The Tulsa Tribune

Wasting away in Oklahoma

Oklahoma is scrambling to overhaul its system of care for the mentally retarded for the first time in decades.

But change is slow for the 90,000 retarded Oklahomans neglected by an archaic system…

Reprint of a series
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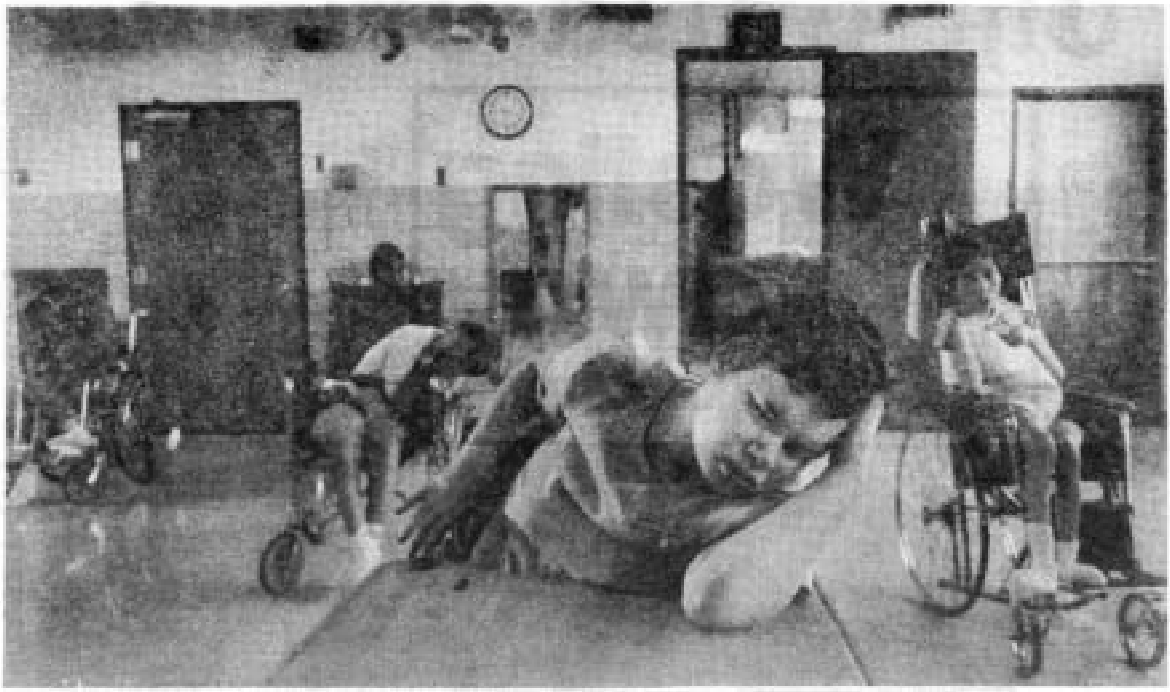
About the series

In the summer of 1984 a dozen employees of an Oklahoma state school for the mentally retarded were suspended after a 7-year-old boy allegedly was abused at the school.

As they looked into the story, editors and reporters at the Tulsa Tribune found the problems in Oklahoma's system of care for the mentally retarded reached far beyond one little boy to encompass the lives of Oklahoma's 90,000 retarded citizens.

Reporters Susan Witt and Joyce Peterson and photographer Eli Reichman spent three months examining the state's

Tribune Special Report



An afternoon at Pauls Valley State School for the Mentally Retarded.

State schools: a one-way door

"The striking feature of the residents I observed is that they simply do not belong in nor can they be helped in this facility....

"It is a tragedy to see such high functioning clients wasting away in this program."

— From a June 1982 U.S. Justice Department report on Enid State School

TUCKED AWAY in Oklahoma's three institutions for the mentally retarded are hundreds of people who don't belong there.

Oklahoma's new welfare regime is scrambling to overhaul outmoded programs that offer help only to those in institutions, isolated from families and communities.

It is a move experts say is long overdue.

At stake is the future for about 90,000 mentally retarded Oklahomans.

Institutions at Sand Springs, Pauls Valley and Enid are home to 1,600; most of the others live with their families.

Many desperately need help Oklahoma has never provided because the state's money has been tied up in institutional care, which experts say is more expensive and often unnecessary.

In a recent survey by a national accreditation society for mental retardation programs, Oklahoma ranked 50th in the nation — dead last — in providing care for the retarded outside of institutions.

A PLAN DEVELOPED a year ago by the Department of Human Services (DHS) calls for hundreds to be moved out of the institutions.

The problem is that alternatives to institutions simply do not exist in Oklahoma.

Outside of a handful of private programs that have few vacancies, about the only place a mentally retarded person can live is with family or in a nursing home designed for the elderly.

DHS officials — under threat of a cutoff of federal funds — say they are creating alternatives from specialized foster care, babysitting and adult day care to group homes and nursing homes with programs geared to them.

Institutions will remain an option, but officials say the kind of care they offer will change.

Most residents will be profoundly retarded and multiply handicapped. The mildly and moderately retarded who do come to the institution will receive short-term training rather than long-term custodial care.

FOR NEARLY 10 YEARS the federal government, which holds the purse strings to Medicaid, has criticized the state's institutions. Those federal funds pick up 55 percent of the tab.

However, political observers say former Oklahoma Welfare Director Lloyd Rader kept an iron grip on operation of the schools and fought "tooth and toenail" every attempt to change them.

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"The feds just never went to the mat with him," said state Sen. Bernest Cain, D-Oklahoma City, a legislator whose subcommittee handled funding for the schools.

"He had a lot of friends in Washington."

Rader retired two years ago.

Both interim DHS Director Henry Beilmon and current Director Robert Fulton made changes in the state's programs for the mentally retarded a top priority.

In July, federal officials threatened to cut off $25 million a year to the three institutions if a plan is not submitted to correct problems.

The plan has been submitted and is awaiting formal approval by the government.

The federal government had been making similar threats for years.

This time, DHS officials did not argue.

"We just took all the comments and decided it was better not to spend time arguing over the validity of them but rather to work on a plan to correct problems," said Jean Cooper, director of mental retardation services for DHS.

OKLAHOMA has provided a one-way door for the mentally retarded.

A lack of community programs has led to the retarded being placed in an institution and also prevented many of them from being released.

"Fifty percent or more of the residents are not in need of and do not benefit from being in" the facilities, reported a physician who investigated schools at Pauls Valley and Enid for the U.S. Justice Department in 1982.

Judges, lawyers, physicians and state officials "ignored" the law and placed people in the institutions because they had nowhere else to put them, said Steven Thomas, who resigned as superintendent at Pauls Valley State School last month.

"They've put some people here — we've violated every right they have," Thomas said.

These people are not mentally ill or "crazy." They cannot be "cured."

Birth defects or injury during their developing years causes them to function at an intelligence. level below average.

Some could be likened to "children" in grown-up bodies although they face adult problems from sex to earning a living.

Some are physically handicapped as well — blind, deaf or crippled.

IN MANY OTHER STATES, national experts agree, most, if not all, of the 760 "mildly" and "moderately retarded" people in Oklahoma institutions would be living in the community or in their own homes.

So would many of the 579 in the state schools whose retardation level is considered "severe" and even some of those 504 labeled "profoundly" retarded.

One DHS official has estimated Oklahoma needs approximately 500 group homes to provide living space for 5,000 mildly and moderately retarded.

But Oklahoma is a long way from that goal.

There are 27 group homes in operation and another 10 or 11 scheduled to open by the end of the year. Group homes are designed for three to eight residents.

DHS plans to move 300 people out of the state institutions by the end of the year. Experts estimate another 500 residents do not belong in the state schools.

Even if all the planned group homes are ready on time, the new homes will have space for only about 60 people.

The majority of those moved from the institutions will have to return to their families or be placed in nursing homes.

THE GROUP HOME is only one of a number of programs DHS plans to finance.

Nursing homes in January are to receive higher Medicaid reimbursements if they provide care specifically for the retarded.

Oklahoma is the last state to adopt such a program. In the past, Medicaid funds for the retarded went only to state institutions.

DHS is applying to the federal government for a Title 19 waiver to use federal funds for community programs instead of institutions. Thirty-three other states already do this.

Cooper said families of the mentally retarded will be assisted by soon-to-be-in-operation "resource brokers" who will help assess the needs of the mentally handicapped.

These 18 case management teams are to be scattered across the state and will refer families to medical professionals and services, such as babysitters, day care or other programs, she said.

"Most people want desperately to keep their child at home," said Cooper. "But now they are pretty much on their own. They don't have any support system. They struggle as long as they can" then, "usually what happens is a family gets desperate and contacts us," she said.

IN FOUR YEARS, total financing of the programs for the mentally retarded has increased by 28 percent while funding for all other state social services has been cut.

Most of the increase has gone into start-up money for group homes and .remodeling at state schools.

The outdated physical structure of the institutions is just one of a series of serious problems the state has been cited for over the past decade.

Federal inspectors have pointed to the failure of the state's schools to provide privacy, proper medical care and adequate training or education.

They have blasted the institutions as archaic places where the mentally retarded are kept in barrack-like dormitories and large groups herded naked into showers for hosing off.

Officials said tranquillizing drugs have been depended upon to control children and adult residents because staffing is grossly inadequate.

Toilet training, feeding and other living skills have been sidelined because there are too few workers, investigators said.

The shortage of nurses and other professionals often shifted the burden of recognizing medical problems to untrained aides, resulting in a delay of treatment and sometimes death, officials said.

Cooper said the schools should be in full compliance with federal regulations by December 1985. She said she expects federal officials will grant extensions as long as a good faith effort is being made to remedy problems.

THE ROLE of state institutions will change; they no longer will need to be a place where people go and stay for years, she said.

A person could be admitted temporarily to the institution to be helped with a particular need, such as toilet training, and released when training is completed.

"A number of clients are going to need long-term care of one kind of another," Cooper said. "The question becomes what facility can meet those needs?

Former Pauls Valley Superintendent Thomas believes the changes — many of them still on the drawing board — will not come overnight.

"Oklahoma has a lot of work to do, and we need to get to it," he said.

A state has to assume some of the responsibility sooner or later because its quality of life stinks if it doesn't."

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> *"We didn't feel like we were the right place for her, hut she was here, and it didn't look like she was going anywhere for a while. So, we just started operating under trial and error."*
>
> — Jeff Chace,
> social worker

Four stories: no place else to call home

ENID — They came to live at Enid State School because they had no place else to go.

These are the stories of four people who are mentally retarded, each with a unique background that led them here.

Unlike many who came before them, they no longer must stay.

Under a new state welfare regime and superintendent, each will be moved to a more appropriate home:

ARTHUR GABLE was only 5 years old when he became ill with diphtheria, a killer disease in that year of 1906.

"He's going to die," a physician told his family before directing that chloroform be held to his face "so he would be more comfortable," a cousin said.

"He didn't die."

The anesthesia froze the little-boy brain at 5, but the body grew to manhood and beyond — to a fragile old

Arthur Gable has lived on the elm-shadowed campus at Enid School for 61 years since relatives brought him after his mother died.

Few know him as Arthur; he is "Grandpa."

A strong young man of 22 when he came, his body is bent by time. He shuffles slowly as the strong young men he lives with scurry about the room.

In recent months, Grandpa has been allowed to retire — he no longer is made to participate in programs designed for the young whose raucous noise makes him nervous.

And the staff-will move him to a nursing home.

BRENDA ADKINS was 9 when a social worker- in her hometown brought her to Enid State School 12 years ago. She is one of 11 children of illiterate parents who need the aid of a guardian to care for their own affairs.

Brenda and her brother Gary are moderately retarded; their subnormal intelligence keeps them from surviving on their own.

Brenda and Gary are learning to survive — mastering skills from cooking and cleaning to recognizing street signs or the instructions on medicine bottles.

Unlike "Grandpa" Gable, they will not grow old at Enid State School

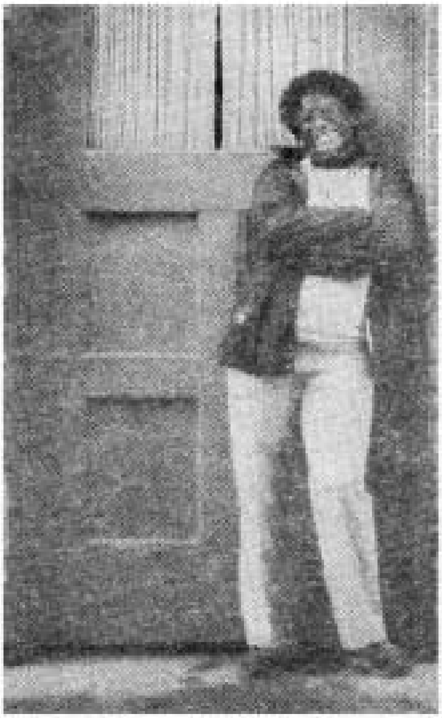
Next week, Brenda will move to the first group home on campus.

Until recently, the brick house had been home to a school physician. Now it has been remodeled, and seven mentally retarded women will live there.

No longer will they eat in a dining hall. They will cook and clean and take care of themselves — with supervision from a house-parent.

Eventually, the staff hopes to place Brenda and Gary off campus in group homes in the same community, so they can live independently but close to one another.


Arthur Gable spends days in the lobby to escape the noise of the younger residents.


Brenda Adkins
. . . on campus

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Pauline Wilkowski has lived here 61 years.

Paula Neumuller

SINCE BIRTH, Pauline Wilkowski's body and brain have been stunted.

She cannot speak or walk, and her days are spent in a crib.

Because of the severity of her handicaps, those who saw her at birth did not expect her to live long.

That was 69 years ago.

Pauline was 8 years old when her father drowned in a flood in Texas. Her mother, unable to manage alone, brought her to the institution in 1923. She is being moved to a nursing home.

PAULA NEUMULLER was normal — a bright and beautiful teen-ager — when it happened.

On a trip to New Hampshire with her mother in 1981, the 16-year-old came down with what they thought was a cold.

She took some antibiotics, but five days later, when she complained of a severe and throbbing headache, her mother took her to a physician.

It was there in his office the attack came. A grand mal seizure wracked her body. She was hospitalized. Preliminary diagnosis: the Bangkok flu.

But her mental status began to deteriorate, and soon she was comatose. Final diagnosis: Encephalitis, inflammation of the brain, caused by virus.

She regained consciousness and slowly started to improve.

Paula was transferred back to Oklahoma's O'Donoghue Rehabilitation Institute, operated by the Department of Human Services in Oklahoma City.

A few weeks later, the O'Donoghue staff reported they had taken her as far as they could and recommended her placement at Enid — in an institution for the mentally retarded.

Here was a girl who only three months earlier had been an accomplished gymnast.

Now she wasn't toilet-trained and couldn't feed herself.

ONCE OUTGOING, she spent most of her time curled up on a bed, refusing to talk.

She couldn't remember her family.

The staff was uncertain about how to train her.

"We didn't feel like we were the right place for her," said social worker Jeff Chace, "but she was here, and it didn't look like she was going anywhere for a while. So, we just started operating under trial and error."

Three years later, Paula once again is a friendly, extroverted teen-ager.

She is almost normal, but she still is different. As Paula describes it: "I was OK until I was 16, and then I lost my memory."

HER MENTAL AGE and IQ are unknown; she has not been tested because the tests used for the mentally retarded at the school are considered inappropriate for measuring Paula's organic brain disorder.

She lives in the Halfway House, a transitional living unit where residents are given responsibilities of washing their clothes and helping in the kitchen.

A social worker says they are trying to find an appropriate home for Paula but are uncertain of what that is.

Her mother, divorced and living in Texas, is searching for such a place near her.

"We would like to see her in a setting where she could be with people of a more-normal intelligence," Chace said.

"We think maybe they might influence her to be a little more mature.

. "We feel like she has reached a plateau here.", ■

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tough with state

Compliance sought on institutions for mentally retarded

OKLAHOMA IS UNDER THE GUN to bring its three state institutions for the mentally retarded into compliance with federal regulations or face a cutoff of $25 million a year in Medicaid funds.

For two years, federal officials and private consultants have issued scathing reports, criticizing the quality of care provided residents of the institutions.

In July, U.S. Department of Health and Human Services (HHS) Secretary Margaret Heckler, speaking before a congressional subcommittee, noted 17 facilities nationwide, including Oklahoma's institutions at Enid and Pauls Valley, were substandard. She cited "major health and safety deficiencies."

"I assure you, Mr. Chairman, that I find this situation appalling," Heckler testified.

She gave the states a month to submit: a plan to correct the deficiencies or face termination, from the Medicaid program.

Oklahoma Department of Human Services (DHS) officials responded with a plan to bring all three schools into compliance with federal regulations by December 1985. The plan is awaiting formal approval by the federal government.

BUILDINGS are being remodeled at all three Oklahoma institutions, additional staff hired and specific problems addressed.

Gov. George Nigh complained Heckler's remarks ignored progress Oklahoma is making and invited her to tour the facilities.

"We are proud of what we have done," Nigh said.

"We are equally cognizant we need to do more, but you can't shut down the institution and put the clients out in the street while you're trying to come into compliance.

"We can't wave a magic wand and improve everything overnight."

BUT PROBLEMS at Oklahoma's institutions had been allowed to continue for nearly a decade. And the shortcomings often involve the most basic of living conditions: group showers, too many drugs, little or no training.

Under the Medicaid program, each state must certify that its facilities meet 116 federal standards.

In Oklahoma, DHS operates the institutions, but the state's Health Department has the responsibility for conducting certification surveys for the federal government.

For years, health department surveyors have granted waivers *to* scores of federal standards the institutions could not meet.

Many exemptions were granted after DHS officials pleaded financial hard ship.

In 1982, Congress gave the HHS the

Sleeping wards like this one at Pauls Valley will be remodeled into bedrooms for four.

authority to "look behind" state determinations by sending a federal survey team to inspect a state facility if the department had reason to believe an institution was substandard.

In January and February of this year, HHS sent survey teams to Enid.

They listed 61 federal standards not met at Pauls Valley and 24 at Enid.

NEITHER FACILITY met standards for "active treatment plans," a requirement designed to prevent "warehousing," strictly custodial care without training.

No survey was conducted at Hissom Memorial Center in Sand Springs, but a private consultant hired by DHS in 1982 found similar problems at Hissom.

HERE ARE EXCERPTS from three reports — two made in June 1982 of Enid and Pauls Valley State Schools by the civil rights division of the U.S. Department of Justice and a February-to-October 1982 study of Enid, Pauls Valley and Hissom by private consultant Thomas Sullivan:

NURSING: A "critical shortage" of registered nurses at both facilities was cited by Leonard Fielding, M.D., who visited Enid and Pauls Valley for the Justice Department.

"This... may explain the observation that six of the death records (at Enid) revealed that there was undue delay in recognition of the resident's health problem resulting in expiration.

"This was an expected result of having health assessments done by (aides) who have no medical knowledge but are, by default, saddled with such responsibilities."

"The nursing staff ... are amazingly dedicated and show every indication of high morale despite the problems they face daily," Fielding wrote.

EDUCATION: "According to staff, all 143 children at Enid State School between the ages of 8 and 12 attend school. This sounded good until I observed what passed for schooling," wrote Robert Carl Jr., an educational psychologist who studied Enid and Pauls Valley schools for the Justice Department.

> ***" We are equally cognizant we need to do more, hut you can't shut down the institution and put the clients out in the street while you're trying to come into compliance. We can't wave a magic wand and improve everything overnight'***
>
> **– Gov. George Nigh**

"... Severely and profoundly retarded youngsters and adolescents get about one-half hour per day of gross motor training.

"This program represents one of the worst distortions of Public Law 94-142 (Education of all Handicapped Children Act) that I have ever observed,"

On a similar program at Pauls Valley, he reported: "The kids for whom the academic program is appropriate simply do not belong (in the institution) while the lower-functioning kids simply do not have an appropriate school program."

School officials say they are rewriting program plans for all residents to see that each receives the maximum schooling and training each is capable of handling.

PRIVACY: " 'Showering with assistance,' an activity which appeared on each resident's individual program, was observed" on a visit to Enid, Carl reported.

"This procedure entailed a gang shower approach; 21 clients were undressed and then herded naked into the bathroom where the two staff hosed the clients down with a large garden-type hose.

"In no way does this activity meet (federal) regulations nor accepted professional standards of practice!

"There were no toilet seats on the toilets, not any privacy partitions in the bathroom."

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A staff member feeds a resident in the infirmary at Pauls Valley State School.

DRUGS: "It appeared that in the absence of adequate resources ... and confronted with the need to minimize disruptive behavior from residents, these schools have substituted medication for the purpose of controlling resident behavior for program activities which would develop resident skills," Sullivan wrote.

"Over 70 percent of sample were using these drugs (tranquillizers and anti-consultants) at both Enid and Hissom and almost 50 percent at Pauls Valley."

BUILDINGS: "The buildings (at Enid) for the most part are abominable, dehumanizing, crowded, lack personal space, are not particularly clean and are certainly not homelike," Carl wrote.

All buildings at Enid State School are being remodeled; eight will no longer be used for living areas, but instead for school or other programs.

INFIRMARIES: "This unit was shocking," Carl wrote of the hospital unit at Enid. "People are housed in the hospital 'for their own protection, for isolation" and, apparently, for medical reasons.

"The odor was bad throughout this unit, with the entire areas smelling of feces, urine and unchanged diapers.

"Individualized programs were almost non-existent. Instead, clients languish in cribs and on mats all day with almost no stimulation or purpose to their life," Carl reported.

"While observing feeding on east ward of the hospital (Enid), I noted at least two residents whose wheelchairs were tipped backward so that the head-neck-trunk position of the resident was essentially prone.

COMMUNITY PLACEMENT: "The community placement program is obviously chaotic and poorly conceived," Carl reported.

"To pretend that most retarded adults are appropriately placed in nursing homes is ridiculous at best.

"It is also probably a denial of needed active treatment services and a method to save dollars by the state at the expense of retarded citizens."

PHYSICIANS: "DHS has relied on physicians with licenses which limit their medical practice to the institutitonal campuses Since most ... are both foreign born and foreign trained, some are likely to experience problems in communicating, and since many of the state school residents have communication difficulties, the potential for problems to arise in the diagnosis and treatment of medical conditions is greater than normal," Sullivan reported.

WORK BY RESIDENTS: "As a result of staff shortages, some institutional residents work without pay in institutional laundries and kitchens and in cleaning residential buildings," Sullivan reported.

"It has been claimed that these assignments are part of a treatment plan. It is not clear how these activities fit into the individual residents' treatment plan.

"It is clear that the three state schools are able to operate with reduced staffing as a result of this work contribution by residents."

ACTIVE TREATMENT: "The records showed very little active programming, generally no more than one hour per day for each client," Carl wrote on his report on one cottage at Enid.

"There was a 'paper compliance' program built on activities of daily living.

"In chasing the federal (Medicaid) reimbursement,*. . both of these institutions pretend to offer individualized active treatment programs. This is a sham, in my opinion," Carl wrote. Said Fielding: "... There is no emphasis on taking the residents into the community even though many are capable of engaging in and learning from many activities, such as clothing purchasing, restaurant dining, Laundromat operations, cosmetics and toiletries purchasing, just to mention a few."

STAFFING: "Professional staffing levels at the three schools are approximately three to four times less than those levels as reported in the national surveys of public residential facilities with the exception of social worker staff levels at Hissom," Sullivan reported.

"Staff shortages are so serious in the direct care areas that client neglect and abuse are almost natural responses for the staff. It is absolutely impossible to render safe and adequate custodial care services given the staffing ratios, let alone provide active treatment," Carl wrote.

Since the report was issued, the state added 200 direct-care staff positions, which brought the schools student staff ratios within federal limits.

The schools' superintendents note, however, those ratios include every staff member, not just those who care directly for the children.

Also, problems with frequent employee absences leave the schools short-handed much of the time.

Jean Cooper, director of the DHS mental retardation. division, has ordered all new employees to receive an intensive two-week course in modern methods of care for the retarded before they go to work with the residents.

In the past, employees received no training except what they picked up on the job.

OVERALL IMPRESSIONS: All three institutions "generally reflect an out-of-date treatment philosophy" reported Sullivan of the Bio Management Corp. in Watertown, Mass.

Another report supported the criticism.

"The main impression one gets is of ad hoc, traditional institutional care. Where the staff works hard, despite what seems to be inadequate direction from the administrative leadership, some fairly adequate custodial care is given.

"This is particularly true at Pauls Valley State School. Frankly, even the custodial care offered at Enid State School is often seriously inadequate, even dangerous, in my opinion," wrote Carl.

"This is not to criticize the staff, who seemed to be typical institutional staff.

"Instead, it is to highlight the extreme staff shortage of direct care and nursing personnel throughout both facilities," ■

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One day of life at Hissom

Tribune writer Susan Witt observed a group of mentally retarded boys at Hissom Memorial Center at Sand Springs from 1 p.m. until after the children went to bed at 9 p.m.

By SUSAN WITT Tribune Writer

THEY WERE LITTLE BOYS - a baker's dozen of them around 10 years old — who did as they were told and sat quietly in chairs lined against the wall of the dayroom.

Nine o'clock bedtime was an hour and a half away.

After about 40 minutes ticked off the clock, it was evident the calm could not last much longer.

They were starting to fidget.

Despite scolding, one began to twist a curtain hanging near him, and another poked his neighbor.

It seemed normal they were restless, given little boys and their endless energy.

But nothing was normal here — neither the children nor the environment in which they lived.

This was one wing of a cottage at Hissom Memorial Center, a state institution for the mentally retarded.

The mental age of these boys who had been told to "sit down and be quiet" is that of a 2 Mi-year-old.

This was their home.

The walls were bare. Teddy bears or toy trucks were not to be seen.

Playthings are kept under lock and key.

Only at appropriate times do workers unlock the cabinet and pass out "toys," such as dog-eared women's magazines, basketballs or a broken See 'N Say, which no longer speaks the names of the farm animals on its face.

"The kids tear them up," an aide explained.

EARLIER IN THE DAY, a reporter's notebook had been a coveted article. Pages torn out and distributed were a source of delight to the kids — but the one ballpoint pen didn't go far among those eager to scribble on the paper.

A day room in a boys' cottage at Hissom Memorial Center in Sand Springs.

> *"/ hate it when I try to write a check and people ask where I work. / say Hissom, and some people took at you like you're some kind of a beast"*
>
> — Hissom aide Martin Whipple

THE CHILDREN sat quietly as aides brought a food tray to each.

When all were served, those who could speak joined in reciting a blessing. The children began eating.

An aide's notebook listed "self-feeding goals" for each resident. A few were to "pierce food with a fork," but mostly merely were to "scoop food with a spoon."

Workers stood nearby as the children ate and helped those who asked for assistance.

AFTER DINNER, a speech therapist and other professional staff, idled during the summer school recess, took groups of four swimming, to arts and crafts activities or to story-time sessions.

Those left behind wandered about the room.

The recreation supervisor took five boys at a time to the playground.

"Sit down on the bench," he said.

One at a time they were told to stand and bounce a basketball back and forth with the recreation leader. Next, they were lined up in a row to shoot baskets.

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When one boy broke rank and headed for a jungle gym on the fenced-in play yard, he was dragged back to the basketball court by an aide who hugged him from behind, the child's arms pinned against his sides.

A tram ride followed with the driver making a stop at the campus garage to have several flat tires aired up. The children were ecstatic as the tram rumbled around the campus and next door to view a fenced-in institution for juvenile delinquents.

After the ride, bedtime was an hour and a half away, and attendants said they wanted the kids to sit quietly and "wind down."

The children sat in chairs lined against the wall. They were given a snack, two cookies and a cup of orange juice, which they quickly consumed.

After the cookies were gone, they had nothing to keep them occupied. No books, no crayons, no toys, no television.

One boy pulled his foot into his lap to contemplate the sole of his tennis shoe. He was told to keep his feet out of the chair,

AFTER THE children remained in their seats for about an hour, attendant James McNabb promised to turn on the radio, "if you'll be good and keep quiet."

A barely audible tune crackled through the air, and before long, the children were clapping to the beat.

"You said you'd be quiet," he warned them sternly. The clapping stopped.

A short time later, one little boy stood up in front of his chair and his arms and feet started moving to the rhythm.

"Nobody said you could get up and dance," the attendant said.

The boy sat down.

TO AN UNTRAINED OBSERVER, the boys in cottage 15 appear to have few physical problems. A few have the facial characteristics of Down's syndrome; others look like the kid who lives down the street.

One child was deaf, another somewhat spastic. Some could not speak, and one small boy was unable to walk without assistance, though aides could not explain why.

Workers described many of the children as "aggressive" and "hyper."

One boy apparently had "torn up" several expensive emergency lights — mounted high on the wall atop a battery pack. The child could reach the lights by standing on a water: fountain, mounted low for handicapped access.

When asked why the child repeatedly tried to fiddle with the lights, a worker said, "He likes to tear things up sometimes he'll spend hours at it."

One aide said the child sometimes would stare off into space and reminded him of someone "who was having a flashback."

"I've asked him what he is looking at, and he says 'the colored lights,' " the aide said.

Tranquillizing drugs were dispensed to a number of the children at four-hour intervals.

By 8:30 p.m., aides started making preparations for bedtime.

Toothbrushes, each already spread with toothpaste, were brought into the room.

Children were called by name and allowed to move from their chairs to retrieve their toothbrush. Some brushed their own teeth; others were brushed by the attendant.

EACH BOY was showered by a worker and sent back to the dayroom in underwear and T-shirt to return to his seat along the wall.

Some were beginning to doze off, but all were kept in he dayroom until 9 o'clock when the entire group was taken into the sleeping ward.

The children scrambled into bed without a fight.

After the showers, the cottage supervisor checked each child for bruises.

THIS IS COTTAGE 15, where 7-year-old Jason George allegedly had been bruised and bitten in June, the marks discovered when his mother took him off campus for a home visit.

A $6 million lawsuit, the suspension of 10 cottage workers and the firing of a nurse officials said failed to report the bruises had followed.

Employees were defensive about publicity that had resulted.

Aide Martin Whipple, who was off work on the-days officials believe the boy was abused, said he was "shocked" when investigators showed him photographs of bruises on the boy. The pictures were taken at a hospital emergency room where his mother took him.

"He was a good kid — he didn't deserve for that to happen to him" said Whipple, a 20-year-old college student who started working at Hissom a year ago.

"I still can't believe it. I don't know how it could have happened. I hate it when I try to write a check and people ask where I work. I say Hissom, and some people look at you like you're some kind of a beast," he said

The incident was demoralizing for employees, many of whom say they ensure lousy hours and low pay because of a commitment to the children.

"I care about these kids, I feel like a brother to them," said aide Tim Collier as he tucked one little boy into bed.

The 19-year-old started working at Hissom eight months ago when he was unable to find construction work.

"IT SURE ISN'T MONEY that keeps me working here," said Collier, who takes home $684 a month in salary.

"I've thought about quitting lots of times," he said, citing the low pay and emotionally draining work.

"Then I think about the kids, and I can't."

Aides receive training in a two-week orientation in which they learn first aid and the basics of cottage life at Hissom.

They work six days in a row and then receive two days off. The cycle is repeated, and then the third week they work five days and are given a three-day weekend.

Both Collier and Whipple say they knew nothing about mentally retarded children before they came to work at Hissom.

THE YOUNG MEN work hard and show genuine affection for the children. But sometimes their lack of experience shows.

Earlier in the evening, Whipple had tried to comfort one of his charges.

The small boy, who couldn't speak clearly, sat near a window sobbing, pointing at the cars in the parking lot and repeatedly gesturing with his thumb alternately at his chin and at his forehead.

"This means mother, this means father," Whipple explained, repeating the sign language the child was using.

"He sees the other kids' parents come and get them, and he wants his to come, too.

"But he doesn't have a mother and father.

"This is the hardest part about this job," Whipple said, hugging the boy tightly.

The child's sobbing grew to wailing and continued half an hour until he was nearly hysterical.

A toy or some crayons and a coloring book might help — anything to distract him.

That this young man cared about the boy was obvious

But sometimes just caring isn't enough.

Tribune Special Report

Old guard clashes with new ways

OKLAHOMA WELFARE OFFICIALS, prodded by federal regulators, promised massive reform in three state institutions for the mentally retarded.

Until two weeks ago, it looked as if changes might be implemented with little controversy.

Time worn practices were being dumped by new superintendents at state institutions in Enid and Pauls Valley.

But the abrupt resignation of one of the new superintendents last month raises questions about the commitment of the state to bring innovative, modernized programs for the 1,600 mentally retarded residents in Oklahoma's institutions.

It is unclear what **the** sudden removal of Pauls Valley State School Superintendent Stephen Thomas means to the program.

Thomas and Dr. Ray Nelson, who took over at Enid State School four months ago, are out-of-state experts who brought a philosophy of treatment that clashes with long-accepted practices in Oklahoma.

Both moved quickly in revamping the schools.

IN CONTRAST, transformation is moving more slowly at Hissom Memorial Center in Sand Springs where the 20-year superintendent is reluctant to abandon methods some experts have labeled "archaic."

The opposing views highlight what state officials face as they overhaul programs for the mentally retarded — a move mandated by the federal government, which has threatened to cut off $25 million in Medicaid funds unless drastic changes take place.

Plans have been outlined by the state's Department of Human Services (DHS) to develop programs that will allow hundreds of mentally retarded to live outside institutions.

Thomas, who was interviewed by The Tribune before his resignation, and Nelson both said they believe in "normalization."

They contend the mentally retarded should live in the "least restrictive" environment, one as normal and appropriate as possible.

Both said they believe institutions for the mentally retarded are unnecessary — even for those whose retardation is considered severe or profound.

JAMES BORREN, superintendent at Hissom, said he believes "there is a place" for group homes and other community programs, but "some people's needs are served best, at this time, and will be for a long time, in a facility such as ours." Nelson and Thomas disagree.

James Borren . . . superintendent at Hissom

" There is no ***one here who*** *couldn't be somewhere else, given the resources and manpower necessary,"*

— Dr. Ray Nelson Enid State School superintendent

"There is no one here who couldn't be somewhere else, given the resources and manpower necessary," said Nelson of the Enid facility.

Said Thomas: "I think clinics and hospitals can take care of those who are ill. Hospices can take care of the older (people) in appropriate kinds of places to give care that you and I could end up in some day."

"Their needs aren't that much different."

But hundreds of Oklahoma's mentally retarded have few options but to live in institutions. There are 1,600 residents at the three state facilities.

While state officials make plans to provide alternatives to institutions, Nelson and Thomas were attempting to make life for those who live there as normal as possible.

Borren said he agrees with the normalization philosophy and has "for years," yet he has lagged in implementing changes at Hissom and defends keeping some policies his counterparts are scuttling.

IN LESS **THAN** a year at Pauls Valley, Thomas reorganized the staff, assigning professionals to living units rather than isolating them in an administration building.

Everyone from psychologists to housekeepers are assigned to a specific unit.

His unit design for staff has been adopted for use at all three schools. Nelson already has implemented it at Enid in the four months he has been there.

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Dr. Ray Nelson


Stephen Thomas

"The staff is totally decentralized. Instead of having five people responsible for 25, which means no one is responsible, we have one person responsible for five." Nelson said.

Hissom parents have been promised such a reorganization by DHS officials, but Borren said he can't say when it will occur.

"It's going to take a while," he said.

Nelson and Thomas moved quickly in making other changes.

Thomas said he found two files for each resident — one medical, one programmatic.

The medical staff didn't know what programs a resident was involved in, and the program staff was unaware of any medical problems, he said.

"That system was destroyed. We built new case files (for 530 residents)," he said.

BORREN SAID some changes his counterparts made will not occur at Hissom because they might endanger residents.

While Nelson brags, "You will not find one locked door (among living units) at Enid State School," Borren said doors at Hissom will have to remain locked in many areas "for the safety of the clients."

Prohibiting locked doors on living units is part of "an attitudinal change that the staff is learning to adjust to," Nelson said.

"If you lock the doors, you don't have to worry about a kid running off, and you might not watch them as carefully. If the door's not locked, you better watch them," Nelson said.

When asked why toys are kept locked up in living units at Hissom, Borren said it is to prevent children from being hurt with toys when there is not enough staff to supervise playtime properly.

Nelson said it is important for residents to have playthings or personal items they can keep and call their own.

tainly would after they had been here for a while."

"Now we're going to be moving into a humane environment with an opportunity for folks to have private space."

NELSON HAS TOLD parents, reporters and anyone interested to come visit the facility at Enid, any time, day or night, without notice.

The invitation left members of the school's Parent-Guardian Association with their "mouths dropped open," said parent Sharon Smith, explaining "everything had to be prearranged" in the past.

That open-door policy "means a lot to a parent, whether I go or not," she said.

Nelson said the institution has nothing to hide. The key is discovering what is normal for each person, Nelson sad.

"For some, this may be a residential facility; for others a group home, others their own home.

"For some, the environment which is normal may be a restrictive environment. It is like a small child, you are not going to give them the same freedom as a teen-ager in your home. What is normal for them is supervision," Nelson said.

YET NELSON said he does not see his role to close down the institution he administers.

Instead, he wants to make it a place where "parents can feel positive" about the training and care their child receives.

All three institutions fail to meet an array of federal standards, ranging from understaffing to overmedication and lack of treatment.

Nelson said Enid will be in total compliance by next year, and once that is done, his goal is to get the school accredited by the Accreditation Council for Services for Mental Retardation and Developmental Disabilities — "looked on as the ultimate in accreditation."

Structural renovation is under way at all three schools to remodel open-bay wards where 24 or more slept side by side into four-per-bedroom units and to provide privacy partitions in bathrooms.

With the large wards, Nelson said, "if (residents) didn't have any problems when they came, they cer-

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"There are some things here that I don't like, but we're working on them, and I'm willing to show them to you.

"This is a state institution, and I want the folks to know what's out here. They are the stewards of the money," Nelson said.

In contrast, Borren at first balked at a reporter's request to spend an eight-hour shift in a cottage at Hissom. The visit was arranged after DHS officials in Oklahoma City contacted attorneys.

Hissom's policy manual states visiting hours for parents are from 1 p.m. to 4 p.m., prohibiting visits by most working parents except on weekends. Parents must make a request two weeks in advance to take their child off campus overnight.

BORREN SAID the policies are "only a guideline" and if they are not convenient for parents, exceptions can be made.

Policy also states parents may not have visiting privileges until after the child's third week at the institution.

"That's always been a suggestion only," said Borren.

"But somewhere, somehow, there needs to be an adjustment on the part of the child and the parents that they are out of the home. They have to learn to live with that," he said.

Until it was discontinued a few weeks ago, Hissom had a policy of allowing parents only one tour of the cottage where their children live.

Borren said he believed the tours were a disruptive influence on other students.

BORREN has been superintendent at Hissom since it opened in 1963. Before that, he spent a year as administrator at Clover Bottom State Hospital and School in Donelsen, Tenn., and a year as administrator at Central State Hospital in Nashville, Tenn.

He was an accountant at the Nashville facility before being named administrator.

Nelson was commissioner for developmental disabilities in Arkansas, overseeing 100 community programs and six institutions.

He also has served as superintendent of a 3,500-bed institution in Virginia, which he said shrunk to 2,200 beds and was accredited for the first time under his administration.

Earlier, Nelson ran a management training program at the University of Alabama at Birmingham, teaching how to run institutions for the mentally retarded.

Thomas was director at the Alpine Regional Center in Gaylord, Mich., a state institution for the mentally retarded that was closed when all residents were placed in community settings.

He had worked earlier as a case worker for Nebraska's Office of Mental Retardation.

Both Thomas and DHS officials said his resignation was voluntary with Thomas wanting to "look at other career opportunities."

THOMAS temporarily has been assigned to the Oklahoma City DHS office to help develop community programs.

Dr. Jean Cooper, head of mental retardation programs for DHS, said Thomas asked for the assignment because he wanted central office experience in the area of community programming.

Thomas received such experience in a job he had earlier in Nebraska.

Jerry Poyner, an aide to Cooper, will serve as acting superintendent at Pauls Valley, directing the school from his Oklahoma City office.

Nelson gives high marks to the Enid staff, which he said is "qualified, dedicated and concerned."

He said they are adjusting quickly to changes he has implemented.

"I've outlined the overall plan of where we want to go, and I've had total cooperation from everyone here," Nelson said.

"They're willing to try. And that is all I can expect."

Tribune Special Report

Gatesway: a vision that grew as nursing home alternative

RONNIE GATES' FAMILY believed he was a little young at age 28 for a nursing home, but that is where the state planned to send him 21 years ago.

Gates was one of hundreds of mentally retarded adults Oklahoma planned to move from its state schools for retarded children to nursing homes in the early 1960s.

"We had these visions of Ronnie in a rocking chair, and we just weren't ready for that," said his sister, Nina Honeyman.

The family made other plans.

Ronnie's mother, Helen Gates, rented a farmhouse at 71st Street and Lewis Avenue and moved in her family and her furniture.

She quit her job and set up housekeeping for Ronnie and 12 other mentally retarded men. The family was the staff.

A few years later, the family rented a second house at 51st Street and Lewis Avenue for 13 mentally retarded women.

More houses were added until "we realized we couldn't just keep renting houses," Honeyman said.

A non-profit corporation was formed, and the Gatesway Foundation began offering mentally retarded adults an alternative to state institutions or nursing homes.

TODAY, Gatesway has expanded to a 25-acre campus in Broken Arrow and offers care ranging from a nursing home-type facility for mentally re-, tarded adults to group homes and off-campus apartment living where residents receive minimal supervision.

The goal is to train residents so they are able to move up to less restrictive settings.

Gatesway has seen some residents move up through program levels until they are totally independent. Many have competitive jobs in the community; some own cars; some have married.

And 21 years after the Gates family solved the problem of finding an appropriate home for Ronnie, the state of Oklahoma is following their lead.

The Department of Human Services is developing a range of programs for the mentally retarded similar to those offered by Gatesway.

Honeyman, who has served as director of Gatesway since her mother retired in 1979, applauds the move.

She said Gatesway's waiting list for admission stays constant, with about 50 to 60 names, an indication of the need for more programs.

Martin Globe sews a label on a placemat woven by a Gatesway resident to sell at a bazaar.

OKLAHOMA is 10 years behind every other state" in providing community care for mentally handicapped, she said.

Ronnie Gates lives with 67 other men and women in Gatesway's main building, an "intermediate-care facility" or nursing home with programs geared to the mentally retarded.

Gatesway has 68 other residents living in seven group homes offering three levels of care. In on-campus cottages, the staff helps residents with chores, such as shopping for groceries, cooking and cleaning.

House parents offer less assistance to those living in off-campus duplexes.

In a Tulsa complex operated by Gatesway, residents live alone in apartments. Staff members check on them on a routine basis to see if they are eating correctly, to-help with checkbooks and to be sure "friends" or others don't take advantage of them.

Gatesway residents range in age from 18 to 60, but most are in their late 20s.

A NEW FACILITY is planned at Gatesway for mentally retarded children with multiple handicaps, pending state approval.

Honeyman said Gatesway stresses teaching residents to live as normally as possible.

"We teach them how to wear makeup. We teach them you don't wear stripes with checks. We teach them to act normal.

"Our vehicles don't say 'Gatesway' on the side. The residents asked for that.

But Gatesway has met some opposition to group homes it recently opened in duplexes in Broken Arrow, Honeyman said.

One resident, a sleepwalker, got confused and accidentally went to a neighbor's house instead of the one she lived in. She was returned to her houseparents with a warning from the neighbor that next time he would "greet her with a gun," Honeyman said.

Community awareness will solve the problem, she said.

"People confuse mental retardation with emotional illness. They think these people are emotionally disturbed or criminally insane," she said.

As group homes become more common, she said she believes people will see they have nothing to fear. £8

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Roger and Sue Ann Bradshaw at home in their Tulsa apartment.

Newlyweds share future

Retarded couple's parents supportive of marriage

LIKE most newlyweds, Sue Ann and Roger Bradshaw are looking forward to a long and happy life together.

Theirs is a love and a life many feared they might never experience.

Roger and Sue Ann are mentally retarded.

Born with a double harelip, a cleft palate and curvature of the spine, Sue Ann has had 16 operations in her 26 years.

Roger's handicap was undetected until he was about 4 years old.

Mildly retarded, his condition was aggravated by petit mal seizures — a short clouding of consciousness that often left him confused or lost.

Both once lived in state institutions, for the mentally retarded — Roger, 22, is a former resident at Hissom Memorial Center; Sue Ann came from Enid State School.

They now live in a Tulsa apartment complex where mentally retarded adults are supervised by house parents.

No one could be happier about their marriage than their parents.

"I'm especially proud of them. To me, they seem to be the perfect couple," said Norma McKinney, Roger's mother.

"I had thoughts Roger might not ever be married, and I think Sue Ann's parents felt the same way about her," Mrs. McKinney said.

"I just think it's wonderful," said Sue Ann's mother, Betty Broaddus.

THE PARENTS' supportive attitude toward the relationship is not always shared by other parents of mentally retarded, said Nina Honeyman.

She is director of Gatesway Foundation, which operates the apartment complex where Roger and Sue Ann met.

"Some parents are appalled by the whole idea. Some have the conception their child is always going to be a child, and it is hard for them to deal with the sexuality of adults," Honeyman said.

Honeyman said Gatesway staff neithey encourage nor discourage romancing between residents.

Instead, they offer sex education but leave decisions about romantic relationships or sexuality to the residents themselves.

"These people have to be taught what is proper, just like a normal child," she said.

"I'm not saying we promote sexuality, we don't.

"But it is a fact of life, and just because you ignore it, doesn't mean it isn't going to happen. We've just chosen not to bury our heads in the sand," she said.

AT GATESWAY, she said, staff recognize "these people do have sexual feelings" and do not make residents feel they are "wrong or dirty."

Sexuality seminars have been offered for parents.

"We try to assure parents this is normal," she said.

Honeyman said most women at Gatesway take birth control pills.

Some married couples have had genetic counseling and have elected for sterilization.

However, some physicians are reluctant to perform such procedures because of lawsuits in which mentally retarded people have sued both the surgeons and their own parents, Honeyman said.

For mentally retarded couples who can have normal offspring, decisions about whether to have children may depend on the ability of the parents to care for a child.

Honeyman said a few Gatesway couples have left the program, had normal children and apparently have been able to care for them with support from their families.

The Bradshaws have discussed the issue with their parents and do not plan to have children, Mrs. Broaddus said.

ROGER AND SUE ANN each moved to the apartments about a year ago as nest-door neighbors. It wasn't long until the romance began.

By July, they were married.

"We were going to be married in September, but we couldn't wait," said Sue Ann, grinning at Roger.

Home to 22 mentally retarded adults, the Gatesway program is the only one of its kind in the state.

Residents live a relatively independent life — sharing an apartment with a roommate and working in the community.

House parents offer supervision, help with menus and grocery shopping and transportation when city buses aren't running.

LENA COLLINS, another resident at the Gatesway apartments, says she and husband, Rick, look forward to having a second married couple to share experiences.

After you get married, you aren't always interested in the things the single people are," she said.

A third couple also is making plans for a wedding, said Andrea Marcum, director of independent living for Gatesway.

Mrs. Broaddus said she and her husband were "really surprised" when they first learned their daughter wanted to marry.

"We told her: 'If you love each other, yes. We want you to get married.'

"We felt she deserved a little happiness."

Sue Ann works at Heritage House restaurant, washing dishes, cleaning tables and cooking pastries.

ROGER WORKS at Magnetic Media Inc., where he does janitorial work and acts as "handyman."

Both parents believe the couple can live productive, independent lives, although they feel they always may need help with finances.

"I think these two kids will have a good life," Mrs. McKinney said.

"Somebody upstairs really cares about them." ■

Tribune Special Report

Finding a place to work, live, love

" We can do anything here that we could do in a regular hospital."

— Ellen Elliott, R.N.

Some of the tasks include throwing away pieces of scrap lumber.

Another worker puts sawdust into vacuum tube.

Nebraska No, 1 in U.S.

LINCOLN, Neb. — If Lloyd and Kyle had been born in Oklahoma, they probably would have grown up in institutions.

But Lloyd and Kyle don't live in institutions, because they were born in Nebraska.

In a survey released last month, a national accreditation society rated Nebraska No. 1 for providing more community-based care for the mentally retarded than any other state.

Oklahoma was dead last, No. 50.

Nebraska is rural, conservative and financially strapped, like Oklahoma.

Ten years ago Nebraska was undergoing radical changes in its system of caring for the mentally retarded, as Oklahoma may be undergoing today.

This is what happened in Nebraska:

AT 29, LLOYD wasn't toilet trained, couldn't feed himself, spent much of his day "throwing fits" and rolling on the floor.

Lloyd's mother, Mrs. Loren Schreiner, was more than skeptical when social workers said they were going to take him out of the institution, put him in a family-style home in a small town near Lincoln and give him a job.

She had placed him in the Nebraska state institution at Beatrice 15 years before. She thought he would stay there the rest of his life.

Now, months later, Lloyd is toilet trained, feeds himself and lives in a home with three other mentally retarded people in a quiet, small town.

He works all day — with help — stacking lumber at a workshop for the mentally retarded. He receives a paycheck — although it may be only a few pennies each week — which he spends as he chooses.

"He used to cry when we would leave him (at the institution)," his mother said.

Now, she said, when she leaves after a visit at the group home, he is smiling.

In 1968, the Beatrice Center for Developmental Disabilities in southeastern Nebraska housed 2,200 mentally retarded adults and children.

After years of controversy, a federal lawsuit and an overhaul of the state's care system, only 461 people live at the institution. About 400 others live in privately run facilities.

Nebraska cares for another 2,000 who live in the community.

".... he died in the arms of someone who loved him very much."

— Ellen Elliott, R.N.

Some clients at Nebraska's workshops for the mentally retarded screw bolts into a board.

It maintains 399 residential facilities; these are apartments or homes in which small numbers of mentally retarded residents are cared for by live-in attendants or supervisors who visit on a regular basis.

Many of these mentally retarded persons go to work each day at workshops designed for them.

Even some who are so profoundly retarded that placing one box inside another is too complicated have tasks at the workshops they perform for pay.

Lloyd stacks lumber other retarded persons will make into furniture.

If all a worker can do is fold a cardboard box along a crease, it is handed to another to paste together.

Staff members might work months to teach one person how to throw waste pieces of wood into a pile.

* * * *

KYLE, an infant in a 5-year-old's body, was placed in the arms of Deborah Fick's family the day before Thanksgiving last year.

Blind and frequently wracked by seizures, Kyle's retardation is so severe he responds to almost nothing.

Sometimes he tries to grasp a hand that holds his or makes a small noise when someone hugs him.

Tubes in his stomach and throat allow him to eat and breathe.

Kyle couldn't stay with his own family any longer because, the emotional strain was wrecking his parents marriage.

"He really spooked us at first," Fick said.

She and husband Jim had been foster parents for teen-agers on contract with the Lincoln-area service for the mentally retarded.

But they, had never taken in a child as fragile as Kyle. They had no special training.

The fears began to subside after a while.

Once, the feeding tube in his stomach came out and they had to slide it back in.

"It wasn't so bad after that," Fick said.

The Ficks' 11-year-old son and 2-year-old daughter help. They talk to Kyle and hold his hand when the seizures make him moan in pain.

"I think our 2-year-old understands him the best," the mother said. "She lies beside him on the floor and talks to him."

Nine years ago the Ficks gave birth to a retarded son who died.

They said they hope Kyle will be able to live with them for the rest of his life, although they know it, too, could be brief.

"We're more accepting now since we lost our own son," Fick said. "I hope we can do enough for Kyle if something does happen. Just so his mother knows that we did try."

* * *

NEBRASKA offers extensive services designed to keep children in their own homes. It requires its public school systems to provide educational and therapeutic services from the time mental retardation is diagnosed, even if that is in the womb.

A school system pays for the diagnosis and provides counseling for parents.

Children who can't attend school are provided with an in-home teacher.

The state provides respite care for a fee based on the family's ability to pay.

Respite care is a service for families who need a day, a week or even a few hours away from the demands of their mentally handicapped child or adult.

It allows them to take that time without having to search, sometimes in vain, for a qualified babysitter.

Nebraska provides most of these services for 2,000 people for less money than Oklahoma spent last year to keep 1,600 people in institutions.

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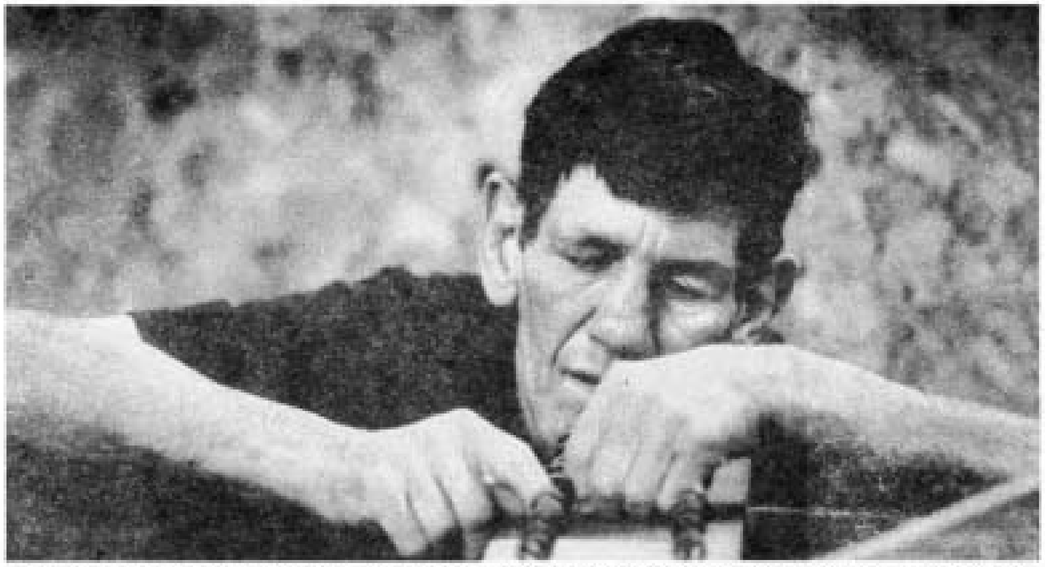
A worker gathers screws, nuts and bolts together at Nebraska's workshop.

* * *

IN THE LIVING ROOM, a young girl with a tube in her throat to help her breathe is lying on a recliner stretched out to its full length.

A boy who can't walk is lying on the carpet between the television set and the aquarium, contentedly watching visitors go by.

In the den, a 5-foot teddy bear sits next to the oxygen resuscitation equipment.

It looks like the other three-bedroom, ranch-style homes in this residential neighborhood of Omaha.

At the children's medical unit of the Omaha area's services for the mentally retarded almost nothing is white.

There are no hospital beds and the only medical equipment is the emergency equipment stashed away in the den.

It is just a house filled with toys, stuffed animals and the kind of furniture anyone would use for day-to-day living.

"We can do anything here that we could do for them in a regular hospital," said Ellen Elliott, a registered nurse who is on duty at the house eight to 12 hours a day.

She and a physician are on call 24 hours a day, and the emergency room of a hospital is less than five minutes away.

At least two people are on duty at all times; only six children may be in the home at one time.

They care for mentally retarded children who are ill, recovering from surgery or in a crisis stage of any of the many chronic medical problems that plague the severely retarded.

When the sick children are better, they are sent back to their homes or to foster homes.

SOME of the children, though, are sick enough they will not leave.

Nathan lived in the medical unit all his six years. He died there a few months ago.

His mother had asked no extraordinary measures be taken to save him.

Elliott said she is grateful she was on vacation at the time.

"I'm afraid I may not have been able to not do anything," she said, "but he died in the arms of someone who loved him very much."

* * *

THERE ARE PROFESSIONALS in Nebraska who speak of large group homes and sheltered workshops as if they were as outdated as Model T's.

None of Nebraska's residential facilities house more than six people, and more are being formed with a maximum of three.

More programs are being started that allow retarded persons to work at regular jobs rather than in sheltered workshops.

In some programs, two or three retarded persons may work at a job and share the salary only one person normally would have.

The smaller size of the living arrangements reduces the number of problems that have plagued the community programs during the years they were being developed, such as complaints from neighbors and allegations of abuse by the attendants.

Some still object, however, to pushing all of the mentally handicapped into the community.

Within the past 10 years, parents' groups have formed to keep Nebraska's state institution and its private institutions open.

They believe having their children living in the outside world places too much pressure on them.

Their children, they say, are happier and safer in the self-contained world of large institutions.

Even those opponents, however, say complaints about community programs have become infrequent in recent years as the state learned how to better run the programs.

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Nurse Ellen Elliott in a house in Omaha where seriously ill children are cared for.

And they don't object to change, they say, as long as community care is available for some but not forced on all.

THE GOAL of community-based care is to help all mentally handicapped persons live as independently as their ability allows, said Dave Evans, director of the Office of Mental Retardation.

It takes time, he said, to discover how much ability a person has.

"Part of a person's rights is the right to the dignity of risk," he said.

"A person, even a mentally retarded person, has a right to experience failure. ■

Mentally handicapped definitions

The American Academy of Mental Deficiency defines mental retardation as below average intelligence and functioning caused by birth defects or injury during a child's developing years, typically before age 16.

It is not mental illness, and it can't be cured.

It generally is measured as feeing ihe 3 percent of the population with an IQ of 70 or below, says Susan Farrell, a physician with Tulsa's Developmental Pediatrics Center.

In addition, the mentally handicapped are divided into categories: borderline, mild, moderate, severe and profound.

Generally. Farrell said, those classified borderline are ones with IQs of 75 to 85 who do not fall into the technical category of retardation but who have trouble adjusting to society. : Most retarded persons fall into the range of mildly retarded with 59 to 69 IQ and typically can function with about two-thirds of the ability of an average person.

The moderately retarded are considered to be those with about half-normal functioning, an IQ of 40 to 55.

Severe is considered an IQ of 25 to 39; profound below 25.

But, Farrell cautions, IQ is only a number measured by tests.

Mentally retarded people often have physical handicaps that can make taking tests difficult.

"It's pretty hard to take a test when you're blind and can't see the test or are deaf and can't hear it," she said.

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Label deters struggle by handicapped

Cheryl Piwenitzky sorts pills into boxes.

> *" The biggest problem mentally handicapped people face is that other people try to put limits on them."*
>
> — Nancy Ward

LINCOLN, Neb. — Over dinner at a downtown restaurant, Nancy Ward was taking an attorney and a lobbyist to task for using discriminatory language against the mentally handicapped.

"The biggest problem mentally handicapped people face is that other people try to put limits on them," she was saying.

Ward is an articulate, animated spokesman for her cause.

It is a fight she knows well — she is mentally retarded.

"I don't like being called retarded," she said as she cut up a steak for her wheelchair-bound friend, Cheryl Piwenitzky.

"I guess it is because of when I was in school," Ward continued. "I remember being called retarded then."

Mental retardation is defined by physicians as below-average intelligence and functioning caused by a birth defect or an injury in the developing years.

It is difficult, though, for a medical definition to reveal the frustration of the words "mentally retarded."

Or to measure how far determination can stretch the limits of the handicap.

PIWENITZKY, a cerebral palsy victim, is confined to a wheelchair and has limited use of only one hand.

She must have help to eat and dress. In addition to her severe physical handicaps, she is mildly retarded.

Intense speech therapy helped her to communicate, although it is sometimes difficult to understand everything she says.

Those who know her have discovered her intelligence and a wry sense of humor, said Lynn Rucker, director of the Lincoln area's services for the mentally retarded.

IQ means little to Nebraska social workers who deal with the mentally retarded, Rucker said.

"It's artificial," Rucker said. "It can't measure how well a person adjusts or how well a person carries on in society."

Today, Piwenitsky lives in her own apartment with a hired attendant. A motorized wheelchair allows her to go to work each day at a sheltered workshop, sorting non-prescription drugs into boxes and doing other hand work.

She, like Ward, is active in People First, a self-advocacy group for the mentally handicapped.

They are fighting discrimination, such as the Nebraska state law Piwenitzky and friends broke at her 30th

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Nancy Ward is pursuing her dream of becoming a nurse.

birthday party.

It is against the law to serve liquor to the "feebleminded.," so her friends had to order a strawberry daiquiri for her.

WARD WORKS at a motel laundry and lives in an apartment by herself. As president of Lincoln's People First chapter, she spends her spare time teaching other mentally handicapped people about assertiveness, handling discrimination and how to lobby politicians for what they need.

She was placed in special education classes in sixth grade and spent years in speech therapy.

Today, she speaks like a pro.

"She ought to be in a courtroom," said the attorney whose terminology she had challenged.

At 34, Ward, has battled discrimination much of her life.

Her dream of becoming a nurse has been thwarted so far, she said, because she was not allowed to take science, algebra or geometry in her high school special education classes.

All these subjects are necessary to be accepted into an LPN nursing program at the local community college.

She has spent the past five years slowly and painfully taking one college or adult education course at a time to get the background she needs for the nursing program.

"Sometimes the classes are too hard for me. It's really hard for me to remember things," she said.

Her friends spend hours reading textbooks to her, making material easier for her to understand.

She has failed the entrance exam to the nursing program twice, the last time by one point. She can take it only once more, and she plans to try again next year.

Her parents and some friends want her to quit. They are afraid, she said, she won't be able to handle the frustration if she fails the third time.

She said she isn't sure how she would handle it, but she isn't going to quit.

But Ward has had her triumphs.

She just finished a college algebra class that one of her high school special education teachers warned she would never be able to handle.

She not only made an "A," she had the highest marks in her class.

The first thing she did was take the report card to the special education teacher.

"She was flabbergasted. She didn't say anything," she recalled. ■

Tribune Special Report

Fighting 'nightmare' system

Dean Louros at Hissom Memorial Center.

A NEW JOB brought Basil and Kathie Louros to Tulsa from Pennsylvania two years ago. A top priority was finding good schools for their three teen-aged sons.

Finding that school for 16-year-old Dean Louros was a nightmare, his mother said.

Dean is severely retarded, a 2 1/2-year-old in a man's body. He can't speak and has autistic tendencies that intensify his condition.

In spite of his handicap, he had been enrolled in public schools in Pennsylvania since he was a toddler. A physician who diagnosed his condition had told the parents early schooling was crucial.

He lived at home with his family, and a school bus picked him up in the morning and dropped him off at the end of the day.

During the summer, he went to camp.

On weekends, he often stayed at a group home with other mentally handicapped youths his age, a plan to ease him into that type of living situation permanently when he became old enough to leave home.

His parents had assumed he would have a similar life in Oklahoma.

BUT ONCE HERE the Louroses soon discovered why Oklahoma is ranked as No. 50 among states in providing community care for the mentally retarded.

Mrs. Louros said the family suffered through two years of bureaucratic wrangling and an emotional setback for their son before finally placing him in a state institution.

The mother said when she first moved to the state she began seeking out programs similar to the ones her son was involved in earlier.

"I couldn't find them. I couldn't even figure out who to call," she said.

"It was like we had moved to a backward country.

"When you come into this state, they < give you all this wonderful information about lakes and mountains.

"Any information we found for our son, we found because we dug for it," she said.

Although federal law requires public * schools provide education for the handicapped from birth to 21, Mrs, Louros said Jenks and Tulsa County schools-offered only "makeshift kind of classes" inappropriate for her son.

She said the family became resigned to the fact the only option was to place the boy at Hissom, a state institution for the mentally retarded in Sand Springs.

MRS. LOUROS made application for her son's admission to Hissom and received a reply from Lloyd Rader, then director of the state Department of Human Services.

The Aug. 5, 1982, letter stated: "... admission to a state facility for the mentally retarded cannot be considered until you have lived in the state for one year prior to admission in August 1983." "I blew up," she said.

"That's unconstitutional. I wrote Gov. Nigh. I wrote President Reagan; I called the newspapers, the TV stations. I talked to other parents. I must have talked to everybody in the state."

She said she talked with parents who were keeping their children at home for a year, without schooling, waiting to meet the "entrance requirement."

She talked to some parents whose marriages had broken up from the strain.

MRS. LOUROS said she was amazed she could find no active advocacy group, no formal parents organization. One reason, she surmised, might be parents are "too buried by problems to" fight back.

A mother with a handicapped child at home can't attend meetings; they have a hard time even talking on the telephone, she said.

"Life becomes so difficult you cannot function.

"In Pennsylvania, the state provided babysitters if I had to go somewhere," she said.

"I came here, I couldn't go to the grocery store.

"It's not right people have to live like that. It's almost like you're being punished for having a handicapped child," she said.

A YEAR OF TURMOIL followed with her son shuffled through special education classes held in a back room at a Tulsa junior high.

"Finally, the school suspended him. They said the child was not for the school, which was what we had been saying all along.

"In the meantime, my son had a psychotic breakdown. He could not cope."

A year had passed, and Dean was eligible for Hissom.

"But now he was psychotic, and Hissom wouldn't take him," she said.

He was sent to Central State Griffin Memorial Hospital for the mentally ill in Norman where he recovered from the breakdown.

"Those are the people who really straightened him out, and I can't thank them enough," she said.

Hissom once again was an option, and Mrs. Louros called to make arrangements to inspect the facility.

She said officials there told her: "You can't see the school until your son has been admitted."

"I said: 'That's crazy! How do I know if I want to send him there?' "

> *"It's not right people have to live like that. It's almost like you're being punished for having a handicapped child"*
>
> — Katbie Louros, mother of retarded son

HISSOM POLICY allowed parents only one tour of their child's living area, apparently after admission, until the rule was abolished "several weeks ago," said Superintendent James Borren.

In desperation, Mrs. Louros recounted her experiences to a state legislative committee. The testimony caught the ear of Jean Cooper, who recently had been hired by DHS to run the state's mental retardation programs.

Cooper intervened. Mrs. Louros toured the facility, and Dean was placed at Hissom.

Mrs. Louros said she is pleased with the care he receives at Hissom, but she is bitter about the treatment the family received when they moved here. She blames the ordeal for her son's emotional problems.

"I felt like dirt. They treated us very poorly.

"If we would have known what we know today, we would not have taken this job (in Tulsa)," she said.

She said she has seen improvements since DHS Director Robert Fulton and Cooper took over.

"It is getting better, and I hope we had some part in it.

"Dean is getting very good care now. They treat him good. They are very kind."

BUT SHE SAID her son "doesn't get much stimulation," and she wants more for him.

"Everyone needs to do something with their life.

"My son was going into a group home in Pennsylvania.

"Educationally, we know he's not going to learn much. But he can do vocational-type things (at a sheltered workshop).

"Many of these other children (at Hissom) they can do a lot more than that. They can get a job.

"These kids can do it if they're given the chance," she said.

"I hope my son will get to that point again." ■

Tribune Special Report

Group homes: families fearful of unknown

Dennis Gray cleans the pool at Alpha House.

BY THE TIME he was 21, Dennis Gray, a mildly retarded young Tulsan, had heard the question from his father many times.

"He would say: 'One of these days, Dennis, I'm not going to be here. What are you going to do, what are you going to do?'"

What Dennis did was move to Tulsa's Alpha House, one of a handful of group homes for the mentally retarded operated by non-profit organizations in Oklahoma.

He is one of the lucky ones.

For many other parents, the question still is a haunting refrain.

What happens to a retarded offspring when parents or other family members die?

Who will care?

Who will provide?

Who will guard?

For years the state's answers to those questions were its three institutions or nursing homes.

AS OKLAHOMA alters its methods of caring for the mentally retarded, however, parents and families of the mentally handicapped are going to be facing choices they never have had before.

And for some, the new choices are as frightening as the old questions.

Dennis' father opposed his son's move into the group home at first.

"He kept telling my mama: 'He'll never make it there,'" Gray said. "I showed him, though. I made it."

LIKE PARENTS in other states who have switched from reliance on institutional care to community care, Oklahoma parents might be split into factions over the direction the state's services should take.

In other states, some parents have lobbied hard to do away with all institutions.

Others, initially opposed to the idea of having their children in contact with other "normal" persons, changed their minds once they saw progress.

And, some still are fighting to keep their children in the institutions they feel are safer and more appropriate for their children.

"I didn't want them in a group home. You hear bad things about group homes, too," said Mary Hatt, a Lincoln, Neb., mother. "It's not that I was embarrassed (by) them. I just didn't want them to be shoved aside by the rest of the world."

She was hesitant but finally consented to allow her twin retarded daughters to leave an institution, after 10 years, to live in a group home.

Now she hopes her daughters remain in the group home for the rest of their lives.

"The decision to put a child in an institution, believe me that's hard. It's worse than losing them to death," she said. "Then to go through it all over again; the grieving happens all over when you take them out."

There are parents who are infuriated by scandals in some community programs and too rapid deinstitutionalization.

The men of Alpha House pose for a "family" portrait with houseparents Myrt and Bill Rushford.

"I THINK there should be a whole array of services to serve the retarded," said Pat Crawford, who is active in national organizations that oppose taking all mentally retarded persons out of institutions.

"It's so hard for people to understand how much a severely retarded person needs. I think it's scary .. that some people want to get rid of (institutions) entirely."

DELORES BOURLAND, whose 33-year-old son has lived at Pauls Valley State School since he was 7, is an Oklahoma parent who fears the move toward community placements.

"My son has not been trained to become independent or semi-independent," she said.

"I don't know whether at 33 he can make the transition. All of us find the older we get, the harder it is to make adjustments.

"He's happy, content. He works at a sheltered workshop, and it's a good routine for him.

"I'm a widow. I'm 58 years old. I do have a lot of apprehension about what's going to happen to this young man when I'm not here."

With the institution, "I've always had the feeling he will be cared for.

"In the community, I don't have that ' security, I don't know what the follow-up will be.

"I just don't see it as the answer for his life," she said.

SHARON SMITH of Enid said she had similar fears for her 16-year-old daughter, Diane.

The girl has lived at Enid State School since she was 6 except for a yearlong stay at home when she was 13.

The mother said she is pleased with the care her daughter gets at Enid.

"If I wasn't, she wouldn't be there."

But, she said, "I want her to be as much as she possibly can."

Tests show Diane works at the third-grade level. This year she is attending vocational classes, learning to cook and clean and care for herself, with the hope of someday moving to a group home.

"It has really done a lot for her self-esteem," the girl's mother said.

Slowly, she said, her fears are subsiding and she sees "group homes are what it's all about."

"I think when they are established people will get used to the idea, and I don't think so many parents will be so frightened," she said.

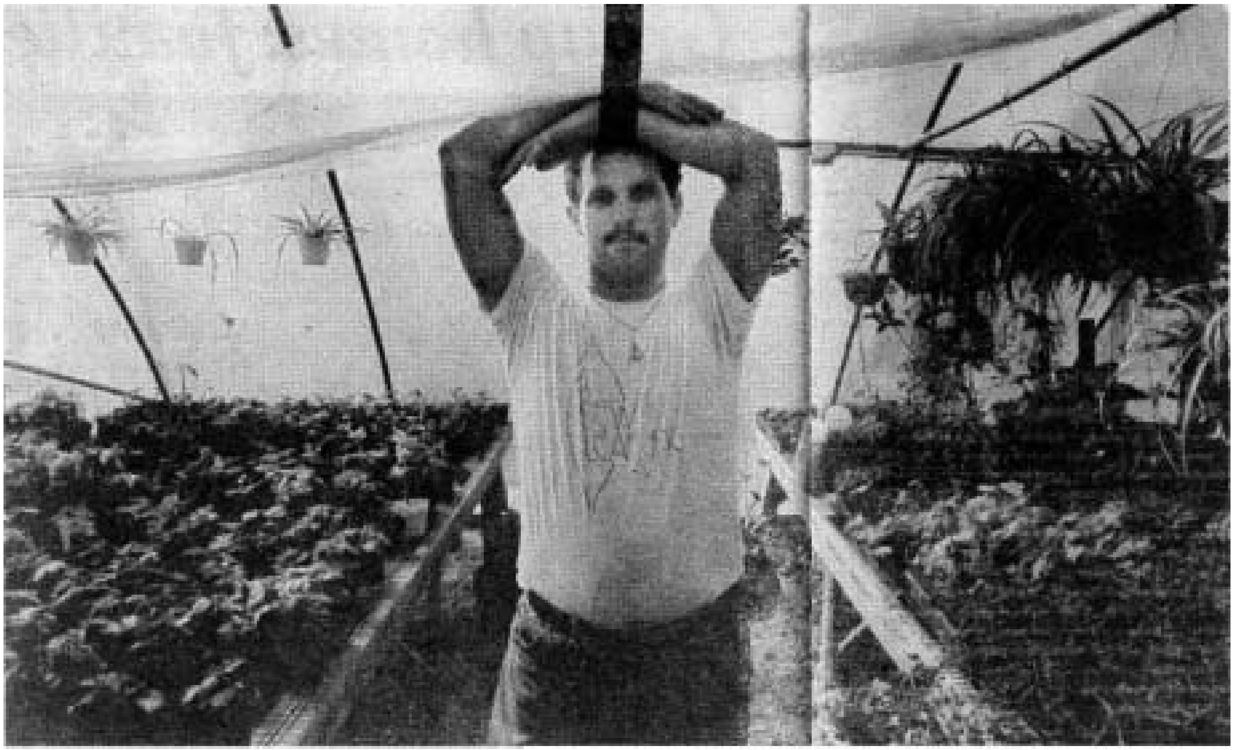
At first apprehensive about plans for her daughter, Smith said staff members asked her to listen for 15 minutes.

"And they set me down and they were able to convince me that this would be good for Diane.

"And that's what it's all about: What's good for Diane." ■

Tribune Special Report

A 7-year-old mind is jailed in Tulsa



Christopher Cross takes a short break at the Tulsa Greenhouse where he works in a special training program

> *" This is no more of a place for someone who is mentally retarded than it is for someone who is mentally ill."*
>
> — Art Lee Tulsa County Under sheriff

SOME of his neighbors are afraid of him. At 26, Christopher Cross is 6 feet tall and weighs 185 pounds.

Tests show he has the mind of a 7-year-old and an IQ of 43.

His brother says he would never hurt anyone unless he was provoked.

Yet Cross is charged in Tulsa District Court with assault with a dangerous weapon.

He is accused of hitting neighbor Janice Craft on the head with a 2-by-4 board. A preliminary hearing is scheduled for Oct. 24.

The victim said Cross may have been reacting to mistreatment and taunting by neighbors.

"People have really hurt this guy. Some of the neighbors treat him awful, and he just fights back," Craft said.

Before his arrest, he was chased by a neighbor wielding a baseball bat, hunted by a police helicopter and threatened with a beating, she said.

Roger Cross said he doesn't know whether his brother hit the woman, but he contends it is wrong for the police and the courts to jail his brother and send him through the criminal justice system with no consideration for his mental handicap.

OKLAHOMA LAW has no specific provision for dealing with the mentally retarded in the court system.

And court officials admit it is difficult to decide "what to do" when someone like Cross is arrested.

Although the victim said police officers know Cross and told her the man is mentally retarded, arrest reports given to jailers made no mention of his mental capacity.

In **a** supplemental report given to the prosecutor, the officer noted Cross had "apparent mental problems."

The jailers on duty the weekend he stayed in Jail, the prosecutor who filed the charge and the judge who set Cross' bail at $5,000 apparently were not told he is a former resident of a state school for the mentally retarded and functions on a first-grade level.

Police make no distinction between the mentally ill and the mentally retarded, labeling all "mentals."

"Our officers can't make that determination. They're not mental health specialists," said Deputy Chief Don Bartlett.

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Bartlett said police department policy requires if officers are aware a suspect has "mental problems" it must be noted on arrest and injury reports.

No such notation was made on either report in the Cross case, he said.

BARTLETT SAID he will investigate to see if the officers did know such information and omitted it.

The officers involved in the arrest could not be reached for comment.

Assistant District Attorney Tom Gillert said cases such as this normally are "flagged" and an appropriate solution worked out "so that he is taken care of and we don't have the situation repeat itself."

"Somewhere or other it broke down. I don't know where that was," he said.

CROSS LIVED at Hissom Memorial Center until he turned 19 and then went to live with his father in Florida where he helped dig holes for his father's realty signs.

About six months ago he moved to Tulsa to live with his mother. Weekdays, Cross waters plants at a greenhouse in a training program for the mentally retarded.

Evenings he rides his bicycle and picks up cans for spare cash in the east Tulsa neighborhood where he lives.

Since he moved to Tulsa, Cross has been beaten up, run off the road while riding his bicycle and shoved to the ground when he visited a garage sale in the neighborhood, the family said.

His latest problems began Sept. 11. The victim describes it this way:

Craft said she was nervous because of a series of harassing phone calls in the neighborhood near Disney Elementary school and because her home had been broken into the previous day.

When her dogs barked in the back yard, she opened the drapes.

"I was standing face to face with this guy," she said.

The "guy," she said police told her later, was Cross.

"I screamed and hollered, fell over the table and chairs in the room and ran to get my neighbor," she said.

The man ran away, and she and a neighbor alerted a police officer who was up the street taking a report on the phone calls. The officer called the police helicopter into the search, she said.

The woman said police returned to her house later, said they had spotted Cross and explained to her he "is a mentally retarded guy who rides his bicycle around the neighborhood."

"He won't hurt you," she said an officer told her.

Craft said officers later brought Cross to her house to be identified.

Four days later, the-woman said she went out to her car about noon to get something, and Cross rode up on his bicycle.

She said he put his hand on her shoulder and said, "You got pretty animals. Cat. I'm going to get you."

She told him: "You stay right here, I'm going to get Buddy (a neighbor), and he's going to beat you up."

She said Cross left cursing.

About 7 p.m., she said she saw Cross ride by on his bicycle.

Her husband ran out of the house to hunt Cross saying, "I've had it with him."

Shortly afterward, Cross drove his bike up her driveway.

"I went to the door and said, 'Stay right here. I'm going to get my gun and call the police.'

"I called a neighbor, and he chased him around the corner with a ball bat but couldn't catch him," she said.

"THE POLICE CAME, and while they were here, he (Cross) drove up in the driveway about three houses down.'"

She said the police officers began to chase him but lost him.

The officers came back to her house. While she was talking to them, the dogs began barking.

She walked in the back yard.

"I turned to go back in the house, and he (Cross) hit me over the head with a board," she said.

"I saw him right before he hit me."

Craft said she went to a minor emergency center, was treated for a mild concussion and released.

Police arrested Cross about 45 minutes later at his mother's house where the two were watching the Miss American pageant on television.

He was handcuffed and taken to jail.

"I was so scared, I didn't know what to do," said his mother, Patricia Riggins.

She called an attorney who uses the answering service where she works.

CROSS was arrested about 10:30 p.m. Police records show he was booked at the police station shortly after midnight. Tulsa Jail records show he was not admitted until 7:30 the next morning.

Police say he may have been kept in a city holding cell until then.

Tulsa County Under sheriff Art Lee said a jail nurse who interviewed Cross when he entered the jail recognized a problem and had him placed in a special section designated for those likely to be intimidated.

Four or five others were placed in the cell with them.

It would have been "nice," Lee said if police had advised them of Cross' mental capacity.

"This Is no more of a place for someone who is mentally retarded than it is for someone who is mentally ill," Lee said.

"We need to know these things and make an effort to keep him in a proper place. It might have made a difference in the whole chain of events had we known," Lee said.

Gillert said it "would have been good to know" Cross' background when deciding how to prosecute the case.

CROSS remained in the jail until Monday morning when his mother and attorney asked he be considered for release under New Day, a county program where certain inmates are released without bail.

The attorney, Delbert Brock, described Cross to New Day counselors as "a little slow."

He was not interviewed for release, possibly because of the seriousness of the crime, said New Day Director Herb Reed.

One counselor said he probably would have interviewed Cross if he had been described as having the mind of a 7-year-old, rather than "slow."

"Frankly, I'm embarrassed," said Reed, saying the program is designed to secure release for people like Cross "who shouldn't be in jail."

Cross was released late Monday after his mother paid a bondsman.

The attorney, Brock, advised the family to ask the judge to send Cross to Eastern State Hospital in Vinita for psychiatric evaluation although he has no history of psychosis, Roger Cross said.

He is back home living with his mother.

She no longer lets him leave the house in the evenings when he returns home from his job at the greenhouse.

"But we can't keep him locked up," his brother said.

RECORDS from Hissom describe Cross' behavior when he was discharged in 1977 as "good."

"A lot of the neighbors are really mean to him. They call him names; the kids ridicule him, Craft said.

"Chris has got this vengeance in him now. Maybe this is his way of getting it out.

"I feel sorry for him," Craft said.

"If I thought he was going to go to the penitentiary, I'd drop the charges in a .minute," she said.

"BUT IF I dropped the charges and he hurt a child later or killed someone, I couldn't live with myself," she said.

"He needs help.

"And maybe this will get him some[1] help." ■

Tribune Special Report

How police deal with the retarded

WHAT WOULD Tulsa police officers do if they arrested a mentally retarded man with the mind of a 7-year-old?

"I've never seen one arrested," said officer John Bowman when asked the question. A reporter was referred to Bowman as one of the department's most knowledgeable officers on the subject.

"If he were that severe, I don't think he would be arrested," the officer said.

Tulsa Police did arrest just such a man Sept. 15. Although officers apparently knew the man was retarded, his mental status was not reported to jailers.

Christopher Cross, whose IQ is 43, was charged with assault with a dangerous weapon. Prosecutors said they did not know the man was retarded until a reporter told them.

Bowman, who works in the planning and research division of the police department, said he has done research into police handling of the mentally ill.

He said Tulsa police have "no policy at all on dealing with mentally retarded people" and receive no training on the subject,

He said a policy is not necessary because "it is such a rarity."

Tulsa attorney Curtis Parks defended a mentally retarded man arrested in 1982.

His client, Timothy Walker, is 20 but has the mind of a 6-year-old. He was accused of fondling a small girl.

WITHIN HOURS after the retarded man walked into Tulsa Jail, other prisoners tried to set him afire.

"There is no way this guy can stay out of trouble," Parks said, "He's as vulnerable as anything.

"If you had any kind of program to occupy his time, he would pose no danger. But you turn him loose without anything to do, he is going to get in trouble.

"I don't pretend to have the answer," Parks said, "but I know it's a problem.

"And I know the police don't make any distinction. I don't necessarily blame them, he said,

Tribune Special Report

A GROUP OF PARENTS of mentally retarded in Tulsa have advocated formation of a crisis intervention team to act as mediator when retarded people are arrested.

In June, the group, Homeward Bound Inc., wrote 18 state agencies and private groups, asking a training program be set up to teach lawmen how to deal with the mentally retarded.

The letter, sent to the Department of Human Services mental retardation office and other agencies said:

Guidelines are needed to ensure "anyone being suspected of having mental retardation if picked up for any reason is not detained with criminal or psychotic element, that DHS be notified immediately and that there would be a place to take this person until details could be sorted out quickly,"

This is important because "a lot of persons with mental retardation are fascinated by police officers and firefighters and the vehicles they drive with their horns, lights and sirens. This goes for ambulances, too."

So far, only two agencies have replied. DHS was not one of them.

The Department of Education thanked them for including them on the mailing list.

A Department of Corrections official wrote back the agency has set up programs to handle mentally retarded inmates and to train guards in handling them. The official, added, however, the department does not have the money or is it its responsibility to train persons outside the agency.

IN OKLAHOMA, the jail regulations state a mentally ill person must be kept away from other prisoners, but it doesn't mention the mentally retarded.

In Lincoln, Neb., an intervention bureau deals with the mentally retarded people who are arrested. A person is hired to act on the defendant's behalf and to act as a liaison among the police, the retarded person's family and the state's agencies for retardation services.

The liaison also draws up alternatives for punishment to offer judges.

The National Coalition for Jail Reform estimates there are about 600,000 mentally ill or retarded persons in jails across the country. They can't separate the two because the people who do the counting, jailers, usually don't know the difference.

"The jail intake person probably doesn't have any idea what a mentally retarded person is," said Judith Johnson, executive director of the organization.

"He thinks they're being rude or obnoxious, and it becomes a downward spiral because the jailer doesn't know how to react," she said.

"The problems are enormous." ■

Tribune Special Report

Editorial

Wasting away

WASTING AWAY in Oklahoma" was the headline on the first in a 10-part series by Tribune writers Susan Witt and Joyce Peterson, detailing the shortcomings in the state's handling of its men-tally retarded people. The headline referred to the custodial care typical of three state institutions for the retarded, care that provides relatively little preparation for life in the outside world.

The two reporters found a national accreditation society for mental retardation programs recently ranked Oklahoma 50th among the 50 states in providing care for the retarded outside of institutions. But they also found the cost of institutionalization in Oklahoma is $85 a child per day, compared with an estimated $36 a day or less that would be required to place the retarded in private facilities.

THEY CONTRASTED Oklahoma's pro gram with that in Nebraska, rated best in the country. Last year, Nebraska spent $33 million on group homes, sheltered work shops and other community care programs serving more than 2,000 mentally retarded citizens, and another $17.4 million for institutional care of 460 persons.

Oklahoma spent $45 million to care for 1,600 mentally retarded persons in its three institutions — institutions which have been under sharp criticism for failing to meet minimum federal standards, Next year, Oklahoma will spend just $5,1 million for community programs such as those that consume the bulk of Nebraska's budget.

Given proper use of our resources, thousands of retarded Oklahomans can be trained to function outside institutions. Many are capable of holding jobs and providing at least a portion of their own upkeep. Oklahoma's Department of Human Services, under new leadership, is struggling to provide adequate staffing at its institutions at Sand Springs, Enid and Pauls Valley, and it is seeking private facilities in which to place hundreds of those now institutionalized.

Resistance comes from some parents who fear that retarded children, now grown to adulthood, will not be able to cope with life outside an Institution. It comes from some administrators who believe sincerely the institutional approach still is required for a high percentage of the retarded. And on a more mundane level, it conies from patronage employees and politicians who fear the loss of jobs if institutional care is sharply reduced.

"Quality of life" is a term often used to describe good schools, cultural and re creational opportunities. But it also has to do with the way we treat those citizens least able to fend for themselves. Oklahoma has a long way to go before it can boast of the quality of life afforded its mentally retard ed. ■

Tribune Special Report

No voices raised for the retarded

> *" You always had to deal with Lloyd Rader before; that didn't foster any kind of grass-roots support."*
>
> — Sen. Bernest Cain, D-Oklahoma City

Dave Powell, president, says his group has a major impact.

WHEN Nebraska Gov. Robert Kerrey-vetoed a $21.6 million bill for services to the mentally retarded this year, the people spoke loudly.

Within an hour, each member of the Legislature had received as many as 200 calls from citizens and local officials angered by the veto.

Oklahoma State Sen. Bernest Cain, D-Oklahoma City, can't remember a single constituent phone call he has received as attempts to cut Oklahoma's budget for care of the mental retarded have been quietly beaten back in the past two years.

Cain is a member of the Health and Human Services Committee that approves budgets for the program for the mentally retarded. " Over the past four years Oklahoma legislators — under pressure from federal threats — have approved a 28 percent increase in the budget for services for the mentally retarded while all other state services have been cut.

Cain said he is not surprised there weren't calls from interested citizens.

"Except for the last couple of years, just tell me what good it would have done to call the Legislature about anything going on in the Department of Human Services," Cain said.

"You always had to deal with Lloyd Rader before; that didn't foster any kind of grass-roots support."

In Oklahoma, citizen advocates for the mentally retarded often are disorganized and ineffective, say national organizers.

THAT FAILING is by design of state officials, charges a former organizer for the national Association for Retarded Citizens (ARC), the country's most prominent lobbyists for causes of the mentally handicapped.

John Foley claims "the state bought the heart and soul of the ARC" by funneling federal grant money to Oklahoma's chapter to pay its executive salaries and office rent.

"Taking state money affected the advocacy relationship. It just didn't allow the ARC to function separate and apart from state government," he said.

A former official of the state ARC chapter denies the charge.

PROFESSIONALS SAY activity by the Nebraska ARC is the reason that state is among the nation's leaders in innovative care for the mentally retarded.

In Oklahoma the state ARC chapter disbanded about four years ago, members said, because of internal disputes and inability to raise private funds for programs.

Care of the mentally retarded in Oklahoma is considered archaic by some experts.

In Nebraska when the ARC and others lobbying for the mentally retarded speak, politicians listen. "That's organization," said Dave Powell, president of Nebraska's ARC.

The Nebraska association's members are the mentally handicapped, parents of the mentally handicapped and professionals.

Its goal is to take mentally handicapped persons out of institutions whenever possible and provide them homes and jobs in the community.

"I have held them up as a text-, book example of folks petitioning their government for redress of grievances," said Ron Jensen, director of Nebraska's Department of Institutions and the target of much of the association's lobbying- .

State funds for community-based care programs for the mentally retarded grew 128 percent in Nebraska within the past six years, Jensen said.

Appropriations for another social service, mental health centers, grew by only i7 percent in the same period.

"There are other factors, but that difference is due to a significant degree to citizen advocacy," Jensen said.

IN CONTRAST, community-based programs for the mentally retarded are practically non-existent in Oklahoma.

For years the money that would have gone to create community programs was, instead, poured into the three state institutions at Sand Springs, Pauls Valley and Enid.

Foley said he spent a "lot of time and energy" in Oklahoma from 1976 to 1980 trying to pump up the state group to work for development of Comprehensive community programs but had little luck.

Rader and DHS employee Ray Ashworth guided grant money to the state ARC, and Ashworth and other welfare department officials sat on the board of directors of the advocacy group, Foley said.

The attitude among state ARC officials, he said, "always seemed to be: 'If we do anything to upset Lloyd Rader or criticize the state institutions, we're going to lose this grant.' "

Ashworth said there are several reasons why the state is just now starting group homes, primarily the cost of startup.

"I would not concede this state or any other state has sold itself out," said Ashworth, who is in charge of the DHS's efforts to establish group homes.

He added it is not unusual for advocacy groups for mental retardation to accept state grants.

"There is no reason to believe you have to be in an adversary role with state government if the state is doing positive things," Ashworth said.

Whether Rader opposed community care or why he distributed the state funds in the manner he did, "only *hi* knows," Ashworth said. "I'm sure he felt that was the best way to do it."

Repeated efforts by The Tribune to reach Rader failed.

FOLEY SAID he heard of first lady Donna Nigh's interest in the mentally retarded and talked to her about the governor supporting the state applying for a Title 19 waiver, which would allow federal funds that ordinarily would go to institutions to be used for community programs for the mentally retarded.

Foley said he told her he believed the governor's support would outweigh that and said Mrs. Nigh told him: "I think you are naive on the politics of Oklahoma."

Mrs. Nigh said she could not recall making that statement.

"Everyone has their priorities and he (Rader) had so much dumped into his lap at that time," she said. "I would not want to be so unkind or unreasonable to say he was the No. 1 problem we had."

Nationwide, advocates for the mentally retarded are not a united front.

In Nebraska, the move to take the mentally retarded out of institutions prompted groups to form in opposition. Among them are Association of America and Congress of Advocates for the Mentally Retarded.

The opposition groups, generally comprised of older parents whose children have been in institutions for years, believe some mentally retarded people can't be cared for except in institutions.

"We've been told if it weren't for us, the institutions would already be closed," said Pat Crawford of Lincoln, Neb., the mother of a mentally retarded man.

They also disagree with the ARC on other points about the philosophy of care for the retarded, such as whether they should be allowed to marry and have children.

THESE DIFFERENCES in philosophy have intensified nation-wide in recent months in a controversy over a proposed federal regulation.

That proposal, Senate Bill 2053, would force all states to phase out their institutions in a five-year period.

It still is in congressional committee, but the proposal is widening the gap between those who support institutional care and those who believe all retarded citizens can be cared for. in communities.

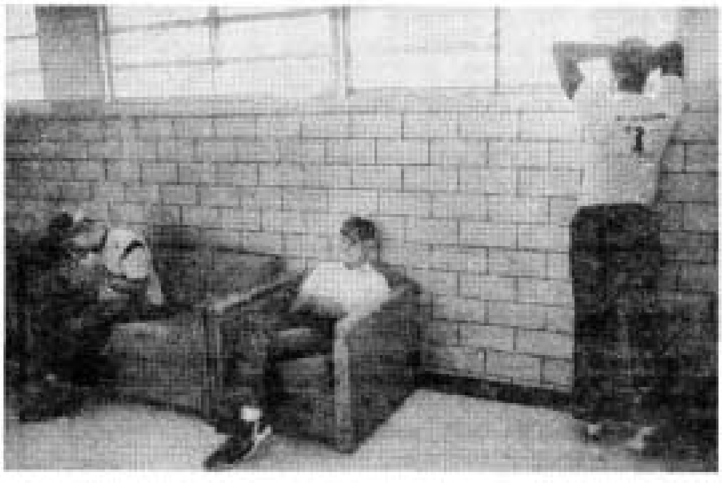
And even some who believe in community care oppose the bill, claiming the five-year deadline might not allow time to establish good community programs.

What all the groups do have in common, though, is no hesitancy to "pound on the desks of politicians," Crawford said.

Some Oklahoma parents, though, have seen a change recently in the interest shown toward the mentally retarded.

Sharon Smith, an Enid mother, told a group touring Enid State School she has seen more attention given in the past year than she ever has seen before.

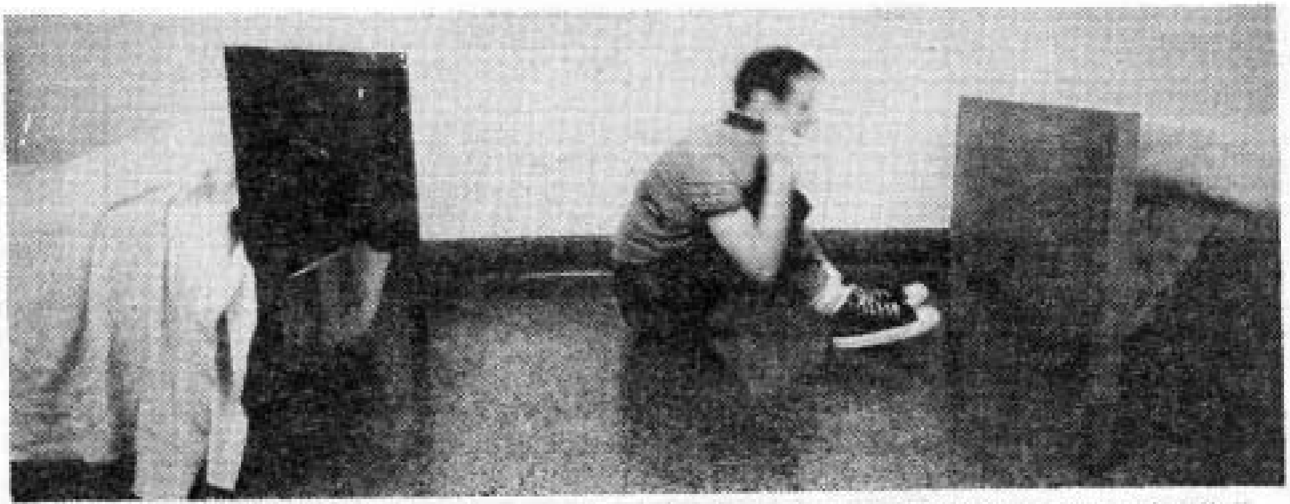
"It's happening everywhere," she said. "It's kind of a revival." ■



Tribune Special Report

Dollars and sense

Oklahoma programs substandard despite millions invested



Patient at Enid State School rocks, an act some experts term "institutional behavior."

OKLAHOMA'S PROGRAM for the mentally retarded has stagnated despite millions of dollars invested in it.

Last year, Oklahoma taxpayers spent $45 million to care for 1,600 mentally retarded people in institutions that failed to meet minimum federal standards.

Almost nothing was spent on the estimated 88,000 other retarded citizens in Oklahoma.

Other states invested less money but provided more services for the retarded.

Nebraska, for instance, spent $33 million on group homes, sheltered workshops and other community care programs for more than 2,000 citizens.

At the same time, Nebraska spent almost $17.4 million to care for about 460 people living in its one institution.

The figures illustrate what many retardation experts say is true: It is almost always cheaper to care for a mentally retarded person in a small home and to provide him a job and schooling in the community than it is to keep that same person in an institution.

Oklahoma spends $85 a day to care for each person in one of Oklahoma's three state schools for the mentally retarded.

Yet, private nursing homes in Oklahoma receive only $29 a day per person in Medicaid reimbursement to care for the mentally retarded.

NINA HONEYMAN, director of the Gatesway Foundation of Broken Arrow, said the foundation's nursing home facility "lives within that $29 a day for operating expenses."

"Any donations we receive are used to add extras," she said.

Group homes operated by Gatesway and other non-profit corporations do not receive Medicaid reimbursement.

They rely on private donations, rent paid by residents, and some state money.

IN JANUARY, Oklahoma is to join the other 49 states and provide Medicaid reimbursement at a higher rate to nursing homes that meet stringent federal regulations and provide specific programs for the mentally retarded.

Under that program, private facilities will receive $36 per person per day in Medicaid reimbursement, still far short of the money spent on institutional care.

The state also has applied for, a Title 19 waiver. This will allow Oklahoma to use federal money, which otherwise would go to institutions, for community-based programs.

Thirty-three other states already fund community programs this way.

Part of the difference in cost is the overhead for running institutions.

A budget for next year shows Oklahoma will pay $1.6 million in utility bills alone for the three state institutions. Half a million dollars is set aside for routine upkeep and maintenance supplies.

IN ADDITION, institutions must provide many of the services a retarded person normally would get in the community if he were living in a family-like environment.

Retarded persons living in the community usually qualify for Medicaid cards that allow them to seek medical treatment from any local physician or hospital.

The state institutions will spend $338,000 for the services of physicians, psychiatrists and other medical consultants.

The federal government reimbursed Oklahoma for about 55 percent of the $45 million spent on state institutions.

Oklahoma currently can't be reimbursed for money it spends on community programs.

THE BUDGET for community programs remains a mere fraction of the state's total mental retardation budget — a projected $5.1 million for next year.

Some of the funding to create community programs could be, freed as the populations, at the three, state schools are reduced to meet federal requirements.

But the states schools can't release students into the community until there are programs in place in the community to handle them.

The only way out will be a period of "double funding," financing both the schools and the community programs until the programs even out, said Stephen Thomas, former superintendent at Pauls Valley State School.

There also is likely to be opposition to any cuts in operations at the schools from all corners of the state for economic and political reasons:

—Legislators who fear loss of patronage and control over the large institutions.

—Communities and state employees who fear loss of jobs as institutions are scaled down.

Pauls Valley State School is the largest employer in Garvin County, providing jobs for 750. Enid State School employs 754 and Hissom Memorial Center in Sand Springs hires 702.

Officials say there are no plans to close any of the three schools.

— Parents afraid their children cannot cope with new-found freedoms and in a world that can be dangerous and cruel to the handicapped,

— Neighbors afraid of mentally retarded persons living nearby:

In one case, a non-profit corporation was prevented in 1983 from opening a group home in south Tulsa.

District Judge David Winslow ruled it violated city zoning law and restrictive covenants in the Park Plaza South neighborhood near 71st Street and Sheridan Road.

The case is being appealed.

SIMILAR opposition was encountered in Nebraska a decade ago when efforts were launched to reduce that state's one institution from a mammoth 2,200-bed facility to the 460 clients it now houses.

Money that once financed the institutions eventually was shifted to community programs.

The mostly rural towns and cities of Nebraska had to be convinced there were economic and social advantages in supporting local programs for the mentally retarded, said Dave Powell, a lobbyist for the Association of Retarded Citizens in Nebraska.

A community must provide^ cheap but easily accessible public transportation, good medical facilities and a place for retarded persons to work, Powell said.

If ,those services do not -exist -in a, ,community, state money may have to be used to provide them. Once established, the services benefit all residents, not just clients in an institution, Powell said.

Community programs also can provide jobs to replace those eliminated by the reduction in the size of institutions.

Group homes must hire house-parents and workshops must hire bus drivers and assistants.

■ Residential programs allow the state to lease and renovate vacant houses, putting them on tax rolls at higher evaluations.

Powell said community leaders in Nebraska soon decided the programs were an asset.

"IT WORKED," Powell said. "We are an industry. We have something to give."

Oklahoma would like to mirror some of these programs, but it is proceeding slowly.

"What we are trying to do is expand the number of options," said Jean Cooper, director of mental retardation services for Oklahoma's Department of Human Services.

"We are trying to take a long-term approach, a system-wide approach.

"I don't think it makes any sense to put Band-Aids on things when they are going to fall apart somewhere else.," she said.

Tribune **Special Report**

Letters to the editor

Editor, The Tribune:

The Tribune and its reporters Joyce Peterson and Susan Witt are to be commended for a very thorough examination of challenges facing Oklahoma's programs for the mentally retarded in their recent ten-part series.

The stories captured quite clearly the tremendous amount of change involved in Oklahoma's transition from almost total reliance on institutions to a more appropriate mix of community services and institutional care.

If anything, the series understated the significance of the commitments the state has now made to improved institutional services as well as to providing the additional community services that can help every mentally retarded person in the state.

While I think some aspects of the discussion of our current institutional services were more negative than is justified, the basic theme that Oklahoma is now on the right road came through clearly. You have done a public service by presenting to the people of the state the importance of staving on that road.

Oklahoma City — ROBERT FULTON,
Director of Human Services

Editor, The Tribune:

With reference to the series on mentally retarded people and state facilities:

I work at the Hissom Memorial Center, and I feel your allegations are extreme. You are sensationalizing on a subject you are not that knowledgeable about. Spending one day with these children could not possibly make you an expert. I have worked at Hissom for several months, and I find that I learn something new every day that helps me understand these children.

The series stated that these children needed more activities and structured programs. Instead of looking at the negative aspect of it, why don't you encourage people to volunteer their time and a little bit of love? ...

We have to face people with negative outlooks, moderate pay, and lots of work to love and take care of these children.

Sand Springs — JACK McCALIP

Editor, The Tribune:

Bravo! Your articles on the care (or lack of) for the mentally retarded were certainly eye-openers. I just hope that something will finally be done for this small but important group of individuals.

I have a brother who is in this group, and I have had first-hand experience with the public's disgust and disinterest. To all who have ever gotten to know him, he has brought a deep joy and better understanding of all people who may be handicapped in any way. He deserves much better than to be placed in one nursing home after another where he receives no special help in dealing with this cruel world he must adapt to.

Let's help these people to become an asset to our society, instead of pushing them back on our list of priorities.

Tulsa — MARILYN L. JONES

Editor, The Tribune:

As a parent of a child who has been a resident of Hissom Memorial Center for seven years, I sincerely thank Joyce Peterson and Susan Witt for the series addressing the appalling situation Oklahoma faces in meeting the needs of our mentally retarded citizens.

I especially appreciate the obviously thorough investigation done before the reports were printed. They are accurate, and the comparisons made between the three- state facilities as well as the Oklahoma vs. Nebraska programs speak for themselves.

In response to a Hissom Memorial Center employee's letter (People's Forum, Oct. 13), I do not believe these articles implied the cottage personnel are not doing the best job possible under the circumstances. Quite the contrary. If the archaic system under which Hissom operates were changed, he would find his job much easier and far more rewarding.

The policies at Hissom have created the negative attitudes to which the previous writer referred. Yes, it takes a lot of work to care for these children; I did for 11 years, 24 hours a day, seven days a week...

Oklahoma needs immediately to revamp the system of providing services to the mentally retarded. Morally and economically, these programs are a disgrace.

We need a strong parent advocacy group so our voice will be heard, and we need the support of Oklahoma taxpayers to protest the inexcusable expenditure of our tax dollar ...

Tulsa — GINNY COLE

Editor, The Tribune:

Your paper and reporters Susan Witt and Joyce Peterson are to be complimented for your courage in printing the articles entitled "Wasting Away."

Conditions for the retarded are deplorable in Oklahomam and have been for years. As a parent of a 16-year-old daughter faced with the necessity of institutional placement, I am well aware of the problems. It was my hope to place my daughter in a group home when the time came that I could no longer physically take care of her. That time arrived, and there were no group homes in Tulsa. Placement at Hissom was a necessity for me this past year.

Much can be said for the majority of the activities at Hissom during a normal day and for the loving, caring people who work with my daughter. But many changes are necessary in administrative procedures and cottage life programs to make Hissom a good place to have to place your child ...

Cottage life, from after school until bedtime, comes nowhere near a normal child's activities. Paper work for attendants is ludicrous, and staff is very small. Privacy for teen-age girls is minimal . . . federal guidelines are met on a minimal basis, not exceeded. Boredom is a problem; television does not catch the attention of my child, yet the books, games, etc., are not available.

It is a heartbreaking situation. I look forward to some major changes as a result of your efforts.

Tulsa — BARBARA THOMPSON