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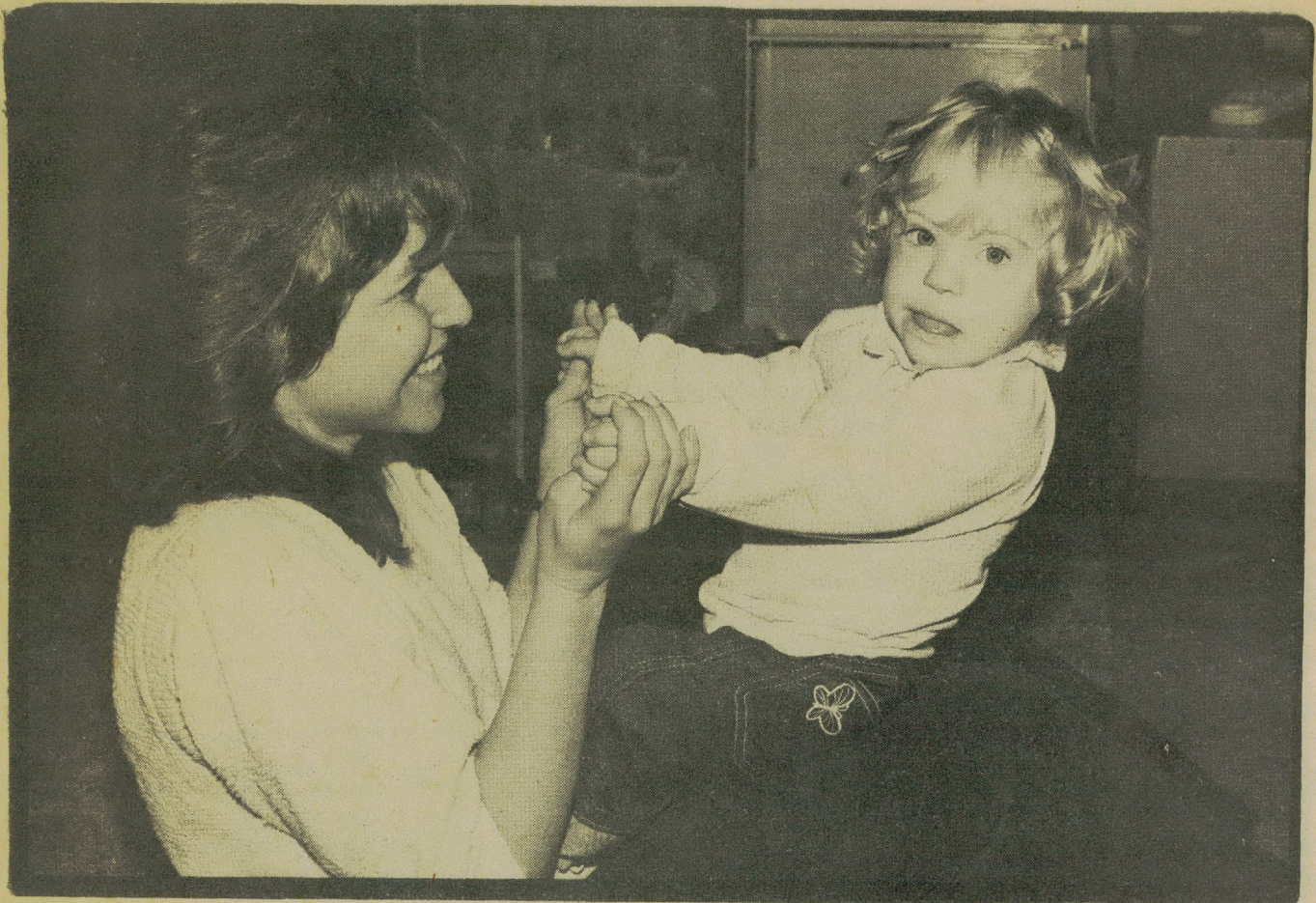
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Sherry L. Grona

Down syndrome: A history and profile

On the cover: Kristin Harrell (right), who has Down syndrome, plays with speech pathologist Janice Nowell at the infant-parent training program of Austin-Travis County MHRM Center.

Down syndrome

The 12th annual National Down Syndrome Congress convention was held in San Antonio in October 1984. Speaking at the meeting were national and international experts in Down syndrome, including Jerome Lejeune, M.D.; John E. Rynders, Ph.D.; Siegfried M. Pueschel, M.D.; Brian Stratford, Ph.D.; Kay R. Lewis, M.D.; and Mary Eleanor Toms, M.D. The following story about Down syndrome is distilled from the lectures and writings of these and other experts in Down syndrome, genetics and mental retardation.

People who are born with 47 chromosomes, instead of the usual 46, also are born with varying degrees of mental retardation and characteristic facial features that led researchers at one time to call them mongolian idiots.

According to John Langdon Down in 1866, the mongoloid-like features in Caucasian children with the disorder were evidence of degeneration of the Caucasian race.

Although Down introduced an unnecessary and inaccurate racial element, it is his name that now identifies this form of mental retardation, which occurs universally and in one of every 660 births in the United States. Down was the first to recognize the condition as a distinct entity.

Once a recurring mystery, Down

syndrome is now a condition that is viewed with optimism. People with Down syndrome, given training and opportunity, have the potential to work, attend school and live in a regular family setting. Physicians no longer automatically recommend institutional placement at the time of birth before the parents become "attached" to the infant.

People with Down syndrome may have been revered in Mexico and Central America 3,000 years ago, according to Siegfried M. Pueschel, M.D., of the Child Development Center, Providence, Rhode Island, and John E. Rynders, Ph.D., of the University of Minnesota, Minneapolis, in their book *Down Syndrome*. Clay and stone artifacts with distinct Down syndrome features have been found. Children with the genetic anomaly were thought to have been sired by a jaguar, the Olmec culture's totem animal, admired for its strength and cunning.

Misinformation about Down syndrome still exists. Mexican-American *curanderos*, or folk healers, have attributed Down syndrome to the influence of a lunar eclipse. Others think it is caused by fluoride in drinking water. The 1970 *Encyclopedia Britannica* described the condition under the heading "Monster." And a psychologist in a 1975 issue of the

magazine *Psychology Today* pronounced people with Down syndrome as "uneducable."

Although Down syndrome features have appeared on faces in artwork through the centuries, it wasn't until 1866 that Down published a paper definitively describing the characteristics. He wrote:

The hair is not black, as in the real Mongol, but of a brownish colour, straight and scanty. The face is flat and broad, and destitute of prominence, the cheeks are roundish, and extended laterally. The eyes are obliquely placed. The lips are large and thick with transverse fissures. The tongue is long, thick and much roughened. The nose is small. The skin has a slight dirty yellowish tinge, and is deficient in elasticity.

In 1934, researchers discovered a correlation between Down syndrome and maternal age. Older women, or those over 35 years of age, they found, had a greater tendency toward having children with the syndrome. This belief still exists today, but with some controversy.

Down syndrome is not inherited per se. It is a chromosomal anomaly that generally causes mental retardation and often causes physical problems also.



Tim Grisham

Trisomy detected

In 1959, Jerome Lejeune, M.D., presently of the Institut de Progenese, Paris, discovered structural differences in the chromosomal makeup of people with the characteristics of Down syndrome. An extra chromosome appears on the 21st pair of chromosomes, making the total chromosome count 47 instead of the normal 46.

The extra chromosome manifests itself in three different ways, which produces three different types of trisomy 21, a form of Down syndrome.

Nondisjunctive or true trisomy is

simply an extra 21st chromosome. Translocation trisomy is characterized by a chromosome that migrates from another position in the chromosome chain and attaches itself to the 21st chromosome. In mosaic trisomy, some body cells have an extra 21st chromosome and some do not.

Further, nearly 2.4 percent of people with Down syndrome are tetrasomic. That is, they have four chromosomes in the 21st position.

People with tetrasomy tend to have more severe mental retardation than those who have trisomy. And those with the mosaic chro-

John Langdon Down

mosomal pattern tend to have a broader range of intelligence. People who carry mosaic chromosomes may have physical features that suggest Down syndrome, yet not have mental retardation or the related physical problems. Generally, there is almost no relationship between physical characteristics and level of intelligence.

The birth of babies with translocation trisomy is more frequent among younger mothers (under 35 years of age), while births of babies with nondisjunctive trisomy are relatively more common to older mothers. Paternal age may be a risk factor in children with tetrasomy, but the effect of this factor on trisomy is inconclusive.

Some statistics show the incidence of Down syndrome to be increasing over the years. If this is true, two explanations can be directly related to corresponding advances in medicine, explained Brian Stratford, Ph.D., professor of special education at the University of Nottingham, England.

First, because of improved health care, women are living longer and bearing children at a later age, when there is a higher risk for having a child with Down syndrome. Also, in the past, women more often died in childbirth, or they may have been more likely to miscarry a fetus with a chromosomal anomaly.

Second, children born with Down syndrome are no longer allowed to perish within hours of birth upon the discovery of their condition, as was often the case even up into the 1960s. And physicians are more able and apt to treat their related physical problems.

Related physical problems

Many people with Down syndrome have heart defects related to their condition. Respiratory ailments are also common. Susceptibilities include thyroid disease, leukemia, diabetes and arteriosclerosis, reported Mary Eleanor Toms, M.D., a clinical geneticist from Delmar, New York.

Medical experts believe that people with Down syndrome may have a higher propensity than those in the general population toward developing Alzheimer's disease early in life. Autopsied brains of people over 40 years of age who had Down syndrome reveal characteristics of Alzheimer's disease. The brain's disturbed metabolism of choline is thought to be responsible for both conditions, said Dr. Lejeune.

It has also been shown that people with Down syndrome have low levels of brain serotonin, reported Dr. Lejeune, but they do not have a deficiency in pituitary growth hormone as some researchers have suggested.

People with Down syndrome commonly experience delayed sexual development, and no cases have been reported of a man with the condition fathering a child. But because people with Down syndrome of both sexes tend to be protected by family and friends, it may be difficult to accurately assess

their reproductive capability, medical experts note.

According to one source, a survey of 14 women with Down syndrome who had children showed that five of the births were normal, five of the babies had Down syndrome, two had nonspecific mental retardation and two others were stillborn. Although this survey is inconclusive, it illustrates the chromosomal variety in Down syn-

drome due to the three types of trisomy 21 and the occurrence of tetrasomy.

Reproduction aside, people with Down syndrome still form relationships and marry. If the woman produces a child, the question arises of her competence as a parent. This question has legal and personal ramifications, and, as with many other aspects of Down syndrome, is probably answerable only on an

Chorionic villus sampling

by Kathleen Kimball-Baker

The Genetics Screening and Counseling Service (GSCS), Denton, is in the early stages of developing a laboratory technique to detect chromosomal abnormalities, such as Down syndrome, in 8- to 10-week-old human embryos.

The technique is called chorionic villus sampling. It involves studying chromosomes taken from a biopsy of tissue that helps anchor the fetus (called embryo in its early formation) to the uterine wall.

The chorion, the outermost envelope of the growing embryo, protects and nourishes it. Villi, branch-like cells formed by the fetus, attach the chorion to the rich lining of the mother's uterus. An obstetrician biopsies the villi by inserting a thin catheter through the mother's cervix into the uterus. Preliminary results may be available within 24 hours.

The other widely used method of studying fetal chromosomes is amniocentesis, a procedure that cannot be performed until the second trimester of pregnancy. Amniotic fluid surrounding the fetus is extracted through a needle inserted into the uterus through the mother's abdomen. Results take two to three weeks.

Chorionic villus sampling is still experimental, and the U.S. Food and Drug Administration has authorized only a limited number of physicians to perform the biopsy.

GSCS medical director Mary Kukulich, M.D., says the Denton researchers are trying to adapt the technique for analyzing the biopsied chorionic villus tissue in their cytogenetics laboratory. They will not do the biopsies themselves.

"GSCS is still a way off from being able to offer the chorionic villus sampling technique, but we are making quite a bit of progress," Dr. Kukulich says.

The July 6 issue of *JAMA*, the Journal of the American Medical Association, reported that in less than one year nearly 300 women had undergone chorionic villus sampling in the United States, with fetal abnormalities detected in about 10 percent.

JAMA reported, however, that an argument exists concerning the procedure's safety to the embryo. Proponents say about 0.5 percent of embryos are lost after sampling (about the same rate as amniocentesis). Others report a rate of 5.6 percent.

The technique is more expensive than amniocentesis because it takes longer to perform and usually involves more technical personnel.

Dr. Kukulich says part of the difficulty in developing the technique for a laboratory is being sure embryonic, not maternal, tissue has been biopsied.

Fetal cells divide actively and can be examined immediately. "Though the direct harvest technique of chorionic villus sampling is faster, you don't really get a good clear look at the chromosomes," Dr. Kukulich says. "Culturing the cells, as is done in amniocentesis, gives a better, more detailed picture."

Applications include prenatal diagnosis of disorders during the first trimester of pregnancy, and someday, perhaps, *in utero* treatment of metabolic disorders, Dr. Kukulich says. □

Kathleen Kimball-Baker is editor of The Emissary, the newsletter of Texas Research Institute of Mental Sciences.

individual basis.

Even though people with Down syndrome share similar physical characteristics, they should be viewed as varying widely in personality and mental capacity, said Kay Lewis of the Texas Research Institute of Mental Sciences, Houston. Not all people with the condition are jolly and passive. And they cannot all be relegated to a particular IQ level.

Although in the minority, some people with the syndrome have normal and even high levels of intelligence.

Early education

Intensive early training and education is probably the best way to enhance the potential of people with any form of mental retardation. Rehabilitation programs for World War II veterans helped the public to recognize that those with mental disabilities could profit from training, say Drs. Pueschel and Rynders in *Down Syndrome*. Previously, residential institutions in which many people with Down syndrome were placed did not offer habilitation programs.

In 1950, parents formed the National Association for Retarded Children and pushed toward institutional reforms. Mental retardation professionals, encouraged by initiatives in the Kennedy era, such as federal funding for training programs for people with mental retardation, began to try new approaches in care, treatment and education for their clients.

Still, controversy persisted about the need for training and even the right to life, explained Dr. Rynders. Theologian Joseph Fletcher, in the

April 1968 issue of *Atlantic Monthly*, wrote that a parent should not feel guilty about placing a child with Down syndrome in an institution or about allowing the child to perish because, he said, "a Down's is not a person."

Most current civil and human rights advocates would find Fletcher's statement abhorrent. Court battles concerning the right to medical care for severely disabled children and adults continue to rage. The line in this instance between personal and familial volition and legal intervention is fuzzy.

The law has intervened in the area of education, though. U.S. Public Law 94-142, passed in 1975, and state ordinances have guaranteed a free, appropriate public education for all school-age children with disabilities, including those with Down syndrome.

Infants with the condition develop fairly normally up to six months of age, when they begin to fall behind other children, some studies conclude. Children with Down syndrome tend to develop motor skills slower than other children because of hypotonia, or weak muscles. But they can achieve competence. Delays in learning can perhaps be attributed to the fact that 67 percent of people with the syndrome have defective eye sight. Down syndrome also tends to be associated with difficulties with language, depth perception and abstract thinking, said Dr. Stratford.

Most experts stress early childhood intervention programs to give intensive attention to the child during these crucial first six months and on until school age.

Family support

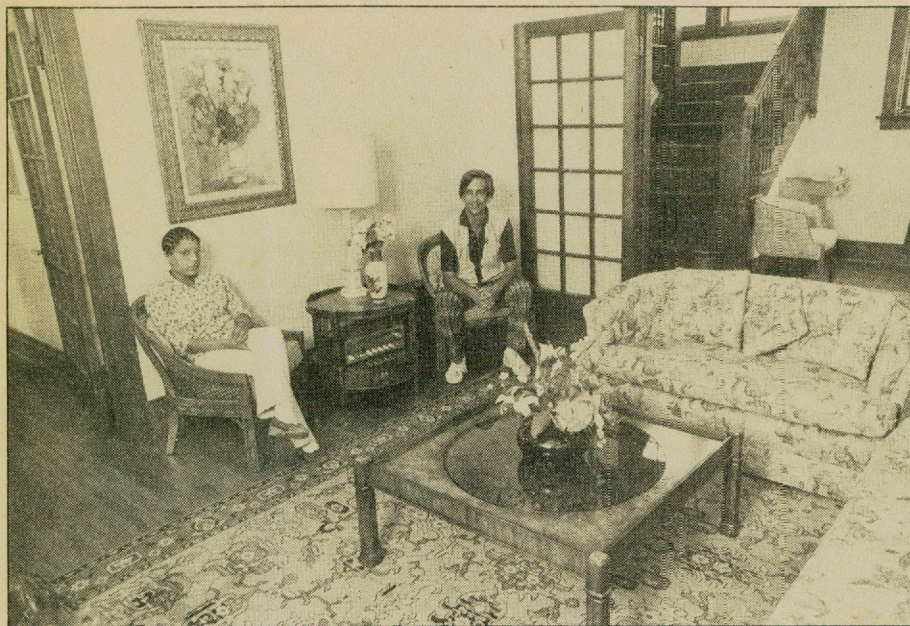
Most children with Down syndrome develop better at home with their families than they do in institutions, other studies show. But the challenge of providing an optimal environment for a child with developmental delays can disrupt even the most tightly knit family. Parent and sibling support groups give family members strength by sharing experiences and learning they are not alone. These groups are becoming more commonplace and are bolstered by larger associations, such as the National Down Syndrome Congress, organized in 1973, and the Down Syndrome Interest Group of the American Association on Mental Deficiency, founded in 1979.

When researchers learn more about factors that control the occurrence of Down syndrome, the condition may be preventable. Meanwhile, greater precision in genetic counseling is anticipated. Genetic screening allows pregnant women to learn of possible chromosomal anomalies in their unborn children through amniocentesis and, more recently, chorionic villus sampling (see box). This knowledge helps with informed decisions about whether to continue the pregnancy. People who feel they cannot fairly parent their child with Down syndrome can use the services of local and national adoption agencies that specialize in "special kids."

Children with Down syndrome now are born into a world more knowledgeable about their condition and progressively more willing to allow them to flourish along with everybody else. □

The art of belonging ... at Pyramid House

by Kathleen Kimball-Baker



Mary Sanders and Gary Soards relax in the comfortable living room of their club, Pyramid House.

CRAZY is a word that comes up often at 3904 Austin Street in Houston.

Few who enter the doors here are afraid of the word; they've lived with it long enough.

When they walk through the gates of Pyramid House's gleaming complex, they stop being patients, or clients, or cases. They are members, people who belong to a club, people learning and relearning how to laugh, how to connect with other human beings and how to survive outside a mental hospital.

Located in the Binz area of Houston—an eclectic mixture of junky houses, remodeled estates, social service agencies, empty lots, clinics, day-care centers and abandoned buildings—Pyramid House brings pride to the community.

Its grounds are scrupulously cared for by members. They sweep

the walkways, manicure the lawn, shine the windows, polish, pick up and perfect.

Inside the remodeled two-story stucco house, not a speck of dust is allowed a moment's rest, and sunlight floods the rooms through spotless panes of glass—all the work of members.

"We use the word crazy a lot around here," says Kate Sexton, director. "We are not diluting or mystifying the issue. It can be scary for people who aren't used to the word. But for the most part, these are people who are chronically mentally ill."

People who belong to Pyramid House have been in and out of mental hospitals for years. One 42-year-old woman was hospitalized the first time at age 14. She's been in an institution 24 times since then. Another woman in her thirties recounts 50 hospital admissions.

Their comments about mental institutions are barbed, often sardonic. "If you're rich, you are eccentric. If you are poor, you are crazy and they put you in the hospital," one man says.

"When you enter the hospital, your priorities are, first, simply try to survive, second, protect your privacy, and, third, protect your personal property—like cigarettes. If by chance you get helped along the way, well, then you're the lucky one," says one woman.

"Yeah, I got something good out of being in hospitals," says another. "It's built my confidence. I now know I can survive no matter where I am. I'm always looking over my back to make sure no one is about to attack me."

At Pyramid House, a part of the MHMR Authority of Harris County, the philosophy departs radically from the way members say they were treated in hospitals. No medication is dispensed and no formal therapy takes place.

"A long time ago, I heard the concept that to help people with emotional problems, one must challenge their wellness, not nurture their illness. I really bought into that and I still believe it," says Sexton, a slender, feisty woman trained as a Gestalt therapist.

"Club members need the same things that normal neurotics need," she says. "Productive action, housing, friends. If a person with chronic schizophrenia can have these things and take medication, he or she can usually stay out of the hospital."

And so, Pyramid House's three components—work adjustment, residential and social—provide exactly that.

Members work in one of four areas. They are the workers' co-op, which has a contract to rewind magnetic tape on sophisticated electronic equipment; clerical services, like photocopying, answering phones and keeping records on members' medications and telephone numbers of social agencies; maintenance, which handles grounds keeping and housekeeping; or food, where workers plan menus, shop for food, prepare meals, serve members during mealtime and clean up.

A Pyramid House staff member is

in charge of each of the areas and serves as a case manager to members.

The residential component includes an apartment complex with 12 units that house 14 members; two communal housing units, with five members in one, four in the other; and four additional separate apartments. Housing is located away from the main building, in the Binz and Montrose neighborhoods.

Members must have an income to live in the rooms or apartments—even if it is county welfare or food stamps. "It's still cheaper than a stay in the hospital," Sexton notes.

Pyramid House also provides recreation areas and activities for members. In a building above the maintenance barn is a large meeting room. Next to it is a recreation room equipped with a pool table, reading material and comfortable chairs.

A member is in charge of planning outings. And several write and produce a newsletter that is distributed in the clubhouse and to others like it throughout the country.

"Members need to network. I don't think it matters why you are crazy," says Sexton.

At 3:45 p.m. each day, members and staff meet to discuss what has happened during the day. An executive committee of seven members, which operates under a set of bylaws, handles complaints about staff and members. "You might call it the Pyramid House Supreme Court," one member joked.

Members are expected to be cooperative and not harmful to self, others and property; take medication as prescribed and follow through on recommended outpatient treatment; be dependable and not abuse alcohol or illegal drugs during program hours or at the clubhouse; show regard for others by not threatening or performing sexual activities while on the premises; and clean up after themselves and show respect for others and the clubhouse property.

As long as members are able to live this way, they can participate in Pyramid House. There have been times when a member begins to show symptoms of a breakdown and is unable to care for her- or himself. When this happens, staff members hospitalize the person.

"For the most part," Sexton says, "our members are making sound decisions or are ready to be accoun-

table for their decisions. It's not all that rosy here all the time...we do gritch at each other.

"However, our tolerance level is probably higher than that of most other health care agencies. That doesn't negate what's going on at other places. We just stretch our boundaries a bit more."

The friends many members make at Pyramid House become their support system. Often, family members have given up, kicked them out, closed and locked the door.

"You can't really blame them," says Sexton. "They're tired, they're burned out. They've exhausted their money and their energy."

Staff members at Pyramid House try to "facilitate a process, to sit back and let things happen. We're dealing with issues of empowerment, and we are trying to share the responsibilities," Sexton says.

Members even help interview potential staff employees. They offer a special perspective that helps Sexton determine, for example, whether an applicant has a patronizing attitude toward members that wouldn't surface in a regular interview.

Pyramid House serves 75 members, with 35 to 40 coming every day. It will soon open a catfish farm in New Waverly to help relocate some of the patients who will be released from Austin State Hospital as part of a court-ordered plan.

"We are cost-effective, and I think the community is impressed. I think the measure of our success is that we are able to maintain members in the community and they are able to live fuller lives," says Sexton.

"I'll be honest. Some of our members will never go to work elsewhere. Either they are too old or disabled or just don't want to. But by coming here, they are productive, and that saves the taxpayers money. What we have here is a place where people can grow and reach their potential—members and staff." □

Kathleen Kimball-Baker is editor of The Emissary, the newsletter of the Texas Research Institute of Mental Sciences, where this story originally appeared.

Mary Seebach (left) and Sheila Schwartz prepare meals for themselves and other members of the psychosocial rehabilitation center.



Brad Perkins

Equalspeak

"I don't like people calling me mentally retarded. I want to be called by my real name."

—Ann Marie in *No More Stares*, a booklet published by the Disability Rights Education and Defense Fund (1982)

Ann Marie, like others with a mental or physical disability, petitions to be seen, heard and accepted as an individual. She dislikes being segregated from the larger population and losing her personal identity under the labels *mentally retarded* and *disabled*. Like taunts from schoolchildren and unthinking adults, labels are dehumanizing and insulting. They are also indicative of a society's view of people with disabilities.

Until recent years, the media, for example, tended to describe people with disabilities in negative or limiting terms or phrases that emphasized *dis-ability* rather than ability. Human service agencies have used words that suggest this population's dependence, helplessness and fixed position in society. Even parents and friends have shown the same carelessness.

As people with disabilities have gained political clout and national visibility, their needs, talents and capabilities have begun to be recognized. This growing public acceptance of disabilities, along with the independent living movement begun a decade ago, has been responsible for positive self-concepts in people with disabilities. However, many popular misconceptions remain.

People with disabilities, it should go without saying, deserve the same respect and dignity afforded everyone else. Many object to calling nondisabled people *normal* because it implies that people with disabilities are somehow subnormal, inferior or childlike. Since an estimated 15 percent of Americans have a disability, it should not be considered abnormal to be disabled. As the population grows older, this percentage is expected to increase.

Some able-bodied and able-minded people may wonder what all the fuss is about concerning language used to describe disabilities. Yet words pose formidable barriers and often create unshakable prejudices and stereotypes.

Image-makers have recognized language as a powerful tool. It influences market trends, job placements and educational achievements. It also reflects the way we think. Linguists Benjamin Whorf and Edward Sapir go one step further. They contend that language—French, Japanese, Swahili—shapes culture.

Various organizations concerned with people with disabilities have published language guidelines for avoiding traditional slights. Most proponents of language that confers equal status on disabled and non-disabled people contend that people should be in control of language used to describe themselves.

Although individuals and groups haven't reached consensus about preferred terms, most agree that people come first, as in the phrase *people with disabilities*. The person should be emphasized rather than the disability, and the disability should be mentioned only if relevant to the context, recommends a North Carolina Council on Developmental Disabilities pamphlet, *People First*. Also, discussions of people with disabilities should reflect the diversity of disabilities and the people who have them. A man with a closed-head injury may have little in common with a woman who was born missing an arm.

TDMHMR's Mental Retardation Advisory Council has proposed guidelines for positive and appropriate terms to use when talking about clients with mental retardation. The council recommends avoiding terms like *the MR* or *retardate*. Outdated terms like *mongoloid*, *mongolian idiot*, and *moron* should be replaced by *person who has Down syndrome*, *person who has mental retardation* or *person with developmental disabilities*, as appropriate. Classifications like *borderline*, *low functioning* and *high functioning* should be disposed of along with disparaging terms like *crib case*, *low grade*, *the severes* and *vegetable* and patronizing terms like *adult children*.

A person who is mentally ill or emotionally disturbed

should not be referred to as *the bipolar manic-depressive* or *the attempted suicide*. Designating someone as a *case* implies he or she can be filed away in a drawer or deposited in an institution, a United Cerebral Palsy Association (UCPA) pamphlet says. This frees others from personal interaction with him or her. People receiving services should be called *clients*, not *patients*;

people with disabilities are patients only when visiting a physician or a hospital.

Judy Wingard-Westbrook, vice president of the Coalition of Texans with Disabilities (CTD), says many words describing disabilities do not offend her personally. What she finds disturbing are many attitudes of friends, family and strangers toward people with

Lazy phrasing

Words are used to "mollify, evade, inflame and incite—and we're not aware of what we're doing," says Leona Bachrach, Ph.D. "Not only do we use words that lack consensus, we sometimes use words quite indiscriminately."

Dr. Bachrach spoke to MHMR professionals in Austin about slogans and euphemisms that can undermine effective service delivery to people with mental disabilities. The October lecture was jointly sponsored by TDMHMR and the Hogg Foundation for Mental Health.

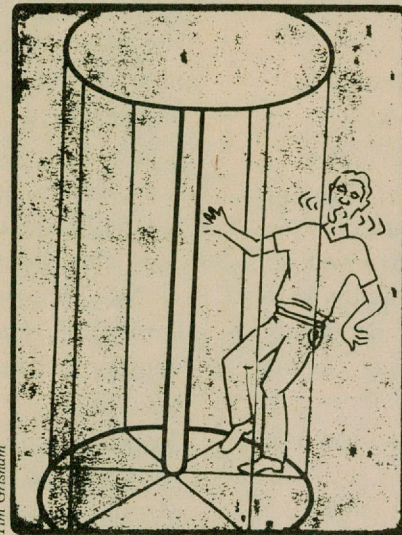
Semantic games are so complicated and subtle that they fool even the people who invent them, says Dr. Bachrach, who is associate professor of psychiatry (sociology) at Maryland Psychiatric Research Center, University of Maryland School of Medicine.

"One of the most insidious semantic games we play revolves around denial that the mentally ill are in fact ill," she says. Once people begin denying the existence of the illness *per se*, it becomes easy to deny the need for special services for people who are chronically mentally ill.

The *exceptional child*, who may be gifted or handicapped, is another case in point. This child needs exceptional types and qualities of care. But when the person is labeled exceptional, public awareness of disability and the need for special services may be reduced.

The *revolving door* is another misleading term, which refers to the repeated readmission of patients to mental hospitals. MHMR professionals tend to use it with negative connotations, which creates an assumption that people with mental illness must move

along an imaginary continuum of progress. The revolving door, a reality for some mental patients, then becomes a concept that implies MHMR service initiatives and clients have somehow failed.



Other terms and phrases can minimize a problem by their loose definition and lack of specificity. How is a *community support program* evaluated if there is no rigorous operational definition of the program and its purpose?

The *least restrictive alternative*, a phrase that describes a goal in program planning, is actually too imprecise to target. For example, a mental institution may be considered a restrictive environment. But a less restrictive alternative—the community and sometimes the streets—may present danger and psychological stress to a mental patient. So the subsequent lack of personal autonomy actually becomes more restrictive even though the environment itself is considered less restrictive.

Deinstitutionalization defines the single major policy thrust of MHMR service in the past two decades, but is itself defined variously by MHMR professionals. The word has been used

to legitimize very complex and sometimes controversial planning decisions, yet has also been called a polite term for the cutting of mental health budgets, says Dr. Bachrach.

People use the word *deinstitutionalization* as if it had only one connotation, Dr. Bachrach says. She calls *deinstitutionalization* a fact, a process and a philosophy. It is events in the shift of locus for mental health care from institutions to communities. It is a process of social change involving all elements of the MHMR service system. And it is a philosophy rooted in post-World War II civil rights protests and the concern for humanizing care for the mentally disabled.

Although *community-based care* was assumed to be more humane and less expensive than institutional care, the assumption was never really tested, says Dr. Bachrach. Policymakers assumed communities could and would provide alternatives to institutional care and that the stigma of mental disability would disappear. So they *deinstitutionalized* before they provided adequate community-based care, a double-edged sword since both terms are nebulous.

The term *aftercare* not only is nebulous; it also can preclude MHMR clients from the services it defines, says Dr. Bachrach. *Aftercare* describes services meant to help clients make the adjustment from residential facilities to community life. But in keeping with *deinstitutionalization* efforts, many clients never enter residential facilities, so they are ineligible for aftercare services.

These semantic games help rationalize what we do and don't do, says Dr. Bachrach. "They help us to evade, displace, deny and obstruct." □

disabilities. Some parents, overprotective of their disabled children, encourage helplessness and dependence. Families may assume that disabled members will be excluded from dating, marriage, child rearing and social opportunities. Or, people with disabilities may be considered inherently saintly or asexual. Yvonne Duffey's book *Anything Is Possible* discusses sex for *differently abled* people and contradicts the latter notion.

Stephanie Thomas, community outreach coordinator at Austin Resource Center for Independent Living, says that when people with disabilities are kept dependent like children, important issues may be ignored.

"Children don't have the same legal rights as adults," Thomas says. "They don't vote or take public transportation alone."

Many CTD members actively flout conventions in their advocacy for people with disabilities. A CTD bumper sticker reads, "Disabled but able to vote."

Virginia Roberts, executive director of the Texas Governor's Committee for Disabled Persons, draws a useful distinction between the terms *handicap* and *disability*. She says *handicap* relates to interaction with the environment. For example, she is handicapped when lack of a wheelchair ramp makes a building inaccessible. Her *disability* is that she cannot walk.

Many active people with disabilities prefer the latter term, Roberts says. They object to the word *handicap* because they think it refers to disabled beggars of centuries ago roaming the streets with "hand in cap."

Another group of people, in Michigan, see it just the opposite way. They prefer the word *handicap* and use it in the sense of "people who compete with a handicap." In their view, a *handicapper* is someone who has been rehabilitated and is no longer disabled in the legal sense. According to the *Oxford English Dictionary*, the word derives from sporting terminology and a game in which bets were pooled in a hand-held cap.

No one likes the word *cripple*, Roberts says, because it connotes pain and unsightly deformity. The National Easter Seal Society eliminated the phrase "for Crippled Children and Adults" from its name because of objections many parents had to the word *crippled*, says Loyd Martin, program coordinator of the Texas Easter Seal Society.

A United States House of Representatives bill, HR 6132, proposes to remove the word *crippled* from all Social Security forms and documents and use *handicapped* or *disabled* in its place.

References to people with disabilities that imply misfortune or evoke pity are also being avoided with more frequency. People who have a disability like cerebral palsy are not *victims* since "they have not been

sabotaged," a UCPA pamphlet says. Few people with disabilities are in constant pain, so they do not *suffer* from a disability. Disparaging phrases like *afflicted with polio* or *stricken with muscular dystrophy* should be replaced by *affected by polio* or *affected with muscular dystrophy*. *Confined to a wheelchair* is inappropriate; people use wheelchairs.

The term *invalid*, which suggests *not valid*, has fallen out of favor along with other terms that contribute to negative images of people with disabilities.

People with disabilities are not necessarily *brave* or *courageous*. They are not super heroes and should not be heaped with exaggerated praise. The image of the *supercrip* who has overcome great obstacles is ultimately condescending and insulting, says Thomas. Calling someone with a disability a *burden* or *drain* on others is negative. A more positive statement would be *added responsibility*.

Betty Bird, National Public Radio (NPR) programming liaison officer and former director of the Service for the Print Handicapped, based in Washington, D.C., says NPR tries to include another role or characteristic when talking about people with disabilities. *Deaf dancers*, *blind athletes* or *disabled demonstrators* would be appropriate. This helps anchors and reporters avoid stumbling over cumbersome or inappropriate phrases.

Bird cautions against using euphemisms and circumlocutions. People who are blind generally want to be called blind, she says. Words that refer to a disability should not be used jokingly or inaccurately, though, she says. *Blind drunk* and *blind rage* are inappropriate and insulting uses of the word *blind*. People should avoid being lazy with language, Bird says.

In 1982, the International Year of the Disabled, a United Nations seminar held in Vienna studied ways of "improving communications about people with disabilities" and published a booklet by that title. The United Nations booklet advises that people with disabilities be included as part of the scene in advertisements, books, films, television and radio. The media should report on the person's disability only when relevant and should depict people with disabilities in a variety of settings and social contexts—at home, work, school and play.

The U.N. booklet criticizes fund-raising campaigns that play upon the public's pity toward people with disabilities or present services as a privilege, not a right. Many campaigns also "perpetuate the myth that with sufficient funds, disabled people can walk away from their disabilities," the booklet says. "Yet, what most people with disabilities need is not a miracle, but an end to stereotyping, prejudice and discrimination." □J.G.

Vital connection

By Carol Mouché

A \$20 home-rigged device is opening a new door for 18-year-old Donovan Aubrey—a communication door that has been closed for this severely handicapped man most of his life.

Aubrey, a client at Brenham State School (BSS) who has no use of his arms or legs, was recently chosen by BSS speech pathologist Cindy Walsh as the first to benefit from the aid of a personalized "Nickie Switch," designed to respond to head movement.

The switch, attached to Aubrey's head by a bobby pin, is made of a basic mercury tube available at Radio Shack. It enables Aubrey to turn on and off battery-operated items such as a tape recorder or a toy car.

Two metal rods run through the glass mercury tube and, when they are covered completely by the mercury, make a connection. Walsh soldered two wires to the ends of the mercury switch and attached them to a radio earphone plug. That plug is then attached to the "remote" outlet on a tape recorder.

When Aubrey lifts his head, the mercury touches the metal rods and the tape recorder goes on. The insistent beat of Michael Jackson's *Thriller* fills the room, and Aubrey smiles and gurgles, signifying his understanding of the process. If Aubrey drops his head, the music goes off.

"We started with a tape recorder, because it gave him immediate aural feedback," Walsh says.

"Devising the switch was a conglomeration of knowing what Donovan can do, reading what other people had done and adapting them to similar types of equipment in the books," she says.

Walsh's second attempt to teach Aubrey the Nickie Switch's communication control involved a model race car, powered by batteries activated by the switch.

"This really has been a learn-as-you-go type of thing," she says. "So many clients have the potential to communicate, and we have to dig to find types of equipment to help them do it."

Aubrey is one of more than 100 clients who come to the school's speech department for therapy, Walsh says.

Staff members utilize a variety of programs ranging from basic, pre-linguistic skills for clients like Aubrey to articulation therapy, which polishes a client's verbal skills.

Once certain clients are recommended for therapy, the pathologists provide intensive, twice-a-week instruction using professional intervention techniques, says Walsh.

"Our therapy doesn't deal with rote learning," she says. Instead she helps to identify specific com-

munication problems with the clients.

Walsh says her department specializes in the use of communication aids such as books, boards and electronic devices to help the clients articulate their needs and desires.

But she says she has found that some clients, like Aubrey, need additional help. He cannot point to pictures in a book, although he can direct his gaze to a particular object when asked to identify it.

Walsh says she got the idea for the Nickie Switch at a seminar in Houston last year. She obtained books by Linda J. Burkhart that showed adaptations of communication items for severely handicapped people using common, inexpensive items such as a tape recorder, a spatula, cookie sheets, bobby pins and even a potato chip can.

Walsh says she experimented with several types of switches before she adapted the final product to Aubrey's motor skills. "Donovan has no use of his arms or legs for functional purposes. So he would not be able to press a switch. Therefore, we had to find a switch to provide him with a way to turn on and off some equipment."

The final version cost approximately \$20 to make.

"Compared with a couple hundred dollars for ready-made equipment, this is a big improvement," she says.

She credits state school electrician Rick Shindeldecker, who donated his time and expertise to the Nickie Switch project.

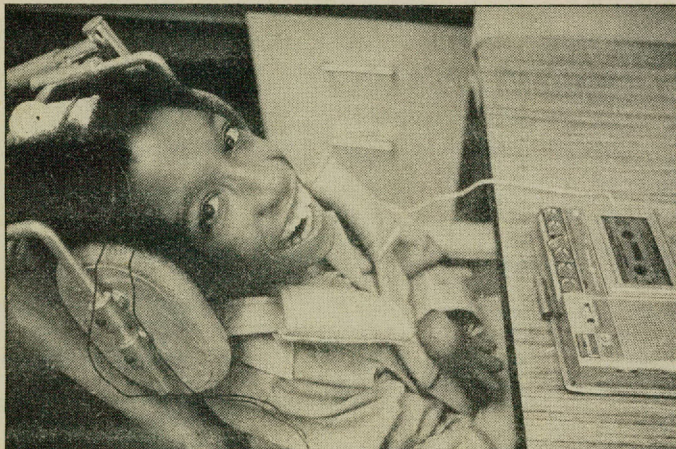
Walsh says she chose Aubrey for her switch experiment because "he has a good receptive vocabulary, and he's a very interactive guy.

"He's responsive and likes to be aware of what's going on around him. He's motivated to want to learn," she says.

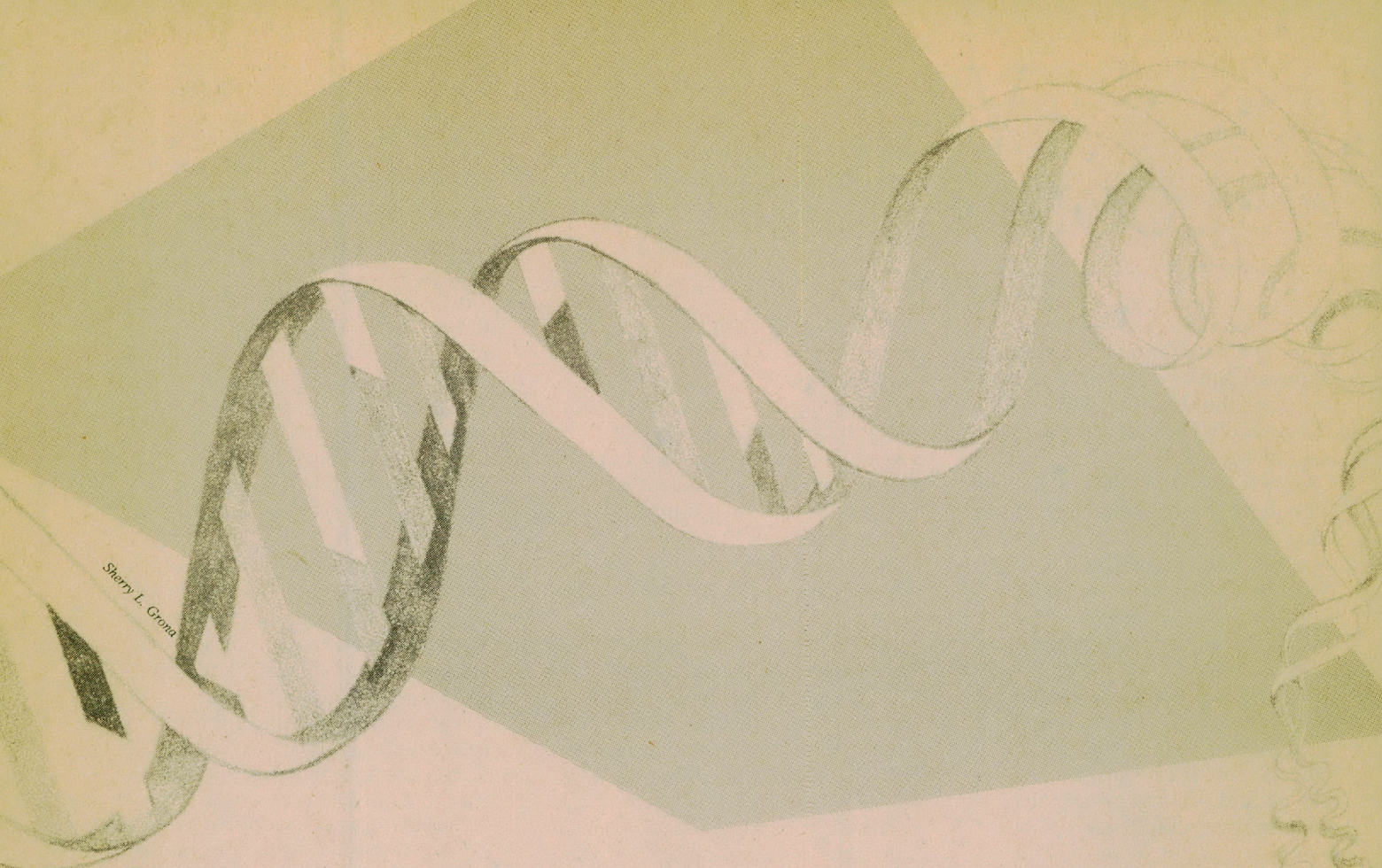
Walsh says it should take Aubrey about a year to become familiar with the use of the switch. Her goal is to attach it to a spring-loaded address book. Pictures will be pasted on the pages of the address book, which could be used as other clients now use picture books to communicate. □

This article originally appeared in the Brenham Banner-Press.

*When Donovan Aubrey, a client at Brenham State School, lifts his head, metal rods connect and his tape recorder plays Michael Jackson's *Thriller*.*



Carol Mouché



Sherry L. Grota

Genetics screening and counseling: Service with vision

"I felt I had failed my husband, as if I were the cause of my son's being born like that," wrote the mother of a child with birth defects to staff of TDMHMR's Genetics Screening and Counseling Service, headquartered in Denton.

"Now I really would like to know what caused it. Why was my son born like this? Was it me? Was it the housework, or the quarrels with my husband? Was it because I was unhappy? Maybe I hit my stomach on something hard, and maybe it punched my son also. Was it the beer? I drank about a six-pack only once when I was three months pregnant . . ."

Questions like these are not uncommon to MHMR professionals. A painful search for answers is carried on in the minds of many parents of people served by

TDMHMR. Often their search is limited by the assumption that they as parents have done something to cause the child's problems.

This year marks the tenth anniversary of Genetics Screening and Counseling Service (GSCS) as a legislatively funded program of TDMHMR. The department's obligation does not stop with care of people who have mental illness and mental retardation. The major reason for the inception and existence of its genetic component is to help parents of people with birth defects understand what has happened. Only then can their guilt and suffering be reduced.

One woman wrote, "For four years I've been thinking, honestly believing, that with hard work and care, my daughter would be OK. But she's not. It would be so

wonderful to know what is wrong." With a clear understanding of her daughter's disability, this woman may be more able to protect her child's future.

A decade ago, the Texas Legislature enjoyed a time of relative economic plenty, making it possible for people of vision to establish the department's genetic service.

Today when the state residential facilities are facing great demand for more and better services with fewer dollars, TDMHMR maintains this program which is geared toward reducing mental and physical disabilities in future generations. It takes a special brand of courage and wisdom to manage current problems without sacrificing programs that offer long-term solutions, as GSCS does.

The double helix, which is the molecular architecture of the genetic material DNA, coils tightly to form each of the 46 chromosomes in humans.

More than 3,000 genetic disorders occur in humans. Those commonly diagnosed include Down syndrome, neurofibromatosis, Turner's syndrome and spina bifida. Families may find what caused a child's congenital heart disease, deafness, blindness, missing finger or webbed toes. Couples may learn why the wife miscarried or an infant died. Immediate genetic information allows families to grieve over a child's malady rather than wonder for years what caused the disorder or death.

If all people at risk of having children with genetic problems are to be reached, genetic services must be made available to the total population. GSCS operates 18 regional clinics so that citizens do not have to travel far from their homes to find answers.

The clinics' staff seek out possibilities through medical records and family interviews. They collect applicable specimens, which are analyzed in Denton, and record medical histories of three generations of the extended family.

Denton-based medical staff travel throughout the state to the local clinics so that families of all socioeconomic groups have access to genetic services. A team of geneticists in Denton pieces

together the laboratory results and medical histories to determine the prognosis, the risk of passing the disorder to children and the client's life expectancy.

GSCS also makes contributions to the body of knowledge concerning human genetics by collecting data and observing patterns.

While the medical staff is centered in Denton, the community services staff that offers psychosocial counseling is spread among the 18 local clinics. This staff serve as advocates for the family throughout the counseling process and ensure that the information is useful to the family.

Often there are emotional, cultural and intellectual barriers to a family's understanding and acceptance of genetic defects. The skills of the community services staff help overcome such obstacles.

Staff assess the level at which the family is functioning so the geneticists will be better able to make the information understandable to each family. Acting as case managers, the community services staff follow up so that families are linked to local service providers appropriate to their needs.

GSCS also is committed to public education. Often, people don't know they have a genetic problem.

"I recklessly had five children," wrote one man. "I didn't think so at the time; I didn't know what I know now. I wish I had gotten ahold of a genetic counselor years ago. I have a lot of bitterness because I've seen two beautiful children die."

By increasing the level of awareness in the general public and allied professions about the need for and availability of genetic services, more people can avoid this man's sorrow. Statistics show that 10 to 30 percent of state school residents and their families may have chromosomal problems, and 12 to 14 percent may have single gene problems. Wrote one mother, "We can manage OK with our child's problems, but if it happened again, everything would crumble. There isn't enough of us to go around."

While other organizations focus on research and the preparation of practitioners who can reach a diagnosis, GSCS will continue to concentrate on the application of knowledge so that fewer and fewer Texans will have to ask, "Why was my child born like this?" □

This story was composed from information submitted by Genetics Screening and Counseling Service, Denton.

New Year's resolution

Mental impairments can interrupt the rhythm of life. Mental illness interferes with a person's daily activities. A child born with mental retardation may turn an entire family upside down for a lifetime.

The Texas Department of Mental Health and Mental Retardation, the state agency responsible for care of Texas citizens with mental disabilities, helps these people live productively in society.

The following stories illustrate a sampling of the services offered by TDMHMR that help clients meet the New Year with resolve toward independent living. In many cases, these services are made possible by the cooperation of communities, employers, families and other agencies. With all parties in stride, mental retardation and mental illness are less of an interruption and more a part of the rhythm of life.

Friends by association



At The Clubhouse in Amarillo, it's hard to tell members from staff. That's the idea at the center, an element of community support programs (CSP) for people with chronic mental illness.

Members of The Clubhouse, and of the Friendship Club in El Paso, find peer support from others who, like themselves, struggle with mental illness daily. In programs like these, both of which were established in the past year, members receive prevocational and vocational training during the day. They live at home or in supervised residential settings.

The success of this CSP, also termed psychosocial rehabilitation center since members strive to recover psychological strength and social abilities, rests squarely upon principles of self-reliance and mutual support.

"Our staff is learning a new role," says John Hudgens, director of community support programs at Amarillo MHMR Regional Center, which runs The Clubhouse. "They can't support members all the time because members are trying to be productive on their own."

Staff at the Friendship Club, as at The Clubhouse, offer guidance and skills training, but leave it to members to govern and maintain the center.

Friendship Club members have an executive committee and make vocational and social decisions.

They gain emotional support from one another because members can empathize with each other, says Debbie Gross, coordinator of day treatment services at El Paso MHMR Center, which sponsors the club.

The Friendship Club has four work crew options: janitorial, grounds maintenance, store operations and production.

The production crew makes wooden toys, decorative mirrors and animal puzzles that the store operations crew sells at their shop, Why Knot Gifts.

The gift shop was opened with CSP grant funds from the National Institute of Mental Health and matching funds from the El Paso MHMR Center. Next year, though, grant money will no longer be available, so Why Knot Gifts will have to rely on its sales to pay rent and utilities.

The Clubhouse and Friendship Club maintain 48 and 40 members, respectively. "We have no capacity limit," says Hudgens about The Clubhouse. "If we get more members, they and the staff will have new problems to solve together."

Fostering independence

As mental illness distances people from reality, it can undermine their support systems. Eventually, people with mental illness may have no one to rely on because their family and friends become burned out and unable to lend constructive help.

Foster care programs, which have long been used to help homeless children and elderly people, are beginning to work—and work well—for people with mental illness.

Through foster homes, chronically mentally ill people share in the home and family life that is so much a part of their recovery. Prolonged hospital stays tend to be antitherapeutic because the patient loses social and familial contacts when he may need them most.

Clients in the foster care program operated by Nueces County MHMR Center, Corpus Christi, formerly resided at San Antonio State Hospital, some for as long as 20 years. After leaving the hospital, they live at the Sunshine House, a residential treatment program in Corpus Christi designed to stabilize clients and smooth their re-entry into society.

Living in a home with a family provides the client with a support system that he may not have known for years, if ever. Clients gradually enter the mainstream of life while continuing to be part of the day treatment program at Sunshine House. It is open weekdays from 10 a.m. to 3 p.m., and

clients may attend as often as they like.

Staff at Sunshine House are available to foster parents around the clock for early intervention and crises. Behavioral problems clients may have at the foster home are dealt with by Sunshine House staff, and medication is monitored.

Foster parents are responsible for operating the home and for minimum supervision of clients. They provide transportation and see that clients eat nutritional meals and maintain certain standards of personal hygiene and appearance.

In return, clients make a contribution to the operation of the home from their government entitlements. Foster parents also receive supplemental per diem payments from the Texas Department of Human Resources, which certifies homes after they have passed health and safety inspections.

Staff members at Nueces County MHMR Center, optimistic about the potential of the foster care program, continue to recruit foster parents. The program already has eased the shortage of beds at Sunshine House, thus making space for patients who are ready to leave the hospital and return to Corpus Christi.

Foster care programs also are in progress at Austin-Travis County MHMR Center, Austin; Bexar County MHMR Center, San Antonio; and El Paso Center for MHMR Services.



Sherry L. Groja

Transcending numbers

"Patients don't stay here very long anymore," says Eugene Wilkinson, who was a patient at Austin State Hospital (ASH) for 17 years. "And when they get out, they have to find work."

That's why Wilkinson volunteers at the ASH work training center. He is one of 11,784 people who volunteered their talents and time at department facilities in 1984.

"I'm old, but I can help," he says. "I've tried for jobs, and I know what it takes to get one."

The 65-year-old Wilkinson, who was admitted to ASH in 1953 for anxiety problems, knows from experience. In 1970, he was released and found a job at a local restaurant. He had received job skills training at ASH in cooking and cleaning, which helped him get the job.

He volunteers at the ASH work training center every Wednesday as a quality control inspector. "Like in any factory, there has to be quality control in the workshop," Wilkinson says. "It helps the patients do better work." This sharpens their skills for employment in the community.

Wilkinson also volunteers at the patients' library one day a week. "I found out it was open only on Tuesday

mornings, and I thought that if I could get there on Thursdays, the patients could read and borrow books for the weekends," he explains.

Volunteers worked 873,800 hours in 1984 for TDMHMR—which contributed \$9,512,589 in cash and in-kind donations—for all kinds of reasons. Wilkinson's reason is solidarity with ASH patients, which represents a triumph of sorts for the department. He lives independently and returns to the hospital to help strengthen its efforts to train patients for life in the community. This type of contribution transcends numbers.

Wilkinson understands reentering the community. He lived in a halfway house with two houseparents and their children. He and several other men shared one large room.

"We took care of ourselves," he says. "We paid rent and had a key to the door."

Through his living and volunteering experience at ASH, Wilkinson has seen changes and become something of an expert. Not only patients ask him for advice. "You can ask Eugene anything and he'll know the answer," says Paula Womack, volunteer services coordinator.



Sherry L. Grona



Working-class heroes

"Clients in this kind of work situation exceed our expectations," says Marty Borth about the work site in industry program in Temple for people with mental retardation.

"They improve faster. They learn more about standing on their own two feet," he continues. "They blossom, and you can't stop them."

As director of adult vocational programs at Central Counties Center for MHMR Services, Temple, Borth was instrumental in establishing the program. Eight clients are transported daily to a woodworking factory where they work an eight-hour shift.

At the factory, clients build prefabricated cabinets for apartments and condominiums. They make drawers, attaching drawer guides and hinges, and put doors on cabinets. They also sand the finished product.

The MHMR center's staff prepared supervisors and employees at the factory for the arrival of the new workers. And to help the clients feel accepted, the factory workers immediately showed them around the plant and made them feel comfortable.

"The prospect of being able to work in this kind of program gives sheltered workshop clients incentive," says Borth. "There is a waiting list for industry jobs. Clients must go through the workshop program before they may apply for a job in a work site in industry."

Initially, the MHMR center's workshop trainers went to the work site to help in communication between the clients and other employees. After six months, the communication liaisons were no longer needed; clients understand the job and do what is required.

"They want to work. They're eager," says Borth. "Last winter when we had 10-degree weather, they would be waiting outside on the sidewalk for us to pick them up in the morning to go to work. They are very protective of their jobs. If they miss a day because of illness, they worry that someone may take their job away from them."

"Once they have been in the factory, they don't want to go back to the workshop. Everyone looks up to them," says Borth. "They are heroes to the others." □

TDMHMR sponsors first annual symposium

Crisis management

"Crisis Treatment and Prevention in the Mentally Ill and Retarded" was TDMHMR's first annual symposium, which drew to Houston nearly 400 MHMR professionals from across the nation.

Topics were chosen for applicability to department needs and covered crisis management in the fields of mental health and mental retardation.

Donald M. Gallant, M.D., professor of psychiatry and adjunct professor of pharmacology, Tulane University School of Medicine, New Orleans, Louisiana, discussed early intervention directed toward actually causing a crisis in alcoholics so that they confront their problem before losing everything—job, family, friends and self-esteem.

The cause for 53 percent of epilepsy cases is unknown, and the disorder is not preventable, said L. James Willmore, M.D., professor of neurology and director of Texas Comprehensive Epilepsy Program, University of Texas Medical School, Houston. He said the goal of treatment is to suppress seizures and avoid side effects that interfere with a patient's life.

Larry Ereshefsky, Pharm.D., associate professor of pharmacy and psychiatry, University of Texas Health Science Center at San Antonio, said stress may counteract antipsychotic drugs and that the drugs may not reach peak effectiveness until a month after they are taken.

Although rapid treatment of psychosis with drugs has meant fewer hospitalizations for mental patients, the question today is not whether drug therapy works, but

whether smaller doses would be as effective, said John C. Kuehnle, M.D., assistant clinical professor at Harvard Medical School. The reduction of side effects is a factor also.

Wade Hitzing, Ph.D., director of Ohio Society for Autistic Citizens, Columbus, said families of people with mental impairments have always tried to help themselves and that finally MHMR professionals are trying to assist them. Instead of hospitalizing a person in crisis, Dr. Hitzing asks, why not provide a trained professional to move in and help at home?

Paul Polack, M.D., chief of research and crisis intervention, Fort Logan Mental Health Center, Denver, Colorado, offered another alternative, for people with mental illness whose families can't cope with crises. He said people with chronic mental illness who often experience crises and are admitted to hospitals fare well in foster homes at two-thirds the hospital cost.

He also said that these people learn to communicate better with their own nuclear family after living with a sponsor family. Aside from family issues, he noted, MHMR professionals have underestimated the effect of environmental issues on mental illness, such as poverty, inadequate housing and unemployment.

"A crisis is a decisive turning point that signals something is going to get worse, but when it is acted upon, things will improve," said G. Thomas Bellamy, Ph.D., associate professor of special education and rehabilitation, University of Oregon, Eugene. He said crises are caused by the ser-

vice delivery system and are preventable through changes in it.

Dolores Norley, an attorney and court advocate for people with mental retardation, Deland, Florida, spoke about another system that needs attention. She said the criminal justice system does not want people with mental retardation, yet doesn't know how to get rid of them. The system welcomes advocates for people with mental retardation.

People with mental impairments who exhibit aggressive or self-injurious behavior should be dealt with calmly and unemotionally, said John McGee, Ph.D., associate professor of medical psychology, University of Nebraska College of Medicine, Omaha.

He said people in institutions may be disengaged from the flow of family and community life and have experienced little positive human interaction. His concept of "gentle teaching" for people who are aggressive eschews punishment and relies on the positive value of human presence, participation and reward. Gentle teaching also reduces staff burnout, he said.

Symposium faculty and topics were selected by a TDMHMR steering committee chaired by Joan Harman, director of training and staff resources, Central Office. The committee was composed of TDMHMR system deputy commissioners, superintendents, directors and executive directors. The department's Office of Continuing Education at Texas Research Institute of Mental Sciences, Houston, coordinated the program. □

A pleasurable change of pace

by Lynn Pearson

Imagine spending every day in the same rooms, seeing the same people, doing the same things. While you may be comfortable, with all your basic needs met, wouldn't you want some new experiences and different sights, sounds and smells? Wouldn't you yearn for a change?

You bet you would.

People who live at Mexia State School (MSS) also look forward to new experiences. Unfortunately, because of their mental and physical limitations, these residents can't just go on a shopping spree or stop for a hamburger. They need a little help.

No one is better equipped to give them a hand than the employees of the state school. Employees take their special friends off campus for shopping, meals and overnight stays, not as part of their jobs, but in their free time as volunteers.

Dorothy Porter, director of volunteer services at the school, says, "Our employee volunteers provide some of the best one-on-one experiences our residents have. Taking them off campus involves a lot of responsibility, and it's difficult to find people willing to take that on themselves. I feel we are very fortunate to have employees here who volunteer their time to take residents off campus."

Gwen Scales, MSS self-management trainer, says the residents are interested in doing "normal things like anyone else." Scales, who's been taking residents on outings for several years, says she and co-worker Suzon Moore can take as many as three non-ambulatory residents off campus at a time.

"We go out to eat at the Dairy

Queen or into town shopping," she says. "The townspeople of Mexia accept our folks. They come over to speak to them and treat them like anybody else. That attitude helps the residents feel more comfortable in the community. And we all have a good time."

Sharon Castoe, who's been a resident trainer for approximately five years, recently decided to make a special wish come true for Dorothy Henry, a long-time resident at the school. Henry had found a "beautiful dollie" advertised in a magazine. She cut the picture out and carried it around with her, showing it to everyone. Although Henry makes trips to perform with a group, the Sunshine Singers, she doesn't get to go shopping often. So Castoe began planning a doll-buying trip. The two women left campus to buy the new "Happy Returns" doll, which comes with its own carriage and says "Mama" when squeezed. It is Henry's most prized possession.

"Dorothy was so proud of her new doll, she showed everyone in the store," Castoe says. "While we were out, we went to the grocery store, baked some cookies and ate chicken at my house. Dorothy played with my cat, but she was a little disappointed that my nine-year-old daughter wasn't at home."

When residents stay overnight, employees and their families pull together to make the visit special. Melanie Lockwood, a registered nurse, invited one of her favorite residents, Deborah Anderson, home for Thanksgiving.

"Deborah behaved like any other guest in my home," Lockwood says. "She played with my son and watched television. We all spent



Sharon Castoe (right), trainer at Mexia State School, took resident Dorothy Henry shopping to buy a new doll.

Thanksgiving with my parents. Deborah really liked my mother and went on long walks with her. She talked with my mother, which is difficult because Deborah has a cleft palate and doesn't talk much."

Lockwood says she had wanted to see how Anderson would react to a normal environment. And, since Anderson has no family, the Lockwoods wanted to make her holidays special.

Another employee who involved her whole family in making a resident's weekend visit a success was Sandra Kroll, an audiometric technician at MSS. She has worked with resident Catherine Hillin for several years and they'd become good friends. Kroll began taking her friend off campus for special lunches. Recently Hillin went home with Kroll for the weekend.

"We went shopping in Waco for a cotton slip. I tell you, Catherine wore me out," Kroll says. "I picked up my mother-in-law, and luckily she knew some stores that carry cotton slips. Still, we went all over town. At the end of the day, my legs were really hurting me, but Catherine was still going strong."

Hillin explains: "I like to walk and walk and walk. And, you know, cotton slips are hard to find."

These pleasures—a new doll, dinner in town, another friend, a cotton slip—may sound simple. With the help of employee volunteers at Mexia State School, though, residents are discovering simple pleasures are often the best. □

Lynn Pearson is information director at Heart of Texas Region MHMR Center, Waco.



Sherry L. Groma

NEW CHALLENGES

Gary E. Miller, M.D.

The commissioner meets periodically with employees in Central Office to update them on administrative news. On Jan. 8, he discussed progress on bills and legislative appropriations. Following are his comments.

The 69th legislative session will be a difficult trial for all state agencies, including TDMHMR. The reason is the projected decline in revenue to operate state government in fiscal years 1986-87 and the difficulty in meeting the increased demands for state services while staying within revenue estimates.

The situation now looks highly uncertain. Legislators, many of whom are entering the Capitol for the first time, are facing an un-

Ground is broken for Houston psychiatric hospital

Ground was broken for the new State and County Psychiatric Hospital in Houston on Dec. 17, 1984. When it opens in 1986, the hospital will provide 250 residential beds for Harris County citizens.

State and county officials, under the leadership of Lt. Governor William P. Hobby and Harris County Judge Jon Lindsay, cooperated in developing a proposal, which the Texas Legislature approved in 1981. Facilities had long since become inadequate at Pavilion Hospital, operated by Texas Research Institute of Mental Sciences (TRIMS), and at Jeff Davis Hospital, operated by Harris County.

The \$16.8 million hospital is being built cooperatively by TDMHMR and Harris County. It will be operated on behalf of TDMHMR by the University of Texas Health Science Center (UTHSC) at Houston and by the MHMR Authority of Harris County. The site was donated by the Texas Medical Center.

The hospital's services are for patients requiring short-term and intermediate-length care. Sixty-two beds will be available to children and adolescents, 144 to the general adult population, 22 to substance abuse patients and 22 to the elderly.

Twenty-two of these beds have been designated for patients of TRIMS, the research arm of TDMHMR.

The three service providers will plan a

joint medical staff. UTHSC will conduct psychiatric residency training programs and provide training programs for nurses and other students.

The three-story complex, with 180,000 square feet of floor space, is divided into two wings, reflecting the dual ownership. Patient rooms have outside windows and access to spacious inside living areas. Secure interior courtyards will provide recreation space for children and adolescents. The most advanced information and telecommunication systems are included, and 24-hour security will be maintained by the University of Texas.

Ground breaking for this facility was preceded by two years of intensive planning and intergovernmental cooperation. These efforts were largely carried out by a steering committee representing the three providers and by subcommittees on telecommunication planning, design and construction, program and policy, legal issues and budget and operation.

Chair of the committee was Charles R. Schotz, executive assistant to the TDMHMR commissioner. Dave Walden, executive assistant to Judge Lindsay, and Eugene Williams, executive director of the MHMR Authority, represented Harris County. Bob M. Inge, Ph.D., executive assistant for Health Organization and Management, represented the University of Texas System. □

precedented set of challenges to the State of Texas. I believe the department has the confidence of key legislators who will be acting upon our bills and budget requests for 1986-87. I have a strong sense that these legislators and the Governor believe that this agency is doing a good job under difficult circumstances and that we need additional dollars to meet our court orders.

We are viewed as a priority agency in state government. Legislators understand we are subject to criticism in the press and to problems that emerge without our direct involvement. We are capable, though, of dealing with these problems and can effectively manage the dollars that are given to us.

One indication of the good faith and support we have is the budget recommendation by the Legislative Budget Board (LBB), which results in the appropriations bill that is considered in the legislature. TDMHMR received an additional \$30.5 million for the next biennium. That is not what the department really needs—but it is better than what any other agency got.

James Adkins, executive deputy commissioner, is responsible for presenting bills to the legislature. This year, the department has four bills to propose.

One bill authorizes the land and buildings at the Routh Street Clinic in Dallas to be sold so that a new, more accessible location can be found. Dallas County MHMR Center runs this mental health clinic.

The next bill allows us to charge for support, maintenance and treatment for clients of our facilities based upon projected costs, as is done in private hospitals. The resulting estimated increase in the general revenue fund is \$750,000 per year.

The third bill increases the limit on

the amount the state would pay in the event judgments are rendered against state employees and officers. The final bill will allow the state to pay for renovation as well as new construction of community MHMR centers.

Every advocacy group and party interested in the department has been consulted about these bills, and we have had no opposition. None of these bills carries a fiscal note.

Funding recommendations by the LBB include two line items that will be used to comply with the *Lelsz* settlement in mental retardation services and with the *RAJ* settlement in mental health services. The recommendations amount to \$14 million for *Lelsz* and \$18 million for *RAJ*, with an additional \$8 million for grant-in-aid to community MHMR centers.

The *RAJ* and *Lelsz* lawsuits are powerful imperatives for our agency since they affect its operation. The legislature will continue to have interest in the lawsuits since they have financial implications.

Jimmie R. Clemons, M.D., deputy commissioner for mental health services, is representing the department in dealing with the *RAJ* panel in the area of requirements for individual treatment plans for people in state hospitals.

The board has approved the mental retardation policy that the department developed to put us closer to complying with requirements of the *Lelsz* settlement. The policy, which goes into effect without the need of additional funds, urges the redistribution of money within the system to follow clients as they are moved from facilities to less restrictive settings. Eventually, additional funds will be needed, though.

I want to commend Richard L. Smith, Ed.D., who as acting deputy commissioner for mental retardation services worked effectively toward

developing the mental retardation policy. He and his staff worked with the Texas Board of MHMR, parent advocacy groups and representatives of the *Lelsz* lawsuit in this challenge.

Other LBB recommendations, as reported by Jaylon Fincannon, deputy commissioner for management and support services, include fiscal year 1987 funding for the new psychiatric hospitals in Houston and Fort Worth.

The LBB also recommended that we maximize our revenue collection and so augmented our request for 12 new employees in the Claims office to 21 new employees.

An overall reduction in funding for administration and auxiliary services was recommended for state schools, hospitals and centers. The LBB did not approve an increase in funding for services for people with autism and new funding for extramural research, physician and dentist salary augmentation, community care waiver, the extraordinary medical fund and psychiatric services for the Heart Institute of Central Texas.

The LBB failed to approve funding increases for Central Office units even when the proposed funding increases were related specifically to the lawsuit settlements. But we will not stop at that. We'll go back to the legislature and make an appeal.

We will make it clear to the legislature that an agency cannot comply with lawsuit settlements without a good, strong Central Office staff to supervise and monitor the system. We cannot merely make little changes here and there. Class-action lawsuits affect the entire system of care, and we must make changes and improvements on a systematic, state-wide basis. The only way to do that is to have a strong staff and enough money to make that happen. □

Images

Newsmakers

► **Jaylon L. Fincannon** was appointed deputy commissioner for mental retardation services, **Central Office**, by the Texas Board of MHMR at its Jan. 18 meeting. Fincannon has been deputy commissioner for management and support services since January 1983.

In his new position, Fincannon will direct TDMHMR's 13 state schools and 3 of the state centers.

Texas Board of MHMR Chairman R. Coke Mills, Waco, says, "The department is fortunate to have career employees who are capable and willing to accept these heavy responsibilities."

Fincannon was superintendent of Fort Worth State School from 1979 to 1983. Prior to that he was assistant superintendent at San Angelo State School.

At Abilene State School, Fincannon directed the quality assurance program, and from 1975 to 1977 he was unit director at Richmond State School.

Fincannon holds a master's degree in special education from George Washington University, Washington, D.C., and an undergraduate special education degree from Hardin-Simmons University, Abilene.

He is a member of the American and the Texas Associations on Mental Deficiency and the National Association of Superintendents of Public Residential Facilities.

Fincannon fills the position left vacant by the resignation of Edward Skarnulis, Ph.D.

► **Lonnie H. Willis** was named superintendent of **Lubbock State School** by the Texas Board of MHMR.

Willis, who has been assistant deputy commissioner for management and support services since 1982, began supervising the 520-bed facility Jan. 18.

Commissioner Gary E. Miller, M.D., says, "Since 1979, Lonnie Willis has given our system facilities professional assistance with their program, administrative and budgetary activities. This experience prepares him for his new post."

Willis served as assistant deputy commissioner for mental retardation services from 1979 to 1982. Before that he was director of training and personnel at San Angelo State School for five years. In 1973, Willis was personnel assistant at Abilene State School.

He holds a business administration degree from Texas Tech University, Lubbock, and completed a management training program at the University of Alabama Center for Learning and Language Disabilities, Tuscaloosa.

James Armstrong, Ph.D., superintendent of Corpus Christi State School, served as acting superintendent in Lubbock since October 1984 and has returned to Corpus Christi.

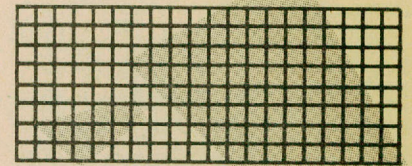
► Three TDMHMR facilities were presented awards for their outstanding employee safety programs Jan. 17 by Attorney General Jim Mattox.

The facilities and safety officers are **Wichita Falls State Hospital**, Paul Yeager; **Richmond State School**, Bill Fair; and **Amarillo State Center**, Jim Stipe.

The award ceremony coin-

cided with the strengthening of the department's employee safety program. General Mattox's accident prevention staff will assist TDMHMR in improving the overall employee safety program. On-site programmatic reviews of each facility's operations have begun, and information about reducing employee injuries and illnesses will follow.

Commissioner Gary E. Miller, M.D., has established a goal of reducing injuries and costs for workers' compensation by 10 percent in the next 12 months. He assigned executive deputy commissioner James Adkins as the department's liaison to the office of the Attorney General.



High-tech training

MHMR aides at San Antonio State Hospital gain a portion of their mandatory training on the computer.

"We're going full steam ahead with the new instructional technology that has become affordable," says David F. Culclasure, Ph.D., director of staff development at the hospital.

The employees enjoy computer training, which takes up 3 of the 11 days of training for new MHMR series personnel.

Dr. Culclasure says "cheap" computers work as well as the big name brands, so "catching up with the times" is not impossible for other TDMHMR facilities.

Always learning

Adult basic education (ABE) is for anyone who wants to learn, and that includes people with mental disabilities. Clients of Pecan Valley MHMR Region, Stephenville, are among those who take classes on the campus of Tarleton State University.

The university setting is ideal for participating clients, says Tom Burkig, director of educational and vocational services at the MHMR center, because they are attending school with their peers. It is also an opportunity to leave the high school or institutional classroom setting.

Tommy Love, a client of Pecan Valley MHMR Region, enrolled in ABE courses mainly to keep busy, but now he realizes that participation in the program also means good exposure to other people. Love completed the 11th

grade. His ABE course load has included reading, history, mathematics and science.

Virginia Kurko-Bazil, Ph.D., assistant professor of education and psychology at the university, says ABE material includes academics but emphasizes interpersonal and personal skills. Students learn to work with one another and are taught skills like money management.

"We have lots of growth in the classes," says Dr. Kurko-Bazil, who is course instructor. "The atmosphere is very positive and supportive."

The student-to-teacher ratio is one-to-one because this twice-weekly class is a required practicum for special education majors, another advantage of the university setting.

The ABE program at Tarleton State University is funded for materials and instructors by the Fort Worth ISD Adult Education Center.

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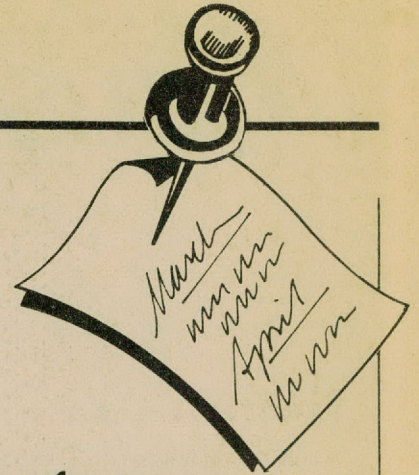
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Conference calendar

March 24-26 The Mentally Retarded Adult Offender

Texas Council on Crime and Delinquency conference

Held in Austin

Contact: Judy Deaver

TCCD

4000 Medical Pkwy.,

Suite 200

Austin, TX 78756

(512) 451-8425

April 11-13 Community Care: Leadership for Tomorrow

National Council of Community Mental Health Centers annual meeting

Held in Washington, D.C.

Contact: NCCMHC

6101 Montrose Rd.

Rockville, MD 20852

(301) 984-6200

April 19-20 TDMHMR Volunteer Services State Council

Spring board meeting

Held in Kerrville

Contact: Volunteer

Services

TDMHMR

P.O. Box 12668

Austin, TX 78711-2668

(512) 465-4660,

STS 824-4660

TRICKY BUSINESS

Leo Cook has always been tricky with his wand, but now he's performing magic with a \$3,500 voice synthesizer.

Cook, a 41-year-old resident at Brenham State School (BSS), cannot speak except to utter a guttural "yes" or "no" in response to questions. Now a machine called a "Phonic Ear" does the talking for him with a touch of his wand, which is attached to a headset he wears.

Cook has no use of his arms or legs. He has used his wand to paint and to communicate by pointing to symbols and words on a slanting board. But the Phonic Ear will take him further.

Cindy Walsh, BSS speech pathologist, arranged to borrow the computerized voice synthesizer from the manufacturer for a two-week trial because she thought Cook could benefit from its higher-level capabilities.

"I see him being able to use the synthesizer in the work-place, where he lives and in the classroom," says Walsh.

The Phonic Ear was developed for people with cerebral palsy who have normal intelligence and for people who have lost the use of their voice.

After the two-week trial, word got out that the Phonic



Carol Mouche

Leo Cook can express himself now with the help of Brenham State School speech pathologist Cindy Walsh and a computerized voice synthesizer.

Ear ought to be a permanent fixture on Cook's lap board attached to his wheelchair.

Brenham State School received private donations from all over the United States, and now Cook has a "voice."

"I want to be able to talk to people every day," Cook says, via the synthesizer, and then he smiles. He has hurdled one more communication barrier without ever leaving his chair. □

This story was adapted from an article written by Carol Mouche for the Brenham Banner-Press.

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