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# Infection Control Policy in Long-Term Care—Who Decides?

**M**y mother-in-law and the other residents in her assisted living facility have been protected from excessive exposure to the novel coronavirus through detailed, coordinated policies instituted by her facility: testing for staff and for residents, transportation for staff to keep them off of public transport as cases rose in the area, maintaining social distance for residents.

At the beginning of the coronavirus disease 2019 (COVID-19) pandemic, mortality rates among long-term care residents were high and accounted for 50 percent or more of COVID-19 deaths in some states (Lau-Ng, Caruso, and Perls, 2020). Rates of infection varied by facility, but climbed as high as 90 percent of all residents in some locations (Abrams et al., 2020). Available data on assisted living facilities as of mid-May 2020 showed an infection rate among residents five times the national rate, and nearly one-third of virus-positive residents died (Ouslander and Grabowski, 2020). With more knowledge, more testing, and more personal

protective equipment for staff, the death rate has, thankfully, slowed. Protecting residents from COVID-19 infection involves a variety of measures, including quarantining those with potential virus exposure, isolating residents who test positive for COVID-19, limiting social interaction among residents, and reducing the number of residents who can dine in the same space.

The benefit of avoided infection, illness, and death is clear. The costs are less easily quantified.

## Hidden Costs of Safety

What has become of these long-term care residents months later? The unintended consequences of infection control for older adults range from deconditioning for those who have been unable to walk freely because of infection control restrictions to serious weight loss among long-term care residents (Schrack, Wanigatunga, and Juraschek, 2020). Excess death rates due to dementia have risen during the pandemic (Wan, 2020). Physical illness left untreated because of fear of travel to medical care—and fear of bringing care providers into facilities—is beginning to take its toll.

Impacts extend beyond physical health to cognitive and mental health. Rates of delirium for these residents

have skyrocketed (Inouye, 2020). Depression is rampant. Isolation has increased as a direct result of infection control policies in these settings, and loneliness rates have increased as well. Beyond the psychic pain, loneliness is associated with greater risk of dementia (Sutin et al., 2020). For the more than 2 million adults in long-term care, including skilled nursing facilities and assisted living facilities (Gardner, States, and Bagley, 2020), these trends represent a lot of suffering, much of it potentially avoidable.

## Who Should Be at the Table?

Throughout life, we make decisions driven by our preferences for balancing safety and risk. In long-term care, decisions about that balance are made by those in charge: facility owners (both for-profit and nonprofit), administrators, clinicians, and state departments of health. **What standing do residents and their families have in these decisions?**

The COVID-19 pandemic underscores the limited representation in decisionmaking of those most affected by long-term care policies—the residents and families. Staff, too, have suffered, with reports of more than 500 deaths among employees in nursing homes (Ouslander and Grabowski, 2020). Some staff have unions, and these

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employees have formal protections. For many staff, the choice between accepting risk or accepting loss of income is fraught, although some can choose to work elsewhere.

Residents in assisted living and skilled nursing homes have limited choices about where to live. Moving from one facility to another is generally not an option, for several reasons. The consequences of moving to a new residence can be dramatic for some older adults, with the move itself leading to decline in cognitive and physical functioning. Also, older adults with limited financial means have few options. Those in long-term care with multiple health challenges and impaired cognition might not be in a position to secure alternative housing. These facilities are their homes. This is where they live (Frank et al., 2020).

For families, moving an older adult with care needs from a long-term care home into the home of a family member can be successful, but it can also substantially increase stresses related to caregiving (Helfenbaum, 2020; National Consumer Voice for Quality Long-Term Care, 2020a).

Community congregate housing often offers an opportunity for residents to share in decisions that affect the community. In residential co-ops, residents make community-level decisions through a representative body—a board. The same is not true in long-term care, where the representation of residents is far more limited and where protections are weaker than most landlord/tenant laws outside long-term care. In assisted living facilities, evictions are possible based on facility decision and may not require a substantiated cause.

The 1987 federal Patient Self-Determination Act established formal rights for residents in long-term care (for a summary, see National Consumer Voice for Quality

Long-Term Care, 2020b). Despite this law, resident self-determination has been compromised by the pandemic (Kusmaul, 2020). Given the clinical risk of COVID-19 to older age groups, *compassionate ageism* has blossomed, adding paternalism to the new literature on unintended consequences of pandemic infection control policies for older adults (Vervaecke and Meisner, 2020).

In Canada, the “More Than a Visitor” campaign led to introduction of the More Than a Visitor Act in September 2020. This legislation clarifies the essential role that families play in the lives of people in long-term care. For example, families provide assistance with eating and other daily activities—roles ended by the pandemic lockdown, which locked them out. This movement has been influential, but it is an example of *petitionary* representation—affected communities or those acting on their behalf petition those with authority to make and implement relevant policies. The locus of authority still rests with long-term care facility management. This is the standard governance model.

A more direct connection between decisionmakers and those affected by their decisions is reflected in *participatory* representation. This approach actively includes affected communities, with or without those acting on their behalf, in developing and implementing policies and in making decisions about policy choice. Although participatory representation offers more autonomy to residents and staff, this model is not yet feasible to implement in most settings, given the need for government officials to authorize regulatory changes for long-term care providers.

However, a new hybrid model is feasible. This model would have participatory representation for development of a policy, then petitionary representation for the formal definition of the policy—as, for example, when a policy

proposal is taken on by the legislative branch and passed into law. Putting the policy into practice would require the involvement of residents and families partnering with long-term care administrators and staff, as represented in Figure 1.

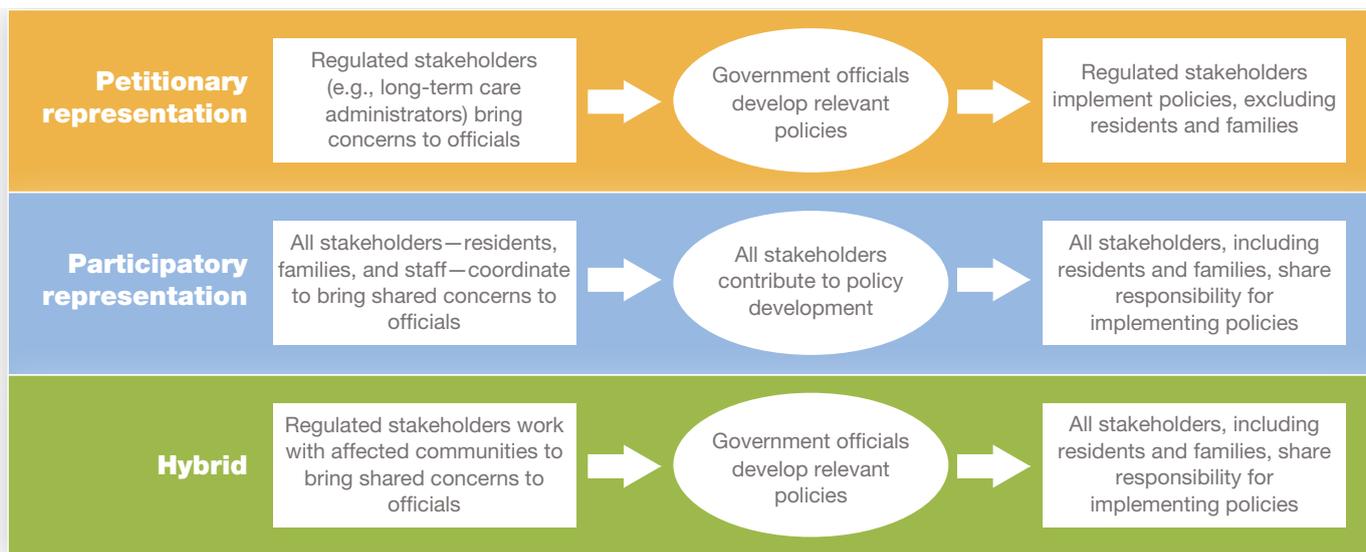
## A Model for Including Long-Term Care Residents in Governance of Their Lives

Long-term care residents would benefit immediately from representational governance. The model needs to encompass development of new policies, review of new evidence for updating policies, and evaluation of policy effects

from multiple perspectives. Developing such a model will require broadening the outcomes assessed to include rates of depression, delirium, cognitive decline, and physical deconditioning, moving beyond assessments of infection rate and death. The impact on quality of living for residents and for their families is a key indicator of the success of any policy, and the trade-off that those affected are willing to make between risk and quality of life might differ substantially from those made based on narrow physical health outcomes.

The American Geriatrics Society (AGS) has published policy briefs to address COVID-19 in assisted living facilities and nursing homes (AGS, 2020a; AGS, 2020b). These are important statements to guide high-quality care. These and other recommendations for improving

FIGURE 1  
Three Models of Stakeholder Representation in Long-Term Care Decisionmaking



long-term care during the pandemic address public health, health policy, staffing and resource needs, and clinical care needs (Ouslander and Grabowski, 2020; Werner, Hoffman, and Coe, 2020). In another guidance document with an explicit focus on stakeholder roles and their recommended function during the pandemic, residents and families and front-line staff are not among the stakeholders included (D'Adamo, Yoshikawa, and Ouslander, 2020).

COVID-19 has highlighted the opportunity to add what is missing from these statements—incorporating resident, staff, and family preferences and voices in governance decisions. The value of including residents and others in governance of long-term care extends beyond the COVID-19 crisis.

The questions to be addressed in developing a new model range from infrastructure to situational ethics:

1. How can differing opinions on risk and infection control be managed in a shared physical space? If some residents choose to isolate and prioritize minimizing exposure risk while others choose to prioritize visits with family, how can both groups be accommodated within a single building? What are the implications of the governance model for rollout of vaccines?
2. How can facilities manage decisions about leave-of-absence requests for residents who might choose

to temporarily leave the facility to reduce infection risk?

3. Who determines whether recovering or actively ill COVID-19 patients should be treated in the facility? The discharge of COVID-19 patients from acute care to long-term care contributed to early surges in long-term care infection rates. How can residents and families have a say, either with administrators in specific facilities or at the state level for policy-setting?
4. What specific trade-offs should be anticipated in permitting local, facility-level decisionmaking about pandemic response versus requiring state- or federal-level responses?

The cultural shift to recognize patients, direct care staff, and families as stakeholders with perspectives to include in decisionmaking could improve infection control practices while also addressing health-related quality of life for residents. This cultural shift is long overdue.

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## About This Perspective

In this Perspective the author presents a model for long-term care governance that actively involves residents and family members in decisionmaking and that balances infection control concerns against resident well-being.

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## About the Author

**Lori Frank** is a senior behavioral scientist with the RAND Corporation. Her work addresses methods for incorporating the consumer perspective into health outcomes research and clinical care. She completed a Congressional Fellowship in Health and Aging Policy and is currently president of the International Society for Quality of Life Research. The focus of her Ph.D. was psychology and gerontology.

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