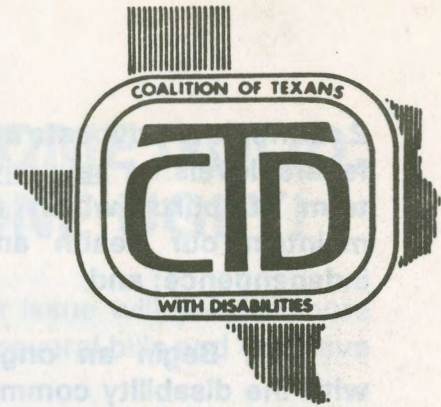


Coalition of Texans with Disabilities Newsletter



June/July 19

GOVERNOR AGREES TO MEET WITH CTD REPS !!

A group of 40 people with disabilities secured Governor Ann Richard's commitment to act on three needs identified by CTD leadership as necessary to help securely fund and broaden community supports in Texas. When they marched on May 4th from the Travis County Courthouse to the Governor's Mansion they also secured her promise to meet personally with five CTD representatives.

The march to the Governor's Mansion, her home, was symbolic of the desire of the Texans with disabilities to live in their own homes. We began at the Travis County Jail to represent our state's bias in favor of institutions. Texas "jails" over 60,000 Texans in nursing homes and other institutions for the disabled and/or elderly.

Two years ago, the Governor also promised to "support funding and services which allow people with disabilities to live and work in their communities." While we believe the Governor is supporting Texans with disabilities, this legislature, like the past

five sessions, resulted in a doomsday budget that could have devastated the lives of Texans with disabilities. It is appalling that the state can consider cuts to community-based services when there are waiting lists of up to five years and over 5,000 long. The loss of state-supported services could put an individual back into an institution, on the streets or into the hands of Dr. Death.

We must stop balancing the state's budget on the lives of Texans with disabilities. At the press conference CTD asked for the Governor to take three actions which Pat Cole, Director of Health and Human Services Policy for the Governor Ann said **the Governor will do:**

1. **Work to assure that families are provided with services and supports which allow them the choice of raising their child with a disability at home rather than being forced to place their child in an institution or a nursing home.**

2. Commit to advocate at the state and federal levels for securely funded long-term supports which enable us to maintain our health and foster our independence; and

3. Begin an ongoing dialogue with the disability community that will create a united front for change. Pat Cole agreed on behalf of the Governor that **THE GOVERNOR WILL MEET WITH REPRESENTATIVES FROM CTD soon after the close of the legislature.**

Ron Cranston, a CTD member from Austin, and Rebecca Johnson, a CTD member from Houston both told their own personal stories. Ron explained, "To me, attendant care programs are the safety net between living in the community and living in a nursing home or other institution which is highly undesirable." Rebecca challenged state leadership with her comment, "I volunteer at the Veterans Hospital in Houston and I tell newly disabled that they, too, can live productive lives--but the state of Texas has to help us to do that and redirect funds away from nursing homes."

Health and Human Services Commissioner, Richard Ladd, also attended the press event and gave us the "up to the minute" on the state budget conference committee deliberations on funding for community-based services. He advised us that he had ranked community-based services at the top for funding restorations. Mr. Ladd also spoke of the Commission's new initiative which will provide community services to approximately 20,000 individuals through the Nursing

Facility Waiver. In-depth articles on the state budget outcome and the new waiver program are in the current issue of PASWORDS.

Two years ago, the Governor promised to "identify the laws and regulations which are a barrier to community-based services" and instructed the Governor's Committee on People with Disabilities to do this research. A workgroup, including CTD, assisted the Governor's Committee in developing an excellent document, "Moving from Institutions to the Community: A Blueprint for the New Texas."

FROM THE DIRECTOR

This CTD Newsletter focuses on only three things: 1. Early reporting on bills passed by our 72nd Legislature; 2. National Health Care Reform; and 3. PASWORDS -- how Texans with disabilities survived the state budget chopping block. As soon as we can, we will send you more legislative results with analysis.

As you know, we set aside 1993 to restructure CTD and develop a five-year plan to take us into the year 2000. CTD is making great progress toward the development of the 5-year plan.

FYI: The CTD Delegate's Assembly has been moved from El Paso to Austin to centralize the location and increase your ability to participate in this pivotal meeting.

THE 72ND LEGISLATURE -- SOME GOOD, SOME NOT SO GOOD AND ONE UGLY!

Following is a first blush of important legislation. The next issue will provide more analysis of the session. CTD is gathering final outcomes of several bills and will have an analysis done in about a month.

There were more than 400 bills filed this 72nd Texas Legislature which could have had direct impact on people with disabilities. CTD, like many of our member organizations, had to limit our legislative efforts. CTD focused on bills which were either cross-disability ADA issues or vital to the efforts of the CTD Personal Attendant Services Task Force to bring about comprehensive personal assistance services.

SOME GOOD BILLS

HB 76 Danburg - Polling Place Access.

Amends the Election Code to eliminate the exemption for accessibility for "private" polling places and adds the requirement that precinct conventions must be accessible. A floor amendment by Republican Rep. Jane Nelson attempts to weaken the gain by giving the state executive committees of political parties the power to exempt precinct conventions from accessibility requirements. A telephone check with the U.S. Department of Justice indicates this amendment contradicts the legal requirements of the ADA.

SB 540 Barrientos - Elimination of Architectural Barriers Act.

We went back this year to get commercial facilities included which makes our state code "substantially equivalent" to the ADA. Texas will now apply to get its code certified by the federal government as ADA equivalent. In order to get the bill passed, we did not oppose an amendment added in the

final days which will allow municipalities to become certified to perform their own reviews and inspections. The Texas Department of Licensing and Regulation, Office on Elimination of Architectural Barriers, enforces the Act.

HB 860 Delco - Human Rights Act.

Adds "regarded as disabled" (the third prong of the ADA definition) to the definition of disability. The state law passed, still excluding protection for people with "certain" communicable diseases, including acquired immune deficiency syndrome or infections with human immunodeficiency virus (HIV). This exclusion contradicts ADA. In the Preamble of the Human Rights Act, however, it says they are adopting ADA Title I for the enforcement standard. The ADA is a higher standard and the state can not diminish the federal law. The Texas Commission on Human Rights is the compliance agency for the Texas law

and the "deferral" agency for certain ADA employment discrimination complaints.

HB 1551 McDonald - Home Health Act changed to the Home and Community Support Act. Creates a separate category for licensure for personal assistance services and will allow for the delegation of health-related tasks. This is very significant because it is the first time PAS is defined in Texas law. **SEE PASWORDS** for full details.

HB 1843 Price - Print Access Machines for visually-impaired in libraries. Replaces the old act and helps movement toward ADA compliance by allowing the Texas State Library to coordinate placement of print access machines in libraries according to community need. It changes the definition of print access machines from only Kurzweil Readers to a broad range of technology and equipment, such as, the Kurzweil Reading Edge, closed circuit television, and hardware and software set up for existing microcomputers. The act also allows for expenditures for equipment repair and maintenance.

REP. WILLIS ROADBLOCK TO STATE SCHOOL CLOSURE SMASHED

On Tuesday, May 18, the Senate Health and Human Services Committee heard public testimony on a proposed amendment to HB 1510 which would require legislative approval for any state school closure. This amendment, commonly known as the "Willis

Amendment" (Representative Doyle Willis of Fort Worth \Democrat) was an effort to block the closure of the Ft. Worth and Travis State Schools. Testimony late into the night appeared evenly divided for and against closure of state schools, with over 100 people signed up to testify.

In Texas, state schools for people with mental retardation are at the center of a major civil rights struggle: segregation versus integration. The Coalition believes that personal assistance and supports should be available to all people with disabilities in the community. This philosophy is the driving force behind the Personal Attendant Services Task Force.

As Bob Kafka put it during the hearing, "People don't like to see drooling or people in wheelchairs. It makes them uncomfortable. But we are not going away." Joyce Dawidczyk spoke to the heart with her comment, "When I was two years old they thought I would be a vegetable. I have a master's degree and I own my own home. Who knows how a child will turn out at the age of two? Who knows?"

The Willis effort was not successful and we will move forward with closing Travis and Ft. Worth State Schools. Approximately 600 will be freed from institutions and move into the community. The state budget allows for the state to remain in compliance with the Lelsz lawsuit settlement and move forward with the closure of two state schools for mental retardation. Additional state schools can only be closed by an act of the legislature.

STATE HEALTH CARE REFORM

IT'S BAREBONES FOR TEXANS WITH DISABILITIES

HB 2055 by Rep. Martin/Sen. Parker - **Small Employer Health Insurance Availability Act.** The act certainly does not meet the needs of people with disabilities and probably would not increase access to health insurance for the millions of Texans uninsured. It is employer based, does not cover PAS and community supports, and it is voluntary -- Employers are not required to buy into it. It is likely many employers will opt for the "bare-bones" hospitalization package.

The act sets up a state purchasing co-op for employers of 3 - 50 employees. Beginning September 1995, employers will be guaranteed access to health insurance; an insurance company can not deny coverage because of the health experience of an employer. Carriers can go up or down 50% in their rates within a class of business. Health status and claims may affect an employer's rates by 15% upon renewal.

The act provides five separate plans which an employer can choose from: a Standard Benefit Plan, a Preventive and Primary Care Benefit Plan and In-Hospital Benefit only. Any policy on the market on today can be sold, including current policies with coverage of existing mandates and HMO plans.

No long-term care, personal assistance services or durable medical equipment provided. All plans will have a 1 year exclusion of coverage for pre-existing condition clause.

Mental illness receives limited coverage in the Preventive package (up to \$15,000 a year) and full coverage in the Standard Benefit Plan. In the Hospital package, mental illness will be treated like any other hospitalization.

SINGLE-PAYER NO-GO IN TEXAS

A single-payer bill sponsored by Reps. Glenn Maxey and Elliot Naishtatt that would provide for cost-containment and would cover community supports for people with disabilities was intended to be used as a standard of comparison for other bills. It was referred to the House Public Health Committee rather than the Insurance Committee. Attempts to have the bill moved back to the Insurance Committee were unsuccessful. The bill never received a committee hearing.

*Next issue we will provide details on important psychiatric and rehabilitation hospital reforms, guardianship reforms and special education reforms.

SPECIAL REPORT

NATIONAL HEALTH CARE REFORM

THE PRESIDENT'S HEALTH CARE PLAN ARE WE IN?

Initial draft work indicates that the Task Force moved toward a social insurance concept. (Medicare is based on social insurance principles.) Under this concept, home and community support will be kept separate from nursing homes and other institutionalized care.

Essentially, the Medicaid system would be folded into the Medicare system. Medicaid as it exists now would be eventually phased out. It is believed that doing so would reduce duplication in our service delivery system and would reduce the stigma attached with Medicaid as the "low-income" program. The co-pay required of Medicare would be picked up for those who could not afford it. (The Medicaid eligible.) Another benefit of going to the social insurance concept would be that an individual with a disability would not lose services if she found employment.

The fear is that if the Health Care Reform Task Force adopts the social insurance concept, that many of the benefits that come out of Medicaid would be lost.

The Health Care Reform Task Force is shaping its reform proposal around

"managed competition" principles. The term in itself is a vague term meaning a system that creates purchasing co-ops made up of consumers and pools of health care providers who practice in groups. It resembles health maintenance organizations. It is believed that if enough people become a part, then the co-op will have buying power to get good deals from providers.

There are problems that the managed competition concept poses to persons with disabilities. First, managed care systems do not always provide a comprehensive array of services. They often create disincentives to providing services, and typically emphasize primary care, instead of preventive. There are also problems with delays in services and in consumer input.

The President's health care reform proposal seems like the best kept secret and late word is the President will not unveil his health care reform package until this fall, instead of June, as earlier promised. The members of the Health Care Task Force have made their recommendations and disbanded. Our research and contacts in

Washington, D.C. say the President's health care reform proposal, at this point in time, will include the following components:

1. Each individual will receive a "health security card" guaranteeing them health care coverage regardless of health or employment status. People will no longer be in danger of losing their coverage.

2. Health co-ops that will allow an individual to buy additional health care above the basic required package will be established. This reflects on the equity issue, because the more money you have, the more health coverage you can obtain.

3. There will be required coverage that employers will be mandated to provide.

4. Considerable state flexibility will be provided, in both price control, and in who they allow to administer the plan (i.e. insurance companies). States will be allowed to create single-payer systems, as well.

5. States will not be allowed to reduce the benefits required by the federal government.

6. States will not be able to exclude groups, such as, people with disabilities and the poor, from coverage, and they cannot change their financing methods.

7. Preventive care coverage and some mental health coverage will be provided. Although the Administration has indicated that it is considering a

broader package of benefits than most private insurance plans, it is likely the package will look similar to the HMOs provided today, with the possible addition of prescription drugs.

8. It is possible that long-term care coverage that would include in-home personal assistance will be provided. (It is obvious it will one of the first things that Congress will want to ax. Because of cost it is clear that there will be considerable opposition to including long-term care and supports. SEE ARTICLE -- Clinton Supports PAS in Package).

9. There will be limited price control initiatives. There is talk about limiting the amount the cost of the premium can go up per year. There could be temporary price limits put on doctor and hospital fees until the program is "up and running."

PAS IN THE PACKAGE DO WE HAVE THE PRESIDENT'S SUPPORT?

During his campaign, President Clinton promised that "...personal assistance services should be a part of any comprehensive health care reform plan." Has the President kept his promise?

It has become clear that any long-term care aspect of the plan would be phased in over time. The real question is how much time? Ten to twenty years will not work! The phase-in time must be minimal.

Clinton has only recently given his TENTATIVE approval to insurance coverage for long-term care to "severely disabled Americans" in his health care reform package. The plan has a \$15.4 billion price tag on it. Ira Magaziner, special assistant to the President, has stated that the coverage would be paid for through a separate fund.

The benefits within the long-term care component of the benefits package will include PAS activities.

Although we applaud the President's step to keep his campaign promise, it comes late in the discussion and key questions remain. For example, how is one deemed eligible for services? How is "severely disabled" defined? Currently, severely disabled is defined using the developmental disabilities definition: a disability that affects three or more major life activities. We feel that this definition could exclude many who don't fit the definition, but still have long-term needs. Our guiding principles state that the delivery system should move toward a functional-needs based system rather than a "medical model" based on diagnostic labels and antiquated definitions.

CTD SEEKS HILLARY'S SUPPORT WILL SHE LISTEN?

On April 6, Hillary Rodham Clinton came to Austin for a lecture at the Frank Erwin Center. Hillary stated that the Health Care Task Force's

recommendations would include some mental health and that long term care might be phased in 10-20 years from now.

Before Hillary's lecture, the Coalition passed out 1,500 flyers that defined personal attendant services and stated that PAS must be included in any package of health benefits.

After the lecture, CTD sent a letter to the President outlining the need for health care that will cover all Americans with disabilities, and that would include personal assistance, durable medical, rehabilitation, habilitation, prescription drugs, and more in the basic benefits package.

THE PRESIDENT'S PROPOSAL WHAT HAPPENS NEXT?

The biggest question on health care remains: how do we pay for it? With the addition of a long-term care component, the cost of implementing the reforms could soar to \$90 billion. Taxes, including a "sin tax" on cigarettes and alcohol have been considered, in addition to a Value Added Tax. CTD supports a personal income tax as a more stable source of funding, but so far it has not been mentioned publicly as a means to fund the Clinton health plan.

WARNING: THE DANGER LIES IN THAT BENEFITS COULD STILL BE LIMITED IF CONTROLLED BY THE STATE, AND THAT PRICES WOULD REMAIN OUT OF CONTROL.

HR 1200/SB 5491 THE SINGLE PAYER PLAN IS IT OUR BEST CHANCE?

Although the Clinton administration health plans have overshadowed other substantive ideas on health care reform, one bill proposed in Congress is not only making waves, but providing a standard of comparison. HR 1200 by Reps. Jim McDermott and John Conyers and companion bill S. 491 by Senator Wellstone, the American Health Security Act, were introduced in this legislative session despite the request of President Clinton to allow his plan to receive first consideration before any other plan. This single-payer bill is the better route to a health care system that meets the needs of people with disabilities and embraces the five principles we must have in any plan: non-discrimination, equity, comprehensiveness, appropriateness, and efficiency.

The CTD PASTF voted to support a single-payer health care system that includes a comprehensive array of services for people with disabilities. In addition, the PASTF agreed that any health care reform must include PAS as part of the benefits package. This bill best meets our needs of any proposed.

It contains costs through restricting the prices providers can charge and allows for local administration. Providers must accept any individual in the plan and consumers can choose their physician.

It would be paid for through a personal income tax, corporate taxes, and

payroll taxes. Other means of funding would come from taxing Social Security benefits and changes to Medicare.

The latest number of sponsors for the bill was at 72 in the House, 5 in the Senate. It is no surprise that the Clinton plan has begun to move closer toward embracing more of the principles of single-payer.

Call your U.S. Senator and Representatives now! Tell them that any health care reform must meet the needs of people with disabilities and include the five principles of health care mentioned in the article. Ask them to support HR 1200, S 491 as the best means to obtaining coverage for people with disabilities.

OREGON PLAN APPROVED IS DR. KAVOKIAN IN THE WINGS?

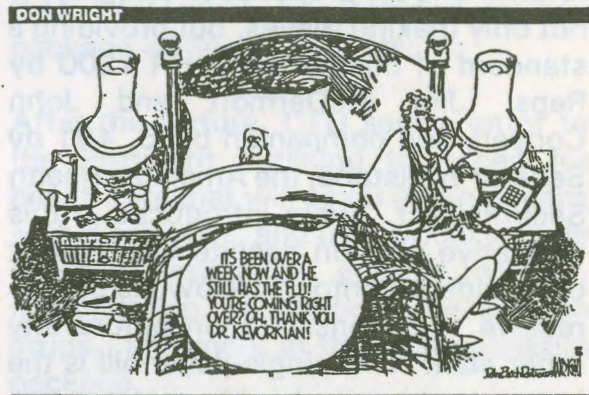
Despite the fears and opposition of the disability community, Oregon received approval recently from the Department of Health and Human Services on its radical approach to universal health care. The state has developed a ranking system of medical services that is based on effectiveness of treatment. The state has a cut-off point: any services falling under the cut-off point will no longer be covered.

The DHS approval came with strings attached--29 strings to be exact. Among the conditions and requirements, Oregon must have adequate funding for the plan. It will

not be allowed to base its funding solely on anticipated savings from implementing the program. Oregon is facing a budget crisis and is uncertain whether they will come up with the money to pay for the plan.

In response to the disability community, who previously challenged the plan as a violation of ADA, Oregon is also required to produce a phase-in timetable for people with disabilities and the elderly into the program. Although this plan purportedly no longer violates the ADA, it still sets a dangerous precedent and brings up a number of questions including who has the right to decide what services are "effective" or not?

Note: Much of the information on health care was taken from a Families USA newsletter called A.S.A.P. You can write to ASAP in care of Families USA, 1334 G Street, NW, Washington, DC 20005-3169.



THANK YOU CTD SUPPORTERS!
June 1992- May 1993

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WORD FROM WASHINGTON

Washington Views

VIEWS

The following is reprinted from the book, PUTTING PEOPLE FIRST: HOW WE CAN ALL CHANGE AMERICA, written by then Governor Bill Clinton and Senator Al Gore. In this particular section they discussed what a Clinton/Gore Administration means for Americans with Disabilities.

"We have long recognized that people with disabilities are some of our nation's greatest untapped resources. We believe that all persons with disabilities must be fully integrated into mainstream American society, so they can live fulfilling and rewarding lives. During our years in public office, we have compiled strong records of supporting public and private initiatives to enhance the independence and productivity of persons with disabilities.

As President and Vice President, we will continue our efforts. We will actively involve people with disabilities in developing a national policy that promotes equality, opportunity, and community for all Americans.

A Clinton-Gore Administration will ensure that children with disabilities receive a first-rate education that suits their needs. People with disabilities will be able to live in their own homes, in their own communities. Adults with disabilities will work alongside their peers without disabilities. And people with disabilities will have access to comprehensive health-care and consumer-driven personal assistance services.

We must not rest until America has a national disability policy based on three simple creeds: inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism.

Here's what we will do:

Americans with Disabilities Act

- * Work to ensure that the Americans with Disabilities Act(ADA) is fully implemented and aggressively enforced-to empower people with disabilities to make their own choices and to create a framework for independence and self-determination. The ADA is not about handouts and it is not a giveaway-it guarantees the civil rights of American citizens with disabilities.

Health Care for All Americans

- * Provide all Americans with affordable, quality health coverage, either through their workplaces or through a government program; prohibit insurance companies from denying coverage based on pre-existing conditions; and contain costs by taking on the insurance industry and the drug industries.
- * Expand long-term care choices for Americans with disabilities.

Improve Educational Opportunities for Children with Disabilities

- * Work to ensure children with disabilities a first-rate education, tailored to their unique needs but provided alongside their classmates without disabilities.
- * Support increased funding for special education services and work to improve the enforcement of laws which guarantee children with disabilities the right to a high-quality public education.
- * Support increased efforts to integrate children with disabilities into their schools' regular activities, instead of sectioning them off in special programs where they cannot interact with other students.
- * Expand early intervention programs in health care and education-such as Head Start- to ensure that children with disabilities live full and productive lives.

Expand Employment Opportunities for Americans with Disabilities

- * Increase the amount of special education, professional training, and job training to reduce the extraordinarily high unemployment rate among Americans with disabilities as part of national adult education, job training, and apprenticeship programs.
- * Sign into law the Family and Medical Leave Act, which George Bush vetoed in 1990, so that no worker is forced to choose between keeping his or her job and caring for a newborn child or sick family member."