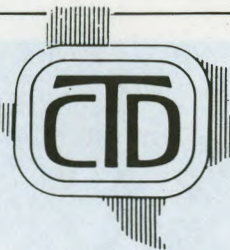


COALITION OF TEXANS WITH DISABILITIES



Fall 1987

NEWSLETTER

The Independent Living Movement

The Independent living centers, of which Texas will soon have seven, are one of the main products of the independent living movement. Although many programs are referred to as independent living programs or centers, a "classic" center for independent living is a community based program run by and for people with disabilities. The philosophical cornerstone of the independent living movement is that people with disabilities have the right to make decisions and choices about their own lives.

The first center to open its doors was the Berkeley Center for Independent Living (CIL), in 1972. Designed and created by a group of UC Berkeley students, CIL was the catalyst for the national movement. Ed Roberts, one of the founders of this center and the movement, described the beginning of the movement this way in a September 1985 interview for the Disability Rag: "When CIL started there were no professionals involved - though some of us were working toward being "professional" in a variety of fields. We had a different attitude about our work, which was born of the civil rights movement in the '60's and the women's movement. We learned a lot from being involved in those movements - that was an important part of what we began with." The independent living philosophy shares many ideas with similar movements which developed just before or around the same time. Adopted from the civil rights movement, were the ideas that all people have certain rights within our society and that segregated systems and services often mean inferior services. The concept that biology, or a person's physical body, is not destiny and does not automatically decide what that person's life will be like, was a concept started in the women's movement.

When discussing independent living, the phrase "consumer control" is often used. This came from the consumer movement started by people like Ralph Nadar. The underlying idea was that people who use a service or a product should be the final authority on how that service or product is designed and delivered. For disabled people that means that because of having had life experiences based on our being disabled, we have certain knowledge of what our needs are and of the best ways to meet these needs.

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AIDS as a Disability

In more and more court cases and administrative decisions AIDS, the Acquired Immunodeficiency Syndrome, is being classified as a disability. The syndrome and related conditions, often called ARC, AIDS Related Conditions, are getting local and national press. These conditions are almost invariably fatal, and as with other catastrophic and debilitating diseases and disabilities. The effects are usually financial as well as logistical and emotional, but there is another set of effects which relate closely to other disabilities. These are the effects of stigma, because for a number of reasons, people who have AIDS are seen by many people as a threat to our society generally and to them personally.

The fact that no one yet has pinpointed the ways in which AIDS is transmitted, coupled with its eventual fatal nature and present lack of a cure, are major contributors to the fear of people who have AIDS. Although the exact means by which one can get AIDS has not been documented, it is clear one must have very intimate contact to get the disease. Activities like shaking hands, coughing, hugging and sharing eating or drinking utensils will not cause someone to get the disease, nor will things like swimming pools, telephones, toilet seats, air, or doorknobs. Also you cannot get AIDS from donating blood. Activities like unprotected sexual intercourse, taking inside yourself semen, urine, feces, vaginal fluid or blood (including receiving contaminated blood transfusions between 1979 and 1985,) could cause you to get AIDS from someone who is infected with the AIDS virus.

AIDS has a particular importance for persons with disabilities for a number of reasons. For one the government more and more is classifying AIDS as a disability, and as such the laws relating to people with disabilities also relate to persons with AIDS. This may have an effect on how these laws are thought of and handled. It also is giving these laws, including good old Section 504 of the Rehabilitation Act, more press coverage than they have had in a long time. This is true of services also. Many of the services used by persons with AIDS are similar to those used by persons with other disabilities. With all the national pressure to "do something about AIDS and the people who have been exposed" there is a great deal of pressure to

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National Commission of Education of the Deaf

The U.S. Commission of Education of the Deaf was established by the Education of the Deaf Act of 1986 and is mandated to study infant, early childhood, elementary, secondary, post secondary, adult, continuing education programs, Federally assisted programs relating to instructional media and captioning services. The Commission is directed to submit its final report to congress and the President by February 4, 1988.

The Commission has drawn up its first set of draft recommendations. The Commission reports that "a major theme shaping many of the draft recommendations is that of improving quality and reducing costs through competition." The Commission has incorporated this theme of "competition" into the recommendations for the regional post secondary programs, for the federally funded research activities, and for captioned television services. There is a total of 18 draft recommendations. The primary draft recommendations with a brief explanation are as follows:

Federal policy should require that determination of an "appropriate" special educational program for a child who's deaf take into consideration the following factors:

- a) Severity of hearing loss
- b) Academic level
- c) Communicative needs
- d) Social needs
- e) Emotional needs
- f) Linguistic needs

This recommendation is an effort to redirect the emphasis placed on "least restricted environment" (LRE) in the traditional interpretation of Part B of the Education of the Handicapped Act. Many people feel that the emphasis on LRE has been more detrimental to many deaf children.

Federal policy should be established to require that school personnel inform parents of all options in the continuum of alternative placements during each Individualized Education Program (IEP-a program developed and implemented to meet the needs of a child) meeting. It is hoped that this recommendation will ensure that parents are informed of all available options for alternative placements. The Department of Education's Office of Special Education (OSEP) has stated that school personnel are not required to provide information regarding all educational options available during an IEP meeting.

Only a base level of Congressionally appropriated line-item funding should continue to be allocated to Gallaudet and National Training Institute for the Deaf for research, development and evaluation projects. An overall reduction in the current funding provided to these two institutions should be made and the remaining monies should then be set aside and used for competitive grants for deafness related research. The commission suggests that this

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A military theme ran through the last Halloween party. EX-VISTA Mel Aarron and an unknown dictator interrogate their dinner companions.

Independent Living *(continued from page 1)*

Off shoots of this line of reasoning are the "self-help" and "demedicalization of care" movements. Self-help is the simple idea that disabled people can offer one another valuable support and resources to help achieve our independence. Demedicalization addresses the problem that people who are physically different are usually classified as sick and as such are exempted from "normal" activities and control of their lives is given to medical professionals. Since people with disabilities are not sick (usually) but have different needs, a major thrust of the independent living movement is to have these needs met in a non-medical fashion.

In the Disability Rag interview Roberts goes on to explain the founders of the original center and the movement abandoned their original idea of a half way house because they wanted to be out in the community. "We recognized that what we had to do was to be politically active advocates to make the service programs work for us. That was another kind of ground rule."

"We didn't really want to set up transportation - we tried it once, but we just couldn't do it - so we went after the local transit system to become accessible." This combination of advocacy and services were the initial ingredients creating the independent living movement. Today, with the pressures of a more conservative climate in our country, the bureaucratic pull to inertia, financial pressures and a host of other pressures, some claim the advocacy is dying in the centers. There are even questions as to whether, in pushing so hard to get the centers, all the energy for disability rights in general was used up. It does not have to be that way (although similar things have happened in similar movements). Centers can be the recruiting grounds for whole new generations of advocates. It is obvious enough we have generations of work cut out for us.

NEWS FROM AROUND THE STATE

Message Relay Update

In an effort to develop a communicative device for deaf and hearing-impaired people, Alexander Graham Bell invented the telephone. Ironically, access to telephone service is not a reality for many of the 120,000 profoundly deaf individuals, and over 900,000 hearing-impaired individuals in the state of Texas.

However, a viable solution to this problem is at hand! Message Relay Services provide the necessary communication link between people who are deaf, or hearing-impaired, and hearing people via the telephone. By using a TDD (Telecommunications device for the deaf), a person who is deaf or hearing-impaired can call the Message Relay Operator (via a TDD) and then the Message Relay Operator calls the hearing person and relays the message, with both parties on two separate phones, at the same time. This procedure can also be reversed, meaning a hearing person could initiate the call.

Currently, there are sixteen locations in Texas in which message relay services are provided. The 16 councils for the Deaf provide this vital service and they receive funding from the Texas Commission for the Deaf. The message relay services vary in degree of sophistication and hours of service, due to limited funding (\$40,000 each fiscal year is divided amongst the 16 councils). The present system leaves a lot to be desired and many areas of Texas are not served.

Many states have already taken the lead to establish statewide message relay services which handle 3-5,000 calls per day. California has appropriated eight million dollars to the message relay system and the funds are

raised through a three cent surcharge system which is tacked onto the local telephone bill received by telephone customers. New York will implement a similar system, beginning January 1, 1988. Connecticut, Arizona, Oklahoma, Massachusetts and Kansas have state funded Message Relay Service systems, which provide services to a much broader range of deaf and hearing impaired individuals than here in Texas.

In February, 1987, a group of individuals interested in expanding the current message relay service system in Texas formed a committee to research the various ways in which this goal could be accomplished. The "Message Relay Committee" has worked cooperatively with the Pioneer Clubs of Texas to distribute free TDD's (telecommunication devices for the deaf) to low income individuals. The Pioneer Club hopes to place 100 TDD's (at no cost) this fiscal year.

The Message Relay Committee Recommends that increased state funding for the FY 1989-90 biennium be sought and that a surcharge system be implemented to supplement such increased state funding and accomplish the goal of centralized message relay services for the state of Texas, similar to those currently in operation in California and New York. The surcharge system would guarantee continuous cash flow on an annual basis throughout the duration of need as opposed to the fluctuations ever imminent within state funding. If you have any question regarding this issue, contact Leigh at the C.T.D. office (512) 443-8252.

from the two program people to answer questions on state-wide related issues. For example the Deaf-Blind Program which was headed by Beth Quarles is now called the Deaf/Blind communication disorders Program and Beth now has regions I, IV and V and Kelly Caudell has regions II, III, and VI.

If you want a copy of the new TRC organization chart let us know at the CTD office.

TCB Hires Supportive Employment Person

The Texas Commission for the Blind has hired a Supportive Employment Specialist to manage the \$280,000 of 1987 dollars going to TCB this year. Keith Kitchens has been hired to develop this new program. Keith has formally worked at Travis State School and Goodwill Industries.

Supportive Employment is a new concept that will place severely disabled persons in competitive employment with a range of support services.

Two New ILC's for Texas!

Crockett and Amarillo will soon be the proud sites of Texas' newest independent living centers. The Tri-County Awareness Association Independent Living Center and the Panhandle Action Center for Independent Living skills (PACILS) have finally become a reality. After years of waiting and months of rumor the final decisions have been made. This will bring the total number of independent living centers (ILCs) in Texas up to seven. When you consider that states such as New York have 19 centers, and when you consider the size of Texas, seven ILCs seem more like a beginning than anything else. However, it is cause for celebration!

Houston county Awareness Association is gearing up at a record pace to open their Tri-County Independent Living Center (ILC) which will serve the three counties nearest to the East Texas town of Crockett. This will be the first "rural" ILC in our state, and one of a very few in the entire country. The current contact person for the Tri-County Center is Glenda Turner and she can be contacted at:

Glenda Turner
Tri-County Center
P.O. Box 536
Crockett, Texas 75835

PASCILS, or the Panhandle Center is also gearing up at top speed. A project of Amarillo Disabled in Action (ADIA), PASCILS has been in the application stage for about three years. Although Amarillo's disabled community has been about the most organized and active in the state, the needs of this community are often passed over, to the frustration of its leaders. PACILS is a major step in addressing this problem. Margaret Robinson is the PACILS contact and can be reached at:

Margaret Robinson
PACILS
4700 Virginia #118
Amarillo, Texas 79109

Consumer advocates in these communities, and indeed across the state should be congratulating themselves in a big way. It was our organized consumer advocacy efforts that brought these much needed centers to these important parts of our state. Other parts of Texas need centers too, and we must keep pushing until at least all the major geographic areas are served. Working together though, we can make a difference.

New Jobs in Texas

Sometimes an advocacy group will have a good idea that catches on. Two new jobs in Texas, while perhaps not outgrowths of CTD positions, indicate that the time for such positions has clearly arrived. As the CTD Client Assistance Project Outreach project was coming to a close, El Paso Texas Rehabilitation Commission administrators decided it was time, if only temporarily, to hire someone to look into what was happening with some of the TRC clients who had, in one way or another, dropped out of their rehabilitation program. In fact they hired the CTD CAP outreach worker to do the job, since he had helped clear up quite a number of problems during his outreach work for the Client Assistance Project. If serving clients is your main goal, it makes a lot of sense to work to find out if there are mutually agreeable ways to iron out the kinks in ones service delivery system. Hats off to El Paso TRC for going the extra mile to meet their client's needs.

Another new position, the time of which has come, is at the Texas Commission for the Deaf. They are looking to hire someone to work on the various Memoranda of Understanding, MOUs, (the new term for interagency agreements,) and monitor the legislative activities which affect the commission and deaf Texans generally. If last session and the activities of the deaf community, TCD, and CTD's Deaf Issues Organizer are any indication, this person should be very busy. In addition with the Sunset Review of the Texas Education Agency and the Coordinating Board of Higher Education, as well as the Human Rights Commission, and the many concerns the deaf community has about education and employment discrimination, even during the interim between now and next session there will be more than enough legislative related work that needs addressing. TCD has taken a major step and should be congratulated for their foresight.

Agency News

Texas Rehab Reorganizes

"Who's on First? What's on Second? and I don't know on third?" is what many in the state are asking after the Texas Rehabilitation Commission went through their second major reorganization in six months.

Effective October 1st, the commission will be managed on a more regional basis rather than by separate program designations. Assistant Deputy Commissioners JoEllen Flores Simmons and Ken Vogel will divide the regions in half with JoEllen managing I, IV and V and Ken managing II, III and VI.

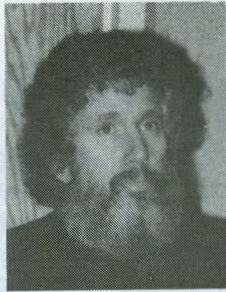
Previously, each TRC program had a program manager in charge of that area of services. Now each TRC program will have two people who will divide their responsibilities among the six regions, each one having three regions. There will be a lead person chosen



Tom Morrison? and DH Howell? feast at the 1981 Halloween Bash!

President's Message

by Bob Kafka



Transition Services! Supportive Employment! In-Home and Family Support Services! Independent Living Council Medicaid Reform! These are the issue areas that will shape the Texas Service Delivery system on the state and local levels, as we move into the 1990's. All of these areas have an opportunity for consumer input in the program design. This will require us to educate ourselves on the make-up of the programs and the implications all these services will have for the people we represent. We cannot focus our attention on only one or two state agencies. The needs of the disabled community are very large and we must look to all segments of both the public and private sector to meet those needs. We must link the programs funded by Medicaid funded programs with those funded by Vocational Rehabilitation dollars and create a package of services that will meet the needs of the disabled population. The independent living movement, for the most part, has avoided Medicaid funded programs because of some of "medical model" requirements and dependence-fostering aspects inherent in the programs. We must make the Medicaid programs, as they are currently

provided, work for us. At the same time we must advocate for changes in the medically offensive requirements of Medicaid and make the program work for Consumers.

The national move for Medicaid reform is a positive step that freezes institutional dollars at the current levels and allows new dollars to be put in community based programs. There is a politically strong developmental disabilities coalition on the national level that must hear from the underserved developmentally disabled person and the person disabled after age 22 that this Medicaid money must also be used to meet their needs. If passed, S. 1673 will have a major affect on how Texas delivers services to disabled people. There is a lot of lip service given to coordination of services by state agencies. The consumer movement must make this coordination happen. The Transition Services Task force created by SCR 123 is one way the consumer voice can be heard. If we let the agency representatives dominate we will again be left complaining about the outcomes.

We have a good opportunity to make our voices heard. We must demand that we be listened to. Advisory committees can be a powerful way to make this voice heard, but we must be willing to speak out on these committees, rather than be informed about what is going on after the decisions have been made.

I leave the Presidency of CTD hoping that CTD will continue to advocate for the disabled consumer and to organize these people to make positive changes that will benefit the consumer and not just the bureaucrat.

Good Luck!

Nat'l Commission (continued from page 3) recommendation will "encourage competition, innovation, and diversity in research on deafness," and that the intention is not to recommend "any reduction of funding for deafness-related research". Obviously, this recommendation has sparked much controversy.

Congress should enact legislation to mandate the Federal Communications commission issue regulations as it deems necessary to require that broadcasting licenses caption their programming.

The intent of this recommendation is to propose that "certain broadcasters should assume responsibility for making their programming closed captioned without relying on federal subsidies."

Other draft recommendations were made regarding funding and expanding Regional Postsecondary Education Programs; Admission policies at Gallaudet and National Training Institute for the Deaf; and setting research priorities.



Bobby "Easy Rider" Simpson, Pat "Woodstock", David Pound, Charlotte Stewart, Larry "The Vampire" Johnson all party hardy!

Editorial

by Bob Kafka

What is at the basis of the perceived conflict between Madeleine Will, Assistant Secretary Special Education and Rehabilitative Services and Justin Dart, Commissioner Rehabilitation Services Administration? Folks are lining up on both sides saying their person is the greatest. In some quarters it is said that the Council of State Administrators of Vocational Rehabilitation (CSAVR) wants Ms. Will out because of her support of Supportive Employment. Others say it is the Non-severely disabled folks versus the severely disabled population and that Justin speaks for the elite and Madeleine speaks for the severely disabled. Others say Ms. Will is paternalistic in her view of disabled persons and that she does not want an RSA Commissioner that speaks out.

I believe the public outbreak of these issues are a result of some concerns that have been festering for years. There is a growing division between those advocating for persons with physical disabilities and those with mental disabilities. In addition, there are differences in philosophy between parents of disabled people and the adult disabled population. There is also a concern that the rubric "developmentally disabled" has not fairly served those with physical disabilities. Is a young child who is blind or deaf developmentally disabled? What about a child with epilepsy or a learning disability? What about head-injury? What is of more importance is how have program dollars been allocated to serve those populations.

Where are the accurate demographics concerning developmental disabilities? I have seen a federal study that says that over 50% of the D.D. population is physically disabled. I have been told 80% of the D.D. population is mentally retarded. What are the accurate figures and are program dollars allocated close to those demographics.

Much of the debate has been focused on the fact that V.R. does not want to serve those with mental retardation. The Supportive Employment regulations as they were first drafted in the RSA office would have allowed cross-disability use of supportive employment funds. As they left RSA and went further up the hierarchy the rules became more narrow and are now more exclusive than inclusive. The issue is cross-disability use of all funds coming from the federal government. V.R. should be more open to those with mental disabilities but the Medicaid program should be more available to those with physical disabilities. There must be equity.

The political scene in Washington, D.C. has in the last five years not had a strong consumer organization representing the interest of the consumer movement. The American Coalition of Citizens with Disabilities (ACCD) was that voice but has gone out of business. The National Council on Independent Living (NCIL) is just beginning to make their presence known in D.C. The Paralyzed Veterans of America (PVA) has turned their sights mostly towards the Veterans Administration.

Groups like the Association of Retarded Citizens, National Association of Protection and Advocacy Systems, the D.D. Consortium, United Cerebral Palsy, and the Association of the Severely Handicapped should be given credit for their political strategies. They have advocated for their interest groups and have had a level playing field in D.C. In doing so, they have dominated the political scenes to the extent that a backlash is developing.

Madeleine v.s. Justin is just a symptom of that backlash.



Visions of things to come? The "Charmings" Redge Westbrook and Judy Wingard Westbrook make their grand entrance, at CTD's last Halloween party.

AIDS *(continued from page 1)*

make these services more responsive. The Texas Department of Human Services, TDHS, is considering medicaid waivers (a Bureaucratic way of bending the rules to better meet a need) for persons with AIDS. Disability advocates have long been trying to get similar waivers for attendant and similar services. Although this may mean TDHS by-passing traditional disability groups for yet another population, it may also be a leverage point for creating more responsive services.

Finally the ways persons with AIDS are being treated are in many ways similar to the ways people with other disabilities have been or are treated. Shunning, desire to blame the person with the condition for their condition, talk of quarantining, lack of concern for the rights of affected persons and mistreatment of these persons based on misinformation and phobia are all actions and attitudes which are well known to disabled persons. Children with AIDS antibodies (who have not even shown symptoms of the disease yet, but whose blood tests show they have been exposed) are shunned in schools, put in segregated educational settings, and have been barred from contact with their peers. Service providers have refused treatment to people with AIDS, employers have fired them, Insurers will not cover "pre-existing conditions", etc., etc..

The misinformation about AIDS runs rampant. In addition, AIDS is often seen in a moral light, rather than simply as another disability or disease. AIDS is not limited to gay white men and junkies. Two out of five Americans with AIDS are Black, Latino, Asian, American Indian and other ethnic minorities; Among women with AIDS half are black and one in five are Latins. People with certain disabilities such as hemophilia are clearly at higher risk than the general population. In addition, there is a notable lack of information on other disability group's degree of risk. It is clear that traditionally the disability community has had limited access to AIDS information. Rarely are brochures brailled or taped, lectures and presentations interpreted. Recently a task force on "AIDS and People with Disabilities" has been established to address some of these issues. For a wide variety of reasons it is important that disabled persons become informed about AIDS and the issues surrounding this syndrom. It may well have major implications for the future of our movement.

JOIN CTD—The Coalition of Texans with Disabilities

The Coalition of Texans with Disabilities is a coalition of organizations and individuals committed to cross disability communication, cooperation and coordination. The Coalition promotes social, educational, physical, and mental well-being of disabled Texans. The Coalition of Texans with Disabilities brings

together people and organizations with similar goals in a united effort to represent all disabled Texans to government, the private sector, and general public. Membership in the Coalition enables organizations and individuals to enhance their effectiveness in improving the quality of life for Texans with disabilities.

MEMBERSHIP APPLICATION

Individual Member

- Yearly \$12.00
 Life Member \$100.00
- Please send me _____ organizational memberships forms
 Please send me the CTD's newsletters on cassette tape.

Please make checks payable to:

CTD
P.O. Box 4709
Austin, Texas 78765

Name _____

Address _____

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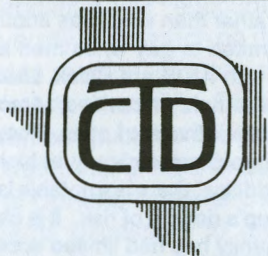
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