



## **Health Care Reform for Persons with Disabilities: Key Principles and Recommendations**

Disability is a natural part of the human experience, and disability knows no social, racial, age or other demographic boundaries. People with disabilities share many of the same goals, dreams, and frustrations as other members of society. They are a resource to their communities and society and should be valued as full and productive citizens. People with disabilities face challenges in acquiring and accessing health care services. Many health care services people with disabilities require are typically not covered under standard insurance plans; in cases where they are covered, the costs are prohibitive. Given the level of unemployment and underemployment of people with disabilities, people with disabilities frequently lack the option of employer-based insurance coverage. Purchasing private health insurance is often cost-prohibitive and people with disabilities often do not receive private coverage due to pre-existing conditions.

Nebraska has 250,534 individuals with disabilities ages 5 and older-- approximately 14.5% of the total state population<sup>1</sup>. Moreover, The Surgeon General's Report on Mental Health indicates that one in five Americans is affected by a mental illness<sup>2</sup>. People with severe mental illness die, on average, 25 years earlier than the general population<sup>3</sup>. Health care for people with disabilities and chronic conditions includes a range of services and devices that include acute care medicine. Such services are often long-term and seek to maximize the health status, full function and participation in society, employment, independent living, and the pursuit of

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<sup>1</sup> US Census (2005)

<sup>2</sup> Surgeon General's Report on Mental Health (1999)

<sup>3</sup> *Morbidity and Mortality in People with Serious Mental Illness* (2006)

fulfilling and meaningful lives. Efforts to reform U.S. healthcare policy must not only address acute sickness and threats to health, but must also include long-term care and other issues pertinent to persons with disabilities. Effective healthcare reform cannot ignore the impact on persons with disabilities and the ability of individuals with disabilities to access, acquire, and follow through with their healthcare. We are concerned that the current debate and discussion around healthcare reform is missing important disability and long-term care components. Efforts to re-design the American healthcare system without addressing disability and its attendant healthcare demands on people with disabilities will only be a piecemeal solution and will continue to force them to encounter significant financial and systemic barriers to maintain their health. To that extent, we have included some principles which we believe should guide the discussion of healthcare reform so that people with disabilities are included in overall healthcare reform efforts.

Disability should be viewed as a litmus test for how well a reformed health care system will address the needs of *all* Americans. In 1998, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry<sup>4</sup> 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 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.”**

A health care system that provides comprehensive and high-quality care to people with disabilities will more effectively meet the wide-ranging healthcare needs of the broader population.

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<sup>4</sup> <http://www.hcqualitycommission.gov/>

## Principles and Recommendations

- 1. Integration**—*Healthcare reform must promote mental healthcare as integral to overall health. As integration of primary care and mental healthcare becomes the norm, continued attention must be paid to addressing the unique needs of people with mental health conditions.*

Integrated health care is an approach that is characterized by a high degree of collaboration among the various health professionals serving patients in terms of assessment, treatment planning, treatment implementation, and outcome evaluation. Evidence suggests that coordinated care that integrates mental health treatment within primary care and other services can enhance access to services, quality of care, and lower overall health care expenditures.

- Healthcare reform must ensure that coverage of and access to treatment and rehabilitation for mental health conditions in the public and private sectors are not more limited than for other health conditions (whether through restrictive limits on the frequency or duration of treatment, cost-sharing requirements, access to providers and specialists, range of covered services, or reimbursement practices);
- Any health expansion must ensure that people with mental health conditions have access to the full array of services necessary for recovery from these conditions and are not subject to arbitrary limits on days, visits, and other conditions of coverage;
- Consumers and families should be meaningfully and significantly involved in all aspects of healthcare reform planning, implementation and evaluation;
- Healthcare reform must promote effective mental health check-ups and early intervention for mental health conditions across the lifespan, recognizing that half of all lifetime cases of mental illness begin by age 14;
- Models of care encouraging primary and preventive care, including medical home models and wellness programs, must be responsive to and inclusive of the needs of people with mental health conditions, including direct access to care by mental health professionals;
- Chronic care management programs must include mental health conditions among the conditions they cover. Intensive outreach, limited or no co-payments and enhanced services are important components of chronic care management that will be particularly helpful for people with mental health conditions;
- Healthcare reform should include a focus on quality of mental health treatment and create incentives for implementation of evidence-based and promising practices;

- Healthcare reform must also include workforce training initiatives to effectively meet the mental health treatment needs of an increasingly ethnically diverse population;
- People should have choices on their health and mental health care that foster recovery and wellness through individualized community-based services and supports;
- Any denials of coverage must be transparent and subject to an independent review process that enables individuals to effectively challenge a denial; and
- Efforts to improve our healthcare system through comparative effectiveness research should ensure that consumers who may require very individualized care (such as individuals with a mental illness) are fully engaged in setting the research agenda and that the needs and concerns of these consumers are afforded special consideration and accommodation in the use of comparative effectiveness research for decision-making regarding coverage. Comparative effectiveness research provides information on the relative strengths and weakness of various medical interventions. Such research will give clinicians and patients valid information to make decisions that will improve the performance of the U.S. health care system.

**2. Full Participation**—*People with disabilities of all ages and their families must be able to participate fully in the nation's health care system.*

People with disabilities and chronic illnesses are often 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. A reformed health care system must:

- Ensure the private insurance system covers all Americans so that people with disabilities are not forced to rely on Medicaid and Medicare as the only option for healthcare coverage;
- Provide access to private coverage without regard to health or disability status on par with access to coverage provided to those without disabilities;
- Prohibit rating practices that make private coverage unaffordable for higher users of health care; and
- Strengthen the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities enrolled in the program (e.g., evidence-based practices, payment structure that attracts providers, etc.).

**3. Accessibility**—*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, people 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.

**4. Continuity of Care**—*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.*

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 thus reducing the need for expensive 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.

**5. Appropriate Services Meet Needs and Preferences**—*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.*

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.

**6. Affordable and Equitable Access**—*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 other factors such as employment 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.

**7. Access to Effective and Quality Care**—*People with disabilities and their families must have access to health care that is effective and high quality with a minimum of administrative waste.*

An efficient health care system:

- 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.