



Highlights

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New possibilities: Obtaining a place to call home

"I passionately believe that everybody deserves a place to call home. That they should not have to earn it. People can live in the community and should not have to graduate through programs."

-- Derrick Dufresne

There's no place like home. Having a home is important to all of us and brings a sense of pride and belonging. It provides the opportunity for privacy, relaxation and entertainment. It also provides a place where we invite others to share meals, music, television and our company.

While everyone needs a home, it can be very difficult to obtain

affordable and accessible housing so that people with disabilities can live in neighborhoods and communities. However, with the right planning, people can achieve their dream of having their own home, whether they rent or buy.

"Somewhere along the way, we have set up this criteria that you have to earn your way to a place called home," explains Derrick Dufresne, president of Community Resource Associates in St. Louis, Missouri.

However, he stresses, individuals with disabilities can live in their own homes if we provide the supports they need. Since 1981, his organization has been working

to develop community housing options for people with disabilities.

"We can make housing affordable just on the basis of two people's SSI (Supplemental Security Income)," Dufresne revealed. The federal government considers housing to be affordable if it costs no more than 30% of the tenant's income, he explained. So we work backwards from that number — from what people can afford — in finding housing.

Dufresne explored the possibilities and complexity of obtaining housing for people with disabilities, as well as financing strategies, at a

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Move brings excitement, responsibility, independence

"This is my home!" Karen Greebon yelled triumphantly on her first night in her own apartment. It was a day full of firsts for her.

Picking up the keys to her own apartment. Making her own grocery list. Hiring her attendant. Deciding where she wanted her

furniture and supervising the move-in. Figuring out how to use a speaker phone by herself and dial with her foot. Watching empty rooms transform into a home. Her own home!

After 12 years in a nursing home, Karen moved into her own apartment in July 1990, with assistance from the Supported Living Demonstration Project, a DD grant* to the United Cerebral Palsy Association of Texas (UCP-Texas)(See related article, page 3).

Now, two and a half years later, she continues to live in her own apartment in Austin and is a strong advocate for other people with disabilities. She testifies before legislators and works hard, fighting for

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A Home of Her Own -- After living in a nursing home for 12 years, Karen Greebon enjoys the first night in her own apartment.

Move brings excitement, independence *Continued from page 1*

the rights of others so more people can move out of institutions.

"I lived in a nursing home in Luling for 12 years," Karen recalled. "Everybody thought I could not make it (on my own), even my own family. I had to fight my family. They said, 'Oh Karen, you can't make it.' I said, 'I want more out of life than this.'"

"So I got with UCP," she explained, "and they helped me a lot." First UCP staff asked Karen what she wanted out of life. Then they worked together to achieve it.

"They helped me get my apartment," Karen said. "They let me choose the location. They provided furniture. They helped me pay half the (rent) money until I got on Section 8 (a housing subsidy)." UCP also assisted in getting food stamps, attendant services, home health care, and other supports.

Karen was able to get on the CLASS Medicaid waiver in June 1991. She changed apartments in March 1992, because the first complex stopped taking Section 8.

When I first moved into an apartment, I was scared, Karen revealed. "I felt happy, very happy, but yet, I was scared because for 12 years I never had to worry about who was going to help me... And here I was in my own apartment. I didn't know if my attendant would show up or not." She stressed the importance of finding good attendants. "I realize you have to respect your attendant, and I want them to respect me. It goes both ways."

Karen spends a lot of her time now working for ADAPT (American Disabled for Attendant Programs Today). "We feel everybody has a right to be independent."

She telephones individuals for the organization, keeps track of addresses and phone numbers of members, and talks to people about what they should do. "We

go see legislators and talk about community and how they can help people...live more independently."

Karen added that she feels like she is accomplishing a lot.

She also enjoys going to parties, bowling, shopping at the mall and out with her boyfriend. While he lives in his own apartment now, he was in a state school 30 years.

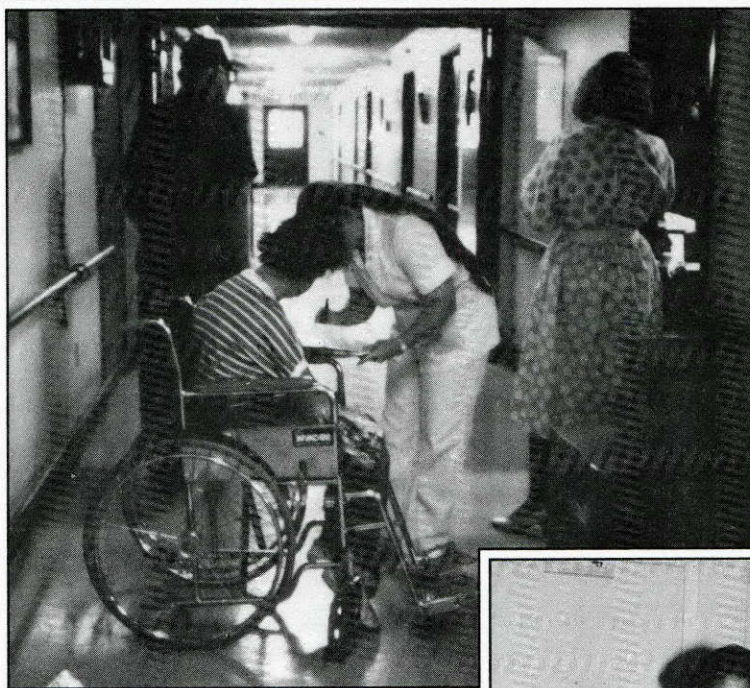
"We want to have a life together," she said. "We love each other very much, but we still have a lot to work out — like attendant care. We have to find out if our benefits will be taken away from us...We are hoping that we can get married like everybody else."

While Karen is a unique and

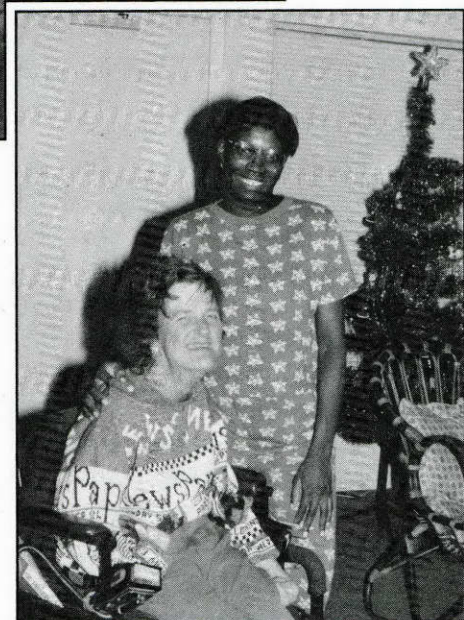
capable individual, the staff at UCP-Texas acknowledge, there are a whole lot of other people out there who could live on their own if they can obtain needed supports and if funding is redirected.

"The difference between individuals with significant support needs moving into and maintaining their own homes in the community and remaining in segregated, institutional settings was not the severity of their disabilities," they reported, "but the availability of and access to ongoing support funding sufficient to meet their needs." ♦

** DD grant funds are awarded on behalf of the Texas Planning Council by the Texas Rehabilitation Commission.*



Karen Greebon (above) signs out of the nursing home where she spent 12 years of her life. She now lives in her own apartment, as she has done for the past two and a half years, using support provided by attendants such as Patricia Washington (right). This support and other individualized services have enabled Karen to become independent and control her own life. She spends a lot of time now working and advocating and so more people in institutions can become part of their local community.



Individualized supports essential

Project demonstrates anyone can live in own home

The stories abound. Over and over again, individuals throughout Texas reveal how difficult it is to obtain services and supports that they need to live in their own homes. Especially if the individuals have significant disabilities and support needs.

Texas traditionally has chosen to serve these individuals in institutions, nursing homes and other segregated environments that isolate them from their families and communities. Nor do they get many opportunities to pursue their own desires and dreams or make their own choices.

Twelve individuals, however, recently took control of their own lives as part of a DD grant, moving into homes and apartments they chose.

Under the three-year grant, the United Cerebral Palsy Association of Texas (UCP-Texas) assisted these individuals in achieving their dreams and becoming part of the community. When the project ended last June, all of the individuals except one continued to live in their own homes in Austin and Dallas.

Exploding "Severity Myth"

"These individuals...have exploded the myth of 'severity of disability' as a basis and a rationale for providing institutional, group or facility care to persons with disabilities in our state," UCP-Texas stated in its final report.

Generally speaking, project participants had been regarded by the service system as having disabilities "too severe" to live in the community. The participants all have severe physical disabilities, and many have labels of cognitive disabilities.

Most were living in nursing facilities, group homes or large ICF facilities when the project began. Three were living with relatives and

were at risk of entering a facility. However, by changing the types of services, supports and choices offered to them, it became possible for these individuals to live in their own houses and apartments.

Rather than making individuals fit into existing programs and service structures, the project built individualized supports and services around participants, with an emphasis on personal choice and self-direction.

Individualizing Supports

Intense effort went into supporting the individuals' decisions as well as working with them to access, coordinate and stabilize fundamental supports such as accessible and affordable housing, attendant care and basic adaptive equipment.

"The greatest effort in working with individuals with disabilities to move involved helping them coordinate their basic support services, such as social security income, housing and home modifications, attendant care and adaptive equipment, to coincide with their actual move date," UCP-Texas reported. Because of gaps in the services structure, individuals often experienced a four to six week delay in receiving food stamps, as well as significant delays in receiving personal assistance services, basic adaptive equipment and removal of architectural barriers.

In its final report on the Supported Living Demonstration Project, UCP-Texas concluded:

❑ *All people, regardless of the nature or severity of their disabilities, can live in the community when given the individualized supports they need to do so.*

❑ *People need supports to live in the community that are not available in the state delivery system right now.*

The final report also includes 10 policy/legislative recommendations for providing individualized supports that persons with significant disabilities need to live full lives in their communities.

These include shifting away from institutional resources to community-based supports; health care reform; maximizing the use of Medicaid waivers; increasing affordable, accessible housing; expanding services offered under Medicaid in Texas; and assisting individuals with the move into the community and with ongoing supports.

These findings and recommendations take on an immediate and critical importance, UCP-Texas points out, with the imminent closing of two state schools and the push to develop a viable community services system.

Two reports are available from the Supported Living Demonstration Project:

"Going Home and Other Adventures: A Guide to Supported Living for Persons with Disabilities," May 1992. It describes how the Supported Living Project was set up, including suggested strategies and tips for others.

"Going Home: Final Recommendations for Development of Supported Living Services in Texas," September 1992. It presents overall findings of the project, along with specific systemic, policy and legislative recommendations to make community living a reality for persons with severe disabilities in Texas.

For a copy of either report, write Joyce Dawidczyk, United Cerebral Palsy Association of Texas, 900 Congress Ave., #220, Austin, TX 78701; or call her at (512) 472-8696. ❖

Exploring possibilities for affordable housing *Continued from page 1*

seminar sponsored by the Texas Planning Council in September. Additional seminars are being planned in the Dallas/Fort Worth area, Austin and Lubbock in April. (For details, see page 5).

Housing is actually the easiest part, Dufresne said. The challenge is providing supports and services to individuals and connecting people with the community.

"A house is a house is a house. Supports are supports are supports. *You should not have to live a certain place to get a certain level of supports.* If you understand that, you've got the concept of supported living.

"It means that somebody who is blind and deaf can live in an apartment or condominium...Somebody

be landlords or service providers. Housing can eat up time and money and keep providers from doing what they are best trained to do. It also turns residents into clients rather than tenants who are in control of where they live.

"The best service systems...in the country have gone outside the bounds of the disability community and are seeing issues as being community issues, whether it be housing, transportation, supports..."

Not Just a Disability Issue

Wipe from your minds that we work with people with disabilities, Dufresne said. Every program that is out there for people with disabilities tends to be still segregated in nature, targeted just toward people

are eligible for them, because they are poor. The more we understand we are working with poor people, the more options are available.

Additionally, a person's home is an exempt asset if the individual is the primary resident and the home is in the individual's name or a trust's name. This allows a family member, individual or trust, etc. to provide the housing without the individual losing Medicaid or SSI.

Choosing a Home

Where people live affects their relationships with others, Dufresne pointed out. Single family houses are not always the best choice because they can isolate people. Frequently neighbors wave to each other but have no other contact.

Condominiums, townhouses and housing cooperatives, however, allow occupants to meet all kinds of people. People are constantly coming and going there. This provides natural opportunities for interaction. And, as an added bonus, condominiums are selling at bargain prices in many areas now.

Additionally, Dufresne explained, people usually accept one or two individuals with disabilities as neighbors. What they frequently object to is group homes. "I find that the larger you get than two (people with disabilities in one home), the more difficult it is for neighborhood acceptance, integration and inclusion," he said.

Know What You're Doing

In buying a home, most of us are involved in a transaction that we don't understand. This also can be true when obtaining housing for people with disabilities. Social service agencies are particularly vulnerable because many of them don't know enough about real estate and tend to pay too much, Dufresne noted.

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"The best service systems...in the country have gone outside the bounds of the disability community and are seeing issues as being community issues, whether it be housing, transportation, supports..." Derrick Dufresne

that has a significant behavioral challenge can live in a duplex with somebody on the other side who does not have a disability."

A New Ball Game

In many cases, providers are applying congregate care concepts to community care, Dufresne pointed out. "If we think we are going to be able to run the community service system using the same philosophy and basically the same approach to staffing as we did the institutional program, we are going to run ourselves into bankruptcy."

Small providers are popping up all across the country that are only serving one to 15 people, he observed. They are providing a piece of the services and are contracting with other professionals for services that used to be provided by staff, such as therapy.

Additionally, he stressed, people that run the services shouldn't own the housing. People should either

with disabilities and facility based in terms of housing.

However, he emphasized, *housing is a community issue.* There are all kinds of federal, state and local programs that providers, advocates and agencies don't know about, because we are thinking about people with disabilities.

Many agencies are providing affordable housing, in-home health care and supported services, but they are not targeted toward people with disabilities. "I'm spending most of my life meeting with housing agencies, state departments, rural housing development cooperatives, and people who have nothing to do with people with disabilities, that we have never built alliances with before," he said.

We need to recognize that most of these programs are for people who are poor. While the programs don't address disabilities specifically, people with disabilities usually

If you are going to be involved in real estate, you must understand the language involved and how it all transpires and works.

Housing Programs

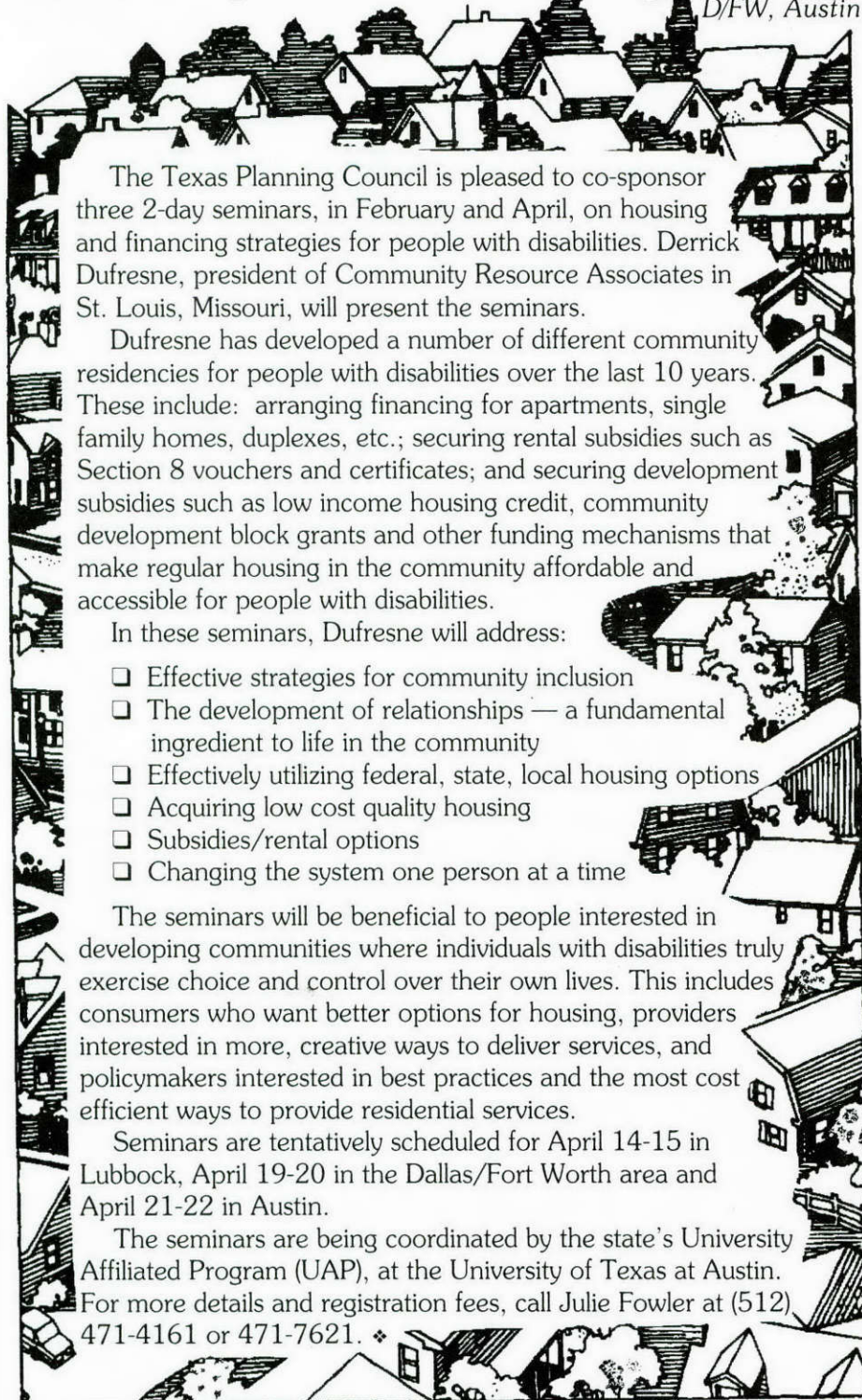
There are various programs disability groups hooked on to which

were not meant for people with disabilities. HUD 202 is one which is actually a program for the elderly. Section 202/8 is a program for people with disabilities. Section 811 is now replacing 202.

I object to Section 811, Dufresne said, because houses

under it must be owned by a non-profit organization rather than the individual; only people with disabilities can live there (except staff); and it requires a 40-year mortgage that cannot be prepaid. He prefers other programs designed for the general public such as:

Seminars planned on housing *In Lubbock, D/FW, Austin*



The Texas Planning Council is pleased to co-sponsor three 2-day seminars, in February and April, on housing and financing strategies for people with disabilities. Derrick Dufresne, president of Community Resource Associates in St. Louis, Missouri, will present the seminars.

Dufresne has developed a number of different community residencies for people with disabilities over the last 10 years. These include: arranging financing for apartments, single family homes, duplexes, etc.; securing rental subsidies such as Section 8 vouchers and certificates; and securing development subsidies such as low income housing credit, community development block grants and other funding mechanisms that make regular housing in the community affordable and accessible for people with disabilities.

In these seminars, Dufresne will address:

- Effective strategies for community inclusion
- The development of relationships — a fundamental ingredient to life in the community
- Effectively utilizing federal, state, local housing options
- Acquiring low cost quality housing
- Subsidies/rental options
- Changing the system one person at a time

The seminars will be beneficial to people interested in developing communities where individuals with disabilities truly exercise choice and control over their own lives. This includes consumers who want better options for housing, providers interested in more, creative ways to deliver services, and policymakers interested in best practices and the most cost efficient ways to provide residential services.

Seminars are tentatively scheduled for April 14-15 in Lubbock, April 19-20 in the Dallas/Fort Worth area and April 21-22 in Austin.

The seminars are being coordinated by the state's University Affiliated Program (UAP), at the University of Texas at Austin. For more details and registration fees, call Julie Fowler at (512) 471-4161 or 471-7621. ♦

CHAS: The Comprehensive Housing Affordability Strategy program (pronounced Ch-az). Under this program, states and cities over 50,000 residents had to write a 5-year plan (their CHAS) on how they would meet their affordable housing needs. This program also includes HOME or HOPE funds.

The HOPE Program: Home Ownership Opportunities for People Everywhere. It has three parts. HOPE 3 is meant to turn properties under foreclosure into home ownership opportunities for people who are poor. Applicants have to be a local unit of government that works in conjunction with a non-profit.

The HOME Program: Home Investment Partnership Act. This is for rental assistance and/or home ownership options. It provides grants to local units of government and non-profits for new construction, rehabilitation, acquisition, and home buyer assistance. One Texas priority is designed to ensure that persons with special needs have access to state and federal housing assistance. In the first 18 months of the program, at least 15% of HOME funds must be set aside for CHDOs.

CHDO: Community Housing Development Organization (pronounced Cho-dough). This program is for housing rental, renovation and ownership. There is a lack of eligible applications nationwide. CHDOs have to be

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Exploring possibilities *Continued from page 5*

non-profit organizations that can demonstrate a one-year previous commitment to providing services. At least 1/3rd of their board must be people who are low income or are elected to represent them.

□ **Farmers Home:** FmHA, under the federal Department of Agriculture for communities of less than 10,000 people or less than 20,000 if they are part of a Statistical Metropolitan Area (i.e. a suburb). Farmers Home can finance loans as low as 1% for up to 38 years if the applicant needs it. The going interest rate is 8 1/4%, but they can write the interest down so the monthly payment isn't more than 29% of a recipient's income. Interest rates can go up annually if income goes up. Farmers Home 502 also has loans to bring homes up to FmHA property standards.

□ **CRA:** The Community Reinvestment Act of 1978 requires banks to invest in their own communities, including loans for housing.

□ **Housing Development Corporations:** There are perhaps 15-20 in Texas. They can act as a real estate developer or a property manager.

□ **HUD Section 8 Vouchers and Certificates** are subsidies to make up the difference between what a person can afford to pay and housing costs. They only apply to certain cooperating landlords who can limit the number of apartments available. Dufresne recommends getting on the Section 8 waiting lists, which are divided up by size of the unit. The lists are incredibly long and may only open for very short periods.

In the Section 8 Certificate program, the landlord cannot charge more than the allowable fair market rent. Section 8 Certificates have mobility; people can take the certificates with them when they

move within state.

Under the Section 8 Voucher program, another person can make up the difference in price if rent is, for example, \$600, but the fair market rent is only \$500. These are hard to get, but very desirable. Section 8 Vouchers have portability; people can take vouchers with them when moving out of state.

□ **Independent Group Residencies:** IGRs were created by HUD in 1990 to provide housing subsidies/residences for two to 12 individuals who need support services. Most housing authorities do not know about IGRs, but they can establish a separate waiting list for them.

Refuse to Go Away

While there are a variety of resources, this does not mean they are easy to access. Nor does it mean they are easy to understand. This is not the traditional way we have served people with disabilities.

If all of this sounds exciting (or confusing) and you want to learn more, you are invited to attend one of Derrick Dufresne's two-day seminars that the Council is co-sponsoring in April. For details, see page 5.

You will run into brick walls in obtaining housing for people with disabilities, Dufresne acknowledges. "Most of what I get done, I get done because I refuse to go away." Consider "No" a temporary sign that will give in with enough pressure.

You don't have to yell or scream. *Be a pleasant militant.* Talk to anybody that will talk to you about housing. And, as Winston Churchill said, "Never give in. Never, ever give in. Never ever, ever give in." ♦



"Child Care for All: Including Children with Disabilities in Child Care Settings" is scheduled March 26-27, 1993 in San Antonio.

Topics for the conference range from how to make child care programs inclusive to ADA implementation and identifying community resources. Training will include hands-on experience with assistive equipment and tours of exemplary programs.

Sponsors include the Inclusive Child Care Project of Texas, a DD grant project. For more details on the conference, contact Rita Siegle at Dependent Care Management Group, 1405 N. Main, Suite 102, San Antonio, Texas 78212; (210) 225-0276. ♦

Congress schedules breaks during 1993

During 1993, the House and Senate have scheduled various "district work periods," when Congress is in recess. At this time, U.S. senators and representatives depart Washington, D.C. and return to their home states. These are good times to contact them regarding federal legislative issues. District work periods are:

Feb. 8-15	Both
March 19-22	House
April 5-13	House
April 5-16	Senate
May 28-June 4	House
May 31-June 4	Senate
July 2-9	House
July 5-9	Senate
August 9-Sept. 7	Both ♦

From the Executive Director: *Reality keeps changing*

By Roger Webb

There are two types of reality: the way things are and the way we think they are. And both are constantly changing.

Every so often, someone drops a bomb on our concept of reality and explodes accepted ideas and beliefs. This makes us, all of us, face a new reality. It also forces us to re-evaluate what we are doing and realize that there may be another, better way to do things.

We've been hit by a lot of bombs in the last decade. Bombs that have shattered beliefs about people with disabilities and their capabilities. Bombs that are forcing people to recognize that individuals with severe disabilities can attend regular classrooms, work in regular jobs, and live in homes of their own in the community.

The most powerful bomb recently is facilitated communication, a technique which is permitting some individuals with severe speech and physical disabilities to express themselves for the first time.

Suddenly parents and professionals all over the country are being hit with a new reality. They are discovering that many individuals whom they believed either have severe cognitive impairments or otherwise have been unable to communicate, do understand language and have

capabilities they never imagined. We simply have not known how to communicate with the individuals.

Last month, I heard a mom tell of the first time she saw her 30-year-old son use facilitated communication. He typed just four words, words he'd never been able to say before and which brought tears to her eyes — "I love you, Mama."

And it forced her and her husband to completely change their minds, beliefs and values about their son's capabilities.

Facilitated communication is challenging virtually every traditional view about people with severe disabilities. It is voiding intelligence tests and demonstrating that people with disabilities have abilities we thought they couldn't have.

Other findings — such as the Council's Supported Living Demonstration Project which showed that individuals with severe disabilities can control their own lives and live independently — also are impacting our world and reality. These breakthroughs are calling for us to re-evaluate our values and beliefs. We also need to re-evaluate what we are doing and programs we have developed. We MUST sense the urgency of people's lives.

It is critical to embrace and celebrate change. To consider new ideas and try new ways of doing things. We must be ready to

innovate. And we have to be willing to accept that some of the things we have done (and will do) are no longer "best practices." That's part of growing and learning.

Times change. Options change. Our reality changes. We must change too.

Equally important, we must accept that *all* means *all*. It is not enough to just give the word lip service. We have to mean it when we say *all* people and ensure that *all* really does mean *all*.

We need to dream about building communities where everyone is valued and all are empowered to make choices about their own lives. And then we need to make our dreams reality. ♦

Funds enable more people to attend conferences, events

During the past year, 16 organizations took advantage of a Council program which enables more individuals with developmental disabilities and family members to attend their conferences, workshops and other events within Texas.

This program began in 1989 and provides stipends to organizations that sponsor events which enhance independence, productivity and community integration for people with developmental disabilities.

Sponsoring organizations must apply for funding at least 120 days before an event. If multiple organizations are sponsoring the program, only one may apply.

For more details on the stipends and an application kit, write to W.D. Nielson, Texas Planning Council for Developmental Disabilities, 4900 North Lamar Blvd., Austin, Texas 78751-2399, or fax your request to (512) 483-4097. ♦

Council welcomes associate members

The Council is pleased to welcome six associate members, including four who were selected to serve a second term (indicated with an *). Associate member positions were created last year to increase consumer input and participation in Council activities. Individuals serve one-year terms, renewable to three years.

Candy Sheehan* and Susan Baker* were selected as associate

members to the Advocacy and Public Information Committee. Shirley Coker* and Alicia Hudson will serve on the Planning and Evaluation Committee. Valarie Crowley and Jean Starnes* will serve on the Grants Monitoring Committee. Associate members were selected from individuals who have graduated from the Council's training program in leadership and advocacy, Partners in Policymaking. ♦

CLASS Program expands Feb. 1

The Texas Department of Human Services (TDHS) plans to expand the CLASS Program (Community Living Assistance and Support Services) into three more counties on Feb. 1, 1993. The Medicaid waiver program currently provides services to about 330 people in 10 counties.

The CLASS Program is now in Tarrant, Dallas, Travis, Bexar, Harris, El Paso, Cameron, Willacy, Hidalgo, and Starr counties. It will expand into Lubbock, Nueces and Jefferson counties.

Under the program, local contractors provide home and community-based services to eligible individuals with related conditions or developmental disabilities other than mental retardation, as a cost-effective alternative to institutionalization. Services may include personal assistance with daily living activities; nursing services; respite care; physical, occupational, and speech therapy; adaptive aids; minor home modifications; and independent case management.

For more details, contact the CLASS Program, TDHS, P.O. Box 149030 (MC W-521), Austin, TX 78714-9030; (512) 450-3228. ♦

News that you can use

❑ **Directory of I&R Providers:** "Finding Help in Texas: A Directory of Information and Referral Providers — 1992 Edition" is available now. Print copies are \$12 plus 8% tax. Computer diskettes are \$10 plus tax. The guide includes information on 389 Texas I&R providers covering all 254 counties. For more information or to order the guide, contact the Texas Information and Referral Project, P.O. Box 12397, Austin 78711; (512) 463-1782.

❑ **Institute on Inclusion:** The first Southwest Institute for Inclusive Schools and Communities is scheduled June 12-18, 1993 in Fort Worth. It is modeled after the Institute for Integrated Education

held each summer at McGill University in Montreal. For more information, contact Karen Miller at 214/238-6563, Paula Mower at 817/377-7302 or Fran Templeton at 817/469-8137. Registration is limited.

❑ **Poster on Job Discrimination:** The U.S. Equal Employment Opportunities Commission (EEOC) offers a free poster on job discrimination. This 18 x 27-inch poster summarizes relevant federal laws and must be displayed conspicuously by employers. It also is available on audio cassette. To obtain, contact your local EEOC or the national EEOC, 1801 L Street, N.W., Washington, D.C. 20507; 1-800-669-3362. ♦



Highlights

Highlights is produced by the Texas Planning Council for Developmental Disabilities for distribution to Council members, grantees and other interested persons throughout the state. Organizations that serve persons who have developmental disabilities are encouraged to submit news for publication. Inquiries may be addressed to Lucy Walker, editor, Texas Planning Council for Developmental Disabilities, 4900 North Lamar Blvd., Austin, Texas 78751-2399, (512) 483-4092 voice or TDD (512) 483-4099. Taped copies and other formats available on request.

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