

# Legislature sponsors statewide hearings on respite care in conjunction with educational forums on family support services

Public hearings on respite care, presented by the state House Subcommittee on Respite Care Services, under the House Committee on Public Health, will be held in four Texas cities this spring and summer. (See accompanying article for public hearing dates and locations.) An initial hearing was held in Austin in late February.

Respite care for persons with disabilities is loosely defined as temporary relief services offered to families who live with individuals with developmental disabilities, handicapping conditions or chronic illnesses. As part of a respite care program, care might be provided to a family member with disabilities in or out of the home. Families may use respite care services for different time periods, from a few hours to several weeks, and for a variety of reasons. Respite care programs have been effective in helping people with disabilities live at home with their families, rather than in institutions.

Subcommittee members The Subcommittee on Respite Care Services is chaired by Representative Frank Madla, San Antonio. Other representatives who serve as subcommittee members are Anne Cooper, San Marcos; Jack Harris, Pearland; Don Lee, Harlingen; and Alan Schoolcraft, San Antonio.

Jennifer Cernoch, coordinator of the Texas Respite Resource Network (TRRN), has been requested by Madla's office to provide the committee with information on the status of respite care services in Texas. TRRN, which is funded through a Developmental Disabilities Program grant award, has been gathering information regarding respite services needed and available statewide.

Educational forums The Association for Retarded Citizens (ARC) - Texas has been working with the subcommittee to combine the public hearings with educational forums

## Respite Care Hearings

Public hearings on respite care, presented by the Texas House Subcommittee on Respite Care Services, will be held at the following locations:

Lubbock	May 10
Dallas	May 16
Houston	June 6
	(tentative)
Harlingen	Mid-summer

For exact times and locations of hearings in your area or to schedule a time period in which to present your testimony, contact Norine Jaloway, Association for Retarded Citizens (ARC) - Texas, at (512) 454-6694 or toll-free at (800) 252-9729. Persons unable to attend a hearing but wishing to submit written testimony can send it to the Texas House Committee on Public Health, P.O. Box 2910, Austin, Texas 78769, attention Cheryl Vanek.

# NON-CIRCULATING

on in-home and family support services. In-home and family support services are broader than the scope of services traditionally offered to people with disabilities. These new services could include homemaker services, training and therapeutic services, specialized adaptive equipment, transportation, and respite services. Information presented at the educational forums will be applicable to persons with physical and mental disabilities. The three- to four- hour educational forums, cosponsored by ARC-Texas, the Texas Planning Council for Developmental Disabilities, Advocacy, Inc., Texas Association for Mental Illness, Spina Bifida Association of Texas, Texas Head Injury Foundation, and the Coalition for Texans with Disabilities, will precede each public hearing.

Madla's subcommittee is primarily looking at respite care services for people with mental retardation and how costs for such services may be incorporated into the budget of the Texas Department of Mental Health and Mental Retardation. However, Jaloway recommends that testimony be presented for family support services for all disability groups, as well as mental retardation.

For more information on the subcommittee hearings, contact Norine Jaloway, ARC-Texas, 833 Houston St., Austin, Texas 78756, telephone (512) 454-6694 or toll free (800) 252-9729.

For more information on respite care or services needed or available, contact Jennifer Cernoch, Ph.D., Texas Respite Resource Network, Santa Rosa Children's Hospital, PO. Box 7330, Station A, San Antonio, Texas 78285, telephone (512) 288-2794.

# Meet the Council

March was a busy month for Council member Pat McCallum. The Seagoville resident was elected vicechairman of the Texas Planning Council and received the 1986 Texas Volunteer Recognition Award.

McCallum, who was appointed to the Texas Planning Council in 1984 by Governor Mark White, was elected vicechairman at the Council's March meeting. She was nominated for the position by the Council's executive committee. Debbie Francis, Dallas, previously served as the Council's vice-chair. The Council chairman is appointed by the Governor.

"It's an enormous responsibility and I'm sure it will be a learning experience," said McCallum, concerning her new position on the Council. "I only hope I do as well as other vice chairs have done in the past."

Jean Elder, commissioner of the federal Administration on Developmental Disabilities, presented McCallum with the Volunteer Recognition Award earlier in March in Dallas. Each state developmental disabilities council nominated a volunteer who was then honored at an awards banquet as part of the Commission's Annual Forum.

"It was a marvelous feeling to be honored with so many other volunteers who have donated their time and efforts," said McCallum, in reference to the volunteer award. "There's such a great need out there to work together, it makes you feel like part of a big team working toward one common goal."

McCallum has a special interest in the needs of people with disabilities, since her 20-year-old son, Jon, has had severe visual and hearing impairments since birth.

In addition to her work with the Council, McCallum also serves as volunteer executive director of the Deaf-Blind Multihandicapped Association of Texas and chairman of the Statewide



Council Chairman Lee Veenker (left) congratulates Pat McCallum, the Council's new vice chairman and recipient of the 1986 Texas Volunteer Recognition Award.

Transitional Services Task Force. She is also co-chairman of the Interagency Task Force for Future Services to Deaf-Blind in Texas, secretary of the Coalition of Texans with Disabilities, a board member to Advocacy, Inc., and a member of the Association for Retarded Citizens - Dallas and the Deaf-Blind Advisory Committee to the Texas Rehabilitation Commission. She works for the Foundation for the Developmentally Disabled and is a consultant to the Helen Keller National Center.

During the past year, she spent considerable time testifying before the Texas Legislature and other decision-making groups on the needs of people with developmental disabilities. She also authored an article, "Transition Trauma," that was printed in the national *Journal* of Visual Impairment and Blindness by the American Foundation for the Blind. She has been recognized by the Coalition of Texans with Disabilities as its Vista Volunteer of the Year and received the Distinguished Parent Award given by The Association for the Severely Handicapped.

### Legislative Ladder

Two pieces of federal legislation now before the U.S. Congress received support from the Council at its March meeting.

Acting on recommendations by the Advocacy and Public Information Committee, chaired by Diana Fricke, Council members voted to support the Handicapped Parking Act of 1985, H.R. 3889/S.B. 1936. The bill would establish a uniform system for handicapped parking. At the present time, handicapped parking rules and decals can vary from state to state.

S.B. 1793, Alternatives to Hospitalization for Medical Technology Dependent Children Act of 1985, also received Council support. The bill would establish a grant program to develop improved systems of caring for children in the home who are dependent on medical technology, as an alternative to hospitalization.

Persons interested in joining the Council in support of these bills should contact their federal legislators. The Texas Planning Council can supply names and addresses of Texas state and federal legislators upon request.

# New Disability Rights Advisory Committee to help state enforce laws in order to improve services

Improving the enforcement of laws protecting people with disabilities will be one of the issues addressed by the Disability Rights Advisory Committee recently created through the office of Attorney General Jim Mattox.

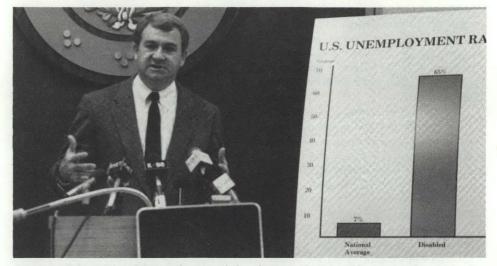
In a February press conference, Mattox said the committee will also make recommendations on how his office can better respond to the needs of people with disabilities in the areas of consumer protection and antidiscrimination regulations. Compliance with architectural barrier laws and transportation needs will also be examined.

The committee is chaired by Bob Kafka, Austin, who also serves as president of the Coalition of Texans with Disabilities. Sixteen volunteers serve as committee members, including two members of the Texas Planning Council, Jerry Hassell and Anita Anderson. Another Council member, Joellen Simmons, assistant commissioner for Special Programs at the Texas Rehabilitation Commission, also attended the committee's press conference as an invited guest.

Mattox said that he hopes the committee can work to improve the system by redirecting funding rather than initiating new funding requests, since the state is working under tighter budgetary constraints than in previous years.

"We want the committee to deal with reasonable, real world recommendations," said Mattox. "We want to redirect our efforts to integrate disabled people into the community."

He also noted concern for budgetary cuts at the federal level for many social service programs, such as the vocational rehabilitation program, if the Balanced Budget Amendment, initiated by Senators Phil Gramm (TX), Warren Rudman (NH) and Ernest Hollings (SC), goes into effect as planned. He mentioned that he is looking into ways to access state funds to bring up the dollar match for state agencies, such



Attorney General Jim Mattox discussed the disparity between the unemployment rate of people with disabilities across the country in comparison to the national average during a press conference to introduce the state's new Disability Rights Advisory Committee.

as the Texas Rehabilitation Commission, that rely heavily on federal funds.

Mattox also said that the committee endorses most of the recommendations in the new report published by the National Council on the Handicapped, entitled *Toward Independence*. He said the report shows a 60 percent unemployment rate for people with disabilities. He indicated that the Committee believes that many Texans are not able to work because they do not have adequate means of transportation to get to the jobsite.

As a result of the new emphasis on the rights of people with disabilities, the Office of the Attorney General will expand its use of Telecommunication Devices for the Deaf (TDDs) statewide, in order to better accommodate people with hearing impairments.

> May is Mental Health Month

# From the Executive Director

#### by Roger Webb

Anyone who is involved with human services is likely concerned about the potential impact of federal and state budget constraints on those services in the years ahead. It is an uncertain time as we face the prospect of reduced federal funds while we also grapple with state budget cuts. While these concerns are very real, we can also see some bright rays shining through the dark clouds.

Some of us have had the questionable pleasure of working in other states during times of similar budget concerns. Although none of us remember those experiences as "fun," we do remember that most service programs survived and in many ways were healthier and stronger because of the experience. We will likely see new cooperative relationships develop at a variety of levels between agencies for specific services; and between service providers for joint use of facilities or other shared resources.

One of the keys to success is the ability to be willing to sacrifice part of our own "turf" for the good of the larger system — and therefore the clients we are serving. We must all recognize those times when selflessness enables us to persevere as a team, when alone any one of us may fail.

Such a spirit of selflessness is also critical as we develop our individual legislative strategies both at the state and the federal level. Most of us understand that legislative items with broad support will succeed while those with divided support will not. Rarely has there been a time when it has been more important to ensure support from the broad disability community. We will each need to compromise on certain issues so that we do not divide the support from those who have been effective before in advocating successfully and who we now need as our supporters. In the spirit of the wild west, it is a time when we need to circle the wagons and band together.

It will not be an easy time. Some of the sacrifices will be painful. But together, we can be successful.

## New grants announced Grantees will work to 'change the system' by delivering assistance statewide

Five new Developmental Disabilities Program grants were awarded last month to projects across the state that will serve as resources to direct service programs for people with developmental disabilities. The grants reflect the Council's recently initiated move toward "systems change."

"The Council elected to follow a course of action based on the philosophy of systems change last spring. Recommendations for fiscal year 1986 grant activities followed that direction," explained Roger Webb, executive director. "We see our systems change philosophy as a move toward impacting the entire statewide service delivery system by working 'from the top down."

#### **Corpus Christi ISD**

"For example," he went on, "through input from the public at our forums and in other contacts with parents, service providers and grantees, we recognized a need for a different kind of curriculum for special education students in our public schools. These students need to develop skills that will help them in the move from school to the work force or adult services and independent living in the community not always included in traditional curriculum plans. Therefore, we're now funding a project through Corpus Christi Independent School District (ISD) that will develop a curriculum which we feel will better meet the needs of these students. Once it has been developed and field tested it will be available for other school districts across the state to use."

The Corpus Christi ISD curriculum project will be directed by Larry McCarron, Ph.D., with a \$128,412 grant award. Other new, one-year grants were awarded to the following groups:

#### ARC-US

The Association for Retarded Citizens - U.S., based in Arlington, received a grant for \$116,648 to develop a plan and to coordinate regional employment-related activities for people with developmental disabilities statewide. Project staff, working with R.A. Wade, project director, will also identify barriers in the service delivery system that might prevent a person with a disability from becoming part of the work force. The Council will use data from the project to address employmentrelated activities as a priority service area in future fiscal years.

#### UTA

The University of Texas at Arlington, Graduate School of Social Work, received a grant for \$107,241 to link technological devices with people with disabilities who can become more independent through their usage. Different kinds of useful technology will be listed on a computer database that will be accessible to consumer groups, individuals and state agencies. Under the direction of Dick Schoech, Ph.D., project staff will also develop a computer software package that can analyze what kinds of technology may be of benefit to an individual given his or her specific limitations.

The University of Texas at Arlington also received a grant for \$136,444, under the direction of Charles Mindel, Ph.D., and Mark Rosentraub, Ph.D., to study the community-based service delivery system. A major part of the project will be devoted to studying client progress over time in a variety of community residential programs. Project staff will also be looking to see if services needed by individuals while living in an institution are also being provided to them after a move into the community.

#### **ARC-Texas**

The Association for Retarded Citizens - Texas, which is based in Austin, received a \$116,648 grant to begin a training program for parents or relatives of people with developmental disabilities and local service providers. Parents will learn to work more effectively with professionals in developing their child's treatment in either special education or community mental retardation systems. Over a three-year period, more than 2,000 parents in 60 communities are expected to become involved in the program, which will be directed by Arnold Reyes.

Grants are awarded by the Texas Rehabilitation Commission, on behalf of the Texas Planning Council. More than \$2 million is awarded each year through the Texas Developmental Disabilities Program to projects across the state that help people with developmental disabilities.

# News You Can Use

#### Voting

The Coalition for Texans with Disabilities (CTD) has information packets available on a range of topics including *How to do a Voter Registration Drive* and *The Most Commonly Asked Questions About Voting.* "Disabled but Able to Vote" T-shirts are also available for a \$5 fee. For more information, contact CTD at P.O. Box 4709, Austin, TX 78765, telephone (512) 443-8252.

#### NAMHIO media contest

The National Association of Mental Health Information Officers (NAMHIO) is sponsoring its Twelfth Annual National Media Contest. The contest is open to groups or individuals involved with mental health, mental retardation, developmental disabilities, alcohol and drug services, and related fields. For more information, contact Judy DeDonato or Cindy Counts, Media Contest Coordinators, 118 E. Riverside Dr., Austin, Texas 78704, telephone (512) 445-8852 or 445-8741.

#### Foundation for DD

The Foundation for the Developmentally Disabled, a non-profit group, has been founded to provide protective services for children and adults who are unable to be fully independent due to developmental disabilities. For more information, contact Edward M. Kirch, Executive Director, 2114 Anson Rd., Dallas, Texas 75235, telephone (214) 634-9810.

#### Mental Health Code

Copies of the revised *Texas Mental Health Code Handbook* are now available from Senator Ray Farabee, Senate State Affairs, P.O. Box 12068, Austin, Texas 78711, telephone (512) 475-2150.

#### Spina bifida screening

The Spina Bifida Association of America has developed a new brochure explaining the prenatal screening test for open neural tube defect. Copies of the brochure entitled, *Alphafetoprotein Blood Screening and Amniotic Testing*, are available from the association at 343 South Dearborn St., Suite 310, Chicago, Illinois 60604, telephone (800) 621-3141.

#### Mary Holdsworth Butt Award

The Richmond State School Advisory Committee is accepting applications for the 1986 Mary Holdsworth Butt Research Award. The award honors the most outstanding research conducted during the past year for individuals with mental retardation. The school's Volunteer Council is providing a \$1,000 stipend to accompany the research award, in order to provide the honoree with discretionary monies for promoting research interests. Nomination forms may be obtained by writing: James C. Griffin, Ph.D., Director of Special Programs, Richmond State School, 2100 Preston, Richmond, Texas 77469. The deadline for nominations is May 31.

#### Posters

Independent Living Research Utilization (ILRU) has developed a series of three posters presenting positive images of people with disabilities participating in their communities. To order, send \$5 for each poster to ILRU, P.O. Box 20095, Houston, TX 77225.

#### Technology directory

The American Academy for the Advancement of Science is compiling a directory of researchers and institutions involved in the study of the impact of technology on people with disabilities. For more information, contact Julie Early, Office of Opportunities in Science, AAAS, 1333 H St., NW, Washington, D.C. 20005.

#### Computers

Apple Computer Co. has created an Office of Special Education Programs to respond more effectively to the needs of children and adults with disabilities. For more information, contact Alan Brightman, Office of Special Education Programs, Apple Computer, Inc., 20525 Mariana Ave., Cupertino, CA 95014, telephone (408) 973-6864.

#### SAT arrangements

If needed, special arrangements can be made for students with disabilities to take the Scholastic Aptitude Test. For more information, contact the Educational Testing Service, Admissions Testing Program, Services for Handicapped Students, CN 6602, Princeton, New Jersey 08541-6602, telephone (609) 734-3867.

#### Life insurance

The Association for Retarded Citizens (ARC)-Texas has worked with National Fidelity Life to develop a participating whole life insurance plan for people with mental retardation. The plan is priced at standard rates and does not expire at age 65, as does the present insurance plan offered by ARC-US. The rates do not increase each year as the insured grows older, but stay the same each year since it is not a term plan. In addition, the policy will build a cash value and pay an annual dividend. There is no extra premium just because a person has mental retardation. Underwriting for the program is done partially on IQ levels. National Fidelity has provided a simplified underwriting program for those with IQ levels above 50 and will individually underwrite those with IQ levels below 50. For more information. contact ARC-Texas at 833 Houston St., Austin, TX 78756, telephone (512) 454-6694.

#### Safety for children

Protecting Your Disabled Child identifies safety rules that parents can teach their child in order to prevent abduction and exploitation. Copies can be obtained by contacting ACTION, Child Safety Program, Washington, D.C. 20525, (800) 424-8867.

Employment and training The National Directory of Training and Employment Programs for Americans with Disabilities is a resource guide to help people with disabilities and their families locate employment and training programs. It may also be used by private sector employers so they may identify programs that can match trained, job ready individuals with appropriate employment opportunities. Copies can be obtained from: Employment Initiative, Administration on Developmental Disabilities, Humphrey Building, Room 347, 200 Independence Ave., SW, Washington, DC 20201.

#### Parents' booklet

A new publication, *If You are the Parent of a Child Who is Mentally Retarded,* is now available from the Association for Retarded Citizens (ARC)-US. For information on ordering a copy contact Nancy Dawson, ARC-US, 250 Avenue J, Arlington, TX 76006.

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# Speed up your SSI application by bringing the 'right stuff' with you

According to the Social Security Administration, many people with blindness and other disabilities are not aware that they may be eligible for monthly cash payments from the federal government under the supplemental security income (SSI) program.

Through SSI, monthly checks are sent to people who are 65 or older, or blind or disabled and need financial assistance. To get these payments, individuals must meet certain income and asset requirements. People with disabilities must accept any vocational rehabilitation services they are offered.

In order to speed up the application process for SSI payments, applicants with disabilities should bring the following information with them when they come to the Social Security office:

- A Social Security card or a record of the Social Security number.
- Proof of age, a birth certificate or the oldest other proof of age available.

• Information about any income and assets, such as payroll slips, copies of tax returns, bank books, insurance policies, car registration, and burial fund records. (If applying for benefits for a child, information about the parent's income and assets will be needed.)

• Information about place of residence; the amount of the mortgage and property taxes on a home that is owned, the lease and landlord's name if renting, and the cost of food and utilities.

• Medical records or the names and addresses or doctors, hospitals, and clinics that have treated the applicant.

For more information about SSI or to file an application, contact any Social Security office.

# Calendar

April 11, meeting, Autism Task Force, Criss Cole Center, Austin.

April 11,12 statewide conference for parents and educators, Texas School for the Blind. For more information call (512) 454-8631.

April 17-19, Board of Directors meeting, Mental Health Association in Texas, Austin. Call (512) 476-0611.

April 18, Transition Services Task Force meeting, 7700 Chevy Chase Dr., Austin.

April 20-22, annual Governmental Affairs Seminar, sponsored by the Association for Retarded Citizens -U.S., Washington, D.C.

May 6-8, Texas 150 Years Later: Designing the Future, sponsored by the Texas Coalition for Juvenile Justice.

May 14-15, Legislative Forum and Public Affairs Seminar, United Way of Texas, Hyatt Regency Hotel, Austin.

May 16, Council on Disabilities meeting. Call Terry Goodman at (512) 463-1814 for more information.

May 20,21, national conference on Charting Change in Infants, Families, and Services, Austin South Plaza Hotel. Contact Julia Kirby, Early Childhood Intervention program, (512) 465-2671 for more information.

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