



Principles for Long-Term Services and Supports

As Americans live longer, healthier lives, all of us will likely need long-term services and supports (LTSS) at some point in our lives or will know someone who does. A strong and flexible LTSS system benefits us all at every age, whether we or our loved ones are facing temporary or chronic illness or disability. For too long, the federal government has ignored the urgent need to address in a bipartisan, fiscally responsible manner the emerging LTSS crisis facing older adults and family caregivers.

All of us should have access to a broad array of high-quality, person-centered LTSS planning and options with a continuum of home and community-based services (HCBS)—which are overwhelmingly preferred by consumers—as the foundation. At the same time, high-quality residential options should also be available to any of us who needs or prefers residential LTSS, and these residential settings should be recognized as integral parts of our communities. This system should adequately support family caregivers and the direct care workforce. It should not require any of us to spend down into poverty before receiving LTSS in any setting. Moreover, the LTSS system must make equity a central priority so that health and economic disparities for women, people of color, and LGBTQ individuals are recognized and reduced.

By creating and enhancing these LTSS options, we can improve quality of life for all of us as we age, thereby reducing long-term health care and social services costs for LTSS consumers, families, communities, and the government. The following principles provide a framework for a high-quality, person-centered, family caregiver–supportive, equitable LTSS system. This system will build on the continuing work of LCAO to strengthen the Medicaid program, secure substantial additional resources for HCBS, enhance opportunities for person-centered planning, and improve the quality of life and quality of care for LTSS consumers in all settings.

Strengthening Access and Financing

National Problem, National Solutions – Recognize that the financing, delivery, and quality of LTSS are national challenges that require national solutions led by the federal government, although states and territories, tribes, communities, families, and individuals have important roles to play as laboratories for policy experimentation. By working together, we can put in place all of the pieces of the LTSS access and financing puzzle.

Universal Access – Ensure universal access to comprehensive LTSS (whether in one program or a multifaceted system) for individuals of all ages and disabilities.

Equity – Make LTSS coverage accessible in an equitable way without discriminating against any individual or group on the basis of age, disability, race, color, national origin, sex, gender identity, or sexual orientation.

Affordability – Make costs affordable so that all of us, regardless of income, age, gender, disability, and health status, have access to LTSS. Ensure that any new program or benefit protects the financial security of individuals and families and does not require any of us to impoverish ourselves to obtain needed LTSS.

System Organization and Integration – Develop a well-organized system that aligns LTSS provision and payment to promote optimal service delivery and outcomes and provides adequate support for the direct care workforce. Integrate LTSS seamlessly with acute, ambulatory, advanced, palliative, and hospice care to ensure efficient and effective coordination across the continuum.

Public–Private Partnership – Promote a publicly financed system of person-centered LTSS planning and delivery supplemented by private-sector options. Ground both public and private coverage options in a strong foundation of consumer protection that ensures affordability, equitable financing, economic efficiency, transparency, and public accountability.

Ensure Adequate Financing – Provide sound financing for LTSS that ensures the ability to pay for future needs while being affordable to individuals, families, and society.

Medicaid – Strengthen Medicaid to ensure equity between this program—which is likely to remain a primary support for individuals and families with low incomes who need LTSS absent single-program coverage—and any new LTSS program or benefit that is developed to provide LTSS for middle- and upper-middle income individuals. Remove the institutional bias within the Medicaid program so that all services, whether HCBS or facility based, are mandatory.

Housing and Transportation – Include a strategy to meet the needs of older adults for adequate, affordable, and physically accessible housing and transportation, which are integral to aging in community.

Technology – Promote affordable, equitable access to technology, including telehealth, to promote efficient access to LTSS, foster independence, reduce social isolation, and improve health for all of us.

Enhancing the Capacity of the LTSS Team

We all rely on the expertise and dedication of other people throughout our lives, and we all value being able to choose the types of services that improve our lives. Moreover, many of us help support family members (whether physically, emotionally, or financially) during at least one point in our lives. A stable, well-trained LTSS workforce—one that not only includes and supports family caregivers, but also recognizes older consumers as the center of the team—helps

all of us to maximize our dignity, health, and independence when we or an older person we love experiences disability, illness, or injury.

Consumer Choice, Control, and Empowerment – Promote independence and dignity by ensuring that consumers have the right to control and choose which LTSS they use, how and where those LTSS are delivered, and who provides them. This includes enabling goals of care discussions and advance care planning, easy access to unbiased information, and assistance with navigating and coordinating services.

Ensure LTSS are flexible, consumer driven, and tailored to each consumer's strengths, goals, preferences, and needs. Develop formal mechanisms to connect consumers who want to hire their own direct care workers with certified candidates who meet their needs. Educate LTSS consumers, family caregivers, direct care workers, health care professionals, and social services personnel about the full array of LTSS—including care during serious illness and at the end of life—through education and other supports. Promote self-advocacy by educating LTSS consumers and family caregivers about consumer rights and provider responsibilities.

Family Caregivers – Recognize and support the critical role played by family caregivers in planning, providing, and advocating for high-quality LTSS for older people, while guarding against designing an LTSS system that relies too heavily on family caregivers. Honor each older person's right to define "family," which might include not only legally recognized family members but also friends, neighbors, and other individuals.

Assess the needs of family caregivers and provide information, referral, training, counseling, respite, and other supports to address their needs. Develop strategies to maintain financial security for family caregivers who balance family caregiving and unrelated paid employment.

Direct Care Workers and LTSS Professionals – Recognize and bolster the professionals and direct care workers who provide essential LTSS in both HCBS and residential settings. Develop, implement, and strengthen the following strategies to attract and retain a sufficient number of LTSS personnel and to address high rates of turnover: enhanced education, training, and credentialing, including grants and loan forgiveness to incentivize students and professionals to specialize in working with older adults; improved compensation, benefits, and other supports, such as career ladder programs; enhanced workplace safety; and robust workforce data collection.

Create and support processes that includes workers in setting standards for compensation, benefits, and policies. Protect the rights of workers to organize so that they can advocate for themselves and for the consumers they serve.

Promoting Quality of Life and Quality of Care

We all strive for the best quality of life for ourselves and the people we love. Our quality of life is intricately connected with the quality of services we use throughout our lives in any setting, such as in our neighborhoods or schools. High-quality LTSS help maximize quality of life when

we or an older person we love experiences disability, illness, or injury. The following strategies benefit all of us.

Financial Investment in Quality – Provide adequate funding to support quality care, including optimal staffing levels and training, protection, and compensation for the LTSS workforce. Provide additional funding to develop, strengthen, and implement oversight, enforcement, quality improvement, and advocacy programs that ensure quality of life and improve quality of care in all LTSS settings.

Quality Standards – Implement, oversee, and enforce strong standards—including quality standards for HCBS—that include quality measures, assessment of the consumer experience, and workforce metrics (such as turnover).

Quality of Life – Promote community inclusion and engagement that enables all of us to participate in activities, events, and work to the extent desired throughout our lives, including at the end of life. Acknowledge that disability, chronic disease, and advanced illness bring their own set of criteria for quality of life, including psychosocial support, pain relief, and person-centered planning.

Rights – Promote the rights of LTSS consumers in all settings, including the right to be free from abuse, neglect, and exploitation; to give informed consent for all health care decisions; to be treated with dignity and respect; to direct the care they receive; to play a direct role in developing and implementing policies at all levels that impact the lives of all of us who use LTSS; and to access independent advocacy support.

A comprehensive, integrated, equitable LTSS system strengthens our communities. LCAO is ready to collaborate with Congress and the Administration to apply these principles to policy solutions that will help us all.