DISABILITY HEALTH COALITION

Disability will touch the lives of most Californians

HEALTH CARE PROBLEM STATEMENT

The disability community adds our voices to the call for health care reform in California. We maintain that timely and affordable health care for all is a basic human right, as well as a necessity for the general health, safety and welfare of society.

People with disabilities can be found at all ages, within every ethnic group, at every income level, and with every type of coverage for medical care, as well as with no coverage. More than one in four California adults (approximately 7.8 million) report having some kind of disability. Approximately 1.1 million working age Californians with disabilities have no health insurance and approximately 1.5 million have been uninsured for part or all of the year.[1]

In our current health care systems, Californians with disabilities face the same under-insurance issues as Californians without disabilities, while also facing additional barriers such as physical and programmatic inaccessibility, a "gate-keeping" insurance market, cultural incompetence, and discrimination. Comprehensive health care reform must remove these barriers for people with disabilities.

CORE HEALTH CARE REFORM PRINCIPLES

These core principles must be included in comprehensive health care reform:

- Disability is a common and natural feature of the human condition
- Disability is a continuum, relevant to the lives of all people to different degrees and at different times in their lives
- Care and services[2] for people with disabilities must assist individuals to maintain and improve functional status, wellness and quality of life on an ongoing or lifetime basis

[1] Office on Disability & Health/UCSF Disability Statistics Center analysis of data from the 2005 California Health Interview Survey.

[2] Wherever this phrase is used, "health care and services," it is meant to encompass care as needed from a range of health care providers, including outpatient services, specialty services, medications, supplies, durable medical equipment, assistive technology, mental health services, vision, hearing, and dental care.

- Respect for the right of consumers to make decisions about their own health care is central to good health care
- Health care systems or providers must not deny health care, provide a lower level of health care, or otherwise discriminate on the basis of disability
- Discrimination based on employment status, source of income or immigration status must be eliminated
- Architectural and programmatic accessibility must be afforded to all persons with disabilities, including:
    - accessibility of all facilities, technology, equipment, and methods of communication used in providing medical care and services, and
    - reasonable modification of provider policies and procedures to the extent necessary for appropriate care and services
- Services to persons with disabilities must be provided in their communities and in the most integrated setting appropriate
- The health care financing system must provide for equitable sharing of costs by including people with disabilities and those with pre-existing conditions in the broadest possible risk sharing pool
- The health care system must have a comprehensive, affordable and seamless schedule of benefits and scope of coverage that includes outpatient services, specialty services, medications, supplies, assistive technology, durable medical equipment, mental health services, vision, hearing and dental care

CRITICAL ISSUES

Architectural and Programmatic Access

- Accessible health care facilities so that individuals with disabilities can approach, enter, move around and use the facilities (including facility parking lots, waiting rooms, examination and treatment rooms, food service facilities, and restrooms) as conveniently as everyone else
- Accessible medical screening and diagnostic equipment, for example, lift equipment, adjustable high/low exam tables, wheelchair scales, and imaging equipment.
- Accessible technology, including all electronic communication (for example, e-mail, billing, and filling prescriptions) and accessible web sites

that can be used and understood by everyone regardless of whatever browser or adaptive equipment they employ[3]

- Provision of sign language interpreters when services are accessed
- Materials in alternative formats such as Braille, audio recording, large print, and CDs
- Transfer assistance when needed
- Modified appointment times and appointment windows when needed
- Culturally competent services including language access services
- Meaningful enforcement of all architectural and programmatic accessibility requirements under current state and federal law

Access to Care and Services

- Appropriate and adequate health care, and treatment modalities, whether in the community or in a facility or institution
- Access to specialty care services including services provided in hospital outpatient specialty care centers and other outpatient or inpatient settings
- Availability of a sufficient number of providers including specialists in and near the communities where people live
- Assistance with transportation to specialty providers and care centers if these are outside the beneficiary's immediate community or coverage area
- Adequate services to persons with multiple disabilities or co-occurring disorders
- Integrated systems of care that meet the needs of people who must access multiple service systems

Work Incentives

- No lesser coverage for employees with disabilities
- No discrimination against employees with disabilities
- Coverage for preexisting conditions
- Elimination of incentives to stop work in order to obtain health care
- Promotion of seamless access to coverage between jobs and for the self-employed

[3] Accessible web sites are constructed in accordance with the guidelines formulated by the Web Accessibility Initiative of the World Wide Web Consortium **(**www.w3.org/WAI/**).**

Community Long-Term Care and Elimination of Institutional Care Incentives

- Elimination of financial incentives to institutionalization
- Proactive promotion of community alternatives to institutionalization
- Elimination of arbitrary “homebound” requirements
- Elimination of biases that compel parents to give up custody or choose out-of-home placements for their children

Coverage/Scope of Benefits

- Seamless coverage and a single comprehensive schedule of benefits to the extent possible
- Elimination of arbitrary and differential caps or limits on payment for health care and services that are based on disability or type of disability
- Elimination of arbitrary and differential caps or limits, and arbitrary homebound requirements, on payment for assistive technology (for example, speech devices), or durable medical equipment (for example, electric wheelchairs)
- Mental health parity, and substance abuse program parity, including elimination of separate caps and limits on reimbursement for services
- Protection of currently mandated coverage under Knox-Keene and the Insurance Code, such as for prosthetic devices and diabetes care and services
- Protection of benefits currently available under public health care programs such as Medi-Cal and Healthy Families
- Protection of benefits (including Medi-Cal carve-outs) currently available under specialized health care programs including the California Children’s Services (CCS) program, the Genetically Handicapped Persons (GHPP) program, the Child Health and Disability Prevention (CHDP) program, the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, and the AIDS Drug Assistance (ADAP) program

Affordability and Shared Responsibility

- The broadest possible risk pool that does not penalize but includes individuals with a disability (e.g., Medicare)
- An understandable and equitable premium and cost sharing structure that does not deprive individuals and families of resources for basic needs
- A financing system that does not force people with disabilities to pay a disproportionate share of individual or family resources for health care
- A system of provider compensation or provider risk sharing that does not penalize individuals for having complex medical conditions or a need for access to particular specialists

Wellness Promotion

- Programs must not stigmatize or otherwise discriminate against persons with disabilities or particular disabilities
- Programs must respect personal choice and involve consumers in the design and choice of services offered
- Programs must be accessibly designed and inclusive of people with disabilities who wish to participate
- Prevention of secondary conditions must be included, for example decubitus ulcers
- Programs must provide rewards and incentives to encourage wellness and must not penalize individuals for failing to participate or for lack of success
- Programs must not deprive individuals of resources necessary to meet basic needs

Consumer Protection and Quality Assurance

- Monitoring and enforcement of state and federal access and nondiscrimination requirements
- Incentives to providers for compliance with access and nondiscrimination requirements
- Monitoring and enforcement of state and federal confidentiality and privacy laws
- Assurance that information about consumers will not be used to discourage consumers from seeking care or services
- Protection of basic due process rights including timely and adequate notice, and grievance and appeal procedures regarding eligibility, coverage, medical necessity, quality of care, nondiscrimination, and confidentiality
- Proactive benefits *planning* services in plain language with one on one counseling available, including general information about due process rights
- Adequate procedures for second opinions and independent medical review
- Quality assurance practices for health care appropriate to a range of functional limitations and needs
- Quality assurance practices for ensuring that persons with various disabilities have input into their own medical care and decisions
- Quality improvement practices for improving the health care system based on input from persons with disabilities

SHORT BIBLIOGRAPHY

- Institute of Medicine, Committee on Disability in America, Marilyn J. Field and Alan Jette, eds. *The Future of Disability in America*. Washington, D.C.: National Academies Press, 2007.
- The Center for Disability Issues and the Health Professions, The Center for Health Care Strategies, and The Lewin Group. *Performance Standards for Medi-Cal Managed Care Organizations Serving People with Disabilities and Chronic Conditions*. Oakland, CA: California Health Care Foundation, 2005. *Available at*: http://www.chcf.org/documents/Medi-CalPerfStandardsRecommendations112205.pdf.
- T. B. Ustun, N. K. Kostansjek, and J. Bickenback. "WHO's ICF and Functional Status Information in Health Records." *Health Care Financing Review* 24, no. 3 (2003).
- RAND Health. *The Health Insurance Experiment: A Classic RAND Study Speaks to the Current Health Care Reform Debate*. Santa Monica, CA: RAND, 2006. *Available at:* http://www.rand.org/pubs/research_briefs/RB9174/.
- Mollyann Brodie, Kaiser Family Foundation. *Insights Into the Public's Views About Health Insurance: Challenges and Opportunities for Would-be Reformers*. Presentation at national Academy of Social Insurance Annual Conference, February 2, 2007. *Available at:* http://www.nasi.org/usr_doc/Mollyann_Brodie_NASI_Presentation_02_02_07.pdf.

DISABILITY HEALTH COALITION

Disability will touch the lives of most Californians

The **DISABILITY HEALTH COALITION** is a coalition of organizations with the common goal of increasing access to health care for people with disabilities.

Access to Independence; Alameda County Developmental Disabilities Council;
AT Network; Brain Injury Center; Breast Health Access for Women with Disabilities;
California Coalition for Mental Health;
California Council of Community Mental Health Agencies;
California Disability Community Action Network;
California Foundation for Independent Living Centers; Californians for Disability Rights, Inc.;
Center for Disability Issues and the Health Professions;
Center for Independence of the Disabled; Central Coast Center for Independent Living;
Communities Actively Living Independent and Free;
Community Research for Assistive Technology;
Community Resources for Independent Living; Dayle McIntosh Center;
Disability Rights Education and Defense Fund; Disability Rights Legal Center;
FREED Center for Independent Living; Handi Habitats;
Independent Living Resource; Independent Living Resource Center, San Francisco;
Independent Living Resource Center, Santa Barbara;
Independent Living Services of Northern California;
LightHouse for the Blind and Visually Impaired; Mental Health Association in California;
Multiple Sclerosis California Action Network; Office on Disability and Health;
Protection and Advocacy, Inc.; RespectABILITY Coalition;
Silicon Valley Independent Living Center;
Spinal Cord Injury Network International; The Alliance for Technology Access;
Through the Looking Glass; Traumatic Brain Injury Services of California;
World Institute on Disability

If you are interested in more information or would like to
JOIN the **DISABILITY HEALTH COALITION**
www.disabilityhealth.kintera.org

DISABILITY HEALTH COALITION
1029 J Street, Suite 120, Sacramento, CA 95814
(916) 325-1690 (Voice) (916) 325-1695 (TTY) (916) 325-1699 (Fax)