

Caregivers—Essential, Frontline, Paid, and Unpaid: Exploring the Differences, Similarities, and Needs of This Important Sector of Community Care

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Prior to the COVID-19 pandemic, paid and unpaid caregivers had one thing in common: they were both relatively invisible. Almost overnight, frontline workers, including those engaged in direct caregiving, were lifted up as our nation's "heroes." But the questions still remain—who are they, and what do they need?

Introduction

Rosalynn Carter, former First Lady of the United States and founder of the Rosalynn Carter Institute for Caregivers, captures it best in one quote: "There are only four kinds of people in the world—those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers" [1].

The Frontline Health Workers Coalition defines frontline health care workers as those who provide services directly to communities, including nurses, midwives, community health workers, physicians, and others [2]. The term "essential workers" began appearing in headlines in 2020 because many types of employees, not necessarily all medical, were "essential" to the operation of business and industry critical to our country's infrastructure during a time of crisis. These same "frontline essential" employees were prioritized to receive the COVID vaccine in early 2021. The result is that the terms "essential" and "frontline" are often used interchangeably, creating confusion.

Direct care workers, a subset of frontline workers who provide hands-on care, often do so in concert with other frontline health care workers in similar settings. They too began being recognized as "essential" during the pandemic, also contributing to confusion. These often-unsung heroes deliver services to vulnerable people with dignity, grace, and care, but for compensation that is much more limited than what other frontline workers receive. These employees work every day with children, adults, and families to offer essential support such as bathing, dressing, feeding, and personal care. The average hourly wage for a direct care worker in the United States is \$13 as of May 27, 2021 (\$11.44 per hour in North Carolina as of 2020) [3]. Hourly pay rates can

vary widely depending on many important factors, such as experience and education, including specific certifications [4]. This type of work is both physically and emotionally strenuous.

The largest group of caregivers—those who provide essential and often unrecognized care—are known as "informal" caregivers. These daughters and sons, wives and husbands, neighbors and friends provide personal care needs as well as medical/nursing tasks like medication management and wound care, primarily to older relatives, with little or no formal training or compensation. The pandemic further isolated these caregivers and their care recipients. More adults than ever before found themselves becoming caregivers for older loved ones who were too terrified to leave their homes. The pandemic also exacerbated many common problems for unpaid family caregivers, many of whom are older adults themselves. These problems include increased stress, anxiety, and depression, as well as out-of-pocket expense. The average annual amount caregivers spend on caregiving is \$7242, which is estimated to be about 26% of their income [5].

These distinct types of caregivers have different titles and terms but all have the common thread of providing personal care. So, coming out of the COVID-19 pandemic, what will we have learned and what do we need to change?

A Clearer Awareness That All Caregiving is Essential

As Winston Churchill was working to form the United Nations after WWII, he famously said, "Never let a good crisis go to waste." One of the benefits of the COVID-19 pandemic is a great appreciation and awareness of the importance of caregivers, paid or not, for anyone regardless of age, illness, or disability. We now have a better under-

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standing of how caregivers provide a variety of therapeutic support services that are vital to helping people live with dignity and maximum independence. This includes those living at home in the community and those living within long-term care and treatment facilities. Providers of these essential services cannot retain nor attract qualified workers

when Walmart, Target, or Starbucks pays more [6]. Many providers are already struggling to fill positions and retain staff, which is even more difficult given that an estimated 53% of direct care workers live in or near poverty [7].

Similarly, all employers must look at their workforce needs differently. Following the literal shutdown of a nation

and a world, countless full-time employees found themselves working productively from home. This newfound flexibility allowed unpaid caregivers the opportunity to provide care and earn a living at the same time. The Society for Human Resource Management suggests employers conduct a COVID-19 Employee Child Care/Caregiving Needs Survey to determine the needs of their staff [8]. Increased flexibility must become standard for our workforce because the

next crisis is within sight—the dramatic increase in the older adult population.

The backbone of long-term care is provided in communities by unpaid loved ones and friends. As of June 2020, AARP estimates that there are 53 million unpaid caregivers in the United States—that is more than 1 in 5 adults [9]. North Carolina's aging population is rapidly growing; about 1 in 5 of our citizens will be over the age of 65 by 2030. To

offer clearer perspective, it is estimated that in 15 years our state will have more people over age 65 than under age 18 [9]. As our citizens age, we know many will require support to meet their daily needs in private homes, nursing homes, assisted living, and a variety of residential care settings.

A New Norm Requires New Responses

There are at least three challenges related to caregiving that need to be addressed or are currently being addressed through public policy and reform of employer policies.

Broadband

In-person medical appointments ceased immediately when the pandemic began, forcing frontline health care workers to care for most patients through telehealth. Stable broadband became essential for both patient and doctor [10]. Governors across the country began pumping millions of dollars into broadband infrastructure in early 2020 [11]. Likewise, the US Congress passed the American Rescue Plan Act that included a \$7 billion allocation to improve internet access. Providing reliable broadband and closing gaps in service areas continues to be a priority for most states [12, 13]. In August 2020, North Carolina Governor Roy Cooper announced a more than \$12 million expansion of internet access to 11 rural communities, but there is much more to be done [14].

Direct Care Wages

AARP North Carolina is collaborating with a diverse group of stakeholders, including for-profit providers, nonprofit organizations, and advocacy organizations, to seek solutions to critical caregiver workforce issues like recruitment, training, and retention. Low wages for Medicaid-funded staff are the result of low rates of reimbursement for Medicaid services. There has been little to no increase in these rates over the last decade. NC House Bill 914: Support Our Direct Care Workforce, if passed by the North Carolina General Assembly, would significantly increase Medicaid reimbursement rates and require providers to pay a living wage [15]. This bill has bipartisan support and is an important step forward in helping to support our state's direct care workforce while elevating these jobs in the direction of an attractive and meaningful career.

Support Unpaid Caregivers

As the largest cohort of care providers, unpaid caregivers need a multipronged approach to solutions at the local, state, and federal levels.

RAISE Family Caregiver Advisory Council. This council was formed in January 2018 as part of the RAISE Family Caregivers Act. The council is poised to deliver its report commendations to Congress in 2021. The report includes five goals with 26 recommendations promoting person-centeredness, financial support, care transitions, respite care, innovation/sustainability, and formalizing caregiver assessments [16].

Biden proposal. In March 2021, the Biden Administration proposed a \$400 billion plan designed to significantly bolster Medicaid coverage of long-term care outside of institutional settings to support caregivers and expand access to home-based care [17]. Depending on the negotiations with Congress and the recommendations made by RAISE, the level of support for unpaid caregivers could dramatically change for the better.

Employers. Overall, there appear to be three clear paths for employers: 1) allow schedule flexibility; 2) allow location flexibility; and 3) allow employees to temporarily reduce their workload [18]. Additional low-cost initiatives employers can embrace include organizing an employee affinity group for caregivers and providing connection to supportive services and care management. Employers can also train managers to be the first line of support and create a family-centered work culture. Human resources materials should also be thoroughly reviewed and updated to reflect this culture.

Unified state caregiver strategy. The National Alliance on Caregiving early in 2021 launched an initiative to create a unified strategy to support family caregivers across the nation. The first element is to "establish and maintain a formally recognized task force of family caregiver stakeholders" in each state [19]. Additionally, the North Carolina Institute of Medicine published "Improving Serious Illness Care in North Carolina" in June 2020. As part of this report, Recommendation 4.12 states as a priority: "Establish [a] Task Force on Caregiving for Those with Serious Illness and analyze additional legislative solutions and financing options to meet the needs of caregivers" [20]. As of this writing, the Task Force on Serious Illness Care is evaluating the best steps toward creating a Caregiver Task Force with either the North Carolina General Assembly or the North Carolina Department of Health and Human Services.

Conclusion

Care for those with serious illness, disability, or advanced age is an everyone issue. It affects all of us personally. The COVID-19 pandemic heightened the awareness of the critical role caregivers, both paid and unpaid, play in our health care system [21]. The question remains: will the efforts listed here be enough to address the challenges currently facing our caregivers, regardless of who they are? **NCMJ**

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