

## ABSTRACT

### Title: SHARED LIVING

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The purpose of this session is to discuss multiple and often overlooked factors that affect shared living in community based housing. Housing should suit a person's lifestyle and demographic background while creating an atmosphere of autonomy.

The presentation will provide information regarding:

1. Choosing a style of living
2. Activities of maintaining a home
3. Planning and using community resources

Consumers will receive directives on aspects of living autonomously while sharing cost of care and expenses.

Service providers will receive information enabling them to provide services to persons with disabilities wishing to establish their first home in the community.

## **INDEPENDENT LIVING PROGRAM**

### **Program Components:**

- **Case Management**
- **Habilitation**
- **Nursing**
- **Physical Therapy**
- **Occupational Therapy**
- **Speech Pathology**
- **Psychological Therapy**
- **Social Services**
- **Nutrition and Meal Preparation**
- **Pre-Vocational Services**
- **Supported Employment**
- **Safety Programs**
- **Communication Skills**
- **Money Management**
- **Sexual Appropriateness**
- **Interpersonal Relationships**
- **Social Development Training**
- **Academic Skills**

## **THE CASE MANAGEMENT FUNCTION**

The case manager serves as the focal point for service planning and delivery as determined by the interdisciplinary team and acts as an advocate for all of the client's needs. The following items are some of the services that the case manager provides in The Independent Living Program.

- **Advocating for the needs, preferences, and choices of the client.**
- **Convening and participating on the Interdisciplinary Team.**
- **Arranging and coordinating services outlined in the service plan.**
- **Identifying and addressing barriers and obstacles to service alternatives.**
- **Maintaining full, accurate documentation of evaluations, assessments, needs, progress, services, financial data, and all other categories of information required in each client's record.**
- **Enabling the client to make informed decisions regarding important aspects of life, such as housing, employment, and personal relationships.**
- **Intervening in emergency or crisis situations.**
- **Developing pre-discharge plans.**

## **THE HABILITATION COMPONENT**

The Well Mill views the habilitator as a care giver that has the responsibility to maximize the client's independence in a home setting through assistance with daily living activities. The habilitation component in The Independent Living Program is an individualized array of training, assistance and support services designed to allow the client to acquire, retain and improve the self-help, socialization and daily living skills necessary to reside successfully in a community integrated setting.

**Habilitation includes training and/or assistance to address functional deficits in:**

- **Self-help**
- **Daily living skills**
- **Mobility**
- **Learning**
- **Communications**
- **Self-sufficiency**
- **Survival skills**
- **Reduction of maladaptive behaviors**
- **Community access**

## **REHABILITATION PROGRAMS AND SERVICES**

### **Nursing Services:**

Nursing services required by the client will be administered in the home and can include but are not limited to:

- **Administering Medication**
- **Monitoring the clients use of medications**
- **Monitoring weight gain or loss**
- **Providing treatments and health care procedures ordered by a physician**
- **Monitoring for possible adverse reactions to medications**
- **Education/training for family members**

### **Physical And Occupational Therapies:**

All physical and occupational therapies will take place at The Well Mill's outpatient clinics or in some cases the clients home. The Well Mill is the largest privately-owned rehabilitation agency in North Texas and specializes in care to long-term, complicated TBI(Traumatic brain injury) and acquired disability cases.

## HOUSING DEFINITIONS

**HOME** - **Housing Opportunities Made Easy**. HUD program to develop affordable housing. Funds provided to entitlement communities, i.e., city, county, state.

**CHDO** - **Community Housing Development Organization**. Non-profit groups certified by entitlement communities to develop affordable housing for low income individuals. 15% of all HOME funds must go to CHDO's. \$270,000 in Tarrant County; \$330,00 in Fort Worth; and \$4,950,00 in Texas.

**HUD** - Department of **Housing and Urban Development**.

**Tarrant County Housing Partnership** - Non-profit organization to expand housing stock in Tarrant county. Provides staff grants and training assistance to non-profit groups based on number of units developed.

**Section 811** - HUD program for Supported Living for Persons with Disabilities.

**Housing Trust Fund** - Funds from Texas Department of Housing and Community Affairs; in the form of either a grant or low interest loan to increase stock of affordable housing.

**Special Needs Group** - Individuals linked together because they share a common factor; one which necessitates the provision of other services in addition to housing; e.g., persons with AIDS, individuals with disabilities, single mothers, mentally ill, etc.

**Leverage** - utilizing funds from varying sources. A single agency does not like to fund an entire project by itself. Combining local (city/county), state, federal, and private contribution funds to develop a project.

**Section 8** - Government provided rental assistance. Low income individuals pay 30% of their gross monthly income for rent. The government pays the balance of the "Fair Market Rent" (FMR). FMR is \$743/month for a three-bedroom home in Fort Worth; \$806/month in Dallas; \$728/month in San Antonio. Usually a two to three-year waiting list to receive assistance.

**FMR** - **Fair Market Rent** established by HUD for acceptable amounts of rents to be collected for residences. Values range from zero bedroom (efficiency apartment) to four bedroom houses. Rental rates for units larger than four bedrooms are determined by adding 15% of FMR for four bedrooms for each bedroom over four.

**Entitlement Community** - established by HUD to receive funds from the HOME program. Tarrant, County, Fort Worth, Arlington, and the state of Texas are different entitlement communities.

**Consolidated Plan** - replacing Comprehensive Housing Affordability Strategy (CHAS). Required by HUD from entitlement communities to provide acceptable housing in the covered area.

## "SHARED LIVING"

- I. Introduction
  - A. Where will I live?
  - B. Needs of person with severe disability
    - 1. cognition
    - 2. physical
    - 3. both
  - C. Three main focus points
    - 1. style
    - 2. activities of living
    - 3. planning for and using community resources
  
- II. Style
  - A. Numbers
  - B. Autonomy of choices
    - 1. authoritarian
    - 2. paternalistic
    - 3. egalitarian
    - 4. democratic
  - C. Demographic
    - 1. rural
    - 2. suburban
    - 3. urban

### III. Activities of Living

#### A. Maintenance

1. house
2. lawn
3. infrastructure

#### B. Cleaning

#### C. Food

1. plan, purchase, prepare, pray
2. EAT

### IV. Planning and Using Community Resources

#### A. Fun

#### B. Social isolation

#### C. Exploitation

#### D. Rest of life

#### E. Transportation

### V. Conclusion

"We must give every American the chance to become something more as an individual so that together we can become something more as a nation."

Congressman Jim Bacchus  
Florida, 1994

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## FOR ADDITIONAL HOUSING INFORMATION

Suzanne Marsden  
Ability Resources, Inc.  
7404 Camelot  
Fort Worth, Tx 76134  
(817) 551-7727

HUD Region VI - HUD area of authority composed of Texas, Louisiana,  
New Mexico, Oklahoma, and Arkansas.  
1600 Throckmorton  
Fort Worth, TX 76113

Stephen Engwall - Manager of HUD Section 811 Program  
(817) 885-5810

Nancy Mattox - Director of HUD homeless programs  
(817) 885-5478

Stephen Weatherford - HUD Secretary's representative to Region VI  
(817) 885-5401

Tarrant County Community Development Division  
1501 Merrimac Circle, Suite 200  
Fort Worth, TX 76107  
(817) 338-9129

Patricia Ward - Supervisor. Manages HOME funds.  
Brian Cramer - Director of HOME funds for Tarrant County

Regina Keith-Scott  
Tarrant County Housing Partnership  
605 E. Berry Street  
Fort Worth, TX 76110  
(817) 924-5091

Regina Marette - Compliance Specialist with City of Fort Worth; develops  
CHDO contracts.  
(817) 871-7542

Director of Housing for City of Fort Worth  
(817) 871-7542

## FOR ADDITIONAL SERVICE INFORMATION

### Community Based Programs:

Anita Anderson  
Texas Department of Human Services  
(512) 450-3195

Glenn Barclay  
Disability Services of the Southwest, Inc.  
(817) 263-6838

Brenda Seawell, P.T.  
The Well Mill  
(817) 263-9197

### Vocational:

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Disability Services of the Southwest, Inc.  
(817) 263-6838

### General Information:

J. Chance Smith  
Kim McDonald  
The Well Mill  
(817) 263-9197

## **The Independent Living Movement Is Born**

In the 1960's for the first time in the history of the United States consumers, advocates, and service professionals took an intensive look at the human service delivery system to decide what was missing. It was at this point that the concept of community based services was born. During this time people with disabilities joined together to advocate for more humane treatment and inclusion in society.

The first independent living center was started in Berkeley, California in 1972. Independent Living Centers became a reality nationwide in 1978 following effective advocacy by people with disabilities. Federal legislation was passed to establish independent living centers (Title VII of the Rehabilitation Act).

### **What Makes Independent Living Centers Different From Other Service Organizations?**

Independent Living Centers are consumer controlled organizations run by people with disabilities for people with disabilities. This means according to the Rehabilitation Act 51% of the board of directors and staff for each of the centers must be people with disabilities.

Why this emphasis on consumer control?

The premise of the Independent Living Philosophy is that the person who knows best what kind of services are needed, is the person with the disability themselves.

### **Who Is Served By Independent Living Centers?**

These services are available to any person with any type of disability.

#### **Types of Services**

Every independent living center offers four core services. They are:

**Advocacy-Individual and Systems**

**Information And Referral**

**Peer Counseling**

**Independent Living Skills Training**

All other services offered by the individual centers depends on the needs and desires of the consumers being served at that center.

**Independent Living**  
**By Jonas E. Schwartz**

**Independent Living-What Is It?**

Control over one's life based on choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's own affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self determination and the decreasing of psychological or physical dependence upon others.

Independence is a relative concept that may be defined personally by each individual.

**Key Points In The Definition**

-Personal Control Over One's Life

-Self Direction

-Freedom of Choice

-Risk-Taking

-Equal Access

-Significant Participation in Society

**Independent living should not be defined in terms of**

-Living on one's own

-Being Employed

-Having an Active Social Life

**The History of The Independent Living Movement**

Although people with disabilities have been around as long as man has been in existence, services for people with disabilities in the form of federal legislation was not introduced until the end of World War I, because veterans with disabilities were returning home from the war. The program that was developed at that time is now known as the federal-state vocational rehabilitation system. This system was a welcome improvement however the primary focus of this program is putting people back to work. It was not until the 1960's during the Social Change Movements were other major services for people with disabilities considered by federal legislation. At that time there were no services for people who did not qualify for VR services.

REV 11/4/94      TEXAS CENTERS FOR INDEPENDENT LIVING

ABLE

Area Base for Living Enrichment CIL  
1101 Whitaker  
Odessa, TX 79763  
(915) 580-3439 (Phone/Fax)

Crockett Resource CIL

1020 E. Loop 304  
Crockett, Texas 75835  
(409) 544-2811 Voice, (409) 544-7315 Fax;

DARE

Disabled Ability Resource Environment  
8929 Viscount, Suite 101  
El Paso, TX 79925  
(915) 591-0800 Voice, (915) 591-3506 Fax;

HCIL

Houston Center for Independent Living  
7000 Regency Square Blvd., Suite 160  
Houston, TX 77036  
(713) 974-4621 Voice, (713) 974-6927 Fax

LIFE

Lifetime Independence for Everyone  
4216 50th Street, Suite D  
Lubbock, Texas 79413  
(806) 795-5433 Voice, (806) 795-9672 Fax

PACILS

Panhandle Action Center for Independent Living Skills  
3608 S. Washington  
Amarillo, Texas 79110  
(806) 352-1500 Voice, (806) 354-0459 Fax

REACH Resource Center on Independent Living

Rehabilitation, Education & Advocacy for Citizens with Handicaps  
617 Seventh Avenue, Suite 304  
Fort Worth, Texas 76104  
(817) 870-9082 Voice, (817) 877-1622 Fax, (817) 870-9086 TTY

REACH of Dallas Resource Center on Independent Living

Rehabilitation, Education & Advocacy for Citizens with Handicaps  
8625 King George, Suite 210  
Dallas, Texas 75235  
(214) 630-4796 Voice, (214) 630-5995 TTY, (214) 630-6390 Fax

SAILS

San Antonio Independent Living Services  
8610 Broadway, Ste. 420  
San Antonio, Texas 78217-6355  
(210) 805-0295 Voice, (210) 822-7249 Fax

ARCIL

Austin Resource CIL  
5555 N. Lamar, Suite J125  
Austin, TX 78751  
(512) 467-0744 V,  
(512) 467-2417 Fax

ARCIL (SATELLITE OFFICE)

400 W. Hopkins, Ste. 101  
San Marcos, TX 78666  
512/396-5790  
512/396-5794 FAX  
800/572-2973

VAIL

Valley Assoc. for IL  
P.O. Box 5035  
Mc Allen, TX 78502-5035  
1-800-880-7733 Voice



# THE CENTERS ASSIST PEOPLE WITH ALL TYPES OF DISABILITIES



People with mobility impairments such as amputations, spinal cord injuries, arthritis, multiple sclerosis, muscular dystrophy, post polio, spina bifida, and cerebral palsy



People with hearing impairments and deaf-blindness



People with vision impairments



People with mental, cognitive, or developmental disabilities such as traumatic brain injuries, depression, mental retardation, and learning differences

FOR MORE INFORMATION on services available, to request assistance, to make a tax-deductible donation, or to volunteer your time and/or expertise, please contact:

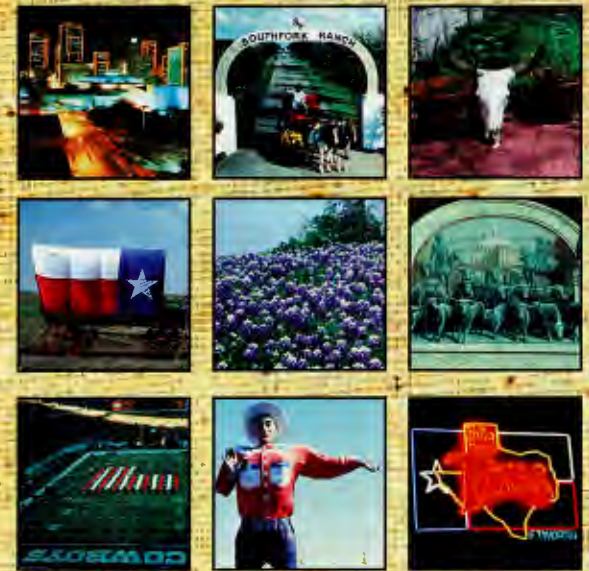
## REACH of Dallas Resource Center on Independent Living

8625 King George, Suite 210  
Dallas, TX 75235-2286  
214/630-4796  
214/630-5995 TTY  
214/630-6390 Fax

## REACH Resource Center on Independent Living

617 Seventh Ave., Suite 304  
Fort Worth, TX 76104-2701  
817/870-9082  
817/654-9614 Metro  
817/870-9086 TTY  
817/877-1622 Fax

**It's Not About Disabilities,  
It's About Capabilities!**



# REACH

RESOURCE CENTERS ON  
INDEPENDENT LIVING

DALLAS AND FORT WORTH

IF YOU ARE NOT A PERSON WITH A  
DISABILITY, YOU PROBABLY KNOW  
SOMEONE WHO IS. SHARE THIS  
BROCHURE WITH THAT PERSON.



REACH, Inc. is a nonprofit corporation with the mission of advocating for and empowering people with disabilities to take charge of their lives and participate actively in society. REACH stands for Rehabilitation, Education and Advocacy for Citizens with Handicaps.

In order to accomplish this mission, REACH operates the REACH Resource Centers on Independent Living in Dallas and Fort Worth. The Centers are non-residential agencies which provide information and services on a wide variety of disability related topics to people with and without disabilities.

The Centers are governed and staffed by a majority of people with disabilities who bring a wide range of knowledge and experience to their work in assisting other people with disabilities.

The Centers are funded by federal and state grants, contributions from foundations and corporations, and individual donors.

## THE CENTERS Offer:

- **Technical assistance** and training in complying with the Americans with Disabilities Act (ADA)
- **Advocacy assistance and training**
- **Employment assistance**—job banks, placement help, computer labs for job seekers, skills training on resume writing, interviewing, marketing yourself and salary negotiation, and help with writing Social Security work incentives
- **Employer education and support** in the areas of sensitivity training, technical assistance on accommodating employees with disabilities, and a resource for qualified job applicants
- **Advice and training** on the removal of architectural and attitudinal barriers facing people with disabilities
- **Loaner adaptive equipment**
- **Libraries** with hundreds of volumes on disability-related topics
- **A newsletter**
- **Braille** of materials
- **Sign language and braille training**
- **Leadership training**
- **Volunteer assistance** with grocery shopping, running errands, and reading/taping materials
- **Skills training** on such topics as cooking, time management, budgeting, assertiveness, basic wheelchair maintenance and repair, and attendant management
- **Peer counseling** on adjustment to disability
- **Training** to become a peer counselor
- **Social/recreational activities**



“

***INDEPENDENT  
LIVING IS SELF-  
DETERMINATION.***

*It is having the right  
and the opportunity to  
follow a chosen course  
of action such as  
having a job or not  
working, driving your  
own vehicle or using  
public transportation,  
renting an apartment  
or living in a group  
home.*

”



## *Personal Attendant Services Task Force*

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—⌘ *PAS: "A key to independence"*

*A project of The Coalition of Texans with Disabilities  
316 W. 12th St. Suite 405 • Austin, Texas 78701  
(512) 478-3366 V/TDD • (512) 478-3370 Fax*

### 1994 DELEGATE RESOLUTION

**SUBJECT:           DEFINITION OF PERSONAL ATTENDANT SERVICES  
(PAS)**

**ADOPTED:         November 21, 1994 at Delegate Assembly**

WHEREAS, the Coalition of Texans with Disabilities (CTD) has previously defined "personal attendant services" as any action to assist a person with a disability in accomplishing activities of daily living. The term "attendant services" covers a broad spectrum of activities including bathing, dressing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, dispensing of routine medications and similar tasks. Most often the term refers to activities a person is unable to do, or has a great deal of difficulty in doing; however, attendant services can also include monitoring and cognitive assistance like reminding a person to take his/her medicine, helping to balance a checkbook or to pay bills, and

WHEREAS, the Texas Senate Resolution 887 stated that "attendant services, also known as personal assistant services, refers to any activity which assists a person with disabilities in tasks which, due their disability they cannot do independently or need assistance to complete," and

WHEREAS, the Texas Legislature, in House Bill 1551, the Home and Community Support Services Act, passed in 1993, defines personal assistance services as "routine ongoing care or services required by an individual to engage in the activities of daily living or to perform the physical functions required for independent living, including respite services. The term includes health-related services performed under circumstances that are defined as not constituting the practice of professional nursing by the Board of Nurse Examiners through a memorandum of understanding with the department in accordance with Section

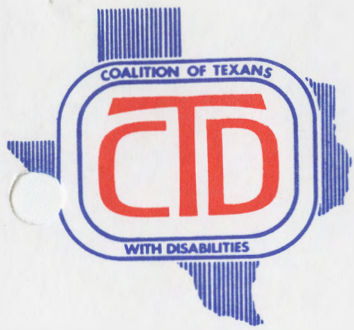
142.016 and health-related tasks provided by unlicensed personnel under the delegation of a registered nurse," and

WHEREAS, the World Institute on Disability (WID) definition states that "PAS shall include, but are not limited to, assistance with personal bodily functions, communicative, household, mobility, work, emotional, cognitive, personal, financial affairs, community participation, parenting, leisure, and other related needs, and

WHEREAS, the Consortium for Citizens with Disabilities (CCD) definition defines PAS as "one or more persons assisting another person with tasks which that individual would typically do if they did not have a disability. This includes assistance with such tasks as dressing, bathing, getting in and out of bed or one's wheelchair, toileting, (including bowel, bladder, catheter assistance), eating (including feeding), cooking, cleaning house and on-the-job support. It also includes assistance from another person with cognitive tasks like handling money and planning one's day or fostering communication access through interpreting and reading services."

WHEREAS, CTD desires to amend and broaden its current working definition of PAS to incorporate concepts from the definitions above, and in order to achieve comprehensive, well-funded, personal attendant services, CTD must look beyond the state level and join hands with national groups in a true cross-disability vision for PAS that does not exclude any disability,

**THEREFORE, BE IT RESOLVED, that CTD define PAS as follows: "Personal Assistance Services are any actions to assist a person with a disability in accomplishing activities of daily living which includes, but is not limited to the following activities: bathing, dressing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, dispensing of routine medications (including injectibles) and delivery of health-related tasks by unlicensed persons, school and educational services, child care assistance, on-the-job assistance, assistive technology, respite, interpreting and reading services and monitoring and cognitive assistance like reminding a person to take his/her medicine, helping to balance a checkbook or to pay bills. "**



## Coalition of Texans with Disabilities

316 W. 12th St., Suite 405  
Austin, Texas 78701  
(512) 478-3366 V/TDD  
FAX (512) 478-3370

### 1994 DELEGATE RESOLUTION

**SUBJECT:                    GUIDING PRINCIPLES FOR PERSONAL ASSISTANCE SERVICES**

**AMENDED:                November 21, 1994 at Delegate Assembly**

The Coalition of Texans with Disabilities defines Personal Assistance Services (PAS):

Personal Assistance Services (PAS) are any actions to assist a person with a disability in accomplishing activities of daily living which includes, but is not limited to the following activities: bathing, dressing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, dispensing of routine medications (including injectibles) and delivery of health-related tasks by unlicensed persons, school and educational services, child care assistance, on-the-job assistance, assistive technology, respite, interpreting and reading services and monitoring and cognitive assistance like reminding a person to take his/her medicine, helping to balance a checkbook or to pay bills.

The current Guiding Principles for Personal Assistance Services are:

1. Programs should serve people with disabilities on the basis of functional need, not medical diagnosis.
2. Programs should be available to people of all ages.
3. Programs should allow for maximum choice and control of the service by the person with the disability (Independent living model).
4. Programs should provide for the recruitment and training of attendants.
5. Programs should provide for 24 hour, 7-day-a-week service availability with provisions for back-up and emergency service.

6. Services should be community-based, non-institutional, portable, should be available where persons with disabilities need them, such as: home, work, in the community, school and during recreational activities.
7. Programs should offer people with disabilities options for employer/employee relationships that include agency-delivered, individual provider, and voucher systems. An income tax exemption for personal assistance services should be available to people with disabilities.
8. Programs should be adequately funded, available to people of all income levels on a co-pay or sliding fee basis, and should not be a disincentive of employment.
9. Programs should provide for the training of persons with disabilities on attendant recruitment and management skills on a voluntary basis.
10. Attendants should earn a reasonable wage and or receive other benefits that promote their ability to provide attendant services.
11. People with disabilities should have significant involvement in the program design and policy development.
12. Programs should provide personal assistance with a non-medical philosophy, allowing for unlicensed attendants to perform health-related tasks.
13. All people with disabilities (and their self-designated or legal representatives if applicable) shall be informed about their rights and options related to personal assistance services in accessible format, and appropriate languages. All levels of personal assistance services should respect the privacy and confidentiality of the user.
14. Programs should provide for an independent and uniform appeals procedure.



# Coalition of Texans with Disabilities

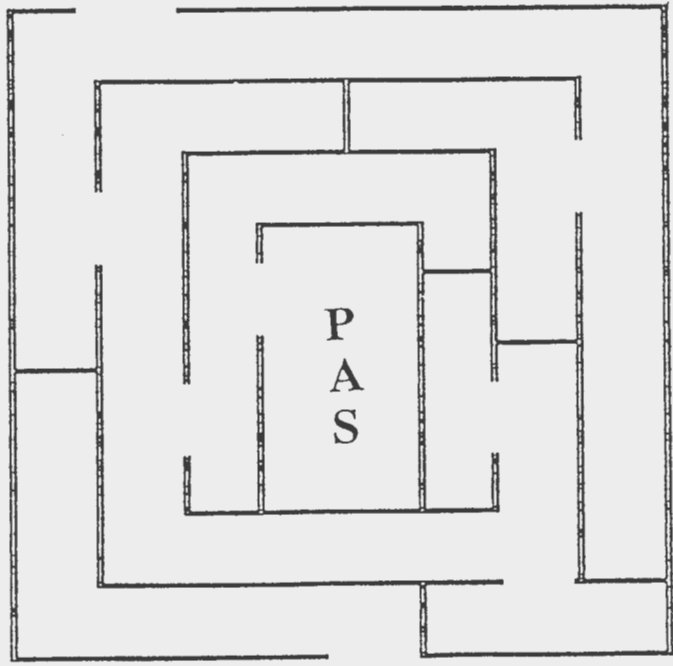
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 (512) 478-3366 v/TDD

## Working the Maze

# An Overview of Personal Attendant Services in Texas

Compiled by the Coalition of Texans with Disabilities'  
**PERSONAL ATTENDANT SERVICES TASK FORCE**  
 a project of the  
**TEXAS PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES**  
 funded by the  
**TEXAS REHABILITATION COMMISSION**

March 1993



EMPOWERMENT THROUGH ACTION

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# DEFINITION OF PERSONAL ATTENDANT SERVICES

## What Are Attendant Services?

Attendant Services can refer to any action to assist a person with a disability in accomplishing activities of daily living. The term attendant services covers a broad spectrum of activities including bathing, dressing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, dispensing of routine medications and similar tasks. Most often the term refers to activities a person is unable to do, or has a great deal of difficulty in doing; however, attendant services can also include monitoring and cognitive assistance like reminding a person to take his/her medicine, helping to balance a checkbook or pay bills.

This kind of help is also known as personal care assistance, personal assistance services, attendant care and home health care; it is also a part of long term care.

## Who Uses Attendant Services?

People who need attendant services are a heterogeneous group. Their ages range from infants to seniors. Their disabilities range from respirator-dependent quadriplegia to ambulatory brain injury, from diabetes to mental retardation. People who need attendant services have an endless number of and combination of disabling conditions.

## ACCESSING THE MAZE OF PERSONAL ATTENDANT SERVICES

Sometimes it is more difficult to ask the right questions than to understand the answers. Often, this is the cruel reality when trying to access a system that we know very little about. Certainly, the realm of HUMAN SERVICES falls into those areas of the unknown for many, when initiating a motivated response to a basic need, such as attempting to access and utilize the current system of attendant services in Texas.

There is a language that must be learned if only to begin that search to satisfy the need. The language often consists of three to four letter words which are acronyms for the names of the agencies and organizations to whom one might look for personal attendant services. Examples of these might be: TDHS, TDoA, TRC, etc. Of course, to find these agencies in the phone book is easy if one knows the full name to begin the process.

Well, let's assume that one knows and can make contact with the agency/organization chosen for inquiry. It is imperative that one have in mind the specific needs about which a contact is being made, because this can become confused with each contact which may, or may not have the scratch to satisfy one's PAS itch.

One will find out early in the quest, that there are many requirements that must be fulfilled before a service can be attained. One will have many questions asked of him or her prior to filling out an application for the request for services (no one wants to waste time). One must not forget the evidence of his or her existence or the maze will surely "dead end." One exists, of course, through the copy of a valid Texas identification card, birth certificate, and one of various types of statements of income. Because the system of services to which one applies for the current system of Personal Attendant Services (PAS) derived from an institutional/medical model, one must have a physician's statement to back-up the existence issue with that of one's present condition. How much time in transit or time on the phone is immeasurable. Least we forget our PAS pellet to possibly come at the end of the maze, we surely would have succumbed to the rigors of such exercise.

One may now realize that as in every maze there is PASSage to the end. This is often seen through the people with whom one meets within the maze. Even though the maze is difficult and is learned only through experience, there really are some people that make the trip worthwhile. Furthermore, it is the intent of the Personal Attendant Services Task Force that this overview of Personal Attendant Services in Texas be of use in working the maze of PAS options for anyone actualizing their PAS needs.

# HISTORY OF PERSONAL ATTENDANT SERVICES TASK FORCE

The Coalition of Texans with Disabilities (CTD) established the Personal Attendant Services Task Force (PASTF) in 1985 to work on issues relating to the delivery of attendant services in Texas. The establishment of a task force was one of the main recommendations of the "Expanding Attendant Care Options for Disabled Texans" conference held in Houston, Texas on December 7, 1984. CTD, being a state-wide, cross-disability, advocacy-focused organization with its diverse membership organizations, as well as, individuals with disabilities, was the most logical environment in which this work could be done.

Over the last eight (8) years, the PASTF has worked with success toward its goals by bringing together consumers, advocates, medical professionals, service delivery providers, social service professionals and government officials to begin positive change in the Texas attendant services' delivery system. The strength of the PASTF has been in its fluid membership, its ability to identify the issues, develop possible solutions and implement plans to effect change in the attendant services delivery system.

One example and a highlight of the process by which the PASTF has promoted a direction for change in the system of delivery of attendant services occurred on October 18-19, 1990. In conjunction with the Senate Committee on Health and Human services, the PASTF of CTD jointly convened the "Attendant Services Roundtable." A cross-section of individuals and legislators were invited to discuss critical attendant services issues and make recommendations for state and federal change. Some recommendations reach far into the future and others have already been realized:

\* The PASTF worked extensively with the Texas Department of Human Services Office and in January 1991 secured a proactive position statement and the commitment of TDHS to take all appropriate and necessary actions to ensure the development of a system of community-based services and supports.

\* In the 72nd Legislative Session, with the support of Senate Health and Human Services Committee, the PASTF Guiding Principles were adopted as a vision statement for the State of Texas through Senate Resolution 887.

\* Incorporating the research, expertise and guiding principles of the PASTF, the Governor's Committee on People with

Disabilities published on March 31, 1992, "Moving from Institutions to the Community: A Blueprint for the New Texas."

The document lays out the current reality in community services to people with disabilities, barriers to the development of community-based services and strategies for the State of Texas for removing these barriers through legislative action, restructuring the delivery system, redirecting funds from institutions to community and maximizing Medicaid waivers.

\* In 1992, PASTF received a three-year grant from the Texas Planning Council on Developmental Disabilities to support PASTF efforts to promote and develop comprehensive statewide attendant services policies and programs.

\* In a March 1992 meeting the TDHS Board approved a Zero Service Break policy, which is especially important for those individuals whose health and safety could be seriously jeopardized by a missed shift of attendant service--a significant victory for the PASTF. In April 1992, the PASTF actively fought for and won an increase from 30 to 50 hours of attendant services in the Primary Home Care and Family Care programs of the Texas Department of Human Services.

\* In November 1992, the PASTF independent study "Improving Personal Attendant Services in Texas: Recruitment, Retention, Training," was completed. This study identifies problems in the current system and makes recommendations for action.

\* Through outreach to communities across Texas, PASTF local groups have been formed to take action on state and local PAS issues. In 1993, these groups have played a significant role in the fight to obtain adequate funding for state PAS programs by holding press conferences and rallies, and writing, calling and visiting key legislators.

\* On November 17, 1992 the Texas Board of Nurse Examiners adopted revised rules which allow registered nurses to delegate "health-related" tasks to unlicensed personal attendants. Before PASTF intervention, and an unprecedented cooperative effort with the Board of Nurse Examiners, a quadriplegic or anyone needing medication, suppositories, assistance with tube feeding who received personal attendant services under programs administered by Texas state agencies could not legally receive those services except from a registered nurse. For many persons with disabilities these tasks are part of their daily lives.

While the PASTF has achievements to celebrate there must be extensive cooperative effort and commitment in the future to achieve the goal of the PASTF -- comprehensive personal attendant services which allow Texans with disabilities to live, work and play in their own communities.

# FUNDING SOURCES FOR ATTENDANT SERVICES IN TEXAS

## Public Funding - Federal

Medicare.....Title XVIII

Medicaid.....Title XIX

- A) ICF-MR
- B) Personal Care Option
- C) Home and Community Based Waivers
- D) Home Health
- E) Frail Elderly - Section 1929

Social Services Block Grant.....Title XX

Older Americans Act.....Title III

Vocational Rehabilitation

- A) Section 110
- B) Title VII A&B---Independent Living
- C) State Programs---Independent Living Services, Community Integrated Employment, Personal Assistance Services

Developmental Disabilities Act  
Veterans Administration

## Public Funding - State

Other State Programs---

In-Home and Family Support  
Client Managed Attendant Services  
Shared Attendant Program  
Options For Independent Living

## Private Sources--

Insurance  
Personal funds

**GUIDING PRINCIPLES FOR  
ATTENDANT SERVICES PROGRAMS AND  
POLICIES ADOPTED BY THE PERSONAL  
ATTENDANT SERVICES TASK FORCE  
DECEMBER 1991**

1. **Programs should serve people with Disabilities on the basis of functional need, not medical diagnosis.**

Historically, people with disabilities have been seen through medical eyes. The attendant service needs of a person with a head injury may be identical to a person born with cerebral palsy, however the service delivery system is frequently categorized by medical diagnosis or types of disability, rather than functional need.

2. **Programs should be available to people of all ages.**

As is true through the United States, families provide the majority of attendant services in Texas. Children with disabilities are frequently ineligible for assistance in most public programs, which causes stress within the family unit. Older people with disabilities often have the same functional needs as their younger counterparts.

3. **Programs should allow for maximum control of the service by the person with the disability. Family and friends may play a supportive role as necessary. (Independent living model)**

Most public programs do not give people with disabilities any opportunity to manage their attendant, or a choice in who their attendant will be and what kind of assistance the attendant will give. Maximum self-direction by the person with a disability is the desired goal. Assistance from a family member or friend may be necessary for some individuals, but the person with the disability must play a major role in the process.

4. **Programs should provide for the recruitment and training of attendants, using both market and non-market systems.**

The inability to find qualified attendants is a growing crisis in this country. Since wages are generally low for these jobs, and will probably not rise over the next few years, non-market strategies must also be tried. Such strategies could include using students in practicum-type programs, using other persons with disabilities or retired people as attendants.

5. **Programs should provide for 24 hour, 7-day per week service availability with provisions for back-up and emergency service.**

The attendant services needs of people with disabilities are not limited to certain days of the week or certain hours of the day. Scheduling must be available at all times, and because these needs are critical, a back-up system must be in place in case the attendant doesn't show up or an emergency situation arises.

6. **Services are community-based and should be available where persons with disabilities need them, such as: home, work, in the community, school and during recreational activities.**

The needs of people with disabilities do not exist only in their homes. If people with disabilities are going to take part in their communities, obtain an education or get a job, attendant service must be available when and where they are needed.

7. **Programs should allow people with disabilities choices where they can live.**

Many attendant service programs dictate where a person may live in order to receive services. This frequently means that individuals who currently have a place of residence must move just to receive service. In addition, such requirements create ghettos for those who use the services. Flexibility must be built into our state programs!

8. **Programs should offer people with disabilities options on employer/employee relationships.**

Some people with disabilities, given the choice, prefer to receive funds and pay their attendant directly; they feel this gives them complete control of their services. Many others do not want to bother being the employer, and having to deal with the paperwork. Choice should be part of our state programs.

9. **Programs should be available to people with disabilities of all income levels on a co-pay or sliding fee basis. Receiving attendant services should not be a disincentive to employment.**

Most attendant services programs have some income eligibility cutoff, (usually at or around the federal poverty level). This means if a person's income exceeds the cutoff amount, the individual loses services. This has stopped people from taking entry-level jobs because they would lose all their services and still be unable to pay the

# SUMMARY OF SERVICES

## TEXAS DEPARTMENT OF HUMAN SERVICES

1. Primary Home Care
2. Family Care
3. In-Home and Family Support
4. Client-Managed Attendant Services
5. Special Services to the Handicapped 24 Hour Attendant Care
6. Residential Care Program
7. Emergency Response

## TEXAS REHABILITATION COMMISSION

1. VR-110
2. Independent Living Services
3. Personal Assistance Services

## TEXAS COMMISSION FOR THE BLIND AND VISUALLY IMPAIRED

1. VR-110, Transition and Deaf-Blind Programs
2. Independent Living and Older Blind Programs

## TEXAS DEPARTMENT OF MENTAL HEALTH MENTAL RETARDATION

1. ICF-MR
2. In-Home and Family Support

## TEXAS DEPARTMENT ON AGING

1. Options for Independent Living

## TEXAS COMMISSION FOR THE DEAF AND HEARING IMPAIRED

1. Interpreter Services
2. Services to Older Hearing Impaired

## MEDICAID WAIVERS

1. Community Living Assistance and Support Services
2. Home and Community Based Services
3. OBRA-Targeted (Omnibus Budget Reconciliation Act)
4. PACE
5. Medically Dependent Children's Program
6. Nursing Facility Waiver Program (Proposed-1993)



# ATTENDANT SERVICES OPTIONS IN TEXAS

## TEXAS DEPARTMENT OF HUMAN SERVICES

### 1. Primary Home Care

#### Service Description:

Primary Home Care is a non-technical medically related personal care service prescribed by a physician as part of a client's plan of care. It is available to eligible Medicaid clients whose health cause functional limitations in activities of daily living. Services are provided by a primary home care attendant and supervised by a registered nurse.

#### Funding Source:

Title XIX, State funds

#### Client Eligibility:

No age limit,  
Medicaid or 1929 eligible,  
Functional assessment guidelines with functional limitation  
in personal care based on medical condition,  
Physician's orders

#### Covered Services:

Personal Care including physical health related activities such as bathing, dressing, meal preparation, feeding, exercising, grooming, routine hair and skin care, helping with self-administered medication, toileting, and transferring/ambulating

Home management including health and safety related housekeeping activities such as changing bed linen, laundering, shopping, storing purchased items, and washing dishes

Escort including accompanying the client (not transportation by the attendant) for medical diagnosis/treatment

#### Service Maximum:

50 hours per week non-priority 1 clients  
39 hours per week for priority 1 clients

Special Considerations/Comments:

A priority 1 assessment is made if a client cannot perform one of the tasks of feeding, dressing, toileting or medicating without assistance. A priority 1 assessment ensures a "no service break" for the client.

Clients may refuse a priority 1 assessment for more hours.

2. Family Care

Service Description:

Family care is a non-skilled, non-technical service provided to eligible aged or disabled adults who are functionally limited in performing activities of daily living. Purchase through Title XVIII and XIX home health agency approved contractors, these services may be provided through a person able to have a family-like relationship with the client such as a family member, friend or neighbor.

Funding Source:

Social services block grants, state funding

Client Eligibility:

Age 18 or older.

Income of \$1,302/month or less for an individual and \$2,604/month or less for a couple.

Resources of less than \$5,000 for an individual or \$6,000 for a couple.

Functional limitation assessed.

Covered Services:

Personal Care as covered in Primary Care above.

Housekeeping as covered in Primary Care above.

Escort as covered in Primary Care above

Meal Preparation including assistance with food preparation as per the needs and wishes of the client not excluding special diet needs. Meal preparation activities include such activities as planning menus; shopping, storing, preparing and serving food.

Service Maximum:

50 hours per week non-priority 1 clients.

39 hours per week for priority 1 clients.

Special Considerations/Comments:

A priority 1 assessment is made if a client cannot perform one of the tasks of feeding, dressing, toileting or medicating without assistance. A priority 1 assessment ensures a "no service break" for the client.

Clients may refuse a priority 1 assessment for more hours.

3. In-Home and Family Support

Service Description:

Direct grant benefits to individuals with physical disabilities and/or his family to purchase services that enable him/her to live in the community. Eligible individuals are empowered to choose and purchase services that help them to remain in their own home.

Funding Source:

State funds

Client Eligibility:

Age: 4+ Income: Co-payment schedule established. SSI recipients eligible as long as functional requirements are met. TDHS's In-Home and Family Support Program serves persons with physical disabilities who will not be covered by TDMHMR programs for mental retardation and mental illness.

Covered Services:

- a. Purchase or lease of special equipment or architectural modifications of a home.
- b. Medical, surgical, therapeutic, diagnostic and other health services.
- c. Counseling and training programs that help provide proper care of an individual with a disability.
- d. Attendant care, home health services, home health aide services, homemaker services and core services.
- e. Respite care.
- f. Transportation services.

g. Pre-approved transportation and room and board cost incurred by person with physical disability or his family during evaluation or treatment.

h. Other services prior approved by TDHS.

Service Maximum:

\$3,600 one time accessibility/equipment grant  
\$300 monthly stipend

4. Client-Managed Attendant Services

Service Description:

Attendant care services are provided through this project to mentally competent physically disabled clients that are willing to supervise their attendant. Clients interview, hire, train, supervise and release their attendants. The contract agencies determine client eligibility, the amount of attendants, and provide emergency backup attendant capability.

Funding Source:

State Funds

Client Eligibility:

Age: 18+

Income: Sliding fee when income is greater than \$1,302/month for an individual, \$2,604/month for a couple.

Personal skill: must be mentally and emotionally capable of self-directing the care.

Physical disability: disability must be expected to last at least six months from the date eligibility is determined.

Covered Services:

Attendant care provided as needed by attendants hired by the client. TDHS staff are not involved with the clients.

Service Maximum:

40-50 hours per week (varies by provider contracts)

5. Special Services to the Disabled-24 Hour Attendant Care

Service Description:

Special services to the handicapped-24 hour attendant care makes attendant care available to clients on a 24-hour

basis. Clients live independently in clustered living arrangements.

Funding Source:

Social Services Block Grant, State Funds

Client Eligibility:

Age: 18+

Income: \$1,302/month for an individual, \$2,604/month for a couple,

Resource: \$5,000 or less for an individual, \$6,000 or less for a couple,

Functional Assessment: Functionally limited in activities of daily living.

Covered Services:

Around the clock availability of attendant care in a clustered living environment.

6. Residential Care Program

Service Description:

The Residential Care Program provides services to eligible adults who require access to care on a 24-hour basis but do not require daily nursing intervention.

Services provided are delivered through one of two arrangements: Supervised Living and Emergency Care.

Supervised Living is a 24-hour living arrangement in which the recipient is expected, if able, to contribute to the total cost of his care. The recipient keeps a monthly allowance for personal and medical expenses, and the remainder of his income is contributed to total cost of his care.

Emergency Care is a State or Title XX-funded living arrangement that provides services to eligible recipients while caseworkers seek a permanent care arrangement. Emergency care recipients do not contribute toward the cost of their care.

Funding Source:

State or Title XX funded

Covered Service:

Services include but are not limited to personal care, home management, escort, twenty-four-hour supervision, social and recreational activities, transportation, food, and room.

Client Eligibility:

Age: 18+

Income: \$1,302/months for an individual, \$2,604/month for a couple

Resources: \$5,000 or less for an individual, \$6,000 or less for a couple

Functional Assessment: Have needs that do not exceed the facility's capability under its licensed capacity.

7. Emergency Response

Service Description:

Emergency response services are provided through an electronic monitoring system used by functionally impaired adults who live alone or who are functionally isolated in the community. In an emergency, the client can press a call button to signal for help. The electronic monitoring system has a 24-hour, seven-day-a-week monitoring capability.

Funding Source:

Social Services Block Grant, State Funds

Client Eligibility:

Age: 18+

Income: \$1,302/month for an individual, \$2,604/month for a couple

Resources: \$5,000 or less for an individual, \$6,000 or less for a couple

Be alone routinely for eight or more hours per day. Have the mental capacity to operate the equipment. Have a telephone with a private line, if the system requires a private line to function properly, and, be willing to sign a release statement that allows the responder to make a forced entry into the client's home if he is asked to respond to an activated alarm call and has no other means of entering the home to respond.

Covered Services:

An electronic monitoring system

TEXAS REHABILITATION COMMISSION

1. VR-110

Service Description:

An array of services, which may include personal assistance services, designed to support persons with disabilities who are assessed as presently eligible for vocational rehabilitation and pursuing a plan of vocational rehabilitation.

Funding Source:

VR 110 Funds

Client Eligibility:

Age 18 and having been assessed as eligible for Vocational Rehabilitation Services through the presence of a disability limiting activities of daily living and, subsequently, employment.

Covered Services:

Personal attendant services including, bathing, feeding, toileting, transferring, mobility, cooking, cleaning, laundering, assistance with self-dispensing of routine medications and similar tasks.

Service Maximum:

Available while a VR client and up to 120 days beyond the first day of employment.

2. Independent Living Services

Service Description:

An array of services, which may include personal assistance services, designed to support persons with disabilities who are not assessed as presently eligible for vocational rehabilitation services, yet may benefit through independent living centers toward the enhancement of their individual activities of daily living.

Funding Source:

Title VII A&B

Client Eligibility:

Age 16 for Comprehensive Services  
No age limit for ILCs  
Assessed presently non-vocational  
Assessed as having a disability limiting activities of daily living.

Covered Services:

Comprehensive Services and IL Centers, both of which may include personal attendant services.

Service Maximum:

Limited catchment areas and availability of attendant services through the Independent Living Centers. Time-limited as per individual's Independent Living Plan.

3. Personal Attendant Services

Service Description:

Personal Assistance Services (PAS) are designed to support persons with disabilities who are presently employed and may benefit through PAS toward the enhancement of their individual activities of daily living.

Funding Source: State Funds

Client Eligibility:

Age 18, presently employed and assessed as having a disability limiting activities of daily living and particularly in the area of PAS such that it would create a barrier in employment.

Covered Services:

Personal attendant services as covered in VR-110 Services.

Service Maximum:

35 hours per week

Special Considerations/Comments:

This is a client income-based, scaled, cost sharing program. This program is limited to the Port Arthur, Austin, San Antonio and Nacogdoches Areas.



TEXAS DEPARTMENT OF MENTAL HEALTH MENTAL RETARDATION

1. ICF-MR

Service Description:

Institutional long term care service for persons with mental retardation. These services are located primarily in small group homes, although larger facilities do exist.

The TDHS, the single agency for administering the Texas Title XIX Medical Assistance Program, is responsible to HHS for the program.

Through interagency agreements, certain activities required to administer the program are transferred to the TDMHMR. Among these activities are provider procurement and selection; provider certification, recertification and decertification; Inspections of Care; review of client enrollment packets; continued determination of clients' ICF-MR levels of care; and other program coordination tasks.

Funding Source:

Title XIX

Client Eligibility:

Mental retardation as assessed by ICF-MR level of care determinations.

Income/Resources: SSI eligible, eligible for Medicaid benefits.

Covered Services:

Services include:

Case Management, room and board, habilitation, nursing services, transportation services, psychological services, physical therapy, occupational therapy, speech pathology, adaptive aids and supplies as covered and needed.

2. In-Home and Family Support Program

Service Description:

The In-Home and Family Support Program is designed to provide funds to individuals or their families

for the purchase of supported living services and/or goods. The purchased items must be specifically linked to the individual's disability and support recipient in their own home or assist the family in maintaining the person in the family home.

Funding Source: State Funds

Client Eligibility:

Must be requested by:

Individuals with mental illness, mental retardation, autism or their families.

Families who have a child under the age of four who has a developmental delay.

Recipients must be residents of Texas.

Covered Services:

Purchase/lease of special equipment, Architectural modification of a home, Medical, surgical, therapeutic, diagnostic, and other health services, Attendant care, home health aide, homemaker, and chore services, Training to assist in an independent living situation, Transportation, room and board during evaluation and treatment, Respite care, Family counseling/training on care of the person, Transportation of the person with a mental disability, Other original and unique services to support the person with a mental disability within the intent of the legislation authorizing this program.

Service Maximum:

\$3600 in each fiscal year

Special Considerations/Comments:

Income level of the recipient determines the percentage of the co-payment required.

TEXAS COMMISSION FOR THE BLIND AND VISUALLY IMPAIRED

1. VR-110, Transition and Deaf-Blind Services

Service Description:

Reader/driver services for blind individuals  
Personal attendant services

Funding Source: VR-110 Funds

Client Eligibility:

Presence of a visual condition for the individual, which constitutes or results in a substantial handicap to employment.

A reasonable expectation that vocational rehabilitation services will benefit the individual in terms of employability.

2. Older Blind and Independent Living Programs

Service Description:

Personal attendant services as necessary to supplement Independent Living goals.

Funding Source: Title VII C, Title VII A&B resp.

Client Eligibility: 55+, 18+ resp.

TEXAS DEPARTMENT ON AGING

1. Options for Independent Living/Area Agencies on Aging

Service Description:

a. Home Health Aide - Primarily personal care service provided by trained home health aides; under the direction and supervision of a registered professional nurse; and if appropriate a physical, speech or occupational therapist; provided to functionally impaired older persons that can be cared for in their own homes. Home health aides may also perform certain household services in order to help prevent or postpone institutionalization. Duties of a home health aide may include: bathing, grooming, feeding, ambulation, exercise, oral hygiene, skin care, assistance with self-medication, taking and charting vital signs,

charting intake and output, and household services essential to maintaining a safe environment in areas of the home utilized by the patient.

b. Homemaker I - Services provided by trained and supervised homemakers involving the performance of housekeeping/home management, meal preparation and/or escort tasks, provided to older adults who need assistance with these activities, in their place of residence. Duties of a homemaker in a Homemaker I program may include: shopping, tidying, dusting, cleaning, washing dishes and utensils, sweeping, vacuuming, mopping, laundering, ironing, emptying garbage, making beds, changing sheets, performing reading and writing tasks, organizing household routines, planning menus, preparing meals, storing and serving food, arranging transportation, and accompanying client on trips.

c. Homemaker II - Services provided by trained and supervised homemakers involving the provision of limited personal care services in addition to housekeeping/home management, meal preparation and/or escort tasks, provided to older adults who need assistance with these activities, in their place of residence. Personal care duties of a homemaker in a Homemaker II program may include: brushing teeth, cleaning dentures, bathing, giving bed baths, brushing and combing hair, shampooing, shaving, toileting, dressing and undressing, cleaning and filing nails with an emery board, assisting with transferring, ambulation and exercise, self-medication and applying non-prescription lotions and ointments.

d. Chore Maintenance - Performing household chores such a heavy cleaning, moving heavy furniture, yard and walk maintenance.

e. Adult Day Care - An array of services provided in a congregate, nonresidential setting to dependent older persons who need supervision without institutionalization. These services may include social/recreation, activities, health maintenance, transportation, meals and other supportive services.

Funding Source:

Title III, State Funds

Client Eligibility:

Age: 55+



## Personal Attendant Services Task Force

⌘ PAS: "A key to independence"

A project of The Coalition of Texans with Disabilities  
 316 W. 12th St. Suite 405 • Austin, Texas 78701  
 (512) 478-3366 V/TDD • (512) 478-3370 Fax

### PAS WAITING LISTS NUMBERS GROW

\*\*\*\*\*  
**Action!! -Visit, write, or call your state legislators and inform them about waiting lists for PAS and ask them to support increased funding for personal attendant services.**  
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The Texas Department of Human Service (TDHS) recently confirmed it has **14,447 people** on waiting lists for community-based personal attendant programs, and projected by 1996 there will be **18,554 people on community care service program waiting lists**. People with disabilities are being told they must wait as long as 3 years or more for life saving Personal Attendant Services (PAS). Funding for PAS in many non-Medicaid state agency programs has remained level for the past **four** years. The 1996-1997 proposed budget for TDHS cuts supportive services to **941 people**. In one of the programs, In Home and Family Support, there is only an average 16 persons per county receiving services. Although TDHS projects a 15% growth in this program, funding was not requested to meet the projected need.

The lack of funding for PAS is keeping people with disabilities from living, working and playing in their communities. The average cost to keep someone in a nursing home care is \$1,415.28 per month as opposed to community care at an average cost of \$387.28 per month.

#### Waiting Lists for TDHS Programs in all Regions

The following are the numbers of people waiting for services from TDHS by region. Call TDHS or CTD to find the region in your area.  
 The TDHS regions are:

Family Care	In Home and Family Support	Medically Dependent Children
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Region 1 High Plains	404	601	8
Region 2 Northwest Texas	80	268	20
Region 3 Metroplex-Dallas	673	1251	89
Region 4 Upper East Texas	140	848	52
Region 5 Southeast Texas	250	764	9
Region 6 Gulf Coast	413	1038	90
Region 7 Central Texas	597	1420	40
Region 8 Upper South Texas	372	683	85
Region 9 West Texas	*	220	10
Region 10 Upper Rio Grande	107	560	20
Region 11 Lower South Texas	<u>133</u>	<u>767</u>	<u>1</u>

*included with Region 2	TOTALS	3169	8420	428
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## Waiting Lists for TDHS Programs Limited to Certain Counties

The following programs are not statewide. They are available only in counties where waiting list numbers are indicated.

	Client Managed Attendant Services  (CMAS)	Community Living Assistance Support Services (CLASS)
Amarillo	8	*
Bexar	150	366
Cameron, Hidalgo, Gillespie, and Star	*	74
Hidalgo and Refugio	147	*
Dallas	67	214
El Paso	29	59
Harris	34	251
Jefferson	64	85
Lubbock	15	90
Nueces	147	47
Travis	82	270
Tarrant	<u>49</u>	<u>307</u>
<b>TOTALS</b>	792	1763

\* = no program currently available

## Texas Rehabilitation Commission PAS Program

The Texas Rehabilitation Commission (TRC) has a PAS program available for people with disabilities who are employed. The program is limited to 19 counties and is serving 71 people. TRC projects the unmet PAS need statewide for this program to be 21,000 people who are working and require assistance at home.

The counties currently receiving TRC's PAS program are Atascosa, Bexar, Comal, Guadalupe, Kendall, Medina, Wilson, Travis, Williamson, Hays, Angelina, Chamber, Hardin, Jasper, Jefferson, Nacogdoches, Newton, Orange, and Shelby.

# MEDICAID WAIVERS

## 1. COMMUNITY LIVING ASSISTANCE AND SUPPORT SERVICE (CLASS)

### Service Description:

The Community Living Assistance and Support Services (CLASS) program provides home and community-based services to people with related conditions as a cost-effective alternative to ICF-MR/RC institutional placement. People with related conditions are people who have a disability, other than mental retardation, which originated before age 22 and which effects their ability to function in daily life.

There are two service providers: one provides independent case management for CLASS; the other provides all other services. The CLASS service model focuses on client independence and integration of the client into everyday community life.

Funding Source: Title XIX (Medicaid 1915(c) home and community-based services waiver), State Matching Funds

### Client Eligibility:

- a. Age: no limit (but age of onset of disability must be prior to age 22)
- b. Income/resources: SSI eligible, eligible for Medicaid benefits under a federally mandated protective status, or is a disabled child who would be eligible for Medicaid if institutionalized and if parental income is not deemed to the child.
- c. Meet ICF-MR/RC Level of Care criteria
- d. Must have a demonstrated need for habilitation services
- e. Individual Plan of Care for waiver services approved by TDHS
- f. Reside in the geographic catchment area.

### Covered Services:

#### Services include:

- a. Case Management
- b. Habilitation

- c. Respite Care
- d. Nursing Services
- e. Psychological Services
- f. Physical Therapy
- g. Occupational Therapy
- h. Speech Pathology
- i. Adaptive Aids/Supplies
- j. Minor Home Modifications

Service Maximum:

There is an individual client cost ceiling based on the waiver formula calculations.

2. HOME AND COMMUNITY BASED SERVICES

Service Description:

Home and community-based services are provided to mentally retarded individuals as an alternative to ICF-MR institutional placement.

Funding Source:

Title XIX (1915c Waiver). State matching funds provided by TDMHMR.

Client Eligibility:

- a. Age: no limit
- b. Income/resources: SSI eligible, parental income/resources not deemed to the child
- c. ICF-MR Level of Care Criteria
- d. Individual Plan of Care for Waiver Services approved by TDHS

Covered Services:

Services include:

- a. Homemaker



- b. Habilitation
- c. Respite (30 days per year)
- d. Nursing Services
- e. Case Management
- f. Psychological Services
- g. Social Services
- h. Occupational Therapy
- i. Physical Therapy
- j. Speech Pathology
- k. Audiology Services

Service Maximum:

\$37,781 individual client cost ceiling per year (Statewide maximum of 1,050 clients for FY 92 and a maximum of 30 client per contract)

3. OMNIBUS BUDGET RECONCILIATION ACT (OBRA) TARGETED WAIVER

Service Description:

This Medicaid waiver will provide various community services during the first three years of operation to approximately 972 persons with mental retardation and/or related conditions who are currently inappropriately placed in nursing homes.

Funding Source:

State funds provided by TDMHMR and matching federal Medicaid funds

Client Eligibility:

- a. Be determined by TDMHMR to have MR and/or RC and be inappropriately placed in a nursing home.
- b. Meet criteria for an ICF-MR/RC level of care.
- c. Have an Individual Plan of Care that does not exceed 125% of the average annualized expenditure for waiver services.

d. Meet financial criteria for SSI, MAO in the community, the institutional income limit, or be a disabled child who meets SSI criteria if in an institution, with parental income disregarded.

e. Be discharged from a nursing home.

Covered Services:

- a. Adaptive Aids
- b. Case Management
- c. Dietary
- d. Habilitation
- e. Minor Home Modifications
- f. Nursing
- g. Occupational Therapy
- h. Psychology
- i. Respite
- j. Social Services
- k. Speech Language Pathology

4. PROGRAM OF ALL-INCLUSIVE CARE FOR THE ELDERLY (PACE)

Service Description:

Provides community-based services to frail elderly people who qualify for nursing facility placement. Uses a comprehensive care approach, providing an array of medical, functional and day activity services for a capitate monthly fee that is below the cost of comparable institutional care. One test site --Bien Vivir in El Paso, Texas.

Funding Sources:

Medicare (Title XVIII), Medicaid (Title XIX) 1115 Waiver, and private pay

Client Eligibility:

- a. Age 55+

- b. Qualify for a nursing facility level of care
- c. Qualify for Medicaid in a nursing facility
- d. Choose PACE services

Covered Services:

Any and all health-related services needed including inpatient and out-patient medical care, specialty services like dentistry and podiatry, social services, in-home care, meals transportation, day activity and housing assistance.

Service Maximum:

Per diem rate

5. MEDICALLY DEPENDENT CHILDREN'S PROGRAM (MDCP)

Service Description:

In-home/out-of-home licensed nurse services and facility-based respite care (less than 30 days/year) are provided MDCP eligible clients as a cost-effective alternative to providing for their care in a nursing facility.

Funding Source:

Federal funds (through 1915(c) Medicaid waiver) and state matching dollars.

Client Eligibility:

- a. Under 18 years of age.
- b. Require the services of a licensed nurse.
- c. Meet the medical necessity criteria for a nursing facility.
- d. Meet the disability requirements specified by SSA for SSI eligibility.
- e. Have individual plan of care approved by the client's physician.
- f. Be Medicaid eligible in the community under SSI, parental deeming or MAO (Medical Assistance Only) provisions defined in the waiver.

Covered Services:

- a. In-home/out-of-home licensed nursing
- b. Facility-based respite care
- c. Regular Medicaid State Plan benefits

Service Maximum:

Projected annual cost of services cannot exceed the cost of Medicaid institutional care.

6. NURSING FACILITY WAIVER PROGRAM (PROPOSED) (1915C)

Service Description:

The Alternative Living Options and Home Assistance program provides home and community-based services to aged and disabled adults as cost-effective alternatives to institutional care in nursing facilities.

Funding Source:

Title XIX (Medicaid 1915(c) home and community-based services waiver), State Matching Funds.

Client Eligibility:

- a. Age: Over age 21
- b. Income/Resources: Be Medicaid eligible in the community under SSI or MAO protected status or meet the income and resource requirements for Medicaid benefits in nursing facilities. Income \$1302/month with resources of \$2000 for an individual. Spousal impoverishment provisions apply.

Covered Services:

Case Management is provided by TDHS staff.

Waiver services include:

- a. Adaptive Aids and Medical Supplies
- b. Adult Foster Care
- c. Assisted Living Services
- d. Emergency Response Services
- e. Nursing Services

- f. Minor Home Modifications
- g. Occupational Therapy
- h. Personal Assistance Services
- i. Physical Therapy
- j. Respite Care
- k. Social Services
- l. Speech Pathology Services
- m. Transportation Services (Non-Medical)

Service Maximum:

The client's individual plan of care cannot exceed 125% of the average annualized expenditure for waiver services

## COMMUNITY LIVING ASSISTANCE AND SUPPORT SERVICES

### Service Description

The Community Living Assistance and Support Services (CLASS) program provides home and community-based services to people with related conditions as a cost-effective alternative to ICF-MR/RC institutional placement. People with related conditions are people who have a disability, other than mental retardation, which originated before age 22 and which effects their ability to function in daily life.

There are two service providers: one provides independent case management for CLASS; the other provides all other services. The CLASS service model focuses on client independence and integration of the client into everyday community life.

### Funding Source

Title XIX (Medicaid 1915(c) home and community-based services waiver), State Matching Funds

### Covered Services

Services include:

- Case Management
- Habilitation
- Respite Care
- Nursing Services
- Psychological Services
- Physical Therapy
- Occupational Therapy
- Speech Pathology
- Adaptive Aids/Supplies
- Minor Home Modifications

### Client Eligibility

Age: no limit (but age of onset of disability must be prior to age 22)

or

Effective 06/01/93, be an individual who would be financially eligible for Medicaid if residing in a Medicaid-certified institution.

Income/resources: SSI eligible, eligible for Medicaid benefits under a federally mandated protective status, or is a disabled child who would be eligible for Medicaid if

Community Living Assistance and Support Services (cont.)

Page 2

	institutionalized and if parental income is not deemed to the child.
	Meet ICF-MR/RC Level of Care criteria
	Must have a demonstrated need for habilitation services
	Individual Plan of Care for waiver services approved by TDHS
	Reside in the geographic catchment area.
Service Maximum	There is an individual client cost ceiling based on the waiver formula calculations.
Provider Base	Public and private agencies
Procurement Methodology	Competitive procurement
Reimbursement Methodology	Unit rate
Rate per Unit of Service	The unit rate varies by type of service.
Annual Expense (Projected FY 1993)	\$9.9 million
Number of Contracts	23
Clients/Month (Projected FY 1993)	382
Service Availability	Geographic catchment areas.
Monitoring	<ul style="list-style-type: none"><li>■ Initial and annual certification reviews.</li><li>■ Prior approval of service</li><li>■ Service control monitoring</li><li>■ Quality assurance reviews (in cooperation with consumer representatives)</li></ul>

Community Living Assistance and Support Services (cont.)  
Page 3

Sanctions

Time-limited corrective action plan  
Recoupment of Medicaid payments  
Vendor hold  
Contract termination/cancellation



## NURSING FACILITY WAIVER PROGRAM

Service Description	The Nursing Facility Waiver (NFW) program will provide home and community-based services to aged and disabled adults as cost-effective alternatives to institutional care in nursing facilities.
Funding Source	Title XIX (Medicaid 1915 (c) home and community-based services waiver), State Matching Funds.
Covered Services	Case management is provided by TDHS staff.  Waiver services include: <ul style="list-style-type: none"><li>■ Adaptive Aids and Medical Supplies</li><li>■ Adult Foster Care</li><li>■ Assisted Living Services</li><li>■ Emergency Response Services</li><li>■ Nursing Services</li><li>■ Minor Home Modifications</li><li>■ Occupational Therapy</li><li>■ Personal Assistance Services</li><li>■ Physical Therapy</li><li>■ Respite Care</li><li>■ Speech Pathology Services</li></ul>
Client Eligibility	Age: age 21 or older Income/Resources: Be Medicaid eligible in the community under SSI or MAO protected status or meet the income and resource requirements for Medicaid benefits in nursing facilities. Income: \$1,302/month with resources of \$2000 for an individual. Spousal impoverishment provisions apply.  Medical Necessity: Meet the medical necessity determination for nursing facility care.  PASARR: Be determined appropriate for nursing facility care through the PASARR process.  Waiver specific criteria: Have an Individual Plan of Care approved by TDHS;  Choose waiver services based on an informed choice;

Nursing Facility Waiver Program (cont.)  
Page 3

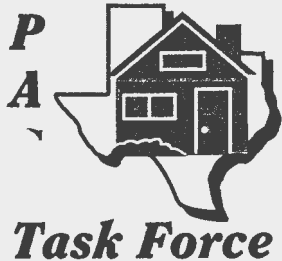
Monitoring

TDHS will perform:

- Authorization of services
- Quality assurance reviews
- Contract/standards compliance audits

Sanctions

Time-limited corrective action plans  
Recoupment of Medicaid payments  
Vendor Hold  
Contract termination/cancellation



## *Personal Attendant Services Task Force*

☞ *PAS: "A key to independence"*

*A project of The Coalition of Texans with Disabilities  
316 W. 12th St. Suite 405 • Austin, Texas 78701  
(512) 478-3366 V/TDD • (512) 478-3370 Fax*

### *F Y I:* **HOW TO GET NURSING FACILITY WAIVER (The NFW)**

The Nursing Facility Waiver (the NFW) is an optional Medicaid program which is administered by the Texas Department of Human Services. The NFW is designed to meet the needs of those currently falling through the cracks of our service delivery - primarily those who are risk of going into a nursing home or those who already reside in a nursing home and need health-related tasks performed as a daily part of their support services or require 24-hour supervision.

**Covered Services:** Adaptive aids and medical supplies, adult foster care, assisted living, emergency response services, nursing services, minor home modifications, occupational therapy, personal assistance (attendant) services, physical therapy, respite care, and speech pathology and physical therapy.

#### **Eligibility Requirements:**

**Age:** 21 years or older

**Income:** Be Medicaid eligible in the community under SSI or MAO (Medical Assistance Only) protected status and meet the income and resource requirements for Medicaid benefits in nursing facilities.

**Medical Necessity:** Meet the medical necessity determination for nursing facility care. Have ongoing health-related needs (such as, tube-feeding, medication administration, 24-hour supervision, etc.) that cannot be delivered adequately on an ongoing basis by friends, relatives, or volunteers. If a person's long-term care needs are being covered by Medicare, they will be determined as NOT having an unmet need.

**Call your Regional Contact at Texas Department of Human Services: LIST ATTACHED**

**What to expect when you call your Regional TDHS Contact:** Your regional contact will direct you to an intake staff person, who will determine your need for services based on a TDHS priority rating scale. If your need for Nursing Facility Waiver services is determined to be an emergency, a nurse will be sent to do an on-site assessment within 24 hours. If your need for services is deemed immediate, but not an emergency, a nurse will do an on-site assessment within 5 days. In non-urgent situations, you will be sent the regular community care needs assessment forms to be filled out and mailed to TDHS. When TDHS receives and processes your needs assessment forms, a nurse will be sent to do an on-site assessment.

**Enrollment:** The NFW enrollment at the end of October was only 110 of 5,000 slots funded. Enrollment is low due to a number of factors including: 1) a lengthy Medicaid eligibility process that can be over 90 days; 2) inadequate money for staffing and services; and 3) lack of availability in larger population areas.

**Expansion of Nursing Facility Waiver:** In spite of its rocky start, the TDHS goal for statewide implementation of the NFW to be serving 5000 people by August 31, 1995. TDHS planned for the NFW to be available in at least one designated county in all regions by November 1 of this year. The following counties are slated to be opened for the Nursing Facility Waiver this year:

<u>DATE</u>	<u>REGION</u>	<u>COUNTY</u>
*August 15, 1994	Region 10	El Paso, Hudspeth, Culberson Jeff Davis, Presidio, Brewster
September 1, 1994	Region 11	Webb (Laredo)
*September 1, 1994	Region 4	Cherokee Red River
September 15, 1994	Region 8	Bexar (San Antonio)
*October 1, 1994	Region 5	Hardin, Jefferson Orange
*October 15, 1994	Region 6	Harris (Houston)
*October 31, 1994	Region 2/9	Taylor (Abilene)
November 1, 1994	Region 7	Travis (Austin) McLennon (Waco)
*November 29, 1994	Region 3	Dallas, Grayson
*December 1, 1994	Region 4	Titus Franklin

\* Indicates counties where the Long Term Care Assessment pilot project will be initiated simultaneously to the Nursing Facility Waiver implementation. The Long Term Care Assessment pilot project identifies people who are seeking admission into a nursing home and determines their eligibility. Then, the individual will be advised of community alternatives to nursing home placement, such as the Nursing Facility Waiver.

## Nursing Facility Waiver Regional Contact Information:

<u>County</u>	<u>Phone</u>	<u>Contact person</u>
Webb (Laredo)	210-725-5195	Alejandro Cisneros
Titus, Franklin Hardin, Jefferson	1-800-722-3401	Donna Glass
Orange	409-835-3751 Beaumont	Nancy Kendall
Travis, McLennon	817-750-9314 (Waco) 512-908-9540 (Austin) 512-908-9555 (Austin)	Greta Brown Karen Gonzales Sue Starnes
Dallas, Grayson	214-319-8422 X2088 (Dallas) 903-583-5535 (Bonham)	Linda Territo Don Morrison
Lubbock	806-797-8870	Vivian Hargrove
Potter/Randall	806-345-4320	Marjorie Hudson
Tarrant	817-625-4529	Cherry Johnson Dorothy Allen
Wise	817-627-3006	Sherryn Smith
Lamar	903-737-0273	Brenda Grooms
Harrison	903-927-0251	Shirley Royal
Bowie	903-821-1275	Donna Cooley
Red River	903-427-3874	Genetta McGregor
Gregg	903-232-3234	Mary Malrey
Cherokee	903-589-2203	Cathy Koen
Smith	903-533-4817	Flo Fuller
Bell	817-774-7263	Jerry Bell
Bexar	210-337-3550	Nola Graham Margaret Landes

## Nursing Facility Waiver Regional Contact Information (cont):

<u>County</u>	<u>Phone</u>	<u>Contact Person</u>
El Paso	915-775-4591 x880	Maria Elena Casas
Brewster, Culberson, Hudspeth, Jeff Davis, Presidio	915-837-3338	Brenda Fierro
Cameron	210-504-4313(Brownsville) 210-361-4293(San Benito)	Olivia Barron Vanessa Quintero
Hidalgo	210-262-4795(Edcouch) 210-316-8451(Edinburg) 210-630-9441(McAllen) 210-565-2692(Mercedes) 210-580-6409(Mission) 210-787-3131(Pharr) 210-969-9115(Weslaco)	Aurora Molina Lucy Rodriquez Edna Salinas Sofia Bocanegra Luisa Solis Connie Garza Cynthia Desiga
*Houston	713-696-7678	Judy Clark
*Abilene	915-695-5750	Rea Barry
*Corpus Christi	210-316-8288	Alberto Cantu
*Beaumont	Contact local TDHS office	

**What choice are people making?** TDHS figures indicate that of those who have been enrolled on the NFW program, 42% are living with their families, 14% are living alone, 34% are in an assisted living arrangement, and 10% are in an adult foster care home. Average annual costs/client for the NFW have run at \$11,509 versus \$17,341 for a nursing home. These figures amount to a savings of approximately \$300,000 to date since the implementation of the Nursing Facility Waiver.

**GOING HOME  
AND OTHER ADVENTURES:  
A GUIDE TO SUPPORTED LIVING  
FOR PERSONS WITH  
DISABILITIES**



**UNITED CEREBRAL PALSY  
ASSOCIATION OF TEXAS  
MAY 1992**

**Written By: Joyce Dawidczyk,  
Lisa Arisco and Patricia Anderson**

**Funding provided on behalf of the Texas Planning Council for Developmental Disabilities  
by the Texas Rehabilitation Commission.**

## PERSONAL CHOICE

Personal choice was the core value that most significantly impacted our mode of operation in providing supported living services and supports.

It has been the common major life experience of many of the individuals with significant support needs that we worked with to live in settings where they had little or no personal choice, and where all major life decisions were made for them. UCP-Texas recognized that when these individuals were assisted to move into the community that many would not have a great deal of experience in making decisions or choices, and some, for example, due to cognitive disabilities, may not ever have the ability to make the complete range of choices available to most people.

There were two paths that UCP-Texas could have taken: one of continuing the previously established patterns of taking away individual power and control, or, what we believed was the right path: that of letting individuals truly test the limits, expanding the range of their control, and helping them to find the ongoing supports they needed.

One of the ways people learn and grow is by making their own mistakes and experiencing the consequences. In the case of supporting individuals with disabilities to live in the community, this did NOT mean sitting back and doing nothing while project participants made bad decisions that could have jeopardized their continued ability to live in the community. What it did mean, was making every effort to ensure that individuals had access to and understood all the information they needed to make choices, including likely outcomes of certain actions. Then, too, it also meant letting them make those choices, while closely monitoring the situation for signs of serious, negative consequences.

While it was imperative for support staff to act swiftly to remedy situations in which abuse was suspected or confirmed, it was also just as important to be cautious about attempting to take control of less serious situations against an individual's wishes.

It is important to note that unless an individual is declared legally incompetent by a court of law to make their own choices, and unless a Supported Living agency is willing to pursue legal guardianship, it may not be possible to stop individuals from making and acting upon potentially dangerous decisions.

However, if the support staff has maintained a relationship of respect and ongoing support, there is now an opportunity to offer boundaries to the individual for making decisions - reinforcing individuals' established support systems, doing all that can be done to eliminate contributing external factors, and attempting to minimize the impact of the negative outcome.



There is always a risk of failure, with resulting consequences that an individual may end up back in an institutional setting or worse. UCP-Texas firmly believes, and our experience has confirmed our belief, that it is far better in the long run to stay true to the philosophy of personal choice. In this manner, we learn how to better support and reinforce people to make good decisions, but also make sure that we do not strip them of the dignity of self-direction and risk-taking, under the guise of “safety” or “protection” from themselves or society.

### **MAXIMIZING PERSONAL CHOICE, WHILE AT THE SAME TIME BEING RESPONSIBLE FOR PROVIDING SUPPORTS: A CLASSIC STRUGGLE FOR SUPPORT STAFF**

It can be tempting for staff, family and friends, who see individuals making what they consider to be bad decisions, to step in and try to “fix” things or take control of the situation. If we as service providers are always trying to restrict individuals’ opportunities to “practice” to those situations in which we feel they are making the best decisions, then we are only thinly disguising our own control needs as supporting personal choice - and rest assured the individual will know the difference. And, most probably, we will lose any trust we may have previously established and be shut out of all future decision making the individual takes on.

It is a fine line support staff walk between respecting personal choice and ensuring that people are as safe as possible from exploitation, neglect and abuse. Unless absolutely sure that the individual is in imminent physical danger or in an abusive situation, when in doubt, the UCP-Texas Supported Living position has been that it is better to err on the side of personal choice - but be prepared to be wrong, and be ready to respond to changing conditions with alternative supports and choices.

One key point to be made about absolute safety is that it does not exist - anywhere. Abuse and neglect occur in institutions and congregate settings, as well as in the community. It is UCP-Texas’ position that it is far better to promote safety in the community where individuals can build, or be assisted to build, their own support networks, rather than in institutions where they are isolated and segregated.

In fact, it has been UCP-Texas’ experience that individuals with disabilities are most safe when allowed to learn, to the maximum extent of their abilities, about the real risks and consequences of decisions made, combined with respect and supportive, ongoing relationships with people in the community who care about them.

# ONGOING COORDINATION AND MANAGEMENT OF SUPPORTS

## **LIFE IS NOT STATIC**

Many times throughout the project, particularly during the first year following an individual's move, we would think that we were just about to get the person's supports stabilized, when something major would fall apart - a roommate would leave, an attendant would quit, the electric wheelchair would break, or serious family problems would emerge. In the beginning, we thought that we must be doing something terribly wrong, that we had failed to correctly assess the amount of support needed, or that we were missing some vital component that would magically hold the pieces together.

While we did make mistakes, more often than not, it took us a while to figure out that these upheavals were the result of life getting in the way of life. Unlike the controlled and stifling environment of the institution, the community is full of life-changing experiences, dynamic relationships, and, in a social/political climate that tends to push individuals with severe disabilities toward institutional care rather than community alternatives, a constant struggle to obtain and maintain basic supports.

In the "real" world, nothing is static. All people, whether disabled or not, change. Their needs and desires change, as rapidly as their life situations change. While some of these changes may be planned, or at least anticipated, very often they catch everyone off guard. Some changes will be positive and some may not - but there will always be change. Any individual, family or agency thinking about pursuing supported living needs to understand this and be prepared to meet the continuing challenges as they arise.

## **STAFF ROLES VS. INDIVIDUAL ROLES**

Staff can and should encourage and support individuals to learn how to manage their own supports to the greatest extent possible. Service providers, case managers, and other support personnel will come and go in individuals' lives. The more knowledge and skills individuals have about all areas of their lives, the better equipped they will be to handle the flow of life changes and upheavals.

While some individuals will gain the skills they need to manage their supports, to feel

confident in their relationships with others and to feel able to deal with crises on their own, others will need lifelong support to accommodate and respond to life's continuing challenges.

Support staff need to be prepared to offer a variety of support as circumstances change. Supporting people to live in the community is an evolving and ongoing challenge. Supports may intensify or lessen, with the ebb and flow of life situations and upheavals.

## **FORMING RELATIONSHIPS WITH ATTENDANTS - THE UNIQUE CHALLENGE**

We have previously addressed many aspects of attendant care, but a discussion of the ongoing coordination and management of supports would not be complete without looking at the unique, and often paradoxical, relationships between people with disabilities, and their attendants.

Relationships between individuals and their attendants are often complex because while they may, on the surface, appear to be the same as that of an employer and employee, they have the added element of often being intensely personal due to the nature and circumstances of the job. These relationships can be satisfactory for both the individual and the attendant, but they also have the potential, particularly for individuals who have lived in institutions, to encompass the following issues:

### **A. FRIEND OR EMPLOYEE (OR BOTH?)**

When individuals with disabilities live in institutions, they often have few opportunities to form relationships with people other than the other "residents" and paid staff. Individuals who live in these situations may gravitate toward paid staff as a way of making contact with the outside world, or they may feel particularly close to staff who treat them with kindness and respect. These previous relationships may provide a very limited frame of reference for the word "friend". When individuals who have this frame of reference move into the community, it may often seem natural for them to "make friends" with their attendants, to look to them for guidance, attention and companionship.

This situation can become awkward, however, if the attendant fails to adequately perform the required job duties. Individuals are then faced with the predicament of reprimanding or even firing people they consider to be "friends" in order to get their physical needs met. The idea of losing the friendship, however, can be even more devastating to them than missing a meal or staying in bed all day. They may decide to

keep the attendant, over the objections of family or staff, in order to keep the friendship.

Aside from looking to paid staff for friendship, individuals who have lived in institutional settings may have had few opportunities to learn the difference between real, supportive friendship and people who may be taking advantage of them. This is a lesson that many people have had to learn, usually the hard way, while maturing and gaining life experience, and it will be no different for people with disabilities who are just beginning to experience life in the community, amid the complexity and diversity of relationships that community life has to offer.

Individuals experiencing these types of situations may need a great deal of support to gradually redefine their definitions of friendship, and to find relationships that are supportive and mutually beneficial. A key element in this will be to broaden their opportunities to form relationships with a variety of people, other than just with people who work for them. (See section on COMMUNITY INCLUSION.)

It is not necessarily inappropriate for employer and employee to be friends, as friendships occur in the workplace all the time. Friendships, however, are based on mutual respect and regard. A situation that can be inappropriate is when an attendant, recognizing the emotional influence they have in the life of an individual with a disability, uses that influence to ignore responsibilities. Support staff need to be alert to the possibility that these types of relationships may result in neglect or abuse, and be ready to offer further support and assistance as needed.

It is important to remember that individuals who have just moved out of institutional settings may be getting their first taste of their own decision-making power. They may have waited a long time to exercise that power. As mentioned earlier, it is critical for staff to remain involved, providing information on alternatives and possible outcomes, and to check in with individuals as needed. However, unless individuals appear to be in imminent danger of physical harm or abuse, in the long-run it is better to respect individuals' wishes with regard to the relationships they choose to pursue in their lives.

## **B. WHO HAS THE POWER?**

Attendants are hired to work for individuals with disabilities or for agencies on the individuals' behalf, which, theoretically, should mean that individuals with disabilities possess the authority and power in the relationship.

However, the reality for people with disabilities, who depend heavily on the services attendants provide, is that they often fear the consequences of losing attendants, and can

feel vulnerable to both physical and emotional retaliation. This is particularly true for those individuals who do not have immediate access to backup/emergency attendant care.

A further complicating factor is that, many times, individuals with disabilities have been taught subtle (and not so subtle) societal messages throughout their lives that they should be "grateful" for any kind of services they receive. By being grateful, particularly in the attendant care arena, they give up all expectations that they deserve respect and "the best" possible care, and give up much of their power in the process.

Although there are many factors that can be used to evaluate the quality of attendant care, we have observed that power and the use of power in the relationship is the key factor. In our experience, the best attendants are those who respect individuals' positions of authority, as opposed to attendants who recognize individuals' dependence and use the power this gives them to their personal advantage.

Individuals who are feeling vulnerable and powerless are often afraid to (or feel guilty about) reporting an attendant's abuse of power to others. They often fear having to do without attendant care at all until a replacement can be found, retaliation by the attendant, disbelief or indifference on the part of service providers, gaining a reputation as a "non-compliant client", and feeling like they are not a "good person" or a "team player". Recognizing that these are significant, ongoing issues that may have implications for the provision of support to individuals throughout their lifetimes, we offer the following suggestions:

- \* Assure individuals that it is "safe" to talk about problems they are having with their attendants or any other support systems, and that they will not lose their supports for speaking out.
- \* Develop an emergency/backup attendant care plan or system that will enable individuals to let attendants go when problems arise.
- \* Empower individuals by offering choices and alternatives to their present situation, supporting them to make choices, and then respecting those choices will go a long way toward creating an environment of trust. Individuals may then feel more comfortable in discussing and addressing the more thorny and sensitive issues of power and control-related situations that they are dealing with.
- \* Be aware that these issues touch on extremely sensitive and personal areas of individuals' lives. Staff who have not established the level of trust necessary to assist when these issues arise should assist the individual to bring in others who

have established that kind of relationship.

\* Make sure individuals know what their rights are within a particular service system, and that they have the support they need to exercise them.

**SPEAKERS' BIOGRAPHICAL SKETCHES**  
**- In Order of Their Presentations -**

**DARLENE PLYTER** is a family member, and active advocate. (817/498-9108) Taking early retirement from a legal career, she became active with the Texas Head Injury Association in late 1986, serving 3 years as a Chapter President. She's been on the THIA Board of Directors since 1988, and has been THIA President and Chair of the Board since September 1, 1992. She serves on numerous other boards and advisory boards, including the Metroplex Long-Term Care Consortium.

**TERRI PETRUCCI-COLEY, MA, CCC-SLP** is a Speech/Language Pathologist specializing in the treatment of individuals with brain injury. She currently owns Interlace Inc. (713/523-3406), a consulting company that provides necessary services and supports required for individuals with brain injury to live independently. Previous experience includes: Director of Life Elements, a community based rehabilitation program for individuals with brain injuries; Speech/Language Pathologist and case manager of the Transitional Learning Community in Galveston TX; and Director of Speech Pathology Services for the Harris County Hospital District.

**LINDA J. COURTNEY, LMSW-ACP** is the Community Integration Liaison of the Southwest Regional Brain Injury Rehabilitation and Prevention Center located at The Institute for Rehabilitation and Research (TIRR) in Houston TX (713/666-9550). Ms. Courtney has worked as a clinical social worker, psychotherapist, and case manager in the rehabilitation field for over 14 years. For the past 8 years, she has specialized in service provision to persons with brain injury and their families. She has also been involved in developing supports and services for the continuum of needs of persons with brain injury. As the Community Integration Liaison for the Southwest Center, she serves as the chairperson for the Committee on Living and Working, and is the co-chair for the Committee on Systems of Service. Current projects of these committees include: housing issues, substance abuse issues, and SSI/SSDI issues of persons with brain injury, and community support services. Ms. Courtney's publications include Social Security Benefits for Persons With Traumatic Brain Injury, The TBI Tool Kit, and Integrating Community Resources. She is currently pursuing her Doctorate in Clinical Social Work at the University of Houston.

**BEN ALMOND** is a survivor and active advocate. He sustained a brain injury in July, 1983, at the age of 18, in an automobile accident. After extensive rehab, he's been employed in brain injury rehabilitation since 1988, and is currently a TRA with HealthSouth-Fort Worth, pursuing a degree as an OT in his copious free time. Married, he and wife Cheryl have two small sons and have a home in Fort Worth. He has been active with the Texas Head Injury Association since late 1986, and is the current President of the Texas Survivors' Council, thus a member of the THIA Board of Directors. He's an original member/graduate of the Committee on Advocacy and Empowerment, now known as the THIA Advocacy Committee.

JONAS SCHWARTZ is with REACH Independent Living Centers, Fort Worth TX (817/870-9082), Dallas TX (214/630-4796). (No info.)

DAVID D. GARZA is the HOME Program Manager, Texas Department of Housing and Community Affairs, Austin TX (512/475-3848). Prior to 1991 and this position, he was with Avenida Guadalupe Association; Neighborhood Reinvestment Corporation; the U.S. Commission on Civil Rights; and The City of San Antonio. In 1994 he was invited to the National Task Force to advise HUD Assistant Secretary Andrew Cuomo on the Consolidation Planning for Community Planning & Development Formula Program. With 20 years in the public sector, administrative experience in city, federal, state and non-profit fields, and policy making experience, he is quite knowledgeable in his field and was recently featured in the Council of State Community Development Agencies Newsletter.

JOE BONTKE is the Coordinator of the Southwest Disability & Business Technical Assistance Center on the ADA, Houston TX (713/520-0232). Prior to this, he worked with barrier removal issues as Vice President of Accessibility Consultants, Inc. During the past few years Joe has spoken to jillions of audiences on different aspects of the ADA and conducted zillions of site surveys to assist owners and building managers with the removal of attitudinal, communicative and architectural barriers. He has creatively written on issues of ADA for Accessible Ideas and The Perspectives Network: "What Is All This ADA Stuff About Anyway? -A Look At How We Got To The Point Of Needing A Law". His entertaining style has educated groups throughout the country on the ADA laws.

DAVID K. KRYCH is the co-founder and Executive Director of The Centre for Neuro Skills (CNS), Irving TX (214/580-8500). CNS has post-acute brain injury rehab programs and community re-entry living/learning programs in Bakersfield CA as well as Irving TX. He graduated from SIU with a Masters in Speech Pathology with a specialty in Cognition and Language. He has traveled extensively throughout the U.S. and abroad presenting numerous professional papers about brain injury. His specialty is cognitive barriers and their removal.

SARAH ANDRE joined Diana McIver & Associates (DMA) Austin TX (512/328-3232) in July 1994 as the Research Assistant for the Consumer Controlled Housing Initiative. In this position she is responsible for researching housing opportunities for persons with disabilities and providing technical assistance to facilitate increased housing opportunities throughout the State. Prior to joining DMA, she completed an internship with TRC where she worked on the development of the Commission's 5-Year Strategic Plan. She recently completed an intensive research project in Paraguay on the urban housing market as part of a joint venture of the U.S. Agency for International Development and the InterAmerican Planning Society. She received her Master's in Community and Regional Planning from the UT-Austin in the fall of 1994.



**MANDY DeMAYO** (DMA: 512/328-3232) has two years' experience in research and training activities relating to affordable housing and an additional two years' experience in the administration of volunteer programs. She joined DMA as a Development Manager in October 1993. In this position, she is responsible for overseeing the day-to-day development activities on Section 202 and 811 Projects. She is also the Project Director for the Consumer Controlled Housing Initiative, a 3-year grant funded by the Texas Planning Council for Developmental Disabilities which will assist Texans in more appropriately meeting housing needs for consumers with disabilities. Prior to joining DMA, Ms. DeMayo completed internships with the Texas Development Institute, where she designed a training curriculum for nonprofit housing sponsors using HOPE III Funding; and developed a relocation plan in conjunction with a home ownership program. She received her Master's in Public Affairs at the UT-Austin in 1993.

**BELINDA CARLTON** is a family member and active advocate. She is the Executive Director of the Coalition of Texans with Disabilities, Austin TX (512/478-3366). She has traveled extensively around the State speaking on issues of the disabled, regarding both community and legislative issues. She's also a member of the Board of Directors of THIA, and a member of the THIA Advocacy Committee.

**BRENDA SEAWELL, LPT**, is a family member and active advocate. She is the founder and Administrator of The Well Mill, P.C., Fort Worth TX (817/263-9197) which is not just a totally equipped physical therapy clinic including indoor swimming pool for water therapy, but an entire network including In-Home Care. The Well Mill Rehab Agency accommodates new independent living programs being funded by the State under the CLASS contract. Recognizing the need for supported housing within the community of persons with brain injuries, she founded Ability Resources Inc. (ARI) in 1991. ARI now operates a series of personal care homes in the D/FW Metroplex area. She employs over 250 people in these various operations, some of whom are persons with brain injuries.

**JOYCE DAWIDCZYK** is Senior Disability Policy Analyst for United Cerebral Palsy of Texas, Austin TX (512/472-8696). While still an infant, she was misdiagnosed as having mental retardation. Fortunately, her caring parents sought a second opinion, and it was found that although she had a significant physical disability of cerebral palsy, she was not mentally retarded. She fought tenaciously for her right to pursue an academic regimen, and by 1980, she had earned a Bachelor's and Master's degree in Social Work. Since that time, she has been an advocate and activist for the disability rights movement, and has worked tirelessly, both professionally and personally, to improve the lives of people with disabilities, particularly in the development of innovative community-based alternatives to the institutional system that many times entraps individuals. Recently, she has focused much of her energy on changing state policy to prevent the institutionalization of children with disabilities in nursing homes.

THE THIA ADVOCACY COMMITTEE  
- As Of November 30, 1994 -

**DIANA WEBSTER - Chairperson**  
1507-A Braes Ridge Dr  
Austin TX 78723  
(512/452-2293)

Diana is a survivor and active advocate. She sustained a brain injury on March 16, 1983, and doesn't mind saying she's had a long hard haul back up the hill since then. She's been very, very busy as an advocate and activist. As a member of CTD and ADAPT, she has been able to travel to Washington DC and other cities and states, not to mention her home town of Austin, to rally and testify before every VIP or legislator who would sit still, about issues such as transportation, accessibility, housing, ADA and other laws, Healthcare Reform, and human rights in general! She is active with the Austin Chapter-THIA and is a contributing writer for its newsletter. She has been a member of the Texas Survivors' Council for several years, and was just elected Vice President 1995. She was an original member/graduate of the Committee on Advocacy and Empowerment, now known as the THIA Advocacy Committee, and took the Chair upon the resignation of the previous chair (Ranee Dewey) in late August. Diana says: "Everyone who's attending this Housing Workshop should realize that affordable, accessible housing is one of the most important issues in Texas, and everyone needs to go home with what they've learned this weekend and work to get some options going, or help somebody else, please!"

**BRUCE RAUSS - Workshop Registrar**  
2821 Trinity Oaks Dr #352  
Arlington TX 76006  
(817/460-5750)

Bruce is a survivor and an active advocate. He sustained a brain injury in 1989 as the result of a 12-foot fall, and has a parent with an acquired brain injury. He's been Co-President of the Arlington/Mid-Cities Chapter-THIA since 1983 and is Chair of the Chapters' Assembly (an organization of the Presidents of all THIA local Chapters around the State), thus was a 1994 member of the THIA Board of Directors. He has been an active working member of numerous other THIA Committees as well. Bruce was recently elected to a 3-year term on the THIA Board beginning 1995, and was nominated by several different THIA members as a candidate for President & Chair of the Board of THIA (the officers' election outcome will be announced December 8). He has been a member of this Advocacy Committee since January 1994, and was instrumental in the development and fruition of this Housing Workshop.

**BEN ALMOND**  
2509 Dell Street  
Fort Worth TX 76111  
(817/831-6278)

[Ben's bio sketch can be found on Speakers' listing.]  
He was an original member/graduate of the Committee on Advocacy and Empowerment, now this THIA Advocacy Committee; he was also instrumental in the fruition of this Workshop.

**RICHARD SANCHEZ**

424 Lafayette  
El Paso TX 79915  
(915/595-1362)

Richard is a survivor and an active advocate. He is an accomplished pilot, and an officer of his local PTA and Lions Club. He was an original member/graduate of the Committee on Advocacy and Empowerment, now this Advocacy Committee, and was co-chair in 1993 with Rita Webster (who resigned). He is a member of the THIA Board of Directors, is its Minority Issues Liaison, and represents the El Paso Chapter-THIA on the Texas Survivors Council as Treasurer and Parliamentarian.

**BELINDA CARLTON**

Coalition of Texans with Disabilities  
316 W 12th St Ste 406  
Austin TX 78701  
(512/478-3366)

Belinda's a family member; bio sketch is on Speakers' list.

**SUE HOLLOWAY**

13588 FM 3271  
Tyler TX 75704  
(903/592-0699)

Sue is a family member and active advocate. She is the President of the East Texas Head Injury Association-THIA, which covers an extremely large area of East Texas, and has several support groups. She's a Counselor with TRC at Tyler. She is a member of the THIA Board of Directors, as well as a member of this Advocacy Committee.

**DARLENE PLYTER, PRESIDENT & CHAIR OF THE BOARD, THIA**

1108 Michael Sean Dr  
Bedford TX 76021  
(817/498-9108)

Darlene's a family member; bio sketch is on Speakers' list.

**TERRI PETRUCCI-COLEY, MA, CCC-SLP**

Terri's bio sketch can be found on the Speakers' list.

**LINDA J. COURTNEY, LMSW-ACP**

Linda's bio sketch can be found on the Speakers' list.

**MELANIE GALL, Consumer Advocacy Liaison -(Committee Advisor)**

Southwest Regional Brain Injury  
Rehabilitation & Prevention Center at TIRR  
4007-EE Bellaire Blvd  
Houston TX 77025  
(713/666-9550)

Melanie is a survivor and active advocate. Sustaining her brain injury as a child, she went on to receive her degree in Cognitive Psychology. She developed and coordinated the Beyond Survival: Advocacy Leadership Training for survivors and family members, which was held in January, 1993. She has worked for TIRR since 1987. She is a member of the Boards of Directors of the National Head Injury Foundation and the Texas Head Injury Association, and has served on the Boards of CTD and Houston Chapter-THIA.

**BIO INFORMATION FOR  
JONAS E. SCHWARTZ**

Jonas Schwartz is the Outreach/Advocacy Coordinator for REACH Resource Center on Independent Living in Fort Worth, Texas (817) 870-9082. Prior to this he was the Employment Specialist for REACH of Dallas Resource Center on Independent Living. During the last two years Mr. Schwartz's work in the Independent Living Movement has focused on person centered employment and being an advocate for the disability community. Currently Mr. Schwartz does Outreach to minority populations and provides technical assistance on the Americans with Disabilities Act. Mr. Schwartz holds a Bachelors Degree in Rehabilitation Services from Stephen F. Austin State University and is pursuing a Masters Degree in Rehabilitation Counseling from the University of North Texas.

Rec'd 12/1/94

## HOW TO ASSIST INDIVIDUALS WITH TRAUMATIC BRAIN INJURY TO MOVE INTO THE COMMUNITY

- \* Must be on SSI and Medicaid (they will have a Medicaid card)
- \* Establish age of person at time of injury:  
-If before age 22, then appropriate for CLASS or HCS-O  
-If after age 22, then appropriate for Nursing Facility Waiver
- \* The individual must be willing to move into the community where services are available.
- \* The advocate must push for referral into the process
- \* Get an individual family member, significant other, or friend to help push
- \* Develop a rapport with the individual. So often the person is fearful of moving into the community.

### PROGRAMS UNDER THE COMMUNITY CARE FOR THE AGED AND DISABLED DHS (512) 450-3902

#### EPSDT-CCP

TEXAS DEPARTMENT OF HUMAN SERVICES (800) 252-82 63

#### IN-HOME AND FAMILY SUPPORT SYSTEM

AUSTIN (800) 252-8263

#### PRIMARY HOME CARE

AUSTIN (512) 450-3902

#### HOME AND COMMUNITY-BASED SERVICES

AUSTIN (512) 323-3211

#### COMMUNITY LIVING ASSISTANCE AND SUPPORT SERVICES (CLASS)

AUSTIN (512) 450-3228 BARBARA STEGALL

#### HOME AND COMMUNITY-BASED SERVICES-OBRA

AUSTIN (512) 323-3211

#### NURSING FACILITY WAIVER PROGRAM

COMMUNITY CARE DIVISION, TEXAS DEPARTMENT OF HUMAN  
SERVICES, (512) 450-3195 GERADA CANTU

PROGRAMS UNDER THE COMMUNITY CARE FOR THE AGED AND DISABLED

Home Delivered Meals or Congregate Meals  
Emergency Response System  
Day Activity and Health Services  
Adult Foster Care  
Residential Care  
DHS (512) 450-3902

EPSDT-CCP

TEXAS DEPARTMENT OF HUMAN SERVICES (800) 252-8263

SHARS

AUSTIN 1-800-873-6768

IN-HOME AND FAMILY SUPPORT SYSTEM

AUSTIN (800) 252-8263

PRIMARY HOME CARE

AUSTIN (512) 450-3902

MEDICALLY DEPENDENT CHILDREN'S PROGRAM

AUSTIN (512) 450-3768

HOME AND COMMUNITY-BASED SERVICES

AUSTIN (512) 323-3211

COMMUNITY LIVING ASSISTANCE AND SUPPORT SERVICES (CLASS)

AUSTIN (512) 450-3228 BARBARA STEGALL

HOME AND COMMUNITY-BASED SERVICES-OBRA

AUSTIN (512) 323-3211

NURSING FACILITY WAIVER PROGRAM

COMMUNITY CARE DIVISION, TEXAS DEPARTMENT OF HUMAN SERVICES,  
(512) 450-3195 GERADA CANTU

# RESOURCES

## AGENCY STATE AND REGIONAL OFFICES

### Texas Department of Human Services State Office

John H. Winters Human Service Center  
701 West 51st Street  
P.O. Box 149030  
Austin, Tx. 78714-9030  
(512) 450-3011

### Regional Offices

Region 02	2109 Avenue Q P.O. Box 10528 Lubbock, TX. 79408 806/741-0541
Region 03	1200 Golden Key Circle P.O. Box 10276 El Paso, TX 79994 915/599-3742
Region 04	4380 Spindletop P. O. Box 663 Abilene, TX 79608 915/695-5750
Region 05	631-106th Street P.O. Box 5128 Arlington, TX 76011 817/640-5090
Region 06	7901 Cameron Road, #2 P.O. Box 15995 Austin, TX 78761 512/834-3458
Region 07	302 East Rieck Road Tyler, TX 75703 903/561-5359
Region 08	2520 North Closner P.O. Box 960 Edinburg, TX 78539 512/383-5344





Fort Worth Regional (Reuben Taniguchi)  
1309 Washington  
F W 76104  
817/921-0244

Region 06

Dallas Regional Office  
10935 Estate Lane, Suite 370  
Dallas, TX 75238  
214/343-0991

Arlington: (Bill Davis) 817/277-9176

Texas Department of Mental Health and Mental Retardation

Central Office 909 W. 45th Street  
Austin, TX 78751  
512/454-3761

Regional Offices

Abilene Regional MHMR Center  
2616 S. Clack, Suite 160  
Abilene, TX 79606  
915/690-5133

Deep East Texas Regional MHMR Center  
4101 S. Meford Dr.  
Lufkin, TX 75901-5699  
817/752-3451

Heart of Texas Region MHMR Center  
110 S. 12th St.  
P.O. Box 890  
Waco, TX 76703-0890  
817/752-3451

Lubbock Regional MHMR Center  
1210 Texas Ave.  
Lubbock, TX 79401-4088  
806/766-0202

MHMR Authority of Harris County  
2850 Fannin, 77002  
P.O. Box 25381  
Houston, TX 77265-5381  
713/654-7100

Pecan Valley MHMR Region  
650 W. Green, 76401  
P.O. Box 973,  
Stephenville, TX 76401  
817/965-7806

Riceland Regional Mental Health Authority  
3007 N. Richmond, 77488  
P.O. Box 869  
Wharton, TX 77488  
409/532-3098

**State of Texas Board of Nurse Examiners**

PO Box 140466  
Austin, TX. 78714  
512/835-4880

**Texas Department on Aging**

1949 S. IH 35  
Austin, TX 78745  
512/444-2727

**Texas State Commission for the Blind and Visually Impaired**

State Office 4800 N. Lamar Blvd.  
Austin, TX 78751  
512/459-2500

**Texas Commission for the Deaf and Hearing Impaired**

State Office 1524 S. IH 35, #200  
Austin, TX 78704  
512/444-3323

**Texas Planning Council for Developmental Disabilities**

4900 N. Lamar Blvd.  
Austin, TX 78751  
512/483-4099

# NATIONAL CONSUMER AND ADVOCATE ORGANIZATIONS

## Association of Retarded Citizens (ARC-US)

PO Box 1047  
Arlington, TX. 76010  
800/433-5255

## Independent Living Research Utilization (ILRU)

2323 S. Shepard Dr., Suite #1000  
Houston, TX 77019  
713/520-0232

## National Council for Independent Living (NCIL)

2111 Wilson Blvd. suite #405  
Arlington, VA. 22201  
703/525-3406 V  
703/525-3407 TDD

## United Cerebral Palsy Association

1522 K Street, N.W.  
Washington, DC 20005  
202/842-1266

## World Institute on Disability

510 16th Street  
Oakland, CA 94612  
510/763-4100

# STATE CONSUMER AND ADVOCATE ORGANIZATIONS

## Coalition of Texans with Disabilities (CTD)

316 West 12th Street, #405  
Austin, TX. 78701-1840  
512/478-3366 V/TDD  
512/478-3370 FAX

## Advocacy, Incorporated

7800 Shoal Creek Blvd., #171-E  
Austin, TX. 78757  
512/454-4816 V/TDD  
800/252-9108 Toll Free

## American Council of the Blind-Texas (ACBT)

PO Box 851274  
Mesquite, TX. 75185-1274  
214//288-7287/

## American Disabled for Attendant Programs Today (ADAPT)

1339 Lamar Square Dr., Suite B  
Austin, TX 78704  
512/442-0252

## Association of Retarded Citizens, ARC of Texas

833 Houston Street  
Austin, TX. 78756  
512/454-6694

## Disability Policy Consortium (DPC)

7800 Shoal Creek Blvd., Suite 171-E  
Austin, Tx. 78757  
512/454-4816

## Director's Association of Texas Centers for Independent Living (DATCIL)

5555 N. Lamar, Suite J-125  
Austin, TX. 78751  
512/467-0744

**Texas Association of the Mentally Ill (TEXAMI-NAMI)**

#3 Clarendon  
Austin, TX. 78746  
512/327-2501

**Texas Head Injury Association**

6633 Hwy. 290 East, Ste. 301  
Austin, TX 78723  
(512) 467-6872 • (800) 392-0040  
FAX (512) 467-9035

**Texas Mental Health Consumers (TMHC)**

PO Box 26685  
Austin, TX. 78755  
512/472-0105

**Texas Paralyzed Veterans Association (TPVA)**

805 Chelsea Blvd., Suite B  
Houston, TX. 77002  
713/520-8782

**Stroke Group of Texas**

PO Box 19506  
Houston, TX 77024  
713/465-0943

**Texas Advocates (TA)**

C/O ARC PO Box 5368  
Austin, TX. 78763-5368  
512/454-6694

**Texas Association of the Learning Disabled (TALD)**

1011 West 31st Street,  
Austin, TX. 78705  
512/458-8234

**Texas Association of the Deaf (TAD)**

1006 Minturn Lane  
Austin, TX. 78748  
512/447-9907 TDD

**Texas Polio Survivors Association**

PO Box 35688  
Houston, TX. 77235  
713/690-0695

**United Cerebral Palsy Association of Texas (UCP-TX)**

900 Congress Ave., #220  
Austin, Tx. 78701  
512/472-8696

## HINTS FOR THE DISABLED

**Dear Pat:** We need as much information as you can give us on remodeling a house to make it a wheelchair-accessible home.

Our problem? Housing. We will be moving out-of-state in the fall and will be staying with friends for a month or two until we find a home to buy. Because we both use wheelchairs, modifications in critical areas (at least one entryway, bath, kitchen/utility area and doorways) will need to be done immediately. Remodeling the house for total accessibility and comfortable living to suit our needs can come over a period of time.

I hope you will be able to supply us with information on remodeling and possibly accessible new-home construction. We do hope to build our own home and will need some guidelines.

— K.K.N., Michigan

**Dear K.K.N.:** Because so many readers request information on modification of existing homes, I'm publishing the following list of resources that are free or low-cost, as well as major reference books. You may be able to borrow some of the books from your library, Cooperative Extension Office or rehabilitation center.

— Pat

● *Designs for Independent Living*, Form No. 1B310 Rev. A., 1986, and *Tools for Independent Living*, Form No. 1B314 Rev. A., 1986. Appliance Information Service, Whirlpool Corp., Benton Harbor, Mich. 49022.

● *The DoAble, Renewable Home: Making Your Home Fit Your Needs*, Consumer Affairs Program Department, The American Association of Retired Persons (AARP), 1909 K St., N.W., Washington, D.C. 20049. *The Gadget Book: Ingenious Devices for Easier Living* is also available from AARP at the

above address. (\$10.50)

● *Housing Information Packet*. Paralyzed Veterans of America, 3636 16th St., N.W., Washington, D.C. 20010.

● *The Hartford House: How to Modify a Home to Accommodate the Needs of Disabled/Older Adults*. The Hartford House, c/o The Hartford Insurance Group, Hartford Plaza, Hartford, Conn. 06115.

● *Modest Home Makeovers: Making More of the Space You've Got*, North Central Regional Extension Publication No. 328, Iowa State University, Ames, Iowa 50011. *The House Planning Handbook*, (\$6) Midwest Plan Service, is also available from Iowa State University.

● *A Consumer's Guide to Home Adaptation*, The Adaptive Environments Center, 374 Congress St., Suite 301, Boston, Mass. 02210. (\$9.50)

● *How to Build Ramps: Reusable, Economical, & Safe*, Metropolitan Center for Independent Living Inc., 1600 University Ave. W., St. Paul, Minn. 55104-3825. (\$10)

Books include:

● *The Accessible Housing Design File*, Barrier Free environments Inc., Van Nostrand Reinhold, New York, N.Y. Paperback.

● *The Complete Guide to Barrier-Free Housing*, Betterway Publications, White Hall, Va. Paperback

● *Housing Interiors for the Disabled and Elderly*, Van Nostrand Reinhold Co., New York, N.Y.

Videos include:

● *Building and Remodeling for Accessibility*, Hometime, 4275 Norex Drive, Chaska, Minn. 55318. This 25-minute video can be ordered by calling (800) 489-9955. (\$11.95 plus \$3 shipping)

Pat Galbreath's Hints for the Disabled appears Wednesday. Send questions and comments to Pat Galbreath, Box 368, Weatherford 76086.