

## *Long Term Services and Supports: Why Should I Care?*

Our country lacks a unified and coherent plan to help people live independently. People are living longer, and the growing population, along with rising rates of people with disabilities under 65 will continue to increase the demand for these long-term supports and services (LTSS).<sup>1</sup> The current patchwork system leaves many families impoverished and with few options, and may not adequately provide the care and supports people want and need. Most of us or someone we love will need LTSS at some stage. It's an issue that affects almost everyone, and we will all share the benefits of a solution that allows people to live with dignity, where and how they choose, without facing financial devastation to get the services they need.

### **What do we mean by “long-term services and supports (LTSS)”?**

Long-term services and supports (LTSS) are a broad range of health-related and social services that include assistance with activities of daily living (ADLs), such as bathing, dressing, eating, toileting, money management, house cleaning, medication management, and instrumental activities of daily living (IADLs). In Medicaid managed care, LTSS is the term used to describe services received by persons who have disabilities that impact ADLs or IADLs. In Medicaid managed care, LTSS are provided in one of two primary locations: in the home or in an institutional setting (as defined by the 2013 Home and Community-Based Services (HCBS) Settings Final Rule). Usually, when the services are received in the home, they are referred to as HCBS and when they are received in an institutional setting, they are referred to as long-term care (LTC). Occasionally, LTC may be generally used the same way LTSS is used to refer to both HCBS and institutional settings/services. In the life insurance industry, LTC refers to the financing model or way to pay for the services and supports, or it generally refers to LTC insurance.

*Disability and aging advocates support not using the term LTC and instead support the exclusive use of LTSS.*

### **The current system – how do people in the U.S. pay for LTSS now?**

Our current LTSS system relies almost entirely on Medicaid and unpaid family caregivers. Most LTSS are provided by family members or a mix of family, friends and neighbors, often at both personal and financial sacrifice. According to AARP, family caregivers provide about \$470 billion in unpaid care annually for their loved ones. We have a fragmented system, with uneven access, and increasing costs. Financing for LTSS is split between federal (generally Medicaid)

---

<sup>1</sup> Commission on Long-Term Care. Report to the Congress. Washington, DC: U.S. Senate, 2013, available at: <https://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>, Bipartisan Policy Center, <https://bipartisanpolicy.org/wp-content/uploads/2014/03/BPC-Long-Term-Care-Initiative.pdf> (More than 12 million Americans need long-term services and supports (LTSS), a figure that is expected to increase to 27 million by 2050).

and state government programs (primarily Medicaid), and private sources, which pay the other third of costs.<sup>2</sup>

### **Doesn't private insurance/Medicare/Medicaid pay for these things?**

Private insurance, often provided through an employer or a health insurance marketplace plan, pays for "medical care" like regular visits to your doctor and "acute care" like hospital care, but not LTSS. Disability insurance is designed to replace a portion of the income lost if you're unable to work due to accident or injury. It provides no additional benefits to pay for LTSS.

Health insurance, including Medicare, only covers very limited long-term care. For example, Medicare will pay for up to 100 days of rehabilitation services after an acute care episode for a person who is 65 or older, or a person with a disability who is eligible for Medicare – that's *not* long-term services and supports. Eventually, a person may qualify for the Medicaid program (after they have depleted all of their financial resources). Billions are paid in out-of-pocket expenses at the same time that Americans are making a huge time investment in unpaid care for family members or friends.

Private long-term care insurance may be capped at a specific dollar amount, and may only provide coverage for a limited amount of time. For most Americans, it's not an affordable option. And once you need that level of care, you may not be able to join this type of plan. In addition, long-term care insurance is not well designed to address the needs of working Americans with disabilities.

Private resources (like from a 401k and/or IRA) can be used to fund LTSS, but few people in this country have sufficient financial assets to cover the LTSS they will need.

### **Medicaid**

Medicaid – a federal program in which the costs are shared between the federal government and the states – was designed to provide publicly funded health care for people with a low income. It is the largest payer for LTSS in the U.S. This heavy reliance on Medicaid as the primary funder of LTSS and with a growing need places tremendous strain on the program. And despite the amount of money that state and federal programs already allocate to LTSS, individuals and their families still pay billions of dollars out of pocket for LTSS expenses.

Medicaid requirements vary by state, including the amount and type of income and assets eligibility requirements. Services are also based on "medical necessity," so not all Medicaid-eligible individuals receive LTSS. There's a real need for an integrated delivery system that's portable across states.

### **Institutional bias**

Most people want to live at home and in their community.<sup>3</sup> However, the Medicaid system has built in "institutional bias." Nursing home services are mandatory, with no enrollment limits.

---

<sup>2</sup> See, e.g., Congressional Research Service, "Who Pays for Long-Term Services and Supports?" (2018), available at <https://fas.org/sgp/crs/misc/IF10343.pdf>.

<sup>3</sup> AARP Home and Community Preferences of the 45+ Population 2014 survey, available at <https://www.aarp.org/research/topics/community/info-2018/2018-home-and-community-preference.html>.

Medicaid Home and community-based services are generally provided under a “waiver.” Almost 3 million people receive Medicaid-funded HCBS, a figure that is expected to increase rapidly with the aging of the population and a continued shift away from institutional LTSS.<sup>4</sup> However, many states have long waiting lists for participation in Medicaid-funded community-based supports and services.

### **Loss of economic resources**

The strict income and asset limits for Medicaid eligibility force people who need LTSS to limit or even avoid economic growth opportunities, thwart family financial planning, and hinder independence and employment. Medicaid’s income and asset limits for people with disabilities and older adults are so low that earning or saving just over the limit still leaves an individual well below the level of income or assets required to pay out of pocket for LTSS. The current situation traps people in poverty for LTSS access, because in order to qualify for Medicaid, a person must exhaust almost all assets, and for most families and individuals who rely on LTSS, leaving Medicaid isn’t an option. For younger people with significant disabilities, including people who are living and working in the community, this could mean a lifetime of enforced poverty to get the services and supports you need.

### **Caregiving issues**

Many people who have high LTSS needs rely on unpaid caregivers for help, and even those who have some paid help may still rely on family caregivers.<sup>5</sup> A majority of LTSS is provided by caregivers, who are friends or family members. Caregiving can result in difficult financial, physical, and emotional challenges. And family caregivers usually have little to no training and have little access to information or support in navigating the LTSS system. A versatile and sustainable LTSS system would not replace the role of the family caregivers, but must be designed in a way that supports families and communities. At the same time, there’s an ongoing need to improve the supply, retention, and performance of direct support workers to meet increasing demand in a profession with high turnover and low wages.

***Be a part of building a coherent and comprehensive plan for LTSS. Your future and the future of people you love are at stake!***

---

<sup>4</sup> Terrence Ng et al., *Medicaid Home and Community-Based Services Programs: 2013 Data Update*, Washington, DC: Kaiser Commission on Medicaid and the Uninsured (2016) available at: <https://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/>.

<sup>5</sup> Amber Willink et al., Commonwealth Fund, *Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports* (Nov. 15, 2017), available at [www.commonwealthfund.org/publications/issuebriefs/2017/nov/use-paid-and-unpaid-personal-help-medicare-beneficiaries-needing](http://www.commonwealthfund.org/publications/issuebriefs/2017/nov/use-paid-and-unpaid-personal-help-medicare-beneficiaries-needing).