



CONSORTIUM FOR CITIZENS
WITH DISABILITIES

PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE

The Consortium for Citizens with Disabilities (“CCD”) believes that the goal of health care reform should be to assure that all Americans, including people with disabilities and chronic conditions, have access to high quality, comprehensive, affordable health care that meets their individual needs and enables them to be healthy, functional, live as independently as possible, and participate in the community. The CCD is a coalition of national consumer, service provider, and professional organizations which advocate on behalf of persons with disabilities and chronic conditions and their families.

Persons with disabilities and chronic illnesses often have health care needs of greater amount, duration and scope than the rest of the population. Many people have multiple conditions, contributing to endless variation in the complexity and severity of individuals in need of health and long term services and supports. In 1998, the President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry published its final report in which it recommended that the President should develop a broad national consensus on improving the quality of the health care system in the United States. The report recommended that, as a first step, the President should articulate a unifying statement of purpose for the health care system and then work with Congress and the private sector to implement it. The Commission suggested the following unifying statement:

*“The purpose of the health care system must be to continuously reduce the impact and **burden of illness, injury, and disability**, and to improve the **health and functioning** of the people of the United States.”*

This statement of purpose of the health care system was well stated and is just as relevant today. The fact is that reform of our nation’s health care system involves more than just covering more people for the acute care services they may need when they become ill or injured. Health care for people with disabilities and chronic conditions includes a range of services and devices that include, as well as follow, acute care medicine. Such services are often long term and ongoing in nature and seek to maximize health status, full function and participation in society, employment, independent living, and the pursuit of fulfilling and meaningful lives.

CCD understands the enormity of the challenge that national health care reform presents. As this effort moves forward, CCD will assess reform proposals based on how they address the needs of people with disabilities and chronic conditions. We view disability as a **litmus test** for how well a reformed health care system will address the needs of all Americans. If a health care system provides comprehensive and high-quality care to individuals with disabilities and chronic conditions, then it will serve the wide-ranging needs of the broader population.

Specifically, CCD uses six principles to guide its assessment of healthcare reform proposals from a disability perspective: **non-discrimination, comprehensiveness, continuity, appropriateness, equity, and efficiency**. Each one of these broad concepts has specific application for people with disabilities and chronic conditions. We look forward to working with the 111th Congress and the Obama Administration in designing a national healthcare system that meets the needs of all Americans, including people with disabilities and chronic conditions.

PRINCIPLES

Non-Discrimination: People with disabilities of all ages and their families must be able to fully participate in the nation's health care system.

Discrimination occurs when people with disabilities and chronic illnesses are subjected to preexisting condition exclusions, excessive costs through medical underwriting, arbitrary caps and benefit limits, or a denial of insurance coverage altogether. It also occurs when the private insurance system fails to adequately meet the needs of people with disabilities and chronic conditions, forcing them onto publicly financed health care programs. To avoid discriminating against people with disabilities, a reformed health care system must:

- Design the private insurance system to cover ALL Americans so that Medicaid and Medicare are not the only option for coverage of people with disabilities;
- provide access (i.e., guarantee issue) to private coverage without regard to health or disability status on par with access provided to those without disabilities;
- prohibit rating practices that “price out” of private coverage higher users of health care;
- strengthen the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities enrolled in the program regardless of where they live;
- permit people on Medicare below age 65 the same access to Medigap policies as people on Medicare above age 65; and
- hold accountable federal and state government agencies involved in funding healthcare and managed care organizations/health plans to ensure that health care providers with whom they contract are physically and programmatically accessible.

Comprehensiveness: People with disabilities and their families must have access to benefits that provide a comprehensive array of health, rehabilitation, assistive device, and support services across all service categories and sites of service delivery.

In a reformed system, individuals with disabilities must have access to comprehensive health benefits that help them achieve and sustain optimum physical and mental function. A comprehensive health care system promotes affordable access to:

- preventive services, including services to prevent the worsening of a disability or a condition that is secondary to a disability;
- habilitation services, rehabilitation therapies, and independent living services designed to restore or improve function, including the lessening of deterioration of function over time;
- condition/disease management services to better coordinate chronic and complex illnesses;
- durable medical equipment, orthotics, prosthetics, and other assistive technologies and related services that do not include inequitable limits and restrictions;
- mental health, counseling, and substance abuse services;

- accessible medical equipment such as examination tables and diagnostic equipment; and
- health and wellness initiatives for people with disabilities that will reduce health disparities;

Continuity: People with disabilities of all ages and their families must have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic conditions.

Adults and children with disabilities often need long-term services and supports that enable them to live as independently as possible. A health care system that supports continuity of care:

- includes mechanisms to assure timely and quality care between health care settings and provider systems, as well as a seamless continuum between health care services and long term services and supports for people with disabilities and chronic illnesses;
- emphasizes home and community based services and, by doing so, reduces the need for and cost of institution-based care;
- enables families to provide care for family members with disabilities of any age in the most appropriate setting;
- does not force impoverishment in order to have needs met for health coverage and long-term services and supports and
- includes a public insurance program for long term services and supports as a meaningful complement to Medicaid.

Appropriateness: People with disabilities and their families must be assured that comprehensive health, rehabilitation, and long term support services are provided on the basis of individual need, preference, and choice.

The issue of consumer choice and participation has particular importance for persons with disabilities and chronic conditions. An appropriate health care system is one that ensures:

- services are patient-centered and consumer-directed to the maximum extent possible;
- informed consumer choice in relation to providers and services;
- an appropriate amount, duration and scope of services, devices and related benefits;
- access to trained, qualified, and appropriately credentialed health care personnel;
- the designation of physicians who understand disability and function to help plan and coordinate care with the rehabilitation team as an alternative to gatekeeper case managers with no experience with disability; and,
- that all patients are responsible for making good individual health care choices.

Equity: People with disabilities and their families must have equitable access to health coverage programs and not be burdened with disproportionate costs.

Health care reform must ensure that people have access to services based on health care need and not because of factors such as employment status or income level. An equitable health system:

- provides access to services based on health needs and not on income or employment status;
- limits the burden of out-of-pocket expenses and cost sharing requirements for participants on a sliding scale based on income and ensures affordability in public and private programs;

- eliminates the 24-month Medicare waiting period so that SSDI beneficiaries have equal access to Medicare coverage as those who qualify for Medicare based on age;
- ensures access to a broad array of insurance options for people with disabilities below age 65, including access to COBRA coverage as a wrap-around benefit, Medigap policies, and individual private insurance coverage that is affordable;
- includes ALL Americans and does not use public programs such as Medicare and Medicaid as the preferred insurance mechanism for high users of care; and
- reimburses providers at levels that are adequate to ensure access to and quality of care.

Efficiency: People with disabilities and their families must have access to health care that is effective and high quality with a minimum of administrative waste.

CCD is concerned that the current fragmented health care system has failed to achieve effective cost controls—or a rational allocation of health resources—and contributes to substantial administrative waste. An efficient health care system is one that:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources by investing in services that will eliminate or reduce the need to spend more later in a person’s life, while maximizing the potential of the individual;
- stresses prevention and wellness;
- presumes that the optimal setting for providing care is in the person’s home and community;
- actively manages and coordinates care for people with chronic conditions in order to improve quality and reduce unnecessary costs;
- ensures that Medicaid financing is sustainable over time with countercyclical mechanisms to provide more funding to states when the economy declines and enrollment increases;
- ensures the delivery of clinically effective services; and
- limits or eliminates fraud and abuse so precious resources can meet patients’ needs.

CONCLUSION

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

The disability community is integral to the national health care reform effort. People with disabilities and chronic conditions are highly vulnerable to the limitations of both public and private health care systems as they are squeezed between a private system which is designed to charge according to an assessment of risk and a public system which subsidizes health care according to age, poverty status, family structure, and an inability to work. The private health insurance market functions on the basic premise of spreading risk. This risk historically has been related to the chances of the insured population incurring excessive costs primarily for hospital and physician services. But the current system needs to meet a much broader set of health, functional and long term needs of Americans. The disability community stands ready to be an active participant and strong supporter of health care reform that meets these principles.

Sincerely,

ACCSES

ADA WATCH

Adapted Physical Activity Council
Alexander Graham Bell Association for the Deaf and Hard of Hearing
American Academy of Physical Medicine and Rehabilitation
American Association of People with Disabilities
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Council of the Blind
American Diabetes Association
American Foundation for the Blind
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Psychological Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition of America
APSE – The Network on Employment
Association of Assistive Technology Act Programs
Association of University Centers on Disabilities
Autism Society of America
Autism Speaks
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Disability Issues & the Health Professions
Community Access National Network (TIICANN)
Council for Learning Disabilities
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Helen Keller National Center
Higher Education Consortium for Special Education
Learning Disabilities Association of America
Lutheran Services in America
Mental Health America
National Alliance on Mental Illness
National Association for the Advancement of Orthotics and Prosthetics
National Association of Councils on Developmental Disabilities
National Association of Social Workers
National Association of State Directors of Developmental Disabilities Services
National Association of State Directors of Special Education

National Association of State Head Injury Administrators
National Center for Environmental Health Strategies
National Coalition for Disability Rights
National Coalition on Deaf-Blindness
National Council on Community Behavioral Healthcare
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
National Multiple Sclerosis Society
National Organization of Social Security Claimants' Representatives
National Rehabilitation Association
National Respite Coalition
National Spinal Cord Injury Association
NISH
Paralyzed Veterans of America
Rehabilitation Engineering Society of North America
Research Institute for Independent Living
Spina Bifida Association
Teacher Education Division of the Council for Exceptional Children
The Arc of the United States
Tourette Syndrome Association, Inc.
United Cerebral Palsy
United Spinal Association
World Institute on Disability

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