Coalition of Texans with Disabilities
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74th Texas Legislature Position
Adopted by CTD Delegates November 1994

TEXAS MEDICAID REFORM: TEXANS WITH DISABILITIES

RECOMMENDATION: The Coalition of Texans with Disabilities recommends reform of the Texas Medicaid system to a managed health care model with acute and long-term community based personal assistance services through a Medicaid 1115 waiver if (1) it is accessible to and fully includes persons with all types of disabilities of all ages, (2) appropriately and adequately meets their health care needs for acute and community-based long-term care, and 3) people with disabilities are guaranteed involvement in the development of the waiver.

BACKGROUND: The State of Texas Senate Committee on Health and Human Services, on November 30, passed a motion that in an attempt to fundamentally reform the Texas Medicaid delivery system, the state should seek an 1115 (c) waiver with the intent of using the waiver to convert Medicaid into a comprehensive managed health care program. The Senate Committee on Health and Human Services passed a motion in earlier hearings on Medicaid reform June 1, 1994 that the goal of Medicaid reform would be to "improve access, quality, and cost containment."

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

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

IMPORTANT SAFEGUARDS FOR TEXANS WITH DISABILITIES:

- The system must shift Medicaid resources away from institutional care toward predominantly community-based services and supports including: 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,

consumer driven psychiatric and medical services and prescription drugs. Long-term and intermittent PAS must be available where persons with disabilities need them: home, work, community, school and during recreational activities.

- The system should combine all Medicaid Long-term Care and Acute Care Funding Streams, not including Federal and State Vocational Rehabilitation funds.

- The system must not burden people with disabilities with disproportionate costs, phase them in at a slower rate than other Texans, save money by serving only current clients or at the cost of unmet health care required by the consumer.

- The income eligibility cap must be raised and a co-pay designed to prevent those working or with higher incomes from losing services thereby allowing individuals with long-term support needs, such as personal assistance services, to work without risk of losing services.

- The system must provide the maximum, appropriate, effective, and quality services with minimum administrative waste by the State of Texas maintaining management of the program; and implementing a fee for service structure rather than contracting with the insurance industry.

- The system must provide a recourse/appeals process involving an independent and impartial review panel that maintains client confidentiality.

- Consumer education on how to access the system and utilize the programs must be provided.

- There must be presumed eligibility from the onset to prevent unnecessary waits for service.

- The system appropriately and adequately meets the health care needs of Texans with disabilities for acute and long-term services and be based on functional-needs, rather than on medical diagnosis.

- The system must provide a choice of providers with a recognition that the primary care physicians for individuals with disabilities and chronic health conditions frequently are specialists. Voucher options that allow clients to go outside the system to acquire appropriate services must be implemented.

- Providers could 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.

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RESPONSES

SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES MOTIONS FOR MEDICAID REFORM

The Senate Committee on Health and Human Services made recommendations for Medicaid Reform on November 30, 1994. Some of these motions will require legislative action. The Coalition of Texans with Disabilities has the following responses to those relevant to the concerns of Texans with disabilities:

SUPPORT

Motion 12 — An integrated, cross-disability model for long-term care should be piloted.

Motion 24 — The Texas Department of Health should identify and remove barriers to cost-effective home care services.

Motion 9 — Guaranteed eligibility for a minimum of 12 months will help alleviate problems associated with individuals who constantly lose and regain Medicaid eligibility.

Motion 8 — Funding should be provided to prevent cuts to services, payment levels or tightened eligibility.

Motion 13 — A pilot for mental health and substance abuse services will allow Texas to begin to understand the many unknowns in integrated service delivery to mental health consumers.

Motion 14 — Residents of Level 1 ICF-MRs should be moved to the Home and Community-Based waiver program.

Motion 16 — The Vendor Drug program should be continued, and the number of prescription drugs should be increased above three.

Motion 19 — A mechanism must be in place to allow for consumer complaint resolution and grievances/appeals that maintains client confidentiality. CTD believes this mechanism must be independent of service delivery.

OPPOSE

Motion 17 CTD opposes privatization of state schools. We believe the state should be moving to shift individuals from state schools into community settings; we support state school closures. Privatization only serves to continue to legitimize and entrench an institutional-based, rather than community-based service delivery system. (for study on whether to privatize)

Motion 5 Under the recommendation that nursing homes be dually certified for both Medicaid and Medicare, examples of dual certification given were community care programs - Primary Home Care and the Nursing Facility Waiver. In Primary Home Care, the Texas Department of Human Services are promulgating rules to remove the requirement for dual certification.

CTD opposes dual certification for personal attendant service providers, because it limits available choice of providers, potentially drives up costs, and because it lends itself to a more "medical-model" service delivery (treating individuals as "patients") rather than an "independent living model" (viewing services as supports needed to maintain independence). We want assurance that if personal assistance services is included in the 1115 (c) waiver, that providers will not be required to have dual certification. (Motion 5)

CONCERNS

Motion 11 Ensure that people with disabilities are phased into the managed health-care system at the same rate as non-disabled individuals. Although Motion 11 does not specifically refer to a timetable for phase-in, the report "Medicaid: Prescription for Change" suggests a slower phase in for people with disabilities.

Motion 8 If local governments are given the first opportunity to administer the Medicaid managed care system, that precautions must be in place to ensure they do not have freedom to limit services, and that services in one area will be comparable to services available in another.

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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

cc: Camille Miller, Chief of Staff
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