

## Coalition of Texans with Disabilities

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### 1994 DELEGATE RESOLUTION

#### TEXAS MEDICAID MANAGED CARE

WHEREAS, the State of Texas Senate Committee on Health and Human Services has made it a goal to fundamentally restructure the traditional Medicaid delivery system and convert to a comprehensive managed health care program if Texas can improve access, quality, and to achieve cost containment purposes, and

WHEREAS, CTD desires a comprehensive, non-discriminatory, equitable, accessible and fully inclusive long term and acute care system for people with disabilities that expands the definition of health from absence of disease and impairment to include the on-going maintenance of health and function, that promotes independent living, and

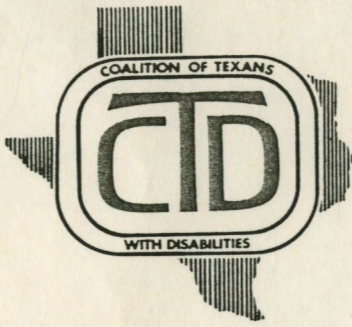
WHEREAS, CTD has adopted resolutions calling for enactment of comprehensive national health insurance for all persons regardless of ability to pay, health status, disability, age, race, sex or geographic residence and equitable distribution of health-related costs in 1984, 1989 and 1991, and

WHEREAS, the research collected by CTD indicates managed care does not necessarily improve quality of care, and may promote inequality and inadequate access for people with disabilities, and

WHEREAS, there is little evidence that current managed care systems significantly reduce cost, and depending upon the financial mechanisms utilized by a managed care plan, there may exist systemic financial incentives for physicians to under treat, especially for populations with disabilities and/or chronic medical needs,

THEREFORE, BE IT RESOLVED, that The Coalition of Texans with Disabilities can not endorse the implementation of a managed care initiative to replace the current Texas Medicaid delivery system, until we feel assured the proposal will follow the safeguards and principles outlined in our position paper, "Texas Medicaid Reform - Inclusion of People with Disabilities: Principles, Components and Safeguards."

SEE ATTACHMENT A



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### TEXAS MEDICAID REFORM

#### **Inclusion of People with Disabilities: Principles, Components & Safeguards**

The Coalition of Texans with Disabilities welcomes the opportunity to provide a vision for Texans with disabilities under a managed care model with acute and long-term community based personal assistance services through a Medicaid 1115 waiver. The Coalition of Texans with Disabilities is a statewide cross-disability coalition of over 40 member organization controlled and directed by people with disabilities who are working together to eliminate all barriers to equal and full participation in life for the 2.8 million Texans with disabilities.

The research collected by the CTD illustrates many inherent problems facing people with disabilities in a managed-care structure; therefore the vision we offer for managed care is not to be considered an endorsement of a Texas Medicaid managed care system.

A group of advocates representing cross-disabilities met July 20, 1994 to discuss pros and cons of conversion to a managed care structure. To improve the Texas Medicaid program for Texans with disabilities it must: (1) be accessible to and fully include persons with all types of disabilities, and (2) appropriately and adequately meet their health care needs for acute and long-term care.

In an effort to describe such a system, CTD offers:

- I. Guiding Principles for Primary/Acute and Community-based Long-Term Services for People with Disabilities
- II. Components of a Managed Care System from a Disability Perspective
- III. Categories of Services
- IV. How the System Would Work for People with Disabilities
- V. Safeguards to Inadequate Health Care Delivery for People with Disabilities

I. Guiding Principles for Primary/Acute Care and Community-based Long-term Services for People with Disabilities

1. The **definition of health** must be expanded from the absence of disease and impairment to include the on-going management of chronic conditions. Health care must cover on-going maintenance of health and function and provide consumer-controlled personal assistance and mental health services.
2. People with disabilities of all ages and their families must have access to health care which is **non-discriminatory** and does not segregate people with disabilities from the general population.
3. People with disabilities and their families must be ensured equitable participation in a health care system and not be burdened with disproportionate cost.
4. Health care must be consumer-driven with participation, decision-making, and choice whenever possible by the person with the disability. Consumers should have significant involvement in the program design, implementation and monitoring. Maximum control of the health services by the person with the disability must be required. Family and friends may play a supportive role as necessary.
5. People with disabilities must be served on the basis of functional need, not medical diagnosis. Individuals should be allowed to select the services and supports required for them to function.
6. Long-term services must include: Personal Assistance Services (PAS), independent living supports, respite, and maintenance/or improvement of function services such as, physical therapy, occupational therapy, speech therapy, assistive technology and prescription drugs.
7. Long-term and intermittent PAS must be community-based and should be available where persons with disabilities need them: home, work, community, school and during recreational activities.

8. PAS programs should be offered for persons with disabilities which have options on employer/employee relationships.
9. Primary/Acute Care and PAS should be provided to people with disabilities of all income levels through a sliding scale co-pay basis that takes into consideration non-traditional costly expenses such as PAS.
10. Eligibility requirements should be standardized with uniform financial eligibility criteria adopted. Income eligibility cap should be raised and disincentives to employment removed.
11. A "quality of life" cost benefit analysis must never be used as a justification for limiting coverage. People with disabilities must not have to continue to justify their existence.

## II. Components of a Managed Care System from a Disability Perspective

1. Combines all Medicaid Long-term Care and Acute Care Funding Streams, not including Federal and State Vocational Rehabilitation funds.
2. Standardizes eligibility requirements and adopts uniform financial eligibility criteria which includes cost sharing.
3. Allows funding mechanisms with direct cash and voucher options based on a Personal Service Plan assessment process which leads to allocation of specific services and dollar amount per client based on individual functional need.
4. Provides specific services, not only to treat acute and chronic conditions, but also to promote and maintain health and optimum functioning and prevent deterioration and secondary complications. Services to be included:
  - a. diagnostic services;
  - b. long and short-term home and community-based services;
  - c. prescription drugs, biological and medical foods;

- d. consumer-driven mental health counseling and substance abuse services without arbitrary limits;
- e. personal assistance services;
- f. independent living supports;
- g. durable medical equipment and other assistive devices and related services appropriate to functional need;
- h. respite;
- i. maintenance/or improvement of function: those services needed to prevent deterioration of a chronic condition which can include occupational therapy, hearing and visual aids, speech therapy, outpatient mental health services, respiratory therapy, audiology services, speech-language pathology services for speech or language problems, augmentative communication, feeding and swallowing problems, cognitive therapies, and mobility training for persons with severe visual impairments.

5. Provides programs and assistance designed to support the individual in the community on the basis of individual need, preference, and choice which ensure:

- a. consumer choice in relation to services and provider;
- b. a menu of service settings through an integrated delivery system;
- c. appropriate amount, scope, and duration of services and;
- d. availability of trained personnel.

6. Provides the maximum, appropriate, effective, and quality services with minimum administrative waste by:

- a. the State of Texas maintaining management of the program; and
- b. implementing a fee for service structure rather than contracting with the insurance industry.
- c. removing disincentives for medical providers to refer an individual for specialized services.

7. Provide a choice of providers with a recognition that the primary care physicians for individuals with disabilities and chronic health conditions frequently are specialists. Often a physician's lack of familiarity with a condition increases risks of undertreatment. Typically, people with

disabilities requiring specialized services face many "gatekeepers" in a managed care system.

8. Includes consumer driven mental health and substance abuse services that will be provided without arbitrary limits and be responsive to functional need rather than a biochemical label.

### III. Categories of Services

#### 1. **Long-term Care**

a. Personal Assistance (Attendant) Services (PAS): Any action to assist a person with a disability in accomplishing activities of daily living. The term PAS covers a broad spectrum of activities including bathing, dressing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, dispensing of routine medications and similar tasks. Most often the term refers to activities a person is unable to do, or has a great deal of difficulty in doing. Can also include monitoring and cognitive assistance like reminding a person to take his/her medicine, helping to balance a checkbook or pay bills. Some health-related tasks are delegated to unlicensed persons per the Board of Nurse Examiners Rules on Delegation of Selected Nursing Tasks To Unlicensed Personnel, implemented December 1992. Other health-related tasks can be delegated to an unlicensed person by a physician.

b. Independent Living Supports: Includes, but not limited to, transportation, assistive technology, assistive animals, habilitation.

c. Respite: Support options that are provided temporarily for the purpose of relief for a primary caregiver in providing care to individuals of all ages with disabilities or at risk of abuse or neglect. Respite services may be provided under home health, hospice, or personal assistance services depending on the needs of the client.

d. Maintenance/or Improvement of Function: Those services needed to prevent deterioration of a chronic condition. Can include physical therapy, occupational therapy, hearing aids, speech therapy,

outpatient mental health services, respiratory therapy, audiology services, speech-language pathology services for speech or language problems, augmentative communication, feeding and swallowing problems, cognitive therapies, and mobility training for persons with severe visual impairments.

**2. Primary/Acute Care:** Responsive to individual needs without service limitations set by a specific disorder or disability, i.e., a cap on mental health services.

- a. Traditional medical acute services, plus.
- b. Vision services to maintain/increase visual functioning including low vision aids and training in their use.
- c. Hearing technology.
- d. Access to disability specialist.
- e. Consumer driven psychiatric and medical services.
- f. Temporary intense living situations in the home. An example of this is someone with mental illness needing close supervision after an severe episode.

#### IV. How the System Would Work for People with Disabilities

Under this waiver application, once a person is assessed, a designated maximum amount is set and a Personal Support Plan is developed which allows the consumer the flexibility to obtain services. The plan specifies the services to be provided, their frequency, and who provides them and the costs. The Personal Support Plan will be jointly developed with consumers and reflect consumer preference and functional capabilities, including physical, cognitive, mental health, and sensory needs.

Existing service categories are eliminated. Instead, participants are offered an individualized, integrated package of services, programs and assistance designed to support the individual in the environment of his or her choice.

There will be options for consumer-managed plans which provide the greatest control over service and support design. The consumer may: (a) receive direct cash payments and maintain and verify payment of services and be responsible for employer/employee responsibilities or (b) receive a voucher for payment of services and hire the personnel, with an intermediary fiscal agency who makes payment to providers, handles payroll, taxes, insurance and other appropriate records or (c) an agency provides or contracts the services.

The Personal Support Plan must indicate a path of access and provision for all services should be developed for people with disabilities. Adequate funding should be provided for all prescribed services in the personal support plan.

A Personal Assistance Services Program would be created, not unlike the proposal of President Clinton: The PAS program would serve people with all types of disabilities by combining funding from several agencies. Personal assistance services will be based on functional need rather than age of onset, severity or cause. The program would be designed to offer a "menu of services" from which the client can choose, including comprehensive outpatient services for maintenance of chronic conditions, cognitive impairments and limitations and mental health conditions. *(Refer to Section III for Categories of Service)*

Involvement of health professionals in the PAS Program would be assigned to various levels with agreement by the person with a disability or family of a child:

- Level 1: no health professional -- delivered by unlicensed personnel.
- Level 2: minimum health professional involvement
- Level 3: maximum health professional involvement

PAS services will be agency delivered, as well as provided by voucher or individual providers. The location of delivery of services would be the choice of the client and include, in-home and other locations. Health-related tasks would be delegated by a nurse as per the Board of Nurse Examiners Rules on Delegation of Selected Nursing Tasks To Unlicensed Personnel or by a physician, as per the Medical Practices Act. Supervision would be at intervals mutually agreed upon by the individual receiving services and the provider.



Coordination of services would facilitate cost savings and maximum utilization. Case management should be an optional and available service delivery component. Case managers should be independent of direct service providers. Private/Public competition should be allowed as a means to facilitate consumer choice and cost savings.

#### V. Safeguards to Inadequate Health Care Delivery for People with Disabilities

Managed health care systems have posed a number of problems for people with disabilities. If Texas decides to adopt a managed health care system, there must be safeguards to ensure people with disabilities are included. The following is a list of safeguards we feel must be included in any health care model:

1. Choice of providers and ease of switching providers.
2. A recourse/appeals process involving an independent and impartial review panel.
3. Design of program should be flexible so that rigid categories are avoided.
4. A co-pay design, to prevent those working or with higher incomes from losing services.
5. Routine billing with costs reflective of actual costs and not a system that bills for services not provided.
6. System that does not penalize individuals with chronic intermittent needs by capping the amount of services they need because of cost. Flexible systems should be developed to meet the needs of "high needs" persons.
7. Presumed eligibility from the onset, to prevent unnecessary waits for service.
8. Maintenance of functional ability - the system must recognize ongoing maintenance to prevent more costly acute care.

9. No barriers to services due to transportation barriers.
10. Adequate funding should be provided for all prescribed services in the personal support plan.
11. Waiting lists can not count as services.
12. Voucher options that allow clients to go outside the system to acquire services.
13. Providers will increase by requiring any medical student accepting state assistance for loans or grants to accept Medicaid until their student loan is paid or for a set number of years. This could be tied to licensure and include non-physician providers such as occupational therapists, speech pathologists, optometrists.
14. The system must not save money at the cost of unmet health care required for the consumer.
15. Consumer education on how to access the system and utilize the programs must be provided.
16. The system must not save money by serving only current clients.

We believe our health care system must provide access to comprehensive health care for everyone. We look forward to working with you on this issue in the future. The Coalition of Texans with Disabilities wishes to express our appreciation for the opportunity to present our vision for an inclusive health care system. Should you require further explanation or assistance please contact Belinda Carlton, Executive Director at 512/478-3366.

FOR A BARRIER FREE SOCIETY,

THE COALITION OF TEXANS WITH DISABILITIES