3 HOME AND COMMUNITY-BASED PROGRAMMING DURING COVID-19

Finding Resilience in Crisis

COVID Chronicles

Focus on the Why, by Michele Allgood, Owner/Director, Gracious Living Adult Day and Health Care Center

During the COVID-19 pandemic, I felt it was important for me to remain focused on our mission, which is to ensure that participants' and their families' needs continued to be met. For those that were able to come, wanted to come, needed to come, we would be there. We would ensure there were "safe distances" in place and not "social distancing." "Safe distances" included the safety of cleaning tables, washing hands, and fogging the center with disinfectant. "Social distancing" would have meant that our participants would miss encouragement, cognitive stimulation, and the love that they receive from each other.

I will always remember the strangeness of Monday, 16 March 2020. I hung up the phone after speaking with a director from another adult day and healthcare center in Matthews, North Carolina. We shared the news of all other adult day and healthcare centers in Mecklenburg County closing. During the conversation, I revealed that I didn't feel it was necessary to close our doors, but that our enrollment might fluctuate. I prayed for guidance, and the only concrete message that I received was that I could not serve God's people in my living room, so I would need to keep the doors open.

That same day, I began receiving calls from families and social workers of the participants currently enrolled in the adult day and healthcare centers that abruptly closed their doors. I could hear their angst as they were scrambling to find a center to care for their loved ones while they worked. Many of the families that were served through these adult day and health care centers were frontline workers earning minimum wages that were vital to maintain their homes. I invited them to visit and tour the center. I still have them enrolled in our center to date.

On the next day, I met with my staff members and explained the current climate that we were in. I also noted that while some things would change, many would not. We would continue to use the same universal precautions we had always used. You cannot always look at someone and see with the human eye who has a communicable disease. We had been fighting communicable diseases each and every day prior to the pandemic, and we would approach COVID-19 with the same commonsense protocols that we used to approach rotavirus, hepatitis, and the many other viral strains that we come into contact with in a congregate setting: clean, and clean more.

During this pandemic we felt like we were left on an island, alone. We were given little to no guidance, which, in our case, was probably a good thing, since we were the only adult day and healthcare center that chose to stay open throughout this pandemic. If we had been given direction, it probably would have leaned toward the masses and required Gracious Living Adult Day and Healthcare Center to close. North Carolina Department of Health and Human Services and Mecklenburg County Adult Services allowed adult day and healthcare centers in Mecklenburg County to close their doors and, if they agreed to contact participants via the phone, be paid at the regular, very low reimbursement rate we received as the lone open facility.

Yes, we were alone. I felt let down by the other adult day care owners since prior to COVID we were requesting an increase in our fifteen-year-old stagnant reimbursement rate of forty dollars by Mecklenburg County. We were reminding Mecklenburg County of the invaluable services that we provide to the families we serve; however, when the other centers pulled those invaluable services from the community abruptly, their reasons for an increase appeared disingenuous.

In September 2020, seven months in, Mecklenburg County remembered that some of my population existed. They supplied our participants who were Home and Community Care Block Grant[1] funded with twenty pairs of gloves, masks, and a small bottle of sanitizer. The other participants of the center received one cloth mask after the distribution to the block grant recipients. My workers were not provided any appreciation bonuses or even a simple "thank you" from the county even though they were frontline workers who understood their assignment and showed up to work to serve the participants who so desperately needed them.

Staffing during this pandemic was very "different." Twelve of the fifteen staff members understood that they needed to be committed to the participants and show up to serve them at "the best place for their best days." One staff member called out Tuesday morning, citing that her back was hurting. The next week, she said she was "scared" to return, and

then it was her "husband would not let her return." There was an endless string of excuses, and then she just stopped calling. I received papers from the Unemployment Security office stating that she had applied for unemployment. I requested a hearing. The hearing officer advised that there was COVID-19 funding that would take care of the employee's unemployment and our company would not be charged. I told the hearing officer that I wanted to continue with the hearing because we will all end up like the mouse that finally figures out where the cheese comes from; it appears free until you hear the "snap." She laughed and scheduled the hearing.

During the hearing, the employee cited her reason for not returning to work was that she did not have PPE available to her. I showed invoices and documented the supply of PPE that we had prior to COVID-19. Cintas was my supplier of gloves, masks, and sanitizer. I informed the hearing officer that we did not close at any time during the pandemic and the worker could return to work because we certainly had participants to be cared for. Her unemployment was denied.

We have communicated with our participants and families throughout the pandemic. The following excerpt is from an update we sent to participants' family members on 28 January 2021 when we were trying to get vaccinations for our participants and staff:

> Continue to pray for the hedge of protection Gracious Living Adult Day and Health Care Center has enjoyed throughout this pandemic. We have had four participant COVID-19 exposures (negative results), three staff exposures (negative results) with one actual case (participant not in the center). We truly thank all of our participant families for ensuring that we are kept abreast of any COVID-19 exposures, securing COVID-19 testing, providing their subsequent results, and removing their loved ones from attendance at Gracious Living for quarantines. We are only as safe as our families assist us in being. Thank you, thank you, and thank you!!

The COVID-19 pandemic spotlighted the importance of staffing, cleanliness, and proactively fighting *all* communicable diseases. We must be vigilant about not only what we do but why we do what we do. In the long-term care arena, the "why" should always be those we serve, including their families. We must not make hasty decisions without weighing the consequences of those decisions. Adult day and healthcare centers closed their doors, leaving a vulnerable, needy population to fend for themselves and a blanket of shame should be felt by those making that decision. We do not want any of our participants plagued with a commu-

Illustration 3.1. "Safe distancing" during the pandemic. Photo credit: Michele D. Allgood, program director of Gracious Living Adult Day and Health Care Center Corporation.

nicable disease, but we also do not want the social isolation, sedentary habits, and lack of routine to plummet them into a downward cognitive and physical slide.

Kellin Smith has worked in public transit for a county in central North Carolina for over twenty years. When the pandemic hit, he was working as a bus driver for older and disabled adults who needed assistance accessing services such as medical appointments and therapies as well as transportation to senior centers and congregate meal programs. Kellin is not someone we necessarily think of as a frontline, essential care provider. His role was clearly essential when he was quickly reassigned to deliver frozen meals to senior center clients who previously ate meals at congregate sites but now were isolated in their own homes. In his narrative, it became clear that his role expanded beyond ensuring the basic physical needs of his clients were met, to also creating social connection during long periods of isolation while many home and community-based programs were closed or limited.

Kellin discussed his experiences in vivid detail, describing his efforts to provide support as he delivered meals to the clients who he regularly drove to nutrition sites pre-COVID:

> So we have to not only make sure that it's safe for us, we have to make sure that they're safe also, so we usually make sure that we see their face. We leave their box inside their door, and then we go on to the next one, but I think it's kind of a habit that we know the ones that we don't see, that don't receive the meals, and we stop by, and if [someone] would tell us that such and such stays here, we stopped by just to check on them and make sure that they were

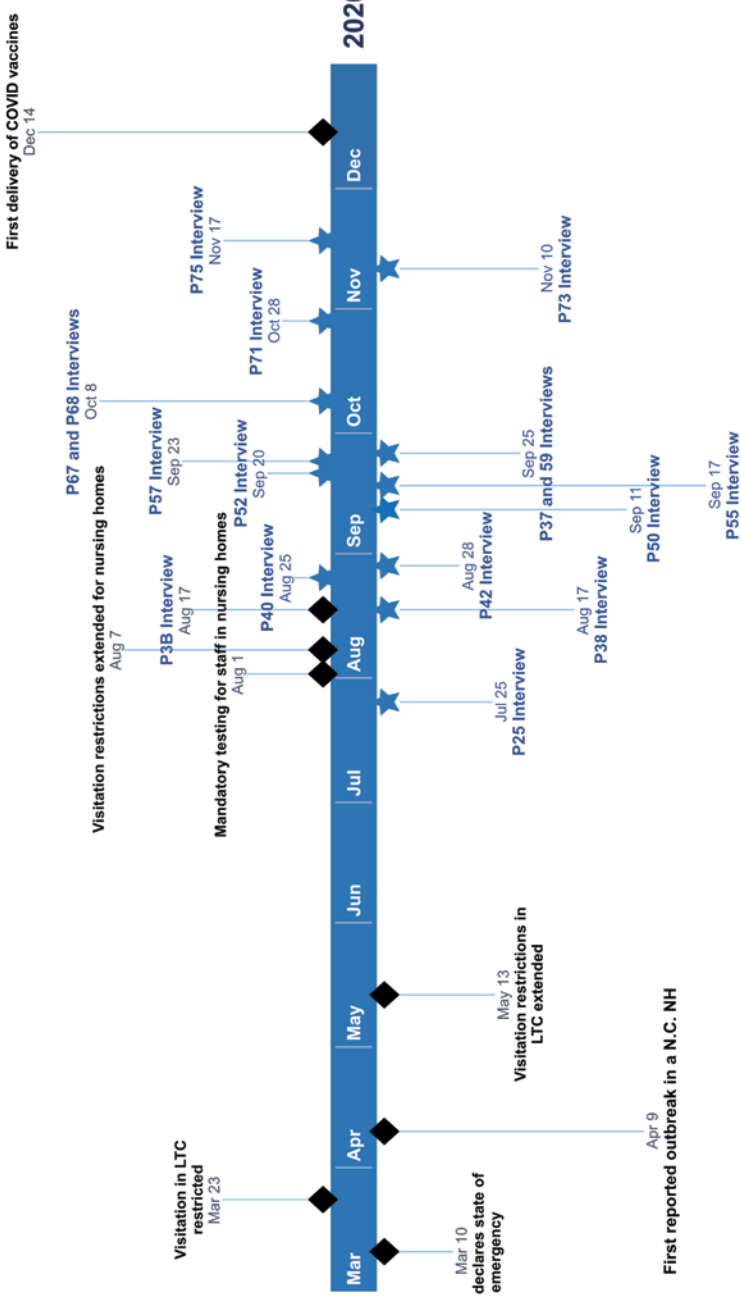

Figure 3.1. Timeline of Interviews Quoted in Chapter 3.

> doing okay, because to me, right now, they're closed up to the partners and not going out at all. So we just checked on them and made sure that they were doing okay, and I think seeing each other's face kinda helped them not only help us, but it also helped them to be able to see your smile and face, to be able to have someone to say, "How you doing?" . . . Basically, we have a route pretty much every day that we would run and making sure that they get in their nutrition also. So it was kind of a good thing, but we still got to kind of see how people were doing that we work with every day. So not only was it a smile on their face, it was a smile on ours . . . Now that they're doing okay. (P68)

Kellin was willing to accept unknown risks because of his dedication to serving clients he knew needed support and services, but also because he was able to gather knowledge in order to protect himself and the clients. He explained, "Information, I think, is one of the keys" to providing ongoing effective care to older Americans. In addition to using a mask and shield and ensuring social distancing, Kellin also sanitized the bus between each client. In what has become a familiar theme, Kellin and his colleagues were "building the plane while flying it."

This chapter focuses on the importance and challenges of clear communication, flexible human infrastructure, and the creativity and resilience of staff who support older Americans living in the community. The ongoing provision of supportive services was crucial to older adults living in their own homes throughout the pandemic and these issues are particularly visible in Kellin's story. The clients were relieved to see a familiar face during a time of isolation and potential loneliness. Due to his relationships with them pre-COVID, he was able to engage them in conversations that led to identifying additional services they needed and also alerted him to other people in need of similar services who had been missed.

Aging in Place

As discussed previously, while COVID-19 has centered attention on older adults living in residential long-term care, in fact the majority of older adults remain "aging in place" in their own homes within the community. We know that ideally, long-term care should be provided in the setting preferred by individuals and their families, and many people prefer to remain in their own homes. Meeting their long-term care needs while supporting older adults in the community requires a range of services, and these are not adequately available. A key principle of long-term care is that it should be delivered in a setting consistent with the preferences of the individual and their family members, and a large majority of long-term care recipients

want care in the home and the community (Grabowski 2021). There has been significant attention focused on encouraging more "aging in place" because it has been shown to prevent much of the depression and helplessness associated with congregate living and results in a higher quality of life and more independence for older Americans (Iecovich 2014).

To sustain older adults in the community, a panoply of services is required ranging from food delivery, management of medicine and special medical equipment, in-home aides, home health aides, and transportation services to adult day care programs, and senior centers (Buch 2018; Iecovich 2014). One creative option is the village model through which members living in their homes can choose from the following services: transportation, minor home repairs, fun and interesting activities, "stay in touch" calls, computer assistance, and various other day-to-day needs with the use of vetted volunteers and a recommended service provider list. Unfortunately, these services and innovative models are largely underfunded, fragmented, understaffed, and unable to meet the level of community demand (Iecovich 2014). While home care workers are the fastest growing workforce in the country (Poo and Conrad 2015), the challenges are similar to those we have discussed for direct care workers in general. "The current situation of the eldercare workforce—low wages, long hours, inadequate training and little chance for career advancement—has led to high turnover in the industry and a resultant low quality of care for people who need it" (Poo and Conrad 2015, 89).

Most older people would choose to avoid residential long-term care. However, home and community-based service options are available primarily to those who can afford to pay for them or are eligible through Medicaid. Medicare funds medical care for older adults, but only pays for hospitalizations, physicians' visits, and short-term rehabilitation following a three-night hospital stay. For a period beginning in the 1980s, Medicare paid for personal care, or help with dressing, cleaning, and feeding (Boris and Klein 2012). The services were so popular, however, that Medicare costs rose and the home care program was discontinued in 1997 (Buhler-Wilkinson 2001). The only home care Medicare provides is skilled, intermittent care and occupational and physical therapy, not personal care such as bathing, dressing, or companionship. Medicaid, the major funding source for the medical care of the poor and disabled, does pay for skilled nursing care (e.g., wound or catheter care) and personal care services at home for those who are eligible. To qualify for Medicaid, older adults need to meet medical and financial requirements, including having few assets, such as a house or savings, making Medicaid a last resort for many people (Coe 2019). As a result, one-third of home care services are purchased directly by individuals, and elder care falls mainly to family caregivers (Buhler-Wilkinson

2001). Furthermore, Medicare and Medicaid have not kept pace with the development of a range of services that create care options beyond nursing care (Institute of Medicine 2008). Home care services are also purchased through long-term care insurance or private savings, but more effective systems could be made available utilizing the aging network, as Polivka explains:

> Over 30 years of experience and research findings have demonstrated that the non-profit Aging Network (developed under the Older Americans Act), with its service delivery and case management capacities and comparatively low costs, could build and administer the infrastructure for home and community-based programs and create well balanced long-term care systems much less dependent on expensive home care. These capacities, which were built over a 30-year period and largely funded through Medicaid waivers, are amply documented in comprehensive and comparative analyses of state long-term care systems conducted by AARP between 2011 and 2017 (Reinhard et al. 2017). (Polivka 2020a)

The data presented in this chapter contribute to arguments of the relative value and overall benefit of home and community-based programs, especially in relation to residential long-term care during a pandemic. During the COVID-19 pandemic, home and community-based programs were able to pivot creatively in an effort to serve the needs of their clients, including ensuring their sustained nutrition, some socialization, and maintaining the safety of both clients and frontline providers. We also report on the challenges they faced, including accessing and using technology, maintaining regular access to PPE, and overcoming personnel issues such as risk mitigation and flexible scheduling for those who found themselves with new childcare responsibilities. The sustained nature of the pandemic also exacerbated the loneliness and isolation of clients that home and community-based providers attempted to address. Despite these challenges, we argue that home and community-based providers were able to effectively serve their clients with a lower risk of COVID-19 infection compared to residential long-term care. The community-based providers, while they faced challenges and had to be flexible, were less traumatized than the workers in residential long-term care. While they were affected by staffing challenges, they talked about feeling safe and well supported by their supervisors.

Home and Community-Based Services Participants

Phase 3 of the research presented in this book focused on home and community-based care workers who provide services and assistance to

older adults living in the community, including managers and staff providing information and referral, staffing adult day care programs, providing home care and home health care, distributing home-delivered meals, running senior centers, and providing transportation and some specialized medical care. We interviewed thirty-two participants in this phase, with the first interview taking place on 26 July 2020 and the last interview on 28 July 2021 (see table 3.1). The length of these interviews ranged from twenty minutes to one hour and twenty-five minutes, with a total of thirty hours of recorded interviews.

Table 3.1. Phase 3 Participants (Home and Community-Based Providers).

Position	# of Participants
Area Agency on Aging Program Coordinator/Aging Specialist	2
County Aging Program Manager (including nutrition and transportation)	2
County Social Worker	3
Certified Dementia Practitioner	1
Dementia Medical Provider: Executive Director and Physician Assistant	2
PACE—Outreach and Enrollment (Program of All Inclusive Care for the Elderly)	1
Director—Community-Based Services Network	1
Community Director of Senior Programs	1
Adult Day Care and Health Director	4
Adult Day Care and Health CNA	2
Senior Center Director	3
Senior Center Program Specialist	1
Senior Center Recreational Coordinator	1
Home Care and Home Health Community Outreach Director	3
Home Care and Home Health Consultant	1
Home Care and Home Health Aide	1
Home-Delivered Meals Provider	1
Senior Transportation bus driver	2
Total Participants	**32**

Pivoting in Response to COVID

Most community-based programs were shut down in mid-March 2020 in an effort to manage infection control and avoid the spread of COVID-19. Managers of these programs quickly pivoted to communicate with clients and coordinate with other service providers to ensure clients' basic needs were met. They struggled to keep up with evolving guidelines while facing challenges in regard to sustaining infection control, managing logistics, and accessing and using technology to maintain communication. At the same time, staff were experiencing personal challenges related to risk of infection and their own family responsibilities. Managers demonstrated a flexible understanding of human infrastructure and worked with staff to support sustainable solutions. They also displayed personal resilience in order to ensure the continuation of essential resources and services to clients.

Staff of many of these community-based programs pivoted immediately to contacting participants by telephone to determine their urgent needs and provide emotional support. They were able to assess clients' needs or provide companionship to those older adults now facing isolation at home, even though initially programming was limited. Some staff were reassigned, as one program coordinator shared: "My understanding is many of the staff were actually pulled over to help out with day care for emergency responders', first responders' children and things like that. So because they're under that Parks and Rec feed or umbrella, they've been pulled over into some of that kind of county response" (P3B).

A significant challenge was addressing the needs of the many older adults who typically relied on receiving meals at the adult day care and day health programs and senior centers. These services were suspended as most of these centers were temporarily closed. One senior center recreation specialist explained: "Some of them did need food, actually, because the senior center sometimes, for some of them, was their only meal, 'cause we give them that main meal, and some of them got bread and coffee in the morning" (P55). Mindful of the urgency of meeting the nutritional needs of clients and community residents, these workers coordinated with area nutrition services and food banks to seamlessly implement home meal deliveries. A senior center director shared:

> If you require meals, then what we do is we will get your name and phone number and get them to DSS [Department of Social Services], and then they will provide you with meals. Right now, DSS is doing seventeen hundred meals delivered. And what they do is a ten-day supply, and they [the meals] come just like a little tray like you used to get on the plane. They're frozen and

> all you have to do is put it in your microwave and heat it up, and then you have meals for ten days. You get meals, milk, you get bread. (P50)

Rising to the challenge of adding more than five hundred fifty people to their home-delivered meals roster, the county nutrition services stood out as exemplary in the earliest days of the pandemic (see chapter 6 for more details). They pivoted quickly and efficiently, as one nutrition program manager discussed: "I remember this was a Friday and the challenge for us was . . . how to integrate with the already existing home-delivered operation, . . . remember with the same number of vehicles . . . and drivers. So we really had to start strategically like thinking, . . . how we're gonna start deliveries on Monday for more than sixteen hundred people instead of eleven hundred" (P42). They brought in a team of drivers who usually drove people to medical appointments pre-COVID and had access to one additional refrigerated truck. The county also continued transportation for medical appointments, following changing guidelines throughout the pandemic, and one van driver expressed their appreciation for the safety precautions their leadership took:

> So I think in the time when it all first hit, everything was kind of up in the air, nobody really knew what to do, anybody, but then they got the information that you needed and they started working on it as quickly as possible to make sure we had what we needed. So, of course, we all still felt nervous and scared and had no idea, but I think they did a pretty good job in getting us what we needed and getting us. . . keeping us safe. Helping us stay safe. (P67)

Many community-based program staff continued regular telephone contact with clients and some developed online programming for those now isolated at home with little contact with family or friends. One senior center director explained their pivot to making wellness calls and developing creative solutions such as developing tailored exercise plans for their clients to do in the safety of their own homes.

One adult day care and day health program stayed open throughout the pandemic, with twenty-five to thirty participants coming each day. (See the essay at the beginning of this chapter.) The program director explained: "For family and participants who needed us, we were going to remain open for them." They used a fogger with a disinfectant that is effective against COVID, partitions, and physical or safe distancing, believing that "those that needed to come, needed to come" (P49). Note the use of the terms "physical distancing" or "safe distancing" rather than the more commonly used term "social distancing." Several research participants stressed the need for physical safety within a framework that ensured social interaction

and engagement, noting that the term "social distancing" was actually not accurate.

Home care agency staff, who provide care to clients in the clients' homes, faced different challenges. One director of outreach and enrollment stated:

> Our owner was very hands on deck as soon as COVID hit. [They] and our nurse were very at the frontline with our caregivers, supporting them. We had our client care coordinators on the frontline as well. We were constantly providing gloves, sanitizer bottles, masks. We still are providing them for them to come and collect those supplies from the office, so I would definitely say it's been a joint effort. (P25)

Home care agencies that relied on in-person assessments of potential new clients quickly adapted new means of assessing and enrolling clients via online meeting tools and then mailing or emailing enrollment forms. This was effective but created a lag before home care services could begin for the newly enrolled older adults seeking assistance. Another director of community outreach attributed her agency's successful pivot to a joint leadership effort in making the safety of staff and clients their top priority.

Mitigating staff fears related to COVID-19 infection and employment status became an integral consideration for those in leadership roles (see chapter 6). One CNA discussed the importance of continued communication from leadership during the closing of the adult day care program where she works:

> As we were closed, leadership or administration stayed in touch with us, occasionally sent everybody out, maybe a continuing ed kind of package to do, or videos, just to do something, which was good. And then we had a meeting on-site a few days before we opened back up. We all sort of went through and hashed through everything, and it was a little bit of getting used to the new routine. (P71)

Challenges: Technology, Infection Control, Personnel

The initial onslaught of COVID-19 brought about logistic challenges for owners, directors, and frontline workers caring for older adults in the home and community-based sector as they scrambled to make decisions about whether to remain open and how to continue to provide care and support, how to obtain funding to support their efforts or in the event of closure, and how to support and retain staff. Additionally, infection control guidelines and mandates were rapidly evolving and posed a major challenge to administrators, staff, and clients. Forced to decipher information about COVID-19

and discern how to best implement and comply with safety measures in a sea of mixed messaging, caregivers rose valiantly to this challenge. These challenges alone would seem insurmountable to many, and then personal issues layered into this mix, making the resiliency and determination to serve older adults in the face of such hardship heroic and worth closer examination.

Technology

Beyond the use of telephone calls to assess the needs of clients and provide support, technology offered innovative ways to offer services to older adults who were quarantined in their homes during the periods of time when most adult day care programs and senior centers were physically shut down or offering minimal programming. Acknowledging the need for activities and a sense of community, many program directors and caregivers turned to virtual programming to provide these critical components to their clients. One executive director of a community-based services network told us, for example, about the challenges of involving participants in virtual activities:

> Well, it's not as much as the in person, and I think a lot of that stems from the technological aspect of it. Some folks just have trouble with Zoom calls and Google Meet, so it's been down a little bit, but we're still carrying on trying to offer that. . . . We've done virtual game days where we'll get a group together and then one of our volunteers administrate that and will either play online *Jeopardy!* or some sort of a puzzle game or whatever, just to try keep to that going. (P37)

While several participants discussed adding some virtual programming during their closures from March to July 2020, one community center stood out in their ability to quickly transition the majority of their services to an online format. Factoring into their successful pivot was the immediate needs assessment conducted to determine what types of programming each participant was interested in continuing during the pandemic, whether they had access to the technology required for virtual programming, and whether they had assistance from friends or family members if needed to set up and begin these online activities. The center director explained:

> After a few weeks, when it became apparent we weren't going to be opening up any time soon, we went back and started polling the participants. Do you have a computer, do you have an iPad, a cell phone, a flip phone? Do you use the internet? Do you use Zoom? Do you use FaceTime? What do you use, and then are you interested in using Zoom if somebody teaches you? And once

> we did that, we started getting people onboarding to Zoom. I reached out to the children of a lot of these people and said, "We need your help." Once we had a core group, we set up a Zoom test, and we had a full screen and it was so cool. (P52)

The challenge of implementing technology-based programming varied greatly, depending on the clients' access to cell phones, tablets, computers, and internet, as well as their comfort level and technology skills.

Infection Control and PPE

Especially early in the pandemic, it was a challenge to get accurate information. The director of a nonmedical home care agency who also worked as a caregiver during staffing shortages related to COVID-19 succinctly expressed the need for appropriate communication and information surrounding basic infection control measures in order to make in-home caregivers feel safe enough to return to providing in-home care: "I practice safe procedures and all of that, and I'm okay with going to a client I already knew and I'm ready to start up, back up with them. So, again, it was checking in with all of our caregivers, even the ones that were not ready to come back and get back out into the workforce" (P73).

Even when information was provided by infection control nurses following CDC guidance, surges in demands and prices for basic items needed to ensure proper infection control created a challenge. A co-owner of a medical home care agency talked about the initial efforts to secure PPE for the home caregivers: "And even that was a struggle because everybody was running out so fast, and all the prices rose to where you really was like, 'Okay, am I gonna pay twelve to twenty dollars for this box of gloves that used to be four to five dollars?' So it was crazy, it was crazy. And it kind of still is, 'cause it's still a little scarce on those PPE supplies" (P75).

Personal Challenges of Staff

In addition to the logistic and infection control challenges, caregivers deal with personal issues that affect their physical and mental well-being, and in some instances their ability to perform the duties required of them. For example, discussing challenges associated with school closures as a result of COVID-19, one program manager pointed out that in-home aides are largely women who were now responsible for caring for their own children who were no longer going to school each day. She explained, "And then there was the impact where the workforce that worked for the home agencies, these working, largely working women, have their children now

at home and not in school, that they weren't able to work, or they were concerned about COVID" (P40). Even when caregivers found ways to continue working, the additional responsibilities for children added stressors associated with online learning and providing the structure their children needed. Multiple participants who were coming to grips with their own isolation and fears surrounding the pandemic, discussed anxiety and depression. One participant said, "It really is an isolating experience," and "this is your world basically right now" (P40).

Kellin Smith, who we heard from at the beginning of this chapter, expressed the motivations shared by several participants about why they continued to show up each day despite the personal challenges they faced on top of the challenges waiting for them once they got to work. He shared his desire to be there for his clients and community and be able to support his family by remaining employed: "I was gonna be one of the ones that was able to still come and perform my job to the safest . . . to my ability that I could. We can continue to do our job because when I see it, I see that they depend on us. Then we turn it around, we depended on them too" (P68).

Challenges Related to the Ongoing Nature of the Pandemic: Isolation

As the pandemic continued, physical and mental decline of clients, in addition to the loneliness that many were experiencing during the ongoing isolation, became a frequently expressed concern. A community coordinator of senior services described:

> Just the pure isolation that it caused, you could hear it in their voices, especially the ones who were used to coming to the senior center often two or three times a week. . . With all of that socialization, all of those friends, it was really, really hard. At the beginning, they didn't mind it 'cause they were so fearful, then they began to realize what a hole it left in them to not have those contacts with those people. . . . Hugs are freely given [at the center]. So they miss those. . . it became evident soon that social isolation, as well as the emergency needs, were gonna be key in our calls every time. (P57)

The ongoing isolation brought on by the pandemic and closures of senior centers as well as adult day and health care centers produced devastating effects and what have come to be called the non-COVID deaths from COVID-19 (see Shenk and Freidus 2020). Caregivers spoke of deaths of older adults that they attributed to COVID-19 even when the person had not contracted the virus. For one manager, the isolation that she knew her clients were experiencing motivated her to continue to show up and do her job and be available for the older adults needing the services and human connection that she and her staff could provide.

> Well, what is the message here? And there's so much sadness right now and isolation, and how has that really impacted a lot of people, but then we're also thinking, "Well, okay, what can I think from a more positive side of it?" . . . So it kinda helps keep me a bit motivated, reminds me why I'm here. I have to remind myself, I have to tell myself, "I'm not here just for my kids and bringing food home to the table, but there are people that really have a need for us, and there's a reason why our program exists to serve in your community." (P59)

We will consider these issues and effects of social isolation and loneliness further in chapter 4.

Discussion

While the issues present differently for home and community-based providers, there is overlap in some of the issues compared to those identified for residential long-term care. Initially, in both models of care, workers struggled to procure the necessary PPE and also reported challenges navigating rapidly changing knowledge about the virus and its transmission as well as the evolving policy recommendations. Pivoting to new forms of service delivery and efforts to engage yet physically protect clients and residents was difficult yet not insurmountable for those providing support through home and community-based services. When assessing what factored into successful pivots and creative solutions, the theme of leadership emerged. Leadership sometimes was identified in the typical top-down form, but was also seen in the creative decision-making of those who felt personally responsible for the older adults for whom they care. Those caregivers who were able to smoothly navigate the challenges of COVID-19 frequently mentioned having supportive supervisors and administrators and particularly good communication within their agency or program.

Key differences emerged in the narratives of home and community-based care providers compared to those in congregate long-term care. Upon reflection, the workers who served home and community-based clients did not report the same levels of trauma as those in residential long-term care who experienced the direct loss of residents and bore witness to the everyday suffering older Americans experienced that were associated with long-term isolation and loneliness (see chapters 2 and 4). Providers also watched as residents were not afforded agency in nearly all aspects of their lives as residential communities were shuttered and most residents were forced to isolate in their rooms for some extended period of time during the pandemic (see chapters 2 and 4). Conversely, clients who remained in their homes (along with their family members as decision-makers in many

cases) were allotted agency to determine whether or not workers could come into their home and how/if they would receive services (e.g., food delivery or online activities). While many senior centers remained closed throughout the pandemic, adult day and healthcare programs opened expeditiously and implemented policies meant to safeguard clients. Families and attendees had power to decide when they felt it was safe to resume participation. Overall, as suggested by the findings in this chapter, home and community-based staff had more agency and flexibility in regard to pivoting and providing services.

The COVID-19 pandemic made visible long-standing structural concerns regarding ageism and care for older Americans. Chapter 2 demonstrates the devastation the virus inflicted on residential care communities. Residential long-term care has historically been criticized for focusing more on the physical needs of residents and less on their social and emotional well-being. Strides have been made in shifting to person-centered care, but the limitations of this evolution became evident when the pandemic caused a reversion to focusing on protecting the physical body, almost exclusively, to the detriment of many residents. This experience was traumatizing to care providers. In contrast, home and community-based staff had a very different experience, as did the clients in their care. While home and community-based clients did experience isolation and loneliness, they were afforded more agency and a wider range of options regarding engagement and the procurement of services, including nutrition. Most people would rather live in their own homes because of the freedoms it affords them, and during the pandemic it seemed a safer environment, suggesting another reason this alternative should be an available option for people in need of long-term care.

Notes

1. In North Carolina, Home and Community Care Block Grant funding is the system for distributing federal funds for community-based services from the state to the county level. It is intended to promote the visibility of aging programs at the local level by giving counties increased flexibility with respect to funding aging services through the Home and Community Care Block Grant.