



# Highlights

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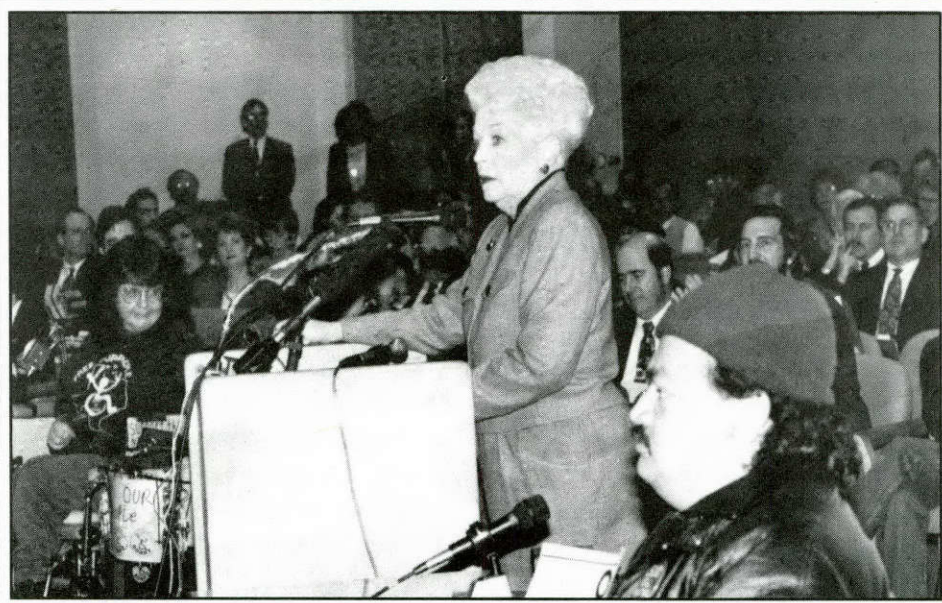
## Hearings address need for community services

Two significant hearings were held in January which centered on whether services are community-based or provided in institutions. The first one addressed services for adults which traditionally have been provided in nursing homes while the latter concerned the fate of children.

### Nursing Home Waiver

On Jan. 21, before a room full of supporters, the Texas Department of Human Services (DHS) board unanimously voted to fund the Medicaid Nursing Home Waiver. This will allow 2,000 adults to receive services in their own homes or community-based programs this fiscal year, rather than in nursing homes.

"With the waiver, we can target services to people's specific needs while allowing them to remain at home," Governor Ann Richards told the board. "This waiver will



Reiterating her support for the expansion of community-based services, Governor Ann Richards testifies in favor of the Nursing Home Waiver. The Texas Department of Human Services will implement the waiver in March.

give many more people the same kind of treatment that we would all want for our family and friends."

Although DHS received federal approval last May to serve 20,000

people with the waiver, start-up was delayed by a lack of funds. The board's decision to transfer \$3.2 million to the program is part See "Community services" page 2

### Texans have opportunities to influence decisions

## Various forums seek input on disability issues, services

What do you need? What do you want? What do you like? What do you dislike? Numerous hearings are planned this year to allow Texans the opportunity to speak out and influence decisions that affect services and supports for people with developmental disabilities and their families in our state.

These hearings will address areas such as education, long-term care and services which help families remain together.

### Special Education

The Task Force on the Education of Students with Disabilities has scheduled six public hearings to examine special education services in Texas. The task force will make recommendations to increase the performance of students needing special education services and to promote excellence and equity for all students.

Hearings are scheduled from 3:30 - 5 p.m. and 6:30 - 8 p.m. at the Regional Education Service

Center in the following cities:

- Amarillo on March 1
- El Paso, March 3
- Edinburg, April 19
- Wichita Falls, April 26

Hearings have already been held in Houston and Fort Worth.

### Family Preservation & Support

Up to \$75 million are available to help Texans over the next five years under the federal Family Preserva-

See "Hearings planned" page 4

## Families share experiences; stress need for services

*"Since receiving the support services we now get, my whole family has become 'a normal family.' We are not always stressed out...(Our son) has improved in every way — social, educational, independence, verbal skills. I now have a child I think might be independent some day."*

— Parent of a child who is medically fragile

Major advances in medical technology have made it possible to save babies and treat children who, not very long ago, would have died shortly after birth, serious injury or

illness. At the same time, there has been a growing philosophical movement to provide services to



children in their own homes and families. Texas, however, continues to struggle with how to provide community-based supports for children who are medically fragile and their families.

A recent report, *"Children in Texas Who Are Medically Fragile: Their Families' Voices,"* contains personal stories, insights and descriptions based on a survey of 223 families across the state.

This report examines families' needs and problems, services they are accessing, what it takes to keep

See "Families share" page 3

## Community services contemplated *Continued from page 1*

of a plan to gradually find funding during the next three years for 8,000 people who are elderly or have disabilities.

The Nursing Home Waiver will begin this March in 13 counties: Lubbock, Potter, Randall, Tarrant, Wise, Smith, Gregg, Bowie, Lamar, Harrison, Bell, Hidalgo and Cameron. Twenty-eight counties will be added in June: Hale, Swisher, Wichita, Dallas, Johnson, Denton, Collin, Cherokee, Red River, Jefferson, Orange, Hardin, Harris, Galveston, Montgomery, Brazoria, McLennan, Travis, Williamson, Bexar, Guadalupe, Comal, Ector, Midland, El Paso, Nueces, Jim Wells and Brooks.

Services will be provided in individuals' own homes, foster homes and assisted living arrangements.

For more information or to apply for the Nursing Home Waiver, call Community Care for the Aged and Disabled at your local DHS office.

### Children in Nursing Homes

More than 450 children in Texas live in nursing homes and other large congregate facilities. On Jan. 24, the Senate Committee

on Health and Human Services held a hearing to investigate the problems facing these children who are separated from their families and communities.

While committee members approved 21 reforms aimed at improving the care of children in nursing homes, they stopped short of adopting a statement to move all children out of the institutions. About 90 people testified at the daylong hearing.

Adopted reforms include appointing a single case manager for each child in a nursing home, establishing a toll-free phone number for complaints and information about services, creating a bill of rights for children in nursing homes, setting up an emergency fund for community services, developing training programs for staff who care for children in nursing homes, and monitoring school districts that have children in nursing homes.

Lt. Gov. Bob Bullock directed the committee in December to identify problems and recommend solutions in response to a five-day series, "The Lost Children," in the Austin American-Statesman. The

comprehensive articles and pictures vividly portrayed the plight of children who live in Texas nursing homes. The series also pinpointed severe gaps in services for these children who have disabilities or are chronically ill.

"Many children are living in undesirable circumstances," Denise Gamino reported, with "little or no adult attention, no peer's or children's activities, few or sporadic educational opportunities, spartan living arrangements, and inadequate medical attention."

The newspaper pointed out that:

- Hundreds of Texas children live in nursing homes designed for geriatric residents.
- Responsibility for monitoring their care is fragmented among state agencies.
- Some of the children get little if any schooling.
- Children are placed in nursing homes because of money.
- Experts say alternatives exist to putting children in nursing homes, but Texas is dragging its feet in providing options. ♦

## Families share experiences *Continued from page 2*

families together and other relevant issues. It also looks at what must be done to meet the families' needs and their demand for more community-based services.

Results of the survey follow.

❑ **Diagnosis:** Of the 223 families surveyed, 160 different diagnoses were reported, with almost all of the children having several disabilities. Only 52 of the children (23%) could walk without assistance, and 69% had been hospitalized during the past year — some more than a dozen times. About 70% used some type(s) of equipment or technology, and 85% received therapy.

❑ **Placement:** 94% of the respondents care for their children at home. Most were vehemently opposed to institutional placement. Parents who had placed children in other living environments frequently cited the scarcity of support services as contributing to their decision.

❑ **Community-Based Services:** Respondents praised the quality of most services, but stressed the severe shortage of services. Additionally, different programs use different definitions of "medically fragile," different eligibility criteria, and different provider qualifications and pay scales. Services needed most were respite (highest priority), in-home care and Supplemental Security Income (SSI).

❑ **Finances:** Most parents spend considerable money out-of-pocket for special care. Middle class parents often sharply feel the injustice of a system that excludes them from programs they desperately need because eligibility criteria frequently do not consider the higher costs of caring for children who are medically fragile.

❑ **Exhaustion:** Parents become weary, frustrated and overwhelmed. They feel guilty and

often wonder if they can continue to cope. They love their children deeply, but the constant care tries the endurance of the hardest souls.

❑ **Siblings:** Relationships with siblings are mostly positive: loving, close and protective. But some understandable frustrations, ambivalence, and jealousy were reported by about one-third of the respondents. Older siblings worried about eventually becoming responsible for care of the child.

❑ **Approaching Adulthood:** Parents worry about who will provide services and supports after

"We have just begun receiving home health care," one mother revealed. "For the first time I am able to work in my yard or around the house. My husband and I were also able to go out alone for the first time in nearly two years!"

When parents cannot care for their children who are medically fragile, there should be good options from which to choose, the report concludes, where children can grow up in a home and with a family. "Community services should be more available to more families and should be aimed at

***"For the first time I am able to work in my yard or around the house. My husband and I were also able to go out alone for the first time in nearly two years!"***

they are unable to provide or arrange for them.

❑ **Regular Kids and Families:** While children who are medically fragile certainly have special needs and problems, they are first and foremost kids, regular kids, with regular thoughts, emotions, and concerns.

The report points out that "Community services are critical for families with children who are medically fragile to remain together. Families should not be torn apart and forced to seek institutional care for their children just because services and supports they need to stay together are not available in the community."

"We are so grateful for the services we receive," one family said. "We haven't considered placement, only because we now receive enough care and financial assistance to keep (our daughter at home). If we lost that we would be forced to consider it."

Community-based services also are essential for families with children who are medically fragile to achieve a life-style that most of us take for granted.

maintaining the well-being, comfort, safety, and positive interactions of the family with the community and society."

Unfortunately, money tends to be more available for institutional or residential services than for services in community settings, the report explains. This remains true despite the fact that a growing body of data has documented the cost-effectiveness of care at home for a majority of children who are medically fragile.

More importantly, growing up at home and in a family nurtures children and helps ensure that they have quality lives. There is no substitute for the love and lifelong commitment that family members have for each other. ❖

*"Children in Texas Who Are Medically Fragile: Their Families' Voices," was produced for the Texas Planning Council for Developmental Disabilities and the Texas Respite Resource Network. Copies of a six-page summary and the full report are available from TPCDD, 4900 N. Lamar Blvd., Austin, TX 78751-2399; (512) 483-4093.*

## Speaking up brings change; decision makers need to hear you

By Linda H. Parrish  
Council Chair

Cheers filled the packed room on Jan. 21, when the Texas Department of Human Services board voted to fund the Nursing Home Waiver, allowing more adults to receive supports in the community. It was a goal that people with disabilities and other advocates had worked long and hard to achieve.

Three days later parents and other advocates packed a Senate committee hearing. This time individuals were working to improve services and supports which help families remain together and keep children out of nursing homes and other institutions. It's an area that still needs a lot of work.

It takes lots of time and energy by many individuals to shape the state's service system so that people get the supports they need to be independent, productive members of their community.

That's where you come in. Decision makers at all levels -- from local board members to agency representatives and legislators -- need to hear from individuals they serve in order to know what is important. They need to hear real stories from real people.

Your story is a very powerful tool. Tell what you want. What you need. And what happens when your needs aren't met. The more personal you make your story, the better.

You don't have to be able to quote facts or statistics to influence decision makers. There are lots of professionals who get paid to provide those. Decision makers want to hear from you how issues touch your life and the lives of people you know. Instead of being intimidated by the complexity of an issue or a person's title, talk about what you know -- talk about how an issue affects you.

I've served on a lot of task forces and committees. And I'm serving on another one right now, regarding special education. So I know first hand the importance of public testimony.

As a general rule, decision makers are hardworking individuals who are dedicated to their job and take pride in their accomplishments. But they need to hear the issues again and again. If people don't contact them, they think a subject is unimportant or resolved. So it's OK to make a loud noise. In fact, it's essential.

If you want things to change, if you want more and better services, you have to make yourself heard. You have to write to decision makers, testify at hearings, visit legislators and make phone calls. The more you can do, the better.

It is only through action that dreams become reality. You have the power to make a difference. ♦

## Hearings planned on disability issues

*Continued from page 1*

tion and Family Support Act which was passed last fall. This law is designed to develop and expand services that will help prevent out-of-family placement of children and help reunify families.

In order to receive this money, the state has to submit a plan by this fall on how it will implement services. As part of this process, the Department of Protective and Regulatory Services (DPRS) is holding 26 hearings in Texas to find out how local communities would like the services delivered.

While DPRS is responsible for distributing the funds, *eligibility for the services is not limited to families involved with child protective services or to children at risk of abuse or neglect.*

The Council recently mailed information on this topic and the hearing schedule to people on our advocacy list. If you did not receive

it and would like a copy, write Erma Henderson at the Texas Planning Council or call (512) 483-4093.

### Long-Term Care

The Long Term Care Task Force is working to prepare a cross-agency vision for a comprehensive system of long-term supports for people with functional limitations due to age or disability. The task force also is to develop recommendations to the Texas Health and Human Services Commission (HHSC) regarding the design of the local service delivery system and the state administrative structure.

Meetings are held in Austin from 10 a.m. to 4 p.m. with time allocated for public comment at the beginning of each meeting. Meetings are: March 25, April 26, May 27 and June 28, 1994. For locations, contact the HHSC at (512) 502-3200.

### Children and Youth

The newly formed Texas Commission on Children and Youth is holding hearings to obtain public opinion and concerns on issues affecting young people in Texas. Everyone is welcome to speak and/or submit written testimony. Commission recommendations will be submitted to the Texas Legislature.

Hearings are tentatively set in:

- Corpus Christi on March 14
- El Paso, April 8
- Dallas, April 18
- Lubbock, May 6
- Waco, May 16
- Bryan/College Station, June 3

Another hearing is planned in Austin in June and one has already been held in Huntsville. For hearing locations, contact the children's commission at (512) 305-9056.

See "Hearings" page 5

## Welcomes, farewells and new Council chair appointed

There have been a lot of changes at the Council recently. Governor Richards has appointed a new Council chair, Linda Parrish of College Station, as well as five other new members. The Texas Health and Human Services Commission also has appointed a representative to the Council, which increases the Council's membership to 30.

Parrish is a professor and the Assistant Department Head in Educational Psychology/Special

Education at Texas A&M University in College Station. She has a bachelor's degree in speech and hearing therapy, a master's in special education/mental retardation and a doctorate in the education and employment of special populations/research.

Parrish brings with her almost 30 years of experience in the disability field. She has served on numerous boards and committees, made more than 200 presentations and directed dozens of projects.

While it was exciting to welcome Parrish as the Council's new chair, it was sad to say farewell to Lee Veenker who served on the Texas Planning Council for 12 years and chaired the Council from 1985 through August 1993.

Veenker made immeasurable contributions to the Council and people with developmental disabilities which will continue to impact the state for many years to come. A dedicated leader and unwavering advocate, she worked relentlessly to create a service delivery system that offers people with disabilities real opportunities for independence, productivity and community integration.



Lee Veenker, Council Chair 1985-93



Linda Parrish, current Council Chair

### New Council Members

Governor Richards also appointed the following individuals to the Council:

❑ Beth Holt from Marshall who filled a vacant position.

❑ Abel Alonzo from Corpus Christi. He replaced Robert Peters, III, of Tyler whose term expired. Peters served on the Council for two years.

❑ David Lee Benson from Houston. He replaced Lee Veenker of Coppell whose term expired.

❑ Raul Garza from San Benito. He replaced Darlene Topp of Harlingen whose term expired. Topp served on the Council for seven years. She also served as the Council's vice chair and chair of the 1990 Report Task Force, both in 1988 - 1990.

❑ Billie Sue Sweitzer from Fort Worth. She replaced Guy McCrary of Midland whose term expired. McCrary was on the Council three years and chaired two committees.

The Texas Health and Human Services Commission selected Dena Stoner to serve in a new position. ❖

## Hearings *Continued from page 4*

### Advocacy, Inc.'s Priorities

Advocacy, Inc., has scheduled seven forums to obtain public comment on its program priorities and other major issues. Advocacy is a federally funded, non-profit organization that protects and advocates for the legal rights of persons with disabilities in Texas. It has regional offices in Lubbock, Pharr, Dallas, Houston and Austin.

Surveys on Advocacy's programs will be distributed at the forums. People unable to attend the forums may call any of the following numbers to get a copy of the surveys.

Hearings are scheduled in:

❑ El Paso on March 12, 10 a.m. - 1 p.m. For the location, call 1-800-880-4456.

❑ Wharton, March 21, 7-9 p.m. Call 1-800-880-0821.

❑ McAllen, March 21, 1-4 p.m. Call 1-800-880-8401.

❑ Austin, April 5, 4-7 p.m. Call 1-800-223-4206.

❑ Galveston, April 5, 7-9 p.m. Call 1-800-880-0821.

❑ Dallas, April 7, 5:30-8:30 p.m. Call 1-800-880-2884.

❑ Crockett, April 7, 3-6 p.m. Call 1-800-880-0821. ❖

All together now...

## Inclusive child care teaches children about life, friends

Children learn more than alphabet songs, games and finger painting at child care. They learn about life.

Kids who participate in inclusive child care programs learn that each person has unique abilities. Everyone has something to contribute. They learn people are more alike than different, but different is OK too. And the playmates of today become the friends, classmates, peers and colleagues of the future.

"ABCs of Inclusive Child Care," a 14-minute video, features three children with disabilities who have been placed in inclusive child care settings under a Council grant to the Dependent Care Management Group in San Antonio. The video also features child care center directors, teachers, a teacher's aide, parents and case managers.

"When I first got Maranda I was kind of scared," one teacher explains, "and then I started working with her, playing with her. Things were not as hard as I thought they would be...She's not different from the other children. She likes doing all of the things that children do."

In addition to describing individuals' apprehensions when considering serving children with disabilities, the video shows how feelings changed with experience. The video also discusses the benefits and importance of inclusion.

All footage was shot on location in San Antonio in a variety of community child care settings, and the video is open-captioned for people with hearing impairments.

For a free copy of "ABCs of

*Inclusive Child Care*," or the Council's other video, *"Working: Stories of Supported Employment,"* write to Erma Henderson at the Texas Planning Council or call her at (512) 483-4093. ❖



Barbara Jordan (left) congratulates Shelley Lamm for her role in "Working: Stories of Supported Employment." Lamm is one of four individuals featured in the Council's video which recently won a Barbara Jordan Award from the Governor's Committee on People with Disabilities. The 18-minute video also has won three other awards. Copies of the video and a new video on inclusive child care are available from the Council.

## Stipends enable more individuals to attend conferences, events in Texas

What do conferences on inclusive communities, interdependence, Hispanic issues and quality of life have in common? In addition to being good places to network and learn about disability issues, they each received funds under the Council's stipends program recently so that more consumers and family members could attend the events.

Eight organizations received stipends during the past year for conferences, workshops and other events they sponsored within Texas which enhanced independence, productivity and community integration for people with developmental disabilities. The stipends program

is now in its fourth year.

Organizations which are interested in requesting the stipends must submit their application at least 120 days before an event. If multiple organizations are sponsoring the program, only one may apply. Applicants are encouraged to apply early enough to ensure there is plenty of time to publicize the stipends, if approved.

For more details on the stipends program and an application kit, write to Lester Sanders, Texas Planning Council for Developmental Disabilities, 4900 North Lamar Blvd., Austin, TX 78751-2399, or fax a request to (512) 483-4097. ❖

## Family support conference planned

Mark your calendar. The Texas Respite Resource Network (a DD Council grant project) is planning its fifth national conference on family support and respite in San Antonio on Dec. 14-17, 1994. To be added to their mailing list, contact TRRN, P.O. Box 7330, San Antonio, TX 78207-3198; (210)-228-2794. ❖

## Creating tomorrow's dream today: Better schools for all

People throughout the country are taking a long hard look at the nation's schools. Reform efforts abound. But just how do schools improve education while meeting the needs of all students?

A conference in Dallas on March 25-26, 1994, will search out answers to this question. Sponsored by Inclusion Works!, a DD Council grant,\* the conference will focus on providing quality education through school reform and inclusion, which both stress a student-centered approach and success for all children.

Featured speaker is Dr. Henry Levin of Stanford University, founder of the Accelerated Schools Project, a model designed to accelerate the learning of all students with an emphasis on pull-in instead of pull-out services and programs.

Breakout sessions will provide resources and supports to general

education teachers that enhance the quality of instruction for all students. Sessions also will address effective inclusion practices related to general school reform initiatives, as well as collaborative planning and problem-solving techniques that can be used with diverse groups.

Pre-conference visits to inclusive education projects in the Dallas/Fort Worth area are scheduled on March 24. These provide an opportunity to see the different ways general and special educators are making inclusion work in Texas.

Conference registration is \$95 and will be limited to 500 people.

The pre-conference is \$20. A satellite video teleconference of Friday's sessions will be available in Texas and other states. Contact your regional education service center for information on teleconference sites.

Stipends are available to cover conference fees and hotel rooms for individuals with disabilities and their family members. Call Partners Resource Network at (409) 838-2366 for details on this.

For other information or a conference brochure, contact Pamela Cook with Inclusion Works! at 1-800-235-0390 or (512)-454-6694. ♦

*\* Inclusion Works! is a project of the Texas Planning Council and the Texas Education Agency, which supports school districts in developing inclusive schools.*

### Applications available for **PARTNERS IN** **POLICYMAKING**

Applications are being distributed now for the next class of Partners in Policymaking, the Council's leadership training program for parents and self-advocates. This program provides state-of-the-art knowledge about developmental disabilities issues and builds the competencies individuals need to become advocates who can effectively influence public officials.

Completed applications must be postmarked by April 29 for the fifth Partners class which begins in August. Participants will attend eight monthly, 2-day training sessions beginning Friday at noon and concluding late Saturday afternoon.

Applications have already been sent to people who are on the Council's mailing list. Individuals who are not on the mailing list can get an application by contacting the Texas Planning Council. ♦

### Inclusive education success stories wanted for database

Have you included a student with complex or challenging needs in general education? Could others benefit from your experience? If so, you are invited to share your success story with Inclusion Works! and the Texas Education Agency. These stories will be compiled into a database to promote networking and provide a resource for parents and educators.

If you have a story you want to share, call Inclusion Works! at 1-800-235-0390 and request their short reporting form. Inclusion Works! is a statewide grant project of the Council and TEA which supports school districts in developing inclusive schools that create opportunities for all students to receive quality education. ♦

### Congress schedules district work periods

During 1994, the House and Senate have scheduled various "district work periods," when Congress is in recess.

At these times, 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:

March 28 - April 10	Both
May 27 - June 7	House
May 30 - June 6	Senate
July 1 - 10	House
July 4 - 10	Senate
August 15 - Sept. 6	House
August 15 - Sept. 11	Senate

Both the House and Senate have set October 7 as their target date for adjournment. ♦

## TDH working to expand respite services and options

Caring for a child with disabilities can be exhausting — physically, economically and socially. The work and stress go on and on, day after day, without end.

“Families need time to rest, relax, strengthen relationships and pursue other activities,” explains Pam Farley with the Texas Department of Health (TDH). “Respite supplies this relief by providing temporary care and giving families a break. This, in turn, strengthens the families and helps them keep their children at home.”

Unfortunately families report that there are still many problems with respite services in Texas: options are limited, it is difficult to find services, and there aren't enough trained workers.

Under a new federal grant, TDH is working to address these problems and expand respite services in our state. This three-year grant, the Texas Respite System Development Project, was awarded to the newly formed TDH Bureau of Women and Children. One of 12 grants across the nation, it will receive \$200,000 per year.

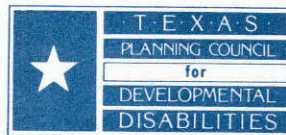
TDH collaborated with the Texas Planning Council and the Texas Respite Resource Network (TRRN — a Council grant) to develop the grant proposal. TRRN also will provide support, consultation, training and technical assistance to the project.

“The top priority of the project is to participate in the development of a statewide respite system that is family-centered, community-based, comprehensive, coordinated, compassionate and culturally competent,” explained Farley, the project consultant. “We want to make a wide range of affordable respite services accessible to

families and caregivers of children with special health care needs.”

Four local projects will focus on expanding services and promoting choice through affordable respite options such as after-school care, in-home care, 24-hour availability and camp programs. Projects were awarded to the Amarillo Area Hospital Home Health Care to serve the Panhandle; Child Crisis Center of El Paso to serve West Texas; Texoma Community Health Services to serve Wilbarger, Hardeman, and Foard counties; and the Austin Respite Network (ABC of Austin).

For more information, call Pam Farley at (512) 458-7355. ❖



# 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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