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These are copies of
Erica Jones' transcripts
for the HC Forum
held at TIR2

Over two thirds (67%) of respondents reported that they were not receiving the kinds of health care services that they needed to maintain optimal health.

26% had been denied insurance coverage

16% had been dropped or canceled by an insurance group

23% had been denied employment because of a health-related problem

21% had chosen not to work so that they could remain eligible for public health insurance

35% had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer

How satisfied were the respondents with the current health care system?

73% of the respondents said that the high cost of treatment represents the biggest problem that they had encountered with the system

48% cited inadequate insurance coverage

45% cited lack of understanding of the health care needs and concerns of people with disabilities by physicians and other health care professionals

**38% cited inadequate preventive and health
maintenance services**

**34% cited inadequate coverage for assistive
technology services**

32% cited problems with access to treatment and services

**30% cited unresponsive insurance companies and
rude and discourteous providers and
administrators**

**24% cited inadequate personal assistance services
to maintain optimal health**

1) Non-discrimination -- People with disabilities and other chronic conditions of all ages and their families must be able to participate fully in the nation's health care system

2) Comprehensiveness -- People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal assistance, and support services across all service categories and sites of service delivery

3) Appropriateness -- People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal assistance and support services are provided on the basis of individual need, preference, and choice

4) Equity -- People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs

5) Efficiency -- People with disabilities and their families must have access to a health care system that provides a maximum of appropriate effective quality services with a minimum of administrative waste

6) Consumer Control -- People with disabilities should be involved in directing their health care, including such things as choosing and directing a physician, personal assistant, or other provider.

An efficient health care system is one that:

- **reduces administrative complexity and minimizes administrative costs;**
- **allocates resources in a more balanced way between preventive services, acute care, rehabilitation, and chronic care management**

- **ensures the delivery of effective services**
- **maintains effective cost controls so that all people can get the health care services which they need**

Perhaps our greatest contribution will be in clarifying the principles which should guide our health care system. These include:

(1) expanding the definition of "health" to include prevention services, rehabilitation therapies, assistive technology, and on-going health-related maintenance services;

(2) distributing all health related expenses equitably throughout the population; and

(3) restructuring our health care delivery system to more effectively support consumer-directed chronic care management.

SINGLE PAYER

VS

MANAGED COMPETITION

Optimal:

Choice/Self Direction/Individual Dignity

Paradigm shift. There must be a shift away from the current "episodic sickness" model of health care and toward a long-term partnership between provider, consumer, and payor that focuses on achieving the maximum wellness possible for every individual

Cost effectiveness. Cost effectiveness needs to be stressed over cost containment. Providing appropriate services at the right time will result in greater savings to the system than will efforts to avoid costs by refusing payment for low-cost prevention and early intervention services.

ACCESS AND COVERAGE

Universal access and mandated coverage make more fiscal sense than does the current system of limited access and selective coverage.

EQUITY

Financing of health care services needs to be arranged in a manner that does not penalize some segments of society in favor of others.

PORTABILITY

Health care coverage should be portable, so that people can pursue careers and life options without fear of catastrophic financial loss associated with changing jobs or life situations.

SYSTEM RESPONSIVENESS

Any health care reform initiative should include mechanisms to promote professional responsiveness to consumer needs.

This approach will require payment for low-cost prevention and early intervention services

Incorporating key features

1) expands the definition of "health" to include prevention services, rehabilitative therapies, assistive technology, and ongoing health-related maintenance services

2) distributes all health-related expenses equitably throughout the population

3) restructures our health care delivery system to support effective consumer-directed health care management