The Future of Long-term Services and Supports in the United States

By Robyn I. Stone

t is widely accepted that the long-term service and supports (LTSS) financing and delivery system in the United States is broken. LTSS encompasses a broad range of paid and unpaid health-related and personal care assistance that people may need — for several weeks, months, or years — when they have difficulty completing self-care tasks as a result of chronic illness or disability. LTSS provides assistance with the activities of daily living (such as eating, bathing, and dressing) and the instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping) and is delivered in a range of settings, including nursing homes, assisted-living and other residential care facilities, adult day centers, and private homes.

Despite several attempts at reform over the past 30 years and a growing population of older adults living with multiple chronic health conditions who will need some form of LTSS during their lifetime, a patchwork system has prevailed. The heavy toll of COVID-19 on LTSS has brought the system's failings into clear focus. The population served in LTSS settings is older and medically fragile with multiple chronic conditions; a high proportion live with dementia. Accordingly, these individuals have the highest risk of complications, hospitalization, and death and were disproportionately affected by the pandemic.

COVID-19 has uncovered stark societal inequalities through its disproportionate impact on communities of color and low-income individuals. This impact has fallen on older residents and clients as well as the frontline certified nursing assistants and home health and personal care aides who provide most of the hands-on care in LTSS settings. These direct care providers are typically women who are Black, Indigenous, or other People of Color earning low wages. One in four are foreign born. Nursing home aides earn an average hourly wage of \$13.38, while home health and personal care aides earn even less, an average of \$11.52 per hour. An average of 44 percent live 200 percent below the federal poverty level, and 42 percent receive some type of public assistance. In addition, the evidence suggests that not only do these workers spend more time working including one in six who hold a second job — but they also spend more time on housework, unpaid caregiving, and commuting than do other health

care workers. Given the poor compensation and other job-related and external challenges, it is not surprising that nursing home and home care providers had significant recruitment and retention problems before the pandemic. These challenges have been seriously exacerbated by the pandemic, which finally shed public light on a history of structural racism and inequities in the LTSS system.

The baby boomers are now about to reach the age where the demand for LTSS will increase significantly over the next two decades. It is time to radically reform our financing and delivery system to meet this demand in a timely and equitable fashion. Reform will involve transforming the following three issues.

Creating a Range of Settings and Service Options

We need a range of services and settings that meet the needs and preferences of an increasingly diverse older adult population. Although most people prefer to remain in their own homes, some may not be able to do so because of a constellation of factors, including the costs of maintaining the house, inaccessibility of the home and neighborhood, and the potential for social isolation, particularly for those living alone without family. We need to expand the options of residential settings available to people living in different communities and geographies across the country. These options should be affordable to all, not just reserved for those who have significant resources or who spend all of their savings until they qualify for Medicaid to receive coverage (assuming that a waiver covers the care). These options include developing more high-quality, affordable assisted-living and memory care settings; developing co-housing and other small-group living alternatives; and supporting the expansion of accessory dwelling units where loved ones with LTSS needs can live separately but close by. Nursing homes will always be needed for high-acuity individuals without social supports, but these dwellings need to be reengineered to provide the feeling of home through various household, small group home, and other culture change models.

Communities should also become agefriendly, allowing older adults with LTSS needs — including those living with dementia — to navigate their homes and neighborhoods safely and with the goal of assisting everyone to live as independently as possible in their communities of choice.

Developing a High-quality LTSS Workforce

Family caregivers and other nonpaid care partners will continue to provide the bulk of LTSS in the United States. Formal programs must be designed to support these caregivers as well as those who need LTSS. Unpaid caregivers need adequate training and resources so that they can continue to provide assistance and with limited burnout.

The frontline paid LTSS workforce, which provides 60 to 80 percent of all the paid hands-on care in the LTSS system, needs to be professionalized. This includes providing competency-based training for individuals to work across all LTSS settings as well as wages and compensation that are commensurate with the skills and knowledge this occupation requires. Home care and personal care aides, home health aides, and certified nursing assistants also need to have a variety of career advancement opportunities. Many will prefer to remain as aides but may want to pursue specialties in areas such as dementia care, medication management, behavioral health, and restorative care. Some may be interested in advancing through the nursing ranks, while others may be more interested in relationship occupations including social work, care management, recreation therapy, or human resources.

Professionalizing this workforce will help recruit individuals into this field, but we also need to expand the pipeline by attracting high school students who are pursuing health career tracks, continuing to attract immigrants and refugees into these positions, and engaging older workers who may be looking for second careers or who need to continue to work because of financial circumstances.

Providing Universal Coverage Through Comprehensive Financing Reform

The need for LTSS financing reform resulting from COVID-19's impact on state budgets and

Medicaid is urgent. A social insurance approach to financing LTSS that is based on individual care and support needs and that covers all Americans, regardless of their financial status, is necessary for adequate LTSS coverage. This approach must provide coverage of living needs — and not just the care aspects — of LTSS. This approach would protect against financial catastrophe and end the current system that is based on the need for people to be financially destitute to access coverage via Medicaid. Such an approach would benefit both individuals and families and would also create a far more stable and more generous funding stream to providers.

Universal coverage is essential to achieving greater equity in access and coverage, but it is also essential to the fiscal viability of the financing mechanism (e.g., everyone pays into the system). Although political concerns about a universal and therefore mandatory approach led to a voluntary program in the form of the CLASS Act, the failure to embrace the universal approach undermined the viability of CLASS. Policy makers cannot afford to make this mistake again when addressing LTSS financing reform.

This three-pronged approach to LTSS reform will lead to a more seamless system of care and supports for older adults, their families, and others who need this assistance. The keys to success will be the availability and accessibility of affordable care and support options in a range of settings; a highly qualified, stable workforce to deliver services; and the means to pay for LTSS when it is needed. •



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