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A safety net that leaves large gaps in access to needed long-term care services in the United States of America (USA)

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Context

Long-term services and supports (LTSS) refer to an extensive range of long-term care (LTC) health and health-related services and other types of assistance needed by individuals who lack the capacity for self-care due to physical, cognitive, or mental conditions or disabilities. LTSS helps primarily with personal tasks of activities of daily living, such as eating, bathing, dressing and housekeeping over an extended period to maintain or improve an optimal level of physical functioning and quality of life among older people and those with disabilities.

No universal LTSS benefits have been established in the USA. The current system consists of means-tested coverage through Medicaid and a small private insurance market. Medicaid provides a safety net for low-income populations, with coverage for approximately 20% of the total population. Coverage of LTSS services ranges from institutional care to community-based LTSS. People become eligible because they have low incomes and assets and meet specific thresholds for functional impairment. Although people of all ages may need LTSS, the majority of users are 65 years and over.

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Key findings

- In 2018, an estimated US\$ 409.2 billion was spent on LTSS, representing 13.3 % of the US\$ 3.1 trillion personal health expenditures. Family members, friends and other uncompensated caregivers also provide substantial care, suggesting that formally reported spending may be an underestimate of personal spending. Medicaid is the largest public payer and, in 2018, accounted for 44.1 % of all LTSS spending, while private sources accounted for 29.2% of LTSS expenditures. Within the category of funding, out-of-pocket spending was the largest component, comprising 14.9% of total LTSS expenditures.
- Medicaid determines eligibility through both federal and state laws. Medicaid defines the population covered, including individuals 65 years of age and older. It is also means-tested to target those with financial need. In addition, individuals must meet state-based functional and/or disease or condition-specific eligibility criteria.
- Almost all states use at least one tool to determine eligibility and/or develop a care plan. More than 100 tools are currently in use and, on average, states use three different tools each for different populations.
- Medicaid home and community based services (HCBS) are not an entitlement, and states choose whether to offer these services as part of various options such as evaluation waivers or amendments to their state plans. Co-payments are allowed for HCBS but are rarely applied.
- Under the Medicaid programme, prices are usually set unilaterally at the state level following guidelines established nationally. Federal statute requires that payment rates are consistent with efficiency, economy and quality of care and sufficient to guarantee provision of services. The base for payment for services delivered through the fee-for-service system ranges from a day of stay for nursing facilities to a unit of service for home-based care. Prices vary across and within states and are also based on adjustment factors, such as geographical location, to the base price.
- Managed LTSS plans play a key role in the delivery of health care to Medicaid enrollees. In 2019, 49% of benefit spending was for capitated payments under managed care arrangements. Managed care plans receive capitated payments per enrollee, covering both home- and community-based services and/or institutional-based services. Prices are determined through either administered pricing or competitive bidding.
- The out-of-pocket cost of LTSS, especially over a long period, may far exceed many individuals' financial resources. For example, among older adults with significant disabilities, only 40% could fund at least two years of extensive home care if they liquidated all their assets. Moreover, public programmes that finance this care, such as Medicaid, may not cover all the services and supports that individuals need, and may leave individuals and their families at financial risk.

Best practices

- **States are required by federal rules to exempt older persons in residential care settings from individuals in Medicaid cost-sharing.**
- **To improve quality, decrease costs, reduce duplication of services, and better predict state expenditures, an increasing number of states are moving the management of Medicaid LTSS programmes to Managed Care Organizations, and are including more complex populations.** Movement to managed care may help decrease fragmentation of services, which in turn can reduce the complexity for beneficiaries.
- **Most states have invested in programmes to transition individuals in need of LTSS from institutional to community settings, such as assisting with housing searches, paying for rental security deposits, and making home modifications.** A few states have also expanded access to a limited set of HCBS for people who would not otherwise qualify for Medicaid or LTSS to slow future needs for more expensive Medicaid services, including institutional care.

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Lessons for other settings

- **Low demand for LTSS private insurance.** Perceptions of risk by younger persons of working age and limited ability to estimate LTSS dependency are the main reasons for low demand for LTSS private insurance. Furthermore, the decline in the private insurance market is also the result of pricing and market instability. Insurers have dramatically increased premiums for policies, both new and in-force, leading to much lower demand. Also, the total number of insurers actively selling in the market has dramatically contracted.
- **Large variation in coverage and access at state level.** Understanding current state-level variation in LTSS eligibility criteria and tools, spending and service coverage is important to design policies that reduce the large and inequitable gaps in access to needed LTSS.
- **Need for a comprehensive system.** A broadly accessible system of LTSS would be an efficient way to mitigate the financial risk associated with LTSS for households, federal and state government and the economy as a whole.

The WKC and the OECD have produced a report summarizing key findings from nine country case studies on "Pricing long-term care for older persons". The cases represent a range of health care systems and experiences in organizing and financing long-term care (LTC) for older persons. The report identifies best practices and policy lessons, which demonstrate the benefits of investing in quality LTC in the context of ageing populations. The summary report and case studies can be found here: https://extranet.who.int/kobe_centre/en/project-details/pricesetting2