruitment on expanding input from those with familiarity with these issues: administrators, clinicians, and advocates. Because we also prioritized collecting input from LTC residents and direct care staff, we did not speak separately with family members during this phase of the research.

Themes from Stakeholder Interviews and Panel Meeting Discussion

Although each interview yielded some unique information, and each panelist made unique contributions to the discussion, as noted earlier, four specific themes emerged in our earliest interviews that carried through to the panel meeting and our later interviews: (1) what needs to change, (2) the role of leadership, (3) the role of regulation, and (4) the role of representation and...
expertise. In the following sections, we elaborate on these themes and their associated subthemes, with illustrative quotes from stakeholders. Each section concludes with action items that stakeholders suggested. Table 3.1, at the end of this section, presents a summary of collected action items organized by theme.

**Theme 1: What Needs to Change**

**Subtheme: Balancing Residents’ Rights Against Facility Functions**

A common theme in our interviews and panel meeting discussion was the paternalistic culture in LTC and the need for policies that promote not only the health of residents but also their quality of life. The administrators and clinicians working in LTC made reference to facility-level incentives to avoid quality citations by regulators. They indicated that these incentives shaped facility policy decisions that prioritized safety concerns, specifically, and that resident rights could be deprioritized as a result. One interviewee, a clinician-researcher, commented that a misreading of Maslow’s hierarchy of needs (Maslow, 1943) was often used to silo the concerns of older adults:

> We tend to put autonomy at the top with self-actualization, but Maslow says autonomy is a precursor to understanding hierarchy of need. . . . Safety can only be defined by the individual: The risks I’m willing to take are different from the risks you may be willing to take. We impose a view of safety first, often without regard to the impact on older adults. . . . When we impose these safety policies without deep understanding of impact on quality of life and autonomy, we do a disservice to those we are presumably protecting.

One LTC consumer advocate interviewee suggested that LTC residents should be allowed to form cohorts based on risk tolerance:

> There is no discussion anywhere at the regulatory or facility levels of allowing residents to cohort by risk tolerance. So much training and resources are spent on cohorting residents by COVID status. We had red, yellow, green zones based on exposures and testing. But no one thought to say, “This resident is not immunocompromised and wants to see their family. There should be a wing for greater access, and maybe another wing for residents who are immunocompromised or more risk averse.” There is an enormous ingrained culture of paternalism and ageism in LTC.

Multiple interviewees suggested that LTC facilities could incorporate principles from small group home models, such as Green House and Eden Alternative, both of which offer strategies for forming resident councils and empowering frontline caregivers (Waters, 2021; Eden Alternative, undated). Interviewees cited the use of universal caregivers in the Green House model as a promising example of staff empowerment in which CNAs, as universal caregivers, are responsible for more activities and also drive day-to-day operations.
Interviewees and panel meeting participants identified the U.S. Department of Veterans Affairs (VA) as another promising model for LTC governance. One interviewee shared that VA has built-in locality pay assessments and benchmarks staff wages annually. Wages that registered nurses make in VA’s LTC facilities are commensurate with those of registered nurses working in hospitals, and all frontline workers receive benefits. Some participants suggested transferring the culture of care in VA to other settings. In the words of one clinician-researcher,

Looking at VA as a model, one thing that’s very different about those facilities is the sense that residents or veterans are due the care they receive, that it’s an honor to work in that facility. I was surprised at the voice the resident council had . . . and how listened to it was, and that when issues arose, they became [quality improvement] issues. It’s a very different cultural orientation—I think that is needed. The sense that this work is honorable work, important work. We just don’t have that in “civilian” nursing homes . . . There is a stigma in this country around the care. Some would argue that it’s a feminist issue—that care of the body is women’s work. At a deep cultural level, we must see this work as more important and reimburse commensurate with what it deserves.

**Action Items**

Stakeholders proposed the following action items to strike an appropriate balance between residents’ rights and facility functions:

- Identify opportunities to optimize resident autonomy and choice through alternative cohorting models by risk tolerance.
- Question the prioritization of safety when countervailing considerations, such as resident-identified health-related quality of life, may be important to consider.
- Review different care models for strategies that can be implemented in different settings—for example, the Green House model and successful VA pandemic strategies.

**Subtheme: Resident Preferences**

The residents we spoke with expressed concern about agency in terms of having a say over some aspects of policies that affected them. Resident councils were important to the residents we spoke with, although other participants indicated that the prominence and effectiveness of resident councils differed greatly across facilities. Residents and direct care staff we spoke with accepted the within-facility authority hierarchy regarding decisions. However, each group expressed that there was value in bidirectional communication within the existing hierarchy.
Although decisions were made by others with regard to infection-control policy, these stakeholders valued opportunities for residents and staff to express concerns to leadership. Residents and staff pointed to the quality of leadership—with proactive communication channels created for residents, staff, and families and sincerity in collecting input. Facility leadership, presented as a separate theme in this report, relates strongly to addressing resident preferences and insights.

**Action Items**

Stakeholders proposed the following action items to better address resident preferences:

- Create standards for leadership regarding channels for and the frequency of the collection of input from and on behalf of residents.
- Create proactive plans for input collection from residents in times of crisis, such as an infection outbreak.

**Subtheme: Technology Infrastructure**

One panelist commented on the lack of technology infrastructure in LTC, a structural factor that limits flexibility in implementing policies that could benefit residents and staff. In the context of the COVID-19 pandemic and the need for greater social distancing, LTC facilities did not have the technology infrastructure to allow residents and families to communicate virtually. A policy researcher characterized the situation as follows:

> In amplifying voices, there is no consensus in this country on the trade-offs of infectious disease control and other aspects of health and well-being. This is playing out in courts all over the country. People are developing frameworks, but there is a lot to be sorted out. If there are to be options in response to those suggestions, we need new tools for less-restrictive alternatives.

Even with lockdown, we still had bad infectious disease outcomes. How do we improve upon that? One suggestion is to introduce technology for social distancing where possible. But so many times, LTC facilities don’t have the infrastructure to implement this. . . . There was a bill early in the pandemic to get access to devices and funding for devices in facilities for people to talk to loved ones. That never passed. There are other meaningful things that will support the ability to act on these recommendations.

Another panelist, a clinician-researcher, agreed, noting that nursing homes were left out of meaningful use initiatives for health information technology (IT). The panelist noted that hospitals are implementing health IT that allows staff to have a greater say in the shifts they work, but many LTC facilities lack the infrastructure to implement similar systems.

Residents and staff raised the role of technology in the context of maintaining connections to loved ones during facility lockdowns, when no external visitors were allowed. This is a distinct use of technology, separate from the medical record and monitoring functions noted by researchers and clinicians. Residents and staff noted that limited staff availability was a barrier to...
residents’ use of technology, such as telephones, that affected residents unable to operate electronic devices independently. Some residents reported helping others, particularly early in the pandemic. However, participants noted that ensuring residents’ ability to maintain personal connections via technology was not a priority.

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“There is no consensus in this country on the trade-offs of infectious disease control and other aspects of health and well-being.”

—Policy researcher

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**Action Item**

Stakeholders recommended incentivizing technology solutions for residents and staff to support communication and infection surveillance and to mitigate the negative consequences of policies, such as lockdowns and isolation.

**Theme 2: The Role of Leadership in System Change**

A strikingly consistent discussion theme in the interviews and panel meeting was the importance of facility-level leadership, including the central role of LTC facility administrators and nursing directors in setting policies for infection prevention and control and conveying them to staff, residents, and families in a consistent manner. Facility leadership was critical, according to participants, in setting the tone for staff action and, ultimately, ensuring resident well-being.

One panelist pointed out the challenges that administrators at nursing home and assisted living facilities faced during the pandemic in responding to constantly evolving directives from multiple sources, such as the CDC and CMS. In some cases, administrators had positive experiences reaching out to local health departments and receiving nonpunitive assistance in managing outbreaks, but many reported challenges.

Panelists also discussed the role of infection preventionists and medical directors in determining nursing home policy, noting that infection preventionists are often overextended in clinical roles, and geriatrics expertise in LTC facilities is lacking. According to one administrator-clinician,

> In most nursing homes the [infection preventionist] is often pulled in multiple directions; what is on paper doesn’t happen. How do we bring together governance, admin, operations, clinical needs in a way that actually works?

One interviewee, an LTC resident in an assisted living community, commented on the need for transparency about why policy decisions are made and the importance of leadership in communicating this information to residents, families, and staff. She pointed to an effective
strategy used by the executive director of her community, which included holding “fireside chats” during the pandemic to discuss infection-control policies:

We have a compliant group. But if we’re all vaccinated, why do we have to wear a mask? We have fireside chats with the executive director—it’s a chance for people to complain and talk about things. If my family tested negative, why can’t I go out and be with them? If you stay overnight somewhere, they ask you to be on isolation for two weeks when you come back.

The same resident mentioned creating a standing resident communication time to overcome some of the challenges with keeping residents informed:

Information transfer is an enormous problem in a place like this. . . . It’s very hard to get information out in a meaningful way to residents. . . . This is why I wanted to start the “resident hours”—that was during the pandemic. What can we do so that residents have a voice and can keep up to date on what’s going on? Some residents say they have nothing to say. I remind them that just their presence reminds other residents they have a voice.

Another resident noted that he had two avenues to communicate concerns about policies: He could either approach the resident council or email the personal secretary of the CEO, who would respond within 24 hours. He was satisfied with the policies his facility had implemented in response to the pandemic and felt that administrators were receptive to concerns raised by residents: “Some of our administration is very receptive to any issue the residents bring to them. The communication is bidirectional and effective.”

Another resident from the same facility expressed similar opinions. Although she did not attend resident council meetings, she felt that she had the opportunity to raise concerns with her floor representative: “I think I have every opportunity to go to the floor representative here. The president of the resident council is a good friend.”

One resident noted that although there were avenues for communication, facility leadership did not always seem responsive to concerns raised by residents and families. In particular, she did not feel that her facility was responsive to family members’ requests to act as essential caregivers for residents during the pandemic:

I think management is open to hearing from residents, but I’m not sure how much credence they give. . . . One family member can be a critical care provider for a resident. I have six children, and they immediately wanted to do this but were told [by facility leadership], “Oh, we have to think this through.” . . . They [my children] went to the executive director. Other residents’ families did the same thing. Their families are trying to get in to see them, to help them.

**Action Items**

Stakeholders proposed the following action items to improve and clarify the role of LTC facility leadership:

- Invest in leadership. Collect leadership suggestions and evaluations from all staff and use that input to improve leadership. This may require regulatory incentives to overcome the
“luck of the draw” with current leadership. Establish LTC leadership centers of excellence for best-practice identification and sharing across settings.

- Create channels for resident/family/administration communication. The “resident hours” mentioned by a resident interviewee are one example of a best practice. Assemble other examples, and scale up those practices across settings.
- Create and fund governance and communication centers of excellence at the federal and/or state level.

**Theme 3: The Role of Regulation in System Change**

Participants frequently mentioned the importance of the interaction between the regulatory environment, incentives and disincentives, and possibilities for change at the facility level. Interviewees and panelists noted the contextual differences between assisted living facilities and nursing homes and the need to differentiate between these settings when discussing opportunities for change. Multiple panelists described nursing homes as medicalized (“mini-hospitals”). *Assisted living* is a broad term that can include a range of residential settings, such as memory care and small group homes that are generally private-pay. Panelists noted that nursing homes are federally regulated and subject to much stricter regulations, while assisted living facilities are state-regulated and have greater flexibility in determining how services are delivered. As one clinician-researcher noted,

There is a culture in nursing homes of feeling they have to do everything they are told or they will get in trouble. Lots of paranoia. We got cited . . . because a resident under our observation walked out of the building into the parking lot; we went from a 5-star to a 1-star immediately. This is going on all the time.

One panelist suggested using existing regulatory structures, such as the nursing home governing body and quality assurance and performance improvement (QAPI) programs (CMS, 2013), to promote accountability in responding to issues raised by advisory councils. The Affordable Care Act requires all nursing homes to develop data-driven QAPI programs focused on improving care quality and outcomes, quality of life, and satisfaction for staff and residents (Pub. L. 111-148, 2010). The panelist, an administrator-clinician, noted that these programs are a potential mechanism to improve policies and procedures, including policies for infection prevention and control:

The nursing home governing body is responsible for hiring/firing the administrator, responsible for policies and procedures, and responsible for QAPI. . . . I believe an accountability loop exists from a survey process to engage the governing body. But most nursing home governing bodies—with the exception of some nonprofits, that governing body is the board of that community and they are active—probably provide a good model for how this should work. . . . Rather than create a new entity or a new accountability loop—don’t reinvent the wheel—use what’s in existing regulations.
Another panelist, a policy researcher, agreed, noting that nursing home boards have legal responsibility for care delivered in nursing homes:

The board is responsible for what goes on in the organization. Whether active nonprofit or paid board members of a for-profit. They have ultimate legal responsibility. The idea is, how do we design a system within that legal structure that optimizes care of residents?

Multiple interviewees acknowledged that the existing regulatory structures in nursing homes can present a barrier to improving policies. According to one LTC consumer advocate,

Infection-control framework is rooted in the idea of the nursing home as a medical facility. SNF [a skilled nursing facility] was seen as a step down from hospital, informed by a medical mindset—long halls, shared rooms, nurses’ station. Infection-control policy is treated the same as in a hospital, which is not consistent with the realities of life in nursing homes. This is a core tension and part of the reason infection control is so difficult to regulate. Imagine a hotel with the same infection-control standards as a hospital; it’s not compatible with daily life. You can’t always socially distance providing intimate care. The federal government and CMS implement policies—federal guidelines about infection control—and it’s up to state surveyors to enforce. . . . There are also state rules for nursing homes, which in some cases can be stricter than federal rules.

According to a clinician-researcher,

When COVID hit, no one knew who to talk to at the department of health. Many nursing homes didn’t have leadership to think this through. They need leaders who understand these regulations and can convey them to staff in a consistent manner. So many facilities are focused so much on compliance with regs rather than quality care.

The limitations of the existing survey process, including inconsistencies across states, were another focus of discussion. One interviewee, an LTC consumer advocate, called for a more resident-centered approach to the enforcement of regulations by state survey agencies and noted the importance of state LTC ombudsman programs:

State survey agencies should center their activities on the resident and talk to those who file complaints. But often they talk to the director of nursing instead. Everything is decentered from the resident—they become numbers. . . . Resident councils and family councils should be incorporated—and also incorporated into the regulatory scheme. State surveyors are supposed to meet and talk with residents; regs must be enforced in a more resident-centered way.

Facilities will not change unless the state and federal government tell them to. Families and advocacy groups should be involved. LTC ombudsman programs are extremely important; they vary across states but are often good. They hear from residents, and their voices are often pushed to the side. State survey agencies don’t listen to ombudsmen.
**Action Items**

Stakeholders proposed the following action items to ease tensions in the regulatory environment at the facility level:

- Review incentives and disincentives embedded in regulatory policy, and work with regulators to make punitive actions meaningful and judiciously applied within the existing accountability structure. Regulatory requirements may undercut facility efforts to improve care quality (see, for example, LeadingAge, 2022).
- Identify and scale up promising state-level enforcement.
- Among the biggest opportunities: View regulatory policies and legal requirements through a *true* resident-centered lens. Involve residents and others in that review. Modify policies that are at odds with residents’ best interests. This would require an objective assessment of “best interest” and a willingness to incorporate and reconcile differing perspectives. See the section “Discussion” for suggestions for achieving this goal (e.g., through deliberative processes [Oortwijn et al., 2022]).

**Subtheme: Need for Greater Transparency in Long-Term Care Financing**

A common theme in our interviews and panel meeting was a lack of financial resources in LTC, including limited reimbursement for LTC residents covered by Medicaid, and the need for better wages for direct care workers. One interviewee called for greater reimbursement from CMS to cover higher nursing hours per patient day in nursing homes. Multiple interviewees also noted the need for greater transparency in how LTC is financed and the need to redirect funds toward care. In the words of one LTC consumer advocate,

> Currently, I don’t see how the system can be fixed. We can create great laws and regs—but absent their enforcement, it won’t work. Industry has such influence on lawmakers, CMS, local enforcement. We need to completely rethink how we do long-term care. We need to take the profit incentive out of care, limit the profit that can be made, guarantee that taxpayer money is going towards care.

**Action Items**

Stakeholders identified two action items to improve transparency across the LTC industry:

- Increase opportunities to “lift the veil” on private financing and ownership of LTC facilities.
- Examine other health care private-ownership regulatory models (e.g., for acute care facilities) that could be applied to LTC.
Theme 4: The Role of Representation and Expertise in System Change

Subtheme: Value Staff Professional Expertise

As noted, panelists commented on the need for geriatrics experts in LTC policymaking at the facility level, as well as at the local, state, and federal levels. According to one administrator-clinician,

> When you engage the experts in long-term care, geriatrics, policymaking decisions—it’s not a matter of asking for recommendations. None of this is sound bite-able. We’re dealing with the most complex population in the history of mankind. No one has ever lived this long. If you don’t include experts in determining policy—they need to be at the table every moment, not just provide recommendations. Until we include geriatrics experts in real-world policymaking, we will not make a huge difference.

A policy researcher noted that the number of residents in assisted living and other non-nursing home residential settings, such as memory care and group homes, will likely increase in the coming years and commented that adding requirements for infection control may contribute to increased medicalization of assisted living:

> Advocates worry about medicalizing long-term care, and the more we add infection-control officers, geriatricians, the more we’re medicalizing. I just think we have to be careful in settings that are not nursing homes. We’re going to be so aggressive in preventing infections that we end up medicalizing these facilities. What attracts people to them—and their ability to be flexible in the care they provide—will be lost.

Other panelists disagreed, commenting that the engagement of geriatrics experts in assisted living, along with improving knowledge of infection prevention and control, was necessary to improve holistic care and would not contribute to medicalization. In the words of one clinician-researcher,

> The problem of lack of knowledge. . . . I don’t think that’s medicalization to improve people’s knowledge of geriatrics and infection prevention and control, caring for people holistically.

One interviewee noted that policies for infection control in nursing homes typically come from CMS, while assisted living policies vary across states, depending on who is licensing the facility. The CDC makes guidelines that CMS often adopts and uses. The interviewee, a leader of an industry advocacy organization, suggested that the COVID-19 pandemic was eye-opening for the CDC because it made overt that more health care is being provided within assisted living facilities than was evident to some in the organization:

> Policymakers didn’t know the difference between SNF [skilled nursing facilities] and AL [assisted living facilities], and others didn’t realize AL had individuals who needed health care or support. ALs did not get the same support that nursing homes did around getting [personal protective equipment], and the lack of a national list of ALs in the U.S. is a hindrance to offering support.
Action Items

Stakeholders proposed two action items to identify the appropriate level of medical expertise required in various types of LTC facilities:

- Proactively address changing medical acuity and care needs across the continuum of LTC. Determine whether assisted living models require further differentiation to address changing needs as a result of the pandemic and demographic changes.
- Review staff composition in terms of expertise in geriatrics and gerontology broadly and in infection control specifically; ensure adequate staffing, at appropriate levels and with appropriate expertise.

“We’re dealing with the most complex population in the history of mankind—no one has ever lived this long. . . . Until we include geriatrics experts in real-world policymaking, we will not make a huge difference.”

—Administrator-clinician

Subtheme: Include Frontline Staff in Long-Term Care Decisionmaking

Interviewees and panelists noted the importance of involving CNAs and other frontline care providers in facility decisionmaking, since they deliver the majority of care. According to a clinician-researcher, “The CNA is also very important. They are the caregivers . . . the ones that can provide quality care or not. Give them a voice to increase their ability to self-actualize the care that’s needed.” An administrator noted, “I always found as administrator that if there is frontline ownership of a policy and the process to develop it, it’s a more successful process.”

Two interviewees who worked as CNAs in nursing homes during the pandemic described staffing shortages, a lack of personal protective equipment, and concerns about sanitation in the facilities where they worked. Both interviewees commented that the contributions of direct care staff were often overlooked by administrators. One noted that staff meetings during the pandemic focused mainly on the care of residents and that concerns about infection-control policies were rarely discussed:

It was a tough time during COVID. . . . A lot got overlooked in the staff meetings. Elderly people were not doing great. We got more into detail about care for certain individuals rather than other things. . . . Staff was just overworked.

She recommended holding a monthly meeting with administrators and staff members to give direct care staff an opportunity to provide input on facility policies. One clinician-researcher recommended including direct care workers in governance boards:
You need the direct caregivers represented in governance boards. That’s how they’re going to hear what’s going on. . . . Information flow depends on individuals. The director of nursing tells the administrator, who relays it to the executive director . . . [and] the message gets diluted or misinterpreted.

Another interviewee, an administrator, described the benefits of monthly forums with frontline staff to discuss their concerns during the COVID-19 pandemic:

> We did monthly forums with associates to talk about concerns. We had an overwhelming response to talk about the stress of the pandemic and coping. We ramped up existing programs to ensure associates had an avenue they were comfortable with to talk about what’s going right, what’s going wrong. . . . We were all navigating it together.

Another interviewee, a clinician-researcher, suggested the American Nurses Credentialing Center Pathway to Excellence in Long-Term Care as a strategy to improve the work environment for frontline staff, suggesting that families could also be included in this model (American Nurses Credentialing Center, undated). However, the interviewee noted that the cost of the program and rapid staff turnover presented a barrier.

Several participants noted that indirect care providers (e.g., environmental services, dining services) also have a wealth of information on residents and should be involved in facility decisionmaking.

Interviewees commented on the role of race, ethnicity, gender, and socioeconomic status in the challenges that frontline staff face in approaching administrators with concerns. In the words of one LTC consumer advocate,

> It’s rare for anything to be elevated to the administrator. I think frontline workers are fearful of retribution, losing their jobs. . . . There are likely extreme differences in culture and socioeconomic status between frontline staff and management. The typical nursing home administrator in California is a white male with an M.B.A. The typical frontline worker is a female immigrant, often ESL [English as a second language] and making barely above minimum wage. It’s a problem in terms of communication. Staff may not want to go to administrators about their concerns; they may just approach their immediate supervisors.

When asked about concerns with sharing observations with administration, the direct care staff indicated that they took concerns to an intermediary, such as a more senior colleague, for communication with administration. When asked about the impact that gender, race, and ethnicity might have on communication between staff and administrators, the direct care staff, who were not white, noted that differing power was more prominent as a communication challenge than race.

Discussion of power relationships between staff and administration led to a discussion of formal labor rights initiatives. Panelists discussed the pros and cons of unions to represent the interests of CNAs and other frontline staff. One administrator-clinician mentioned a study on differences in LTC facilities with and without unions during the COVID-19 pandemic (Dean,
Venkataramani, and Kimmel, 2020) and suggested that unions could be considered a proxy for CNA voices to ensure that they are heard:

I could argue union pros and cons, but, to me, that was a proxy for CNA voices being heard. In many nursing homes they do not have a voice. They provide 90 percent of hands-on care and have far more insight about residents than anyone else.

A policy researcher commented that the unionization of workers may conflict with the interests of patients and families:

The idea of unionization to some degree conflicts with person- and family-centered care. There are good reasons staff may want to be unionized, but it will make it more difficult for residents and families to have a say if their desires conflict with what the union wants.

While the stakeholders we spoke with focused on decisions at the facility level, a broad cultural shift will require participation and involvement in federal-, state-, and organization-level policy and organization-level rulemaking, organization- and department-level operations within facilities, and care provision, including with direct care staff.

**Action Items**

Stakeholders proposed the following action items to increase direct care staff involvement in decisionmaking:

- Create opportunities to collect input from direct care staff, including CNAs but also dining hall staff, environmental services staff, and others with a “front-row seat” to the issues.
- Recognize the power asymmetry between staff and administrators, and actively structure governance boards to minimize the ways that asymmetry stifles staff communication.
- Carefully examine structural solutions to power imbalance, such as unionization, relaying the pros and cons to those affected.

**Subtheme: Value the Lived Experiences of Staff and Residents, and Engage Them in Decisionmaking**

One interviewee, an assisted living administrator, pointed to the need for LTC advocacy groups to proactively define best practices and advocate for their adoption:

We need advocacy bodies for assisted living and SNF [skilled nursing facilities] that can pull together all the constituents—frontline, director level, families, residents—to write those best practice recs. . . . I believe we have the structures in place, advocacy bodies we need to partner with, to push them to be bolder in representing our industry rather than waiting for CDC or the state to define for us what they believe is best. Let’s define it for them proactively and advocate for that.
One panelist, an administrator-clinician, pointed to resident-family-community advisory councils as a model of LTC governance. Engagement of community members and caregiver groups is a key component of this model, as many LTC residents do not have frequent visits from family members. The panelist also noted the importance of an accountability loop to address concerns reported by the council, which may include the facility’s governing body, administrator, and local, state, or federal authorities, as well as LTC ombudsmen.

Another panelist, a policy researcher, commented that effective policy solutions might be local rather than national:

Anecdotally, answers to these questions may not be national. Culture in different parts of the country or different faith-based residential communities may differ. How much flexibility do we want to allow?

An administrator-clinician expressed concerns about accountability:

Have the council address issues of their concern—food, care, staffing, whatever they see. Report that to [the] administrator, governing body, and state department of public health or CMS. Make it reportable; that creates an accountability loop. Now, someone has to respond to their concerns. Throw in the role of ombudsman. Ombudsmen weren’t allowed into a lot of [nursing homes] during the pandemic. So, we have a legislated regulatory mechanism for resident and system oversight that was not used during the pandemic.

This last point links to the participants’ frequent references to the regulatory structures governing the operation of skilled nursing facilities, and the consequences of the lack of federal regulation for assisted living.

**Action Items**

Stakeholders proposed two action items to better engage staff and residents in decisionmaking:

- Create an accountability loop for decisions that includes administrators and staff.
- Create structures to accommodate local-, state-, and national-level policy decisions.

“We need advocacy bodies for assisted living and [skilled nursing facilities] that can pull together all the constituents—frontline, director level, families, residents.”

—Administrator
Summary of Action Items to Improve Policy Decisionmaking in a Pandemic

The discussions with stakeholders yielded four major themes, summarized in Table 3.1, along with the corresponding action items.

### Table 3.1. Action Items, by Theme

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<th>Theme</th>
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<th>Action Items</th>
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| Theme 1: What needs to change              | Balance of resident rights and facility functioning | • Identify opportunities to optimize resident choice (e.g., through alternative cohorting models organized by risk tolerance).  
• Question the prioritization of safety over other resident-identified priorities, such as health-related quality of life.  
• Review care models for strategies that can be implemented in various settings—for example, from the Green House model and VA. |
|                                            | Resident preferences                           | • Create standards for leadership regarding channels for and frequency of the collection of input from and on behalf of residents.  
• Create proactive plans for input collection from residents at the time of a crisis, like an infection outbreak. |
|                                            | Technology infrastructure                     | • Incentivize and fund technology solutions for resident and staff communication, infection surveillance, and mitigating the negative consequences of such policies as lockdowns and isolation. |
| Theme 2: The role of leadership in system change | No subthemes                                  | • Invest in leadership. Collect leadership suggestions and evaluations from all staff and use that input to improve leadership. Establish LTC leadership centers of excellence for best-practice identification and sharing across settings.  
• Create channels for resident/family/administration communication. Assemble other examples and scale them up across settings.  
• Create and fund governance and communication centers of excellence at the federal and/or state level. |
| Theme 3: The role of regulation in system change | No subthemes                                  | • Use existing infrastructure; review regulatory incentives and disincentives, and work with regulators to make punitive actions meaningful and judiciously applied.  
• Identify and scale up promising enforcement approaches.  
• View regulatory policies and legal requirements through a true resident-centered lens. Involve residents and others in that review. Modify policies that are at odds with residents’ best interests. |
| Need for greater transparency in LTC financing | No subthemes                                  | • Change legal rights to examine private financing and ownership of LTC facilities.  
• Examine other health care private-ownership regulatory models (e.g., for acute care facilities) that could be applied to LTC. |
| Theme 4: The role of representation and expertise in system change | Value staff and professional expertise         | • Proactively address changing medical acuity and care needs across the continuum of LTC. Determine whether assisted living models require further differentiation to address changing needs due to pandemic and demographic changes.  
• Review staff composition in terms of expertise in geriatrics and gerontology broadly and in infection control specifically; ensure adequate staffing at appropriate levels and with appropriate expertise. |
<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Action Items</th>
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| Include frontline staff in LTC decisionmaking | • Create opportunities to collect input from direct care staff, including CNAs but also dining hall staff, environmental services staff, and others with a “front-row seat” to the issues.  
• Recognize the power asymmetry between staff and administrators, and actively structure governance boards to minimize the ways that asymmetry stifles staff communication.  
• Carefully examine structural solutions to power imbalances, such as unionization, reflecting pros and cons to those affected. | |
| Value staff and resident lived experiences, and engage staff and residents in decisionmaking | • Create an accountability loop for decisions that includes administrators and staff.  
• Create structures to accommodate local-, state-, and national-level policy decisions. | |
4. Discussion

A wide range of LTC stakeholders gave voice to a set of consistent challenges to LTC infection-control policy development and implementation. Many of those challenges were tied to wider challenges faced by the industry, including high staff turnover and inflexible regulatory requirements that limited facility-level adaptation to changing circumstances.

There was also broad agreement across these stakeholders about the desirability of increasing resident and staff participation in policy-related decisions. However, some stakeholders we spoke with had not considered resident and staff participation in decisionmaking prior to our conversations. The steps to achieve that participation—and the feasibility of those steps—were not clear-cut.

The engagement of residents, families, and staff at all levels of decisionmaking in LTC facilities has not been widely embraced or adopted across the industry. This is particularly evident when examining how these facilities operate compared with other health care organizations. Patient, family, community, and stakeholder participation is challenging in any setting, and LTC facilities are no exception. Nonetheless, the LTC sector is well behind other health care sectors in terms of adopting principles and practices that would facilitate this type of engagement.

The 2001 Institute of Medicine report *Crossing the Quality Chasm: A New Health System for the 21st Century* has been enormously influential in health care, stimulating research, funding, and meaningful policy change and bringing the concept of patient-centeredness to outpatient and acute care (Institute of Medicine, 2001). The 2022 National Academies report on nursing home quality can provide a similar type of stimulus for LTC reform (National Academies of Sciences, Engineering, and Medicine, 2022). That report emphasizes the centrality of person-centeredness in care, but it does not directly address the potential for participatory models of governance to improve resident-centeredness and policy decisionmaking.

The stakeholders who participated in this study helped shape the following conclusions about the current state of policy decisionmaking in LTC and proposed potential action items for improvement. The following points summarize the findings and the implications for next steps.

*The COVID-19 Pandemic Made Known Problems in Long-Term Care Worse*

Problems with quality of care, staff retention, resident autonomy, and resident health and well-being worsened dramatically during the COVID-19 pandemic. Interviewees and panelists shared their perspectives honed over decades of experience; those perspectives included the lived experiences of residents and nursing assistants, and there was consensus on this point.
The COVID-19 Pandemic Can and Should Be a Catalyst for Inclusive Policy Decisionmaking

Grassroots visitor rights campaigns are examples of residents, families, and LTC consumer advocates coalescing around the negative impact of policies that consider only infection control and reductions in mortality without concomitant consideration of quality of life and autonomy (see, for example, the Essential Caregivers Act [H.R. 3733, 2021]). CMS took action to support visits from family and friends this year, but, in practice, flexibility in policy implementation that is needed at the facility level is lacking.

Inclusive Policy Decisionmaking Is Foreign to Long-Term Care Culture, but Small-Scale Models Are Promising

The Green House and Eden Alternative models are examples of small-scale LTC models. The Green House model emphasizes individual resident autonomy and expanded direct care staff autonomy. Although it began in relatively low-density settings, with a cap of 12 residents per dwelling, it is now also being implemented in dense urban settings, with high-rises divided into separate functional units. These projects illustrate how a culturally distinct model could be incorporated into existing LTC infrastructure.

Leadership Within Long-Term Care Facilities and Systems Is Key to Inclusive Policy Decisionmaking

A strikingly consistent theme across stakeholders was the importance of leadership for setting the tone within assisted living and skilled nursing facilities, by either enabling or limiting communication between management and staff. Positive leadership practices can be leveraged to expand inclusive policy decisionmaking, serving as a foundation for the cultural change required. Multiple participants cited the importance of leadership quality at the facility level to care quality and governance improvements. Within the institutional hierarchy, administrative leadership can create opportunities for participatory governance, even absent formal state or federal requirements. The power of leadership at the facility, state, and federal levels, and leadership within ownership for LTC, bears closer examination. Can facilities work with CMS to manage staffing requirements flexibly? Where should the locus of authority lie for policy determinations that are context-sensitive, such as the attitudes and preferences of residents regarding changing visitation policies related to infection control and local labor market realities?

Action Items Need to Be Sensitive to System-Wide Pressures on Long-Term Care Facilities

What can realistically be achieved has to be addressed according to priority and feasibility, given present-day pressures on LTC facilities and providers. Regulatory requirements, limited
financial transparency, and staffing are three areas that any change in governance models for decisionmaking must address:

- **The regulatory environment**: Given that assisted living facilities have a lower state and federal regulatory burden than skilled nursing homes, assisted living is a good initial target for implementing inclusive governance.

- **Financial transparency**: Lack of financial transparency in the industry is a known problem (White House, 2022; Whitlock, 2022) and was a common point raised by stakeholders as an obstacle to governance reform. The Biden administration is taking steps to address financial transparency. Without an understanding of corporate relationships between facilities and related service organizations and providers, levers for challenging barriers to resident and staff participation in policy decisions are hard to identify (Spanko, 2020).

- **Staffing requirements and real-world impact**: For participants who were not residents or staff, issues of federal and payer power loomed large. Many observed that the CMS mandates related to adequate LTC staffing, including recent changes subsequent to the onset of the pandemic, are likely to have unintended consequences, leading facilities that are already struggling with attracting and retaining staff in the current environment to be pushed further behind by citations for inability to meet the requirement (CMS, 2022b; U.S. Department of Health and Human Services, Office of the Inspector General, 2020). Staff retention was problematic prior to the pandemic and was severely negatively affected by the pandemic.

**Enabling Change Requires a Shift in Attitudes Toward Authority**

Residents and staff may reflect cultural attitudes toward authority within institutions on which they depend for a home and medical and supportive care, in the case of residents, and for a livelihood, in the case of staff. Aging and illness may limit resident activism. The acceptance of top-down decisionmaking by residents might reflect wider attitudes toward authority of the generation they represent, born before 1940. The attitudes may instead or also reflect those of individuals accustomed to institutional living. The residents we spoke with had been in LTC for more than five years. Creation of governance structures in which resident and staff participation is accepted may gain support among residents and staff if these attitudes are accounted for. Resident and staff views could be reflective of administration interests, and they could be concordant with acceptance of top-down authority structures. These participants’ interest in changes beyond the facility level—for example, at the level of federal or state policy—was limited. Their focus, as they thought about solutions to improve infection-control policymaking, stayed at the facility level.

Staff-administrator relationship challenges are well documented in acute care (Becktel, Frankel, and Sweeney, 2022). Within LTC, however, these professional challenges are relatively
understudied. Administrators we spoke with emphasized the need for pragmatism when considering options in a regulated environment with market pressures on financing and staffing, but they also spoke with idealism about improving care for older adults.

**The Pragmatics of Representation in Long-Term Care Require New Methods of Inclusion**

Given that many LTC residents do not have family or friends who are actively engaged in their care, and given the cognitive-status limitations of some residents, a model of resident-family-community advisory councils can provide representation and overcome these challenges to participation (U.S. Department of Health and Human Services, Office of the Inspector General, 2020; Wasserman et al., 2021). This and other new models of representation and governance could lead to positive change for resident and staff well-being related to pandemic infection control. The best models will recognize power imbalances between residents and facilities and also support autonomy across a range of resident situations.

**Study Limitations**

Gathering information through structured interviews and meetings is meant to cover the full range of opinion and not to identify a representative or modal opinion. That is to say that the opinions, preferences, and recommendations offered by the stakeholders we spoke with for this project might not have broad generalizability to all LTC settings. What we heard is no doubt colored by respondent characteristics, such as years of experience in LTC, knowledge of rural versus urban settings, geographic region, and attitudes about private versus public ownership models. The approach we took to identifying and inviting stakeholders to participate in our conversations, however, was based on a thorough assessment of all of the actors who make important decisions in LTC, such as when and where to enter LTC, how to pay for it, how to govern LTC through regulation and rulemaking, how to operate LTC facilities, how to advocate for residents, how to deliver care at the front lines, and how to evaluate LTC quality and performance. This thorough assessment of decisionmaking roles was one way we ensured a broad and inclusive range of opinions about the sector.

Lack of input from family members is another limitation of this work. Direct input from family members is warranted and, as discussed earlier, was initially planned. The family view was introduced in other ways, however. The experiences of one of the research team members as a family member of an LTC resident strongly influenced the initiation of this study (Frank, 2021). Details of the family experience, along with a longitudinal set of photos of this team member’s relative, were reviewed with panel meeting participants to introduce the main discussion questions.

The value of the input is also dependent on the structure of the interview guide and the skill of the team eliciting input. In the case of the panel meeting, group dynamics also influence input.
For example, a dominant speaker might inhibit others from sharing alternative viewpoints, or a senior or powerful person in the field could influence thinking among more-junior participants—more so than the reverse. For the panel meeting, we targeted very senior and influential leaders in the field but also included more-junior participants to ensure a diversity of views along this dimension.

Another limitation was related to our ability to address questions of race, ethnicity, and socioeconomic status in communication between administrators and staff. All members of the research team were white, and most of the interviewees and panel meeting participants identified as white as well. Eliciting input from direct care staff who were not white, about the role of race and ethnicity, was likely not as effective as if the conversations were held with researchers who did not identify as white. The limitations of the dominant culture of research were evident in recruiting and scheduling direct care staff as well. These participants could not join from a private location, and their young children were present and interacting with them during the interview.
5. Recommendations

This report provides the collected input from a wide range of LTC stakeholders who were all asked to consider the role of representation of residents, staff, and families in policy decisionmaking. This topic was clearly novel for many, even LTC advocates who viewed themselves as providing a form of representation for residents. Some also indicated that CDC, CMS, and state departments of health are not familiar with the possibilities for different governance and decisionmaking models in LTC.

While the detailed discussions across stakeholder types led to consensus on specific aspects of LTC that should be part of any governance and cultural change, such as the importance of leadership and the need for financial transparency, there are several additional steps that this work suggests.

Change the Culture by Raising Awareness of the Quality Improvement Possibilities of Participatory Decisionmaking

An awareness campaign could improve the possibility for uptake of reform recommendations. Specifically, raising awareness of the potential benefits of participatory decisionmaking in LTC is an important first step to acceptance of this change by those affected. The example of moving health care culture toward patient-centeredness and participatory decisionmaking, spurred by the 2001 Institute of Medicine report, is a concrete example that should be instructive for LTC culture.

Given the novelty of the core concepts for this work even to participants with multiple decades of familiarity with LTC, potentially as a consequence of the prominence of regulatory requirements as noted in Theme 2 above, we curtailed plans to include family members as participants in this phase of the study. Doing so enabled us to collect more input from residents and staff and also enabled us to collect input from additional administrators and clinicians working in a wide range of facility types. The limited attention given to participatory policymaking in LTC suggests that wider stakeholder convenings that span more perspectives, including those of family members, must start with some informational background. Only after all stakeholders are familiar with these concepts can additional input from them about feasibility and implementation possibilities be addressed.

A coordinated set of group convenings would be a useful next step, using the action items developed in this phase of the study as discussion points focused on implementation. These convenings with more stakeholders involved would allow for stakeholder-informed action. While federal and state policy opportunities would be part of these discussions, the discussions could help to identify actions that facility leadership and other LTC stakeholders could
implement immediately. Challenges to implementation and variation in those challenges as a result of specific features of LTC settings should also be part of those discussions. Wider deliberations can capture details relevant for different settings. Longitudinal involvement of those with expertise in LTC management, along with LTC residents and staff, is likely to optimize the feasibility of implementation. The perspectives of family members will be important to capture as well, particularly given the role of informal caregivers in the lives of residents.

Focus More Attention on Leadership Training

Given consensus on the importance of within-facility leadership, leadership training is critical to quality policy decisionmaking.

Fund Examinations of Staff-Administrator Communication, and Assess the Impact of Age, Gender, Race, and Ethnicity on Collaborative Decisionmaking

We asked participants about the communication between staff and administrators and how different identities might influence that communication. Wider collection of input from direct care staff is crucial. Although staffing changes over the course of this project changed the race and ethnicity makeup of the research team, future work to address concordance between interviewers and participants on key variables, including race and ethnicity, is warranted.

To understand ways in which shared governance is affected by race and ethnicity, wider recruitment of administrators and staff across a range of races and ethnicities is also crucial. Relatedly, consultation with unionization experts could help with understanding factors that limit collaborative decisionmaking.

Examine the Ethical Dimensions of Balancing Individual Preferences for Infection Risk Against Community-Level Protections in Long-Term Care

LTC residents face threats to autonomy and self-determination. Infection-control policies that prioritize minimizing infection risk over preserving individual agency assume a balance that does not reflect the views of all residents and other stakeholders.
Conclusion

The COVID-19 pandemic focused attention on infection-control policy and on LTC, highlighting urgent need for change in both areas. The opportunity now is to use the connection between the two to spur that change. In LTC, pandemic-era infection-control policies were developed, implemented, and mandated, in many cases, without the input or involvement of those most affected: the administrators, residents, and staff. The impact on family members of residents was given even less attention.

The last major LTC legislation was the Patient Self-Determination Act of 1990, and a legacy of that legislation was shifting attention from health system requirements for care provision to the needs and rights of residents in those health care systems. In the subsequent three decades, health policy has evolved. In acute care and outpatient settings, clinicians and patients increasingly practice shared decisionmaking. Stakeholder-engaged models of participation have taken hold in clinical research and health system governance, with community representation the norm on health system advisory boards. Although the meaningfulness and effectiveness of these acute care models can be debated, there is no corresponding model within LTC. The LTC setting differs from acute care, and differences in the population served are one obstacle. Cognitive impairment of some residents may be a barrier to participatory models. Inclusion of people living with dementia in other settings provides a model, however (Frank et al., 2020; Frank et al., 2021). Inclusion of staff is the next cultural change.

This initial examination of possibilities for increased participation of those affected in relevant policy development and implementation demonstrates the potential for updating governance models related to policy. The wisdom of the wide range of individuals reflected here yields an actionable agenda, one that can yield benefit from the substantial pain that the pandemic has caused for those who live and work in LTC facilities and those who care about LTC.
Appendix A. Definitions and Glossary

**Assisted living facility (ALF):** Congregate setting to support individual care needs. According to CMS, these facilities “help residents with daily activities, like bathing and grooming, but allow them to be fairly independent” (CMS, 2021). The Administration for Community Living and Administration on Aging (undated) characterizes assisted living facilities as follows:

Residents of assisted living facilities usually have their own units or apartment. In addition to having a support staff and providing meals, most assisted living facilities also offer at least some of the following services:

- Health care management and monitoring
- Help with activities of daily living such as bathing, dressing, and eating
- Housekeeping and laundry
- Medication reminders and/or help with medications
- Recreational activities
- Security
- Transportation.

**Certified nursing assistant (CNA):** Individual with state-level certification recognizing that specific training requirements have been met. According to CMS, “CNAs are trained and certified to help nurses by providing non-medical assistance to patients, such as help with bathing, dressing, and using the bathroom” (CMS, undated b).

**Consumer advocacy organization:** Organization with a mission to advance needs specific to consumers of services. In LTC, consumer advocacy organizations focus on the rights and well-being of residents in LTC facilities.

**Direct care staff:** Individual who provides clinical or other services and programs (e.g., music therapy) in LTC settings. For this project, we limited our definition of direct care staff to individuals who provide hands-on care to residents, such as bathing and toileting assistance, as nursing assistants.

**Industry advocacy organization:** Organization with a mission to advance goals common to a specific industry. In LTC, industry advocacy organizations focus on the regulatory goals of LTC facilities, working to influence policy to be favorable to operation of these facilities.

**Long-term care (LTC):** General definitions include any care provided for an individual for medical, functioning, and/or emotional needs requiring assistance. CMS defines LTC as follows:

A variety of services that help people with health or personal needs and activities of daily living over a period of time. Long-term care can be provided at home, in the community, or in various types of facilities, including nursing homes and assisted living facilities. (CMS, undated a)

This project addressed institution-based settings—specifically, assisted living and skilled nursing facility care for adults aged 65 and over.
Nursing assistant: Individual who provides direct care to support basic activities of daily living (e.g., eating, dressing, bathing, toileting, transferring). Nursing assistants may or may not have educational training beyond high school. CNAs have pursued training and obtained the CNA credential.

Resident: Individual living in a congregate care setting, such as an assisted living facility or skilled nursing facility.

Skilled nursing facility (SNF): Also referred to as a nursing home. The CMS definition is as follows:

A facility (which meets specific regulatory certification requirements) which primarily provides inpatient skilled nursing care and related services to patients who require medical, nursing, or rehabilitative services but does not provide the level of care or treatment available in a hospital. (CMS, undated c)
Appendix B. Structured Discussion Guides

Interview Discussion Guide

Introduction

In the next 30 to 45 minutes, I have some questions for you about governance in long-term care. This interview will inform our project examining the role of different stakeholders in policy within long-term care. We are examining infection control policies specifically, to learn about the different sources of these policies, how they are implemented and enforced. We are interested in identifying the challenges and opportunities for inclusion of residents, families, and staff in policy within long-term care.

We are speaking with 12–15 clinicians and administrators working in long-term care, to help us understand possibilities for engagement of different types of stakeholders in policies. We would like your honest opinions, so please do not be afraid to speak up or to be critical.

As discussed in our consent form, we will keep your identity confidential unless you agree to be identified in study reports.

We will record the discussion, so we can capture your input accurately. RAND staff may take notes during the interview group; however, these notes will be anonymous and will not contain names or identifying information. We will summarize themes from our discussion, and we will not link personal comments with names in any research publications. We will protect your identity and the information you give us.

Feasibility of Resident, Family, and Staff Engagement in Management and Related Policy Decisions

Describe current procedures for how administration communicates about new policies or policy changes to staff.

- Who is responsible for this communication?
- What channels for communication are used (staff meeting, email, online training with verification, other)?
- Who is responsible for implementing changes and ensuring adherence to policy?
- Is there evaluation of the policy adherence?
- Is there review of impact of policy? If so, from what perspective:
  - facility impact (e.g., cost for personal protective equipment); staff impact (e.g., training needs)
  - resident impact (e.g., interaction with other relevant protocols for medication management)
  - family impact (e.g., access to visits)?

Communication Between Administrators and Staff

How do staff express concerns about the working environment to administrators?

Can you give a specific example related to the last two years, during the pandemic?

Communication Between Administrators and Residents and Families

Do you have a family council? Do you have a resident council?

- How often does it meet?
- What sorts of items are discussed?
**Impact of Gender, Race, and Ethnicity**

Now we have some questions to help us understand the demographics of residents, staff, and administrators in some specific long-term care settings.

For administrators and staff working in a limited number of facilities:
- Approximately what proportion of staff are women? What proportion of residents are women?
- Do you have information you can share on race and ethnicity of staff and of residents?

For researchers and others working across more than 3 facilities:
- Do you have information about demographic make-up of long-term care staff, by staff type (e.g., nursing, janitorial staff) and by level?
- In your opinion, are staff/administration relationships impacted by race of staff and administration? What leads you to that answer?

**Impact of Pandemic on Residents**

What impacts would you say the pandemic has had on residents? (Probe: physical health/stability vs. decline, rate of decline; mental health; social interaction; other)

What specifically led to the impacts you’ve identified? (Probe: social isolation, change in routine, other)

What changes would you suggest to mitigate or eliminate negative impacts? Why would you suggest these changes? What are obstacles to making these changes?

**Impact of Pandemic on Staff**

In what ways did the pandemic impact staff in your facility? (Probe staff attrition). What led to staffing changes?

What are the specific and adoptable options for including resident, staff, and family members in policymaking in LTC when those policies impact physical health and social and emotional well-being of residents, their families, and staff who care for them? What are obstacles—cultural, ethical, and legal—to inclusion of their views?

**Your Recommendations**

What groups or organizations should be part of discussions about infection control policy in long-term care?

Do you have specific suggestions for incorporating different types of stakeholders in policy discussions? In policy implementation? In policy evaluation?

Should staff be separated by groups for these discussions (e.g., by service type)?

Is there anything we’re leaving out here that needs to be addressed?

**Closing**

Thank you for your time. Should you have any additional questions or suggestions, please feel free to contact Lori Frank at Lori_Frank@rand.org.
Panel Meeting Discussion Guide

Introduction

In our time today, we will discuss the role(s) of different stakeholders in long-term care policy development and implementation. We are examining infection-control policies, specifically to learn about the different sources of these policies, and how they are implemented and enforced. We are interested in identifying the challenges and opportunities for inclusion of residents, families, and staff in policy decisions in long-term care. We are cognizant that some infection control may involve balancing potentially divergent goals, depending on perspective.

To prepare for this discussion, we have already held one-on-one interviews with clinicians, administrators, researchers, residents, and individuals working in long-term care. These interviews covered how different types of stakeholders might be involved in policy development and implementation.

Hearing from you today is the next step for our work. Our goal is to emerge with actionable recommendations for improving decisionmaking about these policies and improving policy development and implementation.

We would like your honest opinions, so please do not be afraid to speak up or to be critical. As discussed in our consent form, we will keep your identity confidential unless you agree to be identified in study reports.

We will record the discussion so we can capture your input accurately. RAND staff may take notes during the interview group; however, these notes will be anonymous and will not contain names or identifying information. We will summarize themes from our discussion, and we will not link personal comments with names or organizations in any research publications. We will protect your identity and the information you give us.

Thank you. We have a few orienting slides to get us started.

Feasibility of Resident, Family, and Staff Engagement in Management and Related Policy Decisions

Let’s start with some positive examples of how assisted living and skilled nursing facilities have safeguarded resident and worker health and well-being during the pandemic.

- Probes: visitor access, resident movement in facility, family/caregiver engagement in care, frontline staff support, staff assignment, staff pay, other.
- Probe: Do any of these strategies stand out as successful? Which ones, and why?

What are some examples of how long-term care pandemic response has not worked to safeguard health and well-being?

- Probes: restricted visitor access, restricted resident movement in facility, reduced family/caregiver engagement in care
- In retrospect, how could some of the more harmful policies have been avoided?

How can pandemic responses be improved?

How have some of these pandemic responses been evaluated for impact, if at all? From what perspective?

- facility impact (e.g., cost for personal protective equipment); staff impact (e.g., training needs)
- resident impact (e.g., interaction with other relevant protocols for medication management)
- family impact (e.g., access to visits)?
- Probes: How should pandemic responses be evaluated for impact on facilities, staff, residents, families? What is ideal? What is feasible?
Communication Between Administrators and Staff

How do staff express concerns about the working environment to administrators?
- Probes: How can staff be empowered to communicate concerns about their working environment to administrators? Would developing a channel for this communication mitigate the workforce retention challenges? Why or why not?
- Probe, if needed: Can you give a specific example from the last two years, during the pandemic?

Communication Between Administrators and Residents and Families

Are family and/or resident councils a useful method of actively involving families and residents in decisionmaking?
- For which decisions do they work?
- For which decisions do they not work?
- Why?

What are other ways that families, residents, and staff could be apprised of decisions affecting policies like visitor access and resident free movement (e.g., leaving room to go to dining hall)?
(Probe: specific examples)

Impact of Gender, Race, and Ethnicity

Long-term care staff are disproportionately women, immigrants, and people of color. In your experience, what challenges do staff face when approaching administration with concerns, and what role do gender and race play in this dynamic?

Should staff have input into decisions about infection control policy? (If so, how? If not, why not?)
(Probe: does unionization impact this process? Could it?)

Impact of Pandemic on Residents

What impacts of infection control policies have been positive? What impacts have been negative?
What changes would you suggest to mitigate or eliminate negative impacts? Why would you suggest these changes? What are obstacles to making these changes?

Inclusion in Policy and Decisionmaking: The Possibilities

What are the specific and adoptable options for including residents, staff, and family members in policymaking in LTC? What are obstacles—cultural, ethical, and legal—to inclusion of their views?

Your Recommendations

What groups or organizations should be part of discussions about involving residents, families, and staff in policy related to long-term care?
Do you have specific suggestions for incorporating different types of stakeholders in policy discussions? In policy implementation? In policy evaluation?
Should staff be separated by groups for these discussions (e.g., by service type)?
Is there anything we’re leaving out here that needs to be addressed?

Closing

Thank you for your time. Should you have any additional questions or suggestions, please feel free to contact Lori Frank at Lori_Frank@rand.org.
Appendix C. Stakeholder Panel Meeting Participants and Interviewees

Panel Meeting Participants

The following stakeholders shared their perspectives as part of our panel meeting, held in June 2022.

**Lauren Dunning, JD, MPH**
Director
Milken Institute Center for the Future of Aging

**Janine Finck-Boyle, MBA/HCA, LNHA**
Vice President, Health Services Policy and Regulatory Affairs
LeadingAge

**Terry Fulmer, PhD, RN, FAAN**
President
The John A. Hartford Foundation

**Howard Gleckman**
Senior Fellow
The Urban Institute

**Pat W. Stone, PhD, RN, FAAN, FAPIC**
Centennial Professor of Health Policy
Director, Center for Health Policy, Columbia University School of Nursing

**Michael R. Wasserman, MD, CMD**
Chair, Public Policy Committee
California Association of Long Term Care Medicine

**Anonymous panelist**
University of North Carolina
Interviewees

The following stakeholders participated in interviews for this study. Nine initial interviews were conducted between February and May 2022, and the remainder were conducted between June and July 2022.

**Sam Brooks, JD**  
Director, Public Policy  
The National Consumer Voice

**Jana Broughton, BA, MA**  
Licensed Nursing Home Administrator

**Anthony Chicotel, JD, MPP**  
Senior Staff Attorney  
California Advocates for Nursing Home Reform (CANHR)

**Tammy Curry, RN, BSHSM**  
Vice President Health and Wellness  
Brightview Senior Living

**Karen Doyle, MSN, LNHA, HSE**  
Associate Executive Director  
Goodwin House Bailey’s Crossroads

**Theresa (Terri) Harvath, PhD, RN, FAAN, FGSA**  
Clinical Professor  
School of Nursing, University of Minnesota

**Paul R. Katz, MD, CMD**  
Professor and Chair  
Department of Geriatrics, College of Medicine, Florida State University

**Ann Kolanowski PhD, RN, FAAN**  
Professor Emerita  
Pennsylvania State University
Barbara Resnick, PhD, CRNP
Professor and Sonya Ziporkin Gershowitz Chair in Gerontology
University of Maryland School of Nursing

Lindsay B. Schwartz, PhD, FGSA
Founder and Principal
Workforce & Quality Innovations, LLC

Alex Spanko, BS
Reporter, Editor, and Communications Director
The Green House Project
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>CNA</td>
<td>certified nursing assistant</td>
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<tr>
<td>COVID-19</td>
<td>coronavirus disease 2019</td>
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<tr>
<td>IT</td>
<td>information technology</td>
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<tr>
<td>LTC</td>
<td>long-term care</td>
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<tr>
<td>QAPI</td>
<td>quality assurance and performance improvement</td>
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<tr>
<td>VA</td>
<td>U.S. Department of Veterans Affairs</td>
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American Nurses Credentialing Center, “Pathway to Excellence in Long Term Care®,” webpage, undated. As of September 1, 2022: https://www.nursingworld.org/organizational-programs/pathway/overview/pathway-to-excellence-in-long-term-care


CDC—See Centers for Disease Control and Prevention.


CMS—See Centers for Medicare and Medicaid Services.


Eden Alternative, homepage, undated. As of September 1, 2022: https://www.edenalt.org


