

P.A.S. WORDS

A Communication Forum for
The Coalition of Texans with Disabilities'
Personal Attendant Services Task Force

June 1993 - Volume 2/Issue 2

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WE DID IT! FUNDING RESTORED TO PAS!

PASTF participants have played an active and critical role in educating legislators and the public about the need for funding for community-based programs serving people with disabilities. Your press conferences, rallies, testimonials, calls, and visits to the legislators MADE THE difference. PAS programs have received at least current levels of funding. It will take some time for us to examine and determine the implications of this year's budget decisions, and we will provide additional information in the next PASWORDS. On the next page is a summary of what we know right now:

TEXAS REHABILITATION

COMMISSION: Restoration of current levels of funding (\$1 million for the biennium) to its PAS program. This program was initially slated for elimination. Transition services also restored at \$800,000 for the biennium. Funding for Independent Living Services and Independent Living Centers was restored to current level funding. Vocational Rehabilitation received an increase in general revenue funds. The Deaf/Blind Program at TRC received a \$1.3 million increase in the biennium funding. The Deaf/Blind program was also previously eliminated under LBO recommendations.

DEPARTMENT OF HUMAN SERVICES:

The requested \$170 million (for biennium) to community care services was restored to the DHS budget. This figure covers a number of programs. The 31,000 receiving community-based services that were previously cut from the DHS budget will be able to remain in their homes. The one-time capital expenditure money was restored to DHS's In Home and Family Support Program. The nursing home eligibility level remains the same. (Many community-care programs are based on the nursing home eligibility criteria.)

BAD NEWS: \$7.2 million biennial decrease for long-term care eligibility determination and case management staffing. (Only about a year of funding.) These cuts will inevitably create backlogs and longer waits for services.

COMMISSION FOR THE DEAF:

Received funding to maintain current levels of services for the evaluation of interpreters, Services to Older Hearing Impaired, and Interpreter Services.

DEPARTMENT OF HEALTH: Medicaid-covered hospital stays will be allowed to remain at the current 30 days. In addition, the current benefit and eligibility policies will remain in place for Medicaid-covered prescription medications. (Medicaid Drug Vendor Program). **BAD NEWS:** The Chronically Ill and Disabled Children Program sustained a \$19 million decrease in funding. Funding for HIV services has also sustained heavy losses: 4,000 people with HIV will lose medications and other health assistance.

DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION:

Funding increases over LBO levels restored to Children's Mental Health Plan, Clozaril treatment, Rehabilitation, and In-Home and Family Support. (Note: none of the previous programs mentioned received the full-agency requested dollar amount, but all levels of funding are above current levels of funding.)

Approximately \$117 million was requested for the biennium for Nursing Home Transition. (OBRA) About \$16 million was appropriated. In addition, a \$6 million biennium request for additional costs related to state school closure was NOT funded and must be absorbed by the agency.

TEXAS COMMISSION FOR THE BLIND:

Independent Living Services, Children's Program, Vocational Rehabilitation and Transitional Programs received slight increases from the last biennium funding. However, with inflation and the anticipated rise in case load, the number of clients served will remain the same.

NOTE: Texas state agencies are required to implement a 3% employee pay raise this biennium. Because many did not receive specific funding to allow for these pay raises, they must absorb this cost by shifting funding from direct services.

KEYS TO STATE BUDGET FUNDING SUCCESS

THE VALLEY RALLIES

In the last PASWORDS, we told you about the successful press conferences

Brownsville (Lower Valley):
Mike Maddy
Harlingen (Mid-Valley):
Tom Birchfield and Tim Terwin
Pharr (Upper Valley):
Carmen Gonzalez and Mary Jo Klein

POSTCARD CAMPAIGN TARGETS TOP 5

At the March 30th PASTF Quarterly meeting, participants decided the grassroots must KEEP THE PRESSURE on our state's leadership, particularly the budget conference committee, to restore funding to community services. We needed a strategy that was relatively easy, uniform across the state and could happen quickly. PASTF chose a postcard campaign in which the top five leaders in our state would be targeted: Governor Ann Richards, Lt. Governor Bob Bullock, Speaker Pete Laney, Chair of Senate Finance, John Montford, and Chair of House Appropriations, Rob Junell.

The message was: **SUPPORT FUNDING FOR ATTENDANT SERVICES** and specific programs targeted for cuts were named. **THE POSTCARD CAMPAIGN WAS VERY SUCCESSFUL!** We believe about 800 postcards were mailed to each leader.

AGAIN, CONGRATULATIONS TO ALL WHO GAVE THEIR TIME AND ENERGY TO THIS SUCCESSFUL EFFORT TO SAVE OUR SERVICES!

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TEXAS GETS 1915C WAIVER FOR "NURSING HOME ELIGIBLE"

20,000 MORE TO RECEIVE COMMUNITY SERVICES

A Medicaid waiver which will allow approximately 22,000 "nursing home eligible" Texans to get services in the community has received a verbal approval from the federal Health Care Financing Administration. It is uncertain when the program will be formally initiated, although it is expected to begin as early as the fall of this year.

Dick Ladd, Commissioner for Texas Health and Human Services, is responsible for obtaining this waiver for Texas. This is a thrilling step forward in our state's efforts to develop community alternatives.

At the March 30 meeting of the CTD Personal Attendant Services Task Force, Anita Anderson, Lead Policy Specialist for the Office on Services to Persons with Disabilities at the Department of Human Services gave an overview of the waiver, which is called a Nursing Facility Waiver. It will be operated under the auspices of the Health and Human Services Commission, Office of the state Medicaid director (DeAnn Friedholm). The Texas Department Human Services will be the responsible agency for administration functions.

A very broad array of services will be available to those who qualify, including: adaptive aids and medical

supplies, adult foster care, assisted living services, emergency response services, nursing services, minor home modifications, occupational therapy, personal assistance services, physical therapy, respite, speech pathology.

To learn more about this waiver or to put your name on the waiting list, contact Gerardo Cantu at 512/450-3693. If you get the answering machine, please leave your name, address and phone number.

PASTF SETS UP WORKGROUPS

At the March 30 PASTF Quarterly Meeting, participants voted to reinstate a workgroup structure that in the past, developed the concepts behind many attendant programs in Texas. PASTF workgroups in the following areas are developing:

Grassroots Outreach will devise a plan to increase the involvement of under-represented people in the PASTF, identify local leadership and review ways to establish local PASTF groups more formally. The chair has not yet been confirmed.

The Recruitment, Retention, and Training of Attendants workgroup, in response to the PASTF study on this issue, will develop recommendations on ways to improve the upward mobility of attendants and the status of attendants. Methods of recruitment and training of attendants will also be examined. The chair is Francis Sanchez, 1701 Strickland, P.O. Box 68, Orange, TX 77631, 409/882-0850.

Program Design and Review will review and monitor PAS program rules and regulations as well as budgetary issues by attending and testifying at relevant meetings. They will also identify and recommend new innovative programs for PASTF action, and monitor health care proposals. The chair is Pat Pound, TGCPD, P.O. Box 12428, Austin, TX 78711, 463-5743.

National Issues will monitor national health care reform, federal rules, regulations, legislation and budget proceedings affecting PAS and advise the task force on action to be taken. The chair is Vincent Sadowski, DATCIL, 5555 N. Lamar #J-125, Austin, TX 78751, 512/467-0744.

All groups will report to the Chair and will work cooperatively with the Project Coordinator. We believe that the establishment of the workgroups will enhance the PASTF's ability to remain on the cutting edge of PAS issues.

WE NEED YOUR INVOLVEMENT!

If you are interested in participating in one of PASTF'S workgroups, contact Laura Brown at 512/478-3366 or the respective chairs of these groups. This is your PASTF, and we want you to be involved.

WE'RE RECRUITING ATTENDANTS

...That is, we're recruiting more attendants to be involved in the PASTF, particularly to participate in our workgroup on recruitment, retention, and training of attendants. Your input is vital to a productive discussion and balanced recommendations. Call Laura Brown at 512/478-3366 or Francis Sanchez at 409/882-0850.

PASTF ACTS ON KEY CONCERNS

RECOMMENDATIONS ACCEPTED ON RECRUITMENT, RETENTION AND TRAINING OF ATTENDANTS

The Recruitment, Retention and Training of Attendants Workgroup, established at the previous Quarterly meeting, met on March 18 to come up with preliminary recommendations for PASTF action. Francis Sanchez, Chair of the workgroup, presented a written document at the March 30 Quarterly Meeting outlining the results of the first meeting of the workgroup.

Discussion at the Quarterly meeting focused primarily around the issue of training. One of the primary difficulties lies in the fact that there is not consensus on how much training should be required. It is acknowledged that the person with a disability or a family member does a great deal of the training. Many people with disabilities do not want a highly trained attendant, because those individuals are often not as open to being taught and directed by the person with a disability.

There was discussion about the possibility of a tiered training system that would range from training on basics such as CPR and body mechanics, to more complex skills, like tube feeding. The question remains: If a tiered system were implemented, what would the components of each level of training

be? The Recruitment, Retention, and Training Workgroup will examine this issue more closely in its subsequent meetings.

Participants also felt that training for the person with a disability should be more readily available, and should start in junior high or high school. Most people are not born with supervisory skills: these are skills that must be developed with practice and time.

The document presented by this workgroup proves that the workgroup structure is already working and has the potential for bringing about concrete changes in public policy.

The PASTF formally adopted the following recommendations:

- 1. Work with TDHS and other state agency staff to examine program handbooks and revise the handbooks that providers receive with their contracts to include a philosophical statement about attendant services, client descriptions, direction of services, and training principles. Specific programs include TDHS' Client Managed, Family Care, Primary Home Care, and some waiver programs.**

2. Work with local PASTF participants to promote the development of attendant training programs in colleges, high schools, etc. (Note: there is a pilot program in the Washington, D.C. area that trains high school students to be attendants).

3. Advocate for the expansion of innovative programs, such as the one in Lubbock, that trains people with developmental disabilities to be attendants.

4. Develop a brochure for people with disabilities who use attendant services on how to select, train, and manage an attendant.

5. Encourage attendants to participate in a discussion around pay scales, training, recruitment, career ladder and benefits for attendants.

HEALTH CARE POSITION ADOPTED

During the March 30 Quarterly meeting, Bob Kafka updated the PASTF on recent steps taken on national health care, including the initial draft work of the President's Health Care Reform Task Force workgroup on Long-Term Care/PAS. Laura Brown spoke about problems with managed competition systems facing people with disabilities, and transitioned into a discussion about Texas health care proposals, primarily Rep. Mike Martin's HB 2055, that sets up a small employer insurance system.

The outcome of the discussion on health care is as follows:

The PASTF voted to support a single-payer health care system that includes a comprehensive array of services for people with disabilities, and to oppose HB 2055. In addition, the PASTF agreed that any health care reform must include PAS as part of the benefits package.

SEE CTD NEWSLETTER FOR MORE ON HEALTH CARE PROPOSALS.

STATE SCHOOL CLOSURE

Also at the March 30 Quarterly meeting, a summary was given on the attempts by Representative Doyle Willis (Ft. Worth) to put up a roadblock to state school closure by requiring legislative approval for closure. The PASTF formally took a position opposing any attempts to prevent state school closure.

NOTE: Willis' attempt at preventing state school closure failed. See the CTD newsletter for more.

PASTF OPPOSES ATTEMPTS TO WEAKEN OBRA-PASARR

On March 19, the DHS Board of Directors considered agency rule changes that would weaken the federal Omnibus Reconciliation Act of

1987 -- Preadmission Screening and Annual Resident Review Rules (OBRA-PASARR) by allowing for "provisional placement" of an individual into a nursing home if no community alternative can be found. The PASARR process was implemented at a federal level to prevent individuals from being warehoused in nursing homes and institutions and to pressure states to develop alternatives in the community.

Laura Brown, PASTF Coordinator, testified at the DHS Board meeting on behalf of the PASTF, and copies of this testimony were distributed at the March 30 Quarterly meeting. The rule changes were prompted by a report by the Texas House Committee on Human Services. In the report, the Committee outlined its concerns that the PASARR program was not "sensitive to the needs of children." (They wanted to make it easier for children to receive services in a nursing home.)

In her testimony, Laura stated that she realized that families are indeed in crisis because of the lack of needed services in the community. Many families have no choice but to put their children and family members in nursing homes in order to receive necessary services.

Our state has yet to develop adequate community alternatives, particularly for children with high medical needs and for those in rural areas. "Provisional placement" is a bandaid solution to a festering and growing problem. The time is now for Texas

to live up to its obligation to serve these individuals in the community.

The DHS Board approved the "provisional placement" rule changes, but requested that staff revise rules to ensure that "dumping" of individuals in nursing homes would be prevented.

In response, the PASTF took the following position at the last Quarterly meeting: "The PASTF opposes legislation or regulations that would weaken or reduce the intent of federal OBRA law and the PASTF <will> advocate for the state to live up to its obligations under OBRA requirements to develop alternatives in the community, rather than having nursing homes as the only option."

HOME AND COMMUNITY SUPPORT ACT

STAGE SET FOR ATTENDANTS TO PERFORM "HEALTH-RELATED" TASKS

The PASTF, over the last year, has been working cooperatively with other disability advocacy groups to change portions of the existing Home Health Act that has inhibited the delivery of attendant services to people in the community. HB 1551, sponsored by Rep. Nancy McDonald from El Paso in the House and Sen. Frank Madla from San Antonio in the Senate, contained these changes agreed upon by all the

groups, including the Texas Nurses Association, Texas Respite Resource Network, and agency representatives. HB 1551 passed last week.

The Home Health Act requires those who provide home health services to be licensed to provide services. The changes to the Home Health Act will address the need to separate out basic personal attendant services from more skilled home health services in the licensure process. By creating a separate category for PAS, we will move our system toward a more independent living model of service delivery.

CHANGES REQUIRED BY HB 1551

HB 1551 renames the original act to the Home and Community Support Act and creates three categories of services: home health, hospice, and a new category for personal assistance services. This creation of a separate category allows us to lay out more clearly what activities can be performed without nurse delegation, and what activities can be performed with nurse delegation. These activities will be defined by a Memorandum Of Understanding (MOU) between the Board of Nurse Examiners and the Texas Dept. of Health. Before, under the Home Health Act, only a nurse or a person who completed a 140 hour course could administer medications. We needed the changes outlined in HB 1551 to implement the recent changes to the Board of Nurse Examiners Rules on the delegation of health related tasks. Our goal is to

reduce medical intervention and make services more flexible and more broad. The changes allow for flexibility all under one license to meet the needs of program clients with as little nursing as possible.

The significance of the Home and Community Support Act is that it defines personal assistance services and respite for the first time in law, and it will actually allow for the delegation of health-related tasks to unlicensed personnel with the creation of the MOU and the development of rules around the provision and coordination of services.

Under the new changes, **PERSONAL ASSISTANCE SERVICES** means routine ongoing care or services required by an individual in a residence or independent living environment that enable the individual to engage in the activities of daily living or to perform the physical functions required for independent living, including respite services.

RESPITE SERVICES means 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. In the development, modification, or renewal of the MOU, an advisory committee made up of representatives from TDHS, MHMR, TX Nurses Assoc., TX Respite Resource Network, and two representatives from the disability community must be consulted. A 13 member Home and Community Support advisory council

will work with the Dept. of Health board to develop rules around the provision and coordination of treatment and services and any other aspects of home health, hospice or personal assistance services.

NOTE: An individual hired and paid directly by the client or the client's family or legal guardian to provide home health or personal assistance services is exempt from coverage under the act. Also, a **HOME AND COMMUNITY SUPPORT AGENCY** providing home health, hospice, or personal assistance services is not required to obtain a license under this Act until July 1, 1994. Under the proposed changes, some cities and Independent Living centers administering attendant programs would be covered.

Although passage of this bill is a major victory, it requires a great deal of follow up. The PASTF will carefully monitor the development of the MOU to ensure it is reflective of our perspectives. We generally believe in a liberal and broad definition of health-related tasks that can be delegated.

Thank you to Anita Bradberry from the Texas Association for Home Care, who gave us a summary and update on HB 1551 at the March 30 PASTF Quarterly Meeting!

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PASTF RECEIVES \$103,000 GRANT

ROUNDTABLE PLANNED OUTREACH EXPANDED

The Personal Attendant Services Task Force (PASTF) of CTD recently received approval for the 2nd year of funding from the Texas Planning Council for Developmental Disabilities in the amount of \$103,000. In the June 1993-94 grant year, the PASTF will expand outreach efforts and reaffirm continued support of grassroots involvement through the development of workgroups.

In addition to workgroups, the PASTF Chair, Bob Kafka, and Project Coordinator, Laura Brown, have planned several outreach meetings -- they will hit South Texas, East Texas, West Texas, Ft. Worth and Houston.

One of the national issues that the PASTF will examine closer in the next grant year is the move toward national PAS legislation. We will focus on a national PAS proposal put forth by the Consortium for Citizens with Disabilities in a roundtable to be held in February. The purpose of the roundtable will be to pull together cross-disability representation to receive feedback on the proposal, to examine its implications, and to determine whether the PASTF can give its support.

This grant comes a critical time, when there are several issues related to PAS that must be proactively addressed such as health care, PAS legislation, and the federal budget and economic packages. The workgroups, outreach efforts, and the roundtable will provide a forum for involvement and will increase our capacity to respond to these issues. We must remain actively involved or we will not realize the full promise of the Americans with Disabilities Act in our lifetimes.

ADAPT MEETS WITH U.S. HHS SECRETARY DONNA SHALALA

U.S. Secretary of Health and Human Services Donna Shalala met with ADAPT after weeks of negotiations with the Clinton administration. Secretary Shalala, in contrast to former HHS Secretary Louis Sullivan, wanted the opportunity to meet with ADAPT to hear what ADAPT activists had to say. The Secretary first met with a small group of 10 people and then with all of the ADAPT members from around the country.

Stephanie Thomas and Lupe Vasquez, two ADAPT activists from Austin, Texas were at the first meeting which lasted about 45 minutes. Secretary Shalala was handed a list of demands and she agreed to respond in writing in 30 days. The folks at this meeting, most who still lived in or had lived in nursing homes, emotionally explained to the Secretary what life in a nursing home was like. They described the

indignities and abuses they had experienced and contrasted that with their lives with community-based attendant services.

When Secretary Shalala entered the larger meeting room she immediately jumped off the podium into the crowd to the horror of her security people. She stated that our long-term care system had an institutional bias and that the Clinton administration was taking steps to change that bias. She said that the health care reform recommendations would include long-term care reforms and that community-based attendant services would be part of that package.

Stephanie Thomas editor of the ADAPT newsletter "INCITEMENT" and Texas activist said after the meetings: "The words are good, now let's see what they do."

GOVERNOR'S COMMITTEE REP TRAVELS TEXAS TO HELP WIN PAS

Ralph Rouse, a member of the Texas Governor's Committee on People with Disabilities, and a colleague, Kristi Thomas, recently traveled the state to bring the community service issue to the attention of the people in the community and show them what they can do to help further the effort. As part of each meeting, a subcommittee of the local Mayor's Committee was established to give direction to the effort.

175 attended the first meeting in McAllen, in February sponsored by Valley Independent Living Center. The Valley community has pulled together to actively continue community service efforts with a two year action plan.

In the Lubbock area, a newly formed Mayor's Committee took the community service issue as their first official task. They have since developed both short and long term goals to help educate state legislators, other elected officials, and business people on community services with an objective of legislative action and budgetary benefit to the community services program. Other meeting sites included Corpus Christi, Beaumont, Dallas, Fort Worth and El Paso.

To promote the creation in other states of linkages between Mayors' Committees and Governors' Committees on the issue of community services, Ralph, Ms. Thomas, Sherry Hurst, Chair of the Mayor's Committee of Lubbock, and Ernest McKinney, Director of Community Care with TDHS, presented a workshop on Community Services on May 13th in St. Louis at the conference of the President's Committee on Employment of People with Disabilities.

The Governor's Committee on People with Disabilities has made community

services one of its priority issues and will continue to expend 'serious efforts in developing community awareness and organizations in other communities. To assist other communities in educational effort, a "how-to" final report is being prepared.

NURSING HOMES

DID YOU KNOW?

* Nursing home rates rose 6% to an average of \$88 per day for skilled care. Rates for unskilled care rose 14.7% to an average \$78 per day.

* In 1992, three states, California, Illinois, and Texas, reported more than 100,000 long-term nursing home beds each.

* The ratio of nursing home beds to the U.S. population increased in 1992 to 53.3 beds for every 1,000 people over the age of 65.

From the Marion Merrell Dow Long-Term Care Digest, 1993

The PASWORDS is a project of the Texas Planning Council for Developmental Disabilities funded by the Texas Rehabilitation Commission.

NEXT PASTF MEETING

DATE: Tuesday, June 29, 1993

TIME: 9:00 A.M. to 3:00 P.M.

(Extra time has been allotted for workgroups to convene.)

LOCATION: Texas Rehabilitation Commission, Public Hearing Room, 1st floor