

PAS: A Key to Independence

PASWORDS

*A Quarterly Update and Action Agenda for the
Coalition of Texans with Disabilities
Personal Assistance Services Task Force*

June 1995 - Volume 4/Issue 2

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TDHS PAS PROGRAMS IN A CRISIS!

Funding for non-entitlement services at the Texas Department of Human Services is about 25% short of what is required to meet the needs of current clients, including a \$55 million shortfall in the Community Care budget line item. (See "Frail Elderly," page 2 for more information).

People could be dropped from programs. Waiting lists for programs will continue to grow, and access to basic personal assistance services will be limited to those with Medicaid entitlement eligibility.

The Texas Department of Human Services Board will decide at their board meeting July 21, 1995 how to insure that current clients do not lose services. One option is to implement a "hard freeze" on non-entitlement programs starting as early as July 1, 1995. The Board is also considering tightening eligibility requirements and reducing services across the board by 10 per cent. [*Non-entitlement* - even if you qualify, the state is not required to provide you services. *Hard freeze* - even if someone leaves the program and a slot becomes available, that slot will not be filled.]

ACTION ALERT!

- ✓ Call TDHS Board Members today, and plan to attend the TDHS Board meeting July 21, 11:00 A.M. at 701 W. 51st Street, John H. Winters Bldg. in Austin.

Tell the TDHS Board members to advocate for the Legislative Budget Board and the Health and Human Services Commission to shift dollars from other agencies to fill the gap caused by cuts in state funding and the pending loss of the federal Frail Elderly program, which provides services to 20,000 disabled and elderly citizens.

TDHS BOARD MEMBERS: David Herndon, Chair - (512) 480-5683, Austin; Bob Geyer, Vice-Chair - (915) 533-1220, El Paso; Anchi Ku - (214) 661-5114, Dallas; Carlela Vogel - (817) 870-9784, Ft. Worth; Yava Scott - (713) 960-9563, Houston; Carole Woodard - (409) 766-5735 Galveston

Programs that could be "frozen" include:

- * Family Care
- * In-Home and Family Support
- * Client-Managed Attendant Services
- * Shared Attendant Program
- * Day Activity Health Services
- * Adult Foster Care
- * Meals
- * Residential Care

The following programs would remain open:

- * Primary Home Care
- * Community Living and Support Services (CLASS)
- * Community Based Alternative Program

FRAIL ELDERLY PROGRAM STILL ON CHOPPING BLOCK

ACTION ALERT!

Visit, write, or call your U.S. Congressperson and SAY: "Please support reauthorization of the funding of the Frail Elderly program which allows low-income Texans who are disabled or elderly to stay in their homes with personal assistance supports rather than go to nursing homes which cost the state and federal government three times as much!"

Key legislators include:

Committee on Appropriations - Representatives Tom Delay (R), Henry Bonilla (R), Charles Wilson (D), Ronald Coleman (D), Jim Chapman (D)
Committee on Budget - Lamar Smith (R), Charles Stenholm (D), Lloyd Doggett (D)
Committee on Commerce - Jack Fields (R), Joe Barton (R), Ralph Hall (D), John Bryant (D)
Committee on Ways and Means - Bill Archer, Chairman (R), Sam Johnson (R)

Write your U.S. Congressperson at: The Honorable (full name), U.S. House of Representatives, Washington, D.C., 20515

We must ask that Congress continue the Frail Elderly funding source to Texans with disabilities and prevent a crisis for the Texas budget, for the 20,000 Texans who depend on the Frail Elderly community based PAS program, and the 18,000 Texans who are waiting for community based services. This program will stop this October 1 unless Congress reauthorizes the funds in the next U.S. budget.

As reported in the last newsletter, Frail Elderly funds provide Primary Home Care services to those with incomes between \$458

and \$1374 a month. Well over 20,000 people get their Primary Home Care services from Frail Elderly funding, which comes through Section 1929 of the Social Security Act. Attempts to ensure continued funding in the 103rd U.S. Congress failed in part because Texas is the only state using this source of funding.

To prevent dumping, TDHS will shift those currently on the Frail Elderly program to Family Care or the Community Based Alternatives program (formerly the Nursing Facility Waiver). Approximately 2/3 of the consumers from this program will be diverted into Family Care and the remaining 1/3 into the Community Based Alternative Program (formerly the Nursing Facility Waiver). It is the intent of TDHS to serve all current clients by shifting them to other programs.

Anyone who is not currently receiving PAS services will only be eligible if their income is at or below the SSI level, or \$458 a month. Ironically, while consumers whose incomes fall between \$458 and \$1374 a month will lose their eligibility for Frail Elderly funded community services, they will still be entitled to nursing home services that could cost the state and federal government almost three times as much. (See TDHS article, page 1 for more details).

WHAT ARE THESE SERVICES, ANYWAY?

It would take pages to detail the services available in each program, and how a person gets the services. That information is available in CTD's publication Working the Maze. Shad Howell, the new Policy Analyst at CTD is currently in the process of updating the Maze. If you would like a copy, give us a call or write us a letter. There is no charge for the document.

STATE BUDGET CUTS: TAKE MY OTHER LEG, PLEASE!

The final budget passed by the 74th Texas Legislature cut health and human services agencies' funding by about \$125 million dollars! The Texas Legislature imposed additional requirements that affect all health and human services agencies, resulting in more losses.

Agencies are required by Article 9, §153 of the budget to reduce their overall General Revenue funds by 1.26%. That amounts to a loss of \$32.9 million dollars for 1996 -1997 for the Texas Department of Human Services and \$12 million for the Texas Department of Mental Health and Mental Retardation! This section further states that "it is the intent of the Legislature that at least 50% of the reductions be applied...toward reductions in salary and personnel." Staff reductions mean that intake and eligibility determination could take even longer than before.

Further, most state agencies have been directed to reimburse the General Revenue Fund for a portion of Worker's Compensation and Unemployment benefits. This requirement could affect overall availability of funds for services, particularly for agencies funded primarily with General Revenue funds, such as the Texas Commission for the Deaf and Hard of Hearing.

Consumer participation in policy development at state agencies has also taken a direct hit. Advisory groups that are not federally mandated, such as the Aged and Disabled Advisory Committee at the Texas Department of Human Services, will no longer be able to reimburse expenses for out-of-town participants. Without travel funds, many consumers

who cannot afford out-of-town travel will no longer be able to participate. The Texas Rehabilitation Advisory Committee and the State Independent Living Council, both federally mandated, would not be affected.

Funding for community-based services fell far short of what was needed, but some programs received increases. What follows is a more detailed summary of the budget outcome.

STATE BUDGET CUTS: WHAT CAN WE EXPECT?

Texas Department of Human Services

As a whole, funding for Community Care Services is short of what is needed by \$55 million and TDHS is projecting that waiting lists for these programs will grow to approximately 18,000 by 1997. Below is what we know on TDHS programs.

☺ **Primary Home Care** - The appropriation for this program is \$199.8 million in 1996 and \$214.7 million in 1997. This "entitlement" program is open to new clients and funding is sufficient to meet the expected growth. Entitlement means that if a person qualifies, the state is obligated to provide them services.

⊗ **Health-Related Tasks in Primary Home Care** - In the last PASWORDS, we reported that TDHS had requested additional funds to expand Primary Home Care to include nurse delegation of "health-related tasks" to personal assistants. These tasks include

catheterization, a bowel program, and tube feeding. The Department needed approximately \$21 million in state General Revenue to fund this initiative. The PAS Task Force continues to advocate for this expansion, but the Legislature did not provide the funds. The TDHS Board must now decide if available funding will allow them to make the inclusion of health-related tasks in Primary Home Care.

⊗ **Frail Elderly Program** - Unless the U.S. Congress reauthorizes this funding source, the program terminates September 30, 1995. (See Page 2 on Frail Elderly funding.)

⊗ **Family Care** - No funding levels for FY 96-97 are yet available, however \$3.4 million in additional funding will be diverted into this program to handle the influx of people transferring to this program from Frail Elderly. TDHS will divert about 2/3 of the Frail Elderly clients into this program. No new people other than current Frail Elderly clients shifted here will be allowed into the program; slots that become vacant will not be filled and the waiting list of 1200 will see significant growth.

⊗ **Client-Managed Attendant Services** - No exact funding levels for FY 96-97 are yet available, but the program was appropriated \$10.9 million by the legislature. TDHS needed \$5 million more in funding for this program more than it received to meet its current need. This program will be caught in the TDHS freeze, so the 708 person waiting list will increase.

☹ **In-Home and Family Support Services** - TDHS projects that waiting lists for this program will increase from 9,454 in 1995 to 10,196 in 1996. The 1995 funding level of \$6.5 million is continued into the FY 96-97 biennium. Level funding means that the people on the waiting lists most likely will not be served. The hard freeze does not apply to IHFS. However, current waiting time for the program is as high as 5 years in most locations.

☺ **Community Living Assistance and Support Services (CLASS) Waiver** - The legislature appropriated an additional \$2 million to this program for the biennium. This will allow TDHS to expand services in this program and serve an additional 67 people in 1996 and 133 more people in 1997. TDHS expects to have a waiting list of 2,745 for the CLASS Waiver in 1996, compared to 2092 people now on waiting lists as of May 1, 1995. People on the waiting lists will be the first to access services with the additional funds received.

☺ **Community Based Alternatives, or CBA (formerly Nursing Facility Waiver) - The Nursing Facility Waiver program is now named the Community-Based Alternatives Program, or CBA.**

Approximately one third of the clients diverted from Frail Elderly will enter this program. To handle the influx of new people, funding for CBA has been increased from \$10 million in 1995 to \$111 million in 1996 and \$149 million in 1997. TDHS believes that this new funding will be enough to handle

all of the Frail Elderly clients being transferred over, as well as expected new clients.

Texas Rehabilitation Commission

According to the Texas Rehabilitation Commission, no TRC program lost any state funds, although some received level funding. However, because such a large percentage of this agency's budget is federal funding, cuts in the federal budget could limit the availability of TRC services.

☺ **Vocational Rehabilitation** - State funding for Vocational Rehabilitation saw an increase of \$3 million over the 1995 level for the FY 96-97 biennium. This means that TRC will be able to draw down an additional \$11 million in federal funds.

☺ **Personal Attendant Services** - The legislature increased funding for this program from \$500,000 in 1995 to \$1,100,000 in 1996 and \$1,400,000 in 1997. This increase in funding means that only 79 more people will be able to access Personal Attendant Services through TRC in 1996 than could in 1995. The program will be able to serve 119 more people in 1997 than in 1995. The program is expected to expand to Harris County and all bordering counties, as well as counties in the Dallas/Fort Worth area.

☺ **Deaf-Blind Multi-handicapped Services** - This program received an increase of slightly over \$1.5 million for FY 96-97. TRC will be able to serve 50 more people in the FY 96-97 biennium than in 1995.

has dropped to \$174 million in 1996 and \$193 million in 1997. This reduction in funding may mean that there will not be enough dollars to adequately serve the numbers of children with special needs.

- ☺ **Medically Dependant Children's Waiver** - This program is being moved over to TDH from DHS. The legislature gave the program an additional \$2.3 million dollars for each year of the biennium. This increase means some of the 428 children on waiting lists on for this program will be able to access services.

Texas Department of Mental Health and Mental Retardation

- ☺ **Mental Health In-Home and Family Support Services** - The \$6 million dollars appropriated for this program for each year of the biennium is level with the 1995 funding amounts. This means that the 3,633 people on waiting lists for this program most likely will not receive services.
- ☺ **Mental Health Case Management** - The 1995 appropriation of \$25.7 million will remain level for 1996 and 1997. No new people will be served.
- ? **Mental Retardation In-Home and Family Support Services** - The preliminary numbers for this program show a \$1 million increase for each year of FY 96-97. MHMR will not know how this will affect access to services until after their Board meeting.

- ☺ **Mental Retardation Case Management** - Funding for this program remains roughly level for FY 96-97 at \$34 million per year, so new people will not be served.

- ☺ **OBRA Targeted Waiver** - This program was given level funding for FY 96-97 from the 1995 appropriations of \$13.4 million. This means that new people will not be served.

- ? **Home and Community Services Waiver** - Funding for this program went from \$26.6 million in 1995 to \$22 million in 1996 and \$27 million in 1997. More funding may become available through program shifts. 600 slots were preserved and there is the potential for expansion.

Texas Commission for the Deaf and Hard of Hearing

- ☺ **Contract Interpreter Services** - TCDHH needed about \$250,000 more per year of the FY 96-97 biennium to serve the need. Service is on a "first come - first served" basis and funds usually run out in the summer. After the money runs out, the program shuts down for that year.

Texas Commission for the Blind

In general, funding for the Commission's programs remains at the same level for FY 97-97 as it was in 1995. The majority of TCB funds come from federal Vocational Rehabilitation dollars, so the Commission is more worried about what is going on in Congress and how federal funds will be affected.

74TH LEGISLATURE:

BILLS AFFECTING PAS, MANAGED CARE, & WELFARE REFORM

The Coalition of Texans with Disabilities worked on many legislative issues of a cross-disability nature. Those legislative issues more directly related to Personal Assistance Services are reported below. There will be a newsletter published in the immediate future that will report the outcome of other legislative issues relating to CTD's seven priority areas.

Some Good Bills That Passed

HB 2698 by Nancy McDonald - Sets out the vision for long term care, consistent with the CTD PAS Task Force guiding principles, and defines long-term care. Vision includes maximum control of service delivery by consumer and consumer choice. The bill states that maximum independence and autonomy are goals of service delivery. **The Governor has signed the bill; it is effective August 28, 1995.**

HB 1698 by Maxey - Requires state health and human services agencies to provide their clients (and their guardians where applicable) with information on all available community-based services before the agency allows the client to be placed in long-term residential care settings. Consumer must sign statement that they have been made aware of all community alternatives. Additionally, health and human service agencies must report to the Health and Human Services Commission "the number of community-based placements and residential - care placements they make." The bill's original language underwent some

changes. It requires state health and human service agencies to provide clients (or their legal guardian) with information on all community-based and institutional options. **Governor has signed the bill, it is effective immediately.**

Some Bad Bills That Died

HB 861 by Swinford, HB 521 by Delwin Jones, HB 723 by Robert (Bob) Turner - These bills would have required prior legislative approval of all state agency rules, and threatened to impede the already slow process of agency rule making. **Died.**

HB 2333, HB 2334 and HB 2335 by Van de Putte - This series of bills would have established a 1-800 number "hot line" providing information on available services and would have established the Area Agencies on Aging as the "single point of entry" for people with physical disabilities and older citizens. The CTD PAS Task Force opposed because we felt the bills would have created a more fragmented service delivery system. **Did not pass.**

SB 1341 by Moncrief - Would have increased fees for some home and community support services agencies by setting the maximum fee at \$2,000 (current law sets a maximum of \$1,000). We opposed the bill because the fees would have been cost-prohibitive to some smaller providers, and would have discouraged providers from applying for a license as a home and community support service agency. **Died in subcommittee.**

Some Good Bills That Died

HB 894 by Naishtatt - Bill to establish minimum and maximum number of cases a caseworker can reasonably assume for Texas Department of Human Services and Texas Department of Protective and Regulatory Services. **No House vote.**

HB 378 by Maxey - Bill to allow more than three prescription drugs under the Medicaid Drug Vendor program. **Died in Committee, see SCR 56 below.**

HB 864 by Maxey - Required Health and Human Services Commission to adopt and administer a statewide consolidated case management system in which each service recipient is assigned one "primary service coordinator." Would also have required rules to allow individual consumers to be their own "primary service coordinator." **This bill did not receive a vote.**

Some Bills to Turn Medicaid Into Managed Care

The 74th Legislature gave its seal of approval on a number of bills designed to initiate the process of applying for an 1115 waiver to convert the state's Medicaid system into a "managed care" health care system. What follows is a summary of these bills. **All these bills have been signed by the Governor.**

SB 10 by Zaffirini - Directs the Health and Human Services Commission to request an 1115 Waiver and lays out certain guidelines for the systematic design of Medicaid reform. Emphasis is placed on coordination with local governmental entities to ensure matching funds for Medicaid services, and achieve cost savings for the state and local entities. Included in the directive is the development of a plan to expand Medicaid eligibility to children and others. There are provisions for reviewing data from existing or new pilot programs covering ALL prescription drugs medically necessary and implementing changes in Medicaid as a result of this review.

A simplification of eligibility criteria is required. The Commission must consult with consumer representatives for input into the waiver development process.

SB 600 by Zaffirini- Requires the establishment of "complaint system guidelines for managed care organizations serving Medicaid clients." Information on the complaint process must be available in "appropriate communication format" to each Medicaid consumer when a person enrolls.

SB 601 by Zaffirini- Requires the Health and Human Services Commission to establish guidelines for and require managed care organizations to provide education programs for providers and consumers. The information must be easily understandable, and must include: 1) a client's "bill of rights"; 2) how to access health care services; 3) how the complaint procedure works; 4) Medicaid and managed care policies and procedures; 5) importance of prevention, intervention and appropriate use of services. Asserts a consumer "bill of rights" that includes the rights to respect, dignity, privacy and confidentiality, to reasonable choice of providers, to consent to or refuse services, to ask questions and get complete answers, to access a complaint process, and to timely access to services.

The bill also sets up a statewide toll-free assistance telephone, including TDD and assistance for Spanish speakers. The 1-800 number will help people who are having difficulty in applying for Medicaid services and provide educational information on Medicaid and the concepts of managed care. This line will assist in trouble-shooting for problem areas in Medicaid eligibility and service delivery.

SCR 55 by Zaffirini - Resolves to apply for a federal waiver to: set a co-payment for Medicaid clients; allow for a 12 month guaranteed Medicaid eligibility period; allow an integrated pilot for long-term care for people with disabilities; to develop an integrated pilot for mental health and substance abuse services; develop a plan

for statewide expansion of integrated mental health and substance abuse services; allow a pilot program for people with mental retardation and other developmental disabilities that "includes a decision support system and functional assessment," and to allow a cost-sharing pilot for certain recipients of Intermediate Care Facilities -Mental Retardation (ICF-MR group homes) and waiver services to be implemented in rural and urban areas.

SCR 56 by Zaffirini - Resolves to continue the prescription drug benefits under the state Vendor Drug program; and to use savings from a prospective drug utilization review to reduce costs in other Medicaid line items or raise or eliminate the three-drug limit on prescription medications.

SCR 58 by Moncrief - Resolves to take the necessary steps to move people from Level 1 ICF-MR facilities into the Home and Community Based Waiver Program; resolves to conduct a feasibility study, including input from consumers, to identify and remove barriers to the use of cost-effective home care services, including, but not limited to: 1) the array of services available; 2) arbitrary limits on number of visits allowed; 3) the definition of "medically necessary;" 4) coverage of preventive services; and 5) the interpretation of "home-bound."

SCR 59 by Jerry Patterson DID NOT PASS - Attempt to require dual certification under Medicaid and Medicare.

A Bill to Reform Welfare

HB 1863 by Hilderbran - This extensive welfare reform bill requires the Health and Human Services Commission to develop and implement a plan for integrated eligibility determination for health and human services, requires that language interpreters for agency programs be

provided for people who speak Spanish and other languages (we interpret the bill to include ASL), sets out a vision statement for workforce development that says that the "State of Texas shall ensure that all Texans with disabilities have the opportunity and support necessary to work in individualized, competitive employment in the community and to have choices about their work and careers." The bill requires Aid to Families with Dependent Children (AFDC) welfare recipients to sign a "Personal Responsibility Agreement" that requires that your child be immunized and attend school. Participants must not use drugs, and agree to participate in a work program (with a few exceptions.) Benefits are now time-limited depending on one's education and work history. Children can continue to keep their benefits even if their parents are no longer on welfare. **The Governor has signed this bill into law.**

TPCDD CONTINUES PAS TASK FORCE GRANT

The Texas Planning Council for Developmental Disabilities (TPCDD) recently awarded a continuation grant of \$127,000 for the next year to the Coalition of Texans with Disabilities' PAS Task Force. The TPCDD has funded the PAS Task Force Project since December of 1991. Authorization of grant funding has been approved until 1997.

The recent strides the Task Force has made in growth, leadership development, and policy development would not have been possible without the TPCDD's funding, grassroots volunteer leadership and full-time staff, including Project Coordinator Laura Brown, Policy Analyst Shad Howell, and Administrative Assistant Maria Tamez. The task force is headed by

a volunteer chairperson, Kathleen De Silva, an attorney with TIRR, who became a quadriplegic from a gymnastics fall in high school.

Grant funding will be utilized for several activities in the next grant year, including:

- * Conducting outreach meetings in Harlingen, San Antonio, Tyler, Longview, Amarillo, Houston, Arlington and Austin in an effort to inform participants on current issues, provide advocacy skills training, identify and build leadership and plan strategies for taking action;
- * Training regional leaders in local communities across Texas on how to organize PAS advocacy networks that can respond to issues in a timely fashion;
- * Organizing a one-day seminar on national issues with a recognized national leader in PAS issues;
- * Disseminating newsletters, bulletins, and alerts; and
- * Providing policy analysis, including the development of position papers and useful advocacy information for legislators and consumers.

The battles we face with the U.S. Congress over threats to Medicaid, Medicare and other essential funding, as well as future challenges, will be won only by building active networks in local communities. The funding provided by the TPCDD Council has assisted us in meeting our goal of building these networks and winning on issues critical to personal assistance services.

LANDMARK ADA CASE ON PAS

In a landmark decision, the U.S. Third Circuit Court of Appeals has ruled that the Pennsylvania Department of Public Welfare (DPW) violated Title II of the Americans with Disabilities Act when it did not provide Idell S. attendant services in the most integrated setting appropriate to her. (Helen L. v. Didario)

For \$10,500 a year, Pennsylvania could have provided Idell S., a wheelchair user, the personal assistance services she needed and wanted to live at home with her two children. Idell S. needed assistance with bathing, doing her laundry, shopping, getting in and out of bed, and cleaning. She was able to cook, dress herself and attend to her own hygiene and grooming alone. Even though she qualified for the personal assistance services (PAS) program, the Pennsylvania Department of Public Welfare argued that because there was no state funding for the program, she would have to live in a nursing home while she remained on the waiting list for the PAS program.

Title II of the Americans with Disabilities Act prohibits discrimination against people with disabilities by public entities, and requires that people with disabilities be provided services in the most integrated settings. The court ruled that "even though the state was not required by law to provide Idell with any care, since it chose to provide her services, it had to do so in a manner that complied with the ADA." The circuit court concluded that "her segregation in a nursing home was unnecessary since she qualified for the attendant services program." Pennsylvania's DPW argued that: 1) providing Idell would constitute a "fundamental alteration" of their program and 2) once their state legislature

appropriated funds to services, it could not shift funds from nursing homes to attendant services. The court responded by saying that "ironically, DPW asserts a justification of administrative convenience to resist an accommodation which would save an average of \$34,500 a year, would allow Idell S. to live at home with her children, and which would not require a single substantive change in its attendant care or nursing home programs."

What does this ruling mean?

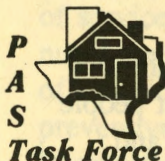
This Third Circuit Court of Appeals ruling applies to people who have been placed in institutional settings which segregate them, even though they qualify for and prefer community-based options. It does not apply to people who are on waiting lists for community-based personal assistance services and are not currently receiving any services. Only the Supreme Court can make a decision that will be binding across the country on this type of case, and it is uncertain how that court would rule.

MARK YOUR CALENDAR FOR NEXT PAS TASK FORCE QUARTERLY MEETING!

WHEN: August 25, 1995

WHERE: Texas Rehabilitation Commission
4900 N. Lamar
Austin, Texas
Public Hearing Room on the First Floor

TIME: 11:00 A.M. to 4:00 P.M.



Personal Assistance Services Task Force

— *PAS: "A key to independence"*

A project of The Coalition of Texans with Disabilities

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