



CONSORTIUM FOR CITIZENS WITH DISABILITIES

CCD Disability Principles for Health Care Reform

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. As we begin a new Congress, the Consortium for Citizens with Disabilities (CCD) Health Task Force issues these updated principles for health care reform efforts.

For the disability community, access to health care is not only a matter of life and death, but a matter of liberty and civil rights. The experience of people with disabilities is a **litmus test** for how well a health care system addresses the needs of all people living in the United States. If a health care system provides comprehensive, high-quality care to individuals with disabilities and chronic health conditions, then it will likely also serve the needs of the broader population.

Specifically, the CCD Health Task Force will use the following 7 principles to guide its assessment of health care reform proposals from a disability perspective: **Comprehensiveness, Affordability, Non-Discrimination, Community First, Simplicity and Enforceability, Implementation and Transitions, and Accountability and Reporting**. These principles build on [principles around inclusion of long-term services and supports \(LTSS\) in health reform](#) produced by the CCD LTSS Task Force.

PRINCIPLES

Comprehensiveness – Comprehensive coverage must be available to all people across all types of health insurance coverage.

- Health care reform efforts should preserve the services provided by existing baseline coverage.
- There should be a mandated, comprehensive, federal benefit package that is available to everyone.
- Health care reform efforts should fill in key benefit gaps in existing programs such as Medicaid, Medicare, and the Affordable Care Act's health insurance marketplaces. This would include ensuring all coverage includes access to vision, hearing, and adult dental services, as well as EPSDT services for children at all income levels and Non-Emergency Medical Transportation for low-income individuals. Reform efforts should not leave out certain categories of services, like LTSS, that are currently provided almost exclusively via public health insurance programs with restricted eligibility.

- Service categories with chronic and long-standing provider shortages, such as home health care, or with providers who are frequently outside the coverage system, such as in behavioral health and habilitation and rehabilitation, should receive extra attention and investment to improve and ensure network adequacy.
- Health care reform efforts should ensure that health care professionals receive training and experience working with people with disabilities.

Affordability: Health care coverage must be affordable for all people, including those who have higher than average health care costs:

- The burden of premiums, out-of-pocket expenses and cost-sharing requirements for participants should be non-existent for low-income populations. Any cost sharing must provide protections for low-income individuals, people with disabilities, and those with chronic conditions, and ensure affordability for people of all incomes in public and private programs.
- Cost sharing is a blunt and largely ineffective tool for improving efficient use of health care dollars, as most health care decisions and costs, particularly those for people with disabilities, are driven by health care providers.
- Cost sharing places a disproportionate and discriminatory burden on people with disabilities and chronic health needs.
- Cost sharing also creates a major barrier to care, especially for low-income people.
- Reforms should emphasize transparency in relation to pricing, provider availability, cost sharing, service availability, grievance and appeals, and all other elements of health coverage.

Non-Discrimination: People with disabilities of all ages and their families must have all their health needs met as they participate in the nation's health care system. While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, disability does not occur uniformly among communities. These differences must be taken into account to ensure equitable reform efforts. A reformed health care system must be physically and programmatically accessible and must:

- Ensure that all health coverage adequately meets the needs of people with disabilities and chronic conditions. People with disabilities must not be forced to remain in poverty in order to access needed services and supports.
- Strive towards health equity and reduce disparities. It is not enough for the health care system to produce improved results “on average;” it must produce meaningful results across populations and subpopulations. In addition to reducing existing health disparities, it must chart a course for their elimination.
- Continue prohibitions on discriminatory health care benefit designs that would exclude or have a disparate impact on specific populations with higher health care costs or of minority status. This includes cost-sharing structures that disproportionately and discriminatorily affect people with disabilities and others who have higher health care needs or require uncommon services or treatments.

- Prohibit using Quality-Adjusted Life Years, Disability-Adjusted Life Years, and other comparative-effectiveness measures which devalue the lives, experiences, and perspectives of people with disabilities and chronic health conditions.
- Ensure that people with disabilities can move anywhere in the country without experiencing a disruption in access to comprehensive, accessible, high-quality health care services and/or long term supports and services.

Community First: Adults and children with disabilities often need long-term services and supports to live good lives and age with dignity in the community. Community living is a civil right. Unfortunately, the history of institutionalization has left much of our health care system with an institutional bias. Health care reform efforts should:

- Include and expand home and community-based services (HCBS) in any health reform efforts.
- Build on decades of progress to ensure people have access to HCBS by mandating access to HCBS and eliminating institutional bias.
- Enable friends and family to provide services and supports for friends and family members with disabilities of any age in the community, while not assuming or compelling the provision of these services in place of formal services.
- Ensure that all people with disabilities of all ages are able to receive services in settings that are truly community-based.
- The CCD Long Term Services and Supports Task Force has developed detailed principles for the inclusion of LTSS in health reform efforts, which can be accessed [here](#).

Simplicity and Enforceability: In any health care system, services must be physically and programmatically accessible and people must be able to enforce their rights:

- Minimize administrative complexity for individuals and families receiving health care services.
- Have mechanisms to ensure sufficient provider capacity, particularly for community-based services for people with disabilities, chronic conditions, and complex medical and behavioral health needs.
- Hold health care providers and payers accountable for making and maintaining settings that are physically and programmatically accessible.
- Include accessible and direct processes for individuals to address issues with their care and services and appeal adverse coverage determinations. Create ombudspersons, consumer advisory councils, and other mechanisms for people with disabilities to provide feedback and address systemic issues.
- Avoid placing a heavy complaint burden on individuals who may be experiencing health crises or are otherwise disincentivized from bringing enforcement actions against needed care providers.
- Provide access to the courts so that individuals can ensure that these protections are enforced.

Implementation and Transitions: In any health care systems transformation, the implementation of new systems and transition from old to new will be challenging for people with disabilities or

chronic conditions who need consistent and constant access to health care. Any reform efforts should ensure that the implementation and transition period:

- Maximizes continuity of care through emphasizing smooth transitions between care settings; a seamless continuum between health care services, behavioral health, rehabilitation, and long-term services and supports for people with disabilities and chronic illnesses; and minimizing disruptions during coverage transitions.
- Increases the capacity of the health care system to address the critical or unforeseen issues that arise during periods of transition, such as shifting from one type of coverage to another, from pediatric care to adult care, or from one eligibility pathway to another in the same program.
- Ensures continuity of and continued access to specialty providers;
- Includes a phase-in or transition period adequate to ensure continuity of care for people with disabilities and chronic health conditions.

Accountability and Reporting: A crucial aspect of health care reform efforts should be robust quality metrics and reporting. The collection and reporting of quality metrics should include standards for physical and programmatic accessibility that are embedded within quality care standards and monitoring that is already taking place among various health care entities and should be:

- Transparent, timely, and accessible for health plan enrollees, potential health plan enrollees, advocates and researchers;
- Comprehensive, including alternative mechanisms, like ombudspersons, to address quality problems in real time.
- Increasing use of and reliance on more person-centered outcomes to augment existing medical model measures or assessments of functioning;
- Subject to sufficient oversight, enforcement, and advocacy to ensure quality of life and improve quality of care in all settings;
- Adequately funded and sufficient to support quality care, including sufficient training, protections, and compensation for the workforce.

CCD will analyze health care reform proposals based on how well they meet these principles and serve people with disabilities and chronic conditions.

Signatories as of March 27, 2019:

Allies for Independence
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association on Health and Disability
American Diabetes Association
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Physical Therapy Association

American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Public Representation
Disability Rights Education and Defense Fund
Epilepsy Foundation
Family Voices
Justice in Aging
Lutheran Services in America-Disability Network
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Disability Rights Network
National Health Law Program
Paralyzed Veterans of America
Special Needs Alliance
The Arc of the United States
United Spinal Association