PASWORDS

An Update and Action Agenda for
The Coalition of Texans with Disabilities'
Personal Assistance Services Task Force

PAS: A key to independence

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WHAT'S INSIDE

Medicaid: An Endangered Species?

DESPITE A DECEMBER 6, 1995 VETO BY THE PRESIDENT, U.S. CONGRESSIONAL LEADERS CONTINUE TO PROMOTE CONVERTING MEDICAID INTO BLOCK GRANTS TO STATES, ENDING THE FEDERAL ENTITLEMENT (GUARANTEE TO CERTAIN MEDICAID SERVICES IF YOU QUALIFY), AND CUTTING MEDICAID BY $117 BILLION OVER SEVEN YEARS.

Features of the Balanced Budget Reconciliation Bill vetoed by the President included: 1) unprecedented authority by states to define what services to provide, with the only required services being immunizations and pre-pregnancy family planning; 2) federal requirement that states must provide services to below-poverty pregnant women, children, and people with disabilities (States would be allowed to define disability); and 3) requirement that states spend only a fraction of previous spending on low-income elderly and persons with disabilities. Estimates are that the Congressional proposal would have resulted in a 20% reduction in Medicaid funds to Texas over seven years.

The most disturbing aspects of this vetoed proposal were that states would be able to define disability, decide what service they would offer, and abolish "entitlements". People with disabilities currently on Medicaid acute and/or long-term care and those waiting could find themselves no longer eligible.

Following his veto, the President promptly introduced his own version of a seven-year balanced-budget. Overall, the President's plan is much different from the Congressional Medicaid proposal. Instead of

block grants, the President proposes a "per-capita" cap on federal matching funds (not a cap on an individual's health care or long-term services.) The President would cut $54 billion from Medicaid over seven years, rather than the $117 billion cut in Congressional proposals, and maintain mandatory eligibility for federal SSI recipients and the current list of required Medicaid services. The plan further allows states to offer Medicaid home and community-based services without requesting federal waivers.

Two serious draw-backs in the President's proposal include: 1) it does not protect funds for long-term community services; and 2) it allows states to require Medicaid recipient's enrollment in managed care without federal waivers, but does not protect the needs of people with disabilities.

Medicaid has proven a "sticking point" in budget negotiations between the Administration and Congress. The President wants to preserve the federal entitlement to Medicaid services, Congress does not. The President wants less dramatic cuts, Congress wants deeper cuts. Neither side is budging.

A coalition of 20 Republican Governors, including Texas Governor Bush, continues to push for broad state flexibility allowed in the Congressional proposal and they oppose "per-capita" caps, entitlements, and mandated benefits.

The appropriations negotiations continue, and last week, Congress agreed to a continuing resolution (expiring late January) to partially reopen government, following the longest shut-down in history. The President has submitted another version of a seven-year balanced budget, based on Congressional Budget Office estimates. The future of Medicaid and other key services remains uncertain. **Do not slow down on your advocacy efforts. Let the President, the Congress, the Governor know what you need and what you believe is the right thing to do for America.**

Supreme Court Lets Landmark Decision on PAS Stand

ON OCTOBER 2, 1995, THE SUPREME COURT DECIDED NOT TO TAKE UP THE HELEN L. VS. DIDARIO PRECEDENT-SETTING LAWSUIT, allowing the 3rd Circuit Court of Appeals ruling to stand. Helen L. charged that the state of Pennsylvania's Department of Public Welfare violated Title II of the Americans with Disabilities Act when it refused to provide her community-based services, even though she qualified. Title II of the ADA requires services to be provided in the "most integrated setting" appropriate to the needs of an individual with a disability. Helen L., a mother of two, could have lived in the community with personal assistance services, rather than a nursing home, at a savings of close to $10,000. But Pennsylvania's Department of Public Welfare claimed that because the community-based services program was underfunded, Helen L. must remain on the waiting list for community services. She was forced to receive services in a nursing home. The Third Circuit Court agreed that the Pennsylvania Department of Public Welfare violated Title II of the ADA, and ordered the DPW to admit Helen L. into community services.

This 3rd circuit Court of Appeals ruling could apply to people placed in institutional settings which segregate them, if they qualify for and prefer community-based options. It does not apply to non-institutionalized people on waiting lists for community-based personal assistance services.

The Supreme Court's decision to let the 3rd Circuit Court's ruling stand, coupled with a Department of Justice "amicus brief" (friend of the court) in support of Helen L.'s case, provides legal precedent for other federal Circuit Courts (Texas is in the 5th Circuit) to adopt the same interpretation of the law if a similar case is brought forward. Had the Supreme Court heard the case, their decision would be binding in all U.S. federal Circuit Courts.

Managed Care: The Future for Long-Term PAS?

While the debate over the future of Medicaid rages in Congress, Texas is proceeding with plans to pilot a "managed care" model integrating acute/primary health care with long-term services using a combination of Medicaid and Medicare funds. This pilot is in response to recommendations outlined in Senate Concurrent Resolution 55 by Senator Judith Zaffirini.

The Health and Human Services Commission and the Texas Department of Human Services are working cooperatively to develop the pilot, which includes aspects that the Coalition of Texans with Disabilities endorses. However, because managed care has the inherent tendency to underserve, we remain concerned about allowing long-term services to be handed over to managed care entities. We want to ensure that a consumer has maximum choice and control over the development of their service delivery, and want to limit unnecessary "medical" intervention. The CTD PAS Task Force has participated in regular meetings being conducted by HHSC and TDHS on the development of the pilot. Additionally, the PAS Task Force coordinated a "focus group" held December 7, 1995 for TDHS with consumers who use Medicaid-funded personal assistance services. This focus group, one in a series of similar meetings, was designed to provide HHSC and TDHS with information for the pilot development from consumers regarding what works, and what does not work in the current Medicaid system.

This pilot is targeted for Medicaid-eligible people with disabilities age 21 and up. For individuals who now receive only basic attendant services from programs such as Primary Home Care or Client-Managed Attendant Services, participation in this pilot could mean a significant expansion of services available to you. Covered services will be similar to the Community-Based Alternatives program, and include: adaptive aids and medical supplies, emergency response, home health services, minor home modifications, occupational, speech, and physical therapies, respite, assisted living, adult foster care and more. This long-term care pilot will offer community-based services, medical acute services, and nursing homes as options. HHSC and TDHS would like to incorporate features unique to consumer choice and control models, such as vouchers for the purchase of PAS, and allowing services to be rendered both in and out of home. Additional services/enhanced benefits being considered include a housing component (to prevent unnecessary institutionalization), all medically-necessary prescriptions, and home-delivered meals.

The pilot assumes that the state will contract with two or more managed care organizations [MCO] to provide the continuum of services -- primary, acute, and all long-term services. The MCOs would also be responsible for preparing, coordinating and monitoring the long-term service plan, coordinating acute care services with a primary doctor, and providing case managers to authorize home and community-based services.

The pilot is slated to begin early in 1997, to allow time for its development and securing service providers. HHSC and TDHS would like to have one pilot site in an urban area, and one in a rural area. The pilot sites have not yet been determined, but the urban site will be in one of the following counties: Bexar, Dallas, Harris, Tarrant, or Travis.

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De-institutionalization and Attendant Benefits Resolutions Passed by CTD Delegates

CTD Delegates voted to accept resolutions submitted by the PAS Task Force on de-institutionalization and attendant benefits at the November 17-19 CTD Delegate Assembly. A resolution on integrated access to services was tabled. *Anyone wishing to provide input in a revision of this resolution, please contact Laura Brown, Project Coordinator at 512/478-3366.* The resolutions were adapted from position papers initially endorsed by the PAS Task Force. SEE THE CTD NEWSLETTER RECEIVED ALONG WITH THE PASWORDS FOR THE COMPLETE TEXT OF ALL RESOLUTIONS ADOPTED BY THE CTD DELEGATES.

Licensure Changes in Primary Home Care Up for Final Decision in January

On December 11, 1995 a public hearing was conducted by the Texas Department of Human Services on a proposed rule change in licensure requirements for Primary Home Care providers. This rule change would allow entities licensed under any category (including the Personal Assistance Services category) to provide Primary Home Care. The PAS Task Force testified in support of the rule change because we believe it is needed to promote consumer choice in providers, and also because Primary Home Care is a **non-medical** program that covers basic personal assistance, homemaker and escort services only. It is not necessary for a Primary Home Care provider to meet the highest level of licensure standards, as is currently required. **The TDHS Board is expected to make a final decision on January 19, 1995 at the Texas Department of Human Services Board Room, 701 W. 51st Street, Austin, Texas.**

BNE Approves Attendants Performing More Tasks Without RN Supervision

On November 8, the Board of Nurse Examiners approved a change in their Memorandum of Understanding with the Texas Department of Health allowing unlicensed persons (i.e. attendants) to provide feedings and routine medication administration through a permanently-placed gastrostomy tube IN RESPITE SITUATIONS ONLY. This change applies to "stable and predictable" consumers. The PAS Task Force supported this MOU revision in both Respite and PAS situations, because we feel it is consistent with our belief that services should be non-medical in nature. Allowing G-tube feedings and medication administration by unlicensed persons in Respite only was a compromise proposed by advocates. We hope it will eventually open the door for the same allowances in PAS, also.

The BNE's decision is contingent upon the development of guidelines to assure an unlicensed person's competency to perform g-tube feedings and medication administration. The Advisory Committee on the MOU, on which the PAS Task Force has a designated representative, will develop draft guidelines for determining competency in January, and submit them to the Texas Department of Health for final approval.

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