



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

**CCD Disability Principles for Inclusion of Long Term Service and Supports (LTSS)
in Universal Health Care**

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. This document lays out principles that the undersigned members of CCD believe must be incorporated into any universal or “For All” health care system in the United States.

For the disability community, access to health care is not only a matter of life and death, but also a matter of liberty and civil rights. People with disabilities of all ages need access to the *right* kinds of health care services and supports to ensure that they can live in the community and have lives and jobs like everyone else--otherwise, people can be and are trapped in institutional settings away from family, friends, jobs, and other fundamental aspects of life. Long-term services and supports (LTSS) refer to the daily living supports that people with disabilities and older adults need. LTSS includes home and community-based services (HCBS), which are the overwhelming preference of service delivery for the disability community and older adults. Expanding access to HCBS has been the focus of the disability community’s advocacy for the past fifty years and there remains much progress to be made.

There is extremely limited access to LTSS in private insurance or Medicare, and few families have the means to pay for these daily services on an ongoing basis, much less for the decades or lifetime that people with disabilities often need these services. This has left Medicaid as the main payer of LTSS. But Medicaid disadvantages HCBS because it has an “institutional bias” that mandates states to cover most institutional services while making coverage of HCBS optional. States can and do cap access to HCBS, creating waitlists or other restrictions to access, which the disability community strongly opposes. These waitlists and restrictions force many people with disabilities and older adults to rely on unpaid family caregivers and other programs that ensure access to housing, nutrition, work supports, and other basic needs, if available. Inability to access needed services and supports can also lead to job loss, unnecessary interactions with the criminal justice system, homelessness, or greatly diminished health and function. For those who can access services, Medicaid’s strict eligibility criteria trap people with disabilities and older adults in poverty to obtain services, hindering the economic opportunities and ability to save for their families’ future or for their own retirement. The state-federal partnership that underpins Medicaid also means that there is substantial state variation in access to LTSS and even greater variation in access to HCBS.

The Affordable Care Act began to establish a federal floor of covered services, which includes mandated access to some of the critical services people with disabilities and older adults need

including rehabilitation, habilitation, prescription drugs, and behavioral health services. A universal or “for all” health care system **must** continue this progress by establishing and **guaranteeing access** to a standard benefit package that includes LTSS in all health insurance. Any new system must also preserve the decades of progress that provides protections for people with disabilities, including the Early and Periodic Screening, Diagnostic and Treatment mandate and other consumer protections.

We urge all proposals to incorporate the following principles:

True Universal Health Care - All individuals must be included in any new universal system, especially people with disabilities, older adults, and others with high health care needs.

- Health coverage should be accessible in an equitable way without discriminating on the basis of race, color, national origin, sex, gender identity, sexual orientation, age, or disability.
- This must include universal eligibility for all people, without income or asset limits that require people to impoverish themselves to access needed services.
- The health care system itself must be accessible for people with disabilities, older adults and others with high health care needs.
- There cannot be a separate system for access to LTSS, and access to LTSS cannot be pre-conditioned on institutional levels of need.
- Any LTSS assessment process, including eligibility and allocation assessments, should be done in a consistent, uniform and transparent way, capturing all individuals with disabilities (including, specifically, people with developmental and mental health disabilities who are often omitted in such assessments).

Comprehensive Coverage of All Services - Any new universal system must include LTSS as part of the universal service package.

- Any new system should focus not only on access to traditional health care services, but also on LTSS and social determinants of health, creating a social model of health care instead of the traditional medical model.
- All care and services should also be consumer-focused and directed. Services should be as expansive as possible, flexible, consumer-driven, person-centered and tailored to the individual’s needs and preferences.
- Any system must recognize and support the central role family caregivers play in planning for and providing LTSS. It should include strategies to support caregivers who are otherwise employed to help maintain their financial security. A system should assess the needs of family caregivers and provide information, training, counseling, respite and other supports to address their needs. The program **must not** compel informal supports in lieu of developing a viable system of LTSS.

Community First Care - Any new universal system must eliminate institutional bias and instead incentivize **Community First**, maintaining and advancing the decades of progress of the disability community to ensure access to HCBS.

- This will also prevent the loss of progress in states that have done more to expand access to HCBS for people with disabilities and older adults.

- This should also preserve and build upon the clear definition of HCBS created by the HCBS settings rule and ensure that all people with disabilities of all ages are able to receive services in settings that are truly community-based.

Coordinated Care and Programs - Any new universal health care system must thoughtfully incorporate and work with current and future social and economic support services. Health care services, including LTSS, should be seamlessly integrated with other service systems and payment and services should be aligned to promote optimal care and service delivery.

- There must also be investment in care coordination, which can be especially important for people with disabilities and older adults who have challenges navigating complex systems.
- In particular, any new system must include and invest seriously in explanation of the new system and outreach and engagement with all populations, but specifically marginalized populations including people with disabilities, low-income older adults and individuals with limited English proficiency.

Inclusive Quality Metrics and Reporting - Any new universal health care system should have robust quality metrics and reporting, with transparency for advocates and researchers. These metrics must be focused on person-centered outcomes, instead of exclusively focusing on medical model measures or assessments of functioning.

- Outcomes measures should be person-centered, reflecting how well an individual is supported in leading a self-determined life, and should include measures of beneficiary experience and satisfaction measures instead of simply relying on medical measures or functional assessments.
- Quality assessment must include sufficient oversight, enforcement, and advocacy programs to ensure quality of life and improve quality of care in all settings.
- Quality metrics must also include examination of funding and if it is sufficient to support quality care, including sufficient training, protections, and compensation for the LTSS workforce.

Sincerely,

Allies for Independence
 American Academy of Physical Medicine & Rehabilitation
 American Association of People with Disabilities
 American Association on Health and Disability
 American Association on Intellectual and Developmental Disabilities
 American Dance Therapy Association
 Association of People Supporting Employment First
 Autism Society of America
 Autistic Self Advocacy Network
 Brain Injury Association of America
 Center for Public Representation
 Disability Rights Education and Defense Fund
 Justice in Aging
 Lakeshore Foundation

Lutheran Services in America--Disability Network
National Association of State Directors of Developmental Disabilities Services
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Disability Rights Network
National Health Law Program
National Respite Coalition
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Special Needs Alliance
TASH
The Arc of the United States
United Spinal Association