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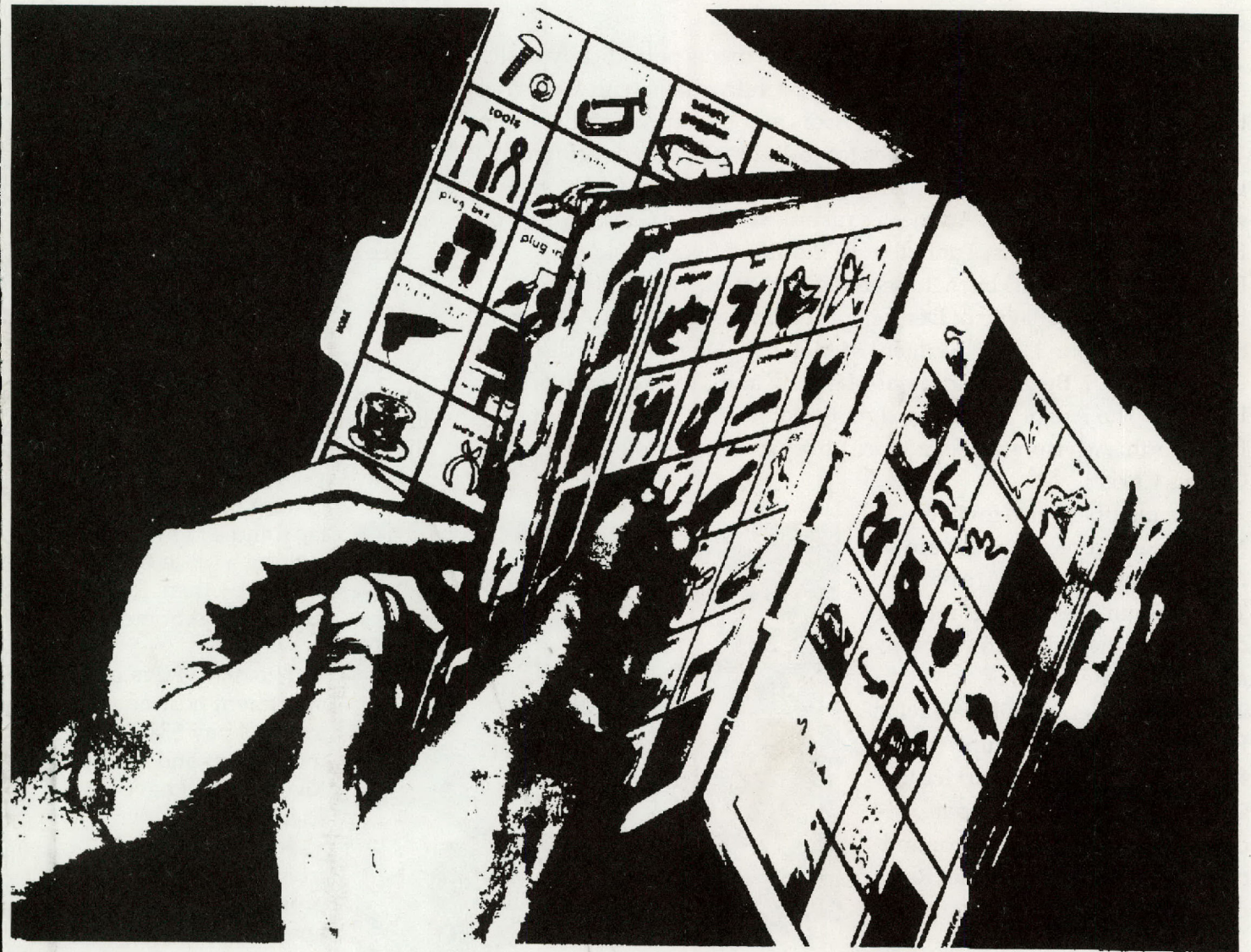
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Winter 1994

# IMPACT

of Mental Retardation Services in Texas



# QA Consumers Speak Out

We, the *Impact* staff, recently had an opportunity to sit in on a Focus meeting of the Texas Advocates' Board of Directors held January 8. Their wishes and dreams were what interested us, so we made ourselves invisible during their last meeting and listened in so we could share with you some of their thoughts.

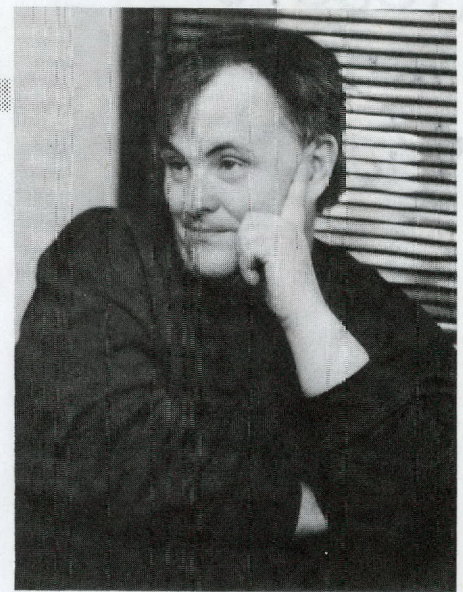
The Texas Advocates' Board of Directors meets periodically to discuss issues important to them and to other individuals with mental retardation. Except for the Board's advisors and the representative from The Arc of Texas (which advocates for individuals with developmental disabilities), the members of the Board are advocates for themselves and others. Texas Advocates members include Candi Ware of Bryan, president; Stuart Tunnell of Burkburnett, vice president; Debbie Varner of Burkburnett, secretary; Rusty Reider of Houston, treasurer; Wesley Payne of Denton, past president; and Board members at large: John Henry Neugent of Marshall, Sherry Edwards of Corpus Christi, Buster Lindsay of Marshall, and Troy Husmar of Houston. The Arc of Texas Board representative is Susan Garrett of Fort Worth. Advisors are Jean Ware of Bryan and Carroll Carlile of Corpus Christi.

The members also invited Mike Bright, director of governmental affairs for The Arc of Texas; Kevin Tracy, program coordinator for the Advocates' Board; and several members of TXMHMR's Central Office: Jaylon Fincannon, deputy commissioner for mental retardation services; Gretchen Claiborne, associate deputy commissioner for community MHMR centers, Mental Retardation Services; and Pat Loftin, director of programs.

Bright emceed the meeting and Candi Ware chaired the gathering.



Candi Ware



photos by Sherry Grona

Buster Lindsay

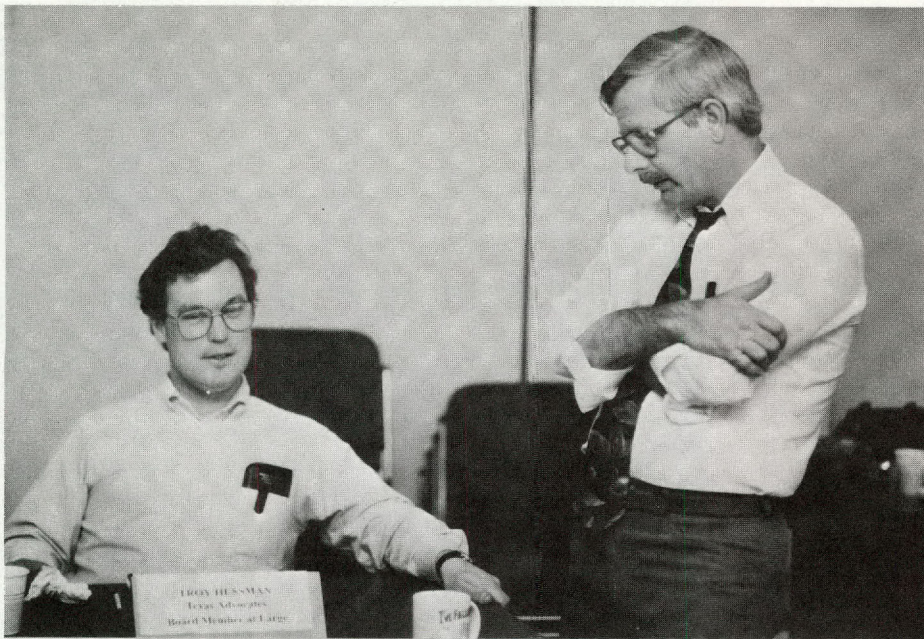
**Q:** Bright- MHMR is developing a plan to guide the agency into the year 2,000. What ought to go into that plan? For example, where would you like to be living in six years? And what do you see changing?

**A:** Varner- I'd like to be living on my own in either Austin or Wichita Falls or maybe sharing expenses with friends. I'd like to show other self-advocates that it can be done.

**Lindsay-** I'm thinking about getting married to my lady and so I might be sharing a place with my spouse by then. Right now I live at home with my family.

**Husman-** I live in an apartment now and love it. I pay \$315 a month rent and would love to stay. I have friends there.

**Reider-** Six years from now I'd consider a group home or an apartment if I had someone to assist me. I'd like to be more independent, but I'd like help, too.



*Troy Husman and Mike Bright*

**Q:** **Bright-** Most of you agree that individuals with mental retardation have dreams of living on their own or with a roommate or getting married someday. Tell us about the obstacles involved while trying to reach for these dreams.

**A:** **Payne-** Money keeps me from moving into an apartment. It costs \$300-\$400 for rent, plus utilities, groceries and more.

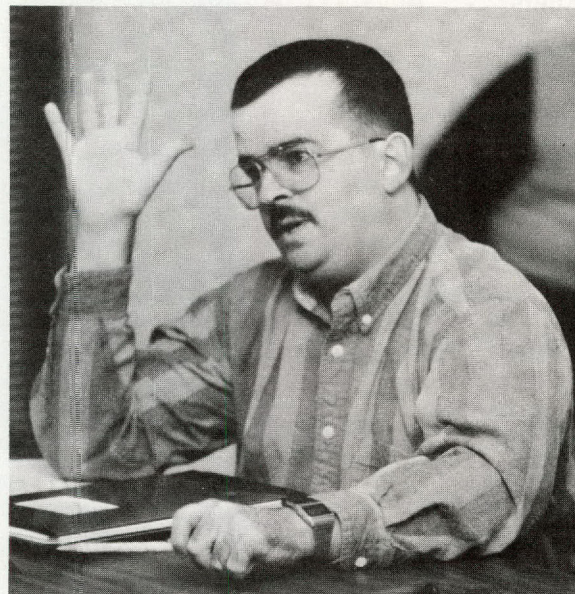
**Varner-** Transportation can be difficult when you live alone. And safety is an issue. Some people may have medical problems and may need someone to check in on them. MHMR helps with that sometimes, though.

**Tunnell-** Some people have trouble getting in and out of their apartments without assistance.

**Q:** **Bright-** Do you think if people received more services like MHMR's In-Home and Family Support they could live on their own?

**A:** **Varner-** If I could get help with my medical bills, utility bills and someone to help me with things like my checking account, it would be a big help.

Many other consumers responded "yes."



*Stuart Tunnell*

**Q:** **Fincannon-** What about Social Security? If you start working or want to work more hours than you currently do, is that a problem?

**A:** **Lindsay-** Yes. When we're on the job, the government says we have to put half of SSI into the apartment [costs]. If we start making more money, they send us less and then we can't afford the apartment.

**Bright-** There might be other problems associated with SSI, too. For example, I know someone who couldn't afford to get a job because she would lose her medical insurance [attached to Social Security].

**Fincannon-** And what about people who want to get married? Or, e might lose Social Security if he or she gets married.

**Tunnell-** I know a couple in Wichita Falls who were advised not to get married because they'd lose their Social Security.

# QA

"I'd like to be living on my own in either Austin or Wichita Falls or maybe sharing expenses with friends. I'd like to show other self-advocates that it can be done."

—Debbie Varner

## Applying the MHMR Vision to the Thoughts of the Advocates' Board

*Impact* Asks Jaylon Fincannon

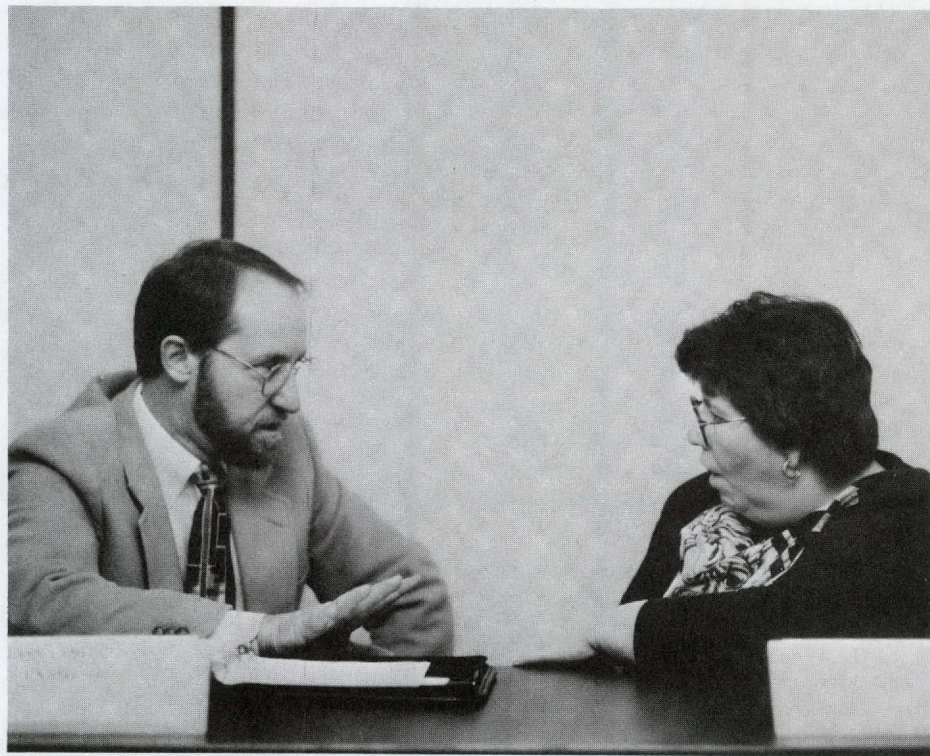
**Q:** How have mental retardation services been provided in the past and what can we look forward to in the future?

**A:** In the past, the majority of services were in facilities. This meant few choices for consumers. In recent years, consumers have seen increased services in a community-based system. Individuals are beginning to let the community centers and facilities know what their needs are and our job at Central Office is to support the community centers and the facilities. We've been evolving into a person-first system. With services like In-Home and Family Support, for example, consumers choose what assistance they need.

**Q:** In all, then, these changes are meant to improve the quality of life for consumers?

**A:** Yes. We must respect each person individually and strive to support his or her goals and dreams. It's all within our grasp.

*Jaylon Fincannon is the deputy commissioner for mental retardation services for TXMHMR. Here, he answers some general questions for Impact about how the MHMR vision reflects the wishes of consumers. Fincannon also attended the January focus group.*



*Jaylon Fincannon and Debbie Varner, member of the Texas Advocates' Board, discuss job issues during a break in a Texas Advocates meeting.*

# Self-Advocates: More Involved and More Informed

**C**ynthia Rico is a self-advocate. In her words, a self-advocate means reaching out to the community, attending conventions and speaking out for herself and others with mental disabilities.

As a former board member of MARC (Midland Association for Retarded Citizens) and current president of the Midland chapter of Texas Advocates, she assists other individuals with mental retardation to attain greater independence. She also hopes to educate the general public about the possibilities for increasingly independent lives for people who have mental disabilities. Rico does this by speaking to audiences like the Lions Club, Women's groups, etc., and also by example.

As a Farabee Conference participant in November, Rico took in five sessions, including one on advocate training. She returned to Midland and spoke to the local self-advocates about her new information.

"I try to get people more involved and more informed," she explains. "Together we organize fundraisers and other events" to subsidize the organization and arrange speaking engagements.

Recently, Rico gave up her board post at MARC to become an employee of the same organization. She is a receptionist and has general office duties. After hours, she likes to spend time with her fiancé. She also enjoys crafts and going to movies.

Rico wishes for a happy marriage, "a big house . . . two children . . . and staying with him forever—we have a good relationship." She also looks forward to continued success at work and maintaining her independence. Rico lived with her parents, then was a resident of a group home, and now lives in and receives assistance from MARC's Apartment Living Program.

For others with mental disabilities, she "would like to see more people involved out in the community and living in their own apartments."

Across the state approximately 70 advocacy groups rally on behalf of individuals with developmental disabilities. Self-advocates may belong to these groups or advocate on their own. And their numbers are increasing.

## What is Mental Retardation?

TXMHMR serves individuals with mental retardation and certain related conditions such as autism. The agency also serves children eligible for Early Childhood Intervention services and individuals in nursing homes eligible for services under the 1987 Omnibus Budget Reconciliation Act.

Mental retardation is legally defined in Texas as a condition that appears before age 18 in which intelligence is significantly below average (roughly, an IQ of 70 or below), and personal care and social behaviors do not meet what is expected for the person's age and culture.

The condition can be found in men and women of all ages, races, cultures and economic conditions.

Mental retardation differs from mental illness in that it is always associated with limited intellectual capacity, is apparent before age 18 and is typically a permanent condition. Mental illness and mental retardation can occur in the same person.

# Our Consumers, Their

## Levels of Mental Retardation

The four levels of mental retardation—**mild, moderate, severe and profound**—are based on both intellectual and social criteria. The level of mental retardation is the main factor that determines the degree of outside assistance that the person with mental retardation needs to live a comfortable, productive life.

- Persons with **mild** mental retardation can often merge into competitive labor and daily community life with minimal assistance.
- Persons with **moderate** mental retardation may need more training and support in order to live successfully in the community.
- Individuals who have a **severe or profound** level of mental retardation frequently have disabilities in addition to mental retardation. They

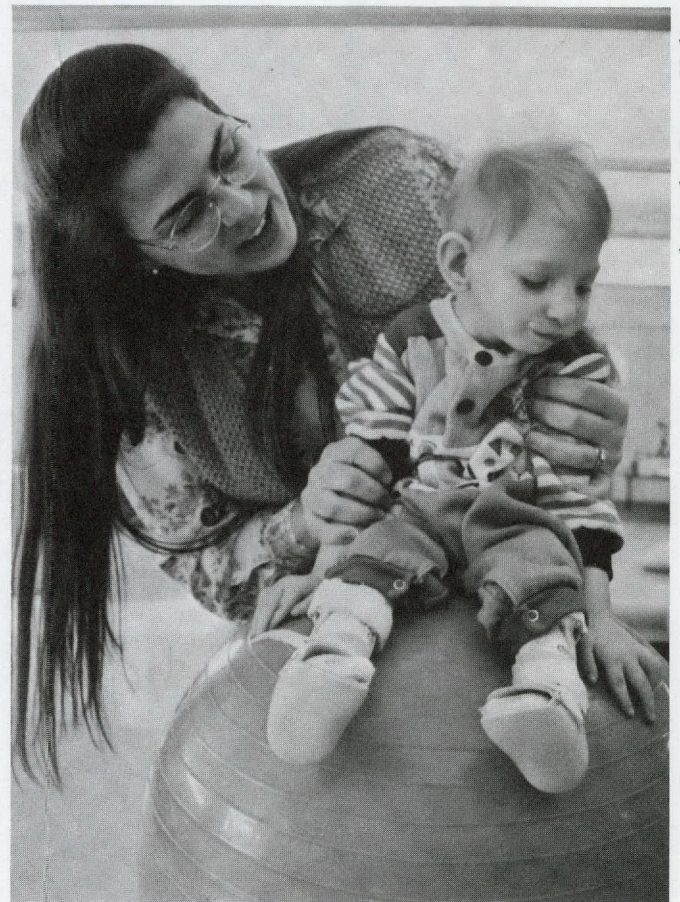
*Therapist Tammy Kimmellnen with the Starbright program out of Brackenridge Hospital assists Blake Simmons, a consumer of services from the P.R.I.D.E. program from Marble Falls.*

need more assistance than persons with mild or moderate mental retardation, such as basic physical care or supervision for survival.

## Causes of Mental Retardation

**Genetic irregularities:** An example is Down syndrome, a chromosomal abnormality which occurs in about one of every 60 births.

**Environmental factors:** malnutrition, poor health habits and/or inadequate medical care.



photos by Bruce Holter

# Needs, Our Services

**Problems during pregnancy:** drug or alcohol abuse by the pregnant mother, inadequate prenatal care and/or maternal illnesses. There is a growing rate of mental retardation due to fetal alcohol syndrome (FAS).

**Problems at birth:** premature birth and/or low birth weight.

**Problems after birth:** childhood diseases such as whooping cough, chicken pox and measles; accidents such as a blow to the head.

## Priority Populations

About three of every 100 Texans has mental retardation. Of that group, about one of every

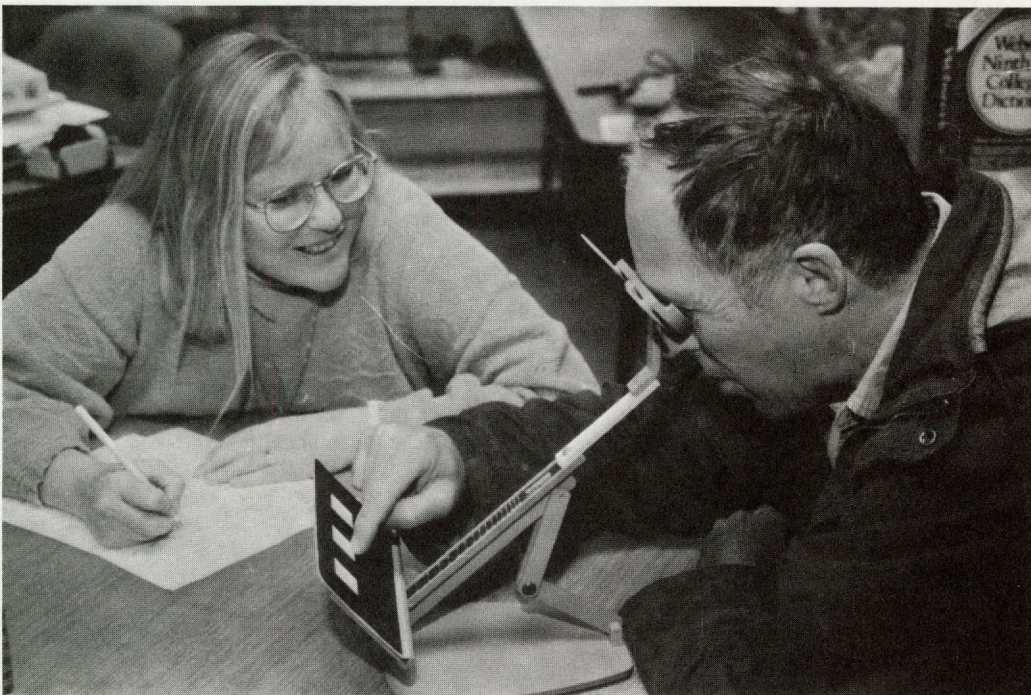
seven individuals with mental retardation qualify for services with the MHMR system. This group is considered the department's priority population, those most in need. Unfortunately, because of budget restraints, only about half of those people in need actually received services.

Close to 8,900 individuals are on waiting lists for TXMHMR services.

The department's core services are provided to the priority population. This group can also be viewed as only those whose needs for services can be most appropriately met through programs offered by

TXMHMR rather than some other service system. This population consists of:

- Persons with mental retardation who are most in need, including those with severe health needs or physical impairments;
- Persons with mental retardation with severe behavior problems;
- Persons with severe or profound levels of retardation;
- Persons with mild and moderate levels of mental retardation who need vocational and independent skills training; and
- Persons with mental retardation who are criminal offenders.



*Bobby Boscamp takes a visual screening test at Travis State School with the assistance of Therapist Kathryn Fletcher.*

## Core Services:

### What They Are and Who Is Served

The following core services are required by TXMHMR to be available across the state.

**Information, screening and referral** (or continuity of care) includes gathering information about and providing information to the individual and identifying his or her service needs and available services.

**Eligibility determination and initial enrollment assessment** (or diagnoses and evaluations) includes determining the initial level of services needed and making referrals to other service providers.

**Case management** is a system in which a single accountable staff person performs activities in the service of an individual.

**Respite care** is any service or program that provides care for a person with a disability while the primary care giver is engaged in some other activity. Campus-based respite care involves temporary residential placement at a state school or center. Community-based respite

care involves introducing respite staff temporarily into the usual living situation, providing a place for the individual to go during the day or other services considered to provide a respite.

**Family training and support** is provided for primary care givers when an individual lives in his or her family home.

### Just the Facts:

Almost 41,000 individuals in the priority population received services from MHMR.

About 35,545 individuals received community services that stemmed from either Community MHMR Centers or state facilities.

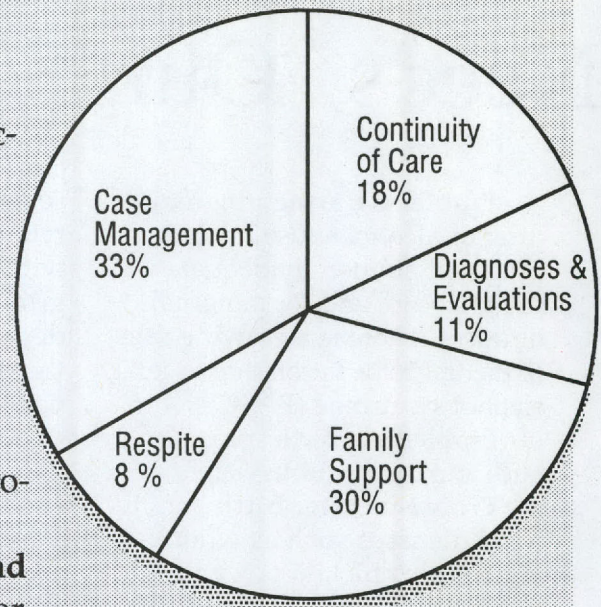
State school and state center campuses served 7,072 individuals on campus.

### The Budget

The total TXMHMR budget for FY 93 was approximately \$1.2 billion, primarily from state general revenue.

This includes

- \$546 million total for mental retardation services
- \$236 million of that amount was allocated to community-based services
- \$310 million of the original figure funded campus-based services.



Core Services Expenditures for FY 93

### Trends in Funding

Increasingly, funds are moving to community-based programs. Services provided in the community typically cost less than the \$126 average expense per day for care of an individual in a state school.

### In Comparison

Currently, Texas ranks 11th for numbers of individuals who reside in state facilities serving persons with mental retardation.

At FY 93 levels, Texas ranks 37th among the states in funding for mental retardation services. If mental retardation expenditures were to double, Texas would rank 8th among the states in terms of this fiscal effort.

*Contributed by John McLane, information specialist for the Community Relations Office at Central Office.*



# Gifts & Donations Enhance Lives

**D**onations of time, goods and funds enable the MHMR system to provide services far beyond what could be done with general revenue and federal funds alone. In FY 92, about 4,525 people volunteered their time at state schools. Together, they worked about 263,565 hours to enhance consumers' lives. Volunteers at state centers and community MHMR centers added greatly to those numbers.

Cash contributions to state schools in the same year totaled \$838,893. Donations of goods and services to the schools had

a value of over \$3 million dollars. Many more thousands of dollars in cash and other contributions came to the five state centers and 33 community MHMR centers.



photo by Carla Prell

*Volunteer Helga Gongaware's gift of time brings friendship and learning experiences into the lives of Julia Martinez and her housemates at Lubbock State School. See related story, page 19.*

## **Donors Contribute to Quality of Life**

Whatever they give, donors improve the quality of life of individuals with mental retardation across the state. Individuals served by Nueces County MHMR Community Center soon will reap benefits of a Coastal Bend Community Foundation grant designed to involve them in community recreation.

In El Paso, 300 vocational trainees work comfortably on adjustable, cushioned stools donated to Life Management Center's Task Masters program by Johnson Medical. The division of Johnson & Johnson also donated a forklift and so much office furniture that Task Masters was able to share items with other areas of the Center.

Retired Dallas County MHMR Center employee Mary Jo Herndon volunteers her time to continue a program she initiated while employed there: training law enforcement staff in dealing with individuals with mental retardation and autism. She also volunteers on the Human Rights Committee at Fort Worth State School.

## **Radio Station Makes Dreams Come True**

During the past 14 years, Christmas has come in the unlikely form of Dallas radio station KRLD and its listeners. KRLD has ensured that each person served by Denton and Fort Worth State Schools receives two gifts he or she wants.

Sometimes the requests have been small, such as a case of diet cola, and sometimes they have been large, such as a million dollars! No matter how great or small the wishes, in some unique way KRLD and its listeners have tried to make them come true. Each year, the gifts and cash have been valued at over \$100,000.

But KRLD has given an even greater gift through its broadcasts. The station has dispelled myths about mental retardation while sending the message that people with mental retardation are individuals striving to achieve their full potential.

# Homes, Support & Choices

photo by Sherry Grona



Ora Jean Ivory works on a quilt in an apartment she shares with a friend in Austin.

**H**ome is where you relax with your cat in your lap, watch a football game, eat many of your meals. Home is where you entertain friends. Home is your personal hideaway from the world. We all crave our own piece of the world, and individuals with developmental disabilities are finding more choices available to them for the homes they need.

TXMHMR assists with housing options and housing support for many individuals with mental retardation in the priority population. Housing options range from living in one's own home to apartment living to group home living to campus-style living. Housing support includes funds for home repairs, assistance with rent, medical services, case management, learning habilitation skills and more.

## In-Home and Family Support

An innovative choice for consumers which assists them in living independently is In-Home and Family Support (IHFS). Approximately 6,000 people in Texas with mental disabilities have selected this service to address their specific needs. The program is not an entitlement and funds are limited to up to \$3,600 per year for eligible families. IHFS is unique because consumers decide how the money will be spent.

Some families or individuals remodel parts of their homes for wheelchair access or to accommodate other special physical needs. Some choose specialized beds or therapeutic equipment and some may use the funds for respite or everyday necessities that relate to their disability.

The Murrillo family of Dell City is appreciative of the grant's assistance. Graciella Murrillo, an adult, receives mental retardation services from TXMHMR and the El Paso State Center, including In-Home and Family Support. IHFS enables her to live at home with her family. Funds from IHFS assisted her family in remodeling a bathroom so

access is possible while she is in her wheelchair. Also, the bathroom is now equipped with a hydraulic lift funded by IHFS that assists Murrillo's mother, Celia, in lifting her daughter in and out of the bathtub. Graciella Murrillo also received funds for a new wheelchair and other items from IHFS.

"Life has become easier and my back hurts less," says Celia Murrillo. "The tub and lift has been a big help for us."

IHFS is a type of service model emerging across the nation. The focus of the program is to empower the consumer while professionals involved in the program serve to guide, not decide.

## HCS: Different Flavors of Housing

"It's like choosing different flavors of ice cream," says Larry North, HCS deputy director of Consumer Service, about the HCS program. HCS, or Home and Community-Based Services, presents persons with mental retardation services with an array of supportive services from which to choose.

HCS supports individuals with mental retardation residing

in their families' homes, their own homes or living in a residence which accommodates three or fewer persons with mental retardation who decide to live together. Individuals receiving HCS must be Medicaid eligible.

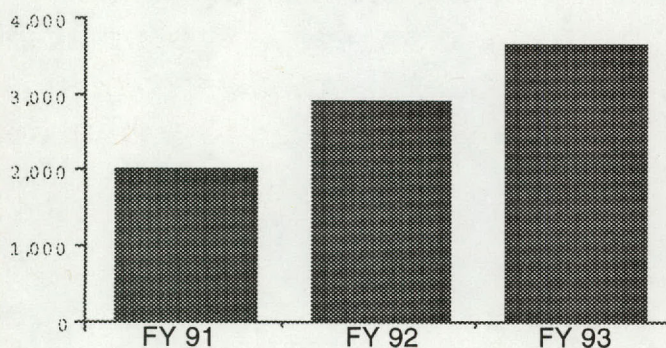
The needs of the persons are the focus of the HCS Program. HCS may include community living skills such as shopping, learning about community resources, and understanding how to use the public transportation system, just to name a few.

A key to the success of HCS is variety. Some individuals reside with their families and HCS provides the extra supports they need to continue to remain there. Others choose a residence with two or fewer roommates. Often the roommates are also individuals receiving services from HCS.

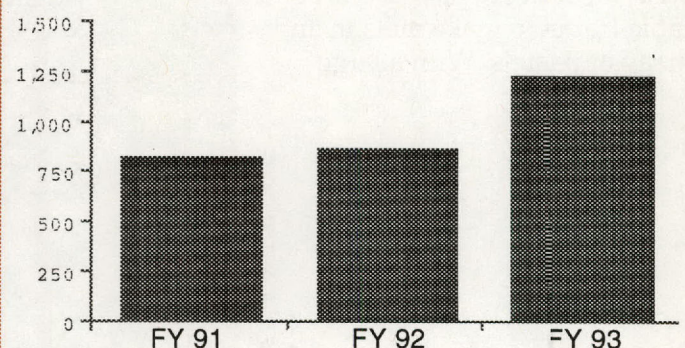
HCS programs are available in most parts of the state. HCS program providers recognize the need for housing in the community for persons with mental retardation as essential to providing an opportunity towards independence.

*Below, the charts for In-Home and Family Support and the Home and Community-Based Services program both show an increase each year in consumers assisted by their programs.*

### In-Home and Family Support



### HCS Program



## Group Homes: Robinson Is Home at Last

To some, Alton Robinson might seem an unlikely candidate for community placement. A resident of state schools since 1921, he did not move to his group home in San Angelo until April of 1993. At the age of 83, Robinson is also the Bethphage home's oldest resident.

Robinson owes his successful placement to the Bethphage staff's understanding of each individual's needs. Tubing crisscrosses the living room ceiling so one resident on oxygen can sit comfortably with his housemates. An automated chair purchased at a garage sale enables Robinson to rise easily to a standing position. Such efforts have not gone unnoticed: As Robinson says, "people like me here."

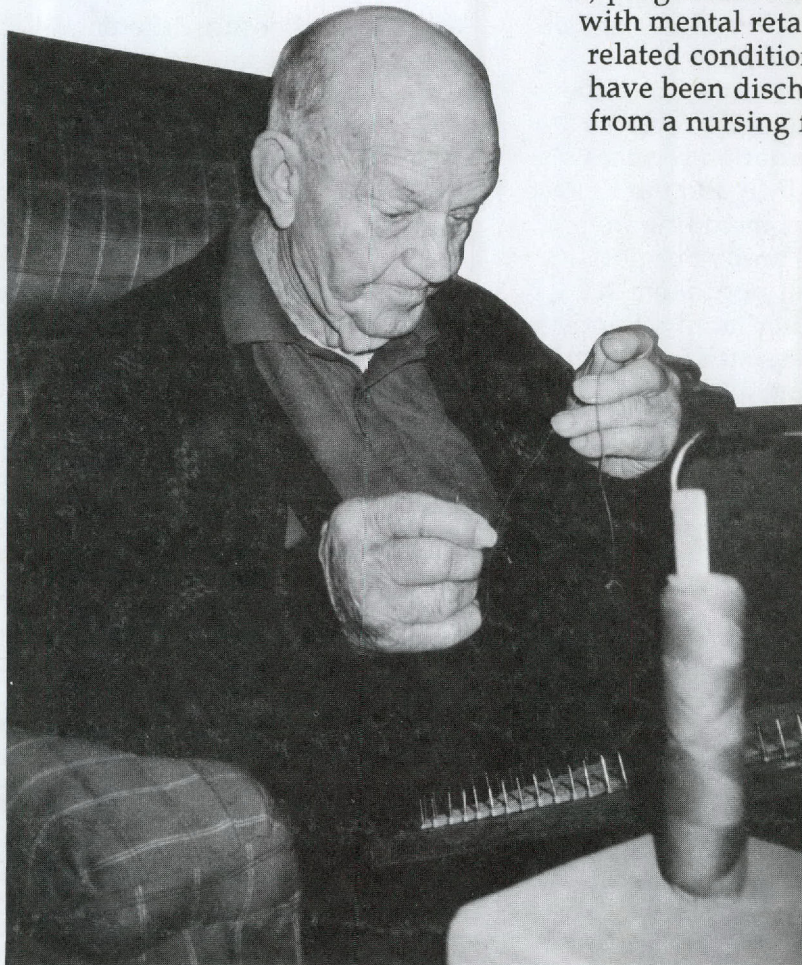
Residents like Robinson make the San Angelo house a home. A small bell reflects the bond that exists between Robinson and his roommate. Nonverbal and subject to seizures, Robinson's roommate depends upon Robinson to ring for staff.

Well past retirement age, Robinson chooses to work part-time in an MHMR workshop. However, his most colorful contributions to his home are his weavings. Every day he sits at his table frame to make mats in an array of pastels. With a large

needle, he knots small squares of thread together into a delicate web, each mat taking approximately a week to complete. The mats are gifts for the Bethphage staff or, according to Robinson, anyone who might like one.

*Contributed by Karen Roop, program specialist for the Lelsz Office in Central Office.*

Residents like  
Alton Robinson  
make the San Angelo  
house a home.



*photos by Karen Roop*

## OBRA, HCS-O Options

TXMHMR offers OBRA services to persons with mental retardation and/or related conditions who reside in nursing facilities. These services may include specialized services for habilitation of the individual and/or case management to locate an alternate placement to live in the community rather than the nursing facility. Persons who have been in the nursing facility less than 30 continuous months require alternate placement. Individuals who have been in the nursing facility more than 30 continuous months may choose to remain in the nursing facility and receive specialized services or seek alternate placement.

The Home and Community-Based Services-OBRA (HCS-O) program serves persons with mental retardation or related conditions who have been discharged from a nursing facility.

The HCS-O program facilitates these individuals returning to their families' homes or moving into the community by providing services to meet each person's needs.

Community living has garnered increasing acceptance as a preferred home by consumers, their families, and by members of the professional community.



## State Schools

State schools in Texas provide a variety of housing options in a campus setting. Campuses offer some or all of the following: apartment style living, dormitory style living or cottage living quarters. Bedrooms on any of the 13 state school campuses accommodate from one to four people. Approximately 6,250 individuals reside in state schools.

Individuals residing in state schools also receive services and opportunities like case management, various types of therapy, job opportunities, skills training and more.

Even so, community living has garnered increasing acceptance as a preferred home by consumers, their families and friends, and by members of the professional community. Therefore, TXMHMR has assisted individuals residing in state schools to move into the community when they choose and the appropriate resources

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*Former state school resident Alton Robinson weaves mats out of multicolored thread at the Bethphage home in San Angelo. Robinson gives his creations away to friends.*

are in place in the community. The department's goal is to place 300 individuals per year in the community. Since August 7, 1991, 660 individuals from Texas state schools have moved into community homes.

Each year, a team representing the consumer collectively decides if community living is recommended for the individual. The team consists of the consumer's mental disability professionals, family members and also, when possible, the consumer. Currently, 1,400 consumers have been recommended for community placement.

## Private Providers

The department's relationship with private providers is a continually evolving partnership. Private providers offer a wide range of living options like apartment living, group home living and campus living.

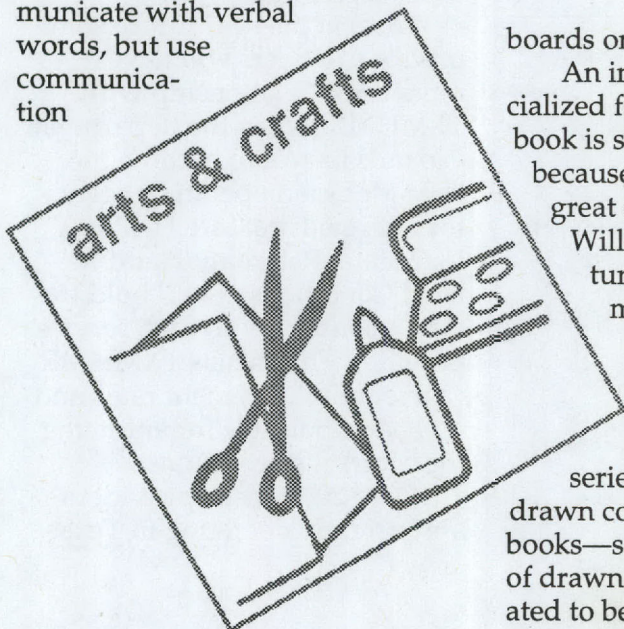
Individuals served by private providers may be a part of TXMHMR's priority population and receive services from private providers who contract with TXMHMR.

Also, in the near future some private providers will have a more direct relationship with TXMHMR. When the department expands its role to become the state Medicaid operating agency for Intermediate Care Facilities for Mental Retardation and Related Conditions, it will hold the state's contract with each service provider. This means TXMHMR will set reimbursement rates and will be responsible for enforcing the contract's provisions.

Over 200 private providers are currently operating in Texas.

# Innovations

**I**nventions of ways to communicate are among many innovations celebrated at TXMHMR. Although most of us communicate verbally with words and gestures, we all have individual mannerisms of getting our ideas across. We may use flamboyant gestures to go with our words, for example. Also, some of us may communicate in a more nonverbal way—body language, sign, etc. If asked what our favorite color is, we might think of a light, medium or dark shade and say “blue.” Some individuals like Jessie Willeford, a resident of Austin State School whose cerebral palsy prevents him from being able to speak or use his hands well enough to sign, point to a specific idea in a picture book when asked a question. Willeford is one of many individuals with disabilities who do not communicate with verbal words, but use communication



photos by Sherry Crona

*Jessie Willeford, left, communicates with Kim Milstead-Ingram, a speech and language pathologist at Austin State School, through his communication book. See a close-up of one drawing used in a communication book below.*

boards or books to assist them. An individual's book is specialized for his needs. Willeford's book is stuffed full of pictures because he communicates a great deal. Sometimes Willeford likes to add pictures to his book and he'll make a rough drawing that gets the idea across to a staff member. Often, his idea will be found in one of several series of professionally drawn communication picture books—sort of a staff data bank of drawn ideas specifically created to be photocopied as addi-

tions to picture books. These professionally drawn pictures are easier for most people to understand, so the staff will copy the drawing and add it to Willeford's personal cumulation of pictures.

Kim Milstead-Ingram, a speech and language pathologist at Austin State School, says the books are actually more complex and more versatile than they seem. Sentences can be created with pictures, for example. Also, their uses can be widespread. Hospitals, for example, may use picture books or boards for patients recovering from injuries or surgery that hamper their speech.

## Rehabilitating Juvenile Offenders: Society's Challenge

Reforming juvenile offenders with developmental disabilities has always been a challenge. Other problems with these special youths may include lack of self-esteem, emotional problems, inappropriate sexual behavior, and no household living skills.

After serving this population with little tangible success, the Fort Worth State School Community Services staff piloted a program in 1990. Replicating the Teaching-Family model which began at the University of Kansas, it offered teenagers structure, a reward and consequence system, and the much-needed stability of family teachers who serve as the equivalent of houseparents. The results: unparalleled success.

Boys between the ages of 10 and 17 who had been in trouble with the law for offenses ranging from running away to assault have improved their lives with the new program. Fueled by its

own steam of achievement and recognized with the 1993 Helen Farabee Showcase Award, the FWSS program expanded from one to three community group homes which are now home to 11 boys. In early 1994, Tarrant County Mental Health and Mental Retardation Services assumed the administration of the program as it absorbed the FWSS Community Services Division.

The program offers youths real homes, where they usually have a room of their own and family teachers that model family relationships. Learning social skills, negotiation, household chores and other behaviors are emphasized with positive reinforcement. This is a dynamic contrast to the institutional settings of the past.

Prior to using the Teaching-Family model, aggression both against staff and other youths was high. Vandalism was a problem also. Although it's not been

easy, those types of incidents generally have become problems of the past. The program is rewarding, not punishing. Most of the youths served by the program dream of getting a job and some day having their own respected place in the community.

*Contributed by Denise Casamento, public information officer for Fort Worth State School.*

### TATP Provides Information About Assistive Technology Devices

Information is available to individuals needing to ask questions about assistive technology devices. An assistance technology device is any item, piece of equipment or product system acquired commercially, that is used to increase, maintain or improve functional capabilities of individuals with disabilities. The Texas Assistive Technology Partnership project was recently awarded to the University Affiliated Program at The University of Texas at Austin.

The TATP participates statewide in disability-related activities to provide public awareness to ensure that all Texans have easy access to information about assistive technology devices and services. One of the TATP's activities has been development of a statewide information and referral program in which individuals can call 1-800-TATP-TEX about 17,000 different assistive technology devices. A resource guide and directory to vendors and providers of the devices and services is available at nominal cost by calling the 800-number.

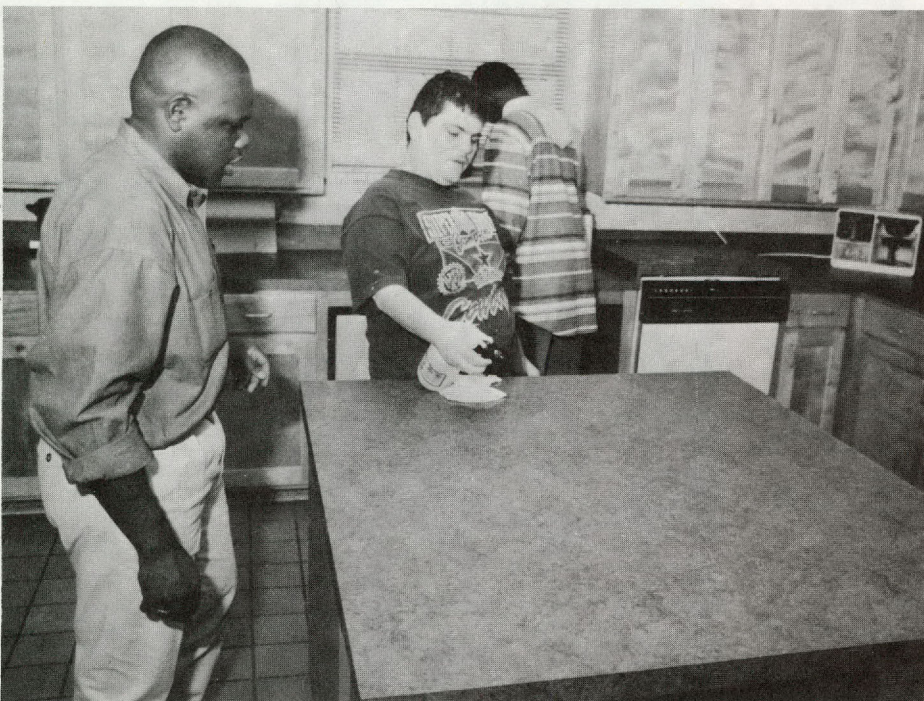


photo by Chet Tackett

*Cecil Bailey, back, and Rodney Vinson, middle, learn how to take care of their home. Their instructor, Billy Thomas, an associate of the Family Teacher Association, shows them how to keep the kitchen area clean.*

## Trykes for Tykes

Remember tricycles? The wind in your face as you pedaled and sped down the sidewalk?

Many kids, including some who are served by MHMR's mental retardation services, don't know the tricycle experience because their arms and legs don't move as well as ours did. Sue Haywood, a physical therapist for the ECI program which contracts with the Sabine Valley Center for MHMR, envisioned a tricycle any kid could ride. With ideas in tow, Haywood met with fellow representatives of a local business club and challenged them to build a special tricycle. The AMBUCS are a national association of American Business Clubs. They did meet the challenge and the Amtryke was invented.

The Amtryke is a modified tricycle that can be propelled by either a child's arms or legs. While they're riding like we did, the Amtryke pedalers are also exercising underdeveloped limbs. Amtrykes are fitted and constructed for

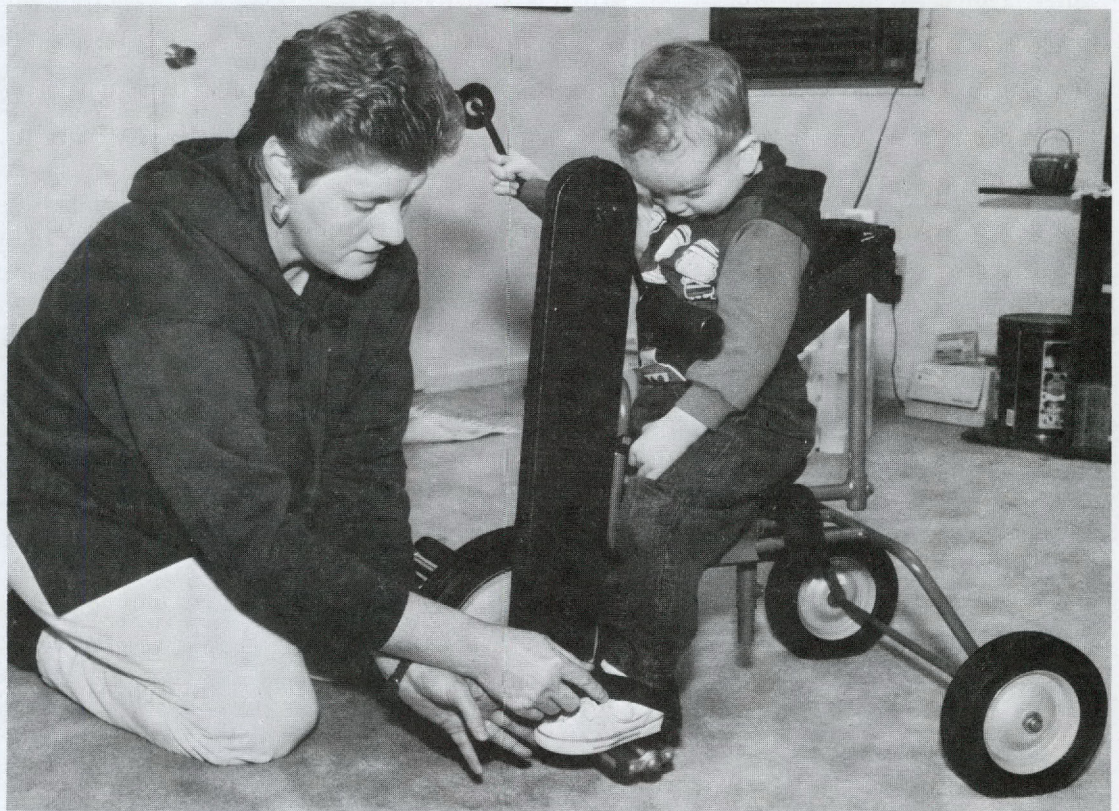
individual kids. Adjustments are made to fit their weight, height and reach.

"We've had so many kids benefit from the Amtryke," says Haywood. "Regular tricycles are often too small for the kids we assist here and they usually don't have the coordination or physical ability to ride a two-wheeler. With the Amtryke, their total coordination can be improved. The fact that they can pedal with their hands and feet is unique for most therapeutic tricycles. Most other tricycles built for children with disabilities only allow pedaling with the hands and there's no therapeutic effect for the legs."

Children with mental disabilities and physical disabilities have received Amtrykes across

the state and country. Although the program was seeded by Haywood, the children's needs at the Sabine Valley Center for MHMR, and the local AMBUCS, Haywood says nearly all the Amtrykes are bought by charitable organizations and donated to children with disabilities across the state and beyond.

The group's collective goals include aiding individuals with functional disabilities. The AMBUCS also support the careers of physical therapists through scholarships and awards. Haywood was a recent recipient of their Therapist of the Year Award, mainly for her ideas on the Amtryke. For more information on the Amtryke, call Amtryke Inc. at 903-759-0758.



*Robert "R.G." Gray III rides the Amtryke toward Sue Haywood, a physical therapist for the ECI program which contracts with the Sabine Valley Center for MHMR. The Tryke assists R.G. with muscle coordination and strength.*



photo by Christopher O. Pearce



## Future Needs

I was having lunch at Wendy's several months ago and observed some teenaged boys teasing a young woman while she was working. She ignored them, cleaning tables and discarding trash until one finally asked, "What's wrong with you?" Her reply, "Nothing. I'm mentally retarded."

As I watched, I remember thinking how matter of factly she responded. She also responded with great dignity. I was encouraged by my unexpected encounter. Yet, I was discouraged, because she had to explain herself with a label rather than being accepted like anyone else doing a job.

Labeling has become a way of life for people served in the public sector. It is unfortunate that helping people requires determining eligibility. And eligibility forces labeling people to show what services can be received.

Inadvertently, eligibility labeling has hampered efforts to integrate people with disabilities into the mainstream of community life. It is especially true when funding streams become attached to labels.

Many times consumers receive services which seem disconnected because the funding sources are different. Some consumers receive more services than they need or want because the funding source stipulates a certain set of services. At times, consumers who would benefit from a single service can't receive it because of ineligibility for an entire package. Confusing? You can imagine how consumers and families feel.

Sometimes our services seem like individual strands of thread. Alone they have limited functions. But when woven together they produce magnificent tapestry pictures. Our goal is to find ways to personalize services so that individual strands of funding simply become part of a person's support system.

One of TXMHMR's challenges over the next few years will be to remove labels and their funding barriers. Our goal for people with mental retardation is to be so well integrated into the community that where they work or live is not an issue. And where they go for services are the same places that unlabeled, ordinary people do.

*\*Permission is needed to reproduce this poem.*

Sometimes i think that  
the only way to really be someone  
is to be  
no one  
at all  
because someones can be labeled  
they "have" or they "are"  
whereas no ones aren't shadowed  
by having or being  
and nobody knows  
what the no ones are seeing.

naomi shihab nye\*

To accomplish this shift of focus from segregated public to integrated community services will require creative new partnerships with businesses and civic groups. Historically, the perception has been that mental retardation is the problem of federal and state government. For permanent change to occur, communities need to understand that

mental retardation is also their issue.

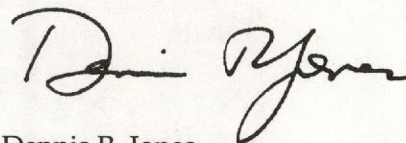
Part of the strength of community programs is local boards of trustees because they have a better sense of ownership of community issues. It is critical for MHMR to turn the corner that says "this community has a responsibility." Communities need to provide opportunities for all their citizens regardless of their abilities or disabilities.

The best champions for people with developmental disabilities are people with developmental disabilities. Given an opportunity, they demonstrate what they can do. They have been pioneers in the true sense, for they risk the pain of nonacceptance and harassment. They tell me it's worth it.

But they need a chance and they need services which support and integrate rather than label and isolate.

Society's values are changing. I think about the TV program "Life Goes On" and realize how impossible that program would have been 25 years ago when I first started in this field. I remember when I would have been surprised to see a young woman with mental retardation working at a fast food restaurant.

As we enter the next century, I hope that I'm not surprised any longer.



Dennis R. Jones,  
Commissioner, TXMHMR

# Advocacy Programs Link Volunteers and Consumers

Men and women with developmental disabilities receiving MHMR services are sometimes without family or friends to visit and advocate for them.

Through the statewide Hands on for Texans program and similar programs, advocacy volunteers fill those gaps.



*Volunteer advocate Glenda Weyand helps Mary Sallie have everyday community experiences, such as having her hair styled at a local salon.*

*photo by Tamy Metzger*

## **Brenham State School**

Glenda Weyand, volunteer advocate for Mary Sallie, introduces her to activities in the community such as eating out and shopping. Additionally, Weyand is part of the interdisciplinary treatment team that works with Sallie to help her make choices and decisions about her life.

Weyand is one of 25 volunteer advocates at Brenham State School. Over the past five years the school's volunteer advocate project has evolved into a successful Hands on for Texans program for recruiting, training and matching volunteer advocates with 29 partners.

Advocacy Coordinator Marty Montgomery explains that he pairs an individual who has little

or no contact with family or friends with a volunteer who has a complementary personality and interests. Montgomery arranges a meeting, after which the pair makes a mutual decision to decline or approve the partnership.

After the two agree to be partners, staff provide insight and information to the advocate about the individual's program plan, daily schedule and interests. Social workers are the primary liaisons with advocates, informing them of upcoming meetings and areas of concern so advocates can represent their partners well.

Most advocates visit their partners regularly and serve for at

least a year. Weyand reports that "Mary is just part of my life." Community Relations Director Tamy Metzger hopes that "as word of the program spreads in the community, more volunteers will accept the challenges and joys of being an advocate."

Thanks to her advocate, Mary Sallie's behavior has improved so much that she can now work with others in the campus workshop. Advocate Glenda Weyand reports, "Mary acts like a lady when she goes out."

least a year. Weyand reports that "Mary is just part of my life." Community Relations Director Tamy Metzger hopes that "as word of the program spreads in

the community, more volunteers will accept the challenges and joys of being an advocate."

*Hands on for Texans is a volunteer program of TXMHMR. About 1,500 individuals at state schools need advocates. To volunteer, contact your local community MHMR center or state school, or call TXMHMR Community Relations at (512) 206-4540. Although current employees in the MHMR system cannot be volunteer advocates, former employees are encouraged to volunteer.*

### **Teacher Becomes Best Friend**

Helga Gongaware and Julia Martinez have known each other since 1972, when Gongaware was an educational aide at Lubbock State School teaching Martinez to sew and do her own laundry. Their teacher-student relationship grew into a special friendship. After Gongaware left the school, she became Martinez's personal advocate in May 1993, through a Hands on for Texans program similar to that at Brenham.

Martinez is always thrilled to see "Hetta," her advisor and spokesperson as well as friend. They enjoy time together at restaurants or Gongaware's home. During on-campus visits, Martinez looks forward to soft drinks and nachos at the canteen and chatting with Gongaware's grandson, Chad.

Benefits of their relationship have spread to Martinez's home, where Gongaware assists the housemates with activities for the annual Christmas party and other special activities.

### **Unique Programs Bring People Together**

In addition to Hands on for Texans, other unique programs link volunteers and individual consumers. Texas Advocacy Program (TAP) brought Tamara Miller and Austin State School resident Janice McGarry together.

A former employee of the school, Miller says being an advocate lets her experience the sat-

isfaction of helping someone grow. "I like it when I see Janice's progress," she says.

Funded by TXMHMR, TAP is administered on the Austin State School campus by The Arc of Austin.

At Abilene Regional MHMR Center, the Volunteer Friends program has linked volunteers

with individuals served by the Center for five years. Volunteer Coordinator Robbye Plummer says pairs are so well chosen that it isn't unusual for volunteers to spend much more time with their friend than the required four hours per month, sometimes including him or her in activities with the volunteers' family.



photo by Sherry Grona

*Janice McGarry and her advocate, Tamara Miller, go shopping or sometimes visit Miller's home during regular get togethers. Miller strives to teach McGarry new skills in all of their activities together and represents her partner's interests in treatment decisions.*

# Vocational Opportunities Mean Self-Fulfilling Goals

**C**lients of TXMHMR services are finding new doors opening to them regarding vocational opportunities. Employers in the private community are assisting with this open door approach to involving consumers in community businesses. More jobs and open minds mean more opportunities for individuals receiving TXMHMR's services.

Zeek Harris, director for Vocational Services, TXMHMR Mental Retardation Services, says "more and more, the system continues to evolve from a person participating in crafts and workshop activities under staff supervision to actually working and interacting with non-disabled co-workers as well as the community at large."

Although sheltered work activities—work which involves the supervision of an MHMR employee—are still available, the focus has shifted toward supported work. In supported work, consumers work for busi-

nesses in the community. They may have assistance, if needed, like a job coach who teaches essentials of the job. However, consumers need only a referral to a community job. Others need no assistance at all.

"Consumers and others are realizing what a person can accomplish," comments Harris. "The intent is to assist and support people in choosing, securing and maintaining employment where the person is a member of the community and workforce, not simply part of a segregated or sheltered environment."

"Through integrated community employment, an individual's abilities may be realized by themselves, their employer and the community. Successful employment occurs when a person is given an opportunity and receives the necessary support from friends, family, co-workers



*Harold Boss has been promoted to stocker at the Wal-Mart in Odessa.*

and agency staff."

Harold F. "Fred" Boss is a successful example of a consumer in a supported work situation. On the job more than a year, Boss has earned a promotion. His fellow workers call him dependable and they enjoy working with him. Boss's career was one that evolved from a sheltered work environment. His working career began in the Permian Basin Community Center's Sheltered Workshop in Odessa.

After expressing a wish for more independence, Boss was placed at a Wal-Mart store as a cart pusher. A year later, he has been promoted to a stockman for the same company. Boss looks forward to gaining more work experience and moving into a succession of even better paying jobs in the future.

## A Niche in Time

Linda Estrada has found her niche in life; she enjoys working with children. After a succession of jobs, Estrada told her family and her job coach that she'd like to swap her fast-food job to work with children. Now, she assists four hours a day at a local daycare center as a paid bus assistant. She's responsible for keeping the children safe while the bus is moving so the driver can concentrate.

"Linda is doing an excellent job with our children. She is helpful to the children, but still encourages the children to do things for themselves. She seems to enjoy working and talking to the children and always has a smile for them," comments the co-director of the daycare.

Estrada's working career began at the sheltered workshop in the Permian Basin Community Center in Odessa. Soon, she was considered for supported work in a community business. The staff

and her family suggested a cooking job in a Kentucky Fried Chicken restaurant. As the weeks wore on, it was obvious to Estrada and all involved that the job was not a good match for her.

After a change seemed inevitable, Estrada spoke up to her job coach and her family and told them her wishes of working with children. Her mother is pleased with the choice for a profession, but also says she didn't realize her daughter was even capable of expressing when she didn't like something.

Estrada's mother hopes that she will eventually become totally independent of the family so that she can take care of herself when they are no longer around to take care of her.

Estrada continues to become more self-sufficient. She began a driver's education course in January. The Permian Basin Supported Employment staff has arranged for her to take the test verbally.

## Ruben Lopez: Bicyclist, Worker and Volunteer

Every work day Ruben Lopez pedals his way to one of two jobs. Lopez surprised his job coach from Tropical Texas Center for MHMR, Erasmo Garza, by discovering safe bicycle routes on his own on which to cycle to work. Lopez has also completed a laws of the road bicycle class.

Lopez, who has Down syndrome, vacuums the floors and also straightens tables and benches at the Peter Piper Pizza restaurant in Harlingen. He also is part of a janitorial crew which tidies a local office building.

"Ruben is very dependable and focused on his work" and his performance has improved since he began working, says Chris Hamby, assistant manager of the pizza establishment.

Lopez's success at work comes from his good attitude, his enjoyment of the work and the training he received from his job coach and other members of the Vocational Department at Tropical Texas.

In his spare time, Lopez enjoys lifting weights, watching MTV (Music Television) and listening to his stereo.

Lopez also spends part of his time volunteering at a local boys and girls club.

*Lopez's vignette contributed by David Kotzur, public information specialist, Tropical Texas Center for MHMR.*



Linda Estrada swapped a job in a fast-food restaurant for a job in a daycare after telling her job coach she would prefer working with children.

photos by Jane Vaughan



# CLOSURE

*By the end of the century, the agency will close state schools and assist many individuals currently in the state school facilities in moving into the community.*

Marjory Vogt and her husband Doc thought about moving their son Michael Vogt to a group home for almost 10 years before he actually made the change. And to hear them talk today, it was one of the best decisions they ever made.

"I can't think of a situation even in a fantasy that would be better for his conditions," says Marjory Vogt, who lives near Lago Vista. Her son Michael Vogt, who is 46, lived in state schools for 30 years before he moved to Blake House in Lockhart, a group home run by Travis State School Community Services.

Michael Vogt, who has mental retardation and cerebral palsy, moved to Lockhart from Travis State School in March. Both he and his parents went through an adjustment period, but now he considers Blake House his home.

"He came home for Thanksgiving and was ready to go back that evening," his mother says.

Michael Vogt is one of scores of individuals who are moving to group homes from not only Travis State School, but also Fort Worth State School and others in the TXMHMR system. Downsizing is moving rapidly at both Travis, which is scheduled to close in 1999, and

*Henry Woo and Shari Maynard, the facilitator for community placement, look at one of Woc's photo albums.*

*photo by Bruce Holter*



Fort Worth, set for closure in 1995.

The schools are being closed because of 1991 legislation designed to resolve the Lelsz vs. Kavanagh class action lawsuit. The case, filed in 1974, sought improved conditions in state schools and increased community placement. A settlement agreement was reached in 1991, and the suit will be dismissed after the first state school is closed and at least 600 persons have been moved into community living arrangements.

Once the Fort Worth school closes, plans already are under way for use of the facility. If the deal is finalized in early 1994 as expected, Tarrant County will pay \$1 million for all 15 buildings on the site. A one-stop, computer-linked mall of health care and social service programs known as the Resource Connection will take up residence at the location in South Fort Worth.

### The Principles of CQI Have Paved an Easier Path for Closure

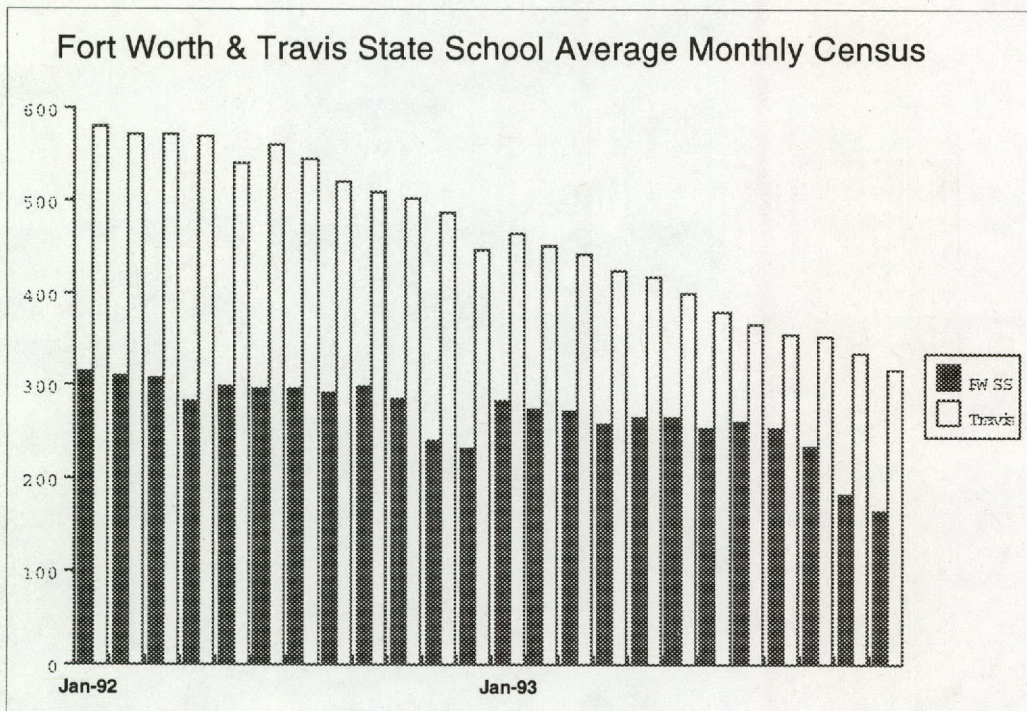
Since the two schools were selected for closure in March 1992, TXMHMR has endeavored to inject the principals of continuous quality improvement into the process.

One of the efforts to surface as a CQI idea is a state school closure evaluation steering committee. The task force has surveyed families to get feedback so the process can be improved. One result of the survey has been providing more information to families about the group home or state school where their family member will be transferred.

Employees at the two state schools have worked hard to ensure that the transfer process is a quality effort. For example, when a group of eight women transferred in August from Fort Worth to Denton State School, staff members went the extra mile to

make sure the move went as smoothly as possible. The Fort Worth residents and their staff went to Denton for a picnic before the move, and staff from both facilities traveled back and forth for several informal adapting sessions. Information on the women's likes and dislikes, habits and family involvement was exchanged. As a result of these preparations and considerable support from families, transfer trauma for the new Denton State School residents was minimal.

"It went much smoother than we expected," says Bobby Griffin, the QMRP, or qualified mental retardation professional, for the cottage at Denton where the women moved. "We thought we'd have adjustment problems, but we didn't have any," he says, noting that the women were accustomed to their housemates from the days at Fort Worth. Such familiarity aided the process.



This chart depicts by month the de-escalating census at both state schools from January of 1992 through December of 1993.

### What About Employees During the Downsizing?

Concern for employees at the two downsizing schools has also been a top priority. Employees were promised choices to accept jobs at other facilities similar to their current jobs once the need for their work diminishes.

They've also been given an alternative of a separation package. Both facilities have been gradually reducing the number of employees, as needed, by attrition. No one has been involuntarily terminated.

*Contributed by Sheila Allee, director of Media Relations for TXMHMR.*



Circulation: Inell Alexander  
Graphic Designer: Sherry Grona  
Editor: Wendy Hazelwood  
Team Leader: Laurie Lentz  
Director: Peg Barry

**IMPACT** is published three times annually to inform, educate and provide recognition for employees and friends of the Texas Department of Mental Health and Mental Retardation about models of excellence within the TXMHMR system for their awareness and for reference in implementing programs and policies. Published for TXMHMR by the Community Relations Office, PO Box 12668, Austin, Texas 78711-2668, (512) 206-4540 or STS 824-4540. *Impact* was chosen the best magazine for 1993 by the National Association for Mental Health Information Officers (NAMHIO).

On the front, augmented communication assists consumers. See page 14. The back page depicts a young man excited about an invention called the Amtryke. See page 16.

## Contents

- 2 Consumers speak out 4 How MHMR's vision reflects the wishes of consumers 5 What is a self-advocate?  
6 Mental Retardation: Our consumers and their needs 7 TXMHMR's priority population 8 Core services of TXMHMR  
9 Generosity enhances lives 10 We all crave our own piece of the world 14 Innovations: inventions, ideas &  
information 17 Viewpoint by Dennis Jones 18 Advocacy programs link volunteers and consumers 20 Vocational  
opportunities mean self-fulfilling goals 22 Agency closing some state schools by end of decade

