CONCLUSION
LESSONS LEARNED AND APPLICATIONS AS WE LOOK TO THE FUTURE

As the pandemic progressed, our research team met daily and talked about what we were hearing from the participants. Shenk, in particular, began following the struggles of family members and other informal but essential caregivers who were frustrated by the ongoing lockdowns and their inability to visit their loved ones. These reports appeared on social media from family members and activist groups, along with frightening accounts in the media. We began following the Facebook groups of "North Carolina Caregivers for Compromise—because isolation kills too!" and "Long-Term Care Nursing," as well as the national movement for long-term care visitation started by Mary Daniel. She took a job as a dishwasher in the kitchen of the memory care community in Florida where her husband is a resident in order to be able to visit with him after her shifts. She has continued to fight for visitation rights, along with other family members of long-term care residents and advocates nationally. Compassionate care visits were arranged for families to visit residents who were dying of COVID, but as we discussed in chapter 2, people were dying alone or with a CNA or housekeeper holding their hand. Family members who helped care for their loved ones when they visited regularly before the pandemic began sought the designation of "essential caregiver" and visitation rights following the guidelines being enforced for any staff entering a long-term care community.

Along with hospitals, long-term care communities set pandemic restrictions on visitors to protect patients, residents, and staff from infection. These concerns for safety led to extensive isolation and decline of residents and exacerbated the demands on overworked staff. New laws have since been developed, and supporters of these new laws say they want to ease the restrictions because the rules harmed patients and residents. In terms of visitation in long-term care, at least nine states have passed "No Patient Left Alone" acts and several others have bills under consideration. Other states including Arkansas, North Carolina, and Oklahoma passed similar

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"No Patient Left Alone" acts that also guarantee visitor access to patients in hospitals. Some laws, like those passed in New York and Texas, are specific to long-term care communities. They allow residents to designate essential caregivers, also known as compassionate caregivers, who are allowed to visit regardless of whether there is a health crisis. In January 2022, the Texas Health and Human Services published a "reminder" that all long-term care facilities must allow all visitation and essential caregiver and end-of-life visits must be allowed for all residents with any COVID-19 status. A facility or agency may be cited if visitation is not allowed.

While we were interviewing participants back in 2020–2021, we were frustrated by the tension between the anguished narratives we were hearing from the long-term care providers who were endangering themselves and their families in order to care for residents and clients, and those who were highlighting the outbreaks and "dangers of nursing home care." The research participants expressed their dedication to the residents and clients in their care, while the "outside world" chastised them for isolating those in need of care and being part of the problem leading to the high number of deaths among this population.

In August 2022, Shenk was invited to a meeting of OPENDOORS, the group started by Black and brown residents at Coler Rehabilitation and Nursing Center, on Roosevelt Island, New York City, which is spotlighted in the essay in chapter 2. At that Zoom meeting, we talked about this book as well as their ongoing efforts through Nursing Home Lives Matter and the impact campaign for the documentary then in production, *Fire through Dry Grass*. I met the founder of the national Essential Caregivers Coalition and offered my support in their efforts to reform long-term care. This online group is continuing to work to pass legislation at both the national and state levels to designate essential caregivers for residents in long-term care, as discussed previously. As described on their website: "This is a national advocacy group dedicated to the establishment of an Essential Caregiver designation in order to prevent long-term care residents from suffering due to the effects of social isolation when faced with measures meant to secure public safety" (Essential Caregivers Coalition n.d.).

We have come to realize that mistakes were made, especially during the early days of the pandemic when little was known about COVID-19 and how to control this rampaging virus. As discussed in chapter 8, the prolonged lockdown of residential long-term care communities and the isolation it caused led to irreversible decline of some older adults and deaths that might have been avoided with a more nuanced approach to protecting residents. This crisis has exacerbated the ongoing problems in long-term care and made very visible the problems in our system for those in need of support and care. This is a moment ripe for change. As it tore through

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long-term care communities and the deaths were shouted in the media, the COVID-19 pandemic has laid bare the inadequacies of the long-term care system in the United States.

The 2022 report from the National Academies of Sciences, Engineering, and Medicine on the national imperative to improve nursing home quality places its recommendations in this context: "despite making up less than one-half of 1 percent of the US population, as of October 2021, nursing home residents accounted for approximately 19 percent of all COVID-19 deaths" (2). Another 2022 report, keyed to interviews with CNAs in metropolitan New York, echoed its call for increasing stability and addressing growing staff shortages (Franzosa et al. 2022). A brief from the ASPE (Assistant Secretary for Planning and Evaluation) Office of Health Policy (2022) also emphasized worker shortages across the healthcare workforce, "increased health care worker burnout, exhaustion, and trauma" (3) and disparities in geographic distribution of hospitals (10). Reinhard, Flinn, and Amero (2022: 4) reported that older people and persons living with dementia at home lost services and socialization, as some states restricted provision of home health care. The COVID-19 pandemic called—and continues to call—attention to many problems across the entire healthcare system in multiple countries and, in the US, across a range of states. Emphasis has grown across the world to focus on how we care for aging people and persons living with dementia in environments including nursing homes, memory care homes, other long-term care communities, and in homes in the community.

Especially during the first few months of the pandemic, there was an emphasis on "the important role of long-term care staff at the frontlines of fighting the virus and preserving the lives of older adults. As a society, it is our duty to ensure the status and benefits associated with direct paid eldercare work are improved so that staff are adequately trained and rewarded for their work" (Ayalon et al. 2020). While these workers were deemed "essential workers," they were not accorded the status and benefits that should come with that designation. Dire headlines notwithstanding, at the time of this writing we are in much better shape than we were at the start of the pandemic. We've discovered a lot more information about how COVID-19 works and now have effective masks, vaccines, boosters, treatments, and rapid tests. We've also learned that having to hunker down comes at a real cost to the mental health and well-being of both the caregiving staff and older adults they care for. The cost of a strict lockdown may have been deemed worthwhile in 2020, but by and large that's not what US experts advise now. A key variable that needs to be examined is the movement of staff in and out and within residential long-term care environments. Early in the pandemic most homes and programs limited

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staff to working in a single building or unit or serving a small number of clients in their homes. The staff were moving in and out of the long-term care environments, however, and were likely the source of at least some of the spread of the virus. Other challenges in preventing outbreaks were residents and clients going out to medical appointments or to visit family. As we saw in chapter 6, one assisted living community that had no known COVID cases throughout 2020 had an outbreak in January 2021, shortly after residents were able to go home for the holidays in December.

Our comparison of the responses of staff caring for older adults in residential and community-based long-term care suggests that home and community-based service providers were generally better able to respond quickly and effectively as they pivoted during the pandemic. While there will always be a need for nursing homes for some people who require skilled nursing care, and a range of long-term care options, most people prefer to stay in their homes as their care needs increase. Home and community-based care is also more cost effective and works better physically, mentally, and socially for older Americans. The pandemic also highlighted the value of agency, which was more easily afforded to those who provided and received care in their homes.

The future of long-term care requires investment in both residential and home-based services. As Grabowski (2021) explains, if there is a silver lining to COVID-19 in terms of long-term care, the pandemic will hopefully accelerate the decades-long push toward expanding home and community-based programs while also causing a reconceptualization of nursing home care. These are not competing goals but rather complementary ones. The goal should not be to abolish nursing homes, but rather to abolish the institutional models and the underfunding of home and community-based programs that have plagued long-term care for far too long (Grabowski 2021).

We agree that following the pandemic, countries like the US should increase their overall government spending on long-term care, and the bulk of that additional spending should go to home and community-based models. The median for countries in the Organization for Economic Cooperation and Development (OECD) is to spend roughly 15 percent of their healthcare budget on long-term care services. In countries that allocate a small percentage of healthcare spending to long-term care, such as Australia (2 percent) and the US (5 percent), dollars could be taken from general healthcare spending and reallocated to home and community-based services (Tikkanen 2017). This increased spending on home and community-based care would benefit not only the care for recipients but also their family members, who often must take time away from their jobs and risk their own health to provide this care (Grabowski 2021).

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Along with an increase in funding for home and community-based services, measures are needed to assure the quality of these programs. We are encouraged by the recent adoption of the first ever home and community-based quality data set by CMS to promote consistent quality measurement within and across state Medicaid home and community-based programs (Gerontological Society of America 2022). "CMS strongly encourages [but does not require] states to use this information to assess and improve the quality and outcomes of their home and community-based programs. CMS expects to update the measure set in the future, including adding newly developed measures to address gaps, as the field of home and community-based measure development advances" (9). This is just a start and would need to be expanded beyond Medicaid-funded programs.

For those who need residential-based care, the goal should be to provide a range of environments where well-educated and well-compensated staff provide effective care in a small homelike setting such as the Green House model. We agree with Polivka that "existing large facilities should be reserved for short term, convalescent and rehabilitative care, which nursing homes are already providing on an expanding basis" (2020b). Small home models like the Green House model have been found to provide higher quality care relative to traditional nursing homes (Afendulis et al. 2016). Early reports during the pandemic indicated that residents in Green House communities, for example, were one-fifth as likely to get COVID-19 compared to those who live in typical nursing homes, and one-twentieth as likely to die from COVID-19 (Tan 2020). Small home models are also able to provide care that affords a higher quality of life and avoids social isolation that were particularly crucial concerns during the pandemic.

While care providers in long-term care were considered essential workers during the height of the pandemic and were expected to show up and provide the necessary care, they are not always treated as valued workers. That leads to another major set of recommendations related to the structure of eldercare work and the way elder care is staffed. Staffing issues include adequate pay, appropriate benefits, and effective career paths. As Picard (2021) outlines from Canada:

> More than anything, the pandemic exposed how important frontline workers are, especially to frail elders; chronic labor shortages are as deadly as viruses. COVID-19 also graphically underscored that the conditions of work are the conditions of care. Improving eldercare begins with fixing the work environment for nurses, PSWs [Personal Support Workers] and others. Staff need resources, structures, support and time to deliver quality care. (164)

Our findings suggest several major staffing issues highlighted by the pandemic that need to be addressed. First, in terms of the inadequate pay for

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those providing care, workers require a living wage so that they don't have to work multiple jobs in order to earn enough to live on. This should include appropriate compensation as well as benefits such as paid sick leave and health insurance. Second, there needs to be clear career paths and professionalization for CNAs and home health workers, in particular. Third, the pandemic demonstrated the need for a specialized wellness coordinator to track testing, symptoms, and quarantining protocols as knowledge and guidelines evolved. Fourth is the need for extensive cross-training of staff, as discussed by the administrators in chapter 6 and highlighted in the essay in chapter 6. Fifth, the resilience that is required of staff requires the support of supervisors in addition to that of family or friends.

It is important to recognize the integral role played by caregivers with established relationships with the older adults for whom they provide care. In chapter 3 we focused on Kellin, the bus driver who took on new responsibilities during the lockdown. Because he knew his clients well, he was able to check in on them and determine whether they were okay. This emphasizes the policy implications of assuring that workers receive appropriate wages, sick pay, and leave, rather than resorting to using temporary workers who do not have established relationships or understanding of the residents' or clients' needs. Full-time staff regularly express the challenges of working short-staffed or with "agency staff" who are generally paid more than residential community staff.

While many of the research participants discussed the importance of the support they received from their informal support networks throughout the pandemic, those who felt supported by their supervisors and coworkers spoke about a sense of agency that enabled them to remain effective in providing care. As demonstrated in the narratives, the staff working to provide care for older adults requiring their expertise stepped up and did the work that needed to be done even when it endangered them and their families. We owe it to both the workers and the residents and clients who require care to assure that well-trained, well-supported, fairly compensated staff are available to provide care.

A major finding of a recent report on nursing home care is that the public view "caring" as an innate characteristic rather than a learned skill (Aasar and Volmert 2022). Their recommendations related to improving the skills of the caregiving workforce based on this finding include: 1) an emphasis on the learned skills required for good caregiving that can be taught and improved; 2) the rigorous training necessary to achieve the necessary expertise and its importance in the day-to-day responsibilities of all levels of staff; 3) the need for detailed understanding of how training, better wages, and improved working conditions impact the quality of care in nursing homes; and 4) contextualizing nursing home work within

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Illustration 9.1. Faces of Caring signs made by director of nursing (PowerPoint slide 106). Photo credit: Attic Angel Assisted Living and Memory Care

broader narratives and conversations about racial and gender justice and linking efforts to reframe care work with the larger movement for a just and equitable society (13).

It is clear from our findings that the long lockdown that began in March 2020 was difficult for the caregiving staff and also detrimental to the health and well-being of many long-term care residents. Looking at the way this was handled in some other countries suggests that a more nuanced approach would have been more successful at protecting the residents from COVID while providing the necessary care alongside adequate socialization. As discussed in chapter 8, the US continued extreme restrictions in residential long-term care, while Switzerland enabled residential long-term care communities to respond to specific situations and open for more visitation rather than continuing with a total shutdown. This more nuanced approach was equally challenging for staff but was positive in terms of the level of isolation and loneliness experienced by the residents they care for. In the Swiss case, they more effectively balanced protective measures with an effort to provide adequate quality of life. Tailored infection control guidelines would have helped assure that better care for residents was pro-

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vided, incorporating more appropriate interaction and socialization during what turned out to be an extensive period of time. This could have partly been accommodated by increasing the use of compassionate care visits and establishing a more effective system for allowing residents to deem select individuals as "essential caregivers" and allowing them to visit utilizing the same restrictions that were in place for staff.

The major themes of resilience of staff, importance of valuing human infrastructure, and communication are highlighted in each chapter, and we have discussed recommendations in terms of the organization of the long-term care system and staffing. We will now go on to address key recommendations related to communication. During the pandemic, the need for effective communication at various levels was paramount and had to be expanded. This includes communication about evolving policies and guidelines to staff, as well as regular updates to residents/clients and their families. Those residential long-term care and home and community-based programs that had strong relationships among staff, with residents and family members, were able to utilize these trust-based relationships to foster effective communication and care as the pandemic progressed. We came to recognize the importance of effective communication that incorporates flexibility as key to navigating the challenging situations facing staff, residents/clients, and families.

The role of strong, sensitive leadership has been crucial throughout the trajectory of the pandemic. The managers and administrators who were particularly successful in guiding their staff and programs through the evolving pandemic demonstrated these skills. Structured leadership within each congregate care community and community-based program was essential to responding effectively and pivoting rapidly to continue to meet the needs of staff, clients, and residents. Effective leaders had the respect of their staff, residents/clients, and family members. A key element of effective leadership during the pandemic was assuring adequate avenues of communication. The staff of residential long-term care communities and community-based programs faced huge challenges in assuring adequate communication with their residents or clients and their own coworkers. A particular challenge was communicating effectively with family and enabling them to keep up to date on their loved one's situation and engage with them.

What did not emerge consistently, even when guidance and direction were needed early on, was an adequate way of communicating across individual long-term care communities and community-based programs to share ideas, experiences, and innovations to address the impacts of social isolation. Professional organizations including the NAAP (National Association of Activities Professionals) and NCCAP (National Certification Council for Activity Professionals) hosted open meetings in the early months of

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the pandemic. Some staff utilized social media and personal and professional networks to commiserate and share information, but there didn't seem to be sufficient safe spaces within which professionals could share thoughts and express their emotions. For example, during the focus groups we held on 30 October 2020, 25 January 2021, and 8 March 2021, with administrators and activities staff who had never met, we noted how they quickly supported each other as they discussed their experiences, and shared successes and failures. The participants all agreed that having connections with other communities, programs, and agencies made it easier to respond effectively to the needs of staff and to pivot quickly to effectively meet the needs of the older adults they care for.

One of the most dramatic changes we observed during the pandemic was the vastly expanded use of technology in many different forms, including communicating with residents/clients and family members. We saw an expanded use of FaceTime and Zoom in addition to telehealth platforms, some of which can be continued beyond the pandemic. All residential long-term care and home and community-based programs should have adequate technology to enable social interaction, because those who did not have it were at a disadvantage during the height of the pandemic. While virtual platforms were used on an expanded basis to foster communication between residents/clients and families during the lockdown, those resources can continue to be used effectively to gather families who are in different locations. The serious issues related to engagement, and avoiding isolation and loneliness, suggest the need to strengthen and keep our in-person programs and services strong with an increased use of technology and telehealth as we move into the future.

Positive Outcomes to Build on and Lessons Learned

While the pandemic was a horrific experience for most workers caring for older adults in long-term care, we were able to identify a set of positive outcomes and creative approaches, as well as recommendations that can be incorporated and built on to improve care. Below we list some examples of how long-term care providers were able to meet the evolving needs of older adults during the pandemic. These operational flexibilities, creative approaches, and positive outcomes can be useful in efforts to restructure and improve long-term care moving forward. An overarching theme from these data is that individuals and communities drew on available resources in creative ways to meet the needs of residents and clients and their families. The resilience and creativity shown by the staff were remarkable in light of the difficult and restrictive circumstances.

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- Telehealth—We know that telehealth does not work for everyone and certainly not for all medical situations, but it has been integrated into more healthcare practices; it will continue to be used in certain situations as part of the system of long-term care, as an effective means of communicating with providers, patients, residents, clients, and their families.
- Collaborative relationships between agencies and programs—Programs that were most effective in pivoting quickly to address the needs of their residents and clients drew on long-standing relationships with other community partners that had different kinds of resources available to them.
- Relationships within teams—A key finding from this study suggests that the environments that were able to provide the most effective care were those where team members felt supported, protected, and informed. In particular, when staff felt they had agency within their workplace and their supervisors were attentive to their input and concerns, they were best able to provide quality care throughout the pandemic.
- Share best practices, mistakes, resources, and strategies—Staff have to be willing to not only share best practices and effective strategies but also admit weaknesses or mistakes made during the evolving pandemic. There needs to be a willingness to share across different organizations and programs.
- Videos of long-term care environments during lockdown—During our interviews, a couple of research participants walked us through their community while on Zoom in order to let us see how things were functioning. Some staff created and shared videos of activities that showed family members what was going on and reassured them about the situation and precautions that were being taken.

We hope that by sharing these examples of positive outcomes and techniques, we can help other providers recognize possibilities to implement in their own communities and programs in the future.

Recommendations

- It is essential to maintain effective mandatory reporting and communication systems, or implement an “emergency outreach communication plan” that allows the utmost transparency between all levels of workers and clients/residents/families.

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- There needs to be adequate attention to infection control. Programs and communities need to maintain a sufficient stockpile of resources including PPE to ensure proper infection control. A specific position is needed in residential long-term care environments to monitor and ensure that infection control protocols are enforced.
- Staff, especially in residential long-term care, need to be cross-trained in the event they need to step into new or additional roles to ensure the safety and health of their residents.
- Recognition of the importance of and improved utilization of existing networks is necessary across various models of long-term care to share information and strategies regarding evolving needs of staff and those in their care.
- In terms of persons living with dementia, particular care needs to be taken to prioritize a person-centered care approach provided by a well-trained staff.
- Innovations like the distribution of animatronic pets should be expanded because they will always provide important interaction and support in the best as well as the most challenging of times.

Conclusion

Our overriding sense as we complete this book, three years after we all weathered the initial brunt of the COVID-19 pandemic, is the disappointingly ineffective and inadequately funded approaches to providing care for older adults and support for those who provide that care. Our system of long-term care in the United States is not well funded. It is not well regulated, and we do not listen and respond to the voices of those extending or receiving care. As we look to the future, we need to do better for our elders and those who care for them. If not now, when?

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